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UNIVERSITIES OF EXETER & PLYMOUTH



# **A COMPARISON OF METHODS FOR THE SYSTEMATIC REVIEW OF QUALITATIVE RESEARCH: TWO EXAMPLES USING META- ETHNOGRAPHY AND META-STUDY**

Submitted by

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of the Peninsula Postgraduate Health Institute to the Universities of Exeter and Plymouth as a thesis for the degree of Doctor of Philosophy.

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*R Garside*

18 June 2008

## **ABSTRACT**

Systematic reviews and meta-analyses have been a central pillar of evidence-based practice and policy-making in healthcare over recent years. Traditionally, this has focused on effectiveness evidence from trials. There is increasing understanding, however, that other study designs also provide essential information and this has led to interest in developing ways to review and synthesis such evidence. Qualitative research has unique potential to illuminate the patient experience.

This research has three aims:

- 1) To review and compare the proposed methods of systematic review and synthesis of qualitative research.
- 2) To develop and assess two methods of systematic review and synthesis of qualitative research.
- 3) To compare these two methods and suggest how they might be used in a policy-making context.

In addressing these aims, this thesis substantially contributes to debates about the purpose and practice of systematic review and synthesis of qualitative research, particularly in the context of health technology assessment and related policy-making.

I undertake a unique critical comparison of the methods suggested for reviewing and synthesising qualitative research, based on their approach to key stages of systematic review. This is used to produce a comprehensive framework for good practice. I use the framework in two systematic reviews, one about heavy menstrual bleeding using meta-ethnography, and one about hysterectomy using meta-study.

These two reviews allow a comparison of the two methods, and in particular explore the impact of expanding the meta-ethnography approach through meta-study, which adds explicit steps to assess the impact of study methodology and theory on findings. The ability of meta-study to unpack the procedures and theories that produce particular findings is key and illuminates the importance of theory in systematic reviews of qualitative research.

Through the two systematic reviews, my thesis also contributes to understanding of these reproductive health topic areas through the creation of new insights and concepts from the synthesis. The synthesis of heavy menstrual bleeding studies produced a detailed patient illness model based on women's experiences. In addition, it allowed an understanding of elements that contribute to women's certainty or

uncertainty about whether or not their periods could be seen as problematic and requiring medical help. This helps to establish the limitations of the medical model for doctors, as well as women who suffer from heavy menstrual bleeding.

The synthesis of hysterectomy studies produced a detailed description of the journey that women make to, and through, hysterectomy, based on their experiences. I also created a theoretical framework, which shows that hysterectomy needs to be understood in the context of personal, physical experiences, together with socio-cultural forces that affect the way in which hysterectomy is experienced, and that the interaction of these micro- and macro-concerns mediate through, and affect, relationships with key other people. Methodology affected the research questions posed and the conclusions of research.

Comparing the two methods of review and synthesis showed the importance of taking account of the methods and theories that produce research findings. However this additional detail may be at the expense of certainty and requires additional resources.

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## LIST OF ABBREVIATIONS

AE	Adverse Effect
ASSIA	Applied Social Science Index and Abstracts
CDC	Centre for Disease Control
CINAHL	Cumulative Index of Nursing and Applied Health Literature
CONSORT	Consolidated Standards Of Reporting Trials
CRD	Centre for Reviews and Dissemination
EA	Endometrial Ablation
FGD	Focus Group Discussion
EBM	Evidence Based Medicine
EMP	Evidence Based Practice
ENDOW	Ethnicity, Needs and Decisions of Women
EPPI-centre	Evidence for Policy and Practice Information and Coordinating Centre
HES	Hospital Episode Statistics
HMB	Heavy Menstrual Bleeding
HRT	Hormone Replacement Therapy
HTA	Health Technology Assessment
GI	Gastro-intestinal
GP	General Practitioner
JBI	Joanna Briggs Institute
MESH	Medical Subject Headings
MND	Motor Neuron Disease
NCCHTA	National Coordinating Centre for Health Technology Assessment
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
PBAC	Pictorial Blood loss Assessment Chart
PMS	Pre-menstrual Syndrome
QUOROM	Quality of Reporting of Meta-Analyses
QARI	Qualitative Assessment And Review Institute
RCOG	Royal College of Obstetricians and Gynaecologists
RCT	Randomised Controlled Trial
TAR	Technology Appraisal Report
UTI	Urinary Tract Infection

*The health of the people is the highest law. (Cicero 450BC)*

*The truth is a mirror that dropped from the sky and broke into a thousand pieces.  
Each person, seeing their reflection in a single piece, thinks "This is the truth".  
(Rumi 1207-1273AD)*

*The shortest distance between a human being and Truth is a story (Anthony De Mello, One Minute Wisdom)*

# 1 Introduction

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This thesis contributes to debates about the purpose and practice of systematic review and synthesis of qualitative research. I critically analyse existing suggested methods and produce a comprehensive framework for the stages of systematic review based on these diverse methods. Further, I evaluate two methods in-depth, meta-ethnography and meta-study, through undertaking an example of each and comparing their potential. These exploratory studies allow me to determine differences and advantages between the two methods of review. Crucially, the key importance of theory in qualitative analysis and synthesis is demonstrated. I consider the implications of this for policy makers and for researchers. Separate systematic reviews of qualitative research focus firstly on women's experiences of heavy menstrual bleeding and subsequently on hysterectomy for such benign conditions. Through these reviews, my thesis also contributes to understanding of these reproductive health topic areas through the creation of new insights from the syntheses.

This research links two strands of my professional life. My early research career was based in social science environments and focused on issues of sexual and reproductive health. I was involved in a number of projects which required different research approaches, both quantitative and qualitative, for survey and evaluation research projects. Since 2001, I have worked for the Peninsula Technology Assessment Group (PenTAG), undertaking and project managing health technology assessments (HTAs), mostly for the National Institute for Health and Clinical Excellence (NICE). This thesis considers the possibilities for the inclusion of qualitative research evidence in policy-making, especially in the context of the HTA work for NICE in which I am currently involved.

## 1.1 Thesis Aims

- 1) To review and compare proposed methods of systematic review and synthesis of qualitative research.
- 2) To develop and assess two methods of systematic review and synthesis of qualitative research.
- 3) To compare the two methods and suggest how they might be used in a policy-making context.

## 1.2 Thesis Outline

Following Mays et al's (2005) distinction, I use the term "review" to describe the whole process involved in bringing together evidence from a range of sources, and "synthesis" to describe the specific procedures within that review by which findings from individual studies are combined (Mays, Pope & Popay, 2005). The term "systematic review" is commonly used to refer to those reviews that involve the identification of all relevant quantitative research (often restricted to randomised controlled trials, RCTs) on a specific question of effectiveness and their synthesis through the formal statistical methods of meta-analysis. I will label these as Cochrane-style reviews, since the Cochrane Collaboration is the best known organisation working with such formalised and standardised procedures for estimating treatment effect sizes based on pooled RCT evidence. As Chapter 2 goes on to discuss, I consider that reviews of other types of evidence and synthesis using different methods can legitimately also be described as systematic reviews.

Chapter 2 describes the environment of evidence-based practice and Cochrane-style reviews which has shaped and focused interest in systematic reviews of qualitative research evidence. I briefly describe the emergence of evidence-based medicine in healthcare research and the current use of systematic reviews, including in HTA. I then outline the potential contribution of qualitative research to the evidence base and consider how such research can be reviewed and synthesised.

Having discussed the value and possible applications for systematic reviews of qualitative research in Chapter 2, Chapter 3 then introduces ten suggested mechanisms for such reviews. This is a rapidly developing field, and the number of published methods for review has doubled since this project began. This chapter provides an overview of the methods currently available.

Chapter 4 comprises a comparative critique of the methods that have been identified, paying particular attention to their proposed approach for each stage of the systematic review process; aims of reviews, defining the review question, the type of research that can be included, searching for study reports, quality appraisal, methods of synthesis and dissemination of findings. I consider the range of suggestions that have been made for each of these steps, and relate them to the discipline from which the methods evolved and their aims, particularly in terms of informing policy-making. Finally, I produce a comprehensive framework for conducting reviews based on elements best described by each of these methods.

In Chapter 5 I present the methods and results of the first methodological example – a meta-ethnography of heavy menstrual bleeding, while Chapter 6 presents the methods and results of the second methodological example, this time using meta-study to review hysterectomy for benign conditions. Meta-study allows the impact of methods and theory on findings to be formally considered in the synthesis. Both these chapters include the outputs from the synthesis as well as critical reflection on the method used.

Finally, I consider in Chapter 7 the similarities and differences between the two methods, meta-ethnography and meta-study. This assessment leads to a consideration of the limitations of meta-ethnography alone, and the benefit of considering the importance of theory in systematic reviews and syntheses of qualitative research. The implications for researchers, policy makers and practitioners are addressed.

## 2 Background

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*The rhetoric of evidence-based medicine creates the impression that medical science has reached a Newtonian age of certainty. The patient can expect precision, and the doctor, if he (sic) embraces the rigors of evidence, can deliver on that expectation. The expectations of doctor and patient are hopelessly unrealistic, of course, and both parties to the clinical encounter will frequently be let down by events. (Horton, 2003)*

In this chapter I provide a brief overview of the rise of evidence-based practice (EBP) and systematic reviews, particularly Cochrane-style reviews, in policy-making. I then consider how systematic reviews are currently used in health technology assessments (HTAs) and the limits of RCT evidence. I contend that the aims of policy makers in relation to patient input would benefit from the inclusion of qualitative research in the evidence base.

### 2.1 The Rise of Evidence-Based Practice

*The work which deserves, but I am afraid does not always receive, the most credit is that in which discovery and explanation go hand in hand, in which not only are new facts presented, but their relation to old ones is pointed out. (Chalmers, 2001)*

*All sciences emphasise innovation and boundary breaking as well as standardization and systematization...The tension between innovation and conventionalizing practice is, we believe, a sign of healthy inquiry. (Freeman, deMarrais, Pressie, Roulston & St Pierre, 2007)*

There has traditionally been an emphasis on innovation and the novel in academic research. Researchers who wish to secure funding or to publish their findings need to establish the originality and novel nature of their work. Journals routinely ask peer reviewers what is new about a submitted paper or what it adds to what is already known, perpetuating an emphasis on the innovative. Strategically, therefore, it could be more in researchers' interests to stress the uniqueness of their methods of investigation and findings in any body of knowledge, rather than the similarities. Within healthcare, however, and increasingly within social care and other disciplines, the impact of evidence-based practice (EBP) is being felt. Researchers are increasingly required by editorial policy to make clear what is *already* known in the total field of

interest in order to situate their work within it. It has been argued that “formal synthesis of both quantitative and qualitative forms of research is essential to address uncertainties in many areas of healthcare” (Dixon-Woods, Fitzpatrick & Roberts, 2001).

Since the early 1990s, EBP has gained increasing currency. It is most visible in medicine and associated disciplines, including nursing, dentistry and mental health, and is increasingly informing policy and practice in other areas such as social work and education. I will focus on its impact in healthcare. Here EBP is intended to ensure that the decisions of both individual practitioners and policy makers are made on the basis of the best available evidence about “what works”. This approach has been driven from several directions. Traditional ways of deciding how to approach a clinical problem might have been based on methods that had become established through tradition, experience or opinion (which might be unreliable) or from text books (which are likely to be out of date) (Sackett, Straus, Richardson, Rosenberg & Haynes, 2000). Increasing amounts of published research information, such as that in journals, may mean that time-pressed practitioners can only keep abreast of relevant, recent findings if these are collated and summarised. Reviews have to be thorough and unbiased if they are to be accurate and useful (Egger M, Smith & O'Rourke, 2001). It has also been suggested that the call for policy decisions to be based on evidence is part of an increasing move away from ideological politics (May, 2006). Policy based explicitly on the theoretical ideals of political conviction is thereby replaced by policy based on “evidence”, with its implied fairness through objectivity. In doing so, policy-making aligns itself with positivist assumptions about the rationality of making decisions based on scientific “fact”, with more rigorous science assumed to lead to better decisions (Leys, 2003).

Systematic reviews and meta-analyses of quantitative data, particularly those evaluating RCTs, have had a key role in creating such an evidence base, as well as identifying where further study is needed if insufficient evidence exists. Single trials are often underpowered to detect real differences between the treatment and control arms, and are subject to a range of potential biases. Pooling of such trials increases the power to detect such differences (Egger M et al., 2001). In the hierarchy of research evidence that informs Cochrane-style reviews, shown in Table 1, expert opinion and anecdotal evidence (neither of which relates to a method of research or analysis) are regarded as the lowest form of evidence while, in this version of the hierarchy as in many, there is no place at all for qualitative research.

The systematic reviews mentioned in this table are assumed by default to be Cochrane-style reviews. This hierarchy assumes that RCTs are always the superior

primary research method. This is, at least partly, because the early focus of EBP in medicine has been on the comparative clinical effectiveness of relatively simple interventions such as drug treatments. As discussed below in Section 2.1.1, even these apparently simple experiments present methodological challenges. That notwithstanding, a hierarchy of evidence to inform decision-making about other types of question would need to display different characteristics. Questions about, for example, adverse effects (AEs) in clinical use, the effectiveness of complex interventions, or patient expectations of a service, require distinct research approaches. Detection of AEs, especially serious but rare effects, will require large cohort studies with long-term follow up, while patient expectations would be best elicited through qualitative methods.

Although attitudes are starting to change, the hierarchy of evidence in Table 1 persists in the consciousness of EBP, with RCTs still sometimes being seen as the “gold standard” methodology regardless of the question being addressed or, indeed, the methodological soundness of any particular RCT itself (Black, 1996; Morse, Swanson, Kuzel & (eds), 2001; Petticrew & Roberts, 2003). Whilst other types of quantitative research are also affected, qualitative research has been particularly marginalised. Healthcare research journals have show scant interest in qualitative, compared to quantitative, research findings. A survey of 170 core clinical journals in 2000 found that only 355 reports from 60,330 reviewed articles were reports of primary qualitative research (0.6%) (McKibbon & Gadd, 2004). Only four journals with the highest impact factors published qualitative research at all (McKibbon & Gadd, 2004). Qualitative research has struggled to be seen as legitimate or meaningful by the scientific community.

The traditional hierarchy of evidence does nothing to assist the lack of acceptance of qualitative research and might intensify it by perpetuating understandings of systematic reviews and meta-analyses of RCTs as the best possible evidence on which to base decisions. It is important to understand how this has come about, what trials involve and the nature of their philosophy and mechanisms. These issues are addressed in the following section.

**Table 1: The hierarchy of evidence of effectiveness**

Rank:	Methodology	Description
1	Systematic reviews and meta-analyses	<p>Systematic review: review of a body of data that uses explicit methods to locate primary studies and to assess their quality.</p> <p>Meta-analysis: A statistical analysis that combines the results of several independent clinical trials considered to be combinable, by re-analysing the original data or providing a weighted estimate based on the pooling of published results.</p>
2	Randomised controlled trials*	Individuals are randomly allocated to a control group and a group who receive the specified intervention – in all other ways the two groups are identical. They are followed up for specific end points.
3	Cohort studies	Groups of people are selected on the basis of their exposure to a particular agent and followed up for specific outcomes.
4	Case-control studies	Cases with the condition of interest are matched with controls without it. Retrospective analysis is used to look for differences between the two groups.
5	Cross sectional surveys	Survey or interview of a sample of the population of interest at one point in time
6	Case reports.	A report based on a single patient or subject; sometimes collected together into a short series.
7	Expert opinion	A consensus of experience from those in the know – expert may only refer to those professionally involved, or may include people with the condition or their carers.
8	Anecdotal	Personal or clinical experience or something reported from this.

Source: SchARR (School of Health and Related Research, 2008)

\* Finer distinctions may be drawn within this group based on statistical parameters like the confidence intervals

### **2.1.1 Current practice in systematic reviews for evidence-based practice**

EBP demands that decisions be made on the basis of the totality of what is known on a particular topic. Traditional ways of gathering literature together in reviews, whether of quantitative or qualitative research, have been open to charges of bias and partiality (Egger M et al., 2001). In particular, articles that reflect the author's concerns might be preferentially included, introducing bias, either intentionally or simply because these are the studies of which the author is most aware. Electronic databases have enhanced the possibility of identifying all the published information relevant to a particular question, both introducing more objectivity into study identification and allowing clarity about how included studies are identified. Systematic reviews have evolved mechanisms to try and minimise such bias through gathering evidence in such a way that key principles of methodological transparency and replicability are observed. One way of ensuring this is through a pre-defined research protocol covering a checklist of elements agreed by the scientific community to be critical elements of trial design and execution. Cochrane-style reviews use protocols that usually address the following areas:

- The research question including specific definitions of the population, intervention, comparator and condition to be reviewed,
- Details of an exhaustive search strategy,
- Explicit inclusion and exclusion criteria for studies,
- Outcomes to be considered,
- Criteria by which quality will be judged and the impact that this will have on the review,
- A description of the methods of synthesis, including formal methods of statistically combining the results of studies that demonstrate suitable homogeneity of design, including the specification of any sub-group analyses.

At every stage, these methods are designed to minimise bias that might threaten the validity of the review results. The protocol is pre-specified to ensure that only the most appropriate study designs in the relevant populations are included and that they are analysed in a planned way to avoid the introduction of researcher bias. Exhaustive searching is important because studies missing from the review, either because the reviewer fails to identify them, or because results are not publicly available, can bias the review conclusions (Sterne JAC, Egger M & Smith GD, 2001). Results from included primary studies, where possible, are formally synthesised through statistical

meta-analysis, and this method relies for its validity on the similarity of the populations, the condition and the treatment studied (Egger M, Smith, Altman & (eds), 2001).

### **2.1.2 The limits of RCT evidence**

Initial concerns of EBP to ensure that the best evidence was used has led to an over-enthusiasm for RCT evidence, and perhaps an over-enthusiastic rejection of other types of research evidence. Currently, there is an increasing realisation that the RCT design itself has limitations, for example where randomisation is impossible or inappropriate; where rare but serious adverse effects, or those manifesting only in the long term, are a concern; or where study criteria restrict the researched population to the extent that results are not generalisable to the usual clinical population. In RCTs, gains in internal validity are often offset by losses in external validity (Hammersley, 2002). Indeed, within social psychology, strong cautions are given against data from experiments being applied outside the experimental setting (Hammersley, 2002).

*[RCTs] provide information on the value of an intervention that is shorn of all context, such as patients' beliefs and wishes and clinicians' attitudes and beliefs, despite the fact that such aspects may be crucial to determining the success of the intervention. (Black, 1996)*

Restricting the study types included in a review leads to loss of information. Important questions about topics other than treatment effects, require different study designs. So, for example, cohort studies are needed to establish disease prognosis, while the accuracy of diagnostic tests needs to be tested in cross-sectional studies of populations at risk (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996). In addition RCTs, and their meta-analyses, have themselves been accused of various biases. These include content bias, leading certain types of questions to remain uninvestigated because they are not answerable with an RCT; process bias, where process data is excluded from trial reports; and "artefact" bias, where, due to the specific way in which RCT questions need to be formulated, the method obscures the meaning of the data (Dixon-Woods, Agarwal, Young, Jones & Sutton, 2004).

Quality assessment of included trials attempts to ensure that sufficient rigour has been applied to the conduct of each research project. Such quality assessment of clinical effectiveness RCTs operates in two ways. Firstly, a minimum set of methodological detail must be reported, relating to technical aspects of the trial conduct, such as how random allocation was achieved, how blinding was ensured, how participants were recruited and how many of them correctly started and completed the trial. These

aspects are outlined in the Consolidated Standards of Reporting Trials (CONSORT) statement, which allows quality to be judged against an agreed checklist of critical aspects of RCT design and execution (validity) (Altman DG, Schulz KF, Moher D, Egger M, Davidoff F, Elbourne D et al. 2001). Secondly, quantitative assessment has established aspects of an RCT design whose absence or inappropriateness have been empirically shown to affect results; for example it has been shown that lack of proper blinding and allocation to treatment group can have a significant impact on estimates of effect size (Chalmers, Celano, Sacks & Smith, 1999; Schulz, Chalmers, Hayes & Altman, 1995; Moher, Pham, Jones, Cook, Jahad, Moher et al. 1998; Kjaergerd, Willumsen & Gluud, 2001).

Despite the wide acceptance of the importance of these quality criteria, some areas remain problematic. For example, blinding of practitioners is impossible if surgical techniques are being studied, so should all surgical trials invariably be marked down for quality? Could their error be assuaged if objective outcomes measured by blinded assessors were used? The term “double blind” does not reveal who is actually blinded, whether practitioner, patient, researcher or analyst, or indeed, which of these is the most important. Evidence shows that industry sponsored trials tend to give more favourable results than independent trials, but how should this be accommodated in syntheses? Despite current understandings about crucial elements of bias in trials, it remains unknown whether methodological quality has the *largest* impact on biasing the results of RCTs and their review, as publication bias and funding by the pharmaceutical industry or other interested party also have important effects (Norman, 1999). In addition, it remains unknown whether lack of attention to several *apparently* small aspects of trial design and execution might have as much impact on validity as lack of attention to something apparently major like blinding (Fletcher, 2002).

There has been a proliferation of quality scales for use in assessing RCTs (Moher, Jadad, Nichol, Fenman, Tugwell & Walsh, 1995). The utility and rigour of these scales has been questioned and different scales can produce very different scores for the same study (Moher et al., 1995). The most commonly used quality score in systematic reviews of RCTs is the Jadad score (Jadad, Moore, Carroll, Jenkinson, Reynolds, Gavaghan et al. 1996), which is simple and based on elements known to materially affect trial results. This too has limitations. Using Jadad, higher scores are given for double blinding, which automatically discriminates against surgical trials and, at the same time, no provision is made for the blinding of those who measure outcomes. In addition, its brevity means that other aspects of failure can go unrecorded. There is, therefore, resistance among some of those undertaking systematic reviews to over-

reliance on a score rather than careful consideration of aspects of quality through careful reading of the report methods as a whole.

The preferred method of synthesis of RCT data in a review is pooling through meta-analysis which produces a single estimate of the treatment effect of the intervention under consideration. Resistance to the use of quality scores is even stronger than outlined above among some reviewers when the question of how to use such information within a meta-analysis is considered. For example, there is debate about whether more weight should be given in the meta-analysis to the results of trials with higher quality scores, or if trials judged to be of poor quality should be excluded from meta-analysis. Given continued debates within the relatively proscribed area of RCTs, it is unsurprising that qualitative research, with its range of methods and theoretical approaches, has struggled with the question of whether and how to judge study validity. I will return to this issue in Section 4.5.

Not all systematic reviews find RCTs that are suitable to be synthesised using meta-analysis. As well as considering whether they are correctly performed, in order for them to be reasonably combined they must represent results from a single underlying effect, rather than a distribution of effects. Statistical tests exist to measure heterogeneity between trials, although these are not particularly powerful and heterogeneity may exist despite an apparently non-significant result (Egger M & Smith GD, 2001). Differences in trials could relate, for example, to substantial differences in overall population health or in healthcare delivery mechanisms and these will only be spotted by careful consideration of the explanations for differences in results. Such assessments rely on the interpretive skills of reviewers and are difficult to codify.

As evidence-based practice has matured, there has been an increased awareness that, while RCTs may answer focused questions about efficacy and effectiveness, other research designs are necessary to understand the more complex, and often more policy relevant questions, about why an intervention works, in what situations, and for whom (Pawson, Greenhalgh, Harvey & Walshe, 2004). The RCT is not equipped to answer questions about context, implementation, attitudes and experiences. In addition, any intervention where human interactions and skills are an integral part of the treatment or service delivery can be regarded as complex, in which elements that make interventions work or fail may be precisely those elements for which RCTs are designed to control. In policy-making where research is put to practical application, there is a need for the whole range of findings on a particular topic to be considered (Hammersley, 2002).

An urgent need to make the best use of *all* available evidence to inform the complex needs of policy-making is becoming increasingly clear (Lomas, 2005). A systematic approach to the review of many types of research is required. Guideline development groups for NICE are more inclined to include non-RCT evidence, both quantitative and qualitative, and to base recommendations on such evidence although this remains strictly hierarchical, with guidelines graded according to the level of evidence on which they are based (Table 1). Ultimately, EBP aims to improve quality of care by informing decision makers at individual and policy level about the best evidence currently available. Relying solely on RCT evidence is a severe limitation on this aim. As I discuss in the next section, Health Technology Assessments (HTAs) already operate beyond the limits delineated by Cochrane-style systematic reviews, both through choice and necessity.

### **2.1.3 Current practice in Health Technology Assessment**

NICE is the body which decides which treatments are acceptable, in terms of clinical and cost-effectiveness, to be funded through the NHS in England. The HTAs which are submitted to NICE comprise a systematic review of evidence for clinical effectiveness about a drug treatment or new surgical tool or technique and also estimate cost-effectiveness using this review and economic modelling techniques. The results are presented to the NICE appraisal committees as a central aid to their policy-making. HTAs, based on systematic reviews of the literature, are fundamentally policy-making tools. As such they have a very functional aim, and pragmatic methods. The decision about adopting a treatment for use in the NHS needs to be made by NICE whether or not high quality RCTs of a treatment have been undertaken. As new treatments are often the focus of such reviews, a limited evidence base means that uncontrolled studies can constitute a large part of, or the only, available data (Garside, Round, Dalziel, Stein & Royle, 2002). Traditional Cochrane-style systematic reviews are likely, in such circumstances, to conclude that there is insufficient evidence to provide an answer to questions about effectiveness. For policy makers, this is extremely unhelpful as a decision about whether to adopt an intervention still has to be made. Pragmatism demands that the best *available* evidence relevant to the research question is therefore considered, which might be restricted in quantity, quality or study design.

NICE is also committed to understanding the impact of a condition and any treatment on patients. This is usually addressed through the involvement of clinical experts and patient groups. Involvement takes the form of written testimonials and patient

representatives who take part in the appraisal committee meetings. In a handbook to inform patient and carer groups of the technology appraisal process and their part in it, four key areas are highlighted by NICE as those they wish such groups to illuminate:

- *How the technology changes the lives of patients and carers. Does it improve quality of life? For example does it change physical or mental health, reduce pain or disability, or help in carrying out daily activities?*
- *The side effects of the technology and how patients feel about them.*
- *Any practical implications of taking the treatment. For example are there any adjustments needed to the patients' or carers' daily routine or lifestyle?*
- *Whether the technology has a financial impact on the patients or carers (this could include cost of travel, lost earnings or the cost of paying a carer). (National Institute for Clinical Excellence, 2004)*

In practice, patient groups tend to favour maximum choice, and usually operate as advocates for all new treatment for their members. Written statements from individuals about their concerns are often provided. Such depositions can be very powerful.

*Humans are persuaded by narrative; that is why Plato proposed banning the artists, not the scientists or bureaucrats. (Lewis, 2007)*

It is not known, however, how such individuals are identified or selected. In effect, they are a source of qualitative data, with all the immediacy and pathos of such material, but without the rigour of collection and analysis using qualitative research methods. Meanwhile, existing qualitative research evidence is not usually taken into consideration although it clearly may address some of these key highlighted areas.

HTAs also involve economic analysis, which may synthesise data from a whole range of sources, from Cochrane-style systematic reviews to the opinion of researchers or clinical experts. Despite this, resistance to the inclusion of qualitative evidence in HTAs is stronger than resistance to inclusion of observational quantitative evidence, perhaps indicating the frequent lack of understanding about the different aims and methods between those engaged in quantitative and those engaged in qualitative approaches to research. Cochrane-style reviews have been criticised for demonstrating “a profound lack of awareness of the potential contribution of qualitative methods of meta-synthesis to our knowledge of health care interventions” (Booth, 2001). In response, a Qualitative Methods Network has been established within the Cochrane Collaboration and together with the Campbell Collaboration, is working

towards a greater understanding and integration of systematic reviews of qualitative research.

As identified by NICE itself above, a central area where qualitative research can be important is in allowing the patient voice to be heard. HTAs systematically identify and collate quantitative research evidence. In order to integrate patient views more systematically, similar approaches could be used for qualitative research. However, key questions remain about how this might be achieved and the nature of the knowledge produced through a synthesis of existing research findings. A review of qualitative review methods, and their potential uses in HTA was carried out by Murphy et al as part of the HTA Monograph series as long ago as 1998 (Murphy, Dingwall, Greatbatch, Parker & Watson, 1998). They concluded that the decision to include quantitative or qualitative methods, or both, as part of a technology assessment should be made on its merits in each case, based on what would “answer the question most effectively and efficiently” (p.iii). The authors suggest the roles of qualitative research could be varied, and might include:

- *Planning research – helping to define or refine research questions, aid conceptualisation and generate hypotheses*
- *Helping to interpret, qualify or illuminate the findings of quantitative research*
- *Aiding policy makers by illuminating the context within which policies are to be implemented.* (Murphy et al., 1998)

Qualitative research is thus seen as more than a help-meet to quantitative research – as a preliminary stage before developing quantitative research to answer specific questions – which has historically been the limit of engagement between much medical research and qualitative methods. Rather, it can offer explanatory evidence about aspects important to policy makers that can only be investigated using qualitative methods. Policy makers may need to understand *why* particular interventions work, or what particular barriers or facilitators there are to implementing a particular strategy.

Despite this, few HTAs routinely use qualitative research as part of the evidence base they consider. Where such evidence *is* used it may form part of the background to the review, particularly to explain quality of life issues related to a particular condition, rather than being considered as part of the evidence base presented. One notable exception presented to NICE was an assessment of riluzole for motor neurone disease (MND) in 2001 (Stewart, Sandercock, Bryan, Hyde, Barton, Fry-Smith et al. 2001). MND is a devastating, progressive disease and riluzole is not a cure. The review identified four RCTs and their meta-analysis suggested that riluzole was associated

with slightly better tracheostomy-free survival of about three months (HR 0.83, 95% CI 0.69, 0.99), although symptoms were not improved and a quarter of those in the trials withdrew due to adverse effects. The cost to the NHS of achieving these outcomes was estimated to be greater than that which is usually considered acceptable by NICE. Submissions from MND organisations commenting on the appraisal were supportive of riluzole and very keen for riluzole to be made available through the NHS. The reviewers also included patient perspectives in the HTA using findings from a published qualitative interview study. In contrast the view of MND organisations, this illustrated the resistance of many individuals with MND to a drug that might only marginally extend life, without improving its quality. For others, any extension in life was felt to be extremely important.

By including evidence from qualitative research, the MND HTA was able to make recommendations about the kind of information that should be given to patients about the possible benefits of the drug, so that they could make informed choices relating to their own requirements. It also highlighted to the policy maker a limit to the number of people who would want to take the drug if it were to be made available. This additional information provided an insight into patient needs and preferences that were not echoed by the organisations apparently supporting them. It illuminated the human context into which the drug would be received if it was funded by the NHS. However, mechanisms for identifying and synthesising study designs other than RCTs are in flux, especially for qualitative research. There are those who, as I discuss in Section 2.2, believe that they cannot be meaningfully synthesised at all.

## **2.2 Potential Place of Qualitative Research in Systematic Reviews**

This section considers the contribution that qualitative research can make to EBP and why it is appropriate to look for formal methods of synthesising the results of different studies on the same topics, and the challenges that such synthesis poses.

Qualitative and quantitative data provide different, but often complementary information. RCTs can tell us what *can* work, but without other information, we may not know *whether* it will work in a particular situation, or *how* and *why* this is so. There are a number of key areas where evidence from qualitative research can add value to existing systematic reviews, or provide justification for undertaking a review of qualitative research alone. The Joanna Briggs Institute has suggested that evidence

about three areas, in addition to effectiveness, is required to enhance healthcare. Each of these can be addressed by qualitative, rather than quantitative, research:

- *Evidence of feasibility (the extent to which an activity or intervention is physically, culturally or financially practical).*
- *Evidence of appropriateness (the extent to which an activity or intervention fits into a particular situation).*
- *Evidence of meaningfulness (the extent to which an activity or intervention is positively experienced – relates to people’s experience, opinion, values, thoughts, beliefs and interpretations). (Pearson, Wiechula, Court & Lockwood, 2005)*

The Cochrane Qualitative Methods group, in collaboration with the Campbell Implementation Process Methods group, has cited the following potential contributions of qualitative research to systematic reviews:

- *Influencing the criteria by which effectiveness is to be judged and hence the process and outcome data to be extracted from trials;*
- *Providing a research-based context for interpreting and explaining trial results including insights into how change was achieved, whether it could be achieved more cost-effectively and the factors that constrained/facilitated change;*
- *Contributing to understanding of heterogeneity in outcomes;*
- *Providing evidence on the subjective experience of all those involved in developing, delivering and receiving an intervention;*
- *Revealing the extent to which the criteria adopted to judge effectiveness are actually adopted in policies and practice; and*
- *Contributing to the methodological development of systematic reviews by expanding the existing concern with publication bias to include other forms of bias in the production of systematic reviews.*  
[\(<http://www.joannabriggs.edu.au/cqrmq/role.html>\)](http://www.joannabriggs.edu.au/cqrmq/role.html)

But systematic review of qualitative research and its synthesis are developing fields and as yet, no consensus has been reached about how to approach them. In the next section I consider some of the objections, and challenges to its practice.

### **2.2.1 Tension between quantitative and qualitative research paradigms**

Central challenges in the synthesis of qualitative research are the epistemological and ontological differences between positivist and interpretive research traditions which I will outline briefly here. These different perspectives inform the types of question that are asked in research, and the way in which they are answered. Quantitative research operates within a positivist paradigm, with the assumption that there is a single underlying truth that can be revealed through careful experimentation and which exists independently of the methods used to observe it. This allows hypotheses to be tested and predictions to be made based on an understanding of the causality of the phenomenon under study. Knowledge accumulates, and over time comes closer to the truth which can be expressed as a generally applicable law. The researcher's role in identifying such truth is minimised and assumed to be objective, so that anyone repeating the methods of investigation would come to the same conclusions and explanations for observed outcomes. Indeed, the fact that such outcomes *can* be observed is part of what marks them as legitimate areas for study. Unobservable outcomes (for example, emotions or intentions) cannot be readily quantified and their impact may be considered minimal, or even contaminating.

Within a positivist framework, the aggregation of data is relatively unproblematic. It reinforces the belief that similar results will be achieved through repetition of the question and methods. By combining the results of several studies about the same question, a more precise answer, one that is closer to the external truth of the matter, can be achieved.

By contrast, qualitative research occupies an interpretive paradigm which suggests that, while the study of biochemical factors associated with disease may be appropriately studied through the scientific, positivist framework, the experiences of illness and medicine are cultural and social phenomena which require a different approach. Because social truths are constructs and may be multiple, more subtle methods are required. Actions may be based on a variety of meanings attached to particular circumstances and phenomena. These meanings must be interpreted if the internal logic of actions is to be understood. Further, these meanings are unstable and may be negotiated in response to different social environments and interactions. The interaction between the researcher and the researched is also a social one, through which data and meaning are created. Findings from such research are based on description and interpretation, and may be used to generate hypotheses.

There are those who are critical of such polarisation of quantitative and qualitative research, and who advocate a recognition of their similarities, as well as their differences (Murphy & Dingwall, 2003; Barbour & Barbour, 2003). Murphy and Dingwall (2003) have described two opposing attitudes towards qualitative research; the “sceptical” and the “romantic”, both of which perpetuate an emphasis on the differences between quantitative and qualitative research, albeit in different ways and for different reasons. Those who are sceptical of the value of qualitative research are usually strong proponents of the positivist paradigm who accept knowledge as reliable and valid only if it is produced through quantitative methods. Qualitative research is likely to be regarded as unscientific, anecdotal and impressionistic. Any role that it might have would, at best, be restricted to supporting the design, development or evaluation of the central, quantitative research focus (Murphy & Dingwall, 2003).

Meanwhile, those “romantically” attached to qualitative methods believe that quantitative research values rigour over meaning, in the naïve assumption that an objective world exists that may be observed without being influenced by the observer. Quantitative researchers are oblivious to their *own* potential political agenda, and thereby perpetuate the *status quo*. Meanwhile the mission of qualitative research should be openly ideological and creative in order to pursue ethical, rather than “scientific” goals (Murphy and Dingwall, 2003).

Neither approach, however, is exclusive. Grounded theory and phenomenology have both positivist and interpretive beginnings, and there are practitioners of both paradigms using these terms to describe their work. The broad church of “qualitative research” does not unequivocally belong to either. Moreover, it is wrong to think that no judgement or interpretation is required in quantitative studies or their review. Suitable topics and populations for study must be identified. Primary outcomes need to be determined, and in some cases, scales for measurement devised. Researchers need to determine which statistical tests are most appropriate for their study and at what level the results of those tests will be considered significant. These decisions will have an impact on any review that includes these studies. Decisions need to be made about which studies, in which populations should be included, about which comparators are most relevant and which outcomes are most important for a review to consider. Such decisions may reflect the interests and concerns of the reviewers. For example, in trials of treatments for heavy menstrual bleeding, which outcome should be given greatest prominence? An objective, measurable outcome, such as amenorrhoea, or some other measure, such as reduced bleeding or satisfaction with the medical process or with treatment options?

Further, if trials do not use the same outcome measures or scales, they may need to be adjusted in order to perform quantitative meta-analysis, possibly requiring judgement to draw equivalences between disparate measures or ways of defining success. Indeed, in a standard textbook about meta-analysis and systematic reviews, interpretation of results is listed as a specific step in the review process (Egger M et al., 2001). This includes thinking about the potential limitations of the review (including possible biases) but also demands more qualitative judgements such as the applicability of the pooled results to a particular setting or patient, or the feasibility of applying the results to clinical practice or policy. Systematic reviews of RCTs on the same topic by different reviewers have come to opposite conclusions, while systematic reviews have also come to opposite conclusions to large-scale RCT results carried out at a later time (Egger M, Dickersin K & Smith GD, 2001). Research rarely provides an answer that represents the definitive, incontrovertible truth; medical statisticians have suggested that all research results should be considered as provisional and evolving (Rycroft-Malone, Seers, Titchen, Harvey, Kitson & McCormack, 2004).

Meanwhile, inherent features of RCT design suggest that there are real, but usually untraceable, impacts of human interactions and expectations on the results of a treatment. Active treatments must be tested against a placebo, since unknown factors mean that some people may get better because they believe that they are receiving beneficial treatment or because they are reassured by the consultation process. The requirement for blinding arises because practitioners may not be able to be objective about outcomes if they know the difference between an “active” treatment and an “inactive” one. Such complex and poorly understood human factors can be powerful and are explicitly removed through controlled trial design in order to estimate a “true” treatment effect, although this “truth” may not apply outside the experimental setting, since in clinical practice these effects are once more part of the whole treatment experience.

### **2.2.2 Challenges for synthesising qualitative research**

Among qualitative researchers, the acceptance of synthesis as a legitimate project might derive, at least partially, from strategic considerations. Qualitative researchers themselves have recognised that to refuse the opportunities offered by synthesis is likely to result in greater marginalisation and further disempowerment in areas of policy and practice, especially within healthcare (Walsh & Downe, 2005). In the past, qualitative researchers have failed to cite other similar research on relevant topics leaving findings isolated, and resulting in information, concepts and theories about a

topic that are not built upon or developed (Campbell, Pound, Pope, Britten, Pill, Morgan et al. 2003). As it stands, individual qualitative research findings have been described as being like a jigsaw puzzle, which, while interesting and illuminating in their own right, offer no clue as to the relationship between the pieces and thus what the complete field of research might look like (Paterson, Thorne, Canam & Jillings, 2001). Synthesis of qualitative research, it has been suggested, may also provide more powerful explanations and theory building. Higher order conceptualisation and more broadly encompassing theories may be possible, (Dixon-Woods et al., 2004) including the ability to explain findings that may initially appear contradictory (Paterson et al., 2001; Greenhalgh, Robert, MacFarlane, Bate, Kyriakidou & Peacock, 2005).

Pragmatically, the failure to synthesise may also be seen as wasteful, since it does not optimise the use of previous findings and the contributions of individual researchers to a body of knowledge. The emphasis on context within qualitative research has led some to argue that findings cannot aim to be generalisable in the sense that findings from quantitative studies may be. For others, it is merely a conflict of terminology; with results considered “transferable” or “applicable” when the context and approaches are described in enough detail for readers to establish whether they might apply them to their own circumstances (Jackson & Haworth-Brockman, 2007). Finally, potential generalisability might be seen at the level of developed concepts and theories, rather than specific findings. Sandelowski and Barroso (2001) draw a distinction between nomothetic and idiographic generalisation. The former, seen in quantitative studies, allows data obtained from statistically representative samples to be generalised to a population. Idiographic generalisations are taken from and about the particular (“informationally representative cases”, p.2) and can be fitted to a range of cases.

Paterson et al state that they are driven to synthesis:

*Not by some frivolous urge to be creative about ideas or by a presumptuous desire to author a new way of thinking, but by the abiding sense that the process may yield truths that are better, more socially relevant, or more complete than those from which we currently operate. (Paterson et al., 2001)*

While some qualitative researchers believe that their methods of research, and particularly analysis, should become clearer and more codified so that they can be articulated and understood with greater transparency, others have argued that the iterative, flexible approach needed to respond to the nature of the data collected, means that this may not be feasible or even desirable (Bryman & Burgess, 1994). There remain those who regard the synthesis of findings from several research projects

as inappropriate to the epistemological underpinnings of qualitative research and who regard the uniqueness of the interaction between those informing the research and the centrality of context - historical, socio-political, intellectual – as rendering any such attempt doomed to failure (Sandelowski, Docherty & Emden, 1997).

The danger of such a position is that such research comes to occupy a rarefied academic position which cannot usefully inform policy. The Health Development Agency has written:

*much of the methodological debate is completely unhelpful from a point of view of trying to bring about reductions in the inequalities in health, does nothing to help develop policy and practice, is a gross oversimplification of important scientific work in a range of methodological traditions, and – as a final shot – is a misrepresentation of the philosophical principles which supposedly are the origins of the so-called divide. (Dixon-Woods et al., 2004)*

The field is moving quickly. The journal *Qualitative Health Research* only formally agreed to start accepting review articles in April 2007, during the course of this research (Morse, 2007). With this change in editorial practice came an explicit request that reviews “contribute to the field conceptually or theoretically” and recognition of synthesis techniques as key mechanisms. The editorial ends with the statement:

*I hope that accepting review articles will facilitate the process of incorporating qualitative results into Cochrane reviews, of making qualitative research appear more solid, of moving qualitative research towards application (Morse, 2007)*

It is important that the qualitative research community recognises the potential of synthesis both as a pragmatic technique for informing practice and as a theoretical tool, if it is to fulfil its potential.

## **Summary**

In this chapter, I have described how current concerns about how micro- and macro-decision-making occurs within healthcare have led to an interest in identifying and synthesising existing research in order to facilitate evidence-based practice. I have considered why qualitative research is important and how reviews of such research might contribute to the evidence base. In the next chapter, I outline the different methods that have been suggested to review and synthesise qualitative research. The approach taken by these different methods to each of the above stages of systematic review are then described and compared in detail in Chapter 4.

# 3 Proposed Methods of Reviewing Qualitative Research

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In Chapter 2 I discussed the importance of qualitative research in evidence-based practice and policy-making and outlined some of the challenges to its synthesis. In this chapter, I consider the meaning of such review in greater depth and go on to give a brief account of the main proposed methods for the systematic review and synthesis of qualitative research. I describe the theoretical underpinnings of the methods and the practical steps proposed for their conduct. This chapter provides an introduction to the methods which are then compared in depth in Chapter 4 where I consider their varied approaches to key stages of systematic review. To my knowledge, this is the first time that all these methods have been presented together and compared in such detail. Although previous authors have considered existing review methods (see for example, (Dixon-Woods et al., 2004) and (Popay & Roen, 2003), they have been either selective or have considered the methods more briefly without such a comprehensive comparative element as I provide in the next chapter.

In all cases, the aim of systematically reviewing qualitative research is to produce a synthesised account of what this body of work means. Therefore, in this chapter, I firstly consider what such synthesis can yield and how we should regard it.

## 3.1 What is Synthesis of Qualitative Research?

Practitioners of systematic review and synthesis of qualitative research have been keen to distinguish this approach from both traditional literature reviews and Cochrane-style reviews. Traditional literature reviews have usually attempted to describe the current state of knowledge in a particular field and are often necessarily partial, in both senses of the word. They very often serve as the introduction to the writer's current research or funding application and are designed precisely to show how the writer has filled a gap in the existing knowledge base (Thorne, Jensen, Kearney, Noblit & Sandelowski, 2004). In Cochrane-style reviews, as outlined in Chapter 2, the basis of meta-analysis is the aggregation of data from separate trials in order to produce a higher powered, more precise calculation of effectiveness. The purpose is to narrow uncertainty and move closer to the "true" estimate of effectiveness of one treatment compared to another (including placebo, no treatment) for a particular condition in a particular population. It aims to increase focus and lessen uncertainty. In contrast,

synthesis of qualitative research, rather than seeking to restrict the answer, seeks to expand and enhance. Through interpretive synthesis it provides new or more overarching, higher level, explanatory concepts or theories, or explanations that are more extensive, or more generally applicable. Transferability of findings may be sought, not through increased precision of findings, but through the generation of more complex, higher level or more widely applicable concepts and theories.

Synthesis of research findings, along with transparency of methods, is one of the main ways in which so-called “systematic” reviews distinguish themselves from traditional reviews (Hammersley, 2002). Hammersley has suggested that there are five interpretations of what “synthesis” might mean and these are briefly discussed below.

**1. Aggregation or pooling of studies** Here, individual studies are treated as though they are investigating different samples of the same population, and so can be combined to produce information on a much bigger sample. This is the way in which meta-analyses of RCTs treat data. Hammersley (2002) identifies this method of synthesis as particularly suitable for survey research, although he also suggests that it can be applied to both experimental and qualitative research. His criticism of aggregation is that the cases studied do *not* necessarily belong to the same population and this is certainly true for some clinical trial data when inclusion criteria or treatment protocols may vary. Moreover, he suggests, cases studied by different researchers at different times for different purposes *cannot* be meaningfully pooled. This might apply to quantitative data as well as to qualitative, as differences in addition to the treatment under investigation may exist between studies. Such differences could be improvements or changes to supportive care over time, or differences in outcomes measured.

**2. Treating studies as replications of each other** In this interpretation, when further studies of the same question come to the same conclusion as previous studies, the findings may be regarded as reliable. This is seen to belong within the tradition of experimental research, and to require limited numbers of studies for a conclusion to be supported, provided all come to the same conclusion. The focus of each study, however, must be very constrained. This may also apply to qualitative research of the same topic, where replicability of themes or concepts in different studies may be regarded as proving evidence that they are generalisable beyond the individual contexts in which they were generated.

**3. Comparative analysis** This allows the systematic development and testing of hypotheses. Hammersley (2002) regards this as an approach that links experimental and qualitative research traditions reflecting both traditional scientific approaches to

theory development and testing and to notions of induction and grounded theory utilised in qualitative research. However, he notes that the process of theory development is sequential, so that developed theories need to be rigorously tested in subsequent research, but since it is unlikely that all stages of such testing already exist in the literature to be synthesised, it is expected that additional primary research would still need to be undertaken.

**4. Complementary synthesis** Applicable in qualitative research, this uses metaphors such as “mapping” or “mosaics” to describe the processes of synthesis. Studies may provide information about related areas, and bringing a series of study reports together on such related areas allows a broader picture to be developed. In such an approach, each study would provide a distinctive contribution, and value is placed on the complementary nature of the evidence, rather than its similarity. Hammersley (2002) regards this approach as the most similar in approach to traditional reviews, and regards it as marginal to the notion of systematic review.

**5. Translation of findings into one another** In this approach, key metaphors and concepts are developed from existing studies that may help future understanding of a phenomenon. This is the main mechanism of meta-ethnography which is detailed later in this chapter.

Hammersley (2002) does not regard this last approach, translation, as “synthesis” but rather as the development of a new explanatory framework “which encompasses existing studies and shows them in a new and illuminating light, or one that is more inclusive or abstract than that in which they were originally framed.” (p.4) Indeed, Hammersley (2002) questions whether some of these approaches are really literature reviews, but rather constitute “actually *doing* research” (emphasis in original). I would argue that most systematic reviewers *do* regard what they do as “actual research” and that synthesis, done well, ought not be regarded as anything else. Traditional literature reviews attempt to describe and summarise an existing body of literature, and existing theories in the literature may, at most, be linked to show their development over time (Doyle, 2003). As Noblit and Hare (1988) have noted, the conventional requirement of a literature review as part of the background to a researcher’s own project has meant that they are often “more ritualised than substantive accomplishments.” (p.15) Meanwhile, synthesis has been *defined* as involving “conceptual innovation” not found in the individual parts (Strike and Posner, 1983, quoted by Britten et al, 2002). The development of a novel explanatory framework, or a line of argument that encompasses elements from a number of sources and expands them, arguably requires the same level of critical, interpretive endeavour as the analysis of primary

data. Further, any newly developed hypothesis could be tested in future studies (Britten, Campbell, Pope, Donovan & Morgan, 2002).

In the synthesis of qualitative research, aggregation and generalisation may be part of the process, although such possibilities should not be at the expense of the specific and the unique which are highlighted by interpretive approaches. However, the review of qualitative research has parallels with the meta-analysis of quantitative data, in that it applies a rigorous procedure to the synthesis of separate studies. According to Noblit and Hare (1988), those engaged in quantitative meta-analysis such as Cooper et al (1984), Glass et al (1981) and Hunter et al (1982) have also acknowledged that meta-analysts bring their own perspective to the analysis which is itself interpretive in nature.

Noblit and Hare define two approaches to synthesis, the integrative, regarded as rooted in the positivist tradition, and the interpretive. This distinction is picked up by the Joanna Briggs Institute (JBI) and by Dixon-Woods, who challenges the association of integrative methods solely with positivism or quantitative data (Dixon-Woods et al., 2004). Techniques that involve assembling and pooling data, such as the meta-analysis of quantitative data, belong to the integrative tradition and encompass Hammersley's first two classifications (2002). However, there are also some methods of assembling quantitative data, such as Bayesian methods, that are integrative. The JBI suggests that, where study findings are well-specified and secure, aggregative synthesis is possible to "generate a set of statements that adequately represent that aggregation" (Pearson, 2006).

The Centre for Reviews and Dissemination (CRD) stated in 2001 that "there are no formal procedures available to aid narrative synthesis of findings from qualitative studies within the context of a systematic review" (Centre for Reviews and Dissemination, 2001) and advised that early involvement of an "expert" be engaged if such a synthesis were to be attempted (Section 1.2, p.5). Although there is clearly support for the possible inclusion of qualitative research in systematic reviews, little detailed information is presented that would assist this. The CRD report emphasises the importance of transparency in any developed methods, and the replicability of findings, both of which are indicators of quality carried over from Cochrane-style reviews. In fact they state that "it is not possible to generate guidance at this stage on hierarchies of qualitative evidence" (Section 2.5, p. 13). Qualitative research over multiple sites research is regarded as having the advantage of offering greater confidence in the generalisability of findings or explanations. CRD cite the methods of Miles and Huberman (Miles & Huberman, 1994) and of Noblit and Hare's meta-ethnography as examples of possible approaches to synthesis, although these

suggestions are not further discussed. Miles and Huberman's sourcebook provides guidance for the analysis of primary qualitative research. Noblit and Hare's approach to synthesis will be discussed in detail later in this chapter (Section 3.2, page 42).

In fact meta-ethnography (Noblit & Hare, 1988), meta-synthesis (Jensen & Allen, 1996) and aggregated synthesis (Estabrooks, Field & Morse, 1994) were both described prior to 2001, and a number of additional methods have since been suggested, among them meta-study (Paterson et al., 2001), meta-narrative (Greenhalgh et al., 2005), realist review (Pawson et al., 2004), narrative synthesis (Popay, Roberts, Sowden, Petticrew, Arai, Rodgers et al. 2006), and the methods outlined by the EPPI-centre (Rees, Harden, Shepherd, Brunton, Oliver & Oakley, 2001), methods for the social sciences (Petticrew & Roberts, 2006) and the Joanna Briggs Institute (JBI) (Pearson, 2006). In addition, meta-ethnography has been further tested over this time period (Britten et al., 2002; Campbell et al., 2003). The number of methods for systematic review and synthesis has doubled since this project's beginning in 2004. As yet, no specific method has been held up as the "gold standard" for the synthesis of qualitative research (Dixon-Woods et al., 2004). The methods share a common goal of going beyond single study findings using qualitative methods and using some method to combine and extend the studies to produce a synthesised account of their findings. Beyond this, there are some subtle and not so subtle differences between them. In this section I provide a brief account of each of these suggested methods. I reproduce the stages of review envisaged by the authors. This chapter thus provides the background to the detailed comparative chapter that follows.

Ten methods are discussed here in the sequence in which they were first described. This gives an insight into the development of concerns over time and allows me to illustrate where authors refer back to previously described methods:

- Meta-ethnography (Noblit & Hare, 1988)
- Aggregated synthesis (Estabrooks et al., 1994)
- Meta-synthesis (Jensen & Allen, 1996)
- The EPPI-centre method (Rees et al., 2001)
- Meta-study (Paterson et al., 2001)
- Realist review (Pawson et al., 2004)
- Meta-narrative review (Greenhalgh et al., 2005)
- Narrative synthesis (Popay et al., 2006)
- Systematic reviews in the social sciences (Petticrew & Roberts, 2006)

- The JBI method (Pearson, 2006)

Key approaches and understandings about review and synthesis encompassed by each method are presented. Where available, a summary box of the key stages of each review method is then reproduced. Detailed comparison between the methods is undertaken in Chapter 4.

## **3.2 Meta-ethnography**

Noblit and Hare describe the theory and methods of meta-ethnography in a book of the same name published in 1988. The method was developed by the authors following their own perceived failure to meaningfully synthesise the results of six ethnographic studies about desegregation in schools in the USA. The prime failing they identified was that the attempt at aggregating findings from different sites led to a “blunting” of the conclusions, leaving only “trite”, generalised explanations for the schools’ failure to desegregate. Noblit and Hare’s original approach did not explore the context of the findings and did not allow explanatory synthesis. It was this experience that led to the development of the meta-ethnography method in an attempt to address this perceived flaw. Meta-ethnography was therefore primarily developed as a mechanism of synthesis, rather than a method of systematic review, as the initial test project was based on study reports with which the authors were already involved.

Its developers see meta-ethnography as linking the positivist and the interpretive paradigms within social research. Through interpretive methods, it allows knowledge to be built upon, in line with the positivist ideal of knowledge accumulating and improving over time. However, it maintains an interpretive perspective and investigates events through the experiences and perspectives of those living them. This is in contrast to positivist definitions of accumulation, which the authors see as focussing on summarising data and on similarities, rather than preserving the unique elements of studies. Providing a perspective is a key aspect of qualitative research, which is also concerned with providing “meaning in context” that should be maintained through the synthesis.

In meta-ethnography the results of qualitative studies are synthesised through the reciprocal translation of study findings on similar areas into one another. The reviewer engages in an interpretive process which reveals analogies between different qualitative research accounts based on the selection of key metaphors, concepts and organisers. As such, the perspective of the researcher is recognised as crucial and the

synthesis produced will be only one possible interpretation of the data. In other words, replicability is not seen as a desirable or necessary attribute of the synthesis.

The authors state that synthesis should not attempt to *aggregate* data, as the process is one of translation, interpretation and comparison. Noblit and Hare also caution against attempts to generalise, which they see as the essential flaw in their initial attempts to synthesise. It appears that “generalisation” here relates to conclusions that are general, and which fail to take account of the way in which competing explanations are related to one another. They follow Turner’s anthropological interpretation of social explanation (1980), that all explanation is essentially comparative, and takes the form of translation; that is, research findings are translated into the researcher’s world view (p.25). In addition, the authors identify Brown (1977) who argues that “[i]n the broadest sense, metaphor is seeing something from the view point of something else, which means...all knowledge is metaphoric.” (p.33) While recognising that such a view may be controversial outside the circle of the most committed interpretivists, Noblit and Hare suggest that regarding knowledge in this relative, symbolic way prevents the “premature closure” of meaning (p.33).

Noblit and Hare categorise all data interpretations as taking one of three forms:

1. *Those that make the obvious obvious*
2. *Those that make the obvious dubious*
3. *Those that make the hidden obvious*

As well as outlining the theory behind meta-ethnography, Noblit and Hare attempt to describe its execution, describing seven “phases” of the process:

1. *Getting started*
2. *Deciding what is relevant to the initial interest*
3. *Reading the studies*
4. *Determining how studies are related*
5. *Translating the studies into one another*
6. *Synthesising the translations*
7. *Expressing the synthesis* (Noblit & Hare, 1988)

I briefly describe the content of each of these phases below to illustrate their approach.

## **1. Getting started**

This refers to the process of identifying an area of interest which the researcher wishes to examine. Such an area of interest is regarded this as almost entirely driven by the researcher's interest as "there is no value in a synthesis that is not of interest to the author." (p.27) However, they recognise that in most cases there will be an anticipated audience, or indeed commissioner, who will also have an agenda of interest.

## **2. Deciding what is relevant**

Noblit and Hare suggest that the relevance of reports included in the meta-ethnography needs to be justified in terms of what may be learnt from their *synthesis* as well as the relevance to the anticipated audience. Indeed, the authors state:

*Unless there is some substantive reason for an exhaustive search, generalising from all studies of a particular setting yields trite conclusions. (p.28)*

It is acknowledged that it may be difficult to identify all relevant research for a meta-ethnography synthesis although, given the date of publication, this section of Noblit and Hare's book omits any mention of electronic data sources.

## **3. Reading the studies**

Through repeated readings and noting of the interpretive metaphors used by the primary research authors, Noblit and Hare suggest a dynamic process which requires that the details of individual study findings are attended to in the context of the meta-ethnographer's substantive concerns. This seems to be similar to immersion in the data and constant comparison that is the backbone of the analysis of primary qualitative data, although focus on metaphors is most familiar to ethnography.

## **4. Determining how the studies are related**

This involves listing key metaphors, phrases, ideas and concepts, from each included study and juxtaposing them in order to initially identify their relationships to each other. These relations may be amenable to reciprocal translation, where concepts can be seen as relating to similar phenomena, or may be encompassed by those of other studies. Alternatively, they may offer refutational positions, where opposite conclusions are drawn. Finally, study concepts may be linked to create a line of argument, developing ideas across more than one study.

## **5. Translating the studies into one another**

This is a central process in the meta-ethnography method in which individual research accounts are treated as analogous. Unlike aggregating results, successful translation allows the central metaphor or concept of individual studies to be maintained, together with its relation to the other key metaphors in the same account. These are compared both within and across studies.

## **6. Synthesising translations**

While the translations themselves are regarded as one level of a meta-ethnography, a second level of synthesis may be possible when the number of studies is large or there are many translations. This involves comparing the interpretations to see if the types of translation are able to encompass other accounts: where this is possible they can be translated into one another.

## **7. Expressing the synthesis**

As most meta-ethnographies are undertaken in the academic world, this is likely to involve a written report, translated into the language of the audience. For example, in the context of this thesis, an audience of policy makers, such as HTA reports for an organisation like NICE, would require a specific approach. In addition, however, this study is being presented for an academic higher degree, which is a very particular milieu, with specific rules and expectations of both content and presentation. The NICE appraisal committee includes clinical and patient experts for the topic under consideration, as well as permanent appraisal committee members, each of which may also have different expectations and references.

Meta-ethnography was the first method of synthesis for qualitative research findings to be described. Although not much work was done on meta-ethnography immediately after the publication of Noblit and Hare's book, interest has revived in the climate of evidence-based practice, and a number of papers have been written over recent years which use and develop the method (Campbell et al., 2003; Britten et al., 2002; Hess Rice, 2002; Feder, Hutson, Ramsay & Taket, 2006; Smith, Pope & Botha, 2005). This is despite its conception outside the disciplines and concerns of EMP. As will be seen below, meta-ethnography continues to inform mechanisms for synthesis in a number of more recent suggested methods for systematic review. In addition Dixon Woods et al produced a large systematic review about vulnerable groups' access to health care, using a technique they call "critical interpretative synthesis" which they developed from meta-ethnography. Key differences to original meta-ethnography were the inclusion of

both quantitative and qualitative research in their review and the use of “line of argument” synthesis as the primary tool (Dixon-Woods, Kirk, Agarwal, Arthur, Harvey, Hsu et al. 2005).

### **3.3 Aggregated Synthesis**

Another early approach to the review of qualitative research is “aggregated synthesis”, described in a short article by Estabrooks et al in 1994. The authors propose synthesis as a way of addressing criticisms of qualitative research, particularly the charge that limited samples and sample homogeneity constrain theory development and generalisability. They note that their definition of aggregation is different from that used by Noblit and Hare. Aggregated synthesis is defined as an interpretive process, which attempts to preserve the context of the original research, and place greater emphasis on theory building as the purpose of synthesis. The goal of aggregated synthesis is theory development, embracing the positivist notion of cumulative knowledge which can not only *explain*, but also *predict* behaviour. One perceived benefit of synthesis is to enhance the credibility of individual studies: where similar findings are seen in different studies, this is regarded as enhancing their reliability.

The stages of aggregated synthesis are not very clearly laid out. However, they appear to be:

- Selection of studies on similar populations or themes
- Identification of themes and labels in the studies
- Constant comparing and contrasting of themes between studies

The approach to synthesis seems to contain elements of grounded theory, in that labels and themes are expected to be grounded in the data and constant comparison is a primary method of analysis. At the same time, there are other elements that sound like the translation phase of meta-ethnography (although it is not defined as such), with the reviewer examining labels to determine whether different labels used in different studies in fact refer to the same data category. Such labels may refer to thematic organisers in the text of the report, as well as to conceptual terms.

Aggregative synthesis values the identification of commonalities between studies. This is seen as increasing generalisability of primary study findings, while also validating them. Alternative explanations for similarities between studies are possible and are discussed below in relation to synthesis through meta-study. It should be noted that

aggregated synthesis has not been much used in the literature as a way of synthesising qualitative research.

### 3.4 Meta-synthesis

The term meta-synthesis was first used in an article by Jensen and Allen in 1996. The techniques for synthesis hinge on Noblit and Hare's description of reciprocal translation. Although Noblit and Hare's book is referenced, it is not totally clear from the writing that this is the source for the main mechanism of synthesis. The authors follow Noblit and Hare in describing all interpretive enquiry as essentially translation thereby facilitating reciprocal translation between primary research accounts. Differences between the two methods are not discussed.

On the whole, this article is rather confused. It poses questions about the nature and processes of synthesis but does not provide clear answers. Consequently, I looked at a number of published study reports that described themselves as undertaking a meta-synthesis, to see if there was illumination through the process they undertook. Despite being labelled with the same methodological tag, the studies in fact proceeded in a variety of ways. The list is not exhaustive, it has been used to describe review and synthesis in many published studies, but it illustrates the range of approaches used under the name of meta-synthesis (Table 2). The table shows differences in a number of review stages, for example, how study reports are identified, what strategies are used for data extraction and quality assessment.

This slippage of meaning or lack of consistency in applying the terminology has also been noted within the qualitative research community. In their book of 2007, Sandelowski and Barroso have recently attempted to clarify what they see as the key elements of meta-synthesis, while some elements were previously described in a paper by the same authors (Sandelowski & Barroso, 2003c; Sandelowski & Barroso, 2007). Their methodological description is based on a meta-synthesis about motherhood in women with HIV living in the USA - a project with a strong methodological development element. Although Sandelowski and Barroso state that the term "meta-synthesis" does not signal the use of any *specific* method of synthesising findings, their description gives guidance for a framework to approach the review and analysis (Sandelowski & Barroso, 2003c). They recommend using an approach that reflects the purpose of the synthesis but warn that:

*Qualitative research synthesis is in danger of meaning nothing, because it means too much. (Sandelowski and Barroso, 2007, p.8)*

They also emphasise the importance of experienced, multi-disciplinary teams undertaking reviews because the method is demanding and needs flexibility of approach.

**Table 2 Summary of the methods used by some studies undertaking meta-synthesis.**

Authors	Aim	Searching	Sampling	Inclusion criteria	Quality assessment	Data extraction/unit of analysis	Synthesis method
(Arman M & Rehnsfeldt A, 2003)	To review the lived experience of suffering in relation to how breast cancer was described in nursing/ caring literature. To interpret this through theories of suffering.	Not totally clear – 1 electronic data base?	Not clear – all those identified included?  14 studies included	Written in English, published in nursing/ caring journal between 1990 and 2000, “acceptable” - qualitative or mixed methods. Focus explicitly or implicitly on suffering. Purely psychological concepts were excluded, as was quality of life as it “expresses a different paradigm”.	Methodological quality was assessed but methods used not stated.	Concepts relating to the experience of suffering in breast cancer.  Theoretical frameworks of suffering described by Casell, 1982p; Kahn and Steeves, 1986; Erikson 1994, 1997 etc. were used by the authors as the lens through which the research was explored.	Sherwood (1999, previous example of meta-synthesis), also Paterson et al’s meta-study. Hermeneutic phenomenological approach. 1. Descriptive step – 2 authors completed an article “protocol”, discussed this analysis. 2. Reflective dialogue asking questions in a “hermeneutical spiral”. 3. Reread the articles with these questions in mind to synthesis to new levels. 4. Findings deductively re-examined in reflective dialogue.
(Attree, 2005)	To explore low-income parents’ experiences of formal and informal support and consider their strengths and weaknesses in the context of poverty.	Electronic databases, contact with experts, website and citation searching.	Included all UK based, high quality papers.  12 papers included	Focus on the subjective views of parenting in poverty. 2 reviewers checked for relevance	Developed checklist based on previous publication. 2 reviewers for inclusion	Not stated	CRD guidelines followed. Synthesis followed meta-ethnography methods for a line of argument synthesis.
(Barroso & Powell-Cope GM, 2000)	To understand the lived experience of those with HIV as described in published research. “Crucial for	“Extensive” electronic searches	USA studies only  21 papers included	Qualitative research on adult experiences living with HIV published in peer review journals.	Peer reviewed through journal publication. Also Burns (1989): Descriptive vividness	Themes & conceptual categories extracted, coded, compared & translated	Constant comparative analysis. Meta-ethnography.

Authors	Aim	Searching	Sampling	Inclusion criteria	Quality assessment	Data extraction/unit of analysis	Synthesis method
	providing direction for practice and research”			High quality.	Methodological Congruence, analytical preciseness, theoretical connectedness, Heuristic relevance. Double author assessment		
(Epstein, Orr & Stevens, 2004)	To accumulate and expand knowledge about the experience of suffering in children with cancer.	3 electronic databases	Not clear ?All identified included  17 papers included	About those aged 5-21, implicitly or explicitly including concepts to do with suffering. (assessed by 2 researchers)	None described	Concepts	Meta-synthesis as described by Jensen& Allen and Paterson.
(Kylma, 2005)	To explore and define the concepts of despair and hopelessness in HIV. Also quotes Estabrooks on development of mid range theory.	1 electronic data-base	All identified included.  5 studies included - all were by the same author as the review	Grounded theory methodology. Studies that describe despair and hopelessness simultaneously in the context of HIV.	None described.	“factors or categories describing the dynamics of hope and the basic process of living with HIV”.	Sandelowski, Jensen and Allen. Steps were : 1. Reading articles 2. Extracting factors or categories describing the dynamics of hope and the basic process of living with HIV. 3. Constantly comparing extracted factors/ categories 4. Selective coding after core category emerged 5. Gathering categories together. Also looked at triangulation of findings with different empirical units as data sources but not clear what this amount to – it says that elements of despair in this study relate to those on Beck’s Hopelessness Scale, not clear if this is what it meant.

The key elements of meta-synthesis are described as:

- *a systematic approach to both collection and analysis of qualitative research,*
- *a focus on the findings of the included studies*
- *the use of qualitative methods to formally integrate (synthesise) these findings.*  
(Sandelowski & Barroso, 2007)

They describe the process as aiming at “the amplification of data and *interpretive innovation*” (my emphasis, p.154) and go on to say:

*Any qualitative meta-synthesis of findings thus constitutes an interpretation at least three times removed from the lives represented in them: it is the synthesist’s interpretation of the researchers’ interpretations of research participants’ interpretations of their lives.*(p.166 (Sandelowski & Barroso, 2003c)

This aligns with Britten et al’s understanding of the synthesist’s reinterpretation of primary researcher concepts as third-order conceptualisation in their description of a meta-ethnography project (Britten et al., 2002).

Crucially, Sandelowski and Barroso (2007) identify two possible approaches to synthesis depending on the type of primary research studies which are available. They base their distinction on the degree to which there is evidence of data transformation in study reports. They understand that some studies, which are apparently qualitative research, actually contain little transformation of data (the quotes from participants) into findings (researchers’ interpretations of that data). Again this can be understood as a failure of researchers to produce second order concepts, from first order concepts (the way in which research participants interpret their lives). Instead, findings are presented, sometimes under descriptive thematic headers, but no attempt is made to interpret the data. Sandelowski and Barroso (2007) call such studies “thematic summaries or surveys of data” (p.17) and do not regard them as suitable subjects for synthesis. Only projects which already represent the transformation of data into findings (whether grounded theory, phenomenology, or “other coherent descriptions or explanations” (p.18) are seen as amenable to further interpretive synthesis through meta-synthesis. In effect, this acts as a quality indicator affecting inclusion criteria for the review. This is discussed further in Section 4.6.2, where I compare different approaches to synthesis.

Sandelowski and Barroso (2007) distinguish meta-synthesis from meta-study, with the former described as “empirical/ analytic readings” and the latter as “critical/ discursive readings”:

*Research syntheses are conceived here as empirically grounded and verifiable interpretations of the lived experiences of the research participants.*

*In contrast, in critical/discursive readings, write up of studies are conceived historically and culturally contingent social products of unique encounters between researchers and research participants, and reviewers and texts, which reveal more about the experience of researching and the disciplinary commitments of writers than about the target experience itself. (p. 22 Sandelowski and Barroso (2007))*

Meta-study is discussed later in this chapter at Section 3.6. I consider, however that the authors of meta-study do not conceive their project in this way, since they are attempting to provide an interpretive synthesis of research findings, while accounting for differences and similarities that may be the result of following particular methods or academic disciplines.

### **3.5 The Synthesis Method Described by the Evidence for Policy and Practice Information and Co-ordinating Centre**

The method of systematically considering research evidence from a range of quantitative and qualitative data developed by Evidence for Policy and Practice Information and Co-ordinating centre (EPPI-centre) aims to use explicit methods for their synthesis “in order to produce valid and reliable results” (Rees et al., 2001). This is the first method which is clearly developed from within the realm of evidence-based practice, with a focus on providing information for policy makers and drawing on existing processes for systematic reviews. It is also the first to concentrate on including mixed methods in a single review; previous methods are concerned with qualitative research only.

Bias is reduced, as far as possible, through the explicit recording of review methods, trying to identify as much of the relevant literature as possible, using standardised methods of coding which are applied by more than one reviewer, assessing the quality of included studies and basing conclusions and recommendations on the most rigorous studies (Rees et al., 2001). Their method has been used in several projects about child health, exploring barriers and facilitators to physical exercise and healthy eating. The description of methods for the 2001 exercise project by Rees et al provide most of the methodological information on which I draw here.

The physical exercise review was carried out in two phases:

1. Descriptive mapping and quality screening of all studies within the review's scope;
2. An in-depth review of quality and findings of a sub-set of identified studies.

Rees et al recommend collaboration with commissioners and end-users about the most relevant focus for the review and this may include defining the focus of research, study design and quality, date and location of research and so on. Types of studies included were arranged into three broad theoretical schools – sociological, psychological and pedagogical and the frameworks utilised within these disciplines are described (p.14, Rees et al 2001). This has echoes of the meta-study method described below in Section 3.6, where similarities and differences within disciplinary groupings are explored prior to full synthesis across disciplines.

A key step of the review is to develop a hypothesis about the topic area on which it is focused. The methods for developing such a hypothesis are not provided. In this case, the authors hypothesised that facilitators and barriers to young people's physical activity could be identified in several ways. These were:

- *By examining those interventions shown to be effective, identifying whether they aimed to remove or reduce barriers and which facilitators were built upon*
- *By examining the barriers and facilitators of interventions that actually reduced physical activity.*
- *By examining research that aimed to describe factors which influence young people's participation positively or negatively (p.51, Rees et al 2001)*

In addition, a conceptual framework was used through which the authors categorise the level at which potential barriers and facilitators operate: individual (knowledge, attitudes, skills and so on), the community (social support networks, family relationships) and societal (discrimination, social class, access to resources etc.) (p.21). It is not clear how, or at what point in the process, this framework was developed. Although it appears to be based on the existing knowledge of the research team, it seems possible that it was developed through an iterative process using prior knowledge and interest but developed through the mapping process, familiarising with the literature and in consultation with the wider research team. In addition, the in-depth review was focused on the last two categories, and again it is not clear at what stage this decision was made, or how (p.51). Presumably, this was part of the consultation process with the steering group and commissioners (Rees et al., 2001).

The EPPI-centre method is different from those previously described in its adoption of the concerns of EBP systematic reviews and explicit policy focus whilst also introducing elements specific to qualitative research.

### **3.6 Meta-study**

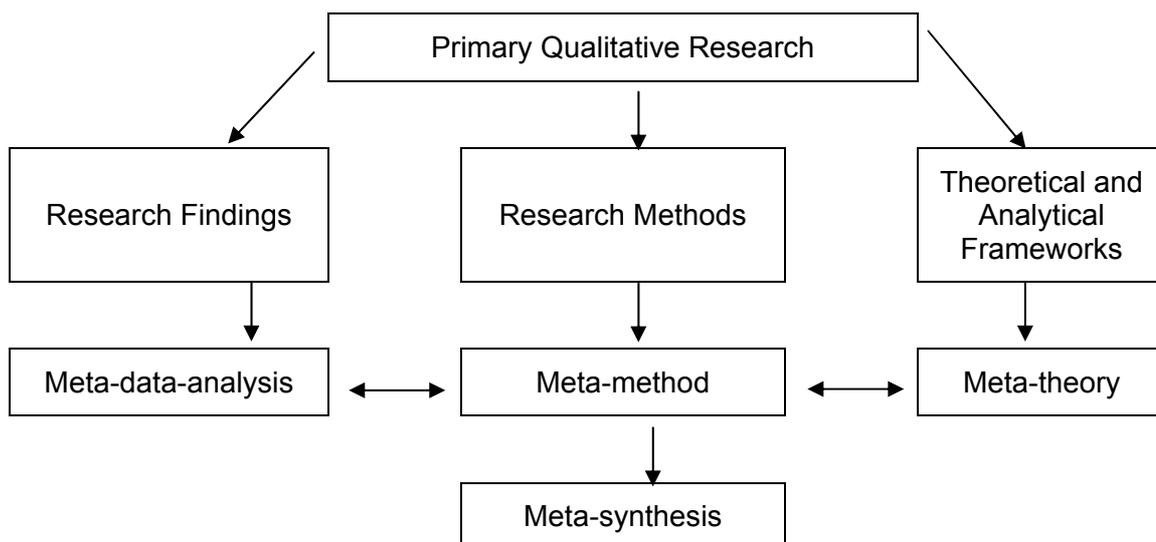
Mechanisms for meta-study are described in a book of the same name published by Paterson et al in 2001. The method was developed from 1995 through a series of projects, the largest of which was an attempt to synthesise qualitative research evidence about the subjective experience of chronic illness. Other projects undertaken by the same team have focused on the phenomenon of adaptation to diabetes and the experience of fatigue in chronic illness (Paterson, Canam, Joachim & Thorne, 2003; Joachim & Acorn S, 2000). It includes only qualitative research and is defined as:

*a research approach involving analysis of theory, methods and findings in qualitative research and the synthesis of these insights into new ways of thinking about phenomenon [which] creates a mechanism by which the nature of interpretation is exposed and the meanings that extend well beyond those presented in the available body of knowledge can be generated. As such, it offers a critical, historical and theoretical analytic approach to making sense of qualitatively derived knowledge. (p.1-2, Paterson et al 2001)*

The aim is to transform the accumulation of findings into a “legitimate body of knowledge” (p.133) with the ultimate aim of both generating new theory, and informing nursing practice, the sphere in which the authors operate. Crucially, the authors were looking for methods of synthesis that incorporated the theoretical, methodological and societal contexts of research findings. The components of meta-study are illustrated in Figure 1. Note that the stage of meta-synthesis in this diagram shares a name, but not a method, with the meta-synthesis described in Section 3.4. The method is unique among those presented here in the extent to which it focuses on the importance of understanding the findings in terms of the methods and theories that drive it, prior to bringing all these elements together as a full meta-study.

The authors usefully distinguish between the processes of “analysis” and “synthesis”, so that scrutiny of existing studies (analysis) must come first in order to facilitate synthesis. A synthesis is defined as a *critical interpretation* of existing research that creates “new and more complete understandings of the phenomenon under study”.

**Figure 1: Components of meta-study**



Source: Paterson et al, 2001

The authors relate meta-study to earlier ideas of meta-sociology described by Furfey in 1953 which suggested that meta-sociology was a focus on the “underpinnings, approaches, and outcomes central to sociological research” (Paterson et al., 2001). Such concerns with the systematic study of sociological theory were later labelled “meta-theorising” by Ritzer (1991), who identified three types of meta-theorising, delineated by their end products:

- *the attainment of a deeper understanding of theory,*
- *the creation of new theory,*
- *the creation of an overarching theoretical perspective (a meta-theory). (Ritzer, 1991)*

Ritzer identified the lack of a clear definition of this field. Work by Zhao subsequently named the systematic approach to analysing sociological knowledge from different perspectives as meta-study (Zhao, 1991). Paterson et al (2001) also cite Noblit and Hare’s meta-ethnography as a previously developed method for understanding different studies in a particular field of research. Meta-ethnography is included as a possible mechanism for the meta-data-analysis phase of meta-study.

A key step in meta-study is articulating a theoretical framework to inform the direction of the project. This may be a “found” framework (available from the extant literature), or an “imported” framework (selected by the team), which defines the phenomenon of interest and its concepts. In the main project through which meta-study was developed, Paterson et al (2001) used Curtin and Lubkin’s model of chronic illness as an imported framework (Curtin & Lubkin, 1990). This directed the shape of the review

in such areas as inclusion criteria and analysis. It appears that this model was chosen at the beginning, although it is not entirely clear from the description if this was a model with which members of the team were previously familiar, or whether it was identified during the course of the review.

Paterson et al (2001) describe how elements of the chosen model came to be challenged over the course of the review, as they became more familiar with the literature and tried to apply it. Nevertheless, it does not appear that they modified or abandoned the model as a result. Ultimately, meta-study is seen as providing a method to refute the model that they used. There appears to be some internal contradiction here, as the authors also state that they viewed with “considerable caution” those primary studies which, although they appeared to be studying the experience of chronic illness, actually seemed to use findings to validate a particular, imported theoretical framework without considering others available. This appears to be the approach they took in their review and indeed the fact that they came to refute the model they used through the synthesis suggests that it was not the most appropriate.

Stages in the research process are listed in Box 1 (p. 61), although these are not regarded as entirely sequential. The key components of meta-data-analysis, meta-method and meta-theory are outlined below.

### **3.6.1 Meta-data-analysis**

The “meta-data-analysis” stage of meta-study involves a systematic, critical examination of the findings in primary research reports in order to establish similarities and differences between accounts of a particular phenomenon. In addition, study reports may be explored through the conclusions and concepts of other studies while theories developed may be tested against data from other research. Like meta-ethnography, meta-study incorporates the metaphor of “translation” to describe the mechanism by which the reviewer interprets the findings of primary research. The process of translation involves making judgements about other researchers’ findings, and looking for relationships between them. However, various other analytic approaches to meta-data-analysis are also suggested as viable, including grounded theory, thematic analysis and interpretive descriptive analysis. Paterson et al (2001) note that grounded theory analysis may be hampered by inherent limitations in the available data, depending as it does on *existing* research reports, thereby potentially preventing data saturation and limiting theory development.

Data is defined as the research findings of the reports:

*whether depicted as themes, categories, domains, patterns or processes. (p.57)*

Such data, it is claimed, should be filtered through the reviewer who should examine given findings for *utility* in relation to illuminating the research questions and perceived credibility of the findings.

The method of analysis is described as multifaceted in the worked example, as Paterson et al (2001) grouped study findings in several ways; by disease, by nature of sample, by whether the disease was terminal, by date of publication and by research method. The study reports were analysed within these groupings in order to identify similarities, differences and outliers more easily. The importance of meticulous record keeping, audit trails and filing of the research process is emphasised, reflecting the primary qualitative research processes with which the authors are familiar.

### **3.6.2 Meta-method**

The “meta-method” stage of meta-study is primarily concerned with the appropriateness of the methods used in the primary studies and assesses whether differences in epistemological approach lead to differences in findings between research reports. The impact of methods on the findings in any particular paper, and on the theory emerging in a field of research, is assessed. Meta-method may also be used to study historical changes, tracing how interest in particular methods, phenomena or populations have evolved and any impact these changing methods have on research findings. This allows an assessment of how “patterns of research may have shaped a particular knowledge base” (p.81). For example, it may reveal that there are similarities in conclusions in those studies conducted by nurses which are different from those undertaken by sociologists, although sociologists’ findings may be similar to each other.

In order to review the methodology of included research, the research question, role of the researcher, setting, sampling procedures and methods of data collection are examined, and the “fit” (p.78) between these elements considered. Methodological orientation may be explicit, or implicit as revealed through the language used to describe the approach or methods used. Paterson et al (2001) note that the stated orientation of the research may be implicit rather than explicit, and that the approach suggested by the language of the study reports or the actual processes described, may be at odds with that named.

### 3.6.3 Meta-theory

Within meta-study, analysis of the theoretical perspectives that both drive, and arise from, the included research is defined as “meta-theory”. Meta-theory may either produce new theory, or expand on that available in the primary research. I use the term “index theory” to describe a theory in the primary research reports that is used in the synthesis as the lens through which other studies are assessed. Primary research may utilise or develop theory in a number of ways. Theory may be tested, generated or evaluated by the research, or may frame its focus. The relationships between emerging theory and the larger contexts in which such theory has been generated may also be examined. The authors note that, as with methodology, use of theory may be implicit and well as explicit.

Theory is understood as:

*A system of interrelated propositions that should enable phenomena to be described, explained, predicted, and controlled. (Duldt & Griffin, 1985)*

Further, Paterson et al (2001) adapt Ritzer’s procedures of meta-theory to describe their processes for a critical analysis of theory in the primary research studies:

1. *Identifying any major cognitive paradigms and schools of thought that are represented in both the theoretical frameworks and the emerging theory of selected research reports.*
2. *Identifying and deconstructing assumptions that underlie the theory.*
3. *Examining the historical evolution of theory (changes over time, adaptation of original theory, evolutionary landmarks.)*
4. *Relating the theory to the larger socio-cultural, historical, and political context, and how these may have influenced the selection of theoretical frameworks or interpretation of findings to support a particular theory.*
5. *Evaluating the quality of the selected theory. (Ritzer, 1991)*

Clearly, a high degree of familiarity with a wide range of different disciplines and theories within them is required to do this thoroughly, as well as knowledge about major theoretical frameworks associated with the particular topic area under examination. The research team may not be sufficient to encompass all this knowledge and additional contact with other experts about specific theories may be required. As Paterson et al (2001) state, use of theory may be implicit as well as

explicit. There must always be the possibility that such theories go unrecognised if they are not previously known by the team.

Additionally, once theories have been identified, meta-theory may challenge and deconstruct these positions.

*By interrogating the provided conclusions against other interpretations that may have been possible, we were able to raise questions concerning the uncritical acceptance of certain theoretical truths.....This analytic process allowed us to shift our interpretation from assuming that the similarities between studies strengthened their collective truth toward recognising the possibility of a systematic influence of one kind of theorizing on the generation of findings. (p.100, Ritzer 1991)*

This is a critical difference between meta-study and other mechanisms of review where similarities between study findings are largely interpreted as enhancing the reliability, validity and generalisability of individual studies and their findings. Meta-study requires that similarities are interrogated in relation to the methodological and theoretical traditions which produce, and are produced by them. Ultimately, meta-theorising is particularly concerned with end products and impacts, rather than processes. Thus, it tries to assess the practical implications for the lives of those studied of the underlying assumptions of theories involved in studying them.

The political, socio-cultural and historical context of theories utilised in the primary studies considered in the meta-study should also be examined in the meta-theory phase. In the authors' example, this involved exploring the popularity or development of prominent theories over time and the associated political and social climates that accompany them.

Finally, meta-theory involves assessing the quality of theory. This was done in two ways. Firstly, the ability of theories to explain findings across studies was investigated, with those applicable across more studies' findings considered the most robust. Paterson et al (2001) also used standards for the construction of theory (Lenski, 1988), although they do not prescribe this framework. Key elements of the quality assessment are:

- *Does the theory contain unambiguous concepts?*
- *Are the relationships between and among the concepts clearly articulated?*
- *Are the theoretical propositions empirically testable? (Ritzer, 1991)*

Such an assessment may establish whether competing theories in the field are compatible or incompatible.

#### **3.6.4 Meta-synthesis**

Meta-synthesis is used here in a different sense from that previously described by Sandelowski and Barroso (2001) or Jensen and Allen (1996). It refers to the three strands of meta-study being brought together in a final phase which aims to produce a thorough, new interpretation of a phenomenon that accounts for the data, methods and theory used in the primary research. Further, the meta-study hopes to influence future work in a field, by illuminating key areas for further research.

*We see meta-study as a methodological strategy to help us in linking subjective with objective realities, speculative truths with probable truths, and theoretically intriguing possibilities with practical real world applications. (Paterson et al., 2001, p.15)*

Having deconstructed and evaluated meanings through meta-data-analysis, meta-method and meta-theory, the meta-synthesis phase of a project “represents the visionary and constructive outcome of an exhaustive analysis project.” (ibid. p.109)

**Box 1: Research steps for meta-study (Paterson et al, 2001)**

*1. Formulating a research question*

- Formulating tentative questions
- Choosing a theoretical framework
- Generating workable definitions of key concepts under study
- Anticipating outcomes of a project
- Refining questions(s)
- Developing evaluation criteria for primary studies

*2. Selection and appraisal of primary research*

- Identifying inclusion/ exclusion criteria
- Specifying appropriate data sources
- Screening and appraisal procedure
- Retrieving data
- Developing filing and coding system

*3. Meta-data-analysis*

- Identifying analytic strategy
- Developing filing and coding system
- Categorising the data
- Obtaining intercoder consensus
- Discussing and interpreting findings as they relate to the research question(s)

*4. Meta-method*

- Specifying methodological characteristics of selected reports
- Elaborating on how methodological characteristics influenced research findings

*5. Meta-theory*

- Identifying major cognitive paradigms/schools of thought that are represented in the theoretical frameworks and emerging theory of reports
- Relating theory to larger social, historical, cultural and political context
- Uncovering significant assumptions underlying specific theories

*6. Meta-synthesis*

- Critically interpreting the strength and limitations of various discrete contributions to the field
- Uncovering significant assumptions underlying specific theories
- Searching for alternative explanations for paradoxes and contradictions within the field
- Determining which existing theoretical stances are not compatible and why
- Proposing alternative theoretical structures within which existing knowledge can be interpreted

*7. Dissemination of findings*

- Determining appropriate audiences
- Determining appropriate vehicles for dissemination of findings
- Writing and presenting the findings.

### 3.7 Realist Review

Realist review has been proposed by Pawson et al (2004) as a potential method for reviewing complex policy interventions in healthcare. It encompasses quantitative and/or qualitative research. It has a very specific focus on explaining *how* such programmes work, and *why* they fail to work in particular contexts. It is unique among the synthesis methods described here in that it focuses on a very specific type of intervention evaluation and because primary research may be undertaken as part of the project. Existing projects using this approach include an assessment of the effectiveness of Megan's law in protecting children and of school feeding projects.

Pawson sets up the nature of this enquiry in explicit opposition to Cochrane-style reviews, which are based on a successionist model of causation whereby the introduction of an experimental agent directly causes a measurable effect. Such an enquiry treats the human elements as biases or "contaminants" (Pawson, Greenhalgh, Harvey & Walshe, 2005a) and seeks to minimise them. In realist enquiry, complex interventions are seen often to *depend* on precisely such human action. Realist review describes itself as a "logic of enquiry" (p.32) rather than a methodology, with its roots in philosophical traditions of realism. In the realist approach, a causal relationship between two events can only be inferred when the underlying mechanism of action, and the context in which the relationship occurs, is fully understood. The aim is to generate explanatory conclusions, rather than definitive judgments, thereby replacing the "what works?" question of clinical effectiveness studies, and instead addressing "what is it about this programme that works, for whom, in what circumstances?"

Central to the approach is the understanding that interventions are built on theories which inform the method, style and content of delivery, expected to achieve some improved outcome. The theories informing interventions may have to travel a long way, from policy makers, to practitioners and the public. Different links in this chain of relationships will be crucial at different stages of the intervention and the possibility of failure is present at any link. Realist review is interested in identifying what inhibits and facilitates the flow between linked actors. As chains of implementation may break down at any point, intermediate outcomes, on which the ultimate programme outcome rests, also need to be identified. Unintended outcomes may also result from interventions, and these need to be identified and explained by the synthesis.

Realist review assumes that interventions exhibit complexity, with implementations proceeding in non-linear ways which are shaped by the relative power of the actors

involved. Their social context will affect the way in which they work, and realist review must be aware of elements that may cause the same intervention to succeed in some settings and fail in others. In addition, interventions are seen as “leaky and prone to be borrowed” (p.8). This means that practitioners in different schemes will learn from each other and thereby change the nature of the intervention, sometimes for the better and sometimes for the worse, between locations and over time. Finally, feedback systems mean that interventions will change the circumstances in which they operate, and may alter the very things that make them successful initially.

Any kind of evidence, derived through any research method can be included in realist review. This has been identified as a negative quality, as all types of evidence are given equal weight and authority (Dixon-Woods, 2005). There are no clear methods of dealing with contradictory evidence.

Key steps in the process are shown in Box 2, although the authors emphasise that the process is iterative, rather than sequential as this listing implies.

**Box 2. Key steps in realist review (Pawson *et al*, 2004)**

*Step 1: Clarify scope*

- a. Identify the review question
  - Nature and content of the intervention
  - Circumstances or context for its use
  - Policy intentions or objectives
- b. Refine the purpose of the review
  - Theory integrity – does the intervention work as predicted?
  - Theory adjudication – which theories fit best?
  - Comparison – how does the intervention work in different settings, for different groups?
  - Reality testing – how does the policy intent of the intervention translate into practice?
- c. Articulate key theories to be explored
  - Draw up a 'long list' of relevant programme theories by exploratory searching (see step 2)
  - Group, categorise or synthesise theories
  - Design a theoretically based evaluative framework to be populated with evidence.

*Step 2: Search for evidence*

- a. Exploratory background search to 'get a feel' for the literature
- b. Progressive focusing to identify key programme theories, refining inclusion criteria in the light of emerging data
- c. Purposive sampling to test a defined set of these theories, with additional 'snowball' sampling to explore new hypotheses as they emerge
- d. Final search for additional studies when review near completion

*Step 3: Appraise primary studies and extract data*

- a. Use judgment to supplement formal critical appraisal checklists, and consider fitness for 'purpose' –
  - Relevance – does the research address the theory under test?
  - Rigour – does the research support the conclusions drawn from it by the researchers or the reviewers?
- b. Develop 'bespoke' set of data extraction forms and notation devices
- c. Extract different data from different studies to populate evaluation framework with evidence

*Step 4: Synthesise evidence and draw conclusions*

- a. Synthesise data to achieve refinement of programme theory – that is to determine what works for whom, how and under what circumstances
- b. Allow purpose of review (see step 1b) to drive the synthesis process
- c. Use 'contradictory' evidence to generate insights about the influence of context
- d. Present conclusions as a series of contextualised decision points of the general format 'If A, then B' or 'In the case of C, D is unlikely to work'.

*Step 5: Disseminate, implement and evaluate*

- a. Draft and test out recommendations and conclusions with key stakeholders, focusing especially on levers that can be pulled in here-and-now policy contexts
- b. Work with practitioners and policy makers to apply recommendations in particular contexts
- c. Evaluate in terms of extent to which programmes are adjusted to take account of contextual influences revealed by the reviewer: the 'same' programme might be expanded in one setting, modified in another and abandoned in another

### 3.8 Meta-narrative Review

Developed by Greenhalgh et al (2005), the meta-narrative method can make use of disparate types of research evidence, both quantitative and qualitative, from different academic disciplines with the aim of informing policy makers about complex evidence in a particular field. The published example focuses on the diffusion of innovation in healthcare and the methodology was developed through the work on this project (Greenhalgh et al., 2005). The commissioners criticised an early version of the review as lacking sense (Greenhalgh et al 2005). As a result of this criticism the authors decided to produce a systematic account of the narratives within various research traditions and to use these stories of research traditions over time (meta-narratives) as their main unit of analysis. Thus the “meta” in the title refers to the overarching narrative of a body of research, rather than to the synthesis itself.

The process is clearly set against the positivist reasoning associated with traditional systematic reviews of quantitative literature, and aligns itself with what it calls “narrative interpretive reasoning”. Thus it accepts that many steps in the review are subjective and negotiable, and led by discussion, both within the team and with the commissioners. The authors see similarities between their method of synthesis and the realist method described by Pawson et al (2005a) and indeed Greenhalgh has been involved in realist reviews. Meta-narrative, however, can be applied to reviews of complex evidence that do not adopt a realist frame of reference.

The phases of meta-narrative synthesis are summarised in Box 3 although the authors emphasise that the phases overlapped and informed one another, rather than being separate and sequential as the listing might imply.

Once the initial searches had been undertaken and meta-narrative identified as the main unit of analysis, the authors described five questions that they used to interrogate each research tradition identified. Similarities can be seen between these, and the concerns of meta-study, such as the desire to understand how theoretical traditions have informed the research undertaken:

1. *What are the parameters of this tradition i.e. its scope, its historical roots, its key concepts and assumptions, and its theoretical basis?*
2. *What research questions (in what priority) have scientists in this tradition asked about diffusion of innovations? What methods and instruments have they used to answer those questions, and by what criteria has the methodological quality of primary studies generally been judged?*

3. *What are the main empirical findings of relevance from the quality literature in this research tradition?*
4. *How has the tradition unfolded over time? (i.e. in what way have the findings of earlier studies led to refinements in theory and/or influenced the design and direction of later empirical work)?*
5. *What are the strengths and limitations of this tradition, and in the light of these, what is its likely overall contribution to the body of knowledge on this topic area?*  
(Greenhalgh et al., 2005)

In order to synthesise the identified primary studies, the authors firstly identified seminal primary research that had provided the model for further work from within its research tradition. The paradigm that this seminal work represented, in terms of concepts, theories and methods and tools of research, was then described. Finally, aspects of the meta-narrative that appeared to be driving the research were commented upon. This included elements such as the social and historical background to the story and the plot as reported in some key publications.

**Box 3: Phases in meta-narrative review (Greenhalgh *et al*, 2005)**

**1. Planning phase**

- a. Assemble a multidisciplinary team whose background encompasses the relevant research traditions (an initial scoping phase may be needed before the definitive research team is appointed)
- b. Outline the initial research question in broad, open-ended format.
- c. Agree outputs with funder or client.
- d. Set a series of face-to-face review meetings including planned input from external peers drawn from the intended audience for the review.

**2. Search phase**

- a. Initial search led by intuition, informal networking and “browsing”, with a goal of mapping the diversity of perspectives and approaches.
- b. Search for seminal conceptual papers in each research tradition by tracking references of references. Evaluate these by the generic criteria of scholarship, comprehensiveness and contribution to subsequent work within the tradition.
- c. Search for empirical papers by electronic searching of key databases, hand-searching key journals and “snowballing” (references of references or electronic tracking)

**3. Mapping phase**

Identify (separately for each research tradition):

- a. The key elements of the research paradigm (conceptual, theoretical, methodological and instrumental).
- b. The key actors and events in the unfolding of the tradition (including main findings and how they came to be discovered).
- c. The prevailing language and imagery used by scientists to “tell the story” of their work.

**4. Appraisal phase**

Using appropriate critical appraisal techniques:

- a. Evaluate each primary study for its validity and relevance to the review question.
- b. Extract and collate the key results, grouping comparable studies together.

**5. Synthesis phase**

- a. Identify all the key dimensions of the problem that have been researched.
- b. Taking each dimension in turn give a narrative account of the contribution (if any) made to it by each separate research tradition.
- c. Treat conflicting findings as higher-order data and explain in terms of the contestation between the different paradigms from which the data were generated.

**6. Recommendations phase**

Through reflection, multidisciplinary dialogue and consultation with the intended users of the review:

- a. Summarise the overall messages from the research literature along with other relevant evidence (budget, policymaking priorities, competing or aligning initiatives).
- b. Distil and discuss recommendations for practice, policy and further research.

### 3.9 Narrative Synthesis

Popay et al (2006) describe narrative synthesis as a method of synthesising findings about effectiveness *and* implementation which is quantitative or qualitative in nature, which is “not meta-analysis”, but which relies on text to “tell the story” of such findings (Popay et al., 2006; Arai, Britten, Popay, Petticrew & Rodgers, 2007). It formalises the methods used for evidence reviews by providing process guidelines that it hopes will lead to lack of bias in reviews. The developed guidelines try to establish ways to ensure that transparency, reproducibility, and quality or trustworthiness, are incorporated into a narrative syntheses. It is these processes that the authors see as distinguishing narrative synthesis from traditional literature reviews (Popay et al., 2006). All the tools and techniques offered are suggestions, however, rather than being prescriptive.

In the literature to date, both traditional literature reviews and systematic reviews of quantitative studies which do not use formal methods of meta-analysis to pool data, have both been described as “narrative” reviews. The guidelines attempt to codify the processes of the latter, and expand it to include non-RCT quantitative, and qualitative research. The key published exemplar review is about the use of domestic fire alarms (Arai et al., 2007).

The guidelines are not intended to be prescriptive. Indeed, this is seen as neither feasible nor desirable as it is likely to depend on the type and nature of the research included in the synthesis. The guidelines themselves are very practical, providing details of a range of tools that might be applied to different types of research and its synthesis, which are taken from the existing literature. Cochrane-style reviews are criticised for focussing too much on *describing* included studies and their findings and not enough on *explaining* them. In particular, the authors regard the development and testing of theories as being neglected hitherto. Systematic reviews of all kinds are seen as potentially powerful tools for the development and testing of theories.

Popay has advocated the value of “bi-lingual” researchers, conversant in both quantitative and qualitative methods and their applications, and of research that does not set up an opposition between what can be known through quantitative research (and its synthesis) and what can be known through qualitative research (Popay, 2008). Their method “lies between” the pooling required for meta-analysis and the interpretation approach required for methods such as meta-ethnography (p.8, Popay et al 2006). They also suggest that such methods may follow an initial narrative synthesis.

Broadly, the steps of synthesis mirror those of traditional systematic reviews and are shown in Box 4.

**Box 4: Steps involved in narrative synthesis (Popay et al, 2006)**

*1. Identifying the focus of the review, searching/ mapping evidence*

This phase is seen as crucial to ensure the scope of the research is refined into a question that is both relevant and answerable. This is achieved through mapping the evidence to establish the type of interventions that have been evaluated, the study designs used in the evaluations and the amount of literature available. At this stage comprehensive searches are used to identify all the relevant literature.

*2. Specifying the research question*

This involves aspects traditionally associated with systematic reviews of effectiveness (including a definition of the population, intervention and outcomes of relevance) together with those specific to the additional interest, such as the context of interventions.

*3. Identifying studies to include in the review*

This is based on the elements described in the focused research question.

*4. Extracting data and assessing study quality*

Again, data extracted should be informed by the detailed review question and care should be taken to include any factors that may affect the interpretation of the results, including extrapolation to different populations or settings.

Assessment of methodological quality (study appraisal) is seen as equivalent to validity or quality assessment, or critical appraisal in Cochrane-style reviews. If poor quality studies are not excluded, these should be differentiated from higher quality studies in the review. No particular appraisal tools are recommended, but examples given.

*5. Synthesise the findings*

This is accomplished through developing a theoretical model, developing a preliminary synthesis, exploring relationships in the data and assessing the robustness of the synthesis product. These aspects are described in more detail below although they should be seen as iterative, rather than linear, stages.

*6. Report the results and disseminate.*

### **3.9.1 The Narrative Synthesis framework**

#### **Developing a theoretical model**

Popay et al (2006) found Weiss's Theory of Change useful in identifying "the chain of causal assumption that link programme resources activities, intermediate outcomes and ultimate goals" (p.18). This, as for realist synthesis, relates to how, why and for whom an intervention works. Such theories may be implicit or explicit. Identifying the theory behind interventions is done early in the review to help refine the review question and the inclusion criteria. It will also contribute to the interpretation of the review's findings, and their applicability.

## **Developing a preliminary synthesis**

A preliminary synthesis phase aims to organise findings from the included studies in order to provide an initial description of patterns identified across them. The authors draw an analogy between this phase and identifying effect size through meta-analysis, and it also has similarities with the analysis phase of meta-study. A number of mechanisms are suggested to facilitate this initial synthesis all of which aim to organise the results so that studies can be compared. Both results and the factors that influence these results are explored.

A descriptive paragraph on each study may be the starting point for the preliminary synthesis. This is produced systematically so that the same information, recorded in the same order, is given for each study. Popay et al note that patterns may be difficult to discern from this type of presentation, especially if large numbers of studies are included, so strategies are employed to facilitate this step. These may include grouping the studies according to elements such as study design, the type of intervention under study, its context, populations, types of outcome measures and so on. Tabulation can also assist synthesis, and may be needed to produce the initial descriptions. The way tables are constructed can influence interpretation. For numeric data, information should be presented in a common rubric where possible (for example, all results expressed as odds ratios). The authors also suggest that “vote counting” (identifying all significant and non-significant results) may also be useful although they are mindful of criticisms of this approach, particularly the fact that all results are given equal weight in this method.

For qualitative research, meta-ethnographic techniques of translating themes and concepts between studies, are suggested. Alternatively, thematic analysis may be used to identify main and recurrent themes identified across studies. Those considered most important to the review will depend upon the review focus. Given the potential for such analysis to lack transparency, it is important that as much detail as possible about the process and how and when themes were identified is provided in the synthesis write-up. Content analysis, where themes are compressed and counted is also a suggested technique for a preliminary synthesis of qualitative analysis. It is also suggested that some quantitative research, such as survey data, may be amenable to thematic analysis.

## **Exploring relationships in the data**

Differences in study results, whether from quantitative or qualitative research, may be explained by heterogeneity in study participants, outcomes or design. The theory of change developed at the beginning of the project may help plausible explanations for such differences to be constructed. For quantitative studies, results may be plotted in a number of different ways to assist the exploration of relationships between findings and study aspects such as population or study design. Traditional tools used to pool data through meta-analysis, such as forest plots (to present individual study, and pooled effect sizes), l'Abbe plots (plotting event rates in the treatment group against those in the control group) and funnel plots (whose plots of study size and treatment effect can be used to explore potential publication bias), are seen as part of this process. All of these tests are part of the usual battery of statistical tests used in Cochrane style reviews of RCTs. Identifying different moderators and subgroups that may impact on outcomes is seen as particularly important. The aim in narrative review is to see what aspects are implicitly or explicitly identified in the primary studies, how much they impact on results and whether there may be relationships between these moderators.

Popay et al describe various techniques used for exploring relationships within-study and between-study findings. Visual tools include ideas webbing (spider diagrams) and concept mapping (using diagrams and flow charts to represent relationships between and within studies that are being explored by the reviewer), while text based techniques include meta-ethnography, qualitative case descriptions (which are to explain any differences that may have been picked up in statistical analysis through describing aspects of the intervention that may have impacted on the results), and triangulation (to consider how methodological and theoretical [the “disciplinary gaze”] approaches may have impacted on the outcomes).

## **Assessing the robustness of the synthesis**

This phase aims to assess the strength and weight of the available evidence in several areas; the conclusions about the effect size and direction; factors that shape the intervention and also about the synthesis product itself – in terms of freedom from bias, generalisability and trustworthiness.

Rather than offering new methods of synthesis, narrative synthesis provides a tool box of techniques for manipulating, analysing and comparing the results of studies from studies in a review. Popay et al (2006) primarily try to codify mechanisms and strategies for explaining the results in reviews that can include mixed methods.

### **3.10 Systematic Reviews in the Social Sciences**

Like narrative synthesis, the methods described in *Systematic Reviews in the Social Sciences* by Petticrew and Roberts (2006) are presented as a practical handbook explaining the mechanisms in existence for systematic review and synthesis of diverse types of research. The book is specifically aimed at introducing those working in the social, as opposed to health, sciences to systematic reviews and is interested in reviews of effectiveness, as well as those that may have other focuses. A broad sweep then, is taken, which describes how to conduct Cochrane-style reviews of effectiveness, including techniques for statistical meta-analysis of RCTs, as well as considering how and why other types of research can be reviewed. No new methods of review or synthesis are described, rather the book summarises key existing approaches, and most of the book is devoted to various methods of dealing with quantitative data. Potential benefits to policy makers and practitioners are a key driver for these systematic reviews, which are regarded as particularly important when the evidence is diverse or uncertain. Systematic reviews are distinguished from other reviews by their attempt to limit bias through the use of pre-defined, transparent methods aimed at answering a specific question.

Petticrew and Roberts distinguish Greenhalgh's meta-narrative review (which they refer to as a "conceptual review") and Pawson's realist review from systematic reviews. Meta-narrative is regarded as aiming to synthesise areas of conceptual knowledge in a field in order to provide an overview which includes an understanding of main ideas, models and debates. In the case of realist review, they relate this distinction to producing generalisable theories through synthesis, rather than synthesising outcomes which is regarded as the output of systematic reviews. I would argue that other methods of review that focus on qualitative research such as meta-study, meta-synthesis and meta-ethnography all aim to generate synthesis at the level of theory rather than findings, and that this is a legitimate goal of this type of systematic review.

Systematic reviews using different types of research are seen as possible, and need to be tailored to the research question. For example, reviews exploring risk factors may require longitudinal studies or surveys, while questions about how interventions are implemented may need to be informed by qualitative research or user surveys. The authors encourage different research designs to be considered in terms of typology rather than hierarchy, thereby allowing the best design(s) to be chosen based on the question that needs to be answered. Possible mechanisms suggested through which qualitative research, alone or in mixed methods reviews, may be synthesised include

realist review, the EPPI-centre methods, Joanna Briggs Institute methods (described below) and meta-ethnography.

Seven stages of systematic review, regardless of the type of research included, are listed by Petticrew and Roberts and reproduced in Box 5.

**Box 5: Seven stages in systematic reviews in the social sciences (Petticrew and Roberts, 2006)**

1. Clearly define the question that the review is setting out to answer, or the hypothesis that the review will test, in consultation with anticipated users.
2. Determine the types of studies that need to be located in order to answer your question.
3. Carry out a comprehensive literature search to locate those studies.
4. Screen the results of that search according to inclusion criteria.
5. Critically appraise the included studies
6. Synthesize the studies and assess heterogeneity
7. Disseminate the findings

### **3.11 The Synthesis Method Described by the Joanna Briggs Institute**

The Joanna Briggs Institute (JBI) has produced a computer program called QARI (Qualitative Assessment and Review Instrument, pronounced “quarry”). This was produced as a pragmatic response to what the organisation perceived as many years of discussion without consensus between key international evidence synthesis bodies – the Cochrane Collaboration in the UK, the Campbell Collaboration in the USA and the JBI in Australia. They argued that there was substantial overlap in the guidance of these three bodies, but refusal to compromise over approaches meant there was no consensus. This summary report is based on a 2006 conference presentation by Alan Pearson of the JBI (Pearson, 2006).

Pearson distinguishes between aggregation (or integrative) and interpretive synthesis. The former is regarded as involving “assembling” the findings of studies, and pooling them through identifying similarity in the meanings of themes, metaphors or categories. This assumes that the categories under which findings are to be summarized are well-specified and secure. The key additional element of interpretive synthesis is thought to be the ability to “anticipate” what might be involved in analogous situations and to

understand how things connect and interact.” (Pearson, 2006) This seems different to the prior discussion of differences between aggregative and interpretive approaches by both Noblit and Hare and by Estabrooks (Noblit & Hare, 1988; Estabrooks et al., 1994). In the JBI method, the term meta-synthesis is used to describe “a higher order form of synthesis” which aggregates processed data (findings) to “generate a set of statements that adequately represent that aggregation.” They assume that this allows research from different approaches and traditions to be used in a single synthesis. Parallels are drawn with the synthesis of RCTs, in that both sorts of synthesis provide “an understanding that is based on a range of populations, settings, and circumstances.” However, the key identified difference is that meta-synthesis “deals in multiple realities and so provides one interpretation of the phenomenon.” Again, this seems to be a different definition of meta-synthesis to that used by Sandelowski and Barroso (2007).

Compared with other review processes, which emphasise the iterative nature of review and synthesis for qualitative research, JBI acknowledge that their method, in common with the EPPI-centre approach, has a more rigid approach; it is outlined by an initial protocol and continues through the process, implying a much more linear approach than other synthesis methods. The use of a computer programme may also reinforce rigid procedures and categories used in the synthesis. With all protocol driven research, the possibility of some flexibility does remain, as long as departures from the protocol are logged and justified. JBI stress the need for transparency of process, and note that they have attempted to mirror the Cochrane process “modelled on an integrative, thematic analysis process.” In this sense, this is the mechanism for synthesis that most closely and, indeed, explicitly mirrors a Cochrane-style systematic review processes – including the need for a protocol and search results to be downloaded through JBI in order for the QARI software to be used.

The JBI approach to meta-synthesis is three step:

- Extraction of themes, metaphors, findings or conclusions
- The categorization of these data on the basis of similarity in meaning
- Developing synthesised findings or conclusions representing an aggregation of categories.

At each step, the QARI programme is used to assist and regulate the process. This may have advantages, such as the ability for two reviewers data extract the same information in a way that initially keeps their findings blind, while allowing them to be directly compared when both are complete. However, it also constrains the information

that is extracted, in some cases limiting the way such information is defined. In addition, the actual processes of analysis may be obscured.

## **Summary**

In this chapter I have considered what synthesis of qualitative research might be and introduced ten suggested methods for systematically reviewing and synthesising this type of research. This has shown some development of the field. Early review methods focus only on qualitative research, and methods such as meta-ethnography and meta-synthesis began to develop independently of the concerns of evidence based practice (EBP). Later methods more obviously embrace the concerns of Cochrane-style reviews and EBP, and most are concerned with the inclusion of evidence from mixed methods. These later methods are also more explicitly directed at answering the needs of policy although non have yet gained prominence as the preferred or most credible method in policy arenas. For the most part, the methods have been subjected to limited testing. Although meta-synthesis has been used in many projects, especially in the USA and Canada, it has not, as yet, come to signify a single approach. In the UK, meta-ethnography has been used the most, and has also been adopted as a possible methods of synthesis for other recent descriptions of systematic review for qualitative research, such as narrative synthesis and meta-study.

In the following chapter I shall consider the differences between the methods in their approach to the key stages of systematic review greater depth. I consider how these suggested methods relate to each other, including where there is overlap in methods and where they are unique. I go on to explore the reasons and implications for some of the differences in approach.

# 4 Comparison of Proposed Methods for Review of Qualitative Research

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This chapter assesses in depth the currently suggested methods for systematic review of qualitative research introduced in Chapter 3. I consider the proposed methods in relation to each other, in order to explore similarities and differences between the approaches. In trying to evaluate how the methods mirror or differ from each other, I paid particular attention to a number of aspects of the synthesis process as I read and re-read the accounts. These are:

- Purpose of the review (Section 4.1)
- Defining the review question (Section 4.2)
- Research designs included in the review (Section 4.3)

## **Discipline from which the method evolved (Shown in**

- Table 3)
- Search strategies, sampling and inclusion criteria (Section 4.4)
- Quality appraisal of research reports (Section 4.5)
- Methods of analysis and synthesis (Section 4.6)
- Data extraction (Section 4.6.1)
- Assessing review validity (Section 4.7)
- Dissemination (Section 4.8)

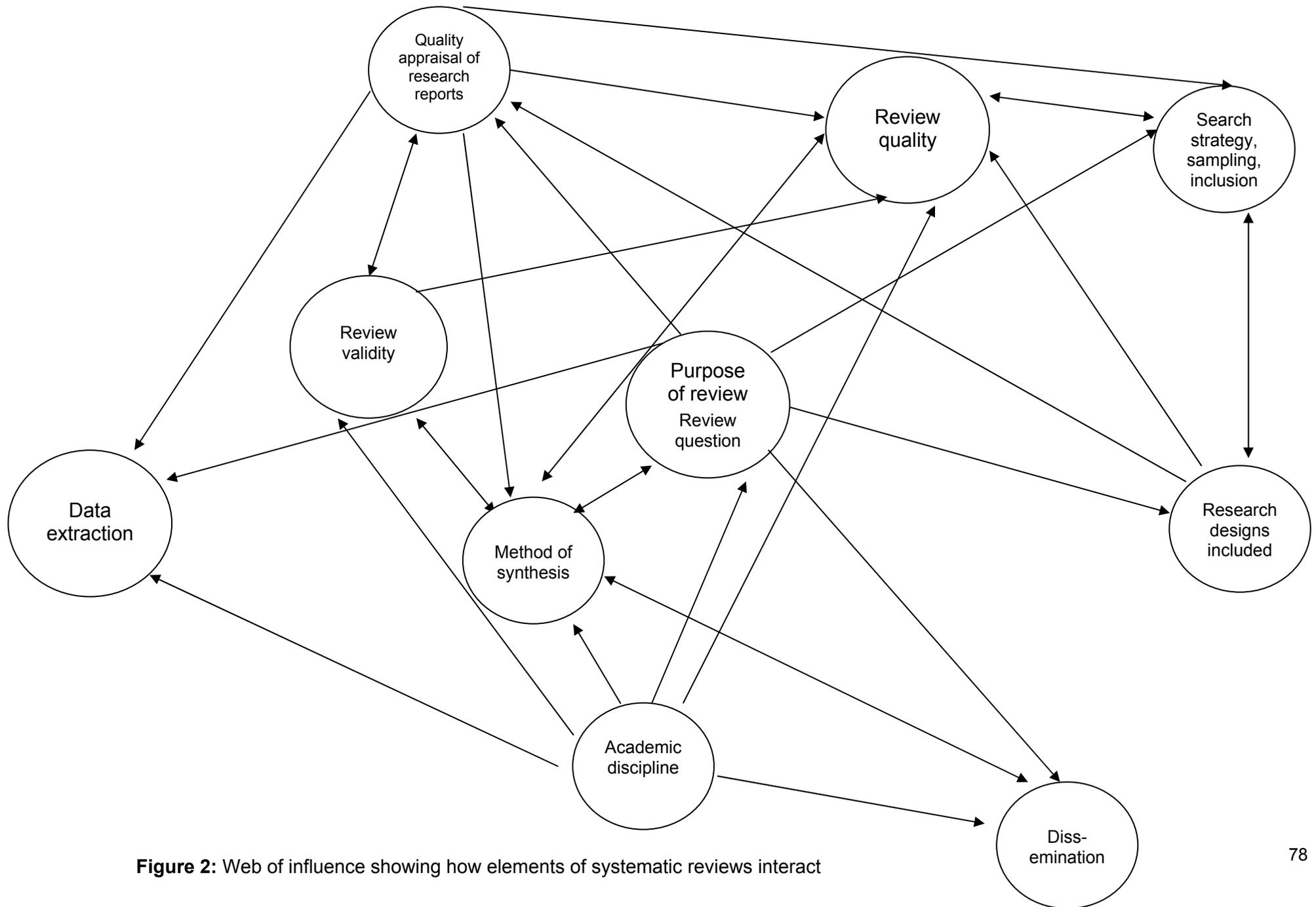
Ultimately, I use details from across all the methods to produce a comprehensive framework for good practice when undertaking a review, based on those methods and mechanisms that I found most illuminating, well described or helpful.

Systematically reviewing qualitative research remains very much an evolving field, with methods still in flux and no one method, or set of methods, yet gaining primacy. Indeed, it has been suggested that we are in “an era of meta-madness” (Thorne et al., 2004). As described in Chapter 2, synthesis, encompassing as it does ideas of both aggregation and generalisability, is thought by some qualitative researchers to be at odds with the purpose of qualitative research, which is context driven and interpretive

(Doyle, 2003). There are a number of sticking places that, because of practical or epistemological difficulties, present challenges even for those who *do* wish to synthesise the results of qualitative research. In addition, different methods have emerged from different disciplines and methodologies, and as described in Chapter 3, different approaches have often been labelled under what has become the umbrella term “meta-synthesis”. Distinguishing between them is complicated by “terminological land mines” (Thorne et al., 2004). Figure 2 gives a diagrammatic representation of how methods and aims are linked to the academic discipline in which the methods evolved and how these impact on the specific steps involved in a review. Arrows show the direction of influence so, for example, the data extraction advised by a particular method will be influenced by the academic discipline in which it has developed and its epistemology, and by proposed mechanisms of assessing study quality. The complexity of the diagram emphasises the degree of inter-relationship between aspects of any review’s design, and its intellectual and professional home.

Table 3 outlines the different review methods described, listed by date of first publication about the method, together with details of the academic disciplines that informed their development and the stated purpose of the syntheses. In this chapter I focus on two key theoretical discussions of meta-synthesis rather than trying to summarise all the different approaches that have been taken under its name. The paper by Jensen and Allen is an early publication that discusses their approach, while Sandelowski and Barroso have published a book and a number of papers that focus on what meta-synthesis might involve, as well as reporting on specific meta-syntheses (Sandelowski & Barroso, 2003c; Barroso & Sandelowski, 2004; Thorne et al., 2004; Sandelowski et al., 1997; Sandelowski & Barroso, 2002; Sandelowski & Barroso, 2003b; Sandelowski & Barroso, 2003a; Sandelowski & Barroso, 2007).

The remainder of this chapter explores the approaches these different review methodologies have suggested for each of the key stages of a systematic review shown in the circles of Figure 2. This comprehensive comparison highlights where methodological controversies still exist.



**Figure 2:** Web of influence showing how elements of systematic reviews interact

**Table 3: Summary of synthesis purpose and academic disciplines**

<b>Authors</b>	<b>Synthesis method</b>	<b>Academic discipline and approach</b>	<b>Purpose of synthesis</b>
Noblit & Hare, 1988	Meta-ethnography	Ethnography (education project), interpretive constructionist	To outline a systematic, interpretive approach to synthesis across studies in order to provide a critical examination of events, situations etc. and provide explanations about them. Aimed at researchers who wish to construct “interpretative literature reviews” and for policy makers.
Estabrooks <i>et al</i> , 1994	Aggregated synthesis	Nursing. Methods suggest grounded theory.	To increase abstraction, enhance generalisability and develop mid-range theory. Authors interested in enhancing practical application of theory-driven research to nursing and teaching.
Jensen & Allen, 1996	Meta synthesis	Nursing research. Methods suggest Hermeneutical phenomenology, grounded theory.	To develop a fuller understanding of the phenomenon under study through identifying consensus across accounts of that phenomenon, so as to illuminate its essence. Theory building.
Sandelowski & Barroso 2007	Meta-synthesis (qualitative research integration & meta-summary)	Nursing research, phenomenology.	To provide a clear and useful description of how to approach meta-synthesis. To develop larger narratives or general theories grounded in human experience.
Paterson <i>et al</i> 2001	Meta-study	Sociology, nursing research, interpretive constructionist approach.	To analyse theoretical, methodological and contextual foundations and features of studies about a phenomenon to provide “more true, more accurate or more real explanations of phenomena and more coherent ways to make sense of them.” To construct “grand theory” from diverse theoretical positions.
Rees <i>et al</i> , 2001	EPPI-centre method	Not clear – clear alignment with CRD/ systematic review approaches, health promotion. Also social scientists.	To extend the methods of systematic review to include information from high quality observational and qualitative research to inform policy makers.
Pawson <i>et al</i> , 2004	Realist review	Sociology, social policy, realist philosophy, complexity theory. Grounded theory informs sampling.	To understand the mechanisms of action that underpin successful and failing complex interventions.
Greenhalgh <i>et al</i> 2005	Meta-narrative	Backgrounds in EBP, synthesis methods, health informatics, education, management, information science. Initial project based on technology transfer in developing countries and social network theory. Influenced by Kuhn’s <i>Structure of Scientific Revolutions</i>	To develop a methodological base for the synthesis of evidence across multiple disciplinary fields. Meta-narrative review attempts to find epistemological explanations for differences in findings between studies from different research traditions.
Popay <i>et al</i> , 2006	Narrative synthesis	Social science, project funded by ESRC and Cochrane Collaboration.	To synthesise evidence from multiple studies & diverse methodologies, to develop and test theories Envisaged as a preliminary stage in a review that includes specialist synthesis methods (eg meta-analysis or meta-ethnography) rather than being a synthesis

<b>Authors</b>	<b>Synthesis method</b>	<b>Academic discipline and approach</b>	<b>Purpose of synthesis</b>
			method itself. May be used to synthesise across study designs and where the question to be addressed by a review dictates the inclusion of disparate types of evidence.
Petticrew & Roberts 2006	Systematic review in the social sciences	Social science, social policy.	To organise and combine research evidence in a non-biased way in order to inform policy-making and practice. Book aims to describe the story of systematic reviews and provide a practical guide to undertaking them.
Pearson, 2007	JBI method	Nursing research, Cochrane-style systematic reviews.	To synthesise evidence from qualitative research in order to generate recommendations for practice.

## 4.1 Purpose of the Review

*We understand that product [of synthesis] to be fundamentally different from the original parts, capable of sustaining a more convincing argument about the major theoretical elements within the phenomenon of interest and positioned to advance the science of that particular substantive field more forcefully. (Thorne et al., 2004)*

This section discusses the stated aims of the different methods of review and synthesis. These depend, to some extent, on the academic discipline from which they emerged and the academic interests of those involved in developing them. Some methods, such as the EPPI-centre method, the JBI approach and narrative synthesis, have been developed in response to existing mechanisms for systematic reviews and meta-analyses of RCTs (Popay et al., 2006; Rees et al., 2001; Pearson, 2006). Indeed, each of these methods explicitly aims to extend the reach of Cochrane-style reviews in order to synthesise the evidence from diverse methodologies. The EPPI-centre method, the methods described by Petticrew and Roberts and narrative synthesis aim to include traditional meta-analyses of RCTs and data from other quantitative research designs, as well as qualitative research into one synthesised product that addresses the needs of decision-makers such as managers and those involved in policy development. Although reviews of qualitative research alone are considered potentially important, this aspect of qualitative synthesis is not explicitly addressed. Review of qualitative research for these methods is thus part of a broader systematic review project and follows similar guidelines. The JBI method is aimed at synthesising qualitative methods alone, but equally, it explicitly echoes Cochrane procedures for systematic review.

The turn to qualitative methods in these cases has developed from the recognition that, while RCTs may be the gold standard for efficacy studies of particular types of intervention, many useful questions about best practice and implementation are better addressed by different kinds of research (Popay et al., 2006). The review's potential *utility* is emphasised, particularly for policy makers (Rees et al., 2001). Whilst welcoming recent thawing of traditional polarisation between quantitative and qualitative research, some authors have warned against the "dangers in under-emphasizing the important differences between the two paradigms," (Barbour & Barbour, 2003) and this may be particularly pertinent in reviews that attempt to account for research from both traditions. Barbour and Barbour caution that ignoring

differences between types of studies may lead to “homogenised and bland synthesis.” This may be avoided if the different scopes of quantitative and qualitative research are maintained within the review. One potential problem for these mixed methods reviews is determining how to value or weight evidence from different study designs, particularly if results are opposing.

Narrative synthesis, it is suggested, may be most useful at the preliminary, scoping stage of a review that will go on to use a specialist method of synthesis; as the main focus of the review where the evidence is too disparate for these specialist methods to be used; or where the research question cannot be answered by RCT evidence alone (Popay et al., 2006). The specialist methods refer to techniques such as meta-analysis or meta-ethnography, depending on the type of evidence available and the specific question to be addressed. Narrative synthesis is also seen as a mechanism for developing and testing theory, and criticises traditional Cochrane-style reviews for failing to do this. Popay et al (2006) recommend developing a theory of change about the intervention of interest, identifying *how* an intervention works, *why* and *for whom*, at an early stage of the review (p.18). In this it has similarities with the concerns of realist review (Pawson, Greenhalgh, Harvey & Walshe, 2005b), indeed Pawson’s work is cited, although the mechanisms used to approach these questions are different.

Where methods of review emerge from the social sciences, most reviewers appear more comfortable with the interpretive nature of any review, accepting that they construct meanings that are informed by specific historical, social, cultural and ideological contexts. Replicability is not necessarily considered feasible or desirable, and alternative legitimate interpretations of the evidence are acknowledged as possible (Noblit & Hare, 1988; Paterson et al., 2001; Sandelowski et al., 1997). However, Paterson et al, (2001) note that it may be difficult to distinguish between legitimate alternative interpretations, and poorly executed interpretations; this is true both for primary qualitative research and its synthesis. Possible methods of assessing review quality are discussed in Section 4.7. Methods such as meta-synthesis, aggregative synthesis and meta-ethnography, all emerging from social sciences, focus on the review of qualitative methods alone, rather than a mixed evidence base.

Much of the drive to systematically review qualitative research has come from within nursing, particularly in the USA and Canada. These reviewers tend to emphasise the importance of findings that have an impact on nursing *practice*, usually through the development of theory. It is suggested that theory developed through the synthesis of several research accounts is capable of being more powerful and comprehensive than those derived from a single study (Sandelowski & Barroso, 2003c; Estabrooks et al.,

1994; Jensen & Allen, 1996). In addition, review methods developed within nursing research tend to operate within phenomenological traditions. Such studies emphasise the ability of qualitative research and its synthesis to “illuminate the essence” of a phenomenon under study (Jensen & Allen, 1996). Particular types of question which reflect the human experience are therefore addressed (Sandelowski et al., 1997). The JBI approach is the exception. Whilst also coming from a nursing tradition, it is largely a-theoretical and views the synthesis of qualitative research as an aggregative rather than an interpretive project, and it mirrors Cochrane-style review approaches. It too has the explicit purpose of generating useful practice recommendations (Pearson, 2006).

Meta-study, also developed within nursing research, distinguishes itself from meta-synthesis by its explicit and detailed concern with the impact of theoretical, methodological and contextual basis of research on its findings (Paterson et al., 2001). However, Thorne has written that, despite the original intent, meta-study may fall short of its intention to construct new and better theory:

*In the final analysis, therefore, some of us concluded that meta-study tends to serve us far better as a method of rigorously and systematically deconstructing existing bodies of qualitative research findings than it does as a technique for synthesizing powerful new products. As we discovered, the more thoroughly you have examined the methodological, disciplinary and theoretical underbelly of the existing body of knowledge about a phenomenon, the more difficult it can become to make definitive claims about its nature (Thorne et al., 2004).*

Further, meta-study has been described as a different “species of scholarship” from meta-synthesis as it provides more circumspect and tentative conclusions precisely because it is tempered by an awareness of the historical, socio-political and intellectual theatres that produced them (Thorne et al., 2004). By contrast, the desires of health practitioners engaged in meta-synthesis have been seen as much more limited and pragmatic, wishing to provide information that is directly usable and practical (Thorne et al., 2004).

Meta-ethnography was originally developed in an effort to provide a critical examination of events explored using ethnographic methods across a number of sites and to develop explanations across them (Noblit & Hare, 1988). It was primarily envisaged as a systematic method for researchers who wished to construct “interpretive literature reviews” (p.11). Sixteen years after their original publication on meta-ethnography, Noblit has confessed himself and Hare “amazed” that their method “is being used

mostly in fields of professional practice, as in evidence-based practice” (Thorne et al., 2004).

*I want to be clear that I would like qualitative research to be more able to inform the truth-maker than other research methods ....Yet, for me, the answer comes from embracing the anticipation over the prediction. Anticipation allows possibility for knowing what might happen....Anticipation is also central to understanding decision itself (Thorne et al., 2004).*

Using research to make policy decisions that affect the future requires an understanding of how what happened in the past might be repeated in the future, and of the intellectual, socio-political and historical contexts in which any study findings operate. This perhaps shows a leaning towards methods such as meta-study that aim precisely to understand these contextual elements. Within meta-study, meta-ethnography is seen as a potential method for synthesising findings. However, as noted above, certainty may be the casualty of such concerns.

Realist review also aims to provide explanations, particularly for policy makers. It is the most specific method in terms of the type of questions it seeks to answer, being focused on complex interventions, and looking to understand what it is about successful or failing interventions that makes them that way, in what situations and why (Pawson et al., 2004). Similarly, meta-narrative seeks to find epistemological explanations for differences in the findings of different studies (Greenhalgh et al., 2005). In this, it has similarities with the meta-theory element of meta-study.

## **4.2 Defining the Review Question**

Having considered the different aims of proposed methods of systematic review, this section considers how the different review methods anticipate that the focus for the review question will be defined or developed. In most of the review methods described, the scope of the research question is not pre-specified in a rigid protocol, as Cochrane-style reviews are, but develops iteratively as the researcher becomes more familiar with the subject area and available data. The process described for this may be more or less formalised. In realist review, Petticrew and Roberts description and meta-narrative, clarifying the scope for the project is an explicit step involving initial searches and negotiation with commissioners, reflecting these methods’ pragmatic focus (Pawson et al., 2004; Greenhalgh et al., 2005; Petticrew & Roberts, 2006).

Those, like Pawson et al, Petticrew and Roberts, and the EPPI-centre researchers who see research synthesis as integrally linked with the needs of policy makers, tend to see the whole review process in terms that have been characterised as “linkage and exchange” between the reviewers and the commissioners (Lomas, 2005). Collaboration with end-users and commissioners helps to refine an initially broad area of research in order to produce a synthesis that is “fit for purpose”: in this case, of use to the decision makers’ specific questions. There is a clear tension between the drive of policy makers for answers and the brakes applied by academic concerns about the kind of knowledge that can be generated through qualitative research. This is seen in Noblit’s concerns about meta-ethnography described above and the problems encountered by Paterson et al, (2001) who only achieve tentative conclusions through meta-study. It may also be that broader reviews, encompassing quantitative as well as qualitative research provide a more specific focus for the type of evidence gaps or questions that qualitative research is required to answer.

Petticrew and Roberts regard formulating the question to be answered by review as a very important step in the process: too narrow and the answer may not actually be useful, while too broad a question might not be answerable by systematic review. As well as collaboration with policy makers, other stakeholders are seen as key collaborators in this process. They also caution about assuming that a systematic review is the best way to answer a question – noting that in some cases primary research, or a traditional review, might be better suited. This is a useful reminder as EBP gains momentum. Systematic reviews of qualitative research would best address questions concerned with meanings or processes of interventions, how such interventions are implemented and the detail of influences and events in people’s lives.

The JBI does not explicitly discuss how it approaches defining the research question (Pearson, 2006). However, it can be inferred that the question is about a particular element of nursing practice. In contrast to other methods, the question is crystallised in a protocol, rather than developed in the process of the review. Study reports not providing information about the pre-defined question would be excluded, rather than being used to refine the research question.

Greenhalgh et al (2005), perhaps because meta-narrative was developed as a method through the particular project on which the report of methods is based, seem to have the longest route to defining not only the range of review interest, but the approach to synthesis as well. This approach highlights potential problems of trying to review too broad a topic. The device of meta-narrative emerged after consultation with the project commissioners on an earlier draft of the report. The breadth of the original research

area, “the diffusion, spread and sustainability of innovations”, is seen as contributing to early difficulties in the project, partly because it was not confined to a particular academic discipline or research tradition, although health service delivery and organisation was the primary area of interest. In particular, the authors emphasise that it was difficult to get started, and one of the reason for this was the broad and sometimes contested nature of definitions for key terms such as “innovation” (I discuss problems of identifying relevant research reports in depth in Section 4.4.1) Ongoing meetings with external peers and others helped to focus the review question and the approach used to address it.

This is in direct contrast to methods that developed from a more purely academic interest in review and synthesis, and prior to the dominance of systematic reviews in EBP. These methods focus the scope of the research question through the researcher’s concerns. Noblit and Hare write “there is no value in a synthesis that is not of interest to the author” (p.27).

The process of focusing the review scope described for meta-study is more informal (Paterson et al., 2001). The area of study is arrived at through prior researcher interest, and a balance is sought between being large enough to fully explore the breadth and depth of the topic and precise enough to be manageable. Clearly this requires considerable judgement by the researchers. In their chronic illness meta-study, Paterson et al, wanted to ensure that they included studies that addressed *concepts* relevant to their prior research experience and which suggested that some, but not all, patients with chronic illness find meaning and hope in their condition. They reduced an initially unwieldy number of research reports by focusing their investigation down to a specific population, based on conceptual *outcomes* in primary research reports.

### **4.3 Research Designs Included in the Review**

Realist review, narrative synthesis, meta-narrative, Petticrew and Roberts’ method and the EPPI-centre method all aim to accommodate research from both qualitative and quantitative methods in order to provide a broad picture of the researched area (Pawson et al., 2004; Popay et al., 2006; Greenhalgh et al., 2005; Rees et al., 2001; Petticrew & Roberts, 2006). Petticrew and Roberts are primarily concerned with mixed methods reviews, and with ensuring that the review includes studies most likely to address the research question. Other methods aim to synthesise only across qualitative studies.

Realist review looks at the broadest range of evidence, including sources such as newspapers or other non-research based reports and may involve the collection of additional primary data from key informants involved in service delivery or policy-making (Pawson et al., 2005b). This has been criticised since no way of weighing one type of evidence over another is described (Dixon-Woods et al., 2004). However, Pawson et al aim to identify the *theory* behind *interventions* in terms of expected routes of successful action, which may well be illuminated by, for example, media portrayals of the impact of interventions such as league tables in education or health.

Meta-narrative takes a different approach. In order to trace and describe the narratives within different research traditions, the starting point was to identify “seminal papers” within each tradition (Greenhalgh et al., 2005). Such papers might describe empirical research of any kind, or key theoretical contributions within a discipline, but are judged to be influential on subsequent research direction and interest. How these are used and developed in subsequent research creates the narrative.

Aggregated synthesis, and the meta-synthesis described by Jensen and Allen, not only advocate using exclusively qualitative studies, but also restrict inclusion to those that use the same methodology. It is thought too difficult to build theory on findings coming from studies with different epistemological bases (Estabrooks et al., 1994; Jensen & Allen, 1996). It is notable, however, that these methods remain little used in the literature. This concern is addressed in a different way through meta-study, which contains specific ways to investigate the impact of different methods and theoretical approaches on the findings of studies. Paterson et al (2001) see this as a strength, as considering different approaches provides counterbalances and checks to individual methods. Both meta-ethnography and Sandelowski and Barroso’s meta-synthesis also assume that qualitative research from different traditions *can* be synthesised. While meta-ethnography was originally designed to synthesise ethnographic accounts, it has since been used with other types of qualitative research (Britten et al., 2002; Campbell et al., 2003; Smith et al., 2005). Sandelowski and Barroso (2007) further note that defining study type may not be as easy as first imagined, since traditions of what is regarded as grounded theory or phenomenology, for example, differ between and within disciplines (p.7). This would make restrictions to similar research approaches difficult and perhaps overly restrictive.

Whilst having no problem in combining qualitative studies across research disciplines, the JBI method *does* restrict study reports according to findings. Crucially, they state that:

*Only interpretive studies that explicitly report findings of use to practice are appropriate for meta-synthesis (Pearson, 2006).*

This criterion recognises that a large amount of qualitative research comes from traditions that do not address “issues of an immediate and practical nature”. In JBI, these would simply be excluded, although it is not clear who decides this, or how, or at what point in the process this might be decided. Research from a non-health service tradition may contain crucial insights for enhancing practice but this could not be known unless they were read and assessed and, I would suggest, attempts are made to synthesise these findings with other studies. However, this exclusion is in line with the ultimate aim of synthesis for JBI, which is to generate recommendations for practice.

Having discussed the different types of research considered appropriate for systematic reviews of qualitative research, I suggest in the next section how the study reports themselves can be identified.

## **4.4 Search strategies, Sampling and Inclusion Criteria**

### **4.4.1 Searching for relevant study reports**

Before a synthesis of any kind can be attempted, it is necessary to find relevant studies to be included. Questions about where to find such literature, and what is relevant to the interest at hand, are more complex in systematic reviews of qualitative research than of RCTs. Qualitative research reports on a particular topic may range across several academic disciplines, and might be found in book chapters, whole books and “grey literature” such as project reports or unpublished theses, in addition to journal articles. This diversity makes traditional searches in electronic databases more complex, and more likely to miss particular types of research report. A wide range of electronic databases may need to be searched if topics of interest are stretched beyond traditional biomedical models, and this will complicate the design of search strategies since not all databases will be organised in the same way.

In identifying journal articles, considerable effort has gone into ensuring that medical databases are indexed and key-worded in ways that assist electronic search strategies to identify all relevant RCTs for a systematic review (Dixon-Woods et al., 2001). Moreover, once the search has been constructed, the title of most recent trial reports leaves no doubt about the research design used, the intervention tested and the population studied. The study conclusion may even make its way into the title too, for

example *Combination of enprostil and cimetidine is more effective than cimetidine alone in treating gastric ulcer: prospective multicenter randomized controlled trial* (Murata, Kawano, Tsuji, Tsujii, Hori, Kamada et al. 2005).

By contrast, different concerns have often led to the nature and focus of qualitative research being obscured. MEDLINE only introduced “qualitative research” as a MESH term in 2003 and, while nursing databases such as CINAHL may provide considerable methodological detail about qualitative studies through their index terms, these are not available in MEDLINE (Evans, 2002). Further, the titles of many qualitative studies show that creativity, wit and intrigue may be valued over clarity of method, for example *Hormonal Hierarchy: hysterectomy and stratified stigma* (Elson, 2004b). Indeed, it is not only the title that may give little clue as to whether a paper reports on a qualitative research project, or a theoretical think-piece, neither may the reported focus or methods of a study. It has been noted that “research purposes and questions are so broadly stated, it is only by looking at the kinds of findings produced that topical similarity can be determined” (Sandelowski et al., 1997) and until recently, few details of the methods used were expected even in full-text descriptions of qualitative research. All of this makes identifying appropriate literature through databases more time consuming and challenging than is normal for Cochrane-style reviews. More study reports may need to be obtained in their full text version (incurring additional expense and time), and read more thoroughly in order to be certain whether they address relevant issues, or use relevant methods that would lead them to qualify for inclusion in a review.

Partly as a result of these factors exhaustive electronic database searches, considered vital in Cochrane-style reviews, may not be the most appropriate way to obtain the best data for qualitative synthesis. As an example, for a meta-synthesis of barriers and facilitators to role development for specialist nurse practitioners, exhaustive searching was considered important (Lloyd Jones, 2004). A carefully developed search strategy initially identified 3162 study reports. Most of these were rejected at the stage of screening titles and abstracts and 132 full-text study reports were acquired for further scrutiny. The final study included 17 reports on 14 studies; 0.5% of the original hits, and only 13% of those for which full text study reports were obtained. A rigorously tested search strategy developed by Maria Grant for MEDLINE, showed 100% sensitivity but only 8.5% precision, emphasising the design difficulties for search strategies (Grant, 2004). Other strategies tested across a range of databases including MEDLINE, CINAHL and ASSIA showed just 4% precision from over 7000 initially identified study reports (Shaw, Booth, Sutton, Miller, Smith, Young et al. 2004). Petticrew and Roberts note that electronic databases for social sciences are less well

developed to aid searching than key medical databases, whatever study design is required. An extensive list of potential key words to enhance sensitivity of obtaining qualitative research based on the Hawaii Medical Library filters for CINHALL is provided, but the precision of this search is not given.

Due to space restrictions imposed by many journals, articles based on qualitative research may only report a small, focused area of findings from the research project undertaken. For this reason, it is suggested that authors should be contacted to obtain the full project report where possible (Estabrooks et al., 1994). The importance of identifying this and other grey literature such as theses, is stressed in several of the review methods (Pawson et al., 2004; Jensen & Allen, 1996; Sandelowski et al., 1997; Petticrew & Roberts, 2006). Contact with experts in the field, and snowballing techniques, such as citation tracking and reference lists, are important sources of information. Indeed, they are regarded as more important than electronic databases for some projects (Pawson et al., 2004; Popay et al., 2006; Greenhalgh et al., 2005). Paterson et al emphasise that the knowledge and expertise of those in the synthesis team is crucial to identify relevant study reports. Petticrew and Roberts also suggest a number of commissioners whose websites might provide information about relevant ongoing research. Such strategies, however, must be balanced against the time and other resources available for the review as a whole.

The difficulties of identifying relevant literature to synthesise were not much considered by the earliest methods developed. Noblit and Hare's original meta-ethnography was based on *known* research reports and they were mostly interested in processes of *synthesising* results from particular projects. Given the publication date, electronic databases and the internet were not so well developed as they are now and the stipulations of systematic review searches, not so well known. As a result, library catalogues, review of study reference lists and contact with experts are the main mechanisms suggested by Noblit and Hare by which to identify relevant research reports. Similarly, electronic search strategies are not discussed in aggregated synthesis, another relatively early review method (Estabrooks et al., 1994).

Realist review suggests that four stages of iterative literature searches are required. These feed into the scope definition and focus of the review:

- *An initial background search to become familiar with the literature,*
- *Progressively focused searches to identify relevant programme theories,*
- *Searches to identify empirical evidence about those theories,*

- *A final search near the review end to identify any further studies that might illuminate and refine the theories which have formed the main focus of the analysis. (Pawson et al., 2004)*

Given the difficulty of designing good search strategies to identify explanatory theories for complex interventions and the range of disciplines from which such theories may be developed, Pawson et al (2004) found techniques other than database searching to be more useful. These strategies have more in common with traditional understanding of scholarly investigation and expertise than the formulas for systematic reviews.

Greenhalgh et al (2004) also describe a process of increasingly refined and focused searches being employed for the meta-narrative project. They became most systematic when meta-narrative was identified as the methodology, becoming a “powerful focussing device” for what to include. How this process might operate in a different project using the method is therefore unclear. Although describing different review methods, Petticrew and Roberts also suggest that searches may need to be refined iteratively. Relevant studies identified through early searches can be examined to identify key words which are then used in further searches.

Sandelowski and Barroso (2007) regard failure to conduct sufficiently exhaustive searches as the most important threat to the validity of a synthesis of qualitative research. They describe five strategies beyond searches in electronic databases to access additional qualitative research:

- *Following up footnotes and reference lists,*
- *Citation searching,*
- *Hand-searching of key journals identified through the initial search stage,*
- *Area scanning - which involves looking at other books located at the same class mark either physically on the shelves of libraries, or through library catalogue searches,*
- *Searching for additional material from identified authors (particularly for theses and dissertations). (Sandelowski & Barroso, 2007)*

Those methods which have emerged from within existing evidence-based practice processes (such as the EPPI-centre, JBI method and narrative synthesis) are more likely to mirror Cochrane–style review methods for identifying studies, relying primarily on electronic database searches and being more likely to aim to identify all the available literature (Rees et al., 2001; Popay et al., 2006). However, little consideration is given to the concerns outlined above – in particular that gaining access to all

available literature may be particularly difficult if electronic searches are solely relied upon. This may be especially true if searches are restricted to medically focused databases. In one recent meta-ethnography about lay experiences of medicine-taking, for example, only half of the 42 included studies were identified through electronic database searches (Pound, Britten, Morgan, Yardley, Pope, Daker-White et al. 2005).

This section has described the proposed strategies for searching. I now turn to different understandings of the purpose of these searches, considering whether exhaustive searching or sampling is most appropriate .

#### **4.4.2 Sampling**

Questions relating to appropriate searching and sampling techniques are closely linked. This section considers how the review methods have tackled the question of whether and how to sample from the available research reports. In systematic reviews of RCTs, it is necessary to identify all the available literature to avoid bias. Failure to identify a relevant study may lead to more uncertainty about the estimate of treatment effect, or may even lead to a conclusion being made in the wrong direction. However, other impacts of bias are also important as discussed in Section 2.1.1 (page 23). While funnel plots can help to establish whether publication bias is a factor that should be considered in a systematic review of RCTs (Sterne JAC et al., 2001), methods for the detection of missing studies in a review of qualitative research, and their possible impact, are much less clear.

Dixon-Woods has suggested that reviews of qualitative research aiming to obtain only some of the available literature on a topic have parallels with Cochrane-style reviews. Both types of review in fact retrieve only partial information about a topic, the main difference being the stage in the review process at which this is done. The amount of data for a qualitative synthesis may be restricted iteratively through gradually focusing the research question in response to scoping searches and reading of the literature, or selecting a particular group of participants to investigate more deeply, or where no new themes are emerging from the findings. By contrast, the study design, population and comparator investigated to be included are pre-determined at the protocol phase of a Cochrane-style systematic review, but it is appropriate to view the study reports finally included as a selected sample of the available evidence on a topic.

While some reviewers of qualitative research consider it important to identify all the available literature on a topic, others adopt alternative strategies such as purposive sampling and saturation, familiar from primary qualitative research. However, these

concepts cannot operate in the same way for study reports in a review as they do for participants in a study, since what exists in the literature is finite. In addition, saturation has been suggested at the level of study reports – where no more searches are undertaken if no new study reports are being identified (Booth, 2001), as well at the levels of themes, concepts or schools of thought within identified study reports (Sandelowski et al., 1997; Petticrew & Roberts, 2006). Realist review searches for study reports that fit the specific requirements of the review, or which test the particular theories that are being investigated. In this case saturation is considered to have been reached when enough evidence has been acquired “to satisfy the theoretical need or answer the question” (p.28) (Pawson et al., 2004).

Perhaps unexpectedly, giving its background in qualitative nursing research, meta-synthesis does not adopt sampling strategies, but regards the identification of *all* relevant literature as vital for validity in meta-synthesis (Barroso, Gollop, Sandelowski, Meynell, Pearce & Collins, 2003). Opposing concerns arising from the identification of all relevant literature area also noted:

*whereas a threat to the validity of a qualitative research synthesis study is not to have conducted a sufficiently exhaustive search, a threat to the validity of any qualitative study is to have a sample size so large that it exceeds the ability of researchers to conduct the intensive analysis of particulars that is the hallmark of excellent qualitative research. (p.23, Sandelowski & Barroso 2007)*

To overcome this danger, a suitable focused research question, or a programme of several syntheses is suggested. The balance between sufficiently exhaustive identification and a meaningfully, manageable number of included reports could be difficult to achieve.

Paterson et al (2001) also suggest a comprehensive approach to identifying relevant literature for meta-study.(Paterson et al., 2001) They identify the omission of relevant research as a key source of “researcher bias” in syntheses, although the reference cited with this statement appears to be about meta-analysis of quantitative research. They reason that omitting study reports may threaten the ability of the project to engage in midrange theory development, which depends upon “comprehension of all the primary research available” (p.35).

More realistically, Paterson et al suggest that the best one can probably hope for is “a representative sample” of the available research in any area. Again, the language used seems more appropriate to quantitative research. It is not made clear how such a sample could be assessed without access to the full literature, and what

“representative” might mean in the context of qualitative research reports, whether in relation to methodological approaches, theories, populations or some other characteristic. In addition, the authors note that inclusion of too many reports may damage the potential for synthesis, permitting only “gross generalisations” (p.37 Paterson et al 2001). In order to try and reconcile these two contradictory pulls on the amount of research to be included, the authors provide three points to assist:

- *Data should be sufficient to permit comparisons among selected dimensions and constructs.*
- *Reports should reflect the work of several distinct and independent investigators.*
- *Data should be sufficient to answer the research questions fully. (Paterson et al., 2001)*

Thus there seems to be both a type of purposive sampling in identifying relevant literature, but also concerns about exhaustiveness. In reality, the authors describe using an iterative process of elimination that was very largely pragmatic. Their first research question was too broad, resulting in an unmanageable number of studies and it was eventually restricted by focussing on a particular set of participants in the original research.

Ultimately, a balance between pragmatism and purity for identifying and selecting studies seems to be sought (Lloyd Jones, 2004). Noblit and Hare, like Paterson et al (2001), warn that “generalizing from all studies of a particular setting yields trite conclusions” (p.28), although they offer little in the way of guidance about how to sample appropriately. Sandelowski et al (1997) are also pragmatic about limiting the sample to be synthesised. They believe that overly large samples of reports (by which they mean more than 10) are likely to hamper the depth of analysis possible in the synthesis. Purposive sampling is suggested to tighten the inclusion criteria and avoid over-generalised conclusions. Separate syntheses are recommended on each of these honed research questions to facilitate fluency and depth in the synthesis. The suggested limit for the number of studies that can be meaningfully synthesised ranges from six (Dixon-Woods et al., 2001) to 100 (Thorne, Paterson, Acorn S, Canam, Joachim & Jillings, 2002).

It may be nigh impossible in practice to identify all relevant literature even using a range of methods beyond electronic database searches. In a recent review of interventions to encourage a shift from driving to cycling and walking, seven out of 69 studies identified as potentially relevant were found “by chance” because they were

included in collections obtained for another reason, or found while browsing (Ogilvie, Hamilton, Egan & Petticrew, 2005).

Clearly there are difficulties in identifying all relevant qualitative research reports for review. This is true even if the topic matter is a particular condition or its treatment, as is usual for Cochrane style reviews and even more so if it is about a mechanism of action for interventions or some concept of illness. Furthermore there remains little consensus about how important it is to identify all available literature. The next section considers suggested ways of determining which of the reports identified should be included in the synthesis.

#### **4.4.3 Determining inclusion criteria**

Once studies have been identified, some strategies for deciding whether it is appropriate to include them in a review are required. Quality assessment and its impact on inclusion is discussed in detail in Section 4.5. Some other reasons for excluding studies, based on study type or approach, are described in this section.

The framework used by the meta-study team to approach the studied phenomenon influenced the inclusion criteria. They used a chronic illness model (Curtin & Lubkin, 1990) which meant that, for example, disability was regarded as a key component of chronic illness which led to the inclusion of studies on disability in the meta-study (Paterson et al., 2001). By contrast, as Estabrooks et al believe that synthesis should only be attempted in studies from the same methodological and theoretical standpoint, this restricts the types of studies they include. They further focused their review by tightly defining the study participants and the review focus.

Meta-study also excluded those considered to have a consistent political agenda (Paterson et al., 2001). This could be the result of clashes between the values in nursing and in social science research, as a clear theoretical framework or development may be more expected and valued in the latter. It is not clear exactly what would lead to a paper being excluded for being over-political, but potentially could involve a study with, for example, an explicitly feminist stance.

Clearly, there are difficulties in identifying all relevant qualitative research for review, especially if a mechanism of action or concept relating to the illness experience is the focus, as opposed to a specific health condition or treatment as is more usually in HTA-type research. There is also little consensus about the importance of exhaustive searching and comprehensive inclusion. In the next section I consider quality appraisal

for study reports, which is one of the ways that might be used to determine inclusion criteria for identified studies.

## 4.5 Quality Appraisal of Research Reports

In the previous section, I showed how different review methods approach identification and selection of study reports for inclusion in a review. This section goes on to consider the problem of quality assessment of those reports; why it should be done and how. In Cochrane-style reviews, appraisal of study quality is an important part of the exercise, as discussed in Section 2.1.1 (page 23). Even where there is overlap about indicators of quality, the language relating to the appraisal of qualitative research is often different from that used in quantitative research. As Denzin and Lincoln (1994) have observed:

*Terms such as credibility, transferability, dependability and confirmability replace the usual positivist criteria of internal and external validity, reliability and objectivity. (Armstrong, Gosling, Weinman & Marteau, 1997)*

Within systematic reviews of qualitative research, much debate has centred on how to decide which evidence is valid (or most powerful, or most “true”) and how to incorporate such judgements into the review. Key areas of debate include when in the review process study quality should be assessed, how to judge it and how to deal with studies judged to be of poor quality, perhaps through their exclusion, or through giving them less weight in the synthesis. By and large, those who believe that qualitative research *can* be synthesised are agreed that there is a need to distinguish well conducted and reported qualitative research from poor, but consensus about which aspects of design, execution, analysis and description are most crucial is yet to be reached.

*Standards for qualitative research have variously emphasized literary and scientific criteria, methodological rigor and conformity, the real-world significance of the questions asked, the practical value of the findings, and the extent of involvement with, and personal benefit to, research participants. (Sandelowski & Barroso, 2007)*

It may be helpful here to consider some of the arguments that already exist about assessing quality within qualitative research communities. Sparkes identified four schools of thought within qualitative research traditions that have been used to assess the reliability and validity of qualitative research:

- *The replication perspective,*
- *The parallel perspective,*
- *The diversification of meanings perspective,*
- *Letting go of validity* (Sparkes, 2001).

### **Replication Perspective**

*“Anything you can do I can do better.....”*

The replication perspective regards ideas about validity from quantitative and qualitative research perspectives as compatible, so that one set of criteria could be applied to all forms of research. From this perspective, any distinction between qualitative and quantitative research is minimised rather than emphasised. Sparkes reports five, largely procedural, ways of critically assessing validity suggested by Silverman (2000):

- *The refutability principle*
- *The constant comparative method*
- *Comprehensive data treatment*
- *Deviant case analysis*
- *Using appropriate tabulations*

Silverman acknowledges that there is a temptation for researchers to pursue strong, initial conclusions about their data. He cautions against this, suggesting that initial, strong ideas should only be followed once researchers have subjected them to the refutability principle. By trying to falsify the assumptions associated with initial interpretations, these can be either rejected, or strengthened.

As well as being alert to alternative interpretations, other methods of ensuring validity are procedural. Analysis using the constant comparative method is a key element of analysis in grounded theory (Glaser and Strauss, 1964). A systematic set of

procedures are used through which theoretical categories are defined. Initially, data is coded into categories so that related parts can be grouped. The properties that relate to these categories are explored in the data until no new properties are revealed (theoretical saturation). Theory development is grounded in the data, and data collection may continue until saturation is achieved. Validity is likely to be enhanced where researchers actively seek, and try to explain, “deviant cases” that contradict the emergent dominant ideas and, where appropriate, modify their explanations in response to these alternative positions. Tabulations will help to manage and explore findings, assisting analysis and providing auditable detail.

### **Parallel Perspective**

*“You say tomato, I say tomato....”*

The parallel perspective suggests that, unlike the replication perspective, different criteria for judging validity should be developed since quantitative and qualitative research come from different paradigms with different purposes and philosophical premises. Lincoln and Guba call for “trustworthiness” of qualitative research to be judged on credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). These terms have parallels with common concerns in the design of quantitative research and may be mapped onto them as shown in Table 4.

**Table 4: Comparison of quality criteria for qualitative and quantitative research**

<b>Core value</b>	<b>Term used in experimental research</b>	<b>Term used in qualitative research</b>
Truth value	Internal validity	Credibility
Applicability	External validity (generalisability)	Transferability
Consistency	Reliability	Dependability
Neutrality	Objectivity	Confirmability

Source: (Seale, 1999)

Research credibility may be demonstrated through the extent of engagement that a researcher demonstrates with the field of study generally or an investigation specifically. External confirmation of findings through peer review, respondent checking or triangulation methods may also enhance credibility (Seale, 1999; Miles & Huberman, 1994). Transferability suggests that the findings might be applied outside the specific context of the research in question. It relies, however, on detailed description of the contexts in which the research was generated, and to where it may be transferred, in order for such a judgement to be made. Transferability may also be judged at the level of theory which can be applied to other contexts.

Dependability is demonstrated through the creation of an audit trail. This requires systematic, reflexive and detailed documentation of all the methods followed for a project. Any field journals, or notes made at the time of data collection and those kept through the development of interpretation are also considered important records. The audit trail is then available for peer review which can assess the adequacy of the processes (Seale, 1999). The audit trail also allows confirmability, which relates to the extent to which the researcher's findings are considered to be a truthful interpretation of the collected data. Full details of the methods and procedures followed in the research also allow confirmation of the author's attempts to avoid bias. These features of high quality research relate to characteristics of the researchers as well as adequate procedures and descriptions of these procedures.

Although these are different criteria from those for quantitative research, they again mirror the concerns of validity and reliability in empiricist methods in quantitative research that ensure research *processes* have been carried out correctly. Within quantitative research, this focus on the technical aspects of performing the research is the crux for determining validity and reliability. The parallel perspective approach has been criticised for attempting an untenable balance between the relativism of qualitative research and the positivist assumptions of quantitative traditions. The protagonists have responded to such criticism through recognising that their initial strategies, while useful, perpetuated the quantitative paradigm without challenging it. Focus on the methods of research has been described as "insufficient to guarantee that the intent of the inquiry effort was achieved." (Guba and Lincoln, quoted on p.542). This perspective is therefore contested, and developing. In addition, in the context of systematic reviews, assessment would rely on a detailed level of reporting of methods that is rare in study reports. Contacting researchers for details is a possibility.

### **The Diversification of Meanings Perspective**

*"Don't fence me in..."*

*It is neither desirable nor possible to reach consensus about or prescribe standards of evidence in this diverse field. Such prescriptions....amount to disciplinary action (Foucault 1975) that constrain the generation of knowledge rather than improve it. (Freeman et al., 2007)*

Assessments of validity in quantitative research assume that there is an objective reality and that research can uncover it. From the diversification of meanings perspective, any notion of universal truth is rejected and validity is assumed to be a

social construct. Validity is therefore seen as something established within research communities whose discourses are bound by particular historical moments and for particular purposes and interests:

*validity is a rhetorical organisation of (scientific) facts. It is a feat of persuasion – and therefore social construction. (Aguinaldo, 2004)*

The basis of trustworthiness becomes “social agreement” within these communities (J Smith (1989) quoted by Sparkes). This renders fixed criteria inappropriate and allows diverse perspectives to be promoted to fit with particular perspectives of any piece of work. Sparkes quotes a number of kinds of validity available to researchers “negotiated, ecological, catalytic, communicative, pragmatic, craftpersonship, reflexive, rhizomic, voluptuous, paralogical, successor, consensual, situated, imperial, interrogated”. (p.543) New meanings may be ascribed to the term “validity”. For example, in qualitative inquiry it may relate to the personal qualities and skills of the researcher, while traditional concepts of validity, based on realist assumptions, may have no meaning in narrative studies. In addition, accepted norms of study conduct and description may be different in different academic disciplines.

### **Letting Go of Validity**

*“Come fly with me....”*

From this perspective, validity is inappropriate, or even absurd, as a criterion for judging qualitative research. Research that aspires to evocative story-telling, such as *heartful* autoethnography, may be “best judged by whether it evokes in the reader a feeling that the experience described is authentic, believable and possible” (Ellis, 1995, quoted in Sparkes, 2001). Such attributes are related to the assessment of literature or other art, and are communicated not just through language exchange, but also through the feelings and sensitivities evoked through the reading. Sparkes notes that some people question whether such enterprises are really research, which brings the debate about criteria for assessing validity full circle.

These perspectives provide an insight into the range of debates, still unsettled, about the meaning of quality and validity in qualitative research. It provides a background to understanding the difficulties and arguments alive for those wishing to undertake systematic review qualitative research and these are described below.

#### 4.5.1 Strategies to assess validity in proposed methods of review

Sparkes' typologies of validity helps to identify the various perspectives that have informed the approaches suggested by those involved in qualitative research reviews. A checklist approach to assessing validity is commonly advocated for systematic reviews. Originally, this approach replicated Cochrane-style review methods and concerns, leading to the adoption of replication or parallel perspectives on validity. A wealth of checklists have since been developed to assess quality. Given the range of methods of data collection, as well as approaches to qualitative research, simple checklists are more difficult to design than for RCTs and, if the diversification of meaning perspective is adopted, different checklists will be required for study reports from different research traditions. Petticrew and Roberts (2006) caution against the uncritical use of checklists, especially since those developed with clinical studies in mind may not be sensitive to key issues of concern in social science research.

The EPPI-centre researchers developed their own guidelines to assess validity and reliability and they concentrate on the clarity of reporting for various methodological elements within the study (Rees et al., 2001). There have been concerns that such lists are used unreflectively, or prescriptively (Barbour, 2001) and that they can anyway judge only the *report* of a study rather the actual *conduct*. The parallel perspective focus on technical aspects of research has been criticised. It has been argued that, whilst good quality research and the most valuable theoretical insights *might* be linked in qualitative research, this is not necessarily the case:

*Had checklists been a feature of the history of qualitative research to date, it is likely that many of the most influential papers in this genre would have been de-selected from review exercises on the grounds of failing to fulfil all the stated criteria and some might never have been published. (Barbour & Barbour, 2003)*

Sandelowski et al (1997) are also resistant to studies being judged as poor because the researchers "have used the "wrong" language and method citations to describe their work". It is not clear what the use of the inverted commas suggests - their use could imply that the authors believe that there is no such thing as a wrongly executed study, or that it does not matter if, for example, a descriptive study is labelled as phenomenology. Such errors can still relate to a "generally good study" (Sandelowski et al., 1997) which appears to mean that they may yet contain meaningful findings. The main plea is that evaluation of study credibility should not overshadow the important work of appreciating the study on its own terms. However, Sandelowski et al

(1997) provide an extensive checklist of items to guide study appraisal although it is not clear how this information should then be used.

It is noted that there is great variety *within* schools of qualitative research as well as between them:

*Good or bad, one investigator's phenomenology may be more like another's grounded theory than two researchers' grounded theories. Right or wrong, one investigator's rendering of symbolic interactionism may be more like another investigator's rendering of critical theory. (Sandelowski & Barroso, 2007)*

As noted before, however, they seem unwilling to judge this, noting only that any assessment of the methods should not rely wholly on the labels given to them in their write-up, and that in reading the study reports, an understanding is not complete without some attempt to record the impact of the author in terms of their academic background, interests and experience (reflexivity). Additionally, such misappropriation of terms may also be the result of journal publication guidelines enforcing the use of terms that have been called "hurrah" words (Hammersley, 2002): that is, words that become blindly associated with an indication of quality. Within qualitative research, a description of the analysis process as using "grounded theory" has become shorthand for a recognised analytic process in some health-related journals and may be routinely included in a research report regardless of the actual approach used (Green, 1998; Barbour & Barbour, 2003).

Petticrew and Roberts see checklists as crucial in answering the demands for transparency that systematic reviews entail. However, a checklist may simply systematise consideration of a number of items that still require considerable judgement on the part of the reviewer:

*Some quality criteria require an explicitly theoretical approach (e.g. Seale and Silverman, 1997), with an emphasis on language and concepts that may appear inaccessible to those from more traditional medical research backgrounds (Dixon-Woods et al., 2001)*

A range of other approaches have been suggested. For example, Paterson et al (2001) made initial judgements about the utility of the research in answering the review questions and study credibility. Sandelowski and Paterson et al suggest using Burns' (1989) markers of quality:

- *Descriptive vividness*

- *Analytic preciseness*
- *Heuristic relevance*
- *Methodological congruence.*

Such items require considerable judgment and interpretation on the part of the reviewer. “Descriptive vividness” may include elements such as whether the study description is considered credible, “analytic precision” about whether hypotheses are verified by the data, and “heuristic relevance” about whether the phenomenon is well-described and the findings thought important (Cesario, Morin & Santa-Donato, 2002). It is perhaps not then surprising that Dixon-Woods has reported that agreement about the quality of study reports was not improved among six reviewers by the introduction of such a checklist (Dixon-Woods, 2005). In addition, Paterson et al note that the relevance of these elements was limited in the case of their particular research interests (2001). They also noted that whether studies met these criteria was highly dependent on the academic discipline of the authors and the type of journal in which papers appeared, highlighting the constructed nature of validity within qualitative research, sympathetic to the diversification of meanings approach to validity.

In the meta-narrative approach, Greenhalgh et al (2005) also adopt this line, and suggest that quality frameworks should relate to the methods used and the discipline within which the research was conducted. This allows the diversification of meaning within and between research traditions to form the basis of the validity check, drawing on the priorities from within each tradition. However, there is a danger that this may magnify the problem, as consensus within each tradition may be lacking, hampering the choice of appropriate and valid sets of criteria (Sandelowski et al., 1997). Greenhalgh et al (2005) and Paterson et al (2001) recognise that the conduct and scope of research is bound to particular socio-cultural moments, and the aspects of design considered indicative of good quality may also change over time (Barbour & Barbour, 2003). It is also noted that different journals may have different policies about what is required from a study description or conduct in order to be accepted for publication. These diverse structures for quality must be near impossible to account for within one review, and cannot be fixed as they may be continually evolving.

Popay has argued for three criteria for quality to be considered, and has emphasised that guidelines for how studies are *reported* (technical criteria) need to be separate from *study* quality appraisal (epistemological and theoretical criteria):

1. *Epistemological: if the study is trustworthy, judged by whether or not the voices of participants come through.*

2. *Theoretical: whether an explicit theoretical framework shapes the design of the study, thus enhancing claims for generalisability.*
3. *Technical: the methods of study, full and appropriate description of the stages of search, background to the project, etc. (Popay, 2008)*

This approach allows for a parallel perspective to inform the technical elements while diverse meanings of validity could still be explored.

In aggregated synthesis, quality markers appear to be informed by grounded theory. Estabrooks et al thus regard studies that use themes and category labels not obviously grounded in the data as poor quality. “Bias” introduced through “deductive contamination” from other theories is also criticised, in opposition to the Popay guidelines above. Other suggested criteria include “superficial analysis”, although it is not clear how this is measured, and “unclear methods”, which relates to the technical elements of their reporting. Estabrooks et al suggest that studies which “stand out” as anomalous may be poor quality, coming from superficial, biased or misrepresentative analysis. In contrast, meta-study’s focus on the impact of theory and method on findings means that similar findings may be explained by a narrow evidence base and disconfirming cases are actively sought (Paterson et al., 2001). Poststructuralists may not agree that such things as disconfirming cases truly exist (Freeman et al., 2007) since all points of view are regarded as valid subjective truths.

Methods developed within nursing research also value findings and conclusions that are clearly grounded in the presented data while being suspicious of “uncritical verificationism” of theories brought to the research, even excluding studies where the “political” agenda of the researcher was too strongly evident in the research (Paterson et al., 2001). Use of theory as a study framework is contentious and this may indicate tension between sociological and nursing paradigms. It is not clear whether a study informed by an explicitly feminist perspective, for example, would be acceptable by this criterion. Paterson et al also considered unusual or skewed study samples to be an indicator of poor quality, although this seems to preclude innovation and perhaps some theoretical sampling strategies.

Noblit and Hare originally suggested that the quality of research accounts should be judged through the contribution that they make to meta-ethnography. This makes sense in the context of translation of metaphors and concepts, as more comprehensively adoptable metaphors are likely to be used to encompass those derived from other studies. However, it is more difficult to judge what to do with a long paper that presents a complex set of themes compared to a short paper that develops

a single, well-described concept or theory. Sandelowski et al (2004) extend this idea to encompass how study reports contribute to the synthesis both overall and by type of finding within the studies. Paterson et al (2001) note that a lack of fit between a study's research question and that posed by the review means that such a study is unlikely to contribute much to the synthesis. Quality in all these cases is likely to be judged through trying to synthesis studies, rather than as a step of the review process prior to this.

The different purpose of realist review questions leads to a focus on the robustness of particular *theories*, rather than the robustness of the evidence itself (Pawson et al., 2004). Studies or elements within them are assessed for relevance and rigour, with the latter involving a judgement as to whether an inference by the author "has sufficient weight to make a methodologically credible contribution to the test of a particular intervention theory." Quality is therefore also judged through the synthesis process rather than prior to it. All study reports are likely to be "both illuminating and flawed" (Pawson et al., 2005b).

The computer programme developed by the JBI (QARI) contains a quality appraisal checklist, which aims to "limit bias" and "establish validity" (Pearson, 2006). This is the approach closest to that in Cochrane-style reviews. The programme has a drop-down menu with "yes", "no" and "unclear" options to ten validity items applied to all study reports. This is envisaged as a "point of engagement" with study quality, rather than a tally and there are no set rules defining how many or which elements of this checklist would lead a study to be considered of poor quality, or what would happen to it if it was.

In QARI, the data of interest ("units of extraction") are findings (defined as "a conclusion reached by the researcher and often presented as themes or metaphors") together with "illustrations from the text that demonstrate the origins of the findings" (Pearson, 2006). This extraction of an illustrative quote for each finding is felt to assist the reviewers' judgment of a study's authenticity or "credibility" – a key quality indicator. Three levels of credibility are described:

1. *Unequivocal – relates to evidence beyond reasonable doubt which may include findings that are a matter of fact, directly reported/ observed and not open to challenge.*
2. *Credible – those that are, albeit interpretations, plausible in light of data and theoretical framework. They can be logically inferred from the data. Because the findings are interpretive they can be challenged.*

3. *Not supported – when neither 1 nor 2 apply and when most notably findings are not supported by the data.*

The “unequivocal” category suggests that some conclusions are not interpretations, and that they represent truths or facts. Alternatively, it might be interpreted in terms of Noblit and Hare’s distinction between types of interpretations, with this being those that make “the obvious obvious” (Section 3.2). More analytic approaches, which can be more intellectually and analytically demanding, that make the “hidden obvious” or the “obvious dubious” require more obvious interpretation. The greatest credence is given to less theoretical studies; in Sandelowski’s terms, the studies whose findings are the least transformed data. Studies at the top of this hierarchy are those which claim to be reporting “facts”. Terry Eagleton wrote:

*The economist J. M. Keynes once remarked that those economists who disliked theory, or claimed to get along better without it, were simply in the grip of an older theory. This is also true of literary students and critics (Eagleton, 1983).*

The same may also be true of reviewers. A conclusion given as a JBI example is that more training is required to help doctors understand the rigours of systematic review evidence. This finding is graded as unequivocal (Pearson, 2006). However, such a conclusion relies on particular kinds of expectation and assumption about how people behave in relation to educational input (the nature of which is not defined), the impact of training styles and people’s own preconceptions and experiences about the validity of systematic reviews. In addition, the “unsupported” category may include those studies which are published in journals where limited space may preclude providing substantial justifying material for each finding. Agreed reporting standards for the methods of research in articles would address this latter problem.

While most synthesis methods seem to agree that there is a need to distinguish good quality studies from poor, methods and purposes of such appraisals remain very varied. This raises the question of the impact of decisions about how to handle studies rated as poorer quality, and I turn to this in the next section.

#### **4.5.2 Study validity and inclusion**

Several review methods advocate excluding studies that are judged to be of poor quality (Paterson et al., 2001; Estabrooks et al., 1994). Popay et al (2006) believe that this decision should be up to the reviewers involved, emphasising instead the importance of recording how and why such selections are made. By contrast,

Sandelowski et al (1997) are sceptical about judgements on quality that lead a study to be excluded from the synthesis. They regard any judgements made about quality to be most important “in order to achieve an understanding of each study on its own terms” and are critical of studies unnecessarily excluded for reasons of a technical or descriptive nature that do not affect the credibility of the results (Sandelowski & Barroso, 2007). They instead suggest excluding specific *findings* in reports if no data to support them are presented. It seems possible however, that as with absent methodological details, absent supporting data could also be a result of limited space in some journals (Sandelowski et al., 1997).

Noblit and Hare argue against the exclusion of studies based on quality assessment from meta-ethnography. They argue, that definitions of “methodological deficiency” (p.15) are often based on untested theories about which methods are important and what might constitute a fatal flaw in design or execution of research, as was shown in Section 4.5.1. However, they believe that poor quality studies will contribute less to the synthesis. Campbell et al (2003), however, noted that failure to exclude a poor quality study from their meta-ethnography initially caused them problems in the synthesis. This perhaps shows that it is through *doing synthesis* that critical elements of quality are illuminated, although practical difficulties may be encountered.

The EPPI-centre method replicates Cochrane-style review methods through attempted sensitivity analysis based on study quality (Rees et al., 2001). As the findings from studies judged as poor quality did not contradict those from high quality studies, they concluded that the synthesis would not have been affected by their exclusion. However, it seems equally logical to reach the opposite conclusion: since the findings were similar, one could conclude that there was no fatal flaw in the design or execution of the so called “poor quality” research reports. Their inclusion may have strengthened the evidence for particular findings in the synthesis, specially if they had emanated from different research disciplines or had used different methods to those included in the review.

Rather than determining an absolute measure of validity, the question “what is this research valid for?” has been suggested as more appropriate given the range of methods and philosophies represented in qualitative research (Aguinaldo, 2004). Such a question does not foreclose on any particular research approach. Given the newness of reviews of qualitative research, it may be advisable to mirror existing methods of quality reassurance at least initially – that is by using some consistent strategy, in the form of guidelines, to assess the validity of research and by including more than one person in the assessment, to ensure that multiple perspective are

brought to bear on the final statement. Popay's distinction between epistemological, theoretical and technical aspects of quality is helpful, and in the longer term, an agreed minimum set of required technical information should be developed to inform the reporting of research in all publications. I would suggest that this should include details of:

- participants,
- sampling procedures,
- approach to data collection and analysis and
- impact of any imported theory.

Given the increasing use of additional information provided by e-journals, this information need not use up limited word counts at the expense of greater description of the study findings, but could be provided as an online technical appendix.

## **4.6 Methods of Analysis and Synthesis**

### **4.6.1 Data extraction**

Within systematic reviews of quantitative research, double data extraction is a common feature designed to enhance reliability, increase accuracy and validate interpretation of data. Although the use of more than one researcher to code themes may be advocated in qualitative research syntheses, the reason for this may be very different (Booth, 2001). The JBI method does use double data extraction because it strives for a high level of agreement between researchers, which is regarded as enhancing reliability as it is in Cochrane-style reviews. By contrast, the value of multiple researchers assessing qualitative research is alternatively seen as lying precisely in their disagreements, which may provide additional depth in the synthesis:

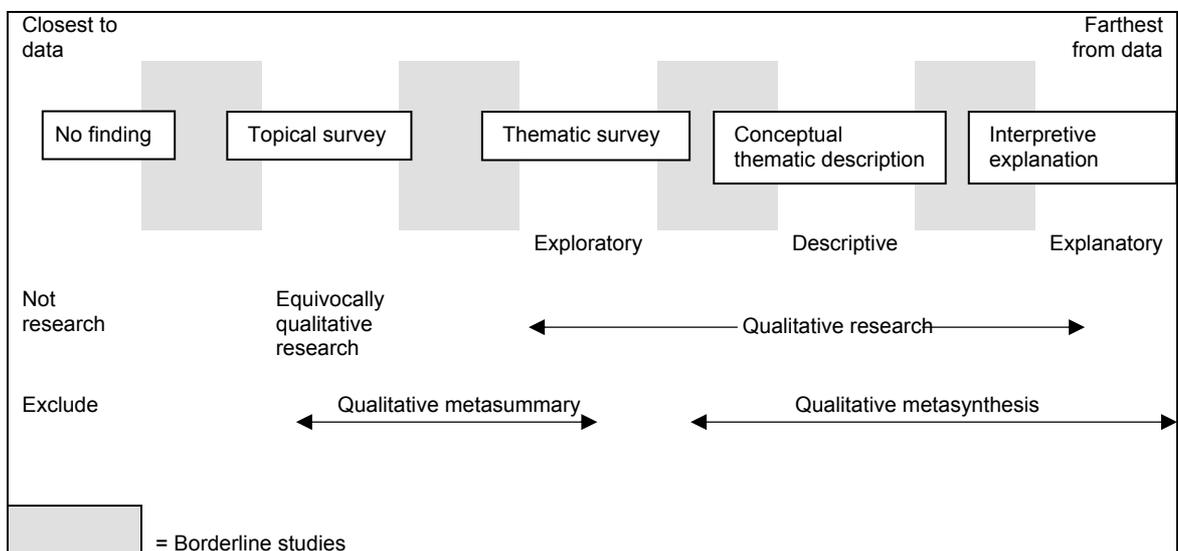
*the value is the content of the disagreements and the insights that discussion can provide for refining coding frames. (Barbour, 2001)*

Meta-study emphasises that the context of findings and relationships between them also need to be maintained in data extraction (Paterson et al., 2001). This adds to the complexity of the task and again might be assisted by using multiple data-extractors.

A further consideration is identifying all the relevant findings in a paper. Some qualitative research simply reports the data generated in the research interviews and she regards this as uninterpreted *data*, rather than research *findings* (Sandelowski &

Barroso, 2002). Even where data has been interpreted, it is sometimes difficult to identify the findings in qualitative research reports. The difference between the participant voice and the author voice (first order and second order interpretations) may be difficult to locate, and sometimes concepts are difficult to distinguish from themes. Data extraction can therefore be challenging, and if multiple reviewers are employed they need to be clear about such definitions. Prior to considering how to synthesise research findings, Sandelowski and Barroso emphasise that it is necessary to identify and classify the nature of the findings. Their categories of research findings are shown in Figure 3 and are based on the degree of transformation of data into findings by the researcher.

**Figure 3: Types of qualitative research findings by integration method**



Source: Sandelowski and Barroso, 2007 p. 134

Using these distinctions, I would classify findings that offer descriptions and explanations of the phenomenon under investigation as involving conceptualisation. If themes are simply presented or explored (thematic surveys in the diagram above), I would not consider these as concepts. Where concepts are then linked together to provide explanations, this can be seen as theory building.

#### 4.6.2 Methods of synthesis

This section outlines the different suggested methods for synthesising the findings of studies included in a review. Developing and communicating the methods used for synthesis of qualitative research is difficult, just as it is in primary qualitative research (Sandelowski et al., 1997). Paterson et al (2001) struggle to describe the procedures through which synthesis progressed, referring to the “mystery and magic” of the

process and falling back on descriptions of a “dynamic and iterative process of thinking, interpreting, creating, theorizing, and reflecting” (p.112). The description of narrative synthesis, and the sourcebook by Miles and Huberman offer much in the way of analytical tools to approach this problem (Popay et al., 2006; Miles & Huberman, 1994).

As shown in Figure 3, Sandelowski and Barroso (2002) note that much qualitative research does not go beyond identifying themes in the data, in what she describes as “thematic surveys”. They describe the method of combining these as meta-summaries, since more complex methods such as grounded theory or meta-ethnography require primary synthesis of the data into conceptual models, concepts and metaphors by the original authors (shown in Figure 3 as descriptive or explanatory research findings). Meta-summary is a method of quantitatively aggregating research findings because they consist of reports of common findings without further analysis. In these cases, data remains simply collected together and presented without transformation by the researcher into second order interpretations (Sandelowski & Barroso, 2002). In contrast to true synthesis, Sandelowski and Barroso (2002) describe these cases as amenable only to a summary which is “approximately equal to the sum of its parts”. I would argue that it is possible to synthesise such thematic surveys if other studies included in a review offer more sophisticated explanatory concepts which can be meaningfully imported and used to interpret the thematic findings. Reviewers themselves may also introduce such concepts.

In contrast, the EPPI-centre synthesis used thematic analysis to synthesise the findings of included studies. Findings from the studies were extracted and transcribed verbatim into NVivo, and this is the only synthesis method that described using computer software designed for the analysis of primary qualitative findings (Rees et al., 2001). A coding framework was developed in order to construct a hierarchical tree structure to illustrate the findings. Three members of the team then met to develop a more abstract set of analytic themes. Details about how findings are identified and different types of findings are not given.

The process of synthesis described by Noblit and Hare in 1988 has been very influential in the approaches to synthesis described since, notably meta-synthesis, meta-study and narrative synthesis (Noblit & Hare, 1988; Sandelowski et al., 1997; Popay et al., 2006; Petticrew & Roberts, 2006). Noblit and Hare describe identifying studies’ key concepts and metaphors and then translating them into one another through reciprocal translation, refutational analysis or to form a line of argument. This allows the studies to be reconceptualised in terms of each other. Studies are read and

reread to gain an in-depth understanding of them in their own terms. Using constant-comparison, key concepts are extracted, or are created for each case study. These are then juxtaposed, and translations between cases are undertaken.

Sandelowski and Barroso suggest that different methods of synthesis should be used depending on the aims of the review. Grounded theory is suggested as particularly useful in theory development, while the reciprocal translation of meta-ethnography is seen as particularly appropriate for understanding the relationship between research reports' findings; discourse or narrative analysis should be used to illuminate types of discourse produced by research findings or as an example of particular cultural stories (Sandelowski & Barroso, 2003c).

The JBI approach to meta-synthesis is three step:

- *Extraction of themes, metaphors, findings or conclusions*
- *The categorization of these data on the basis of similarity in meaning*
- *Developing synthesised findings or conclusions representing an aggregation of categories.*

JBI draws parallels with the transformative steps of first order, second order and third order interpretation. They align these with extracting paper concepts, refutational or reciprocal translation and developing a line of argument respectively. However, this is not my understanding of these terms; first order interpretations are the interpretation of experiences by research participants, second order interpretations are those from the researcher in primary research, while Britten et al (2002) have described the synthesisers' further interpretation as third order interpretations.<sup>i</sup> In the JBI method, reviewer developed themes are referred to as second order interpretations.

The guidelines for narrative synthesis devote a lot of space to describing different visual tools and techniques to assist initial analysis of data, and in developing what the authors describe as a preliminary or descriptive synthesis (Popay et al., 2006). The narrative synthesis guidelines suggest using textual descriptions of studies, groupings and classifications of findings, tabulation of different elements within and across studies, vote counting, and thematic and content analyses as methods which reviewers

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<sup>i</sup> Dixon-Wood et al, have suggested that the term "third order interpretation" is inappropriate as it is still a social science researcher's interpretation and therefore, they suggest, is properly referred to as a second order interpretation.

utilise to explore and familiarise themselves with study findings (see Section 3.9, page 68). This useful list provides the most detail given about *processes* that may be employed to manipulate and juxtapose findings - a crucial stage if an interpretive synthesis is to be undertaken. Translation, as described in meta-ethnography, is seen by Popay et al as a method for exploring relationships between studies and findings in a subsequent synthesis phase. Idea and concept mapping, triangulation and the development of conceptual models are also suggested methods for exploring relationships in the data. Like the meta-method stage of meta-study, methodological and investigator triangulation seeks to explore heterogeneity in study findings in terms of the differences in discipline and approach (Popay et al., 2006). It is suggested that several people should be involved in the synthesis and that the contribution of the “multidisciplinary gaze” (p.37) may be particularly useful when using triangulation.

Petticrew and Roberts also base their synthesis plans along the lines of narrative synthesis. In addition, the tenor of best evidence synthesis, whereby results from a number of study designs are included provided they reach minimum standards of adequacy and relevance, is followed. In some cases this will apply to qualitative research, although it is not entirely clear how the authors envisage this would be used. Approaches such as meta-ethnography, the EPPI-centre approach and realist review are mentioned but not detailed, as mechanisms for synthesis.

The meta-study approach also distinguishes between an initial analysis phase, where findings are grouped and juxtaposed to help identify similarities and differences, and the following synthesis phase (Paterson et al., 2001). For meta-data-analysis, the authors suggest that reciprocal translation, grounded theory, thematic analysis or interpretive descriptive analysis may be used. As previously noted in relation to search strategies, grounded theory may be limited by the available literature, preventing saturation being identified. It is recommended that multiple researchers undertake meta-data-analysis to avoid one perspective being over-emphasised. Paterson et al (2001) also emphasise the importance of a complete audit trail to record how categories were developed.

Meta-study is the method that most explicitly describes the steps to assess the impact of methodology and theory on findings (Paterson et al., 2001). These elements are touched on by meta-synthesis and narrative synthesis but are not given such prominence. Aggregative synthesis, in restricting included studies to a single methodological type, avoids the need to address this aspect of synthesis (Estabrooks et al., 1994). Meta-method examines the appropriateness of the methods used in the primary studies and tries to establish whether differences in epistemological approach

are responsible for any differences in findings between research accounts. Thus the research question, role of the researcher, setting, sampling procedures and methods of data collection are examined, and the “fit” (p.78) between these elements considered (Paterson et al., 2001). Paterson et al note that the stated orientation of research and the one suggested by the language of the study may not align, so careful consideration of what was actually done by the researchers is required. Changes in focus and approach over time within disciplines may also be identified through meta-methodology.

The third arm of analysis in meta-study is meta-theory which examines the theoretical drives or development in the primary studies (Paterson et al., 2001). This involves identifying the major theoretical underpinnings of the research and, in a similar way to realist review, explores the assumptions that underlie any such theories (Pawson et al., 2004). Historical preferences and development are also examined and related to wider socio-cultural movements. This step is more formal in realist review, as other sources of information, such as media inputs, are considered in order to explore the contemporary socio-political context. Crucially, this allows the reviewer to question whether similarities between the findings of individual studies *strengthens* them, as the EPPI-centre approach and aggregative reviews claim. Similar findings may indicate limited frames of reference within which studies of a phenomenon have been undertaken, rather than identifying more powerful, transferable findings. In addition, Paterson et al (2001) state:

*If the conclusions of a particular study are articulated in such a way that they confirm the relevance of the theory by which the study was guided (what Johnson [1999] refers to as “uncritical verificationism”) the meta-synthesist may conclude that this body of research might yield insight for a meta-synthesis of the theoretical position but not for a meta-synthesis of the clinical condition on which the theory was tested. (p.118)*

This observation raises questions about the way in which the aims of synthesis are formulated: whether most appropriate in the field of theory testing, which might be seen as a more purely academic pursuit, or in the field of examining particular topics, which may be regarded as most useful, or familiar, within healthcare research and the way in which policy makers such as NICE are used to framing review questions.

The explicit aims of realist review are to provide better explanations, through increasingly refined theory. Theories that inform complex interventions are examined and refined through the review process, seeking ultimately to provide an explanation

about what determines the effectiveness of a particular type of intervention, in what respect, and for whom. This is rather different from other review methods which focus of topic areas such as a type of illness or a particular response to it. Pawson et al (2004) state:

*Perhaps the best metaphor for the end product is to imagine a sort of Highway Code to programme building, alerting policy makers to the problems that they might expect to confront and some of the safest (i.e. best tried and with widest application) measures to deal with these issues. The highway code does not tell you how to drive, but how to survive the journey by flagging situations where danger is lurking and extra vigilance is needed. (p.33)*

Realist review identifies the theories that underpin a particular policy. The review may explore whether these theories are compatible, or whether blocks and weak points lead to the breakdown of the intervention under review. The review may require competing theories to be examined and judged for validity, based on evidence about the policies in action. Alternatively, the same theory could be explored in different settings. Finally the review may explore the misfit between official expectation about how policies are expected to work and what happens in practice.

As noted previously, the method of synthesis described for meta-narrative was intricately linked with the topic that was studied, and it is unclear what differences may be evident if it was applied to a different subject (Greenhalgh, Robert, MacFarlane, Bate & Kyriakidou, 2004). The process is described as being very laborious because each study is analysed within its own research paradigm before being added to the sum of evidence across all research traditions. It is possible that the analysis may be influenced by the order in which the different research paradigms are examined, although this is not discussed. Thirteen meta-narratives, key accounts within a range of research disciplines, were identified about the diffusion of innovations. The authors identified seven key dimensions across the range of disciplines investigating innovations. It is not clear how these dimensions were identified but may be through thematic analysis, or whether these are found or constructed categories. The papers were examined to see what questions had been asked about each of these seven key elements within each discipline, and then to see if the questions could be meaningfully grouped across traditions. The findings were examined for similarities, and where there were conflicting findings, attempts were made to account for them. Overall key findings across the traditions were identified and their implications for practice examined. Finally, gaps in the research evidence were used to inform recommendations for further research about how to spread innovative practice successfully (Greenhalgh et

al., 2004). Commonalities in findings across different disciplines were therefore seen as an indicator of their robustness.

These different formulations reinforce already noted difficulties about describing or codifying how the analysis of qualitative research proceeds. There are some similarities across methods, including several reviews that do not prescribe a particular approach to analysis and synthesis. This suggests that reviewers should choose the methods that best fit with the reviewers' own experience, and with the type of evidence available. This could mean adopting meta-ethnography where well developed conceptualisation is evident, but undertaking a thematic analysis where studies largely just report common themes identified in the data. Methods might also change in response to specific requirements of a review.

## **4.7 Assessing Review Validity**

Just as there are different approaches to assessing the validity and reliability of individual primary qualitative studies, a number of approaches have been suggested to assess the synthesis of qualitative research. To an extent, these depend on the priorities and academic influences of the authors, with some more aligned with existing mechanisms to assess systematic reviews and others taking their lead from primary qualitative research. The challenges of such quality appraisal have some similarities and some differences to those encountered when appraising the quality of primary studies. Pawson et al (2004) note that established quality markers for reporting standards in Cochrane-style reviews (Quality of Reporting of Meta-Analyses, QUOROM) are unlikely to be appropriate for qualitative review and synthesis. The process is unlikely to be fruitfully driven by a protocol, cannot be standardised and may not be reproducible. In some cases perceived markers of review quality are not explicit in the accounts reported in this chapter, but they may be inferred from descriptions of what practitioners regard as the strengths of their described approach. For example, Paterson et al (2001) clearly value richness of description in meta-study and they caution against sacrificing it for precision within the synthesis although they acknowledge that this may prove a difficult balancing act. Several methods, including meta-study, meta-ethnography and meta-synthesis, also caution that attempting to synthesise too many findings is likely to lead to conclusions that are trite or too general: "Overly large sample sizes can impede deep analysis and, therefore, threaten interpretive validity of findings" (Sandelowski et al., 1997). Unhelpfully, "overly large" is not defined.

Acknowledgement that any systematic review of qualitative research is the product of one set of authors' interpretations is also endorsed by meta-ethnography and meta-study. Jensen and Allen take a different approach in their description of meta-synthesis, suggesting that replicability is possible and desirable: "synthesis is auditable when the same or comparable conclusions can be achieved given the data". Replicability is a cornerstone of quality for Cochrane-style reviews. Replicability of different researchers' analyses of primary qualitative data has been empirically tested. Armstrong et al (1997) attempted to assess the inter-rater reliability of different researchers' analyses of a script from a focus group. They found that there was some consensus about identifying main themes in the data although they were described and packaged in different ways: "subjectivity does not necessarily mean singularity" (Armstrong et al., 1997). A similar test for the synthesisers of qualitative research may show similar results.

Paterson et al offer six strategies for remaining "analytically honest" (Miles & Huberman, 1994) and avoiding bias in the analysis and synthesis of study reports which can be seen as mechanisms of quality assurance. Elements thought to potentially bias analysis include researchers producing codes that reflect their interpretations and preconceptions leading to some elements being over- or under-emphasised. To try and minimise the chance of this they suggest:

- *Data analysis is independently conducted by at least three researchers.*
- *Keeping as much information as possible about how codes or categories are developed.*
- *Developing an overview table of major categories and sources from which they were derived.*
- *Avoiding developing overarching categories too rapidly.*
- *Reflecting on developed metaphors to illuminate underlying assumptions about the studied phenomenon. Ensure that all members of the team mean the same thing when they use a term.*
- *Being wary of codes that are "too tidy" as they may not capture all the variation in the data. (p. 68/69):*

Several elements for ensuring the validity of primary research described by Lincoln and Guba (1985) are adopted or adapted by reviewers. Both meta-study and aggregated synthesis advocate keeping an audit trail of all decisions made in the process (Paterson et al., 2001; Estabrooks et al., 1994). Paterson et al (2001) list four criteria by which trustworthiness may be established:

- *All reviews were conducted by three researchers independently.*
- *The reviewers met to identify differences in their reviews and to arrive at an agreement.*
- *Negative or disconfirming cases/ incidents in the research were identified.*
- *Rival hypotheses were tested by seeking explanations other than the researchers' original hypothesis to describe the meta-study findings.*

Such elements should be documented throughout the review process. Reviewers can try to follow this advice. Readers of reviews, meanwhile, can only assess if they believe that such steps have been followed and followed appropriately.

Rigour in the description of meta-study was likewise determined by criteria adapted from Lincoln and Guba:

- *Truth value (faithfulness of the researcher in presenting data from the study reports rather than their prior conceptions, in such a way that authors of the primary research would think the conclusions drawn are compatible with theirs.)*
- *Applicability (consistency between conclusions of the meta-study and "the domains within which the interpretation may have an impact")*
- *Consistency (the degree to which the conclusions follow the research processes and analysis.)*
- *Neutrality (absence of bias) (Paterson et al., 2001).*

Both Estabrooks and Jensen and Allen value credibility in the synthesis. By this they mean that the descriptions are rooted in the data and not pushed beyond them. Estabrooks calls for "scholarly vigilance" to ensure that findings are not exaggerated.

Barbour and Barbour (2003) have suggested that all methods of synthesis should have at their heart constant comparative methods, adopt purposive sampling, and multiple coding in a multidisciplinary team to draw on "a wider store of theoretical frameworks and insights". The multi-disciplinary team is also seen as a key check on validity in meta-narrative, realist review and narrative synthesis (Pawson et al., 2004; Greenhalgh et al., 2004; Popay et al., 2006).

In narrative synthesis a clear and complete description of all stages of the review is advocated (Popay et al., 2006). The uncritical inclusion of poor quality studies is considered likely to affect the quality of the synthesis negatively. Similarly, studies that are of high quality should be given a similar weight in the review.

Five possible approaches to assessing robustness are described in the narrative synthesis guidance.

- The EPPI-centre approach which considers the weight of available evidence by setting criteria for relevance, including only those studies that meet these criteria and assessing their methodological quality.
- Best evidence synthesis in which minimum standards of methodological quality are set for studies and only those meeting these are included in the review. Different study methods will have different criteria for good quality. However, decisions about inclusion are made early in the synthesis process.
- Validity assessment (the Centre for Disease Control, CDC approach), one of numerous approaches to assessing the strength of the evidence, which lists categories to determine if there is insufficient evidence about a topic, although these categories may overlap: insufficient designs or executions, too few studies, inconsistency, effect size too small.
- Critical reflection, in which a structured discussion of the review is recommended which outlines how the synthesis was carried out. This should include a discussion of potential limitations of the approach, a description of the evidence included together with potential biases and impact on the synthesis, assumptions, the identification of uncertainties and discrepancies in the results and how these were handled, any expected changes in the technology or evidence, and the generalisability of the results to practice.
- Checking the conclusions of the synthesis with primary researchers which would allow interpretations about primary data to be checked with the authors of the included reports. It is suggested that this is likely to be most useful only where the number of included studies is small.

Booth has also suggested that syntheses should be validated through triangulation methods such as checking the developed conceptual framework or theory with a subset of case studies, or by consulting with key informants or focus groups (Booth, 2001). Respondent checking is not without its problems in primary research as participants may not read the report with sufficient attention to detail or critical attention, and the purpose of the participants' and researchers' accounts of a phenomenon may be different (Murphy & Dingwall, 2003). It is also difficult to judge the meaning of lack of criticism from participants of a research report, and while it may be interpreted as showing results are reliable, it may also be interpreted as showing the inadequacy of the method as such a check (Murphy & Dingwall, 2003). The method of obtaining feedback from participants, such as interviews and focus groups may also influence the

outcomes. Some of these problems may also be encountered for qualitative reviews. If quality assessments made about primary studies find them to be poor, this could also create problems when author checking.

“Trustworthiness” in primary research may focus on whether the voices of the research participants are allowed to come through the report. It has been suggested that the “trustworthiness” of a qualitative research synthesis may be easier to establish than for primary qualitative research. The raw data of reviews, in the form of published research reports, is available in the public domain and any reader can go back to this and form their own view of the appropriateness of the reviewers’ interpretations (Doyle, 2003).

## **4.8 Dissemination**

Reflecting concern with the utility of reviews, dissemination of results is considered as a specific step of the review process in meta-ethnography, realist review, meta-narrative, Petticrew and Roberts’ handbook and meta-study. All state that the audience for the review and their needs should be considered early on, so that reports can be appropriately tailored. In realist review this is most explicitly a collaborative process. Innovative methods to disseminate findings to audiences beyond the academic are suggested by Noblit and Hare.

Noblit, in a discussion paper with Thorne et al (2004), has written:

*We should do as much work on those who use our knowledge to inform their practice and/or policies as we do on those who are vulnerable to our institutionalised systems. (Thorne et al., 2004)*

In particular, he is interested in learning how information and research is used by health care professionals and policy makers, and to empower patients.

Petticrew and Roberts take a systematic approach to dissemination, suggesting (based on an approach by the Canadian group, Research to Policy) that consideration of five key questions can help knowledge transfer (p.252):

1. What message do you want to transfer? This should be clear, compelling, and relate to the decision faced by decision makers.
2. To whom should the message be delivered? The target audience should be specified, and the message tailored to them and the context in which they work.

3. By whom should the message be delivered? They should be credible, to target audience and to researchers.
4. How should the message be delivered? Interactive mechanisms are preferred where possible.
5. With what effect? Evaluation should be against explicit objectives appropriate to the target audience.

They are particularly concerned that research findings be accessible to potential beneficiaries, but note that other crucial elements, such as advocacy, policy adoption and behaviour change must also be in place if findings are to be implemented.

## **4.9 Prospects for the Systematic Review of Qualitative Research**

Despite the increasing acceptance of and desire to use existing qualitative research to produce synthesised accounts, the proliferation of review methods for qualitative research means that most have only been tested in a limited number of projects. As this chapter has shown, the methods are still evolving, with no fixed best practice having been established. Indeed some methods, such as meta-narrative, currently seem highly associated with the particular project through which they were developed and it is unclear how the process might be applied to other reviews in the future. There are signs of increasing impatience among those who believe that synthesis is possible and potentially useful, because extensive methodological debates have led to no action:

*Synthesis projects require methodological craftsmanship, not “methodolatry” or methodological “purity” (Sandelowski & Barroso, 2007)*

In order for qualitative research to find a useful place within policy-making, including within HTA, methods need to be used that are viewed as appropriate by decision makers. The best way of doing this would seem to be through the type of linkage and exchange processes between reviewers and their commissioners described by those reviewers who are already focussing on policy-making (Pawson et al., 2004; Rees et al., 2001; Popay et al., 2006). This process is likely to be time consuming if done thoroughly and repeatedly.

There is no doubt that qualitative research can be extremely powerful, but its very ability to illuminate experience and emotion vividly may lead to suspicion:

*Psychologists have repeatedly demonstrated that people are notoriously poor at processing statistical information (the form in which most evidence arrives) and will routinely discount such information when confronted with a vivid counter-example. (Nisbett & Ross, 1980)*

It is vital that some agreement about the quality of qualitative research and its synthesis is reached. Popay's distinction between technical aspects of reporting and validity of the study itself is useful here. It may be that a combination of approaches is most appropriate. Firstly, researchers should report a minimum set of information on aspects of design and execution. A consensus agreement about what these aspects would be could be sought, in the same way that reporting guidelines for RCTs have been standardised by the CONSORT and QUOROM statements. It is worth noting that there was little consistency in the reporting of vital methodological details for RCTs until the CONSORT statement was agreed. For qualitative research, diverse methods could be used to assess validity, based on the values of the disciplines from within which the research has been conducted. Reviewers will have to exercise their judgement when assessing whether research reports have met such criteria, and it should be accepted that this is the case (Pawson et al., 2004). A minimum set of reporting requirements should include details of the participants, recruiting, sampling, methods used and influential theory. For journal articles, these details could be provided as additional web-based information, to avoid limited word counts being consumed by these details and allowing additional space for study findings. In systematic reviews the contribution that a research report makes to the synthesis is also a key indicator of quality.

Without a clear idea of what constitutes unacceptable procedures in qualitative research, there will be particular problems in HTA, where pharmaceutical companies supply information in support of their product. Companies already use funding of patient groups and web-site support groups as ways of trying to influence the targeted population in favour of their particular treatment (Mansfield, 2007). Were qualitative research and synthesis to become recognised sources of evidence in HTA, it is likely that they would try to use it as another tool of influence. The label "systematic" review carries with it the implication that other types of review are *not* systematic and therefore *must* be flawed or biased. However, a systematic approach is not always a positive attribute, as illustrated by the common understanding that "systematic bias" in research is something to be avoided (Hammersley, 2002). Mechanisms to try and identify biased or dishonest, but systematic, reviews are needed.

Another element that remains unresolved is whether or not it is desirable or acceptable for reviewers to use imported conceptual or theoretical frameworks through which

existing studies are examined. Where imported concepts are not permitted, it may be that reviews are more likely to be reproducible if subsequently undertaken by a different research team. They may be less subject to potential bias, as this avoids introducing a particular conceptual or theoretical framework favoured by the reviewer. In addition, more “truthful” accounts might be produced; in the sense that they will reflect the interpretations provided by the authors of the primary research alone. However, restricting the use of imported concepts and theories may reduce the intellectual, creative and explanatory possibilities of synthesis. The knowledge and experience of the research team might be underused if they are aware of potentially illuminating theories from other fields or conditions that have not been used in primary research analyses, and if they cannot introduce them as a tool in the synthesis. This may be particularly true where all, or most of, the located studies are theoretically weak.

The stages of qualitative research reviews described by various authors follow slightly different procedures and use different language. There are, however, similarities between the core elements - defining the research question; identifying relevant literature; deciding what to include and exclude; making some assessment of the strength of the evidence; repeatedly reading the study reports and identifying key findings; using tools and techniques to examine these findings in relation to other findings in that project and across other research projects; synthesising the findings and producing an account of this. All methods are alike in mirroring the existing stages of systematic reviews of quantitative research although the emphasis and order of these may be different. Nevertheless, it may be that qualitative research reviewers need to accept that the exact processes by which interpretations are made are difficult to describe, and that even if the *processes* are replicable, *conclusions* may not be. In addition, the processes may need to be flexible and iterative, with discoveries throughout the project feeding back and refining earlier stages.

“Transparency” is the key attribute of the systematic review, “perhaps the most important, and distinctive, meaning of the term systematic” (Hammersley, 2002), in the sense that its rejection leads to suspicions about a researcher having something to hide, and, according to Hammersley, “even more obviously a ‘hurrah word’ than ‘systematic’ in current parlance.” Hammersley asserts that explicitness is a matter of degree and further, that it implies there is no requirement for the audience to work at understanding the processes. Any specialist work is likely to be obscure to non-specialists and some audiences. Reviewers of qualitative research presenting their findings to policy makers more familiar with quantitative systematic reviews, will find it necessary to adapt to this audience. Unfortunately, strategies for describing difficult

work to non-specialists often rely on drawing parallels, metaphors and analogies – which might be seen in this world as the antithesis of “transparency”, although they are key to understanding what was done. Conversely, even when describing to an expert audience, it is unlikely that description will include a totally explicit account of why what was done was done. Indeed, “tacit knowledge necessarily plays a key role in scientific investigation.”(Hammersley, 2002) Finally, transparency is assumed to be achieved if a set of procedures is rigidly followed. Hammersley argues that this may be a hindrance, precluding reflection on the process and findings and removing the possibility for skilled judgement being exercised, all of which are important components of qualitative research analysis. Its removal is likely to decrease the value of the review rather than increase it. Other authors, including Noblit and Hare (1988), agree that an over-emphasis on rigid procedures amounts to the “bureaucratisation” of data analysis. Clearly, phases involved in reviews can be broadly described, and descriptions of the review should try and provide an understanding of what decisions were made and why, and how discoveries made through conducting the review informed the final mechanisms and conclusions.

## **Summary**

Work for this thesis originally began with a focus on meta-ethnography and this approach forms the core method for actually synthesising research findings described by a number other reviewers. Descriptions of alternative review methods often provide much more complete accounts of additional necessary stages of the review process than Noblit and Hare. This chapter represents the first critical comparison of all the suggested methods for review and synthesis of qualitative research. I have used it to produce a new, comprehensive framework of the nine key stages and procedures for any systematic review (Table 5). This brings together some of the most useful and pertinent insights from all the review methods considered here to form a good practice guide for review procedures which I believe will enhance utility, validity and reliability.

In some cases, one particular description of a review method may contain the clearest explanations of a stage or its purpose. While this may be included in several review methods, others may include them only implicitly, or in less well defined descriptions. For example, realist review is most explicit about the importance of researchers, commissioners and other interested parties collaborating to produce a review that usefully addresses policy-makers’ concerns. Popay et al provide the best account of the tools researchers may use in the analysis and preliminary synthesis stages of a review. Meta-study is most explicit about how the impact of theory and methods on findings should be assessed. By taking the best from existing descriptions an overall

plan may be formulated that could be adapted to specific reviews and researchers' wishes. This outline should be considered as a set of ingredients rather than a recipe, and it should always be understood that the any set of researchers is likely to bring their own preferences and creativity to their utilisation. In addition, it attempts to highlight the sources for the more comprehensive consideration of how each stage should be approached. This framework also informed the approach for the methodological studies that form the following two chapters.

**Table 5: Comprehensive framework for good practice in the conduct of systematic reviews of qualitative research**

<b>Developing research question</b>	<p>Develop an initial, tentative broad research question (Pawson et al., 2004; Paterson et al., 2001; Greenhalgh et al., 2005)          Researcher interests (Noblit &amp; Hare, 1988)          Assemble multidisciplinary team (Pawson et al., 2004)          Commissioner interest (Pawson et al., 2004)          Policy makers' questions (Pawson et al., 2004)          Identify evidence gaps or lack of explanation about why something works          Agree on preliminary approach, methods, outputs (Greenhalgh et al., 2004) but these may be refined</p>
<b>Scoping exercise</b>	<p>Identifying where relevant research is being done (Pawson et al., 2004)          Talking to stakeholders (Pawson et al., 2004)          Preliminary searches led by knowledge, experts, browsing etc (Greenhalgh et al., 2005; Pawson et al., 2004; Popay et al., 2006)          Identifying main reservoirs of research          Identifying team to be involved          Refine approach and methods          Generate workable definitions of key concepts under study (Paterson et al., 2001)</p>
<b>Identifying relevant literature</b>	<p>Refining research questions and focus          Deciding what, if any theoretical framework will be used (Paterson et al., 2001)          Type of questions to be answered and appropriate types of research to inform it (Popay et al., 2006)          Pragmatic balance between breadth and focus based on amount of available evidence (Paterson et al., 2001)          Consider splitting into several more focused review questions if appropriate (Sandelowski et al., 1997)          Developing preliminary inclusion/ exclusion criteria          Focused searches, contact with experts, seeding/ citation searches.          Purposive sampling for competing approaches (Pawson et al., 2004)          No over reliance on electronic data bases, but broad subject range searched</p>
<b>Initial assessment study reports</b>	<p>Preliminary reading and re-reading.          Structured form to extract relevant information (adapted for each specific project) (Pawson et al., 2004)          State whether methods and theories are implicit or explicit (Paterson et al., 2001)          Note where described approach is not the apparent approach (Paterson et al., 2001)          Assessment of utility / relevance for research question (Pawson et al., 2004)</p>
<b>Analysis and synthesis</b>	<p>Reading and re-reading study reports          Constant comparison          Extracting findings while maintaining context and relationships in each report (Paterson et al., 2001)          Technical elements of reporting recorded          Validity within a study reports' own terms and its context (Sandelowski et al., 1997; Greenhalgh et al., 2004)</p>
<b>Preliminary</b>	<p>Categorising the findings (Paterson et al., 2001)          Tools for analysis and preliminary synthesis: tabulation, mind maps etc. (Popay et al., 2006)          Exploring relationships in the data within and between studies</p>
<b>Full</b>	<p>Synthesis through thematic analysis of findings, (Paterson et al., 2001) translation of concepts and metaphors. (Noblit &amp; Hare, 1988)          How methods and theories inform the findings, and their development over time. (Paterson et al., 2001; Greenhalgh et al., 2005)          Which theoretical stances are incompatible (Paterson et al., 2001)          Quality through contribution to synthesis – record this. (Noblit &amp; Hare, 1988)          Explicit focus on identifying competing explanations (Paterson et al., 2001; Greenhalgh et al., 2004)          Theory development (Sandelowski et al., 1997; Jensen &amp; Allen, 1996; Paterson et al., 2001)</p>
<b>Dissemination</b>	<p>Dissemination to appropriate to audiences, in collaboration with them (Pawson et al., 2004)          Initial draft report as consultation document (Pawson et al., 2004)          Critical assessment of the strengths and limitations of the review (Paterson et al., 2001; Popay et al., 2006)</p>
<b>Throughout</b>	<p>Multidisciplinary team, value of multiple viewpoints          Reflexivity.          Audit trail, recording reasons for decisions made, concepts collapsed etc.          Link with commissioners, expert advisory group.          More than one person making all decisions about quality, inclusion exclusion, concepts, metaphors used etc.          Review purpose drives the review processes</p>

# **5 Methodological Study I: Meta-ethnography on Heavy Menstrual Bleeding**

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Having reviewed the suggested methods for synthesising qualitative research, I undertook a methodological study of meta-ethnography, using heavy menstrual bleeding (HMB) as the subject matter. Meta-ethnography forms a core synthesis technique used by several of the methods described in Chapter 4. As it is also the method that one of my supervisors, Nicky Britten, had experience of using, this was the most logical method with which to undertake my first synthesis. However, as described in Chapter 4, some elements of the full systematic review process are less well described by meta-ethnography. For these, procedures were informed by the framework shown in Table 5. I am aware that some elements identified, such as the need for multiple coders or negotiation with commissioners, were not possible or appropriate in the context of the thesis.

The first stage in this review framework is to develop a research question, and so this chapter begins with a description of why and how I came to use heavy menstrual bleeding (menorrhagia, HMB) and its treatment through hysterectomy, as my review subjects. Through these topics I undertook the two methodological studies of mechanisms for systematic review and synthesis that are reported in Chapters 5 and 6. I describe the anomalies in an HTA about HMB and its treatment in which I was involved, and how this piqued my interest in the possible benefits of including qualitative research in systematic reviews. I outline the nature of this project and give some background to HMB as a health condition and as a subject for clinical trials. This chapter then goes on to present the results of the first of these reviews, a meta-ethnography of HMB. In Chapter 6 I present the results of the second methodological study of methods, which uses meta-study to review and synthesise the findings from qualitative research about hysterectomy for the treatment of benign conditions.

## **5.1 Developing the Review Focus**

In 2002/3, PenTAG was commissioned by National Coordinating Centre for Health Technology Assessment (NCCHTA) to undertake a HTA of two new surgical techniques for HMB to inform a NICE appraisal (Garside, Stein, Wyatt, Round & Price,

2004; Garside et al., 2004). This involved a systematic review of the data from controlled trials, and economic modelling, to assess the effectiveness and cost-effectiveness of microwave and thermal balloon ablation compared to first generation techniques and hysterectomy. There were 10 RCTs or non-randomised controlled trials comparing first and second generation endometrial ablation (EA) techniques and two systematic reviews – one of which examined first generation EA techniques compared to hysterectomy (Lethaby, Shepperd, Cooke & Farquhar, 2000) and the other first generation techniques compared to second generation techniques. My previous experience researching aspects of sexual and reproductive health meant that this was a topic in which I was interested. Moreover, as I describe in Section 5.1.2, a number of issues were highlighted by this project which were unanswered in the traditional HTA process, and which pointed to a need for the input of qualitative research.

HMB is a common complaint. It is clinically defined as the loss of more than 80ml of blood for several cycles. One in 20 women aged 30-49, amounting to about 400,000 women in England and Wales, consults her general practitioner (GP) each year with HMB (National Statistics Online, 2002). There were several reasons why this topic was considered appropriate for further investigation through qualitative techniques. As one of the authors of the HTA report for NICE, I felt that there were a number of problematic areas that were unrecognised, or at least unexplored, by the included trials. Indeed, it seemed that such questions could not be explored in any meaningful way in the context of RCTs, but which were amenable to investigation through qualitative methods. These included:

- Definitions of HMB
- Experience and impact of HMB
- Issues of patient preference for and expectation of treatment
- Defining treatment success (appropriate outcomes)
- The experience of being assessed and treated for HMB within the health care system.

### **5.1.1 The experience of heavy menstrual bleeding and its definition**

Definitions of HMB and normal blood loss are difficult. The clinical definition of menorrhagia is the loss of more than 80ml of blood for several consecutive cycles (Royal College of Obstetricians and Gynaecologists, 1998). As such objective measurement of blood loss requires the collection of used sanitary pads and tampons

and the extraction and measurement of their blood content, such methods are rare outside clinical studies. In practice, HMB is most commonly self-defined. In most clinical situations, HMB is defined by the woman herself through her presentation with a complaint. Subjective and objective assessments of blood loss are not, however, well correlated.

Studies have found that 35-60% of women presenting with HMB have blood loss within the normal range when it is measured objectively (Chimbira TH, 1980; Fraser IS, 1984). Conversely, some women do not seek help for HMB despite having objectively very high bleeding levels (Hallberg L, Hogdahl A., Nilsson L. & Rybo G., 1966; Wyatt KM, Dimmock, Walker & O'Brien, 2001). It has been estimated that 50% of women undergoing hysterectomy for HMB do not have loss of 80ml or more (Fraser IS, 1984). Different women have different perceptions about unacceptable blood loss and what constitutes "normal" bleeding, and this also suggests that women's assessment criteria may not relate to the absolute volume of blood lost. In looking to satisfactorily treat HMB, individual expectations need to be considered. One study found that women with HMB who had had this definition objectively confirmed were more likely to rate their EA treatment "successful" than those whose bleeding was not objectively menorrhagic (Gannon, Day, Hammadieh & Johnson, 1996). It is possible that for some women it may be menstruation *per se* that is unacceptable. Alternatively, some attributes other than absolute blood loss – pain, for example, or impact on quality of life, might be the symptoms that matter most to individuals. Meanwhile, lack of clarity and ability to defined the condition objectively means that doctors' attitudes might affect access to treatment and referral.

In a trial context, these difficulties of definition affect inclusion criteria and outcome measurements. Of the 10 trials that were included in the HTA, only one used patient defined HMB as an entry criterion (Cooper, Bain & Parkin, 1999). Of the others, three did not supply a definition of HMB and the remainder used a score from the Pictorial Blood Loss Assessment Chart (PBAC, see Figure 4 for an example). This is a self-completed chart which allows the both the number of pads and tampons used and the amount of staining on each to be taken into account, and which is used to provide a summary score relating to blood loss. The chart also records the presence of clots, flooding or pain. The size of clots is recorded by relating them to the size of coins. The scoring method, however, demonstrates poor correlation with actual blood loss (Reid, Coker & Coltart, 2000). Moreover, the PBAC score used to indicate HMB varied between trials, with one using a score of 80 or more, two of 150 or more and one of 185 or more. A score of 75 or less is generally considered to indicate blood loss within the normal range, while a score of 175 or more is generally thought to indicate HMB.

How any of these cut-off scores relate to the population of women who consider themselves to have HMB is not known.

**Figure 4: Pictorial blood loss assessment chart**

Name: *Ann Other*

Day start: *1<sup>st</sup> July 2002*

Towel	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7	Day 8
								
								
								
Clots/ flooding		50p x 1	1p x 3					
Pain								
Tampon	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7	Day 8
								
								
		-						
Clots/ flooding								
Pain								

Source: *The Management of Menorrhagia p.73 (Royal College of Obstetricians and Gynaecologists, 1999)*

### 5.1.2 Treatment for heavy menstrual bleeding

There are a number of current treatments suggested for HMB. Drug therapies include tranexamic acid, (a non-steroidal anti-inflammatory drug) and mefenamic acid (an anti-fibrinolytic drug). There are also contraceptives which reduce blood loss such as the combined pill or the progesterone releasing intra-uterine device (Mirena®). Current guidelines (Royal College of Obstetricians and Gynaecologists, 1998) state that at least three cycles of medical treatment should be tried before being referred on for possible surgical treatment. In England and Wales, 20% of all referrals to specialist gynaecologist services are for menstrual disorders (Coulter, Bradlow, Agass, Martin-Bates & Tulloch, 1991).

Once women with HMB have been referred to secondary care, surgical intervention is likely. Traditionally, this has meant hysterectomy – removal of the womb, often with removal of the ovaries at the same time. Hysterectomy is a common procedure in Western countries. There is wide variability in rates, however, both within and between countries suggesting a lack of consensus about its appropriate use. The USA has the highest rates: approximately 6,000,000 women undergo hysterectomy there each year, three to four times the rate found in Europe or Australasia (Elson, 2004a). In the UK, 20% of women will have a hysterectomy by the age of 55 while one in three American women has hysterectomy by the age of 60 (Vessey, Villard-Mackintosh, McPherson K, Coulter & Yeates, 1992). About three-quarters of these procedures are performed on women who are between 20 and 49 and so likely to be pre-menopausal, and commonly for benign conditions. In about half of all hysterectomies heavy menstrual bleeding (HMB) is the presenting complaint and in half of hysterectomies performed for HMB, a normal uterus is removed (Maresh, Metcalfe, McPherson, Overton, Hall, Hargreaves et al. 2002).

Many women with objectively heavy bleeding do not seek medical help, while some of those who do, including those who proceed to hysterectomy, have blood loss within the normal range (Garside et al., 2004). Changes in bleeding pattern, including to more frequent or heavier bleeding, may be a normal part of the peri-menopausal process. At the same time, descriptions of severe, life-disrupting symptoms of bleeding are common place. Such anomalies make it difficult to determine whether too many, or too few, hysterectomies are being performed within a particular health care system.

Different surgical approaches to hysterectomy are used. In abdominal hysterectomy the uterus is approached through the anterior abdominal wall, via a vertical or, more commonly, horizontal incision (the so called “bikini-cut”). In vaginal hysterectomy, the uterus is removed through the vagina, in some cases with the assistance of a laparoscope. Different extents of surgery are also performed; removing the complete uterus (total hysterectomy), leaving the cervix (sub-total or partial hysterectomy) and removing the ovaries and fallopian tubes in addition to the uterus (total hysterectomy with bilateral salpingo-oophorectomy, bs-o). A large study of over 37,000 hysterectomies performed in the UK for all indications, found two-thirds were abdominal (of which 4% were sub-total) and ovaries were removed in 57% of hysterectomies (Maresh et al., 2002).

Hysterectomy is a major procedure. Current data suggests that women in England and Wales aged 15-59 years undergoing abdominal hysterectomy spend an average of 5.2 days in hospital, and those having vaginal surgery an average of 3.7 days.

(Department of Health., 2006) Full recovery may take four to six weeks, although those undergoing vaginal hysterectomy return to normal activities an average of 9.5 days earlier (weighted mean difference, 95% CI 6.4, 12.6) than those undergoing abdominal hysterectomy (Johnson, Barlow, Lethaby, Tavender, Curr & Garry, 2006). Short term complications are shown in Table 6. One in 30 women suffers peri-operative adverse events. Post-operative complications affect at least one in 10 women and may include incontinence and other urinary problems, fatigue, infection, pelvic pain, hot flushes, dry vagina and sexual problems. In addition, women undergoing bilateral salpingo-oophorectomy at the time of hysterectomy will experience menopause (Maresh et al., 2002). Women undergoing hysterectomy without oophorectomy may still experience early menopause, and it is speculated that this may be the result of disrupted blood supplies to the ovaries during surgery.

**Table 6: Adverse events following hysterectomy**

Very common (>1/10)	Common (>1/100 <1/10)	Uncommon (>1/1000 <1/100)
Sepsis Pyrexia Wound haematoma Hypergranulation Urinary tract infection	Haemorrhage Blood transfusion Anaemia Vault haematoma Anaesthetic Gastro-intestinal obstruction/ ileus Diarrhoea	Death Fluid overload Visceral damage Respiratory/heart complications Deep vein thrombosis

Source: Garside et al, 2004

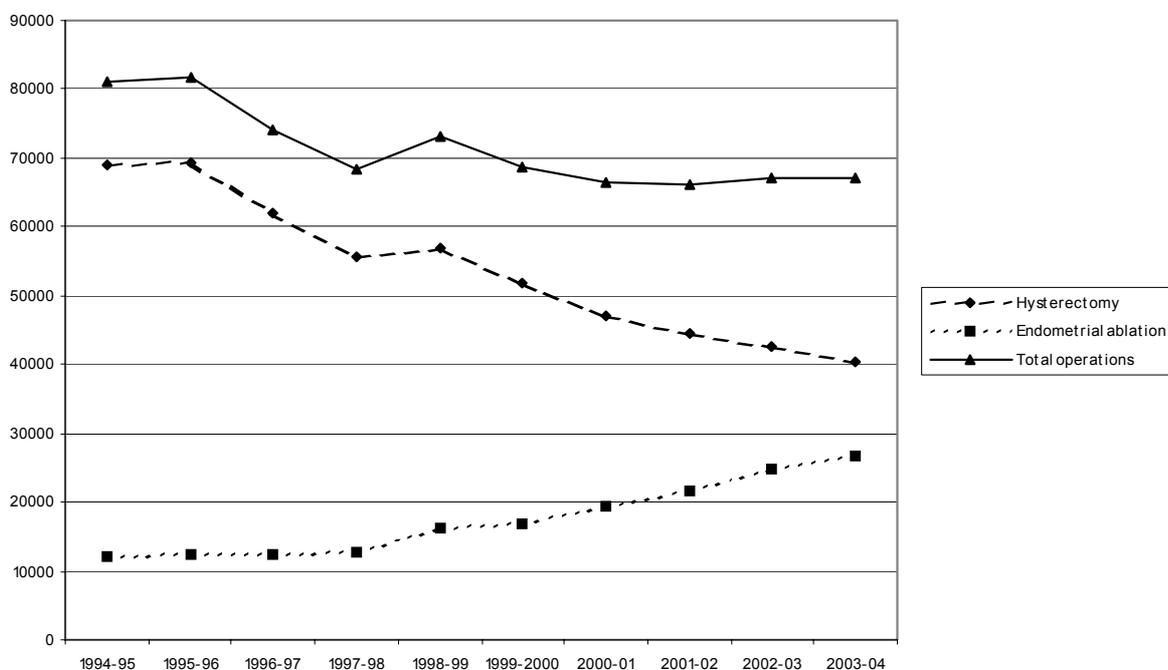
There are fears about long terms affects of hysterectomy. Particularly controversial have been debates about the effects on women’s subsequent sexual experiences. A systematic review of RCTs examining the effect of hysterectomy on sexuality, however, found little evidence that hysterectomy had a detrimental affect. In most women, sexuality was unchanged or enhanced following the operation, although the quality of the trials included in the review was considered generally poor (Farrell & Kieser, 2000). There is evidence that long term, women who have undergone hysterectomy may suffer increased risk of some symptoms such as urinary incontinence, (Brown, Sawaya, Thorn & Grady, 2000) vasomotor symptoms and some psychological symptoms compared to their peers who have not (Kuh, Wadsworth & Hardy, 1997). In clinical trials, however, satisfaction with hysterectomy is reportedly very high (Lethaby et al., 2000). There are, however, known problems with measuring “satisfaction”. In this case there may be differences in attitude soon after hysterectomy compared to the longer term, especially where symptoms that had led to surgery are initially resolved. This is considered in Section 5.1.3. This was one of the key impetus for undertaking systematic reviews of qualitative research in this area. Given the serious nature of hysterectomy as a procedure, and its potential for some serious adverse effects, it

seemed important to try and better understand what women's experiences of HMB were and what their wishes and expectations of treatment might be.

Alternative surgical treatments for HMB have been developed. In the 1980s, endometrial ablation (EA) in which a surgeon cut or burnt off the lining of the womb under telescopic visualisation, was introduced as a less invasive and drastic surgical treatment for HMB. This method relies heavily on surgeon skill; rare but serious adverse effects, such as those resulting from excess fluid absorption, are a concern. New ablation techniques, microwave and thermal balloon endometrial ablation, were introduced in the 1990s and use even more "minimally invasive" ways of thermally destroying the lining of the womb to prevent excessive menstrual bleeding. These do not require direct visualisation, eliminating the need for fluid irrigation and the associated risk of fluid overload which can cause serious adverse effects, including death. Safe success with these methods relies more heavily on the technology than the surgeon.

After a steady initial uptake of EA, national figures from the last few years have seen a reduction in the number of hysterectomies being undertaken and a corresponding increase in the number of endometrial ablations, while combined number of operations has stayed stable (Figure 5). Note that these figures relate to surgery for all indications, not just HMB. About half of all hysterectomies are believed to be for HMB although this may be changing with the increase in EA procedures. The increase in EA operations from 1997 coincides with the introduction of non-hysteroscopic second generation techniques. Such procedures are quicker, and to date have shown fewer short and long term complications than hysterectomy. They are also cheaper for the health service and require less time in hospital and on recovery for women. Again, understanding women's experiences and expectations around HMB and its treatment seem important if we are to understand what elements of treatment are important. In the following section, I outline how RCTs of surgery for HMB have assessed treatment success.

**Figure 5: Hysterectomies and endometrial ablation operations in England**



Source: HES 1990-2004, (Department of Health., 2003) <sup>i</sup>

### 5.1.3 Defining measures of treatment success

Heavy menstrual bleeding is a chronic, cyclical condition. The aim of treatment is assumed, therefore, to be an improvement in quality of life. From the trials included in the HTA, however, it was very unclear what the most important outcome for women might be. Further, the methods used to measure the reported outcomes varied or were unclear. In addition to the variety of inclusion criteria used in the studies, there were also differences and questions relating to the outcomes assessed. Primary outcomes

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<sup>i</sup> Hospital episode statistics do not have a separate category for endometrial ablation. Data used here for EAs is coded as Q16 *Other vaginal operations on uterus*, and Q17 *Therapeutic endoscopic operations on uterus*. This may overestimate the number of EAs performed. Hysterectomy data comes from Q07 *Abdominal excision of uterus* and Q08 *Vaginal excision of uterus*.

chosen by the included studies and the methods used to measure them are shown below in Table 7 and discussed below.

**Table 7: Primary outcomes used by the trials assessed for the Health Technology Assessment**

Primary Outcome	No. of studies	Method of measurement	Details
Amenorrhoea	1	Telephone interview	"Absence of menses"
Menstrual bleeding	4	1. PBAC score 2. PBAC score 3. PBAC score 4. PBAC score	<=75 <=75 <185 <80
Patient satisfaction	4	1. Patient questionnaire 2. Dr inquiry at follow up  3. Patient questionnaire 4. Physician enquiry	"Totally" or "Generally" satisfied "Very satisfied", "Satisfied" "Not satisfied" "Excellent", "Good", "Moderate" "Bad" Satisfied with treatment
Surgical re-intervention	1	Dr Inquiry at follow up	Hysterectomy or further ablation

### **Amenorrhoea and menstrual bleeding**

When undertaking the HTA, I did not identify any studies that investigated whether the absence of bleeding, reduced bleeding or normal bleeding is the most desired treatment outcome for those suffering HMB. As Table 7 shows, all these options were used as the primary outcome for some of the trials. Although it was the primary outcome in only one trial, six studies reported rates of amenorrhoea, which allowed data from this outcome to be pooled through meta-analysis. A meta-analysed outcome will have more weight in a review than data points that are not suitable for pooling. This was the case in our HTA, in spite of our lack of knowledge about whether amenorrhoea was the desired treatment outcome for women with HMB. In addition, amenorrhoea has appeal as the only objective measure available in the trials.

In addition, all trials included in the HTA used a score from the PBAC as an outcome measure and for four this was the primary outcome measure. Just as they had for inclusion criteria, the trials used a different PBAC thresholds to indicate treatment success (See Table 7). There was no justification given for using these different scores as outcome measures, although it is possible that individual women may want less bleeding, normal bleeding or no bleeding to be the result of their treatment. Given that many women are unaware of what is objectively "normal", this may not be helpful.

## **Satisfaction**

Although patient satisfaction was a reported outcome measure in the trials, methods of measuring this and its meaning are unclear. For example, patient ratings of satisfaction may relate to the experience of care (influenced by such aspects as the behaviour of staff or state of surroundings) or may reflect the process or the outcome of the treatment or some combination of these. It is known that reports of satisfaction are related to patient characteristics, such as age and health status (Crow R, Gage H, Hampson S, Hart J, Kimber A, Storey L et al. 2003). Further it has been shown that single-item satisfaction measures, such as those used in these EA trials, may have less validity than well constructed multi-dimensional scales (Crow, Gage, Hampson, Hart, Kimber, Storey et al. 2002).

The studies also used a variety of scales to measure satisfaction (see Table 7). Whether these might be considered equivalent is unclear. For example, whether “totally or generally satisfied” for example, can be considered as the same as being “very satisfied or satisfied” with treatment, or as describing satisfaction levels as “excellent”. In a meta-analysis, this affects whether results can be pooled. In addition, it is not clear how this relates to women being satisfied with the results of their treatment in terms of addressing their HMB concerns. There are subtle differences in the meanings of these words and their impact on patient response is not known.

The approaches taken to elicit information about satisfaction also differed. Two studies used a patient questionnaire, while two relied on the enquiry of the physician in at clinical follow up. This latter method may not be sound. In order to register dissatisfaction, women are required to tell the doctor responsible for the treatment that it was unsatisfactory. Given the imbalance in power between physician and patient, and the potential for social desirability bias, this may be problematic.

## **Surgical Re-intervention**

The need for further surgery was considered to be an indication of treatment failure, and was the primary outcome measure in one study. In the vast majority of cases, the additional surgery was hysterectomy, although a few women had a repeat EA procedure. This may be thought to be a clear indication of treatment failure. As hysterectomy is a major procedure, it seemed probable that it is regarded as the last resort, by some women at least. If this is the case, EA may be a necessary step in the increasingly drastic approaches to treating HMB. Some women may prefer to try all other less invasive treatment options before they take the final decision to have their womb removed. In this case, women may not have felt so negatively about the EA, as

it delays the need for hysterectomy and provides reassurance that no other treatment option would have been suitably effective.

As discussed in Section 2.2, among the suggested roles for qualitative research in systematic reviews are the ability to illuminate the patient perspective, and to influence the criteria by which the success of treatment is judged. These are relevant to the HTA described here and so I felt it was appropriate to use this topic area to explore the mechanisms for reviews and syntheses of qualitative research. It offered the opportunity to see whether these areas could be further illuminated through such techniques in a way that could have been useful in the context of this HTA. In particular, it offered the potential to explore aspects of their condition and its treatment that women themselves identified as important or problematic. Two systematic reviews, one focusing on the experience of HMB which is described in the remainder of this chapter, and one on the experience of hysterectomy for benign conditions, which forms Chapter 6 are therefore used as the example methodological studies for review and synthesis of qualitative research.

## **5.2 Methods for the Meta-ethnography on Heavy Menstrual Bleeding**

This section describes the processes involved in the review about heavy menstrual bleeding (HMB). I used, as far as possible, the framework from the comprehensive framework for the conduct of systematic reviews developed through my critical review of methods and shown in Table 5.

### **5.2.1 Developing the research question and scoping**

My existing interest in sexual and reproductive health together with the questions raised by the HTA on HMB which are outlined above in Section 5.1 both contributed to my initial choice of research question. As this project formed part of the PhD, it was only theoretically concerned with the needs of policy makers, so the suggested procedures for negotiating needs with commissioners were not appropriate in this case. I initially approached the review with a broad aim of investigating the experience of women with HMB. Inclusion criteria for studies required them to use qualitative research methods among women and about HMB. Through initial readings of studies identified through scoping searches, this was refined in response to the concerns identified by existing research so that two key strands of question for synthesis emerged:

- What are the experiences of women with HMB?
- What are the experiences of medical encounters for women with HMB?

### **5.2.2 Identifying relevant literature**

Suggested search strategies for electronic databases are described in Section 4.4.1. In MEDLINE, I used the strategy developed by Maria Grant from the Cochrane Qualitative Methods. In other databases, I used key word searches alone to identify studies relating to the topic area. Databases searched were PSYCLIT, BIDS, ASSIA, AMED, BNI, CINAHL. The full search strategy and databases searched is shown in Appendix 9.1. I screened titles and, where available, abstracts identified using this search strategy and obtained full text papers of any. I also searched key journals by hand, and examined the citation lists and reference lists of relevant papers.

Seven study reports were obtained in full text form. All papers were read by the author (RG) and two supervisors (N. Britten and K. Stein). On reading the complete texts, three of these initially identified papers were excluded. Reasons for exclusion are given below – these were refined through reading the papers themselves.:

1. Skultans conducted an anthropological study among women in a small Welsh village. The women interviewed were asked about attitudes towards menstruation, rather than HMB. Where HMB was mentioned by the women interviewed, it was in the context of positive attitudes towards “copious” menstrual blood loss. No discussion was made about problematic HMB. The focus of the study and the population studied were therefore felt to be inappropriate in this context. In addition, we had some ethical concerns about the researcher’s access to medical notes (Skultans, 1988)
2. Chapple et al was excluded because it focused on the views and experiences of GPs. Although women with menorrhagia were the focus of the discussion, this was mediated through the opinions and experiences of the GPs, not directly through the voices of women themselves (Chapple, Ling & May, 1998).
3. Lee interviewed women whose primary menstrual concern was pre-menstrual syndrome, not HMB. There was little discussion of HMB, and this was not identified as a theme in the women’s accounts by the author (Lee, 2002).

### **5.2.3 Initial assessment of study reports**

Four study reports were therefore included in the review. Preliminary readings of the studies were undertaken, and details about their conduct extracted and tabulated. Basic details about the sample and method of enquiry for these are shown in Table 8. They are listed in order of publication and this is the order in which they were read. Chronological order was chosen in case previous publications were referenced by later papers and may have influenced them.

**Table 8: Basic methodological details of the included studies of HMB**

<b>Author</b>	<b>Method of investigation</b>	<b>No.</b>	<b>Population</b>	<b>Recruitment strategy</b>	<b>Location</b>
(Marshall, 1998)	Semi structured interview	43 <sup>i</sup>	Women referred to outpatient department for “excessive” menstrual bleeding, interviewed prior to gynaecologists consultation.	All women arriving for appointment at the clinic were invited to take part.	One outpatient gynae. clinic in UK
(Chapple, 1999)	Interview	30	Women with menorrhagia (self defined)	W.I.s, play groups, church groups, political organisations.  Family centre and snowball for S. Asian women.	One town in UK.
(O'Flynn & Britten, 2000)	Semi structured interview	21	Women consulting GP about “heavy periods.” Those attending secondary care were excluded.	Through GPs	One South London HA area
(Elson, 2002)	Open-ended, semi-structured interviews	40	Women who had undergone hysterectomy for benign conditions	Word of mouth, medical referrals, advertisements.	Not stated – USA?

WI = Women's Institutes, GP = General Practitioner, HA = Health Authority

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<sup>i</sup> Only 23 were actually analysed – see Section 5.3.2.

## **5.3 The Preliminary Analysis**

### **5.3.1 Identifying themes and concepts in the studies**

When the four studies for inclusion had been decided, all three readers (myself, N. Britten and K. Stein) read the papers and identified, extracted and listed the themes and second order concepts identified through the analysis. A meeting was then held where our ideas were discussed. The three readers had different amounts of experience of both qualitative research and meta-ethnography. Nicky Britten is a medical sociologist and experienced qualitative researcher. She has previously undertaken meta-ethnography syntheses. I have previously undertaken qualitative research but this was my first attempt at producing a meta-ethnography. Ken Stein has a background in public health medicine and had little direct experience of either qualitative research or meta-ethnography. Despite these differences, there was considerable agreement about the broad areas of key thematic concerns and main concepts. It was more difficult to decide when descriptive findings could be considered as explanatory concepts, although these differences were resolved by discussion.

Our thinking about the type of findings represented in the study reports was influenced by Sandelowski and Barroso's categories shown in Figure 3 (p. 109). Therefore, where findings were simply ordered in an exploratory way and presented without the researcher attempting to produce conceptual descriptions or explanations for those findings, the findings were regarded as themes. That is, they were untransformed data without evidence of second order conceptualisation. Where findings had been interpreted through an explanatory framework, this was considered to be second order conceptualisation. Likewise, theory (after Paterson et al (2001), see p.58) was considered to have the most explanatory power, and showed broader attempts to link concepts in order to explain, describe or predict findings. There is clearly some overlap between the categories "theory" and "concept", though themes may be distinct.

Preliminary analysis involved reading and rereading the studies, consolidating understandings of themes and concepts and their relations within and between papers. I produced a structured summary for each of the papers, which describes the nature of the inquiry, the ensuing publication type and the key findings for each study. These are reproduced in Section 5.2.3. Key findings, quotes and concepts from each paper were listed and tabulated so that they could be explored, compared and juxtaposed.

Through this, a third area of synthesis was identified which linked women's experiences of HMB and their expectations and experience of medical encounters. I describe this stage as "certainty and uncertainty" and it relates to the different forces that some women experience that affect their ability to determine whether or not they have a legitimate complaint. This makes it difficult for them to determine whether or not they should seek medical help for their HMB.

### **5.3.2 Summary description of individual studies**

1) The article by Marshall (1998) *An exploration of women's concerns about HMB loss and their expectations regarding treatment* was published in a psychology journal (Journal of Reproductive and Infant Psychology). The author describes herself as having clinical psychology skills and has worked as a psychologist within Well Woman centres. She is the only author to reflect on her role as a researcher and the possible influences of this on the research, which she does in some detail, describing the manner in which she was introduced to participants and the written information with which interviewees were provided about the project. She discusses her status as "Research Psychologist" within the interview encounter, noting the potential power imbalance between researcher and researched.

In addition, Marshall is explicit about her research perspective, which she describes as feminist, influenced by an interest in women's health, a psychology background and an awareness of the research literature. Despite this, the paper is largely descriptive, with little development of themes or conceptualisation.

The article by Marshall is the only one to sample women already referred to a gynaecologist for HMB. The women were interviewed at the outpatient clinic while waiting for their appointment. The author states that confidentiality was assured to each interviewee, although they were told that if they wanted information passed on to staff then this could be arranged. They were also told that they would not lose their place in the queue by taking part.

The study grew out of a planned intervention study for a hospital service which aimed to reduce the number of women with non-clinical HMB undergoing hysterectomy. The author, however, abandoned the planned intervention after interviewing women because she concluded that the originally planned research was based on the needs of the service, not the needs of women.

The starting point for the author's subsequent enquiry remains the discrepancy between objective menorrhagia and the high rates of surgery. The interviews are broadly aimed at providing a rich account of women's experience of HMB and of its treatment. Semi-structured interviews were used to gather information, and the author stated that the focus of the question was dictated by the research goals, but was also a matter of negotiation with the women interviewed. Although 43 interviews were undertaken, only 23 transcripts were judged of "sufficient quality" to be analysed and the analysis is based on these. Transcripts were read and re-read and texts coded according to themes defined by the author.

The stated area of enquiry for the research is three-fold:

1. What is it that prompts women's presentation and referral about HMB.
2. The nature of women's concerns and anxieties about treatment and the condition
3. The desired outcome after gynaecological consultation.

Results are ordered under broad headings by the author:

- Physical symptoms:
  - Menstrual loss (problems associated with the amount and duration of loss, frequency of bleeding, presence of clots, unpredictability, change in bleeding pattern)
  - Physical symptoms associated with the menstrual cycle (including anaemia, tiredness, dizziness, pain, bloating, breast tenderness, bowel problems, epileptic seizures)
  - Anxiety associated with physical symptoms (specifically anxiety about cancer as a possible cause)
- Consequences (staining of clothes and bedclothes, restriction of normal activities, affect on role as a carer, impact on sex life, tiredness and irritability, cost of sanitary protection)
- Ideas about what is normal
- The role of doctors
- Hopes and expectations (in terms of treatment)
- Women's lives (impact of other life stresses)

2) The article by Chapple (1999) *Menorrhagia: Women's perceptions of this condition and its treatment* was published in *The Journal of Advanced Nursing* as a follow up study to the same author's interview study with GPs serving an area in the UK with a large South Asian population. This study showed GPs perceived that women of South Asian descent rarely complained about HMB and that they encountered particular difficulties if they did seek help.

There is no evidence of reflective practice and the position of the researcher, also a qualified nurse, in relation to her subjects is not discussed. Despite an interest in the particular problems of South Asian women, she does not state her own race and makes no attempt to assess how race may have informed the interview encounter. Neither does she explore the possible impact of the presence of a key worker at some of the interviews with South Asian women nor of using this woman as a translator in three of the interviews. In addition, she discusses in some detail the self-regulation strategies of some South Asian women to avoid "hot" foods if they felt that their bleeding was excessive. The list of avoided foods included eggs, fish, meat, coffee, tea and coconut. Chapple speculates that this may relate to both temperature or spiciness although notes that some of the foods listed are hot in neither temperature or spice. The foods listed are regarded as "heating" foods in Ayurvedic medicine, of which Chapple seems unaware.

Chapple described her approach as influenced by symbolic interactionism and "a form of" social constructionism although the paper is largely descriptive. Transcripts were manually coded and recurrent themes identified.

Data were collected through in-depth interviews. Thirty women, 13 of South Asian descent, all of them Muslim, were included. All the women were recruited through community locations rather than clinical situations, so may include women who believe that they have HMB but who have not yet medicalised the problem through contact with the medical profession.

The stated aim of the study is "to show that women suffering from menorrhagia, or perceived menorrhagia, may respond to their condition in various ways." However, she also states that she wanted to explore, through the research, women's perceptions of menorrhagia, and whether or not women would identify other difficulties not raised by GPs in her previous study.

Results are organised under four headings:

- A time of uncertainty (deciding if periods were a serious problem).

- Watchful waiting, alternative treatment or self-treatment (strategies of treatment outside conventional medicine, and reluctance to see the GP through fear of “wasting” their time).
- The decision to seek help (triggers that lead women to seek medical help).
- Women’s experiences of primary care (includes GP failure to take their complaint seriously, or to investigate for anaemia)

Chapple concludes that women reacted to menstrual blood in different ways, depending on the meaning of the blood to them. The wording for this “conclusion” is identical to that used in the “study aims”. In particular she asserts that South Asian women may welcome heavy bleeding, which is seen as cleansing; menstrual blood being negatively associated with dirt and congestion. She also notes that meaning may change through discussion with female relatives and friends. Finally, Chapple follows previous work in noting that, despite the impact of socio-cultural factors, “the effects of menstrual symptoms should not be under-estimated” and medical help was sought if symptoms became “intolerable”.

3) The study by O’Flynn and Britten (2000) *Menorrhagia in general practice – illness or disease* was published in *Social Science and Medicine* and is the only paper included that pursues an explicitly theoretical thesis. Its starting position is concepts of disease and illness, applied to both lay and medical models of explanations of ill-health. The authors cite previous work that has argued that lay models may be interpreted as rational, plausible and sophisticated, and that these are as legitimate as those used by doctors and other clinicians, despite sometimes being at variance with them. Relating in particular to previous work about menstruation, Scambler and Scambler (1993) are cited as noting that women may not regard health problems to do with menstruation as “real illness”.

The study re-evaluates the model of menorrhagia used in clinical practice through analysis of the lay concepts of disease and illness seen in women’s accounts of HMB. It argues that the disease model of HMB used in clinical practice, based on blood loss above a certain volume, is unhelpful to women’s needs and experiences. The paper explores medical and lay models of HMB, and argues that they are not necessarily distinct entities.

The study used a semi-structured schedule to interview 21 women recruited through 10 GPs in South London. None of these women had been seen by a gynaecologist although three were waiting for a referral appointment. The authors state that the interview was used to explore women’s own definitions and experience of their

problem. Analysis used the framework method of content analysis and interviews continued until no new themes emerged.

The findings are discussed under the following headings:

- Definitions of the presenting problem (ways in which women come to identify their bleeding as problematic).
- Explanation of symptoms (models women use to explain their symptoms).
- Experiences of the consultation (the type of clinical consultation women want).

4) The study by Elson (2002) *Menarche, Menstruation, and Gender Identity: retrospective accounts from women who have undergone premenopausal hysterectomy*, focuses on a group of 40 women who had undergone pre-menopausal hysterectomy for benign conditions. The paper considers initiation of menarche and menstruation in general as well as a limited amount about HMB. These other aspects of the paper are not discussed here. HMB was identified as a problem among some of the women interviewed and these aspects are considered in the synthesis.

Descriptions of HMB are divided by the author into three main sections:

- Descriptions of the experience of heavy bleeding: length of time of bleeding, the amount of blood, and the inconvenience and mess this caused.
- Impact on quality of life. This is largely reported on in retrospect, based on women's account of their experience post-hysterectomy, especially positive attitudes to the *absence* of bleeding.
- The way in which suffering may be regarded as "normal". It was noted that several women suffered with pain and heavy bleeding for some time before they sought medical help, believing that their experience was normal. This, it is implied, is related to the belief that suffering is a normal part of life or at least, of a woman's life.

These summaries were produced as part of, and informed, the preliminary analysis. Other tools included tabulation of extracted findings, and grouping findings under the three topic headings, experience of HMB, certainty and uncertainty and the clinical encounter. This allowed me to develop sub-headings to describe the experience of HMB. It was possible to see where findings were similar or oppositional and if they could be coherently linked to describe the phenomenon of HMB. Through these mechanisms, the full synthesis was undertaken.

## **5.4 Methods of Full Synthesis**

Identified study findings were synthesised using Noblit and Hare's meta-ethnography framework described in detail in Section 3.2. The three topic areas: women's experiences of HMB; certainty and uncertainty about identifying bleeding as problematic; and experiences and expectations of the medical encounter, are considered separately below (Sections 5.5.1, 5.5.2 and 5.5.3 respectively), although there is inevitably some overlap. The synthesis is expressed through textual description and conceptual diagrams.

I decided to use the paper by O'Flynn and Britten (2000) as an index paper, since this was the only one with a strong theoretical and conceptual framework. The index paper provides the main concept against and through which findings from other studies can be assessed. The other study reports, while organising their data under emergent themes, show little attempt to provide explanatory concepts. For Marshall (1998) this is acknowledged, and purposefully pursued:

*the emphasis on themes rather than discourses is an attempt to produce ideas which may be relevant to the interaction between women and their doctors.  
(Marshall, 1998)*

Lack of explanatory concepts means that, for the most part, while the other studies provide illustrative and expansive elements to inform a possible lay model of HMB posited by O'Flynn and Britten (2000), third order conceptualisation through synthesis is difficult to achieve. Many themes were identified without conceptualisation, that is, raw data obtained from participants was not transformed by the researchers into findings (see Section 4.6.2). I have therefore used participants' quotes illustratively in the synthesis below. This seemed appropriate for similar reasons to some of those for using quotes in primary research – they add richness and vividness to the account, and maintain a connection with the expression of women's experiences .

## **5.5 Synthesised Findings**

### **5.5.1 The experience of HMB: a congruent synthesis**

Samples in the included studies were recruited from community sources, where a quarter of the sample had not consulted a health professional (Chapple, 1999), women referred to a gynaecologist (Marshall, 1998), women consulting their GP (O'Flynn &

Britten, 2000) and those who had already undergone hysterectomy (Elson, 2002). The first three are all from the UK while the study by Elson is from the USA. It might be expected that women from these very different stages of problem identification and levels of engagement within different health care systems would provide evidence of different levels of HMB severity and attitudes. However, all of the included papers discuss the aspects of their periods that women come to regard as problematic and the accounts are, in fact, very consistent.

O'Flynn and Britten (2000) argue that the disease model used in medicine is unhelpful in relating to women's experiences and beliefs: this is the paper's key concept. The clinical model, which defines menorrhagia as the loss of more than 80ml of blood for several cycles, is based on objective measurement of blood loss among women, where 35ml was found to be average, and 80ml representing the 90<sup>th</sup> centile. For women, however, HMB relates to a number of physical, psychological and practical factors. Based on the physical descriptions, I have highlighted how HMB feels and looks, and how it is assessed by women as key overarching themes.

O'Flynn and Britten (2000) note that although all the women in their sample described their bleeding as "heavy" this had a number of meanings including the length of their periods, how it impacted on their functioning and how it felt. Length of period was also noted by Marshall (1998) and Elson (2002) as a marker women used to identify that their periods were heavy. Indeed, all three papers of the other studies provide support for the concept of a patient "illness" model, with similar aspects of their periods identified as important by women as they come to define themselves as having problematic, heavy periods. This concept finds resonance with the stated purpose of Marshall (1998) who writes that her mission as a feminist researcher is to present information in the hope that it will influence "those (doctors) who have the power to attend to or to disregard women's "subjective" experience and to treat them as complex "subjects" rather than "objects" in need of treatment." The centrality of women's subjective experience ascribed to by Marshall maps onto the concern of O'Flynn and Britten to establish women's methods of defining their problem through a "lay" model of illness, and both sets of authors place this in opposition to the clinical, objective definition of menorrhagia as a disease. However, the idea is not developed further by Marshall.

The sub-headings used below about the feel, look and quality of HMB experienced are my organisers for the themes identified in the studies.

### **How does it feel?**

A number of aspects relating to bleeding are cited as being of concern to women. The sensation associated with blood loss was important in defining the experience of HMB and women in all studies used graphic language to describe how the flow felt: “flooding” (participant, Chapple 1999), “pouring”, “flushing” (participants, O’Flynn and Britten, 2000), “with such force - such a gush” (participant, Elson 2002) and “gushing...trickling” (participant, Marshall, 1998, my edit). This sensation of heavy loss epitomises the difference between experiential definitions of women compared to objective measurement of clinicians.

In addition to blood flow, women in the studies describe a constellation of symptoms experienced with their periods that they also found problematic. These included recognised pre-menstrual syndrome (PMS) symptoms such as breast tenderness and bloating (Marshall, 1998; O’Flynn and Britten 2000), again often graphically described: “I seem to swell up like a poison pup” (participant, Marshall, 1998) and pain. Women also described feeling tired, run down and irritable as a result of their periods (Marshall, 1998; O’Flynn and Britten 2000; Elson, 2002).

O’Flynn and Britten (2000) show that the models used in medicine and by women to define HMB did have some potential overlap. While measurement of the actual amount of loss is not possible or desirable in daily life, women did use proxy markers to quantify the amount of blood they lost. O’Flynn and Britten (2000) note that the type and amount of sanitary protection required was used to indicate heavy blood loss. This is also described by Marshall (1998) and Chapple (1999). Women used these to “measure” loss in several ways: based on the frequency that towels or tampons need to be changed, needing more absorbency through better quality towels or wearing “nappies” (participant, Chapple, 1999) and wearing both tampons and towels.

### **How does it look?**

Women also became concerned about the particular appearance of blood lost:

*Very deep red and it’s still wet. (participant, O’Flynn and Britten, 2000)*

*It’s not that blood, it’s like losing my proper blood. (participant, Chapple, 1999)*

*I started passing clots. (participant, Marshall, 1998)*

Both O’Flynn and Britten (2000) and Chapple (1999) suggest these concerns may arise from misunderstandings about the nature of menstrual blood. Clots may be associated by some women with the appearance of a miscarriage, especially when associated

with a lot of blood. In fact the clotting may be a result of rapid bleeding (O'Flynn and Britten, 2000). Both Chapple (1999) and O'Flynn and Britten (2000) found that some women believed that their menstrual blood was qualitatively different from the blood in circulation. This may help to explain why some women with HMB do not seek help; not associating menstrual loss with systemic effects.

*The blood that comes out is separate from your own...you're not losing your body blood as such...as long as I'm not losing two pints of my own blood I don't worry too much. (participant, O'Flynn and Britten, 2000. My edit)*

Chapple (1999) identified this as being peculiar to South Asian women. However, O'Flynn and Britten (2000) also noted this among those from other cultural backgrounds. The race of the woman speaking is not given, but there were no South Asian women in the sample which contained mostly women who described themselves as European, and six who described themselves as Afro-Caribbean.

### **What's it like?**

Crucially, O'Flynn and Britten found that women came to define their periods as heavy based on a change from their previous experience of bleeding in amount, duration or frequency. This was also noted by Marshall (1998) and Chapple (1999). Marshall describes this change as being key in deciding whether or not they were right to consider their experience as normal, or more severe than normal. She notes that "[a]ll women can usually do is identify what is normal for them". Changes from a previous pattern of experience are used by women to identify that their periods are not "normal" and this legitimises their concern. O'Flynn and Britten (2000) note that for some, this was a purely self-referential definition, citing one woman who was concerned by an increase in length of her period from three to five days, despite being aware that a five day period was normal for others. However, they also note that this method is not possible for women who have had the same type of heavy bleeding from menarche.

This leads onto the theme, found in three papers (O'Flynn and Britten, 2000, Chapple, 1999 and Marshall, 1998) that comparing experience with other women is an important way of defining whether or not their bleeding experience was usual. Many assumed that their experience was similar to others' until evidence to the contrary emerged. All the papers noted that this could be difficult to assess. In particular, usual social reticence about discussing the details of menstruation may only be relaxed in certain specific settings, such as an ante-natal group described by O'Flynn and Britten (2000). This point is characterised by Chapple as interpretable through the symbolic interactionism writings of Blumer (1969) and Plummer (1996). Thus the socio-cultural

meaning of copious blood loss as a positive cleansing of unclean or polluting blood that she observed in South Asian women was not a fixed interpretation and might be adjusted in the light of discussion with other women whose experience of menstruation was not as extreme as their own.

Using the framework of O'Flynn and Britten (2000) about the importance of women's models for problem periods, it is possible to conclude that there are consistent ideas from all the included studies which can be used to build a picture of women's experience of HMB. The clinical model of an objective amount of blood loss that defines HMB is very narrow, and bears little relation to the descriptions that women themselves provide. While some women do use the amount and type of sanitary protection to indicate the amount of blood they are losing, other aspects seem to be just as important to them. These are shown in Figure 6 and include:

- The sensation associated with losing blood.
- Associated physical menstrual symptoms such as pain, bloating, breast tenderness, and tiredness.
- A change from previous patterns of bleeding experienced.
- Evidence from other women that their experience was worse than others'.
- Specific types of blood loss, especially the presence of clots.

There are also particular problems for women who have HMB from menarche, who cannot use previous experience as a marker for what it is reasonable to expect from their periods.

### **Impact of HMB**

The consequences of HMB, physical and emotional, and how these impacted on quality of life, were thought to be important in all the included studies. Commonly identified themes were leaking and staining and their impact, and restrictions that women felt on their lives when they had their period. The language of "stains" and "leaks" however, fails to convey the extreme nature of some of these reported events:

*I woke up in the middle of the night ....It was just as if someone had been murdered. (participant, Marshall, 1998 my edit)*

The possibility that sanitary protection is insufficient to contain the amount of blood lost meant that women were restricted in what they felt they could wear (Elson, 2002) and several studies mentioned particular problems at night, with stained sheets (Chapple,

1999, Elson 2002, Marshall 1998). Staining was noted as a frequent cause of embarrassment (O’Flynn and Britten, 2000, Elson 2002) and contributed to women feeling “unclean” (participant, Elson, 2002) or “dirty” (participant, O’Flynn and Britten, 2000).

Further, HMB interferes with women’s normal activities and can both prevent planned activities and force women to plan in advance to accommodate their periods. In different studies, many different facets of women’s lives are mentioned professional, parental, social and sexual.

*I’ve got four other kids as well so being tired is not good to me. (participant, Marshall, 1998)*

*I was thinking, I won’t do that [schedule shift work] when my next period is on...now I’m thinking about the next Bank Holiday (participant, O’Flynn and Britten, 2000, edit in original)*

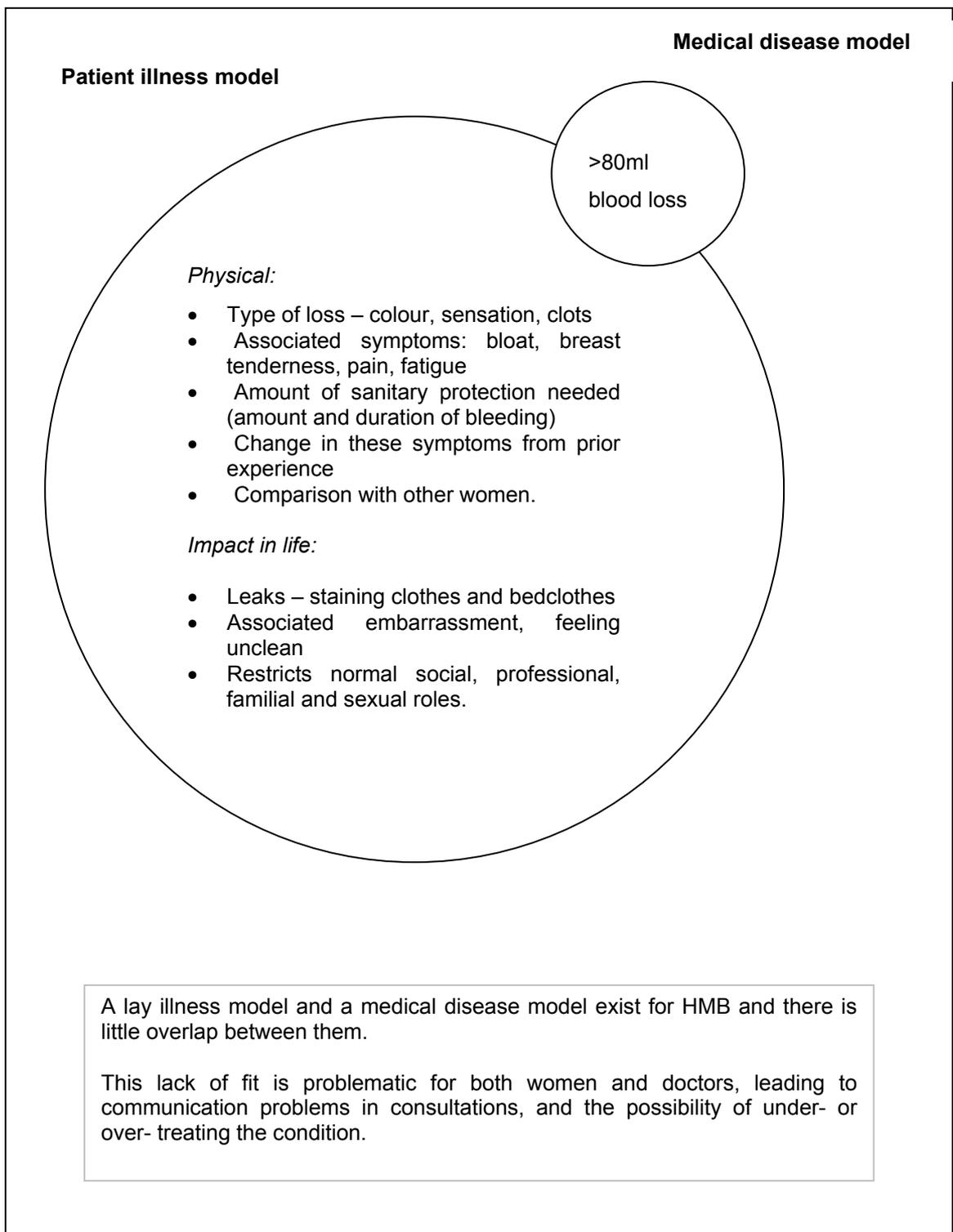
*I couldn’t walk....I stayed home from work for 23 days [in a year] (participant, Elson, 2002, my edit)*

*We’ll have a romantic evening and then hey presto I end up bleeding and then I’d be upset because everything had just been spoilt (participant, Marshall, 1999).*

Chapple (1999) found that symptoms that “started to disrupt their lives” were commonly the trigger to seek medical help.

Physical and practical effects of HMB were accompanied by, perhaps caused by significant, emotional symptoms. The impact of HMB is a key element of women’s experience. Unlike the medical model, the model of illness used by women incorporates effects on their ability to function in their various roles and their quality of life. The lay model which results from this synthesis is shown in Figure 6.

**Figure 6: Lay and medical models of HMB**



### 5.5.2 Certainty and uncertainty: refutation synthesis

The next area of synthesis concerns the certainty or otherwise that women felt about their condition. O'Flynn and Britten (2000) found women they interviewed to be confident of their own definition of HMB based on their subjective experience. The authors describe this as "authority for the patient definition". Women's reaction to methods of actually measuring the amount of blood lost was "dismissive and angry". Although external validation might be welcome if it confirmed their experience, women did not rely on it.

By contrast, the findings of the other papers found that women were often uncertain as to whether their negative experiences of menstruation should be considered "normal" or if they were justified in being concerned about them. This affects their decision to seek help. Chapple (1999) notes that, in common with those suffering from other chronic illnesses, women with HMB are "unsure about the "reality" of their condition". As noted in Section 4.7.1, she found that comparison with previous experience, or the experience of others was needed to confirm their experience as "abnormal". Marshall (1998) also found that "sometimes women questioned the validity of their experiences and opinions" and whether they "have a right to be concerned about symptoms and to expect treatment".

Chapple (1999) notes that for individual women, their level of concern may even vary from period to period. While Marshall (1998) is the only researcher to suggest that, for some women, the decision to seek help may come when other aspects of their lives are psychologically difficult due to life stresses such as, for example, divorce, or death or illness within the family. Although this is not explicitly stated in the Chapple paper, this theory fits with a provided quote:

*If things are going fine generally, I can easily go along with it. But if I do get a bit depressed, I think I brood and that usually presses me into going to see the GP.  
(participant, Chapple, 1999)*

Chapple (1999) identifies a lay interpretation of copious blood loss as being cleansing and therefore positive, which she ascribes to South Asian culture. But O'Flynn and Britten also note that women in their sample valued "[c]leaning out the womb [which] was considered both necessary and healthy." They found this view to be informed by women's understanding of the mechanism and purpose of menstruation. This suggests that the view of menstruation as a cleansing process is not confined to women of South Asian extraction. Indeed, within the Chapple study itself, a quote from a white woman supports this view:

*I'm a bit old-fashioned. My mum used to say, "If it comes away it's good for you."  
You shouldn't stop it. (participant, Chapple, 1999)*

The conflict between believing that the process of menstruation, even when the bleeding is heavy, is a natural and necessary physical function for women may help to explain why some women suffer very heavy periods without seeking help, or delay seeking help from the medical profession. Again, this is accommodated by the theory of O'Flynn and Britten (2000), that women's models of HMB do not fit easily with the disease model.

Coupled with the view of menstruation as cleansing, there was evidence that some women believed menstrual blood to be different and unconnected to other bodily blood (see Section 4.7.1). In addition, Elson (2002) asserts that for some participants, there appeared to be a belief that "women's suffering" was "normal". She reports on women who, despite severe symptoms "just figured it was part of life, of being a girl" (participant quote).

Another aspect mentioned in two studies was a perception of the pressure on the health service and on GPs in particular (Marshall, 1998; Chapple, 1999). Women expressed a fear of being viewed as a timewaster if they sought medical help (Chapple 1999)

Elson (2002) reports that women's complaints about HMB to "family members, friends or co-workers" as well as some doctors, were not taken seriously, were disbelieved or their experience was belittled. This contrasts with Chapple (1999) who found that the input of others to enter the "sick role" (Parsons, 1951) was important in legitimising some women's concerns and encouraged them to seek medical help. These are refutational findings.

These different attitudes are shown in Table 9. Quote marks are used to indicate where the author's own words are given (second order concepts). The first and last rows show the refutational findings in the papers by Chapple (1999) and Marshall (1998) compared to that by O'Flynn and Britten (2000). In other rows, I have drawn equivalences between the themes in the different papers. Apart from the paper by O'Flynn and Britten (2000), the papers are largely descriptive. There are, therefore, few second order interpretations in the included papers. The column entitled "interpretation" show my "translation" of similar themes and concepts into each other. This column gives my interpretation of these concepts (third order concepts).

**Table 9: Themes reflecting uncertainty and influences on seeking help**

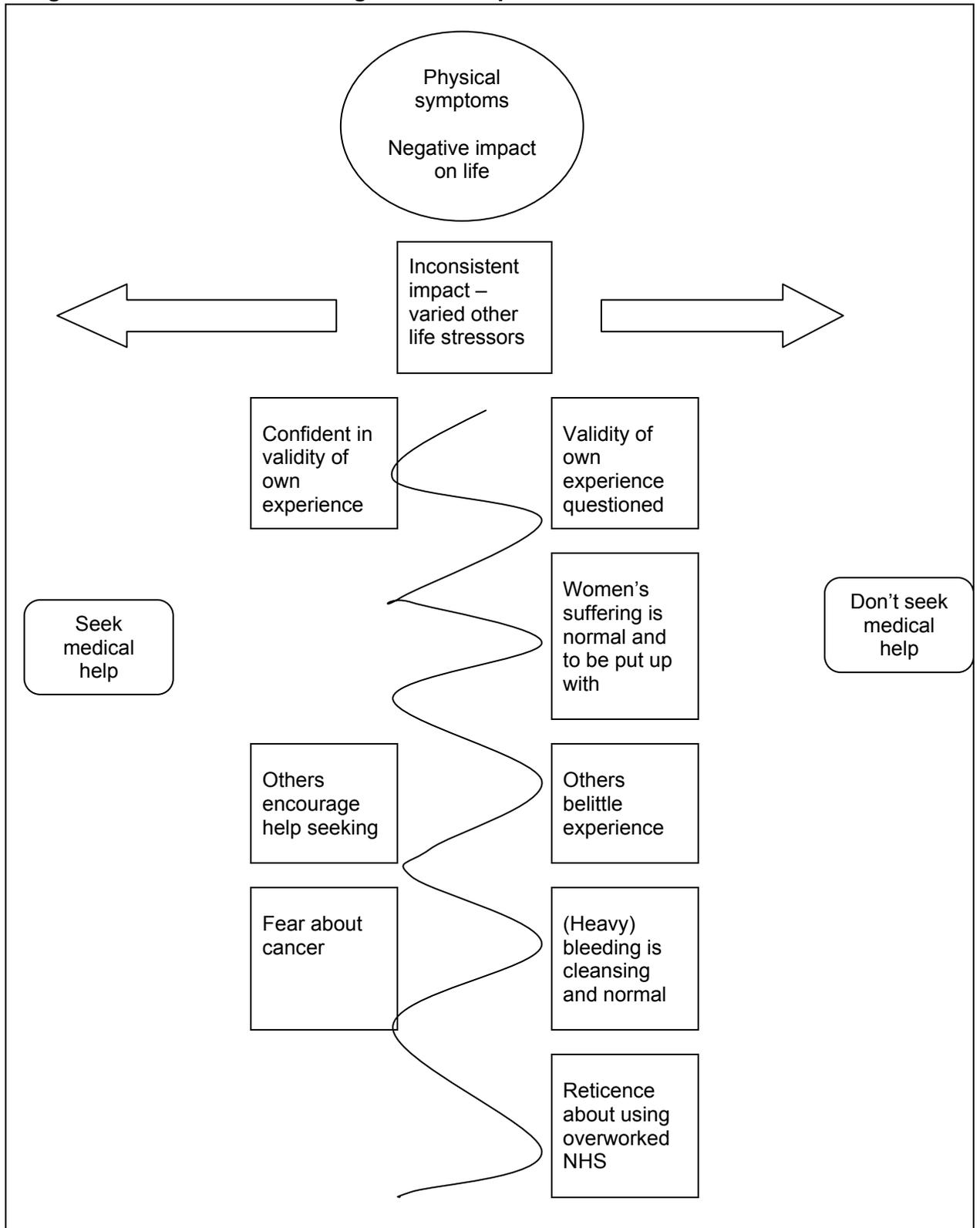
O'Flynn and Britten (2000)	Marshall (1998)	Chapple (1999)	Elson (2002)	Interpretation (3 <sup>rd</sup> order conceptualisation)
"Authority for patient definition"	"Question the validity of their own experiences"	Unsure about "reality of condition"	-	Refutational findings - suggest that women's confidence in their experiential model of HMB varies
-	-	-	"Women's suffering is normal"	Women feel that they should put up with periods even when they are an unpleasant experience
"Cleaning out the womb is necessary and healthy"	-	"Welcomed heavy periods"	-	Internal conflict between understanding of purpose of periods (even HMB) and impact on life.
-	"Life stresses and traumatic life events"	"Level of concern varies" "watchful waiting"	-	Impact of HMB may not be consistent – physical and psychological/ emotional input.
-	"Everybody is overworked in the health service"	Worried about "wasting doctors time"	-	Reticence about accessing health care as unsure whether they have a legitimate complaint.
		Others encourage to enter the "sick role"	Others belittle level of suffering	Refutational findings - suggest that women are influenced by external sources and these may either encourage or discourage accepting validity of experience

There may be a number of factors feeding into the uncertainty of women about the validity of their complaint, and these could be seen as a mosaic of internal and external barriers to defining HMB as a problem and in turn affecting their decision to seek medical help. It is not clear why women interviewed by O'Flynn and Britten (2000) seemed to have greater confidence about their condition than those interviewed by Chapple (1999) and Marshall (1998). Some of those in the Chapple (1999) sample had not yet seen a health professional about HMB and this may be a factor. Women in the Marshall (1998) study, however, had already been referred to the gynaecologist and were therefore some way along the treatment path.

I have interpreted the above themes and concepts to show that there is in fact considerable ambivalence, at least for some women with HMB, about their ability to confidently and consistently define their periods as problematic. This may be due to some or all of the difficulties shown in Table 9. An internalised belief that suffering is part of women's lot, together with the difficulties of knowing how one's own experience compares to that of other women, means that some women find it difficult to have faith in the validity of their own experience. This may be further compounded by an understanding of menstrual blood loss, even when heavy, as natural and necessary due to a belief that menstruation has a cleansing purpose. In addition, the experience

of bleeding may not be the same every cycle. This may be due to physical differences or the impact of other aspects of life on the experience of periods. Negative psychological or emotional elements related to life stresses may lead women to determine that their HMB experience has become unacceptable. The impact of other people may either encourage or prevent women from accepting their bleeding as problematic and seeking medical help. Finally, an impression of the health service as overstretched may inhibit women from seeking help at their General Practice, especially if they are uncertain themselves about how to regard their experience of menstruation. This synthesis is represented in Figure 7.

**Figure 7: Influences on seeking medical help**



### 5.5.3 Expectations and experiences of the medical encounter

All the studies found it important that women's experiences of HMB should be elicited and considered seriously by the doctors they consulted. Several women in Elson's (2002) study, described pain and bleeding that had been denied and dismissed by their doctors and others when they initially complained about it: "They were usually repeatedly told that there was nothing wrong with them physically....she probably had "a very low pain threshold"". In two reported cases, their experience was only legitimised by a health professional when, on eventual surgery, they were found to have a ruptured ovarian cyst or extensive endometriosis. After this discovery, the doctors acknowledged that the women's suffering had in fact been great. One doctor is quoted as saying "I never realised that your menstrual cramps were as bad as what they were." This may give some clues as to why the medical model and the patient model are so difficult to reconcile. The doctors appear unwilling to accept the woman's experience as sufficient evidence for a serious condition and that this can lead to under-treating women.

The women interviewed by Elson (2002) had all already undergone a hysterectomy for benign causes, but not all had HMB. However, the same phenomenon was found by Chapple (1999) in one woman who, after having a polyp removed, was told by her doctor that her periods were "unusually heavy". The women described here had an underlying, identifiable physical cause for bleeding and pain. Once this had been diagnosed, doctors were prepared to legitimise the women's subjective experience of heavy bleeding and of pain. However, in a clinical context, HMB is a definition of exclusion – it indicates that excessive bleeding is present *without* any identifiable pathological cause. The medical model of disease is ill equipped to deal with HMB; a problem that in normal clinical practice can neither be seen or measured and the aetiology of which is often poorly understood. This is a powerful illustration of the lack of fit between the clinical and lay models of HMB and suggests that the disease model is not useful to either the medical profession nor to women with HMB.

Chapple (1999), herself trained as a nurse, seems to be working from within the medical model. She is thus particularly concerned that women consulting their GP have not been investigated for anaemia, a clinical sign that "proves" excessive blood loss. However, O'Flynn and Britten (2000) found that women did not want their GP to focus on blood loss, but the impact of this and other symptoms on them and their lives – in other words to recognise the relevance of the model of illness discussed in Section 4.7.1 that they used to describe HMB. A similar theme was identified by Marshall

(1998) who found that women assumed that gynaecologists would not be interested in the range of symptoms they experience, but would privilege blood loss.

Gender may be an issue for women consulting about HMB. O'Flynn and Britten (2000) found that some women valued the input of practice nurses for gynaecological problems, while some women interviewed by Marshall (1998) felt more comfortable talking to a female GP. However, a preference for nurses may indicate a better experience of a listening consultation, or more time in the consultation, rather than being related to the gender of the nurse.

The call for using a lay illness model rather than the medical disease model in HMB by O'Flynn and Britten (2000) is reinforced by their finding that women felt GPs' "missed the point" if they concentrated on volume of bleeding rather than the broader impact of HMB. However, women interviewed by Marshall, who had been referred to a gynaecologist, assumed that they would primarily be interested in blood loss. It may be that both these expectations, together with the focus of the HMB model on blood loss means that both women and medical practitioners privilege this over other aspects of problematic menstruation leading to lack of the clear communication so wanted by women and perpetuating the unhelpful disease model.

Finally, O'Flynn and Britten (2000) identified a wish to be able to "name" their problem and to find an explanation for their experiences. Marshall (1998) also found that some women were looking for "explanation and reassurance". This is true both for encounters with the GP and with the gynaecologist; O'Flynn and Britten (2000) found that some women expected a more thorough examination if they were referred. Underlying this, and specifically mentioned in both these papers, was a fear of cancer as a possible cause of HMB. Where this is unrecognised, women may be treated for the symptoms of HMB without being examined, and potentially reassured, about their fears and this is likely to lead to dissatisfaction with the encounter.

These four aspects of women's expectations and experiences of the medical encounter were found in more than one of the included studies and are shown in Table 10. Quote marks are used to show where the authors' own words are used (second order concepts). Rows show where I have assumed an equivalence between the themes identified in the included studies. The final column is my interpretation or translation of the themes through the synthesis (third order concepts).

Table 10: Experience of visiting the doctor for HMB

O'Flynn and Britten (2000)	Marshall (1998)	Chapple (1999)	Elson (2002)	Interpretation (3 <sup>rd</sup> order concepts)
"Need to be listened to and understood"	Drs need to "hear and respond in a way that is concordant with [women's] concerns."	"GPs did not listen carefully to women"... "women's concerns not taken seriously."	"Repeatedly told that nothing was wrong"	Disease model unhelpful to doctors as well as women.
"Good experience of dealing with practice nurses...more caring"	Gender of doctor importance "varied".	-	-	Gender was a concern for some women.
GP's "miss the point" if concentrate on blood loss"	Women "assumed that these [range of] symptoms would not be of interest to the gynaecologist"	-	-	Women and doctors may conspire to privilege blood loss.
"Need to name" Wanted referral for "more thorough examination"	"Desire for explanation and reassurance"	-	-	Concern about potential causes including cancer.

## 5.6 Summary of the Review of Heavy Menstrual Bleeding

This systematic review of HMB produced new information and innovative concepts. It allowed conclusions to be drawn that were not available from any one single paper. These include a detailed patient illness model based on the symptoms that women identified as important and the impacts of those symptoms. This model shows little overlap with the medical disease model that relates to volume of blood loss. The synthesis also showed that women varied in their confidence to judge their periods as problematic enough to warrant medical intervention, and provided details of elements that contribute to women's certainty or uncertainty about their condition. A matrix of uncertainties were identified which suggest reasons why women may, or may not seek medical help for HMB. The synthesis showed that women and doctors may conspire to privilege blood loss over other symptoms and that, in fact, the disease model for heavy menstrual bleeding was little help to doctors, or to women.

Key themes and concepts were extracted from four reports of qualitative research with women with HMB and were synthesised using Noblit and Hare's technique of meta-ethnography in which the key process is translation. Three of the identified reports were largely descriptive. These provided support for the fourth paper's conceptual framework of a lay model of HMB which shows little overlap with the traditional clinical definition. Details of physical, practical and emotional elements of this lay model were

identified which could be used to develop women-centered outcomes for trials of HMB treatment.

## **5.7 Dissemination**

The results of this review have been presented in a number of different ways to several audiences. The most detailed account is written here as part of my thesis. I have also produced simplified accounts, which focus more on the mechanisms of the review, for presentation at a local conference for post-graduate studies at PMS and for my colleagues in PenTAG. These have emphasised the difficulties encountered in trying to describe the mechanisms of synthesis, as well as the problems of explaining the process and meaning of such synthesis to people more at home with quantitative methodology.

I also presented to the results of the review to the steering group for the development of the NICE guidelines for Heavy Menstrual Bleeding, which were developed during the course of this thesis. This received very positive feedback, particularly from representatives of patient groups on the committee. However, the synthesis was not formally included in the review. The review group responsible for drafting the guidelines uses publication as an inclusion criteria for evidence. Publication acts as a proxy for quality, and they do not include any reports that have not undergone peer review as part of a publication process. A version of this chapter has since been accepted for publication by the *Journal of Advanced Nursing*.

## **5.8 Reflections on the Heavy Menstrual Bleeding Review Using Meta-ethnography**

This systematic review used meta-ethnography to synthesise the findings of four qualitative research reports. These were used to build a detailed, experiential description of HMB symptoms. What is possible in terms of synthesis is, of course, contingent on what already exists in the literature. Thus, the HMB synthesis contained a section of what Sandelowski and Barroso (2007) might call “meta-summary” – the aggregation of thematic findings which represent relatively untransformed data. Sandelowski and Barroso (2007) suggest that such data may only be suitable for producing meta-summaries of research, not meta-syntheses. I would argue that the techniques of meta-analysis used in this project, whereby findings from one study may be understood in terms of concepts imported from another included study, did

ultimately allow these themes to be interpreted conceptually, and that this was possible through meta-ethnography.

The four papers that were identified relating to HMB were largely descriptive in nature with little theoretical input or explanatory conceptualisation. The quality of the meta-ethnography depends crucially on the quality of the primary research on which it is based and particularly the development of explanatory concepts. In this case, further interpretation was limited because there was little second order interpretation. What was found was supporting evidence for O'Flynn and Britten (2000) in their suggestion that the disease model of HMB was largely irrelevant to women and their proposal that a lay illness model was more helpful. Beyond this, most of the synthesis focused on identifying common themes between the papers. This allowed me to build up a fairly detailed picture of the physical aspects of HMB that many women find worrying and the impact of these on their life both practically and emotionally. Further, some possible explanations for women's uncertainty about whether or not their experiences provided valid reasons for concern were identified and may start to explain why some women with HMB do not seek help, or delay seeking help. In addition, expectations and experiences of the medical encounter were discussed. Most important was the desire for women to explain their concerns and be heard. Failure to do this may lead to under or over treating of the HMB because the actual concerns are not addressed. Crucially, this allowed me to extend the theory of O'Flynn and Britten (2000) and suggest that not only is the disease model unhelpful to women with HMB, it is also unhelpful to clinicians trying to treat it.

In the next chapter, I report my second methodological study: using meta-study to review of women's experiences of hysterectomy for benign conditions. Chapter 7 then considers how the experience of conducting these two reviews has contributed to the debates about the review and synthesis of qualitative research that were discussed in Chapter 4.

## 6 Methodological Study II: Meta-study on Hysterectomy

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*Hysterectomies were commonly performed only for “chronic and persistent uterus” (Elson, 2004a)*

This chapter describes the synthesis of qualitative research with women about hysterectomy using the technique of meta-study. Initially, I outline the methods followed for the systematic review and analysis of the studies, and I then present the synthesis itself. Expressing the analysis and synthesis proved to be a difficult exercise as meta-study contains three interlocking strands in which the findings are examined in terms of the methods and theory in the primary studies. I have presented information about the theory (meta-theory) prior to discussing the meta-data-analysis, although in fact these stages are best understood in parallel. I think that the findings of the meta-data-analysis are best understood if the theoretical context that produced and/or explained them is first understood. For the sake of clarity, this necessarily leads to some repetition in this chapter although I have tried to minimise this by including internal references between relevant sections.

As with the heavy menstrual bleeding (HMB) review described in the previous chapter, I used, as far as possible, the framework for the conduct of systematic reviews that is shown in Table 5 (p. 125). The most obvious deviation from this is the lack of a multi-disciplinary team involved in the day-to-day detail of the review and synthesis, primarily because the review was carried out under the protocols required for a PhD thesis. Although I was able to discuss my decisions and progress with my supervisory team, they were not involved in every decision made about, for example, data extraction or quality assessment. The review and synthesis remain, therefore, primarily the work of a single person, which is a potential weakness of the review which remains, necessarily, one possible interpretation of the available evidence. As the review operates as a methodological exercise as well as a review I am comfortable that the process is still valid as it allowed me to explore the differences between meta-ethnography and meta-study.

## **6.1 Methods for the Meta-Study of Hysterectomy**

### **6.1.1 Developing a research question and scoping exercise**

As with the review of HMB, my interest in the experience of hysterectomy initially grew out of the Health Technology Assessment (HTA) project about treatment for HMB (Garside et al., 2004). Hysterectomy is the surgical procedure against which new, more minimally invasive surgical procedures have been compared. I originally wanted to understand women's experiences of the new endometrial ablation techniques, but scoping searches failed to identify any qualitative research which focused on women who had undergone these procedures. One study included in the final review contained a very small number of women who had undergone EA but focussed on hysterectomy. I contacted manufacturers of these devices as well as women's groups who had been involved in the original HTA process with NICE, but none were aware of any such research undertaken or likely to be. I instead proposed a review of hysterectomy, the comparator treatment in the original HTA, which still permits exploration of key elements such as relevant outcomes and women's experiences of treatment for HMB.

As discussed in Section 5.1.3, most trials used single measures of satisfaction to measure the experience of hysterectomy, and this measure was recorded by the clinician rather than the patient in two of the four trials that used this measure. Single measures of satisfaction may have less validity than those using multiple items, and it is difficult to assess which parts of the process or outcome may be being measured. By undertaking a synthesis of qualitative research, I hoped to understand more clearly what aspects of the hysterectomy experience were considered important by women themselves.

Broadly then, I was initially interested in the experience of hysterectomy for benign conditions. On obtaining study reports about hysterectomy, I read these through and was able to refine this broad area of concern. Several pertinent research questions were identified which were grounded in the findings of the papers included in the review:

- How do women make decisions about having a hysterectomy?
- What are the experiences of women having a hysterectomy for benign conditions?

- What are the experiences of medical encounters for women undergoing hysterectomy?
- What elements contribute to positive or negative experiences?

I had originally planned to use meta-ethnography to synthesise the reports on hysterectomy. However, having undertaken the initial reading of the study reports, meta-ethnography seemed less appropriate for several reasons. Firstly, far more study reports were identified for this review than the one on HMB and they were in different forms – journal articles, book chapters and one whole book. In addition, they came from a wider range of disciplines than the HMB papers, and some employed quite different, well-developed theoretical frameworks. I was keen to explore the use of other methods to allow an assessment of how different methods might affect the synthesis. Meta-study, with its emphasis on examining findings within academic traditions and trying to account for differences related to this, seemed particularly appropriate. It allowed, in effect, a staged synthesis, although the stages run concurrently and feed back into each other rather than run consecutively. The translation techniques of meta-ethnography were used for the meta-data-analysis stage of meta-study. This was expanded and extended through the meta-theory and meta-method steps. Crucially, this allows an assessment of what is gained or lost through these – whether these additional synthesis elements produce substantially improved analysis, interpretation and theorising.

### **6.1.2 Identifying Relevant Literature**

As with the HMB synthesis, the Maria Grant search strategy for identifying qualitative research was used. This strategy was used in MEDLINE, while keyword searches were used in CINAHL, Psychlit, ASSIA, the British Nursing Index, BIDS and AMED. The search strategy and databases searched is shown in full in Appendix 6.1. In addition, key journals were searched by hand and the reference lists of included study reports examined for additional relevant studies. Potentially relevant literature was identified through reading the titles and, where available, the abstracts of research reports. Likely reports were obtained in full text form and these were read to make final decisions about inclusion.

### **Inclusion and exclusion criteria**

Research was considered potentially relevant if it was about hysterectomy for benign conditions and used qualitative methods with women participants. These conditions

were further developed in response to literature identified in the searches so that study reports were included in the review if they were:

- Qualitative research
- Focusing on the experience of hysterectomy for benign conditions
- Among pre-menopausal women (or among mixed groups where the voices of women could be separated from those of, for example, doctors or partners)
- Written in English

Studies were excluded if they were:

- Shorter, focused reports of the same research project that was published in its full form elsewhere.

For example, there were two journal articles (Elson, 2004b; Elson, 2002) published by Elson which also appeared in expanded form as chapters in her book (Elson, 2004a). As the articles did not contain any additional or different information, they were excluded from the synthesis while the book was included.

I did not include books about hysterectomy that were aimed at the self-help market for women about to undergo surgery, or produced as critical essays on the medical management of women - even if they included quotes and case histories from women who had a hysterectomy. These studies were not considered to be qualitative research - understood to be the systematic collection and analysis of data, despite using data that could have been collected as part of such a study. For example, *Experiences of Hysterectomy* (Webb, 1989) used data superficially similar to that of her included 1986 study. No details of data collection or methods of analysis were included, however, so it was not considered to be qualitative research and was excluded.

### **6.1.3 Initial assessment of the study reports**

Twenty reports of qualitative research with women about hysterectomy were included. All the reports were read and re-read. Details of the study methods, findings, concepts and theoretical input were extracted and recorded on standardised data extraction sheets that were based on those reproduced by Paterson et al's book describing meta-study (Paterson et al., 2001). The completed data extraction sheets are shown in Appendix 2 (p. 289). Basic methodological details extracted from the study reports are shown in Table 11.

**Table 11: Basic methodological details of included studies of hysterectomy**

Author	Method of investigation	No.	Participants (age)	Recruitment strategy	Location
(Bernhard, 1985)	Interviews	37 <sup>i</sup>	Pre-menopausal Black women admitted to hospital for hysterectomy for benign conditions (mean 36)	Consecutive women presenting for hysterectomy	Large Mid Western teaching hospital USA
(Webb, 1986)	Interviews	25 25 30	Women undergoing hysterectomy pre-operation and 3 months post-. Women 3 months post-hysterectomy Female gynaecology nurse (age NS)	Recruited at gynaecological department through initial contact letter from nurse researcher (all agreed to interview).	UK
(Chasse, 1991)	Interviews	10	Women who had undergone hysterectomy within the previous month (range 24-39)	Not clear – “selected” women interviewed	1 Teaching hospital, USA
(Wood & Giddings, 1991)	Letters	987	Women responding to a questionnaire sent out in a NZ Women’s magazine. Not clear how many supplied written rather than survey responses. (range 24-84)	Self selected sample of women – those responding to questionnaire distributed in a women’s magazine	New Zealand
(Chapple, 1995)	Interviews	41 +4	Women who had had hysterectomy (3 interviewed before and after). 20 NHS, 8 private – 13 pilots? (age NS) Women who “avoided” hysterectomy	Quota sample (½ well educated, ½ achieved statutory education). Snowball	Outpatient clinics in one area of NW England
(Kinnick & Leners, 1995)	Ethnographic interviews	6	Women scheduled for elective surgery (“all in their 40s”)	Introductory letters from gynaecologist to patients to take part in a quantitative study. Those replying too late were invited to take part in the qualitative study 3 months post hysterectomy.	One hospital USA.

<sup>i</sup> Although 63 women were interviewed, only 37 interviews were analysed for Bernhard’s paper. This paper is part of the ENDOW project and may only report Black women’s experiences from a broader sample of women interviewed.

Author	Method of investigation	No.	Participants (age)	Recruitment strategy	Location
(Bernhard, Harris & Caroline, 1997)	Interviews	48 22	Women who had had a hysterectomy for non-cancer reasons (mean 38) Partners of the above women (38% response rate)	Women approached in hospital 2-3 days post surgery	One USA hospital
(Marchant-Haycox & Salmon, 1997)	Recorded encounters with gynaecologists	16	Women with dysmenorrhoea or menorrhagia whose consultations led to hysterectomy or conservative treatment (mean 39)	Selected from 88 encounters with gynaecologists as leading to one of the treatment decisions	One UK hospital department
(Dell & Papagiannidou, 1999)	Interview	10	Greek women who had had hysterectomy and oophorectomy for "benign conditions"(range 40-52 )	All recruited through one woman who was personally known to the interviewer.	One Greek town.
(Dell, 2000)	Interviews	10	Middle class Greek women who had had hysterectomy for benign conditions (as above)	Not stated, but assumed to be the same as above	One large Greek town
(Groff, Mullen, Byrd, Shelton, Lees & Goode, 2000)	23 FGDs	148	Women aged 30-65 who had not had a hysterectomy. (mean NS)	Face to face recruitment by researchers and nurses at public health clinics, community centres, housing developments and community locations. All women approached until required number obtained.	Houston, Texas, USA
(Mingo, Herman & Jasperse, 2000b)	23 FGDs	156	Women who had experienced natural or surgically induced menopause (mean non-Hispanic White 49, Hispanic 50, Navajo 59)	Advertisement in local newspaper, bilingual posters in community centres, healthcare centres, grocery stores and word of mouth.	New Mexico USA. One urban and three rural centres of recruitment
ENDOW					
(Richter, McKeown, Corwin, Rheaume & Fraser, 2000)	17 FGDs	82	Rural African American and non-Hispanic white women aged 30-65. (same sample as above)	Convenience sample recruited through key and natural leaders in churches, public schools, women's clubs and workplaces. Snowball.	South Carolina, USA
ENDOW					

Author	Method of investigation	No.	Participants (age)	Recruitment strategy	Location
(Williams & Clarke, 2000) ENDOW	5 FGDs Interviews	33 5	Women who had undergone hysterectomy. (mean 48)	University Health Science Centre, advertisements in campus newspaper, community locations, work sites, civic organisations.	SE USA
(Lees, Shelton & Groff, 2001)	3 FGDs	12	Women aged 30-65, who had not had a hysterectomy and self identified as lesbian. (mean 43)	Meeting of local lesbian professional group, flyers at a health centre located in the gay community.	One city in USA
(Augustus, 2002)	6 FGDs Interviews	23 7	African American women who had had hysterectomy (mean 49)	Flyers at gynaecology offices, community contacts, snowball.	One University town, USA
(Richter, Kenzig, Greaney, McKeown, Saunders & Corwin, 2002) ENDOW	17 FGDs Interviews	82	Rural African American and non-Hispanic white women aged 30-65. (40% aged 35-44)  Physicians	Convenience sample recruited through key and natural leaders in churches, public schools, women's clubs and workplaces. Snowball.	South Carolina, USA
(Bhavnani & Clarke, 2003)	Interviews	16	Women awaiting hysterectomy for benign conditions (mean 45)	Systematic non-probabilistic sampling from waiting lists for hysterectomy.	6 hospital outpatient depts in S. England
(Fleming, 2003)	Case study	1	Had undergone a hysterectomy for dysmenorrhoea and menorrhagia (age 35)	Endometriosis support group, plus the patient's partner, primary nurse and gynaecologist.	One UK hospital.
(Elson, 2004a)	Interviews	44	Women who had undergone hysterectomy for "benign conditions" (mean )	Convenience sample – personal contacts and snowball. Notices in restrooms, colleges and shopping malls (n=2). Medical clinic serving low income population. Advert in gay newspaper.	Medium sized urban area in New England USA

Key: NS Not stated; SE South East; NW North West; NZ New Zealand

## **6.2 Analysis and Synthesis: Preliminary**

The data extraction form used to identify methodology, appraise the research approach and to extract findings and concepts was based on that in the guide to meta-study (Paterson et al., 2001) and additional elements from Sandelowski and Barroso's (2007) suggestions for meta-synthesis. Completed forms for each study are shown in Appendix 9.2. Having extracted information from individual studies, these were further examined for similarities and links, conformations and disagreements. Summary paragraphs about the use of theory in each study report were produced. Various tables were produced which explored particular aspects of the studies. For example, Table 11 was produced in date order so that possible developments or clustering of research approach could be seen. I looked at groups for findings related to, for example, how the data was collected, or the approach to analysis taken. Web diagrams were used to explore the findings and their possible relationships.

The meta-data analysis phase used the approaches of meta-ethnography, described in Chapters 3 and 4. In addition, I looked for explanations for these similarities and differences based on the methodology (meta-method) and theory (meta-theory) employed in the studies. Further details of the meta-study approach have been described in Chapters 3 and 4. The three strands of meta-study proceeded together – as findings are considered in relation to theory and methodology, and these in turn feed into understanding of those findings. However they are described sequentially below.

### **6.2.1 Study participants**

All the studies looked at hysterectomy for benign conditions (this was an inclusion criterion for the synthesis) although it was not always possible to ascertain how many women had HMB, as opposed to conditions such as dysmenorrhoea or fibroids. People with different degrees of experience participated in the research: 13 studies involved women who had had a hysterectomy, including two longitudinal studies that spoke to women both before and after their operation and two which also included women who were treated more conservatively (with medication or endometrial ablation). A further three studies sampled women waiting for a hysterectomy, and two involved women who had not had a hysterectomy. In addition, two studies held separate focus group discussions (FGDs) with those who had, and those who had not had a hysterectomy. In some cases the

information gathered through these groups were complemented with the perspectives of partners, nurses and doctors. These studies have been included where it is possible to separate the findings from the different groups. Studies focusing solely on populations other than women, for example men's views or the views of clinicians, were excluded from the synthesis.

Participants were further distinguished in the study reports by sexuality; as straight women or lesbians, and by ethnicity. In particular, six study reports were part of ENDOW (Ethnicity, Needs, and Decisions of Women). This project, based in four locations in the USA used qualitative and quantitative methods to explore how women from different ethnic groups (African-American, Caucasian, Hispanic and Navajo Indian) make decisions about hysterectomy and oophorectomy and the use of hormone replacement therapy (HRT) (Richter & Galavotti, 2000). The researchers were also explicitly interested in the views of medically under-served women, and lesbians. Although linked, some of the individual studies have slightly different emphases and methodology. Some of the results from qualitative research undertaken for ENDOW were used to design questionnaires for a survey phase of the project which is not reported here. Both phases of the project were eventually used to develop culturally specific information videos and workshops to assist women's decision-making around hysterectomy, oophorectomy and HRT. In this sense the ENDOW project studies had a slightly different set of aims from other included studies as they had a utilitarian focus aimed at uncovering language and attitudes that could be used to inform interventions, and also developing hypotheses to be tested through the quantitative surveys.

Most of the studies were undertaken in the USA (n=12). Five were undertaken in the UK, two reports (in English) described the same study among Greek women and one came from New Zealand.

### **6.2.2 Study methodology**

#### **Data collection methods**

Nine studies used interviews to collect data, four used focus groups and three used both. In the remaining three studies, one took a case study approach (largely based on interviews), one analysed encounters between women and gynaecologists and one analysed letters written by women about their experiences. Basic details of location,

participants and approach to generating data are shown in Table 11, where the study reports are listed in order of publication.

### 6.2.3 Study aims

Study aims are listed by order of publication in Table 12, where the language and phrasing used in the study reports has been maintained.

Broadly speaking, the studies can be grouped into three main areas of investigation:

1. Those concerned with women's experience of hysterectomy in the context of the health care system, usually organised by an understanding of the care pathway (these include meanings attached to those experiences, beliefs and attitudes, and how women prepare for surgery).
2. Those focused on communication and decision-making around hysterectomy.
3. Those taking a social constructionist view, placing experiences in the context of socio-cultural forces shaping and framing such experiences.

Most of these studies used interviews, either with individuals or focus group discussions, to produce data, one analysed women's written accounts. One study, by Marchant-Haycox and Salmon (1997), is methodologically unique because it analyses actual consultations with gynaecologists leading to hysterectomy or more conservative management of symptoms, in order to identify the strategies used by the actors in these situations.

**Table 12: Stated aims of the included research reports**

<b>Author</b>	<b>Stated aim(s)</b>
Bernhard, 1985	To determine the expectations that women have about the affect of hysterectomy on their sexuality, and the outcomes they actually experience.
Webb, 1986	To explore how women prepare for their hysterectomy, who gives them support and whether their expectations were fulfilled.
Chassé, 1991	To explore the experience of hysterectomy for women including implications for emotional and physical wellbeing.
Wood & Giddings, 1991	To explore the symbolic meanings of hysterectomy.
Chapple 1995	To explore the experiences of women who have, or avoid, hysterectomy and whether they receive the information they need.

<b>Author</b>	<b>Stated aim(s)</b>
Kinnick & Leners 1995	To describe quality of life before hysterectomy To understand decision-making process around electing to have a hysterectomy. To describe the knowledge base women have before surgery. To describe concerns and fears women have about hysterectomy To make comparisons about life before and 3 months after the hysterectomy To discover advice that women would give to others about hysterectomy.
Bernhard et al 1997	To explore: How partners experiencing hysterectomy usually communicate with each other. What partners communicate about the hysterectomy. If communication behaviours related to hysterectomy similar to their usual communication behaviours.
Merchant-Haycox & Salmon, 1997	To add to existing ways of understanding dr-pt interaction by delineating components of patient presentation and surgical response whereby either party might influence the other To propose a theory, grounded in an account of such interaction that would explain why patients receive one clinical response or another. This theory should be amenable to testing quantitatively.
Dell & Papagiannidou 1999	To explore how historico-cultural discourses produce ways of “being hysterectomised”.
Dell, 2000	To explore the materio-discursive construction of hysterectomised woman and explore the range of meanings it might sustain.
Groff et al 2000	To elicit what women belonging to three racial/ethnic groups expressed as important criteria and processes for making decisions about hysterectomy.
Mingo et al 2000b	To gain an understanding of ethnic variations in women’s attitudes to menopause, hysterectomy and HRT.
Richter et al 2000	To examine women’s decision-making regarding hysterectomy, in particular how women perceive men’s knowledge and attitudes and how women define men’s role in the decision-making process.
Williams & Clarke 2000	To elicit women’s perceptions of the experience of hysterectomy, oophorectomy and surgical menopause.
Lees et al 2001	To identify lesbians’ beliefs and attitudes regarding hysterectomy.
Augustus 2002	To identify the (negative) cultural beliefs within the African American community related to hysterectomy. To explore if women told people about their hysterectomy and if they would recommend the operation.
Richter et al 2002	To investigate women’s perceptions of the role of the physician in hysterectomy decision-making and to examine physician-patient communication in the decision-making process. Women’s definitions of optimal physician-patient communication were also examined.
Bhavnani & Clarke 2003	To explore women’s attitudes to, and sources of information about, hysterectomy, menopause, HRT and oophorectomy, (pilot study)
Fleming 2003	To explore the meaning of abdominal hysterectomy for one woman.
Elson 2004a	To explore how – whether they perceived loss, stability or enhancement – participants dealt with the possible contradictions in gender identity presented by absent sexual reproductive organs.

Table 13 below shows which study reports included in this synthesis referenced other projects also included in the synthesis and so shows potential directions of influence

between them. Other qualitative research that these papers referenced but which are not included in this review, for example about men's views of hysterectomy or about experiences of menopause, are not listed here. Use of referenced material may not be substantial, or relate to pertinent research findings: while Dell, for example, references the report by Chapple, it is only actually used as a source for hysterectomy statistics. In other ways the referencing follows a predictable pattern, with more older than newer study reports being referenced and publications from the ENDOW project referring to each other, especially in the case of papers with shared authorship. Elson (2004) refers to the most other study reports, perhaps because this is a recent and much bigger publication. Unlike some journal policies, a book has no limitation on the number of permitted references. It may also be that, as a medical sociologist, Elson reads more broadly across nursing and medical as well as social science publications, while those in health research are more likely to be primarily aware of others in the same field.

**Table 13: Referencing between included study reports**

<b>Author</b>	<b>Other included study reports referenced by author(s)</b>	<b>No. of included refs referencing author(s)</b>
Bernhard 1985	-	2
Webb 1986	None	0
Chassé 1991	None	1
Wood & Giddings 1991	None	1
Chapple 1995	None	2
Kinnick & Leners 1995	None	3
Bernhard et al 1997	Bernhard 1985	3
Merchant-Haycox & Salmon 1997	None	1
Dell & Papagiannidou 1999	Chapple 1995	2
Dell 2000	Chapple 1995, Dell & Papagiannidou 1999, Kinnick & Leners 1995, Merchant-Haycox & Salmon, 1997	1
Groff et al 2000	None	4
Mingo et al 2000	None	2
Richter et al 2000	Bernhard et al 1997	2
Williams & Clarke 2000	Bernhard et al 1997	2
Lees et al 2001	Groff et al 2000, Williams & Clarke 2000	1
Augustus 2002	Groff et al 2000, Richter et al 2000	0
Richter et al 2002	Groff et al 2000, Mingo et al 2000b, Richter et al 2000, Williams & Clarke 2000	0
Bhavnani & Clarke 2003	None	0
Fleming 2003	Kinnick & Leners 1995, Wood & Giddings, 1991	0
Elson 2004a	Bernhard 1985, Bernhard et al 1997, Chassé 1991, Dell & Papagiannidou 1999, Dell, 2000, Groff et al 2000, Kinnick & Leners 1995, Lees et al 2001, Mingo et al 2000, Richter et al 2000	-

Table 14 briefly summarises the discipline to which the authors were affiliated, as far as this was discernable from the reference, and any use of theory in the study reports. Half of the included study reports (n=10) are written by nurses, (Chapple, 1995; Chasse, 1991; Kinnick & Leners, 1995; Williams & Clarke, 2000; Bernhard et al., 1997; Augustus, 2002; Bernhard, 1985; Fleming, 2003; Wood & Giddings, 1991; Webb & Wilson-Barrett, 1983) and a further six (the ENDOW studies) from teams within medicine or health services research departments, although their academic discipline was no clearer than this from the information provided (Richter et al., 2002; Galavotti & Richter, 2000; Groff et al., 2000; Bhavnani & Clarke, 2003; Lees et al., 2001; Mingo et al., 2000b). Three study reports took

a psychological perspective (Dell, 2000; Dell & Papagiannidou, 1999; Marchant-Haycox & Salmon, 1997) and one was framed through medical sociology (Elson, 2004a).

When arranged by date, some patterns related to discipline emerge. Early studies in the mid eighties and early nineties were all undertaken within nursing, although some authors also aligned themselves with sociological or psychological perspective and nurses continued to research hysterectomy into the 21<sup>st</sup> century. In the late nineties, there were a couple of projects by psychologists, while papers since 2000 showed most interest among health services research units or medicine, mostly because this is when studies related to the ENDOW project were published.

Not all the study reports stated their methodological approach or genre clearly. Table 14 reports the methodological approach stated in each paper where it was available. Where no clear description was given, I have labelled the study's approach according to my own interpretation of what was done. This is indicated by the prefix "not stated" and a question mark alongside the ascribed methodology. If I was unsure how to categorise the approach, I used Tesch's graphic representation of qualitative research types to assist me (reproduced by Miles and Huberman, 1994). This schematic is not comprehensive, nor is it detailed enough to always distinguish between different approaches. This is further compounded by the fact that sometimes the stated approach does not seem to match the methods described. For example, Augustus et al (2000) describe their method as ethno-nursing, using ethnographic interview techniques but there does not appear to be any field work or observational element to the research and it is not clear how, if at all, the interviews can be described as ethnographic: women were interviewed in groups or individually and content analysis was used. The authors' use of "ethnographic" to describe their approach appears to relate to the research interest in cultural understandings of hysterectomy among a particular sub-group or sub-culture, that of African-American women. However, cultural meanings could also have been explored within other academic frameworks, for example sociology.

Table 14 shows the discipline of the authors and if and how theory was used in each of the included studies, and briefly identifies any such theory. There is clearly some overlap between methodological approach and theory. In many cases I have summarised the methodological approach as "phenomenological". This is a broad interpretation, not made by the authors of the study reports, but interpreted as such by me if the interest seemed to focus on the lived experience of hysterectomy. In many cases these papers are structured

by following women through the pathway of care in the health care system. Such an interpretation may be more in line with the way in which nursing studies define phenomenology than how sociologists may use the same term. Such interpretations are labelled with “? phenomenology” in this table to indicate such uncertainty. The use of theory in the studies will be expanded upon later in this chapter.

**Table 14: Discipline and use of theory in studies included in the hysterectomy synthesis.**

Author	Discipline	Genre & Methodological approach	Theory	Use of theory
Bernhard 1985	Nursing	Not stated ?phenomenology – identifying themes in women’s concerns about hysterectomy ? Thematic analysis	Ladner’s (1971) theory of elements crucial to becoming a women among African American adolescents – menstruation and attraction to men – may help to illuminate why women find hysterectomy a difficult operation.	Interpretive element.
Webb, 1986	Nursing, sociology	Not stated – Feminist reflective phenomenology? ?Thematic analysis	Feminist research	Informs research interest and its conduct (for example her information giving role), also frames concerns and interpretations about negotiations of women as patients and nurses in a male dominated environment such as the health care system.
Chassé 1991	? Nursing	Not explicit. ? phenomenology, focus of research question is experience. ? narrative analysis as author responds to women’s wish to “tell their story” from the beginning – recognising symptoms ?Thematic analysis ?Social construction as recognises that social and personal values are attached to the uterus and may influence women’s reaction to its removal.	“Establishing the boundaries of normality” is the basic psychological process through which women cope with hysterectomy and this occurs through the three main stages of hysterectomy – experiencing a disruption, struggling to preserve self and recovering.	Generated through the research.

Author	Discipline	Genre & Methodological approach	Theory	Use of theory
Wood & Giddings, 1991	Nursing	Thematic analysis	The uterus is not just another organ but carries symbolic meanings. Its removal is therefore experienced as a symbolic event for women	“Symbolic meanings” of hysterectomy form key themes.
Chapple 1995	Nursing, Medical Sociology	Not explicit ? phenomenology – concerned with differences and similarities in experience across private and public healthcare ? Thematic analysis	Poor doctor-patient communication and information may lead to women treated under the NHS feeling unhappy with the service they receive. Private patients are more likely to think their care excellent.	Interpretation of findings
Kinnick & Leners 1995	Nursing/ ethnography	Ethnographic interviews investigate hysterectomy as a cultural phenomenon, and hysterectomised women as a sub-culture from whom the medical profession can learn.	Women’ experience of hysterectomy is “from resourceful endurance to unexpected relief.”	Frames research
Bernhard et al 1997	Nursing, Women’s studies	Mixed methods – Primary Communications Inventory, Interviews analysed with constant comparative methods.	Communication between marital partners about hysterectomy may be difficult and is a potential source of marital conflict	Informs research question – how do couples communicate about hysterectomy?
Merchant-Haycox & Salmon, 1997	Psychology (paper published in Psychosomatics)	Grounded theory	Shorter, 1992 of psychosomatic illness – in the absence of organic signs of disease, patients and doctors use strategies unrelated to symptoms to negotiate a clinical decision.	Inform the study area and the focus on strategies used by doctors and women to influence treatment decision-making.  ?? are same strategies used which lead to different decisions??

Author	Discipline	Genre & Methodological approach	Theory	Use of theory
Dell & Papagiannidou 1999	Psychology	Discourse analysis	Feminist post-structuralism Foucault  Women experience the body as separate from and alien to the self – uterus or whole body may be pathologised as uncontrollable. For others, removal (infertility) signifies lack of control and loss of femininity.	Frames questions, informs analysis, tested by analysis.  Generated by the research.
Dell, 2000	Psychology	Discourse analysis	Feminist post-structuralism  The “hysterectomised women” is a materio-discursive construct.	Frames questions, informs analysis  Generated by research
Groff et al 2000	Health science/ medicine	Not stated ? Thematic analysis Part of the ENDOW project.	No	Findings are about the attitudes of different ethnic/racial groups to hysterctomy.
Mingo et al 2000b	? Medicine	Ethnographic interview techniques. Interviews also focuses on participants’ story telling – narrative? ? Thematic analysis Part of ENDOW	Women from different ethnic backgrounds are more alike than different. The experiences of women from Navajo and Hispanic/Latino groups vary according to how isolated they are from their traditional lifestyles. Women with more traditional diet, exercise, social support, language and healthcare lifestyles are less likely to experience menopausal symptoms. Meanwhile, whites have always associated hot flushes and craziness with menopause.	Interpretation of research

<b>Author</b>	<b>Discipline</b>	<b>Genre &amp; Methodological approach</b>	<b>Theory</b>	<b>Use of theory</b>
Richter et al 2000	? Health Studies, Medicine	Not stated Broadly phenomenology? – identification of similar themes ? Thematic analysis Part of ENDOW	Theory of reasoned action	Informed FGD guide
Williams & Clarke 2000	Nursing	? None. Broadly phenomenological ? Thematic analysis Part of ENDOW	None stated, but the findings about decision-making involving weighing risks and benefits echoes the Health Belief Model	Emerges from findings
Lees et al 2001	?Medicine ?Public Health	Not stated. Thematic analysis of FGDs. Part of ENDOW	Multiattribute Utility Theory  Loss is an ontological as much as sexual notion.	Informed interviews - to elicit perceived outcomes.  Emergent from the research.
Augustus 2002	Nursing	Ethno-nursing, ethnographic approach to investigating cultural beliefs and perceptions. Content analysis.	Transcultural nursing (Leininger, 2002) Theory of Cultural Care Diversity and Universality (Leininger, 2002) “Invisible stigma” associated with hysterectomy	Informs research question – hysterectomy beliefs and experience in African American women.  A conclusion of the research.
Richter et al 2002-	? Health Promotion ?Medicine ?Public Health	Not stated Broadly phenomenological? – identification of similar themes ? Thematic analysis Part of ENDOW	Emanuel & Emanuel, 1992 framework for four styles of patient-doctor interaction – paternalistic, informative, interpretive, deliberative	Use to interpret study findings

<b>Author</b>	<b>Discipline</b>	<b>Genre &amp; Methodological approach</b>	<b>Theory</b>	<b>Use of theory</b>
Bhavnani & Clarke 2003	? Health Services research Unit	Framework approach to analysis. Implicitly, elements of grounded theory – saturation, discrepant cases sought.	Health belief model Comprehensive model of information seeking  The “resourceful patient” (Muir Gray 2002) - individual perceptions about susceptibility to ovarian cancer and its seriousness, coupled with the risks and benefits of, and barriers to, taking action influence decision-making.	Theoretical framework  Interpretive element of findings.
Fleming 2003	Nursing	Hermeneutic phenomenology Case study approach looking at the meaning of the hysterectomy experience for one woman.	? theory and method are one? Researchers should seek the invariable essence of the experience, while acknowledging that individual’s experiences are different.	Theoretical framework
Elson 2004a	Medical Sociology	Grounded theory elements – constant comparison methods, data analysis as an ongoing process, development of themes and construction of theory.	Embodied sociology Social construction - hysterectomy as a threat to constructed sense of womanhood/ femininity	Frames questions, informs analysis, tested by the findings.

## **6.3 Methods of Full Synthesis of Hysterectomy Studies**

### **6.3.1 Meta-theory**

Details about the theory used in each of the studies, and how it was used, were extracted from all the included papers. I wrote summary paragraphs for each paper describing *how* theory was used, whether as a framework for the research itself, devised through it, or imported as an explanatory device. The study findings were considered in relation to the theory used, and where there were differences in the findings, it was considered in the data-analysis phase whether different theory use was implicated.

The book by Elson (2004a) was by far the strongest theoretically, and this was therefore used as the one through which other findings and concepts were examined and tested, as a kind of “index” theory, as described Section 6.4. This was the key theory against and through which others were compared. Where other study reports provided conceptual building blocks these are noted and tested to see if they could be interpreted within the overarching theory posited by Elson, or if they offered differences or disjuncture.

### **6.3.2 Meta-method**

As described by Paterson et al (2001, see Section 3.6.2), meta-method is concerned both with the methods used to gather information (reported in Table 11), and the methodological orientation of the research itself (reported in Table 14). The impact of this on the findings and theory used were considered. There is clearly an inter-relation between some types of method and theory – phenomenology for example is both a methodology and philosophy. Because of this, I have chosen to look at the methods and theory together, by grouping together the theory used in studies that have the same broad methodological approach in Section 6.5.

### **6.3.3 Meta-data analysis**

The initial assessment of the study reports and preliminary synthesis was needed for me to plan how I would approach the synthesis of the included papers. I decided to use a framework from one of the included studies, augmented by understandings from the body of literature and my own interpretations of these, to help structure the meta-data analysis.

The meta-data-analysis was structured around the care pathway that women experience – from identifying problematic symptoms, to recovering after hysterectomy. The Chassé report (a book chapter) produced a comprehensive description of the journey that women make when they experience hysterectomy, and so this paper was used to provide the thematic headings to organise the descriptions in the meta-data-analysis Section 6.7. These were supplemented by conceptual headings that provide a more transformed interpretation of the data, taken either from the other literature in the review or, more often, using my own interpretive labels.

A number of studies, particularly the ENDOW studies and other phenomenological studies, were very largely descriptive; producing rich description of women's experiences and understandings of hysterectomy. These descriptive findings were tabulated in a huge single table, printed on a number of sheets of A3 paper, so that I could see them all together, explore similarities and differences and draw possible groupings and links. Columns in this table represented studies and rows used the headings related to the journey of hysterectomy. Drawing up this table helped me to understand this journey and to define the interpretive labels used. Many of the study reports used descriptive headings that were not particularly useful beyond highlighting a stage in the journey, rather than a concept; for example "the hospital experience" (Chapple, 1995), or such a broad theme that it operated solely as report organiser, but did not any offer any thematic principle, such as "perceived outcomes" (Groff et al., 2000; Kinnick & Leners, 1995; Lees et al., 2001). These types of headers did, however, offer markers of the main sections of the hysterectomy narrative – and allowed me to map these onto the descriptive headings used by Chassé.

I found determining the best structure for the remainder of this chapter challenging. The strands of meta-data-analysis, meta-theory and meta-method inform each other and proceeded together in practice, but need to be written in a linear fashion. I have chosen to present details of the theory for each of the studies prior to presenting the meta-data-analysis. This is for two reasons, the presentation of the theory allows me to articulate the influences on own conceptual framework which both informed the synthesis as a whole, and is a product of the synthesis. I also believe that it is easier to understand the findings once their theoretical context is known. The theoretical sections begin with a detailed description in Section 6.4 of the approach taken by Elson, as this was used as the index theory. I then present details of the theory used by the other included studies, organised by broad methodological approach Section 6.5. I describe the theoretical framework and

how it was used in the synthesis in Section 6.6. Meta-data-analysis and synthesis is described in Section 6.7.

## 6.4 Meta-theory

### 6.4.1 Outline of the key theoretical paper

Elson wrote the only book included in the synthesis and, perhaps partly due to the increased possibilities of this format, this is the theoretically most sophisticated and well developed report. All the interviewed women for this study had undergone hysterectomy for benign conditions, mostly HMB. In this section, I outline her arguments in order to provide detail about her theoretical argument which I used to explore that in other papers. Elson considers several competing theories of sex and gender in the context of her research findings, but finds social constructionism the most useful approach. She also considers its limitations. None of the other study reports demonstrate testing competing theories through their work. It is possible that this was part of the research process that was excluded from the research report due to lack of space for such detailed descriptions in journal articles. A key identified limitation is the fact that theories of social construction are poorly equipped to interpret the *embodied* experience, in this case, of hysterectomy. This leads Elson to consider an embodied sociology, attempting to link the lived experience (which is emphasised) *with* cultural representation:

*the body is not totally constructed by social discourse or socialization processes, nor does it exist completely independently of these. (Elson, 2004a)*

This allows her to move between descriptions of women's lived experiences and interpretations of these experiences as socio-cultural artefacts.

Elson notes the great cultural and personal significance carried by the uterus and ovaries as the site of sexual difference. The uterus has historically been particularly considered synonymous with the category "woman", although more recently, ovaries have come to carry greater symbolic meaning with their hormones, especially oestrogen, seen as central to femininity. These reproductive organs thus occupy a central role in woman's body image, as well as her social and gender roles. Despite big changes in the expectations of women in the workplace over the past 30 years, contemporary women are still expected to conform to socio-cultural norms of reproduction and of physical, (hetero)sexual

attractiveness. Given this centrality in understanding gender identity, if reproductive organs are surgically removed, women may find themselves feeling “defeminised”, and experience hysterectomy and oophorectomy as a challenge to their gender identity.

Traditional cultural constructions of women’s bodies see them as inherently unstable and defective, in need of constant monitoring and control. Elson further notes that female bodies are frequently objectified, and this can be reinforced in gynaecological surgery where women feel reduced to an organ(s): their womb and/or ovaries. Some women internalise this to the extent that they regard their womb as a separate object, not part of themselves. This may be particularly the case where it is seen as threatening, through current symptoms or as a potential harbourer of disease such as cancer later in life. Distancing herself from a physical part of herself makes it easier to decide on its removal, and may provide women with a coping mechanism.

Another powerful construction of the female body is powerlessness. Elson suggests that “elective” surgery may be so only from the perspective of the doctor, not the woman. While medical use of this terminology is to distinguish it from emergency surgery, lay understandings may expect to exercise greater choice. Participants in Elson’s study sometimes felt powerless regarding possible treatment options. When making a decision about how to treat their symptoms, hysterectomy is, at best, only a *constrained* choice for women. In some cases alternative treatments to hysterectomy were not offered while in others previous, more conservative treatments had failed and women felt they had run out of options. Severe symptoms, however, were felt to demand hysterectomy.

Given the special socio-cultural status of reproductive organs, women perceive that stigma (Goffman, 1990) is associated with their removal through gynaecological surgery. Many women in Elson’s sample identified the uterus primarily with childbearing, while, increasingly, women identify hormones as crucial markers of womanhood and of sexual difference, leading to the investment of great symbolic power in the ovaries. In consequence, hysterectomised women create a stratified “hormonal hierarchy”, based on whether all, some or none of their ovaries are removed. Elson goes on to suggest that “castration” is the proper way to describe removal of the ovaries, as they are the female gonads. She contends that the failure to name it so leaves women unprepared to deal with physical consequences of sudden, induced menopause, as a result of this surgery.

If the ovaries are removed at the time of hysterectomy, some women feel that symptoms of menopause may make visible the otherwise invisible stigma related to their lack of

reproductive organs. Vasomotor symptoms, causing, for example, hot flushes and sweats, may be more “sudden, frequent and physically devastating” in sudden, surgically induced menopause (Elson, 2004a). These concerns may impact on women’s subsequent decision about taking Hormone Replacement Therapy (HRT). In addition, women perceive their bodies as usually under the control of hormones. Losing this control through ovarian surgery means they feel out of control, and in need of “regulation”. HRT can be seen as a strategy to recover the lost control of the hormonal body.<sup>i</sup>

Elson categorises women as “resisters”, “stoics” and “martyrs” in their decision not to take hormones. She notes that most women were not aligned with those advocating “resisting” HRT, and were critical of those who did, seeing them as foolishly choosing to “tough it out” through being “martyrs”. Accepting HRT is the norm among participants and, although its adoption may not be enthusiastic, the usual, moral cultural concept that avoiding medication is a virtue is undermined in this instance.

Participants in Elson’s study were aware of possible long term health risks with HRT, both minor and serious, and these needed to be weighed up together with potential benefits. It should be noted however, that this research was undertaken before recent publicity about the increased cardiovascular risk associated with HRT use. Women sought information about HRT from a number of formal and informal sources – personal as well as professional and many found the equivocal advice confusing. In the absence of definitive evidence, most women preferred to take HRT and these decisions were made on the basis of retaining or regaining “femininity”, rather than on health risks or benefits.

Elson uses the distinction between *enacted* stigma (resulting from the discrimination of others) and *felt* stigma (shame induced in the person themselves due to feeling deviant from some social norm, (Scambler, 1984). Those who felt that that hysterectomy and oophorectomy were stigmatising undertook biographical work and impression management to mitigate against this and reclaim their internal and social identity as

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<sup>i</sup> Note however, that the ovaries are constructed as the locus of the uncontrollable body in patriarchal constructions, causing instability and over-emotional responses. Women are seen here as preferring this hormonal control to its loss, although HRT will produce a *regular* hormonal dose without the cyclical, changing nature of bodily hormones.

women. These strategies mirror those of review, maintenance, repair and alteration of biographies noted by Corbin and Strauss (1987) in relation to regaining control of personal identity during chronic illness. A number of strategies were observed which women adopted to ensure they dressed or behaved in ways that they associated with being “feminine”. Examples of this were reclaiming the “nurturing” aspects of themselves through attention to other people’s children, in the face of no longer being able to bear children of their own, and looking at ways of defining gender through behavioural, rather than biological “womanly” traits. Such gendered behaviours included gentleness, kindness or empathy which women identified as important expressions of their feminine nature.

Women also tried to present an appropriately gendered image socially, including enhancing physical presentations of the “feminine” through clothes and beauty regimes. This work allowed them to “pass” as “normal” women and might be combined with selective informing of their hysterectomy status. She frames this through Goffman’s (1959) notion of “discreditable” stigma, in which it is assumed that the stigmatising quality is not generally known or perceivable. This is in contrast to the “discredited” stigma, where the cause of stigma is known and perceivable to society at large. Concealment was especially fraught in relation to sexual partners as there were particular fears of negative attitudes about hysterectomy from men. Partners were an important source of emotional and practical support and, where present, this helped women to maintain a sense of unspoilt gender identity.

Despite changes in social attitudes, and expectations of women over recent decades, it is still culturally expected that women must mother. Most participants in Elson’s study also felt that motherhood was a crucial part of “women’s work” – contributing the complete sexual identity. Even if they had not intended to have (more) children, hysterectomy removes this possibility and the resultant infertility was felt as a threat to gender identity. This was true regardless of whether individuals believed that maternal desire was natural or socially constructed. Childless women were particularly vulnerable to what Elson terms “identity shock” precipitated by undergoing hysterectomy. Further, these women might also feel inadequate in their role as wives, leading them to fear being abandoned by their partners.

Gender identity and sexuality are linked. As sexuality, like gender, is a socio-cultural construct, any physical effects of surgery are mediated through social interpretation. In the West, expectations of female sexual attractiveness are governed by ideals of physical

perfection and youthfulness, both of which may be threatened by hysterectomy. In contrast, some women felt that they were *more* available as a sexual object post-hysterectomy, because any threat of pregnancy was removed. Elson interprets these positions as being two sides of the same coin:

*Whether woman was stigmatised for becoming “sexless” or “oversexed”, the common theme is that both stigmas are cultural consequences of women’s perceived role as sexual objects (Elson 2004).*

Elson notes that while a hysterectomy scar may act as a “stigma signal” of women’s “lack of wholeness”, the medical language of a “bikini cut” implies women will, perhaps should, be interested in maintaining a particular, sanctioned kind of female sexual attractiveness (Elson, 2004a). Other conflicts, Elson labels them “battles”, between women’s priorities and understandings and those of the medical establishment were also noted. For example, the medical model may advocate removal of the cervix as prevention against cancer, while women may be concerned that this will alter their capacity for, or experience of, orgasm. Those women who acquiesced to total hysterectomy but then found that their sexual response was altered after hysterectomy, “felt impotent both literally and figuratively” (Elson, 2004a). I would suggest that Elson’s use of traditional male sexual language, such as castration and impotence, reproduces the binaries associated with sexual difference whilst simultaneously trying to disrupt them. Such language operates within the expectation that male experience is generally privileged in patriarchal societies and so aims to increase their impact by applying these descriptions to women’s experiences.

In common with people with chronic illness, hysterectomised women undergo “accounting reviews” (Corbin and Strauss, 1987) during which they re-evaluate past life failures and successes which can no longer be made right, and may therefore be reframed as a cause for remorse. This may be especially true for “life choices they had previously made that did not conform to a traditional feminine lifestyle” (Elson, 2004a) such as delaying childbearing, previous miscarriages or abortions and remaining in, or leaving, particular relationships.

While it was found that women participating in Elson’s study tended to replicate traditional binary definitions of gender, they also exercised agency, through working to enhance traditional biologically based definitions of gender difference to ensure it encompassed post-hysterectomised women. Participants merged biological, cultural and social

definitions of gender identity post-hysterectomy in order to reclaim and reconstruct this identity for themselves.

Elson concludes that gender identity may indeed be disrupted by hysterectomy and that following conditions are more likely to lead to such disruption:

- Bilateral salpingo-oophorectomy, (bs-o).<sup>i</sup>
- Women who were still fertile prior to surgery (regardless of whether they had already given birth)
- Straight women who feared diminished sexual attractiveness and who did not have supportive partners
- Women who perceived negative changes in sexual response
- Women who believed they had no control over decisions to undergo surgery

Elson's argument has been summarised in Box 6. Having described this index theory in depth, I now go on to describe the use of theory in the other studies included in the hysterectomy review.

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<sup>i</sup> Removal of both ovaries and Fallopian tubes

**Box 6: Summary of line of argument from Elson**

The category of “woman” is a cultural construct.

In Western society, “woman” signifies being a mother and being a sex object.

Sexual attractiveness for women is focused around youth and physical perfection.

Hysterectomy threatens gender identity on these levels.

Psychologically, hysterectomy may be associated with feeling of loss – of physically losing their uterus (“insides” removed, concern about “hollow” space left by uterus removal.), and with it their periods and fertility, which leads to feelings of lost youth, femininity and womanhood which are related to feelings of lost sexuality and sexual attractiveness.

Hysterectomy is seen as an invisible stigma with the potential to become visible through physical marks (scar) and signs of non-menstruation (such as not bonding with other fertile women over cyclical disruptions, or signs of menopause such as hot flushes).

These concerns lead women to create a “hormonal hierarchy” based on whether women have both, one or some of their ovaries intact after surgery.

Women also cultivated strategies of identity management, through biographical work and impression management to maintain or reclaim their identity as a woman. The quality of intimate relationships was a significant factor in the success of this work.

## 6.5 Meta-method: The Impact on Theory

This section on meta-method considers how methodology impacted on the theory used in the studies. Theory, to a lesser or greater extent, is found in most of the included studies, whether as a framework for analysis, a tool for interpreting the findings or a construction through the study findings. The degree to which such theory is pivotal in the reports varies greatly, as does the theory used. These are briefly outlined below, grouped by broad categories of methodological approach; social constructionist approaches, phenomenological studies (including those which I have aligned with this approach although they do not self-identify as such), studies investigating mechanisms of decision-making, the ENDOW projects and finally individual study reports that do not share the ENDOW approach. I return to the impact of methods on findings later in this chapter where, in Section 6.8, I outline the impact of interviews compared to direct observation on the findings of the studies.

### 6.5.1 Social constructionist studies

Only two of the studies, resulting in three included reports, take a clear constructionist approach. While other study reports may discuss women feeling “unfeminine” or “less of woman” after hysterectomy, these categories are not examined or problematised. In fact, as Dell suggests, these categories are not fixed, but are complex sites which are capable of sustaining contradictory meanings. Elson found that generally, many women do not confront issues of gender and their own relationship to the categories of “woman” or “femininity”, until facing a crisis such as that precipitated by hysterectomy and/or oophorectomy. This attack on the self leads them to contemplate the meaning in the context of illness and surgery of female identity. Elson’s work was used as an index theory, driving the examination of alternative conceptual approaches. Full details are found earlier in this chapter in Section 6.4.

Dell produced two study reports from the same set of interviews, one authored alone in 2000 and one with Papagiannidou in 1999. The sole authored report is a book chapter, and the collaboration a journal article. Both use discourse analysis to explore women’s accounts of hysterectomy and cover similar theory, based on the same set of interviews. Dell and Papagiannidou note that, in research literature, women’s experiences of hysterectomy have largely been understood from a medical perspective. This has constructed the “hysterectomised woman” as a distinct clinical entity or syndrome, comprising a set of endocrinal, physiological and psychological symptoms which construct her as depressed, asexual and hysterical. They state that this hysterectomised body has been wrongly understood solely on the level of the individual, rather than being seen than as embedded in medical discourses which systematically create the phenomenon they describe. Supporting this, is the suggestion that psychological sequelae of hysterectomy suggested as ubiquitous in the mid part of the 20<sup>th</sup> century (such as low self-esteem, depression, decreased sexual function), were rarer or absent from the medical literature at later dates. The authors state that this relates to socio-cultural developments in the ways that women and their roles are regarded, and in which women see themselves. In her chapter, Dell contends that, despite growing evidence that women who *have* had hysterectomies do not have different physiological, emotional or psychological profiles to women who have *not*, hysterectomy research is often still framed in these ways. Any *lack* of difference found between these two groups is interpreted as revealing how some women “successfully” adapt their attitudes, or to have “appropriate” social support, or relate positively to perceptions of the feminine role.

Dell and Papagiannidou claim that contemporary research into women's experience of hysterectomy have reproduced classical constructions of infertile women, and the female body in general, as intrinsically pathological. This diseased and uncontrollable body must therefore be brought into line through (iatrogenic) medical intervention, in this case, through hysterectomy, oophorectomy and HRT.

They note that, in patriarchal societies, the feminine role emphasises sexual functioning, fertility and childcare. The uterus is the cultural signifier for women's sexuality and fertility; metonymically signifying the whole woman. Its presence is therefore normalising and its absence is felt. They also note that there is a move away from this, towards seeing ovaries, with their hormonal production, as the most potent signifier of woman. Women may internalise this discourse, so that the post-hysterectomy body is experienced as undesirable and non-desiring. Both the womb and woman are commodified – seen as having a shelf-life after which they may wear out or no longer function in ways sanctioned by society. They note that women may therefore be ashamed of their missing uterus and hide the fact that they have had a hysterectomy. This is not described as an element of coping with stigma, as it in other studies, but rather is aligned with other studies of menopausal women that describe the “silence” that must be endured by women who do not have a legitimised discourse. In this case, the reference is to women who are deprived of their traditional sexual and reproductive roles through hysterectomy.

Finally, Dell and Papagiannidou propose that positive descriptions of hysterectomy as liberating (from menstruation, from pregnancy, from contraception, from their “otherness” to men) offer a site of resistance, and should be encouraged as an antidote to prevailing negative hysterectomy discourses as threatening femininity and sexuality.

Dell suggests that hysterectomy is framed as an inevitable consequence in consultations with both doctors and women patients constructing menstrual symptoms within a biomedical model. Thus the symptoms of HMB are seen as signifying disease of physical origin which requires surgical intervention, rather than, for example, as a part of the natural aging process. To see HMB as predominately a medical problem, when two-thirds of women making this complaint have bleeding within the normal range, demonstrates society's continued concern with regulating the female body, rather than concern for women's health. There are several consequences of this:

- The experience draws attention to the usually taken-for-granted body, a demanding and consuming “inescapable embodiment”, revising age-old associations of women

as physical beings compared to men's superior intellectual and spiritual preoccupations.

- This body changes the sense of self - simultaneously empowered to act and disempowered (handed over to medical authority).
- Defining the body as diseased is a shock which provokes fear and anxiety.

Traditionally women who have had hysterectomy have been constructed as ill and depressed. Dell concludes that the post-hysterectomy body should be reconstructed as healthy, and free from symptoms and the risk of cancer and that researchers should be encouraged to elucidate these positive experiences.

### **6.5.2 Phenomenological studies**

The use of theory in the phenomenological studies is briefly summarised here. Authors are presented in alphabetical order and I have included those studies which are broadly concerned with the lived experience of hysterectomy even if they do not explicitly align themselves with phenomenology.

Augustus frames her study of African American women within Leininger's transcultural nursing model. This *Theory of Cultural Care Diversity and Universality* is "directed at helping health care professionals grasp the world of the client and to use their viewpoints, knowledge, and practices as a basis for making culturally congruent professional action and decisions" (Augustus, 2002). This theory is used on a basic level to highlight the authors' interest in understanding the shared understandings of a particular subgroup – in this case, African American women. The article is published in the *Journal of Transcultural Nursing*, and this does feel a little like a *post facto* addition, rather than, as stated, a theoretical framework during the research. The study findings themselves are interpreted through brief allusion to another theoretical framework –disease and stigma (Scambler, 1998). In particular, participants felt their sexual desirability was diminished because they felt that they were different from other women, as they were somehow damaged or incomplete. This was interpreted as part of the stigma attached to hysterectomy. They therefore chose carefully who to tell; secrecy was likely with current or potential male partners. Such strategies of nondisclosure and concealment, are consistent with other individuals who are coping with invisible stigma (Scambler 1998).

Bernhard's 1985 study is largely a descriptive analysis, but her focus on the experiences of women has led me to categorise this as a phenomenological study. In her discussion of the results, Bernhard suggests that the fears and concerns she identified among the black women awaiting hysterectomy for benign conditions could be understood in terms of factors that had been identified as key among black adolescents in a previous study. She uses the findings of Ladner (1971) who found that menstruation and relationships with men were key factors that indicated to African American adolescents that they had become women. Indeed, she suggests that in some cases sex becomes a substitute for other forms of gratification that are not available to them. Bernhard suggests that this explains why the focus of black women's concerns may be around fears associated with sexuality and men's reactions to perceived altered status. These areas form a particularly important part of their identity as women, and so are particularly threatened by hysterectomy. She does not directly relate this to constructions of gender identity although this is clearly interpretable as such. It should also be noted that more recent studies have suggested that young women are increasingly regarding other, non- sexual or reproductive, achievements as key markers of the transition from adolescent to adult - financial or residential independence, for example (Aronson, 2008).

The included paper from Chassé is long, being a book chapter, and very descriptive, to the extent that I found it difficult to separate findings and theory in the report. I have categorised this paper as phenomenological due to the strong focus of the lived experience of women who had undergone hysterectomy. However, as the chapter contains no references, potential theoretical influences are difficult to assess. From the research findings, she theorises that women cope with the symptoms and experience of hysterectomy through establishing a frame of reference for the "boundaries of normality" at the various stages of the experience - before, during and after hysterectomy. Chassé suggests that three interdependent stages of this process exist which are shown in Figure 8. This suggested three-stage split of women's hysterectomy story was found to be useful as a tool to organise themes from other, largely descriptive studies and is used later in this chapter.

**Figure 8: Frame of reference for the stages of hysterectomy experience**

Stage 1: Experiencing a disruption	Experiencing the problems Perceiving a health problem Learning to read the body Evaluating the illness experience Negotiating medical management of the condition Hysterectomy decision-making
Stage 2: Struggling to preserve self	Managing the separation Becoming a patient Observing the changes
Stage 3: Recovering	Adjusting to the changes Coming to terms with the hysterectomy

In addition, Chassé suggests that the presence or absence of various dimensions of support, also affect women's coping abilities. Thus, when women are evaluating their symptoms, the influence of social networks, particularly female friends or relations, and husbands and doctors have a strong impact on how women feel and their behaviour towards the medical profession. Absence of support in one or more of these areas negatively affects women's experience. Chassé presents this diagrammatically in two by two matrices which show women's emotional response given the presence or absence of key types of support. I have not reproduced these here, as they are shown later in this chapter where they are considered in greater depth in the context of the synthesis (Figure 12 on page 212 and Figure 13 on page 213).

Hospitalisation forces women to become patients, a role which is characterised by loss of control and a sense of fragmentation. Chassé suggests that women's perceptions of the patient role are driven by their ability to master medical language, and their knowledge of the purpose of various hospital rituals (such as medical procedures) which allowed them to keep a sense of control. Again, I have not reproduced these here, as they are reproduced in the context of the synthesis (Figure 14 on page 232).

Finally, Chassé considers that women's perception of the experience of hysterectomy overall, depending on how they felt their recovery had been, and how much input they felt they had into the decision to have a hysterectomy. Again, she conceives this in a two-by-two matrix shown which is reproduced in Figure 15 (page 236).

Chapple does not explicitly use a theoretical framework (Chapple, 1995). As her aim is to explore the experiences of women undergoing hysterectomy, I have categorised her approach as broadly phenomenological, although her analysis is largely descriptive. Although unstated, her standpoint is feminist. She is concerned in her introduction with the lack of female consultants in gynaecology and the "patronising" way women are sometimes treated by their male doctors in gynaecological consultations. In addition, one challenge she rebukes is the suggestion that the concern for more information is a preoccupation of "feminist journalists and sociologist" that is not reflected in the desires of "ordinary" women. Despite referencing Glaser and Strauss, there is no real development of theory through her research. Although mechanisms of analysis are based on those used in grounded theory Chapple uses them primarily to identify themes in the findings.

From her findings, Chapple suggests that UK women using the NHS have less satisfactory experiences than women who pay for private hysterectomies. She suggests that this may be due to poor communication and lack of information from consultants and time pressures within the NHS leading to women feeling rushed and dissatisfied. She concludes that organisational aspects of healthcare can negatively impact on women's experiences.

I found it difficult to be sure where method and theory began and ended for the paper by Fleming (2003). She explicitly takes a hermeneutic phenomenological approach, and is unique among the included study reports in her consideration of what this approach may mean. She suggests that previous nursing studies have lost the unique and diverse elements of their findings due to focus on the *common* themes in experience (she references three other studies also included in this synthesis – Giddings and Wood,

Kinnick and Leners and Webb and Wilson-Barnett). Fleming uses Merleau-Ponty's (1984) definition of essence:

*In order to grasp an essence, we consider a concrete experience, and then we make it change in our thought, trying to imagine it as effectively modified in all respects. That which remains invariable through these changes is the essence of phenomenological reduction. (Fleming, 2003)*

Fleming uses a case study approach, based on interview findings from a range of people related to one woman undergoing hysterectomy, her partner, gynaecologist and primary nurse, as well with the woman herself. The paper is largely organised under four thematic headings (doubts and justifications, pain, embodied experience, sense of betterness), which she examines in the context of existing literature, not all gynaecological, for support or contradiction. She does not attempt to theorise based on the results, but these conceptual headings are assumed to represent the phenomenon of hysterectomy.

The paper by Kinnick and Leners describes its approach as ethnographic, regarding hysterectomy as a cultural phenomenon and the women who undergo it as a subculture. They claim that the interview schedule was guided by this approach, although it is not clear if or how this was manifest from the questions used, which are reproduced in the paper. There is little obvious theory guiding or emanating from the research. One statement they do make in the conclusions is:

*Media that sensationalise the unnecessary hysterectomies that women have historically been pressured into probably have a direct influence on women's delaying surgery longer than necessary (Kinnick & Leners, 1995)*

There are potential tensions between the desire to resolve unmanageable symptoms, and political arguments that suggest women should resist hysterectomies that are seen as being foisted on women unnecessarily – for reasons of profit or lack of concern. The case study by Fleming also supports this. There, after a successful recovery from hysterectomy, the subject of the case study felt:

*I am challenging my own feminist views, though – that's really what stopped me doing this years ago! (participant quote, Fleming, 2003)*

This highlights the controversy between the medical profession and other sources and their views of hysterectomy.

### **6.5.3 Communication and decision-making**

Bernhard et al (1996) explicitly seek to explore communication about hysterectomy between (married) partners. This frames the research question, and uses a known quantitative instrument, the Primary Communication Inventory (PCI) to assess the general levels of communication between the couples, who were then interviewed specifically about hysterectomy. They speculate on a number of reasons that might explain the apparent lack of communication about specific aspects relating to hysterectomy. This research is hampered by the fact that half of the interviews with men occurred more than four months after the initial interviews with their female partners. Recall bias is a possibility. Alternatively, conversations may have taken place during the time between the two interviews, leading to the interviewed male partners reporting topics that had not been discussed at the time that the women were interviewed.

Bhavnani and Clarke use the Health Belief Model, (1974) updated into the Comprehensive Model of Information Seeking, (Johnson & Meischke, 2000) as the theoretical framework for their research (Bhavnani & Clarke, 2003). The Health Belief Model outlines dimensions that individuals take into consideration when they are making decisions about their health. These include their perceived susceptibility to a problem, the seriousness of the problem, the benefits of taking action and the barriers to taking action. The study concluded that these dimensions emerged as important in decision-making about oophorectomy through the interviews. Women wanted more information about the risks and benefits of removing ovaries and of HRT, particularly in the long term, so that they could make good decisions about keeping or removing their ovaries for themselves. The authors conclude that, ideally, decisions are made in response to full, factual information. However, this ignores the symbolic associations of the uterus, ovaries and HRT which were identified as important in both phenomenological and social constructionist based studies included in this review. These differences in the findings of different studies are understandable through meta-theory, which explores the impact of different theories on the interpretations of the studies. Understandings of gender identity as socially constructed, based on sexual and reproductive roles, allows hysterectomy to be understood as a potential threat to this identity.

The authors further suggest that the concept of the “resourceful patient” (Gray, 2002) should be extended to women who undergo hysterectomy and oophorectomy. The resourceful patient uses a variety of information sources, and “their own sophisticated

assessment of costs and benefits to them of the operations concerned” in order to make decisions about hysterectomy and oophorectomy. They noted that concerns about ovarian cancer, “the silent killer” drove some women’s decisions, whilst others conceptualised their ovaries as “worn out” or “redundant”.

#### **6.5.4 Studies using thematic analysis: the ENDOW project**

The initial phase of the ENDOW project aimed to examine the factors that influence women's choices and how women approach decisions regarding hysterectomy, oophorectomy and postmenopausal HRT, with special emphasis on exploring the potential roles of cultural identity and ethnicity. A key use of the research was to inform the wording of future quantitative questionnaires and in this sense is largely “hand maiden” research, where qualitative findings are used to prime or illuminate related quantitative studies that are likely to be given greater weight. Ultimately the findings of the project overall were used to produce culturally appropriate information leaflets and videos for women of different ethnic groups undergoing hysterectomy.

The paper by Groff et al organises results by the ethnic backgrounds of the participants. They found that the groups expressed similar ideas and that only the emphasis given to each item differed by ethnicity. Despite a clear interest in the possible impact of different local cultures, there is no obvious use or generation of theory in this paper, although this could have been undertaken in a number of ways, using, for example, ethnographic methods, or transcultural nursing approaches.

The study of middle aged lesbians contains little in the way of theory (Lees et al., 2001). One conceptual element is the suggestion that these women perceived any “loss” associated with hysterectomy as being as much ontological as sexual. That is, they felt that women would internalise a sense of *being changed* due to the surgery. The authors contrast this with the effects described by straight women which they see as prioritising physical loss over psychological impact. It is possible that this group is ideally placed to avoid some of the threats to gender identity faced by straight women. Through their sexuality, they have already had to reinvent their sense of womanhood outside of mainstream concerns with phallogocentric ideals of sexual attractiveness, and for some, may place less value on the reproductive role.

Mingo et al (2000b) conducted focus group discussions with women from different ethnic groups about the attitudes and experiences of hysterectomy. Although concluding that the

different groups were more alike than different, they also found that the experiences of women with Navajo or Hispanic/Latina origins varied according to how isolated they were from their traditional lifestyles. They conclude that women with more traditional diet, exercise, social support, language and healthcare lifestyles are less likely to experience symptoms associated with menopause in developed western nations. Meanwhile, whites have always traditionally associated hot flushes and “craziness” with menopause. These findings are not explored in terms of social construction but are clearly amenable to such an interpretation.

Richter et al (2000) use the Theory of Reasoned Action to help construct the focus group schedule. Analysis is thematic, and there is little attempt to produce theory from the research. They suggest that some of the themes may vary by race when examining how women perceive men’s attitudes towards hysterectomy – in particular African American women were more likely to feel that a man might leave his partner if she had a hysterectomy. This led to them feeling that they may need to conceal the operation from their partners. Although it is what they are describing, the terms “stigma” and “concealment strategies” are not used in this paper and the authors do not make use of existing theories of stigma such as those described by Goffman or Scambler.

Richter et al (2002) investigated women’s (and doctors’) perceptions of the role of the doctor in decision-making about hysterectomy. They assess the described interactions in terms of the four styles of physician-patient interaction described by Emanuel and Emanuel (1992), although this framework does not appear to directly influence the thematic categories used in the analysis.

- *Paternalistic – Physician as guardian performing the procedures that they deem to be in the patient’s best interest without reference to their desires.*
- *Informative – the patient is in complete control – physician is a source of information.*
- *Interpretive – Physician as counsellor, examines and interprets patient’s values, and provides treatments that best fit their values.*
- *Deliberative – Patient control, while physician provides information and helps apply it to the patient’s values. (Emanuel EJ & Emanuel LL, 1992)*

Emanuel and Emanuel suggest that the “deliberative” interaction style is the ideal for most patients. Using this framework, Richter et al suggest that reported interactions most

closely fit the “informative” model although both women and doctors express a wish for a partnership approach, which would fit with the “deliberative” model of doctor-patient interaction. The authors suggest that viewing doctors simply as information providers precludes the development of a relationship on both sides. This may feed women’s distrust. In addition, because they are just seen simply as providers of information - “ a human book or an interactive computer” (Richter et al., 2002) – this leaves doctors with little reason to invest in patient relationships.

Williams and Clarke (Williams & Clarke, 2000) explore decision-making about, and the experience of, hysterectomy. There is little use of theory. However, the description of women’s decision-making, where risks and benefits are weighed up across biophysical, psychological, sociological and spiritual domains has echoes of the Health Belief Model although this is not cited.

These papers do not, on the whole, engage with the implications for meaning behind the language or assumptions used. For example, the paper by Groff et al states that after conducting the qualitative research, questionnaire wording for a subsequent quantitative part of the ENDOW project was changed from “loss of femininity” to “feeling less of a woman”. However neither of these phrases are examined and, although the implication is that they are in some ways interchangeable, the substitution of one for the other also implies that, in important ways, they are not.

In addition, the ENDOW papers make less use of imported constructs than other study reports, such as stigma and strategies to deal with it. It is possible that the authors, working within a health services research environment, have less access or familiarity with sociological theory, or that such theory is not seen as so important given the practical aims of this project – to inform questionnaires and educational materials.

### **6.5.5 Other approaches**

Marchant-Haycock and Salmon’s (1997) research approach stands out because they are the only researchers to actually observe encounters between women and their gynaecologists rather than relying on women’s anticipated or recalled experiences. They observe that treatment decisions are negotiated by calling on material other than the symptoms. In contrast to fears reported elsewhere in the literature of doctors’ unnecessary over-reliance on hysterectomy, Marchant-Haycock and Salmon observed

that consultations leading to conservative treatment were steered by the doctor, while those leading to hysterectomy frequently showed the patient's power over the doctor. The consultation is seen in terms of opposition rather than collaboration. This is in opposition to the suggestion by Richter et al (2000).

From their observations, Marchant-Haycock and Salmon state that doctors prefer to disengage with treatment if there are no organic signs of disease, while women press for engagement to the point of surgery. In order to do this, each actor appeals to an authority that they alone possess. Thus doctors appeal to their ability, though medical equipment, to see inside the uterus and to thereby establish its normality. Doctors were sometimes seen to use lay models to describe what they saw. A description of a machine-based model is used as an example, with one woman being reassured that she just needed "finer control" to manage her symptoms. In contrast, women establish unique authority through appealing to their experience of symptoms and their effects. In addition, they may try to co-opt the biomedical model in order to explain their symptoms. Failure to improve despite conservative treatments may additionally lead women to position the doctor as culpable for their current plight.

It is reported that only one consultation showed the doctor pressuring a reluctant patient towards hysterectomy. It may be that this study shows the crucially different viewpoint that different methodology may bring to a topic. Through actually viewing consultations, the study suggests that women's fears about manipulation into unwanted surgery are largely unfounded, at least in the UK and in recent times. However, it must also be possible that both doctors and women may change their approach when they are knowingly observed for research (the Hawthorne effect). An initial pool of 88 patients were approached to take part in the study. From these, eight of the 15 consultations leading to hysterectomy were "chosen at random" for in-depth analysis. These were compared to eight out of 73 consultations leading to conservative management also chosen at random for analysis. The possible impact of these selections is not clear – random selection should guard against selection bias, but the absolute number of cases examined is small.

The chapter written by Webb (1986) takes a reflexive, feminist approach. Her study reports on interviews with women undergoing hysterectomy and gynaecology nurses, and also uses her own experience as a gynaecology patient as research data. In addition, she herself is a gynaecology nurse. She consciously uses access to these multiple view points to build up her interpretation of the experience of hysterectomy. The study uses results

from a previous study by the same author from which she hypothesised that the quality of women's recovery after hysterectomy might be affected by the type of social support, especially emotional support, available to them. The paper is theoretical in the sense that it falls within the tradition of emancipatory, politically motivated, feminist research – that is, research by women with women, about issues of concern to women, that involve the acknowledgment of *both* parties as subjects who share and create meanings likely to be different from those assumed in dominant discourses (Roberts, 1981). Here, the comparison is with masculine dominated medical practice and opportunities occur for radical change in how women are understood and are treated within that system.

From this feminist standpoint, her findings emphasise a number of issues. Firstly, in common with other studies, she notes that women experience gynaecological complaints as different from other kinds of complaints, because of their link to sexual and reproductive functions that were felt to define womanhood. She also notes that women who worked outside the home appeared to have better social support and information than those who worked in the home. Women in formal workplaces also found it easier to get time off from their work.

Webb notes the different status of women's stories and doctors' stories about hysterectomy. She notes that women's negative accounts about the impact of hysterectomy are referred to as "old wives' tales", a term which implicitly devalues their importance and credibility. Meanwhile, accounts in medical journals are accorded much higher status, despite largely being based on an absence of personal experience due to the predominance of men in gynaecology, and themselves sometimes appearing to be "myths and fantasies". To support this latter claim, she cites psychoanalytic interpretations of hysterectomy which suggest depression post surgery is due to "penis envy", which women suffer acutely if they can no longer produce a substitute penis through bearing a male child. As a strategic device, she labels these stories "old doctors' tales", to emphasise the different weights given to women's experience and medical discourse. She further suggests that women's accounts of hysterectomy will change as sensitivities to women's needs improve.

Webb also reports on the impact of her work on the research participants. Although no statistics are given, she reports that the women she interviewed both before and after surgery were less hostile (as measured on the Mood Adjective Checklist) and more satisfied with the information they had received about surgery than those who were only

interviewed post-hysterectomy. They were also more critical of their treatment. She suggests that her research acted as an intervention, allowing more opportunity to ask questions, but also perhaps raising expectations, or legitimising complaints if they felt their treatment was lacking.

Wood and Giddings report on an analysis of letters women wrote to accompany questionnaires about hysterectomy that were distributed in a New Zealand women's magazine. The main theoretical stance is that the uterus should not be treated as just another organ, as there are symbolic meanings attached to it which influence the way women experience hysterectomy. These symbolic meanings emerge from the data and are simply used as thematic organisers in the report – the uterus: reshaping womanhood; sexuality: redefining sexual experience; power: retrieving control and life-force: reclaiming energy.

This section has described the use of theory in the included studies and related this to study methodology. Understanding the different approaches allowed me to consider how theory and methods interacted and also to articulate a unifying framework that could be used to understand the processes and experiences of hysterectomy. This framework is described below.

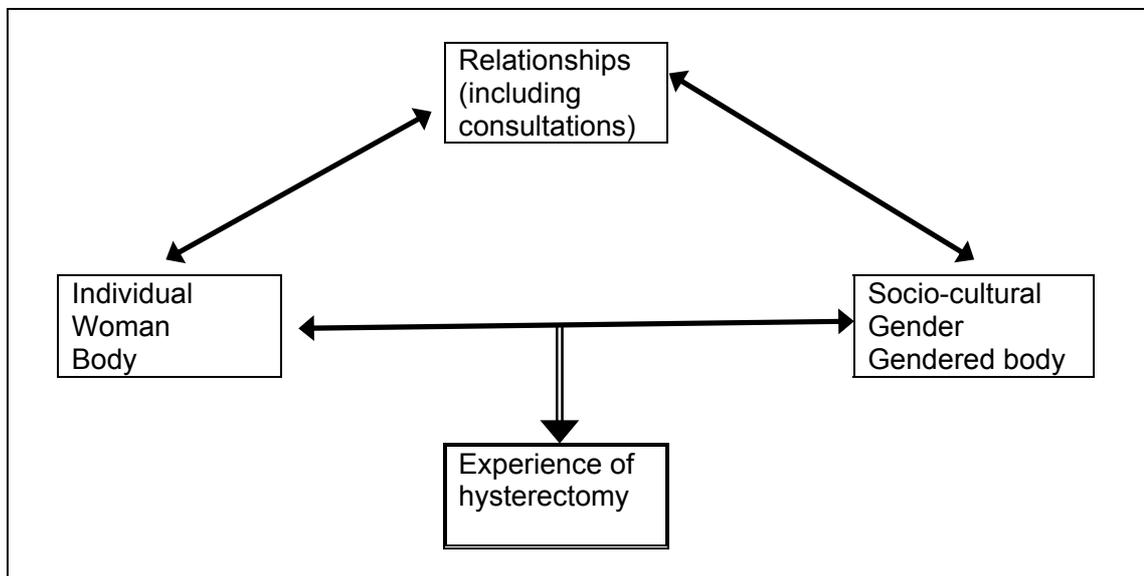
## **6.6 Theoretical Framework Developed for the Hysterectomy Review**

A key step in meta-study is articulating a theoretical framework to inform the direction of the synthesis. This is both a product of the synthesis, as it is constructed through an understanding of the concepts and themes in the included studies, and a tool for synthesis, since it provides an explanatory framework for those findings. The framework may be a found construct (taken from the literature included in the study) or an imported construct, selected by the synthesiser (Paterson et al., 2001). In this case I constructed the theoretical framework, using sociological concepts of micro- and macro-influences with which I was familiar in order to provide a single structure in which findings and theories across studies can be understood. Based on the included studies, I believe that meanings of menarche, menstruation and menorrhagia together with their treatments, can only be understood when they are seen as embedded socio-culturally:

*Menstruation is both a biological event and a cultural event; the biology cannot be separated from the culture and neither is a predetermined category with consistent impact on individual women's lives. (Kissling, 1996)*

Based on the papers included in the review, I suggest that women's experiences of hysterectomy are framed by the interaction between their personal experiences, and socio-political and cultural forces. These in turn are affected by and affect, relationships and interactions with kith and kin and with health professionals and with systems (healthcare system, hospital). I have represented this in Figure 9.

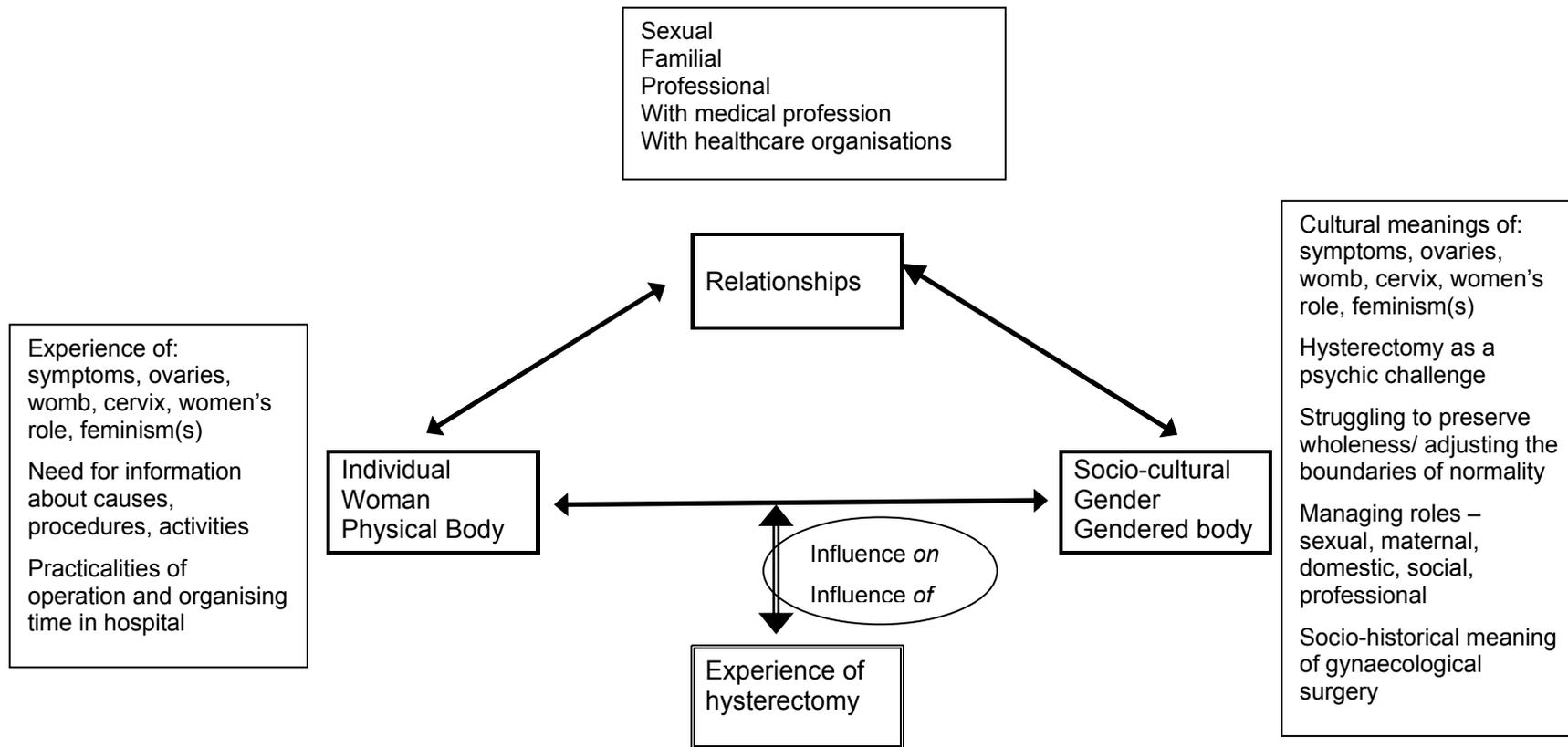
**Figure 9: Influences on the experience of hysterectomy**



For an individual undergoing hysterectomy, all of these elements influence her understanding of what hysterectomy means and her experience. The personal journey will be influenced by an individual's psychological and emotional, as well as physical, hysterectomy experience. Understandings of this personal journey cannot be separated from the socio-cultural context which produces and is produced by them. Similarly, relationships interact on a personal level, but expectations and experiences of these relationships are shaped by socio-cultural forces which produce expected roles and scripts for behaviour, for example in patient-doctor interactions. This may be especially so in the case of gender specific experiences.

The included studies had different focuses and concepts, some of which can be seen in the expanded version of the conceptual frame work shown in Figure 10. The boxes show themes within the socio-cultural, individual and relationship domains.

**Figure 10: Expanded conceptual framework for the experience of hysterectomy**



## **6.7 Meta-data Analysis: Key Stages of the Hysterectomy Experience**

This section analyses the findings of the included studies and synthesises them using meta-ethnography (Noblit & Hare, 1988), identifying and translating key themes and metaphors into one another, and particularly looking for reciprocal translation, refutational findings and findings that could be used to create a line of argument. Initially, I have grouped together themes emerging from those research projects that offer a phenomenological or thematic analysis to assess the similarities within these research methodologies and provide a thematic overview. I then consider the theoretical input of these studies into each stage of the hysterectomy journey, how these approaches contribute understanding the findings, and how they may account for any similarities and differences. Finally, I consider how methodology has influenced these findings.

As stated in Section 6.3.3, I have used the Chassé structure (shown in Figure 11) to help organise the findings of other included studies as it provides the most comprehensive thematic outline. Because the focus of this synthesis is hysterectomy, I am not repeating my earlier work about the type of bleeding and other menstrual symptoms that women experienced, although some studies do report on this, as this was focus of the meta-ethnography about HMB. Such themes are greyed out in Figure 11. However, where understandings about symptoms substantially affect the decision-making process, they will be included.

Most of the included studies are richly descriptive, presenting data organised into themes but not proceeding to much conceptualisation. One of the main areas of investigation and description is the journey women experienced through hysterectomy – from identifying a problem for which they sought medical help, gathering information about possible treatment, deciding to have a hysterectomy (with or without oophorectomy and HRT), the hospital experience of the operation itself, and recovery. This journey is characterised by Kinnick and Leners as:

*From resourceful endurance to unexpected relief. (Kinnick & Leners, 1995)*

This corresponds to the hysterectomy experience of “individual, woman, physical body” shown in the left-hand box of the theoretical framework (Figure 9). Conceptually, this relates to a time when normal life experiences are challenged. However, these

experiences are also substantially influenced by the relationships women have with friends, partners and doctors, as well as affecting, and being effected by, their social roles.

The first stage of the journey is given the overarching theme of “experiencing a disruption” by Chassé and is divided into three interdependent stages; identifying problematic symptoms, efforts to manage symptoms without surgery and decision-making about hysterectomy. The second stage of the journey through hysterectomy is identified as “struggling to preserve self” through the processes related to surgery. The interlinked sub-themes for this stage are: managing the separation, whereby women have to organise their familial and other social responsibilities while they become an inpatient; “becoming” a patient, and the difficulties of relinquishing control that this involves; and then observing the differences they feel after surgery. The final stage of the journey is “recovery” after surgery which involves coming to terms with resultant changes (Figure 11).

**Figure 11: Thematic organisers for descriptive studies of the hysterectomy journey**

Stage 1	Experiencing a disruption <sup>i</sup>	Experiencing the problems
		Perceiving a health problem
		Learning to read the body
		Evaluating the illness experience
		Negotiating the medical management of a condition
		Hysterectomy decision-making
Stage 2	Struggling to preserve self	Managing the separation
		Becoming a patient
		Observing the changes
Stage 3	Recovering	Adjusting to the changes
		Coming to terms with the hysterectomy

Source: Chassé 1991

Chassé suggests that the basic psychological process through which women coped with the experience of hysterectomy is continually *establishing a frame of reference for normality* which is repeatedly revised as a mechanism of retaining control and protecting self-esteem (Chasse, 1991). Elson expands this idea through an experience of illness perspective. Using a social constructionist perspective she notes that “illness is

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<sup>i</sup> Themes shown greyed out are not included in this synthesis as these relate to the experience of HMB

experienced as an attack on the embodied self, not just a physical attack” so that to change embodiment is to change identity (Elson, 2004a; Turner, 1992). Illness and its treatment are experienced as a *biographical* disruption. Chassé notes that her original study aim had to change in response to initial input from the women she interviewed. She had originally wanted to find out about the hysterectomy experience, but this had to change because she found women were compelled to begin with their original experience of symptoms, thereby constructing a full narrative arc of illness through to recovery. This supports the experience of illness as a biographical disruption.

Synthesised findings about the hysterectomy experience are described below, using the stages from Chassé for structure: experiencing a disruption (Section 6.7.1), struggling to preserve self (Section 6.7.2) and recovering (Section 6.7.3). Details of how I mapped the thematic organisers of included descriptive studies onto these Chassé headings are shown in Appendix 9.3.

### **6.7.1 Experiencing a disruption**

This section describes the first part of the hysterectomy experience narrative, from evaluating symptoms to the decision that a hysterectomy is an appropriate treatment. The contributions made by each included study to each part of this framework are tabulated in Appendix 9.3.

#### **Evaluating the illness experience**

When symptoms become unmanageable, women experience a disruption to their normal roles and experiences (Chasse, 1991). Symptoms are linked to the hormonal changes of the menstrual cycle, (Richter et al., 2000) and the onset of menopause (Mingo et al., 2000b) both of which may impact on physical and psychological wellbeing and leaving women feeling “miserable” (Kinnick & Leners, 1995). The disruption is on practical, physical levels; involving a break in their normal lives while they experience symptoms, undergo surgery and recovery. Elson adds that this is also potentially psychic interference, challenging women emotionally and potentially threatening their gender identity (Elson, 2004a). Much of this phase echoes the detailed concerns identified in the previous chapter about HMB. In the context of this synthesis, I have interpreted this stage as the beginning of women’s hysterectomy journey and its justification.

As women try to evaluate what is happening to them, Chassé suggests that women's ability to cope with and evaluate their symptoms (and make treatment decisions, although this is discussed further below) is influenced by the availability of support from partners and from female friends or family, highlighting the importance of relationships, and that both of these are required to enable a woman to adjust successfully to what they are going through. Figure 12 shows Chassé's model for the impact on women's coping when receiving various combinations of support, with full adjustment only conceived as possible if both partners recognise the legitimacy of her claim to illness, and if female support is available.

**Figure 12: Influence of significant others on women's coping**

		Accessibility of supportive women	
		+	-
Husband's recognition of illness	+	Adjusted	Isolated
	-	Limited adjustment	Distressed

Source: Chassé, 1991

Chassé uses the word "husband" to describe partners, and it may be that all the participants in her study were married. It is not clear if different relationship needs might be seen among unmarried women with partners, single women or lesbians. However, other authors also recognised the importance of support from partners, family and friends (Bernhard et al., 1997; Kinnick & Leners, 1995; Richter et al., 2000; Webb, 1986). Williams and Clarke (2000) suggest that partner support was the most important assistance to coping among the women interviewed, while Webb (1986) found that women who had no particular confidant missed out on an important source of comfort, which echoes the findings shown in Figure 12.

Problems involved with having menstrual symptoms taken seriously by doctors and others were highlighted in the meta-ethnography of HMB (see Chapter 4) and were also evident in these studies. Some women in these studies were also found to trivialise their own experience of symptoms (Fleming, 2003). In other cases, women found it hard to get recognition that they were suffering (Chasse, 1991). Chassé suggested that the combined acceptance of male partners and of doctors was needed for women to trust their experience of symptoms and to feel they could get the treatment they needed, as summarised in Figure 13. Where doctors did not acknowledge their bleeding as problematic, women searched for another doctor who would ("doctor hopping"). It is

possible that this strategy is more usual in the USA, the impact of different healthcare systems, in the UK for example, is not known.

**Figure 13: Influence of spouse and physicians on women’s coping and view of illness**

		Physician’s acknowledgement of illness	
		+	-
Husband’s recognition of illness	+	Confirmed illness	Doctor hopping
	-	Attempted to convince spouse	Doctor hopping/ distressed

Source: Chassé, 1991

Other studies also found that women wanted doctors who would “respectfully listen” to their symptoms and concerns (Mingo et al., 2000b). While this was available to some, (Richter et al., 2002) other women felt that the impersonal nature of the healthcare system, staffed largely by male doctors, added to women’s feelings of powerlessness (Wood & Giddings, 1991). Some women expressed a clear preference for a female doctor (Chapple, 1995; Groff et al., 2000), while others found that unsatisfactory encounters could occur regardless of gender or sexuality of the doctor (Lees et al., 2001). One author’s experience as a patient in a gynaecology department was that the consultant dismissed her concerns and fears, which led to her describe the encounter as resembling:

*A caricature of the sexist male expert putting down the emotional woman. (Webb, 1986)*

Most doctors failed to take the time needed in “getting to know” the individuals under their care, with even small signs of this, such as remembering women’s names and asking them how they felt, lacking (Kinnick & Leners, 1995). In some cases, nurses were found to be better (Kinnick & Leners, 1995).

Women’s support requirements from partners is described below in the section on decision-making, since in most reports these types of support were described together and are intimately linked. My summary of the themes incorporating within “evaluating the illness experience” is shown in Box 7. These can be understood within the theoretical framework where personal experiences interact with socio-cultural forces which are mediated through relationships women have with female friends and relations, partners and doctors.

**Box 7: Summary of themes in evaluating the illness experience**

- The physical and mental impact of symptoms disrupt women's lives.
- The way in which they cope with this disruption is influenced by the type of support they get from partners, physicians, and female friends and relations.
- These relationships can help or hinder women's confidence in identifying problematic symptoms and seeking help.
- Some physicians fail to give women the personal attention and respect they want.

**Negotiating the medical management of the condition**

This section describes women's initial experiences with physicians and the broader healthcare system. Early experiences are important as they set the tone for further encounters, including those about serious interventions such as surgery. As was found in the synthesis on HMB, some women felt disenfranchised from their own experience. Chassé found women felt disadvantaged when approaching doctors about information and treatments, since doctors were seen as the holders of privileged knowledge about women's physicality as well as about disease. In addition, they controlled access to medication and other treatments (Chasse, 1991).

There are some contrary forces around clinical examinations. Women want to be reassured that there is no obvious benign cause for their symptoms (such as fibroids). Their absence, however, can cause women to worry about possible malignant causes at one extreme (Chasse, 1991) or to doubt the validity of their complaint at the other (Fleming, 2003). Most of the studies also highlighted experiences of the doctor-patient relationship, including their role in information provision, communication and decision-making (Richter et al., 2002).

In the UK, Chapple (1995) reports that women using the NHS could not always access a consultant, and that when they did, they rarely saw the same person more than once. This lack of consistency was distressing. In addition, appointments often felt rushed and women found that the information they received was poor generally, and specifically was poor when test results needed to be communicated. Women who felt rushed or pressured in consultations often felt angry about their treatment (Wood & Giddings, 1991). Chapple found that women in the UK private system generally did not feel rushed, saw the same

consultant more consistently and perceived that their information needs were well met. This was not borne out in research in the USA, which also found women's information needs about treatments were not met (Kinnick & Leners, 1995; Mingo et al., 2000b) even though most people access healthcare through private medical insurance.

Such organisational issues may impact on the relationships between women and their doctors (Chapple, 1995). Kinnick and Leners (1995) suggest that women requiring hysterectomy should be seen as a "subculture from whom doctors can learn" about the symptoms that plague them, and the types of information and services that they require. Women wanted detailed information about a number of topics, including how their bodies work, the impact of different possible treatments both physically and mentally, including possible adverse effects and for surgical treatments, what the recovery strategy would be (Webb, 1986; Richter et al., 2002).

Various medical systems were perceived differently by different ethnic groups in the included studies, emphasising diverse socio-cultural forces associated with these different groups. Hispanic women in the US tended to have a higher opinion of American doctors than Mexican ones, largely because they felt the litigation culture ensured that doctors in the USA behaved correctly (Groff et al., 2000). By contrast, there was a general distrust of doctors among African American women, (Groff et al., 2000) perhaps because of different histories of these populations in the US. As discussed later, African American women felt that doctors used a perception of low educational status among this group of women as an excuse not to explain conditions, treatments and potential problems. Doctors were felt to proceed too quickly to surgery (Groff et al., 2000; Richter et al., 2002; Lees et al., 2001). Among women in the USA, there was a suspicion that doctors who favoured hysterectomy were motivated by financial incentives (Groff et al., 2000).

Hysterectomy was seen in a particularly political context by some African Americans, and this influenced their relationships with health care workers and their attitudes to the surgery. Hysterectomy, together with programmes of contraception and sterilisation, could be seen as a vehicle of "racial genocide" through its prevention of childbirth (Groff et al., 2000).

Different findings focussing on ethnicity or on women's ability to negotiate with the medical system reflect different research focuses used by the authors. The ENDOW studies explicitly wanted to explore potential ethnic differences in attitude and experience. None of the other studies mention possible differences between ethnic groups. Webb and

Chapple both take a feminist perspective, and this frames expectations of women's experiences within the medical system. In both cases, these various approaches are compatible with social construction as a tool to understand how different individuals' experiences may be shaped.

A summary of the key thematic strands about negotiating medical management of the condition is shown in Box 8.

**Box 8: Summary: Negotiating the medical management of the condition**

- The way in which women cope with negotiating initial treatment is influenced by the type of support they get from partners and physicians.
- Women want, but rarely receive, detailed information about their bodies, their condition, treatment options and risks and benefits.
- Physicians control information and treatment leaving women feeling disadvantaged.
- Some physicians fail to give women the personal attention and respect they want.
- Organisation elements, such as service fees, or lack of time and consistency with consultants, may affect the patient-doctor relationship.

### **Hysterectomy decision-making**

Decision-making about hysterectomy was a main investigative drive among many of the included study reports, notably the studies that made up the ENDOW project, but all of the other study reports also included some discussion of information needs, support required or impact of partners. There is some overlap with the previous section, as not all study reports distinguished between relationships leading up to hysterectomy and those directly involved with hysterectomy decision-making itself. The boundaries between descriptions of primary and secondary care encounters are not, therefore, always clear. This may in part reflect different organisational patterns of care, for example in the USA, women are likely to have direct access to gynaecologists while in the UK, GPs act as gatekeepers to gynaecologists who are based in secondary care. I have subdivided this theme identified by Chassé into four sections. These divisions are based on the key thematic areas related to decision-making identified in the studies (see Appendix 9.3): the decision-making process, decisions about oophorectomy, men's understanding of hysterectomy and men's role in decision-making.

### **Information seeking**

Chassé found that hysterectomy was regarded as a last resort and that initially, women were often shocked and disbelieving that this was an appropriate option for them (Chasse, 1991). This led some to doubt whether their symptoms really necessitated surgery (Fleming, 2003). In order to make decisions about the appropriateness of hysterectomy for them, women gathered information and advice. Across ethnic groups, women sought information about hysterectomy from multiple sources including friends and family, and women who had undergone hysterectomy (Groff et al., 2000; Lees et al., 2001; Richter et al., 2000). One study found that Caucasian women in the USA were more likely to consult co-workers and friends, while African American women were more likely to rely on family (Williams & Clarke, 2000). Some African American women also included prayer as a useful tool to help decision-making (Groff et al., 2000; Williams & Clarke, 2000). Books, magazines, other media and the library were also used to gain information (Mingo et al., 2000b; Williams & Clarke, 2000). Despite this, women were found to be ill-informed about the effect of details of hysterectomy, such as its effect on menopause (Mingo et al., 2000b) and the risks and benefits of hysterectomy generally, specific procedures and HRT (Williams & Clarke, 2000).

### **Fears and concerns**

The environment in which women have to make such decisions may be fraught. Kinnick and Leners (1995) found that lay sources of information about hysterectomy and HRT were often negative and that these negative attitudes and stories usually came from people who had *not* had a hysterectomy, while those who *had* had a hysterectomy voiced positive opinions. Bernhard (1997) also suggests that most fears about hysterectomy come from external sources – particular partners and other women.(Bernhard et al., 1997) The media was also felt to concentrate on how to avoid hysterectomy, and to “sensationalise unnecessary operations” (Kinnick & Leners, 1995).

Augustus et al (2002) found that all of the African-American women interviewed had heard what the authors call “old wives’ tales” about hysterectomy, mostly relating to loss of sexual attractiveness and reduced sexual desire. As discussed in Section 6.5.5, Webb also refers to “old wives’ tales” and suggests that these are not taken seriously by the medical profession despite the fact that they are based on women’s experiences. She attributes fears around the impact of hysterectomy as “old wives tales” shared between

women, and suggests that as practices improve over time, the nature of these “old wives’ tales” will also alter.

Fleming’s 2003 case study showed a woman whose doubts about medical necessity for surgery led her to feel she needed to justify her experiences, maybe through discovery of pathology. However, there is often no obvious pathological cause for heavy bleeding or dysmenorrhoea. Where investigations showed no underlying benign cause, however, some women worried about cancer (Chasse, 1991).

Participants in Lees et al’s 2001 study felt that those of lower socio-economic status may find it more difficult to access information. Some African American women suggested that this was used by doctors as an excuse for not providing them with sufficiently detailed information. This led to women finding medical encounters unsatisfactory, (Richter et al., 2002) although it is not clear whether Lee et al found this to be due to a patronising attitude that assumes such women are unlikely to be able to make use of more information, or because these women are treated with public healthcare or for some other reason. In the UK, women treated through the NHS perceive that they are provided with less information while women treated privately perceive they get more. (Chapple, 1995) In the focus group with lesbians, another potential barrier to seeking relevant information was a fear of disclosing sexuality (Lees et al., 2001).

Many women had pre-surgery concerns relating to the impact of hysterectomy on their physical, sexual attractiveness. This might relate to the scar, but also to response to and initiation of sexual desire and becoming less feminine due to the loss of menstruation. There were also fears about menopause causing weight gain, facial hair, and generally being old (Bernhard, 1985). Fears of depression associated with menopause were also identified (Groff et al., 2000). Chassé found that an acknowledgement that they had finished childbearing could be the deciding factor for many women choosing hysterectomy, and that it was a very painful decision if they wanted (more) children (Chasse, 1991).

### **Role of the doctor**

The role of the doctor in decision-making was a central theme in several study reports. Medical information sheets were generally seen as too general, (Kinnick & Leners, 1995) and more information was available to inpatients than outpatients, both in written form and from nurses (Chapple, 1995). This may be unhelpful for the decision-making process which is likely to take place before women become inpatients. Some women in the USA

felt that doctors were too quick to recommend surgery, particularly to African American women (Groff et al., 2000) and felt that multiple medical opinions were required to ensure the right decision was made (Groff et al., 2000; Lees et al., 2001). This may be different to the UK, where no studies mentioned seeking a second opinion. Indeed, Chapple found that women struggled to get consistency in NHS staff and would have preferred to build up a relationship with one consultant (Chapple, 1995).

Richter et al (2002) explicitly investigated women's (and doctors') perceptions about the role of the doctor in decision-making about hysterectomy. As outlined in Section 6.5.4, they assess the described interactions in terms of the four styles of physician-patient interaction described by Emanuel and Emanuel (1992) (paternalistic, informative, interpretive and deliberative). Richter et al (2002) conclude that most women in their sample currently perceive the doctor's role as information provider, rather than informed advisor which limits the development of patient-doctor relationships.

The information seeking strategies described by other studies support the conclusion of Richter et al that doctors are seen primarily as sources of information, indeed they are just one of many sources of information for women who may value alternative sources just as highly. It also suggests a possible explanation as to why doctors do not invest time in establishing personal relationships with their patients – a trait criticised in a number of studies. Elements that may be particular to decision-making around gynaecological surgery such as the fact that most women do regard the womb and ovaries as different from other organs are, however, not considered in this framework. Also, other studies found that there were some strongly negative opinions about hysterectomy among women's peers, and this may make it difficult to know whose information to trust.

Chassé found decision-making varied greatly between individuals – some making the decision alone, and others relying on varying degrees of input from partners or physicians. Wood suggests that making treatment decisions is an important way of women “retrieving control” lost through persistent symptoms (Wood & Giddings, 1991). This is supported by Groff who found women wanted to be in charge of the decision, but welcomed information from “knowledgeable others” (Groff et al., 2000). Dell suggests that the decision to have a hysterectomy:

*Is not so much about exercising informed choice, but rather is seen as necessary to regain control over a body discursively constructed as diseased by reason of its bleeding. (Dell, 2000)*

This is in opposition to some studies, particularly the ENDOW studies, and is likely to be the result of the different theoretical approaches used by these studies.

There is a weight of historical mistrust around hysterectomy, of a male dominated healthcare system blithely butchering women's bodies as a method of social control, for profit or through carelessness, with little understanding or regard for the impact on the women themselves (Ehrenreich & English, 1978; Fisher, 1986). Such an understanding may, or may not, be justified in current practice. Awareness of the contentious nature of hysterectomy was noted among study participants. There was evidence hysterectomies were perceived as "unnecessary" (Kinnick & Leners, 1995; Mingo et al., 2000b) which adds to the anxiety about whether the decision they had come to was the correct one (Williams & Clarke, 2000). After her successful surgery, the case study revealed one woman's anger with "feminist" health campaigns that had led her to resist treatment with hysterectomy for as long as she did (Fleming, 2003).

In the USA, this distrust is compounded by understandings of healthcare as big business, leading women to believe that financial gain influences doctors' preferences for hysterectomy (Groff et al., 2000; Lees et al., 2001). Historically racist, sometimes eugenic practices, around sterilisation and contraception still resonate with some (Groff et al., 2000). This concept was particularly found among African American men:

*Black males have historically associated fertility (as an aspect of virility) control with feelings of powerlessness, attitudes about the value of children, and fear of racial genocide, whereas black women relate controlling fertility with economics and a desire to control their own lives (Williams & Clarke, 2000) .*

This historico-cultural mistrust can compromise the development of healthy individual relationships between individual men and women (Williams & Clarke, 2000). This is a powerful example of how the cultural and the personal interact, sometimes negatively.

### **Decision-making about oophorectomy**

Once a decision to proceed with hysterectomy has been made, women must also consider whether to keep or remove ovaries at the same time. The included studies revealed refutational findings around this decision. Chassé (1991) reported that women did not understand why *doctors* preferred ovaries retained, having no clear preference themselves. In contrast, Bernhard et al (1997) found all women they spoke to had a preference about their ovaries. There are no obvious methodological or theoretical

explanations for these different findings. Bernhard et al define women as ovary “removers” or “preservers”. The former regard their ovaries as redundant, associated with painful symptoms and the risk of cancer, while their function is replaceable with HRT. Wood and Giddings (1991) also reported “redundant” being used by women to describe their uterus. Such language appears to frame the body as a commodity and is discussed below. Preservers on the other hand see their ovaries as healthy and unproblematic and, while they didn’t actively want menopause, when it came they preferred it “natural” rather than “medicalised” – leading to an early menopause and use of HRT (Bhavnani & Clarke, 2003). Women interviewed by Groff et al (2000) also saw loss of “natural” hormones as negative and most preferred to keep their ovaries, despite the fact that most regarded their function as replaceable by HRT. Some women saw the possible need for HRT as a strongly negative factor (Lees et al., 2001), and were anxious to retain their ovaries, ovary or even part of an ovary:

*I wish she'd been more sensitive as to why I wanted to keep an ovary. (participant quote, Mingo et al, 2000)*

Women felt ill informed about HRT, and considered it to be associated with negative side effects (Williams & Clarke, 2000). In other studies, women were not always aware exactly what had been removed during their surgery, shown through their lack of understanding why they might still be suffering pre-menstrual symptoms post-hysterectomy (Webb, 1986).

One of Elson’s key concepts is that a “hormonal hierarchy” created among women who have hysterectomy. The ovaries’ role as generators of female hormones, especially oestrogen, makes them key in female identity, particularly symbolic of sexual difference (Elson, 2004a). Lay understandings of female hormones associate them with pre-menstrual emotions, and their consumption is a marker of male to female transsexuals. Women create a stratified hormonal hierarchy based on whether all, some, or none of the ovaries are removed. Retaining (part of) their ovaries, important markers of (youthful) femininity through the production of appropriate hormones, allowed women to continue to identify with other biologically “normal” women. They valued the cyclical menstrual “waxing and waning”, even including pre-menstrual symptoms (Elson, 2004a). Dell & Papangiannidou (1999) also suggest that post-hysterectomy, women are pathologised as “oestrogen deficient” leading them to develop physically “unfeminine characteristics” which render them undesirable and libido-less.

The language that women use when describing degrees of surgical removal does not match that used by the medical establishment. Groff et al. (2000), found that women did not on the whole distinguish between hysterectomy and oophorectomy. Their language reflected this, as they described removal of their uterus alone as a “partial” hysterectomy, although clinically this refers to a hysterectomy which retains the cervix. This suggests that ovary removal is regarded as the default procedure. Thus, total hysterectomy for clinicians refers to the removal of the complete uterus, including the cervix, while for lay women, “taking it all” uses a symbolic meaning of “all”, perhaps referring to all the seats of their gender identity, and so refers to removal of ovaries as well as uterus (Groff et al., 2000).

Elson forcefully argues that women are ill prepared for the impact of having their ovaries removed because the language used is not meaningful enough. She suggests that “castration” is the appropriate term to use, as it relates to the removal of female gonads, and would alert women to the seriousness of the operation and the way it may affect them. Participants in several other research study reports also use this term (Groff et al., 2000; Lees et al., 2001; Wood & Giddings, 1991). In two cases, this is in conjunction with animal imagery, which suggests a further degradation resulting from oophorectomy – not just from woman to non-woman, but from women to beast:

*Personally I have always felt akin to a castrated animal. (participant quote, Wood and Giddings, 1991)*

*[I feel] calm, like a spayed dog. (participant quote, Groff et al, 2000)*

Bhavnani and Clarke (2003) use the Health Belief Model (1974) updated into the Comprehensive Model of Information Seeking, (Johnson & Meischke, 2000) as the theoretical framework for their research about decision-making. The Health Belief Model outlines dimensions that individuals take into consideration when they are making decisions about their health. These include their perceived susceptibility to a problem, seriousness of the problem, the benefits of taking action and the barriers to taking action. The study concluded that these dimensions emerged as important in decision-making about oophorectomy through the interviews. Women wanted more information about the risks and benefits of removing ovaries and of HRT, particularly in the long term, so that they could make good decisions about keeping or removing their ovaries for themselves. Bernhard et al. (1997) also suggest that individual perceptions of susceptibility to ovarian cancer and its seriousness, together with assessment of risks and benefits associated with

taking action and barriers to action, influence women's decision-making about oophorectomy, although they do not reference the HBM. Both sets of authors conclude that ideally, decisions are made in response to full, factual information. This approach ignores the symbolic associations of the uterus, ovaries and HRT which were identified in both phenomenological and social constructionist based studies. Elson suggests that the decision is, at best, always constrained by the absence of alternatives perceived as effective and that this puts women in a position of relative powerlessness (Elson, 2004a). These refutational findings are understandable through meta-theory. Elson understands gender identity to be constructed socio-culturally. Hysterectomy and oophorectomy are potential threats to this identity as they affect sexual and reproductive qualities that signify femininity and womanhood. The studies by Bhavnani and Clarke and Bernhard et al do not adopt this perspective, and consider the information needs of women purely in terms of health risks rather than gender threats.

Bhavnani and Clarke further suggest that the concept of the "resourceful patient" (Muir Gray, 2002) should be extended to women who undergo hysterectomy and oophorectomy. The resourceful patient uses a variety of information sources, and "their own sophisticated assessment of costs and benefits to them of the operations concerned" in order to make decisions about hysterectomy and oophorectomy. This was noted in most of the studies. They noted that concerns about ovarian cancer as "the silent killer", drove some women's decisions, whilst others conceptualised their ovaries as "worn out" or "redundant". Dell discusses the commodification of both women and their wombs and ovaries. Traditional female sexual and reproductive roles are seen as having a shelf life, and as women age, these may "wear out" and no longer function in ways sanctioned by society (Dell & Papagiannidou, 1999). The language used by some women in these studies described above suggests that, for some women, such ideas are internalised. They view their reproductive organs functionally, and if they have served their purpose (for example they are finished with child-bearing) then they can be removed. Other women, as discussed by Elson (2004a), do not accept this view and retain value for their reproductive organs as markers of identity, or intrinsic to bodily integrity or important in their sexual response.

Table 15 shows a synthesis of the concepts used by the study reports relating to decision-making. The first column shows identified themes within the study reports. The second column shows how a concept from a single study could be used to explain these findings (second order concepts) while the final column shows how the synthesis has allowed these concepts to be extended or challenged through additional information provided in

other studies, (third order concepts). In terms of the conceptual framework, these findings can be understood in terms of the interaction between micro- and macro-concerns.

**Table 15: Synthesis of concepts in decision-making about hysterectomy and oophorectomy**

<b>Themes (1<sup>st</sup> order concepts)</b>	<b>2<sup>nd</sup> order concepts in single studies</b>	<b>Third order concepts from the synthesis</b>
Women seek information from multiple sources before making decision to have hysterectomy	Resourceful patient	There are threats to this including socio-economic or organisational (inability to get multiple opinions), fear of disclosing lesbian status, media and female negativity about hysterectomy.
Lack of distinguishing between oophorectomy and hysterectomy	Lack of detailed information available	See above
Decisions are made by weighing up personal risks and benefits	Health Belief Model	Symbolic meanings for womb and ovaries may make women wish to retain them
Potential misinformation from media, women, untrustworthy Drs	Poor communication may add to perceptions of bad information. Perceptions of unnecessary hysterectomies	Historical understandings of the meaning and practice of hysterectomy – unnecessary, as social control, as racial control affect perceptions
Women express clear preferences for keeping or removing ovaries	Removers – redundant, replaceable with HRT Preservers – healthy and unproblematic, prefer natural menopause.	Commodify womb and ovaries vs Symbolic meanings attached

### **Men's understanding of hysterectomy**

Several of the ENDOW studies focus on the role of male partners in decision-making. Other study reports also highlight perceptions of partner support around symptoms, as described above, and hysterectomy, as described below, as important. However, this potential source of support could be hampered by perceptions of their knowledge and opinions. Women believed men to be ill-informed about women's bodies and about hysterectomy (Richter et al., 2000; Williams & Clarke, 2000). In one study, a number of women said they did not know their (male) partner's opinion about their hysterectomy (Webb, 1986). Some male partners, spoken to as part of the study on partner communication together with women who had undergone hysterectomy, did not spontaneously use the word hysterectomy, preferring to use the term "surgery" (Bernhard et al., 1997). It is not clear, however, whether this is due to lack of clarity about what had happened, or preference for euphemistic language, or an acknowledgement that this may

be a sensitive subject, or for some other reason. Lesbian participants, perhaps predictably, thought that female partners were likely to be more supportive than male ones (Lees et al., 2001) and indeed, women in Chassé's study felt their husbands did not consider women's feelings about the possibility of having to undergo a hysterectomy. Others reported men were inclined to dismiss their partners' concerns (Fleming, 2003). Bernhard et al, whose study focused on partner communication, offered some possible explanations (Bernhard et al., 1997). They found that some men avoided talking about their feelings either because they did not want to appear vulnerable at a time when their partners obviously were, or because they felt that the decision was not their business. Some avoided involvement so that they could not be implicated in the event of problematic outcomes. However, all of the women interviewed by Williams and Clarke reported having supportive partners (Williams & Clarke, 2000). It is possible that detailed communication is not an essential component of supportive behaviour.

Women were concerned that hysterectomy would affect them negatively, leading to loss of sexual desire and of sexual attractiveness to men (Bernhard, 1985). This was particularly reported by groups of African American women, but was also found among women from other ethnic groups. Sexual attractiveness was seen to rely on physical attractiveness which might be threatened by the surgical scar, a propensity to gain weight after surgery and being perceived as old (Bernhard, 1985). It is not clear why women think they may gain weight, perhaps due to a rest period post surgery, or as a result of early onset menopause. Similarly, it is not clear why hysterectomy is related to being old; whether due to loss of the ability to bear children, or again due to early onset of menopause or for some other reason. Other studies also identify unwelcome physical changes as a result of hysterectomy such as scarring, (Groff et al., 2000) weight gain, (Groff et al., 2000; Webb, 1986) facial hair, (Groff et al., 2000; Webb, 1986) and the body "drying up," (Groff et al., 2000) all of which were thought to negatively affect physical attractiveness. I would suggest that such concerns are a reflection of the narrow boundaries for sexual attractiveness proscribed by western culture, where physical perfection and youth are extremely highly prized.

One study also suggested that hysterectomy reflected badly on both partners, as a reminder that both were getting old, which could negatively impact on the male ego (Richter et al., 2000). As mentioned above, Williams and Clarke suggest that different perceptions of fertility control between African American men and women might compromise relationships. While men have historically associated fertility control with their

own powerlessness and fear of genocide, women felt that fertility control afforded them control over their lives, including economics, allowing them to regulate spending and organise employment (Williams & Clarke, 2000). This discord in attitudes of African-American men and women towards hysterectomy illuminates the noted tension between them in the ENDOW studies. Studies among other ethnic groups did not explore this theory, and it would be interesting to know if men from these groups also felt their virility was threatened by a partner's hysterectomy.

Women reported to Chassé that men were concerned about the possible impact of hysterectomy on women's sexuality (Chasse, 1991). The language used to describe the hysterectomised woman was quite extreme. In some studies this was particularly so among African American men, although women also used such terms, both those who had, and those who had not had hysterectomy. All of the below are quotes from female participants. In most cases these are the views of the participants. The quotes from Groff et al (2000) are explicitly women's understandings of men's views:

*Not "whole", "stripped....you're ruined" (Augustus, 2002)*

*"Castration". Women preferred "staying whole" (Lees et al., 2001)*

*"not whole" "less of a woman" "something wrong" (Richter et al., 2000)*

*African-American men described such women as a "bottomless pit", "dry hole", "mute", "empty shell", "like falling into an empty hole." (Groff et al., 2000)*

*Not "useful" as women. (Groff et al., 2000)*

*Dried up like a prune. (Elson, 2004a)*

Unfortunately, the meanings informing this powerful language are not, on the whole, closely explored by the studies in which they occur. For example, it is not clear whether the images of hysterectomised women as a dry or empty hole were envisaged as descriptive of a physical change, relating to the removal of the womb but affecting women's sexuality, or were to be interpreted symbolically, as a woman no longer reproductively fruitful, or alternatively could relate to physiological changes, such as vaginal dryness brought on by menopausal changes.

Women were concerned about whether men would be able to tell, during sex or otherwise, that they were hysterectomised (Groff et al., 2000; Richter et al., 2000). In some cases, women concealed their surgery from partners, (Augustus, 2002; Bernhard, 1985) and this was thought to be most common among African American women (Richter et al., 2000). We can understand these concerns in terms of stigma attached to hysterectomy as discussed more fully in Section 6.4. Stigma associated with hysterectomy is noted by Augustus et al, (2002) Elson (2004a) and Dell and Papagiannidou (1999). Other studies' descriptions of women's fears around disclosing their hysterectomy status are compatible with the concept of stigma, although this is not named as a concept (for example, Richter et al, 2000). This stigma results from associations of womanhood with reproductive capacity, and of femininity with ideals of physical perfection and youth which are challenged by hysterectomy and ooporectomy, giving rise to the language described above – a language which combines physically descriptive and symbolic language about women post-hysterectomy. This in turn explains why supportive partners are found to be so important in a number of studies, as they provide reassurance that hysterectomy is not considered stigmatising, or will not result in rejection.

Box 9 summarises women's perceptions of men's understandings of hysterectomy.

**Box 9: Summary of men's understanding of hysterectomy**

- Men's support over hysterectomy is important.
- Women believe many men to be poorly informed about women, their bodies and the operation.
- "Old wives tales" and some men's opinions about women post-hysterectomy lead women to be concerned about losing physical attractiveness after hysterectomy, including the possibility that partners may leave them.
- Hysterectomy represents an invisible stigma, and women may engage in image management and non-disclosure strategies to avoid possible consequences.
- Male support reassures women that they will not be rejected due to hysterectomy.

**Men's role in decision-making**

The 1997 study by Bernhard et al (1997) study focused on communication between partners about hysterectomy. They explored stated and actual communication between women who underwent a hysterectomy and their male partners. They found that women

often did not often involve their partners in decision-making, and even told them that they had been advised that it was medically “necessary” in order to avoid this (Bernhard et al., 1997) so that men were rarely directly involved in decision-making, despite some physicians’ direct suggestion that the decision be made in discussion with partners (Chapple, 1995).

Both men and women in this study stated that they “talked about everything”, however, targeted questions about physical, emotional and sexual effects of surgery revealed that little detail had been discussed (Bernhard et al., 1997). Some men referred to their partner’s “surgery” rather than “hysterectomy”, (Bernhard et al., 1997) suggesting lack of comfort, knowledge or engagement with the details of their partner’s treatment. In particular, “concerns” from both sides were not usually discussed (Bernhard et al., 1997). Where they were, women were worried about the practicalities associated with any surgery – dangers of anaesthetics, the possibility of not waking up or dying in surgery (Bernhard et al., 1997). Other studies also found that women did not know men’s opinion of their hysterectomy, or that men did not know about hysterectomy or women’s bodies (Williams & Clarke, 2000; Webb, 1986; Richter et al., 2000). Such knowledge gaps could potentially be addressed through shared communication. Bernhard suggests that:

*Communication is a symbolic process of sharing and creating meaning. (Bernhard et al., 1997)*

Although not explicitly stated, men and women’s failure to share their understandings and fears about hysterectomy suggest that men and women may attach different symbolic meaning to the operation.

Men’s role was more positively reported elsewhere, with the recognition that men do prioritise their partner’s well-being, (Richter et al., 2000) and that they were valued, as “a sounding board,” a source of “practical support” (such as taking women to their appointments) as well as the emotional support offered through “sympathy” and understanding (Richter et al., 2000). Bernhard also noted the value of general positive support felt by women through comments such as “don’t worry”, “everything will be all right,” although specific consequences such as infertility, menopause, or initial lack of intercourse, were not discussed in any detail (Bernhard et al., 1997). As well as sympathy, general practical help, such as driving women to appointments, (Richter et al., 2000) ensuring that they ate and slept well and help around the house, was valued.

Chassé (1991) found that coping with symptoms and decision-making is influenced by interaction with others and six of the included studies also focused on the theme of support (shown as “relationships” in the conceptual frame work, Figure 9.) Of the women Webb (1986) interviewed, a “significant minority had no particular confidant” and this was seen as a disadvantage. Those who felt supported valued someone, especially a partner, they felt was “there for me” (Kinnick & Leners, 1995). One focus group among lesbians felt that support would be better with a female partner as they perceived they would have a better understanding of the female body, leading to more empathy and more willingness to accept any decision the partner made about treatment (Lees et al., 2001). Chassé also suggests that female support, regardless of relationship, was important, as women were better able to empathise and may be able to share their own experiences (Chasse, 1991). While many women did find their male partners to be a great source of “comfort”, others did not know their male partner’s opinion of the operation (Webb, 1986).

I would suggest that it is possible to interpret these findings through an understanding of hysterectomy as stigmatising which may mean women and men fail to share meanings that are potentially hurtful or damaging to the relationship. Where women felt supported by partners, even where this was expressed as practical help rather than verbal support, this provided a much needed sense of security.

**Box 10: Summary of men's role in decision making**

- Women and their male partners may not discuss the details of hysterectomy together, before or after surgery and they are rarely involved in decision making.
- Failure to communicate precludes the creation of shared understandings and meanings about hysterectomy for men and women.
- Fear of stigma may help to explain this failure to communicate between partners.
- General reassurance and practical help from their partners were seen as supportive by women.
- Support from women confidantes, as well male partners, is needed by women.

**6.7.2 Struggling to preserve self**

Once women have decided to go ahead with surgery, they will be booked into a hospital appointment, and subsequently spend some days in hospital as part of their initial stage of recovery. Chassé describes the struggle involved in preserving a sense of self as they move through surgery and recovery.

This section of the Chassé narrative meshes most closely with the conceptual concerns of Elson. Elson (2004a) describes the struggle that women who had never previously considered the nature of gender, undergo when negotiating their way through lay interpretations of biological essentialism, cultural essentialism and social constructionist definitions of “woman”, as they adjust their self understanding through the disruption represented by hysterectomy. Briefly, biological essentialism assumes that there are “natural” biological differences between men and women, which align with differences in “masculine” and “feminine” character. Cultural essentialist theories suggest that essential biological differences are clarified and solidified through cultural expressions. Through culturally acceptable behaviours and roles, individuals who are born as male or female reinforce these categories socially (gender). Social constructionist theories maintain that gender is *created* through interpersonal interaction, that is through the performance of gendered behaviours in given socio-cultural situations. This allows biological sex and social gender categories to be uncoupled, most strongly seen in performance theories of gender, where gender is seen as an unstable, evolving identity that must be continually reworked (Butler, 1993). As discussed below, hysterectomy is a potential disruption to biological and cultural essentialist visions of gender identity as it removes corporeal markers of difference, as well as threatening key sexual and reproductive female roles.

Elson notes that nobody in her study located their gender identity in their chromosomal expression.

### **Managing the separation**

Women were concerned about how they would “manage the separation” from their families during the hospital stay to undergo hysterectomy and many prepared in detail who would cover their usual caring roles while they were absent (Webb, 1986). Planning the logistics of their stay was important (Bernhard et al., 1997). Women wanted to minimise the impact of their absence on their families, and some put a good deal of effort into the practical management of their absence and recovery period, such as ensuring that they had filled the freezer with enough meals for the family (Chasse, 1991). It was suggested that it was easier to gain time off from paid work than from domestic responsibilities, and women wanted to make partners understand that this was also needed for their recovery (Webb, 1986; Webb, 1989). However, resting during this period could be particularly difficult where women had small children who were less able to understand their need for rest (Chasse, 1991).

#### **Box 11: Summary of managing the separation**

- Many women carefully planned the logistics of their hysterectomy in order to continue fulfilling their usual domestic role while they were in hospital.
- Some partners did not understand that they would need recovery time and would not be able to do everything they usually did when they came out of hospital.

### **Becoming a patient**

A number of studies whose participants had undergone hysterectomy focus on the inpatient experience of hysterectomy for women. Chassé (1991) notes that this is a key time in the hysterectomy journey where women struggle to preserve a sense of wholeness and control. The medical model, which sees patients in parts - as their condition, or as their organs, rather than holistically - can lead to a sense of fragmentation. Chassé suggests that women’s comfort and struggle to “preserve wholeness” depends upon their knowledge of “hospital rituals” and “mastery of medical language”. Women with both of these abilities perceived their role as a patient as being collaborative, while a lack of both

or either of these skills negatively affected the patient experience as shown in the schematic below (Figure 14). Failure to understand why and how things were done in hospital contributes to the loss of control experienced by women in hospital. As noted above, information needs are frequently unmet, which may threaten women’s ability to adapt successfully to the patient role.

**Figure 14: Women’s perceptions of the patient role**

				Mastery of medical language	
				+	-
Knowledge of the purpose of rituals	+	the	-	Collaborative	Resistant
	-			Acquiescent	Isolated

Source: Chassé 1991

Experiences of the patient-doctor relationship were crucial and sometimes criticised as stark examples of continuing patriarchal power:

*I was treated like a naughty little girl who didn’t appreciate what this wonderful doctor was doing for her. (participant quote, Wood & Giddings, 1991)*

*Like a caricature of the sexist male expert doctor putting down the emotional woman. (author quote on her experience as a gynaecology patient, Webb, 1986)*

Chassé notes that the patient role necessitates loss of control, with few opportunities to initiate, select, or orchestrate events. Other studies also see that entering the healthcare system forced women to relinquish control over themselves (Wood & Giddings, 1991) although women felt a great need to *feel* in control, (Fleming, 2003) and such disquiet may be exacerbated by attitudes such as those above. The impersonal nature of a largely male healthcare system added to perceived powerlessness (Wood & Giddings, 1991). In addition, women in the NHS reported an impersonal and unsympathetic system left them feeling :

*“on a conveyor belt”*

*“like battery hens” (participant quotes, Chapple, 1995)*

Adding insult to injury, waiting times for this service were often long (Chapple 1995).

A number of studies identified women’s practical concerns about the detail of their condition, the surgery and the hospital stay. Reports by Kinnick and Leners (1995) and by

Webb (1986) both noted that women did not know “what to expect” from the surgery, the details of its potential impact on mental and physical self (Webb, 1986) such as the impact on menopause (Mingo et al., 2000b) Williams and Clarke (2000) also noted that women were not well informed about different types of hysterectomy procedure or HRT and specific risks and benefits of these. Women wanted detailed knowledge of how their bodies work and what the operation involves but did not always feel able to ask about the practicalities of what would happen to them and how to manage the post-operative period (Webb, 1986).

There was also concern among the women Chassé interviewed about how medics would handle the body when they were under anaesthesia, (Chasse, 1991) which I suggest could be seen as an extreme element of women’s fear of losing control, as they will be unconscious. Particular elements of surgery that women felt “scared” about were the anaesthesia and “not waking up” (Chasse, 1991; Bernhard et al., 1997; Williams & Clarke, 2000; Kinnick & Leners, 1995) and post-operation pain, (Kinnick & Leners, 1995; Bernhard et al., 1997; Chasse, 1991) other reports also mentioned vomiting, use of the bedpan and how to protect stitches (Webb, 1986). Long term outcomes of surgery, such as mental, emotional and sexual changes (Kinnick & Leners, 1995) as well as hormonal instability and possible changes in relationships, were also concerns (Chasse, 1991).

Other authors also note that women are not prepared for some specific elements of their surgery and recovery. Surprises included being shaved prior to surgery and having to get up and walk immediately afterwards (Kinnick & Leners, 1995). Standing up induced a disconcerting sense of dropping away within them: “like your insides were falling out” (participant quote), which was unexpected, though women reported being reassured by nurses that this was common (Chasse, 1991).

Some post-operative experiences were intense, with women feeling vulnerable and sick. Several studies noted that women were not expecting the degree of post-operative pain that they experienced (Kinnick & Leners, 1995; Fleming, 2003; Chasse, 1991), although one paper suggested that this was an immediate problem only that was soon forgotten (Fleming, 2003). One study reported that patient administered analgesics were found difficult to use (Fleming, 2003). Medication used to relieve pain left women feeling dozey, and heightened a sense of unreality. Women were unable to recall any details about the operation or how they should behave when they got home if it was told to them during this time – some preferred pain to these side effects (Chasse, 1991). Some women reported

feeling panic attacks which a nurse referred to as an “out of uterus experience” (Kinnick & Leners, 1995), suggesting that it was not uncommon.

Experiences of embodiment changed through experience, women reported disassociating themselves from technical aspects of care (Fleming, 2003) although intense awareness of their physicality was experienced in the immediate post-operative period. One study found that therapeutic touch from nurses was emotionally very important later on (Fleming, 2003).

**Box 12: Summary of Becoming a Patient**

- Becoming a patient involves a loss of control (over choices, environment and what happens to them)
- Knowing how and why hospital events occur (rituals) and understanding medical language helps women to feel more in control.
- Doctor attitudes can contribute to feelings of powerlessness.
- Women wanted to know the detail about exactly what would happen to them and the possible consequences in the short and long term, but this information was often not provided.

**Observing the changes**

Following hysterectomy, women take time to observe and assess what changes they experience and how they feel about them (Chasse, 1991). Several studies report that women needed to adjust to various perceived losses, which they may grieve about (Chasse, 1991; Wood & Giddings, 1991). Lees et al (2000) note that there are physical losses of “a part of oneself” (participant quote) the loss of their womb (Chasse, 1991) and their periods (Wood & Giddings, 1991; Bernhard, 1985; Chasse, 1991; Wood & Giddings, 1991). Physically, this is related to something being removed (Bernhard, 1985), and some women were concerned that there would be a physical absence, a “hollow” (participant quote, Groff et al, 2000) as a result. However, this was also associated with loss of the reproductive self through loss of fertility (Wood & Giddings, 1991) plus additional emotional and psychological losses. Mingo et al (2000b) suggest that loss of fertility may be traumatic, and note that it is inappropriate for women post-hysterectomy to find themselves in mixed gynaecology wards where they may be with women who have just given birth.

These losses may cause women to question whether they were “less than ordinary women” (Chasse, 1991) or, symbolically, had lost their “womanhood” (Bernhard, 1985; Wood & Giddings, 1991): potentially a major challenge to their sense of self as noted by Elson (2004a). This also relates back to the fears noted in the section of hysterectomy decision-making about desirability and desire post-hysterectomy. Those in Lees et al’s sample suggested loss of a sense of “femaleness” might be a concern for others, but did not think that this was a problem for them. Elson suggests that women in her sample had not usually considered how their gender identity was constituted prior to their need for hysterectomy. All the women in Lees et al’s sample were self-identified as gay. Given this sexual identity, they may have already worked to find ways of satisfactorily understanding their own gender outside the usual heterosexist assumptions.

Most of these studies that mention women’s concern about losing their “femininity” or “womanhood” do not attempt to unpack the meanings behind these terms. Bernhard’s 1997 study among African American women notes such concerns but does not explore how women defined these terms or if there were other associations. This paper also does not attempt to explain why African American women seemed more concerned about losing a partner if they had a hysterectomy than women from other ethnic groups. However, in her previous study (1985) Bernhard suggests that the fears and concerns she identified among the black women awaiting hysterectomy for benign conditions could be understood in terms of factors that had been identified as key among black adolescents in a previous study. As outlined in Section 6.5.4, she uses the findings of Ladner’s (1971) study which found that menstruation and relationships with men were key factors that indicated to African American adolescents that they had become women. Bernhard does not directly relate this to constructions of gender identity although this is clearly interpretable as such.

Several study reports noted that women were not always satisfied with the information they were given about the operation itself (Chasse, 1991) and what to expect in recovery (Chapple, 1995). A lack of counselling was found in the NHS (Chapple, 1995) while Chassé found women thought health professionals were “indifferent” to their concerns and sense of loss. In addition, if reports of tissue analysis came back “normal”, this could trigger doubts about whether or not the hysterectomy had been the correct decision.

**Box 13: Summary of observing the changes**

- Many women feel a sense of loss immediately after hysterectomy – this may be physical (loss of the womb), functional (loss of fertility) or symbolic (loss of womanhood).
- Physicians are not always found to be sensitive to these feelings of loss.
- Given these feelings of loss, if uterine tissue analysis shows no clinical reason for their symptoms, women may feel having a hysterectomy was the wrong decision.

**6.7.3 Recovering**

**Adjusting to the changes**

Women go through a period of adjustment after hysterectomy. Generally, they were satisfied if their main symptoms were resolved through hysterectomy (Mingo, Herman & Jasperse, 2000a; Williams & Clarke, 2000; Chapple, 1995) and this was true even if they experienced side effects (Mingo et al., 2000b). Two studies reported that women were overwhelmingly glad to have had the operation (Webb, 1986; Fleming, 2003). Their recovery was seen as a way to regain power through “retrieving control” (Wood & Giddings, 1991) and energy over their lives. Williams and Clarke noted that there was a full continuum of responses, from very negative to very positive (Williams & Clarke, 2000).

Chassé suggests that the way in which women adapt to their hysterectomy depends on their input into the initial decision-making about hysterectomy and the nature of their recovery (Chasse, 1991). If the recovery was positive, women were satisfied even if they felt they had not had enough input into the decision-making. By contrast, those women who felt they had been responsible for the decision to have a hysterectomy but failed to make a good recovery felt “out of control” as their original expression of control over their body had negative consequences (see Figure 15.)

**Figure 15 Women’s perceptions of the hysterectomy**

		Recovery	
		+	-
Input on decision-making	+	Snapped back	Out of control
	-	Satisfied	Depressed

Source: Chassé 1991

Initial limitations in their activities were self managed through rest, good nutrition and a gradual build up of activities (Chasse, 1991). Two study reports noted that women preferred to control their own pace of recovery, (Webb, 1986) and appreciated being told to listen to their bodies in order to gauge their own capabilities (Chasse, 1991). Women wanted to get “back to normal” (Bernhard et al., 1997), and Chassé noted that negative experiences were related to an inability to re-establish normality. Wood and Giddings described this as the ability to “reclaim energy” but I would suggest that they are referring to the same thing.

There were some anxieties about the resumption of sexual activity. Five study reports mentioned this theme, and all found women reported sex was the same or better than prior to the hysterectomy (Chasse, 1991; Augustus, 2002; Bernhard, 1985; Kinnick & Leners, 1995; Wood & Giddings, 1991), although some noticed discomfort initially, (Augustus, 2002) or found that their experience was altered (Chasse, 1991).

**Box 14: Summary of adjusting to the changes**

- As they recover from hysterectomy, women are generally satisfied if their main symptoms are resolved, although a range of responses was found.
- Recovery is experienced as a regaining of normality and of control.
- Women’s perceptions of the hysterectomy depend on how they recover and how much they felt involved in decision making – women felt out of control if they made the decision, but their recovery poor.
- In most cases, fears about the impact of hysterectomy on sexual experiences were unfounded.

**Coming to terms with hysterectomy**

Relief from pain and bleeding was a major benefit of surgery. Several study reports noted women’s “freedom” from periods (Augustus, 2002; Groff et al., 2000; Lees et al., 2001; Wood & Giddings, 1991; Bernhard et al., 1997; Williams & Clarke, 2000), which included freedom from previous fears about embarrassing leaks (Augustus, 2002), the cost of sanitary products (Groff et al., 2000) and interference with sexuality (Lees et al., 2001). Women also felt freed from worry about contraception and unwanted pregnancy (Groff et al., 2000; Kinnick & Leners, 1995; Richter et al., 2000; Williams & Clarke, 2000). These study reports included those that did, and those that did not note women’s sense of “loss”

about some of these same elements. Only one paper reported women's relief from fear of cancer (Williams & Clarke, 2000) although this is seen as a potential benefit of hysterectomy from a clinical perspective.

Dell suggests that precisely these elements of freedom should be emphasised in order to counteract previous constructions of hysterectomised women as depressed and pathological. Other reports' identification of these feelings of freedom support these outcomes being more widely accepted and publicised.

**Box 15: Summary of coming to terms with hysterectomy.**

- Many women emphasised a new found freedom after recovering from hysterectomy – freedom from previous symptoms about also from menstruation itself, and worries

## **6.8 Meta-method: The Impact on Findings**

Most of the study reports included in this synthesis used interviews – of individuals or groups, to elicit information about attitudes or experiences. There is little in the way of differences in findings which can be attributed to the methods used. However, Marchant-Haycock and Salmon's 1997 research approach is crucially different to all other included studies as they are the only researchers to actually observe encounters between women and their gynaecologists rather than relying on women's anticipated or recalled experiences. They observe that treatment decisions are negotiated by calling on material other than the symptoms. Their findings are in contrast to fears reported elsewhere in the literature about doctors' unnecessary over-reliance on hysterectomy. Marchant-Haycock and Salmon observed that consultations leading to conservative treatment were steered by the doctor, while those leading to hysterectomy frequently showed the patient's power over the doctor. The consultation is seen in terms of opposition rather than collaboration reversing the suggestion by Richter et al, (2000) about preferred styles of doctor-patient consultation.

The findings are described in Section 6.5.5 (p.202) but are repeated here for ease of discussion. From their observations, Marchant-Haycock and Salmon state that doctors prefer to disengage with treatment if there are no organic signs of disease, while women press for engagement to the point of surgery. In order to do this, each actor appeals to an authority that they alone possess. Thus doctors appeal to their ability, though medical

equipment, to see inside the uterus and to thereby establish its normality. Doctors sometimes used lay models to describe what they saw. A description of a machine-based model is used as an example, with one woman being reassured that she just needed “finer control” to manage her symptoms.<sup>i</sup> In contrast, women establish unique authority through appealing to their experience of symptoms and their effects. In addition, they may try to co-opt the biomedical model in order to explain their symptoms. Failure to improve despite conservative treatments may additionally lead women to position the doctor as culpable for their current plight.

It is reported that only one observed consultation showed the doctor pressuring a reluctant patient towards hysterectomy. It may be that this study shows the crucially different viewpoint that different methodology may bring to a topic. Through actually viewing consultations, the study suggests that women’s fears about manipulation into unwanted surgery are largely unfounded, at least in the UK and in recent times. However, it must also be possible that both doctors and women may change their approach when they are knowingly observed for research.<sup>ii</sup> In addition, as discussed in Section 6.5.5, the absolute number of cases examined is small, and the methods for “randomly” choosing observed consultations not detailed.

These findings show the importance of understanding clinical consultations as social interactions. The real world nature of the observation study shows that the way in which people really act may differ from how they think they act or how they report these actions. Findings from interviews and focus groups are themselves the result of social interactions which may tap into existing norms and expectations for behaviour. A previous study of general practice consultations found that, when talking among themselves, there was a tendency for people to dramatise stories about previous encounters with doctors through subsequent “stories of criticism” (Stimson & Webb, 1975). This leads them to emphasise the critical or even combative elements of medical encounters. Stimson and Webb

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<sup>i</sup> This language could also be interpreted in terms of the commodification of the female body – in this case, the machine is not yet totally worn out, but only needs fine tuning. It may also be an example of doctors’ tendency to use simplistic rather than technical language with women patients, which could lead to them feeling poorly informed.

<sup>ii</sup> The Hawthorne effect

suggest that this may be in reaction to perceived power imbalances within the actual consultations themselves. This could help to explain the contradictory findings in the hysterectomy review.

## **6.9 Synthesis Summary**

My original aims when approaching this synthesis were to explore the following questions shown in Section 6.1:

- How do women make decisions about having a hysterectomy?
- What are the experiences of women having a hysterectomy for benign conditions?
- What are the experiences of medical encounters for women undergoing hysterectomy?
- What elements contribute to positive or negative experiences?

The synthesis has allowed a detailed description of the journey that women make through negotiating initial treatment, deciding to have a hysterectomy, the hospital experience and recovery, and has allowed those inquiries to be answered. I created a theoretical framework (Figure 10, p. 208) which suggests that personal, physical experiences, together with socio-cultural forces affect the way in which hysterectomy is experienced and that these twin aspects are mediated through, and affect, relationships with key others – female friends and relations, partners and medical staff. The interaction of these micro-concerns and macro-concerns, are shown in Figure 16 and summarised below in the relation to the review questions.

Women's decisions about having a hysterectomy are influenced by their personal experience of symptoms and their understandings of the meaning of hysterectomy in the context of social expectations of women's role. The support or otherwise of significant others (female friends and relations, partners, medical staff) is important but on the whole, women make these decisions for themselves. Male partners are thought to be ill informed about women's bodies and their needs, and couples may avoid talking in detail about hysterectomy. This is exacerbated in cases where women believe there is stigma attached to hysterectomy to which they believe men will react negatively, perhaps even leaving partners who have undergone surgery. While women want to have detailed

information about their bodies, treatment options and risks, symbolic understandings of the uterus and ovaries as markers of femininity, through their role in female sexuality and reproduction, may be influential in decision-making.

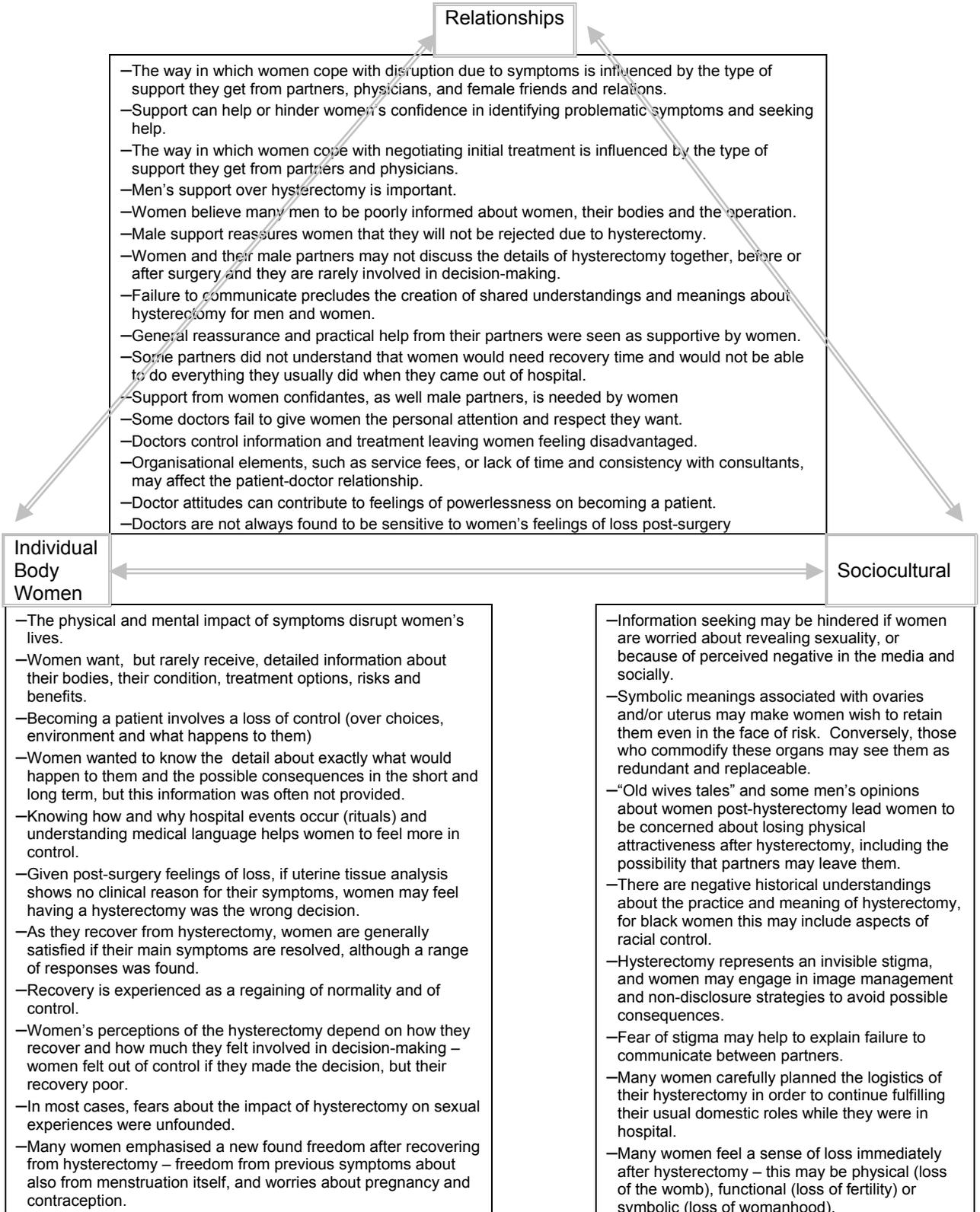
The experience of women undergoing hysterectomy for benign conditions is mixed, and again personal and social influence affect the experience, as do relationships with important others. Women often felt that they did not receive sufficient information about what would happen to them and the possible side effects. At all stages, women want respect and support from physicians, who need to be sympathetic to the complexities of individuals' decisions. Organisational issues, such as lack of consistency in staff or lack of time for appointment can negatively affect the doctor-patient relationship. Loss of control is a common feeling on becoming an in-patient, and doctors may intensify this through control of information and treatment options. Knowing how and why events occur in hospital help women to maintain a sense of control. Knowledge about exactly what happens to them under anaesthetic and what to expect immediately post surgery is very welcome.

Post surgery, many women feel a sense of loss. This may relate to the physical absence of organs, the functional loss of reproductive capability or a symbolic loss of femininity and womanhood. Physicians need to be sensitive to such feelings.

Women often try to maintain their domestic (role) role when going into hospital through, for example, preparing meals for the family to have while they are away. While they are usually able to take leave from paid work, some women found that their partners were not fully aware of the limitations on maintaining this role that would be encountered during convalescence.

Generally, women have a positive recovery if their main symptoms are resolved, and if they can regain a sense of normality. Post-hysterectomy, the freedom from symptoms, periods, and anxiety about pregnancy and contraception should be emphasised. Women may have negative reactions if they feel out of control because symptoms remain, they experience side effects, or they feel that they did not have enough input into the decision to have a hysterectomy and recovery is poor.

**Figure 16: Synthesis summary through conceptual framework**



## **6.10 Dissemination**

As the hysterectomy review has been completed much more recently than the HMB review, I have not yet had chance to present the results other than as part of this thesis. It may be more difficult to disseminate through usual channels of journal articles and conference presentations because it is more complex and much longer than the HMB study. That said, I believe that it is potentially important both to audiences interested in mechanisms of synthesis, especially as meta-study is much less known, but complementary to, meta-ethnography, as well as those with an interest in women's health.

## **6.11 Reflections on the Hysterectomy Review**

Those studies that did not contribute particularly strongly to the theoretical examination of the issues women face, nonetheless provided rich information that tells the story of this journey. Meta-study involves considering how different methodological and theoretical inputs alter the findings of individual study reports. In this case, those studies contributing detail to the story of women's experiences were largely those taking a phenomenological or feminist framework for their approach. Theory that was used here was often limited to explaining a particular aspect of the findings, rather than a conceptual whole. By using Elson's paper, which offers a medical sociologist's perspective, as the index theory, I was able to see where these theories that were more limited in application and development, were supported or challenged. A key example is the use of the Health Belief Model to explain how women make decisions about hysterectomy and oophorectomy. Some aspects of this model, such as evidence that women sought multiple information sources before making their decision, were supported in the synthesis. However, it did not explain why some women felt poorly informed despite seeking advice from multiple sources, or why they communicated poorly with their partners about hysterectomy or why some women valued retaining their ovaries or even part of an ovary. Adding Elson's insights about the way in which hysterectomy and oophorectomy may threaten gender identity, and the resultant feelings of stigma helped to expand on this. It suggests that "factual" information may not be sufficient given that women have concerns about their psychic response to the surgery, and the social status of hysterectomised women. I believe that the synthesis is enhanced by including these different approaches.

It seems to me that one of the unspoken difficulties for assessing hysterectomy is different feminisms and this accounts for some of the difficulties that appear in the synthesis. In almost all the studies, it is felt that removal of the uterus and oophorectomy are qualitatively different from removal of other body parts, so a hysterectomy needs to be treated with more sensitivity than an appendicectomy. However, accepting this perspective operates within biological determinism, suggesting that “femininity” is located in crucial reproductive organs. A quick search for books on hysterectomy on Amazon website reveals any number of self-help books advocating the avoidance of hysterectomy at all costs. They have titles such as *The ultimate rape: what every woman should know about hysterectomy and ovary removal* (Plourde and Plourde, 1998) and *Misinformed consent: women’s stories about hysterectomy* (Coulter-Steel, 2003). But it seems to me that refusal to undergo these organs’ surgical removal, leaves women potentially destined to remain defined by them, and to be defined as “other”, perpetuating a misogynist social culture, including medical culture. In addition, it may mean the continuation of sometimes unbearable symptoms.

Social constructionism, on the other hand, sees female gender as socially constructed as essentially different to the norm, which is the masculine. Women are seen as under the control of raging hormones that produce unpredictability, moodiness and unreliability, and this goes along with a long history of medicine regarding woman as a problem that needs to be fixed. This may be especially true if they suffer from heavy or painful periods – confirming signifiers of the uncontrollable female body. However, removing these organs potentially leaves women as doubly disadvantaged, not only not the male norm, but now not even the female norm. Hysterectomised women may end up pathologised as non-woman *as well as* non-man, whose pseudo female body now needs to be artificially supported by the hormones it now “lacks” in order to simulate “woman”. This has links to radical understandings of “camp” behaviour, as “the lie that tells the truth” (Cocteau). Usually applied to gay men, this could also apply here to women who, feeling reduced to “non-women” status are obliged to artificially recreate, through medical hormonal support and “feminised” behaviour, the women that they really are. Although Elson suggests that women in her sample did not on the whole identify with the notion of gender as performance (Butler, 1993) they *did* manage their physical presentation and behaviour to “act out” their femininity.

Reproductive and (hetero)sexual identities are conflated in these studies. It has been noted that menarche confers sexual visibility on adolescent girls, (Lee, 1994) while

feminist critiques have bemoaned popular understandings of post-menopausal women as invisible sexually. The ambiguous status of menstruation means that it is both an important marker of fertile womanhood, but also a taboo that needs to be concealed. It may be that one of the reasons that HMB is so difficult to manage relates to its potential for making menstruation visible, through leaks, or impact on behaviour. Meanwhile, hysterectomy is a potential cure for the undesirable elements of menstruation, but through ending reproductive identity, may threaten the associated sexual identity.

Dell suggests that the positive aspects of hysterectomy need to be emphasised to counter medical literature as defining post-hysterectomy women as depressed and ill. She suggests championing the “freedom” that hysterectomy can bring – from symptoms, periods, and worries about unwanted pregnancy. Which seems to bring us full circle, since these messy, undeniably corporeal female reproductive functions are precisely those that have been focused on by misogynist objections to the otherness of women.

Elson tries to incorporate these concerns through a call to an embodied sociology, which values both the physical experience and the socio-cultural context, but it seems clear why some women find it so difficult to negotiate the rocky ground of gender identity in relation to menstrual symptoms, hysterectomy and oophorectomy.

The key element of meta-methodology that impacted in the findings was the observation of actual consultations compared to interviews about attitudes and experiences. Ironically, it is possible that the weight of negative popular opinion about women being pressured into hysterectomies they do not want or even need, has caused so profound a change in actual behaviour that doctors are very conservative, and women who really want a permanent solution to their symptoms are left to fight for their much-wanted hysterectomy.

### **6.11.1 Limitations of the meta-study**

This review about hysterectomy used meta-study to synthesise the findings of 20 reports of qualitative research about hysterectomy. Because this project was undertaken as a doctoral thesis, it had to be the work, primarily, of one person. This is a particular limitation in a meta-study because the method values a wide range of experience and multiple perspectives in order to be sure that the influences on research included in the review are recognised and that alternative explanations that may be used as part of the synthesis process are explored. This requires expertise in a number of different

disciplines and experience of different theories and methodology. However, I did produce a synthesis alone, and I hope that the descriptions of how and why the conclusions I made are transparent and can be challenged or endorsed by the reader.

Some of the included studies are very focused, for example, Chapple's description of the different experiences of patients in the NHS and in private practice (Chapple, 1995). This makes their key concerns difficult to integrate with other studies, although individual findings, such as those around patient information needs, are highlighted both in this study and in others. Syntheses struggle to maintain the power and relevance of individual studies, whilst also producing meaningful syntheses across the studies. Getting the balance right may help to avoid producing smoothed over, bland syntheses. For example, these findings highlight particular problems in NHS patterns of care and so may be considered particularly important to UK policy makers. Meta-study may help to avoid this "smoothing over" because it highlights differences between studies and attempts to understand them, as well as focusing on similarities.

I would speculate that, although the theoretical development of some of the study reports used in this meta-study was quite sophisticated, when it comes to mobilising the findings in a practical way, simpler, more thematic descriptions may be found easiest to translate into practice on the ground. For example, information about the optimum process of hysterectomy for women in hospital may be easier to translate into policy or guidelines than those findings which explore women's needs in the context of understanding hysterectomy as a potential challenge to gender identity. Currently, this is a speculative observation, but it does highlight a potential difficulty in translating the concerns of the researcher and those of the policy maker into mutually comprehensible and meaningful information.

The meta-study, despite containing 20 study reports, showed great homogeneity between study concerns, designs and approaches. This was partly because there were a number of study reports from a national programme, the ENDOW study, but also because many studies came from similar disciplines. Perhaps the most obvious gap in the literature is the lack of ethnographic studies that explore the different meanings and linkages between women, motherhood, menstruation and hysterectomy among different cultural groups. The tantalising suggestion that women from traditional Hispanic or Navaho communities are not subject to the same menopausal symptoms as Western women presented by Mingo et al (2000b) is not investigated and ultimately not supported by the presented data,

but it is difficult not to speculate. Traditionally, women are marked as other from men by virtue of blood, and rites of passage in women's life have been marked by it – from girl to women at menarche, and from woman to wife in the marriage bed. Motherhood is accompanied by bloody childbirth. Menopause marks the change to a place outside of blood, which may be a blessed relief and accompanied by socio-cultural privileges (Fonseca, 1996). Such clear ontological pathways are disrupted in contemporary Western societies. Menarche occurs earlier and education continues later, prolonging childhood and creating adolescence. Meanwhile, sex and marriage are uncoupled and menstrual blood may be contained or even stopped through medical control of fertility (contraception). Further medical intervention, such as increasing rates of Caesarean sections, change the birth experience. Menopause may be artificially offset with HRT or hastened with hysterectomy. These changes create and are created by increased flexibility in women's roles and identity.

Problems that may be encountered with identifying relevant study reports are a consideration in these reviews. For example, Chassé's research report uses a narrative framework, where the stories women told are the basis for analysis. In most cases, women began their tale by describing the symptoms of HMB; what these were like and what led them to seek medical help. Clearly, these details are relevant to the HMB review. However, this study was not identified through the searches for HMB given that the title emphasised hysterectomy, not HMB and, as a book chapter, no abstract was available. As the hysterectomy review progressed, I began to think that a fuller understanding of hysterectomy might be gained by including studies about oophorectomy alone or about menopause, given the centrality of these issues in the eventual synthesis report. Given the project restrictions of time and person power, this was not possible.

## **Summary**

This chapter has described the methods and outputs of a meta-study about hysterectomy. For reviews that contain studies from a number of methodological and theoretical perspective, meta-study has the advantage of providing a structure for understanding findings in the contexts that produced them. This is not available when using meta-ethnography alone. Through the review I have provided new concepts not available in any one study and offered explanations for differences between them. The synthesis produced a detailed description of the journey that women experience when they undergo hysterectomy for benign conditions. The theoretical framework highlights the need for the

personal, physical experience of hysterectomy to be understood in the context of socio-cultural understandings of womanhood and femininity. The interaction of these personal and the cultural concerns affect, and are effected by, relationships with key others. Meta-theory showed the limits of considering decision-making without awareness of the cultural context in which such decisions are made. Methodology affected the questions asked by research, and the answers produced. Fears about being pressured to undergo surgery or reports of such pressure observed in interview studies among women where not borne out in the study that actually observed examples of consultations leading to hysterectomy.

In the next chapter I will address in detail the different approaches to synthesis that have been used for the syntheses of hysterectomy and of HMB. I will also consider whether these syntheses of qualitative research findings might enhance a traditional systematic review of quantitative research, and how they may be of use to different audiences, such as clinicians, academics and policy makers.

# 7 Discussion

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In the previous two chapters I have reported two novel reviews using different methods, about heavy menstrual bleeding and about hysterectomy for benign conditions. In this chapter I consolidate my findings. In Section 7.1 I first explore what these reviews contribute to the debates outlined in Chapter 4 concerning the procedures of systematic reviews of qualitative research. Section 7.2 considers the implications for researchers of this research in terms of both methodology and topic. It outlines the potential for my comprehensive framework for good practice in the conduct of systematic reviews and then compares the methods of meta-ethnography and meta-study, before considering what has been added to the reproductive health topics examined. In section 7.3 I consider the implications of my experience for policy makers.

## **7.1 Contribution to Debates about Systematic Review of Qualitative Research**

### **7.1.1 Purpose of review**

Through the synthesis of existing research findings, systematic review of qualitative research has the potential to develop greater understanding of, and contribution to, a body of knowledge. As discussed in Chapter 4, many people involved in developing methods of review and synthesis are particularly concerned with how their findings may be used to inform policy-making and this provides a central drive for their scope and focus. My interest in undertaking both these reviews was to explore and compare the methods, so my aims were slightly different and this might be seen as a weakness. However, as discussed in Section 5.1, I also took a Health Technology Assessment (HTA) and the questions that it precipitated, as a starting point for my thesis, and this remained a concern throughout the project. The impact of this will be discussed in Section 7.2.

### **7.1.2 Defining the research question**

My research questions were formulated both from my experience of undertaking the HTA report on HMB, and were in response to the findings of the included studies. So, for

example, the hysterectomy review developed a focus on decision-making about hysterectomy due to the number of papers that focussed on this subject. This responsiveness to existing material may not always be appropriate. It seems fitting that reviewers remain flexible about research questions in order to ground their findings on the literature, just as primary research aims to develop theory from what is said by participants. Depending on the type of review, however, some types of questions may need to be more focussed to address a particular query or area of concern. This is a potential tension between researcher and policy-maker priorities that may need to be negotiated. It is possible that no existing research relating to the policy makers' initial questions will be found. This could lead to primary research being commissioned or to further iteration and negotiation around the question to be addressed in a review. This process may help to clarify both researcher and policy maker focus.

### **7.1.3 Research designs included in the review**

One of the main queries among those who are investigating methods of review, is whether or not different types of research, from different traditions and perhaps focussing on slightly different research questions and methods of inquiry, can be meaningfully synthesised. This variation, or heterogeneity to use the term from meta-analyses of quantitative research, has been called "the central problem in research synthesis projects" (Sandelowski, Voils & Barroso, 2007). Both examples of synthesis in this thesis included different types of qualitative research, and through the process, I came to agree with Sandelowski and Barroso's observation that study methods may be regarded differently within different traditions. In many cases, the research approach is undefined, and open to interpretation. In other cases, it is not clear from the study report how a cited approach has influenced the conduct or analysis of the research. An example of this is the paper by Mingo et al (2000b) which reports using ethnographic interview techniques, without providing further details. There are no obvious differences in the conduct or analysis of the focus groups between Mingo's study and other, non-ethnographic studies in the review that also utilised focus groups.

The experience suggests that it would be very difficult to make firm boundaries around what is or is not any particular type of research, and many studies do not provide a definition of their methods or influences. For these reasons, trying to exclude study reports on this basis would be very difficult, and could reduce the usable evidence base. Despite apparent differences, I believe there are more similarities than differences in the

way that most of the included research is undertaken, and in any case, the example review suggests that it is possible to synthesise across traditions.

The study reports included in the hysterectomy review have different foci; concentrating on decision-making, descriptive phenomenology, exploring gender identity and so on. Meanwhile, the methods, despite a variety of stated approaches (ethno-nursing, phenomenology, grounded theory) actually looked very similar in terms of content, form and mechanisms of interpretation. This has been noted previously in other syntheses; Sandelowski et al (2007) stated they found “less methodological diversity but more topical diversity” than they expected in an investigation of methods to synthesise quantitative and qualitative studies.

The Joanna Briggs Institute (JBI) suggest that only studies which are “of use to practice” should be included in a synthesis of qualitative research (Pearson et al., 2005). I would find this suggestion difficult to implement on the basis of my experience. From the work here, I cannot determine at what point it would be clear that any paper was of no use to practice, or indeed, of no use to policy. In the meta-study, many of the nursing studies produced narratives describing the hysterectomy through presenting the patient journey which could, superficially, be seen as the most relevant to practice as it sensitises practitioners to expectations, fears and concerns. It also highlights some crucial clinical aspects, such as the kind of information that women wanted, when this is best delivered, and their experience of the immediate post-operative period. I suspect that the JBI are trying to exclude the more theoretically focused studies. In the meta-study example, I suspect that this mechanism may have led to the study reports by Dell, which took a constructionist, feminist approach, being excluded (Dell & Papagiannidou, 1999; Dell, 2000). However, Dell’s study helped to illuminate the way in which expectations of any procedure, particularly a gendered one, may be negatively constructed and offered positive ways to disrupt this.

On the basis of my experiences undertaking these two reviews I believe that all relevant qualitative research on a topic should be included in a review and that it is possible to synthesise research reports resulting from different types of qualitative research. It may, in any case, prove difficult to agree on which studies use the same method.

#### **7.1.4 Search strategies, sampling and inclusion**

##### **Searching for relevant studies**

As discussed in Chapter 4, the authors of different suggested methods of review are divided about the importance of trying to identify and include all available qualitative research reports on any topic in a synthesis. I attempted to identify all the published reports of qualitative research for both examples of synthesis reported in this thesis. However, after they were completed, I found that I had not managed to identify all relevant study reports despite extensive searches and tracking bibliographies. Details from the development of the NICE guideline, available after these syntheses had been completed, showed that they had identified three qualitative papers about HMB, one of which I had excluded at the abstract stage of my search because it was about “menstrual symptoms” rather than HMB explicitly (Byles, Hanrahan & Schofield, 1997). The other two were not identified by my search strategy. Conversely, one of the papers included in my review had not been identified through the searches by NICE (Elson, 2002).

For the hysterectomy synthesis, the NICE guideline included seven qualitative papers, four of which I included in my review and three I did not. One of these I excluded at the abstract phase because the interviews were used to clarify or validate two existing measures of control in decision-making and I did not feel that this reflected the concerns of my review. Two others were not identified through my searches, while 16 of the study reports included in my hysterectomy review were not included in the NICE guideline. This lack of consistency in identifying reports of qualitative research on the same topics is potentially worrying, however, the NICE search strategy did not search social science databases which may explain why I identified more study reports.

Searching remains a key problem in the synthesis of qualitative research. It remains unclear what sort of bias might be introduced by failing to identify all the available literature. With more time, the studies I did not initially identify could have been included, although trying to thread a new study into an existing synthesis might prove challenging. Although it was not possible in the time frame to redo the HMB synthesis containing the “missing” paper, a quick assessment suggested that this was another largely descriptive paper which would not have substantially altered the synthesis findings, but rather would have confirmed existing information from other included study reports that had been used to detail the lay model of HMB. However, if it had been a conceptually well developed paper this might have had a greater impact on the synthesis. I would argue that every

effort should be made to identify all the relevant study reports. The most conceptually well developed reports are the most pertinent to include, but it is not easy to identify these at an early stage.

It is to be hoped that continued efforts to improve indexing and reporting in electronic databases together with increasing experience among information scientists conducting such searches, will assist identification in the future. In the meantime, every effort should be made to supplement database searches with alternative methods, such as hand searching and contact with experts, to identify study reports. The previous reviews by Campbell et al., 2003 and Pound et al., 2005 both showed that qualitative researchers rarely referenced other similar work. It may be that they are unaware of it. Improved indexing would allow primary researchers, as well as reviewers, to identify work on related topics more easily. I believe that this is important if qualitative researchers are to avoid isolation. In addition, it will allow a body of work to be developed, and prevent unnecessary repetition of research. More research into and experience of effective identification of qualitative research from within the information science community would also be helpful.

As more systematic reviews of qualitative research are undertaken, search strategies will also need to identify these. There is a proliferation of terms used for such reviews which may prove challenging. In a deliberate act to try and improve identification through searching, a recent meta-ethnography used the term “qualitative meta-analysis” (Feder et al., 2006) and another, published in the *Lancet*, used “qualitative synthesis” (Smith et al., 2005). This terminology has the advantage of also making it likely to be picked up by searches looking to identify quantitative research. However, it may also add to methodological confusion in the literature, for example, a “qualitative synthesis” sounds as though it could be a non-statistical way of synthesising quantitative data. Descriptions which describe the process as a systematic review of qualitative research would be picked up by searches for both qualitative and quantitative research, and could be supplemented by a specific or generic description of the specific method of synthesis.

### **Determining inclusion criteria**

When starting the reviews, I felt that my inclusion criteria were very broad, since I included anything that was qualitative research of any sort, and which was about the general topic of HMB or hysterectomy respectively. However, I became less sure of the best way of dealing with inclusion as each project progressed. Once I was immersed in the

hysterectomy review, it seemed clear that, given additional time, the synthesis could have taken a different, and potentially fruitful, direction if it had also included studies about related topics revealed through the process of synthesis as important. For example, cultural meanings attached to the ovaries, rather than the uterus, as key markers of gender and gender difference, were found to be important and these meanings impacted on decisions about their removal or retention. This finding had not been anticipated. It might have been profitable, given more resources and time, to include studies that focused specifically on oophorectomy. Initially, such studies had been explicitly excluded, and it was not possible to revisit this decision in the time scale of the project. In addition, decisions about oophorectomy were also informed by understanding and perceptions of HRT, which were related to women's fears and expectations around menopause and aging. These understandings of HRT in turn linked into perceptions of women's role and identity, and how hysterectomy and oophorectomy challenged these perceptions. Again, it is possible that including studies about HRT would have resulted in enhanced understandings, or broader concepts in the review. However, broadening the inclusion criteria in this way would have resulted in a huge synthesis about gendered diseases related to menopause and aging. Where it is possible that the review focus may shift in response to material, the need for a multidisciplinary review team that contains topic specialism is highlighted.

The identification of additional areas for research may be endless, with each selection producing new, unanticipated directions and ideas for further work. It remains important to draw realistic boundaries around what is feasible and practical. This would effectively look at gendered life stages which could form a neat and informative future project. For researchers, pursuit of expanding topic areas will remain a matter of judgement and practical consideration. Revisiting and revising the direction of any review may be the ideal, but pragmatism for researchers may have to prevail. In addition, the concerns of policy-makers may help guide review focus.

One study in the hysterectomy synthesis was conceptually more sophisticated and well developed than other included study reports, and was used as an index paper against which the other study reports were compared. This study explored how hysterectomy affected women's understanding and experience of gender identity. Again, studies focussing on ill-health in women, or on other gender specific conditions, could have added more to this element of the synthesis. For example, conditions and treatment such as breast cancer and mastectomy, sexually transmitted infections or infertility might give

additional information about how such conditions affect perceptions of gender identity. Focusing reviews through social meanings of illness rather than clinical topic areas could be particularly useful for specialist practitioners who are likely to be familiar with groups of similar disorders, and this is not restricted to gender. For dermatologists, for example, a review could investigate similarities and differences revealed through patient concerns about the appearance of several conditions, such as eczema and psoriasis.

In addition, women's identified desire for elements such as supportive partners, and for respectful, responsive doctors are not likely to be restricted to consultations about HMB and hysterectomy, or even to gender-specific conditions. Similarly, some of the hospital experiences related to having a hysterectomy may be generic to many patients undergoing surgery as an inpatient.

Another issue relating to inclusion criteria focuses on the way projects may be written up in the public domain. Qualitative research projects usually produce a large volume of primary data which, in turn, may produce a large volume, or depth of findings. The outputs from such studies may be very varied, depending on the amount of time researchers have to devote to analysis and writing, the demands of the funding body and the type of project undertaken. For example, funding bodies may require a full, in-depth project report. This large report might be split into one or more shorter papers to be published in journals. However, these shorter papers are unlikely to have the same breadth or depth of coverage as the full project report and so will provide more limited details about findings, analysis or theory. Similarly, studies undertaken as post-graduate projects will result in a thesis, but shorter papers may also be published. These longer project reports and theses may be more difficult to identify and obtain than the fully published papers, and these latter publications may also be more trusted from a quality perspective because they have already been through a peer review process. The British Library is beginning a project to publish frequently requested theses online, and some individual university libraries are also starting to provide electronic access to theses. Both of these measures would increase accessibility but may bring additional problems. Publication bias is a clear possibility with the British Library strategy, and this could become self-perpetuating, by making less frequently cited theses even less visible.

My reviews used fully published study reports only, due to time constraints as well as validity concerns. It is not possible to know, however, in what way the synthesis would have been altered if more detailed project reports had been identified and included. It is

possible that such reports would contain more conceptual sophistication, but it is also possible that they may be less worked through – certainly such grey literature is unlikely to have been peer reviewed. Clearly trying to synthesise a number of very full research reports would have big implications for the resources required for a review, and may be too extensive to meaningfully synthesise. Exploring the impact of using unpublished study reports is an area for future research.

### **7.1.5 Quality appraisal of research reports**

Based on the experience of previous meta-ethnographers, I took the decision not to use formal checklists for assessing quality indicators in the meta-ethnography (Campbell et al., 2003; Noblit & Hare, 1988). However through the syntheses I gave more value to studies that were more theoretical, using or generating complex explanatory interpretation. I implicitly conferred on these studies more credibility and potential transferability, since generalisations could be made and tested in other contexts. Instinctively then, I opted for elements of parallel perspective on quality assessment in qualitative studies (see Section 4.5, p.96). This is interesting as one of the criticisms of the parallel perspective on validity has been that it may lead to over-reliance on the report of technical, rather than substantive, matters: but this was not the case here.

More complex theoretical studies could be mapped onto Sandelowski and Barroso's classification of types of qualitative study where study reports that show the greatest transformation of findings from the data are valued because they have the most explanatory power (2007) (see Section 4.6.2). In the example of the HMB review it was clear that the most theoretically sophisticated paper was the most influential in the synthesis. It was used as the index paper and provided the framework against which other study reports were explored.

In the meta-study, I used the suggested data extraction and quality assessment questions recommended by Paterson et al 2001 (see Appendix 9.2). Using the distinction that Popay makes, these forms contained information about three distinct types of quality indicator (Section 4.5 p. 96). Questions therefore explored technical concerns, such as whether sampling procedures were fully described; epistemological concerns, such as whether the findings clearly flowed from the provided participant quotes; and theoretical concerns, such as whether a conceptual framework was identified. Completing the forms was time consuming, however, and I found this more useful as a reading guide, or

sensitiser, than a quality assessment process. It was not at all clear whether or how this process might be used to inform the synthesis. Again, the conceptually most well developed study report had the greatest weight in the synthesis. One problem here is the possibility that greater detail was available because the study was published as a book with expanded possibilities for describing the project methods and theoretical content. Most other study reports were in the form of journal articles, and restricted space may have limited the amount of detail that could be provided.

### **7.1.6 Methods of analysis and synthesis**

Meta-study includes meta-ethnography for the meta-data analysis stage of analysis, but it also adds dimensions to the understandings of a review. After working on the meta-ethnography of HMB for some time, and producing different versions of its description - for meetings, for a conference audience and ultimately for a journal article, I began to wonder if I had been over harsh in my initial depiction of the 1999 paper by Chapple. I felt the analysis lacked depth, and was disturbed by the author's lack of reflexivity when investigating the experiences of South Asian women. Further, I felt some of her conclusions were not backed up by participants' quotes and, crucially, that her use of Parsons' "sick role" had not been developed, appearing almost to be mentioned in passing. I therefore dismissed this use of the sick role as not meaningful in the analysis. However, through presenting and re-presenting this synthesis, I concluded that the meta-ethnography could in fact have been conducted through the lens of the "sick role" and HMB, and that doing so could have been revealing. Using the sick role in the synthesis would have required considerably more input from me to apply the theory to this context and try to explore how it might be used to understand women's experiences of HMB. At the time, I was unsure that such extensive re-interpretation of the original study findings was legitimate within the framework of meta-ethnography, and I remain uncertain that it is. Now, I realise that it would have been possible by using meta-study methods which could have given greater flexibility to explore undeveloped concepts in the synthesis.

Meta-study explicitly allows for an imported concept to be used as a mechanism of exploration and of synthesis. For example, the concept of the sick role regards illness as a social construct governed by rules of rights and responsibilities. Women in the included studies identified interruption to their every day life (including their social roles) as a key part of interpreting their bleeding as unacceptable. Such an interpretation of HMB fits with Parsons' idea that people might be excused from normal activities if they were ill, providing

that they then tried to get better by seeking appropriate help (Parsons, 1951). However, part of the problem women face is a lack of fit between the sick role and women's roles generally. Women described feeling that they were *not* permitted to opt out of their social roles, especially traditionally female ones of childcare and domestic duties. Such a finding could be seen to challenge Parsons' understanding of the sick role which allows those occupying it to be excused from their usual social obligations. The model of the sick role has previously been criticised for not accommodating chronic illnesses that may need to be *managed* rather than *cured*. HMB can be understood in this context. Within this framework, we could interpret hysterectomy as a treatment for HMB as having particular legitimacy with health professionals because it offers a "cure" (the end of bleeding), rather than a management strategy.

Another breakdown point between women and clinicians may come if the doctor does not recognise a woman's symptoms as representing "true" HMB (as understood by the clinical definition of >80ml of blood loss) and so she is denied a legitimised sick role. Women may be very dissatisfied if they do not experience the doctor-patient relationship that they were expecting. In terms of the sick role, they have reason to expect that assistance will be forthcoming if they seek medical help, and plan to follow the resultant advice.

This discussion briefly considers how meta-study might have been used to develop an alternative exploratory synthesis of the HMB papers. Meta-study, however, does permit additional explanations and possibilities and through allowing imported concepts to be used, permits more obviously interpretative input by the synthesisers. Whether greater freedom to import concepts as part of a systematic review is seen as a positive or a negative thing may depend on the readers' ultimate expectations, their comfort with obviously interpretive research and their degree of alignment with the final arguments. It also brings into sharp relief the interpretive nature of these reviews. While I stand by my interpretations of the HMB evidence, consideration of HMB in the context of the sick role clearly shows that alternative, or at least additional, explanations are possible.

Another example of a different method of synthesis can be seen in the NICE guideline for Heavy Menstrual Bleeding (National Institute for Health and Clinical Excellence, 2007) which uses a purely thematic analysis of included qualitative research and reports studies' thematic findings. Such a thematic analysis does not distinguish between first order and second order concepts in reports of primary research, so that the findings from descriptive

papers are given the same weight as more conceptually well-developed reports. Meta-ethnography, by contrast, allows for a synthesis at the level of second order concepts.

One paper included in the meta-study (Marchant-Haycox and Salmon, 1997) came to conclusions about how women find the clinical encounter that were directly opposed to those of other study reports. How much weight should be given to this paper was not initially clear. Potentially, it is extremely important but, as others have noted, synthesis tends to give cumulative weight to findings, with more certainty or validity felt to accrue if more study reports confirm a similar finding. In this case, the use of meta-study was crucial. It allowed weight to be given to these different findings, because it recognises that similar findings may simply be the result of similar methods of enquiry, coming from similar theoretical perspectives. This means that the Marchant-Haycox and Salmon paper can be given *additional* weight rather than less in this type of synthesis, because of the unique nature of both its methods and its academic discipline among the included studies. This allowed me to suggest, if not actually conclude, that women seeking relief for unacceptable menstrual symptoms are not the victims of some patriarchal medical hegemony, but are agents who use sophisticated and determined methods to receive a treatment they want. Furthermore, it paved the way for the possible conclusion that hysterectomy is not a butchery practiced on an unwilling victim by an uncaring surgeon, but may be a much wanted solution, that is performed only when the doctor is convinced that it is really demanded.

### **7.1.7 Assessing review validity**

It is difficult for me, as the author, to judge the validity of my own syntheses. Credibility is a crucial potential element of the validity in qualitative research, but must be judged by the reader. I hope I have provided enough detail about the included papers and their findings for a judgment to be made about the trustworthiness of the synthesis. In addition, trustworthiness may be judged through readers' assessment of my interpretations of the included papers, which are publicly available. I am now certain that, in both cases, I have produced a genuine synthesis, where new information is generated through reinterpretation of a body of findings through the lens of the whole, and, in the meta-study, the creation of a sociological conceptual framework with which to view the findings. It seems likely, however, that the conceptual framework, and so the synthesis, might have looked different if the primary researcher had come from a different academic background, for example a psychologist or a clinician. It is impossible to negate personal expectations

which are brought to any reading of a study. For example, the traditions of nursing research, which often focus on individual aspects of reports that are meaningful in nursing or other health service practice, may be different from those of sociologists, who frame individual experience in terms of broader socio-cultural forces. But the unfamiliar studies may be more useful or credible to those operating within similar traditions. This has been noted by other synthesisers:

*Disciplinary anxiety arises from the recognition that the acceptance of studies as credible is dependent on the judgements of the disciplinary communities (eg, nurses, cancer researchers and clinicians) to which researchers belong and want their studies to appeal (Sandelowski, 2006).*

It is important for reviewers to be reflexive about their own relationship to the study reports that are included. In addition, involving people from different disciplines within the review team will allow differences across traditions to be accommodated and explained both within the team and in the review write up. It might also mean that competing theories are more likely to be considered for the synthesis and for the reasons why a particular theory is ultimately used to be more fully articulated.

In the future, a number of methods might be used to try and assess the quality of the synthesis. As Feder et al (2006) did, a copy of the synthesis could be sent to the authors of the primary reports to ask if they felt it was a good representation of their findings. Alternatively, some future reviews relate to live projects that are feeding into policy-making, including in NICE. The impact could then be evaluated. However in both these cases, a rejection of the synthesis findings could be due to reluctance to accept the systematic reviews of qualitative research *per se*, or due to a disagreement with the review conclusions, as well as being due to specific concerns about the way in which studies are interpreted. Following the framework for good practice outlined in Chapter 4 should help avoid this with policy makers, as it emphasises the need for communication and iteration with the policy makers as well as suggesting strategies to enhance the quality of the review itself, such as multidisciplinary team, reflexivity, creation of an audit trail, multiple team members involved in decision making and so on.

Existing debates about judging validity reviews of qualitative research were outlined in Section 4.7. Where possible, I followed Paterson et al's (2001) suggestions for remaining "analytically honest". Although it was not possible in the confines of this PhD thesis to involve three independent researchers in the analysis as they suggest, elements of

identifying and extracting data for the HMB synthesis did show strong agreement between myself and my supervisors. Other aspects of validity, such as seeking out disconfirming cases, are already part of the meta-ethnography process, as refutational findings are identified.

In addition to being reliant on the prior research of others, the reviews I carried out are also crucially reliant on me as a researcher. For example, I felt relatively comfortable with leaning heavily on the ideas used by Elson (2004a) in the hysterectomy synthesis, but I am aware that this is, at least partly, because they conform well with my own experiences and beliefs as someone who has studied cultural and social forces in gender and sexuality and who takes a sociological perspective when considering health and illness. It is likely that if a clinician or a psychologist, for example, were to undertake the same synthesis, they would use a different framework. As mentioned above, this is a weakness of the synthesis – having only one person undertaking the work limits the chance for alternative view points and interpretations to be accommodated.

## **7.2 Implications for Researchers**

This thesis has a number of key implications for researchers engaged in the review and synthesis of qualitative research which are outlined in this section. My comparative review of suggested methods for the review and synthesis for qualitative research that forms Chapter 4 resulted in a novel framework for good practice (Table 5, p. 25) which I evaluated through the two reviews. Benefits and disadvantages of the two methods used in these reviews, meta-study and meta-ethnography, have been identified, offering methodological insights, as well as those specifically relating to the reproductive health topics on which they focussed. Finally, some of the methodological findings may be relevant to all systematic reviews, not just those of qualitative research.

### **7.2.1 Lessons from using the framework for good practice in the conduct of systematic reviews**

#### **Systematic Reviews of Qualitative Research**

The comprehensive framework for good practice shown in Table 5 is a superset of the best elements of the methods for the review and synthesis of qualitative research suggested from the ten methods critically reviewed in Chapter 4. Where possible I

followed these steps in my reviews. As they were carried out as part of a doctoral thesis, it was not appropriate or possible to adhere to all the elements of the framework. This is likely to be the case for most projects, with the framework representing a “wish-list” for best practice, while in practice full compliance with all elements is neither desirable nor practicable. For example, my work was based on *perceived* evidence gaps for policy makers, so any reference in the framework to negotiations with commissioners or end users could not be utilised. Other studies may not have a policy focus or may not find it possible to gain funding where the protocol is not finalised prior to the project commencing. In addition, as noted elsewhere, it was not possible to employ a multidisciplinary team to work on my reviews, and this is probably the aspect of the framework that I would in future be most keen to ensure was in place, in order to explore competing interpretations of the data, and mechanisms of synthesis. I remain convinced that more robust and valid syntheses should result from such teams. However, other key steps of both projects were definitely enhanced through use of the framework. In both reviews, the research questions were developed through my own interest and a perceived potential use for policy makers. Scoping searches identified reservoirs of information that were not initially anticipated – such as the volume of research about decision making and hysterectomy – which allowed the focus of the review to be expanded to include this information. Similarly, if an unmanageable amount of research on a broad topic had been identified, it would have been possible at this stage to refine the area of interest, or identify several separate, more focussed reviews in the area.

As discussed in Section 7.1.4, I discovered after the reviews were completed that my searches had not identified some of those identified for the NICE HMB guideline (and indeed, *vice versa*). This was despite supplementing electronic databases with citation tracking and hand-searching. Given that I found low levels of referencing between the studies, this may not be surprising. Future reviews should investigate the impact of using additional suggested methods such as contacting experts in the fields, although it is possible that this will reveal a similar lack of awareness of related research in relevant areas.

In the meta-study, articulating a conceptual framework was a key part of the synthesis. It was both a product of the synthesis and a tool for undertaking it. I was not able to usefully articulate the basic framework (shown in Figure 9, p.125), however, until the initial assessment and analysis phases of the project. Paterson et al. (2001), by contrast, suggest developing “workable definitions of key subjects under study” at the scoping stage

of the project and identifying a conceptual framework for the project when relevant literature is initially identified. Although these phases of the project clearly overlap and inform each other, I suspect that the framework will emerge rather later in the assessment and analysis phases of the review than suggested by Paterson et al. The exception might be where members of the team are already very familiar with the literature and a known imported conceptual framework is used, as was the case in the chronic illness project through which Paterson and colleagues first tested the meta-study method.

I found the four interlinked steps of analysis and synthesis articulated in the framework for good practice (initial assessment of study reports, analysis, preliminary and full synthesis) particularly helpful in undertaking this stage of the review. This was true in both syntheses but particularly so in the meta-study, with its large number of more complex papers. Structured forms are vital for data extraction and, where used, for recording information about quality indicators. It is also useful to establish early on which methods and theories were employed, whether these are implicit and, where they are explicit, if the reviewers agree that those stated are in fact the ones used. Crucially, the techniques suggested by Popay et al (2006) to manipulate and juxtapose data during initial analysis and preliminary synthesis were extremely helpful. Although interpretative skills of the researchers are still required, these practical tools were invaluable in these initial analytic stages.

### **Systematic Reviews of Quantitative and Qualitative Research**

It is likely that the comprehensive framework for good practice could be used for systematic reviews that include mixed methods, or focus on quantitative evidence, as well as for those focusing on qualitative research. Reviews informing policy-making might particularly benefit from the collaborative style and iterative approach to question formulation, searches and inclusion criteria. The ability to explore and map potentially relevant questions and the related available evidence is likely to be valuable no matter what type of research is to be included and it is hoped that this would avoid misunderstandings or disappointments where the evidence base and policy makers' initial questions are not a perfect fit. In addition, assessments of complex interventions may also benefit from a clearer awareness of theory. In this case, understanding the theoretical informing the mechanisms through which interventions are expected to work will allow a more careful examination of the processes which contribute to success or lack of the success of an intervention.

The methods of initial analysis and synthesis described above are also likely to be useful for reviews of quantitative data – especially if RCTs are not amenable to statistical pooling, or where other data from different study designs, including mixed quantitative and qualitative data are included. It is helpful to understand the processes through which data of any sort is manipulated, presented and juxtaposed as crucial steps in any synthesis.

Finally, the good practice framework suggestions for dissemination would also benefit all types of systematic reviews. It is just as important for meta-analysis to be presented in ways that are meaningful to diverse and non-specialist audiences, and may be more important where statistics need to be described and interpreted. In particular, it is important that any limitations of review findings are understood.

### **7.2.2 Comparison of meta-study and meta-ethnography**

As discussed in Section 7.1, the experience of undertaking these two reviews using different methods has offered insights at each of the stages of review. However there are also key differences between the two methods. Meta-ethnography is primarily a method of synthesis and was not conceived in the context of established methods for systematic review of quantitative research, whilst meta-study is more in tune with these existing methods and debates around expanding the application of systematic reviews. Meta-study offers useful inputs into many stages of the comprehensive framework for good practice shown in Table 5.

Meta-study allows meta-ethnography to be used as the technique for meta-data-analysis (as I did here) while adding the dimensions of meta-method and meta-theory. The greater awareness and use of theory in meta-study means that theory is more prominent in the analysis. Findings may become transferable at the level of theories and concepts. In addition, theories are tested through the synthesis to established how they have been used and how successfully they have been used, as well as whether they can be subsumed by other, competing theories or may themselves encompass other theories used in included studies.

Different methods of quality assessment are suggested by meta-ethnography and meta-study, with the former emphasising that the value of studies should be judged through their contribution to the synthesis and latter using an extensive checklist. However, I found in both cases that the most conceptually developed study report contributed most to the

review. The quality checklist allowed consistently applied assessment criteria to be recorded but did not influence the way in which the synthesis was performed.

The crucial difference afforded by these additional steps is that meta-study offers a way of extending meta-ethnography through a structured mechanism to consider how research findings are produced in relation to authors' use of methods and theory. This allows the mechanisms that shape studies and their findings to be revealed. While meta-ethnography does allow different findings to be highlighted through the refutational synthesis, in practice, similar findings between studies are likely to be given more weight. In effect, repetition of similar findings is likely to be seen as validating:

*Just the place for a Snark! I have said it thrice;*

*What I tell you three times is true.* (Carroll, 1939)

Where similar findings are noted in a synthesis, these are assessed in a meta-study in terms of the methods and theory that produced them. This allows findings to be seen as constructions, which may be similar because they lack innovation - being produced by similar research techniques among similar populations and analysed according to similar theoretical standpoints. In such cases, they may not be seen to add cumulative weight to the findings. Rather, greater validity may be inferred if similar findings are seen despite *different* research methods. Similarly, a single study with refutational findings may be given as much weight as several studies with reciprocal findings, where the former are produced through different research approaches and the latter use similar.

Meta-study explicitly allows for theoretical frameworks to be imported by the reviewers as a way of understanding findings and of producing the synthesis. This allows greater flexibility in the synthesis and for researchers' knowledge and skills to be utilised to a greater extent. However, it also highlights the interpretative nature of the review as it is not bound by structures existing in the included study reports. Larger, multidisciplinary teams which include subject experts as well as methodological experts will enhance this process through familiarity with a greater number of explanatory frameworks, which would allow these to be tested and the best to be used.

Given the awareness of how findings are constructed, and the flexibility afforded in interpretation by allowing theoretical frameworks to be imported, meta-study highlights the potential variation in reviews carried out by different teams. Uncertainty is seen in both the interpretation of primary research findings and the way that the synthesis is conducted and

expressed. It is possible that this may be less acceptable to those who are more familiar with traditional systematic reviews, and researchers will need to be sensitive to ensure that the way they conduct the review and synthesis also includes an assessment of how validity and reliability might be established. This may include outlining the value of multiple opinions at all stages of the review, evidence of testing competing theories and the creation of comprehensive audit trails that record the reasoning for decisions made during analysis. Continued communication and negotiation with commissioners and end users will also be important.

### **7.2.3 Implications for reproductive health researchers**

As well as producing the new insights described in Section 5.6 and 6.9, the reviews of HMB and hysterectomy may also be used to identify areas for future research in these areas. The meta-ethnography of HMB showed that several studies had been undertaken assessing which symptoms women found problematic and these were synthesised to develop a detailed lay model of HMB. There was much similarity in the symptoms identified across different studies, suggesting that this is now a “saturated” category which is unlikely to be elaborated by further similar primary research among similar populations. These findings should help both researchers and practitioners understand which symptoms may be troublesome and may help targeted treatment.

The HMB review also identified factors influencing women’s understanding of their symptoms as requiring medical help. Refutational findings were identified about women’s confidence in their own experiences and about support from others. Future research could explore what influences these opposing viewpoints.

The meta-study of hysterectomy showed the importance of understanding women’s experiences of hysterectomy, including decision making about hysterectomy, should be understood in terms of macro- as well as micro- forces. Crucial concepts include understanding the symbolic meanings attached to the womb which influence women’s opinions about hysterectomy, and associated fears of stigma and of loss.

Areas of future research could address existing gaps in the literature such as a lack of understanding how different ethnic communities understand heavy bleeding, hysterectomy, and menopause.

## **7.3 Implications for Policy-Makers**

This section considers the implications for policy-makers, particularly in the context of HTA.

### **7.3.1 Reproductive health**

As described in Section 5.1, I became interested in the topic area for the reviews undertaken here through a HTA about heavy menstrual bleeding. Undertaking the HTA had produced a number of unexplored areas which I felt were important but not understandable through quantitative research or its synthesis:

- Definitions of HMB
- Experience and impact of HMB
- Issues of patient preference for and expectation of treatment
- Defining treatment success
- The experience of being assessed and treated for HMB within the health care system.

The reviews have successfully addressed most of these areas. In particular, the reviews have provided good detail about women's experiences of HMB, its impact on their lives, how they come to define their bleeding as problematic and about the experience of being assessed and treated in the health care system. Definitions of treatment success, both in trials and in practice, could be developed from these understandings about the elements of HMB that women find most distressing and disruptive. They may also contribute to understandings of heterogeneity between women's treatment choices and expectations by highlighting the importance of different personal, socio-cultural and relationship contexts. The meta-study of hysterectomy shows that women's experiences need to be understood in the context of micro- and macro- forces which shape it as a gendered experience, and that mean it may be experienced as a threat to femininity and womanhood.

No formal attempt was made to synthesise the findings of the reviews in this thesis with that of the original HTA review of quantitative data. This could form a future project, as the HTA would require updating. The qualitative findings do appear to bridge some of the gaps in the original HTA. The meta-ethnography produced a definition of HMB based on

women's experiences and concerns, and which could be used to challenge the currently used measures of HMB and the associated trial outcome measures.

One of the concerns I had after completing the original HTA report was the use of amenorrhoea as a key outcome measure in trials of treatment for HMB. The findings of the meta-ethnography of HMB could certainly provide direction for the development of alternative, women-centred outcomes or quality of life measures for trials – reduced sanitary protection requirements, for example, or less fear of leaks or less interference with women's usual activities. As with any review, however, the conclusions are bounded by what already exists, in both the qualitative and the quantitative literature. In this case, establishing that blood loss or its elimination might not be the most important element of HMB for women does not really help the policy maker at the point of decision-making. These are the outcomes used in existing trials, whatever their limitations. This is a potential threat to the utility of qualitative research in influencing policy, rather than future research. I also wanted the focus of the synthesis to be grounded in the literature, in the same way that the findings of primary qualitative research are grounded in the data. This tension may be an ongoing problem for researchers caught between the traditions of qualitative research and the requirements of a policy agenda. The findings of the meta-ethnography may therefore be more use for planning future research which could investigate appropriate outcomes for future trials. Practitioners might also benefit since awareness of the different elements that cause women concern will help them to diagnose HMB based on women's experiences and to tailor treatment to address their most pressing concerns.

### **7.3.2 Methods of systematic review**

A limitation for systematic reviews of qualitative research in HTA may be an incompatibility between the timing of research about experiences of treatments and the policy-making process. Although endometrial ablation (EA) had been offered as a treatment for HMB for a decade prior to these reviews and had been increasingly used in the previous five years, I was not able to identify any qualitative research about EA. Many HTAs are about drugs which have only been used in trials or in limited clinical practice. It is unlikely that qualitative research will exist for many health technologies. The focus of any review might therefore be restricted to information about the experience of the *condition*, with perhaps some information about older treatments. Potentially, this could introduce bias in favour of newer treatments, due to an absence of evidence about the people's experience of using

them. This could be addressed if qualitative research into people's experience of using new treatments became more routinely undertaken. Potentially this could be incorporated alongside phase II studies or phase III trials or alternatively during post-marketing surveillance to enhance understandings of the patient perspective about use in clinical practice.

In HTA, and in other policy-making arenas, subjects for review are usually delineated by a particular disease area or treatment and it is possible that topics delineated in this way are not the most fruitful areas for investigation through reviews of qualitative research, as discussed in Section 7.1.4. This was the case in the syntheses undertaken here, and it was not possible to predict what additional, alternative or refined areas of interest would emerge. This might prove problematic in mixed methods reviews where the potential differences in area appropriate for reviews of qualitative or quantitative research might emerge. Iterative negotiation about the focus and scope of any review with the commissioners will be crucial. It is also important that the differences between quantitative and qualitative research are considered. The practical constraints of the project, such as staffing levels and timelines, might restrict project development, although potential areas for future research can be noted.

In the context of policy-making, it is still unclear how knowledge derived through qualitative research enquiry is valued, and what elements would give policy makers confidence that they are basing their decisions on reliable qualitative evidence. It is possible that there is a conflict between social scientists' preference for well-developed theories and policy makers' expectations, which could be more responsive to the cumulative evidence of recurring themes. Based on the experience of these reviews, qualitative research may not feed into existing HTA projects as I originally envisaged. In reality, this might be complex because different frames for research questions, project timings, and types of conclusions are probable. It may be that the most fruitful collaboration between quantitative and qualitative research in policy making is either to use the results of the review of quantitative research to formulate very specific queries which qualitative research may illuminate, or to investigate very broadly the experience of patients with a particular condition, with the focus led by the existing research evidence rather than being constrained at the time of formulating the HTA research question.

Positive movements towards reviews of qualitative research are visible at a national level. The Strategy Unit in the Cabinet Office recently commissioned research to develop a

framework to guide the quality assessment of qualitative research, although this has yet to be tested or accepted by wider research communities. Based on a review of the literature and in-depth interviews with government commissioners of research and policy makers, Spencer et al (2003) developed a framework based on eighteen questions for quality appraisal. The framework is based around four guiding principles for the design and conduct of research, and suggests that it should be:

- contributory by advancing wider knowledge or understanding,
- defensible in design by providing a research strategy which can address the questions posed,
- rigorous in conduct, through transparent collection, analysis and interpretation,
- credible in claim through offering well-founded and plausible arguments about the significance of the data generated.

These criteria are reasonable but, as they are subject to interpretation, it remains to be seen how they are implemented.

As Thorne et al, have noted, meta-study is concerned with exploring the “methodological, disciplinary and theoretical underbelly of the existing body of knowledge of a phenomenon” (Thorne et al., 2004). This objective is likely to be of interest to researchers, but not necessarily compatible with the aims of policy-making, although the cautions that it may raise are important. While there is a certain amount of leeway for this in the meta-ethnography, as the researcher is encouraged to look for possible explanations for refutational findings, which may include different research approaches or disciplines, meta-study, however, is more systematic in its methods. Importantly, meta-study urges close assessment of *similar* findings (“reciprocal translation” in the language of meta-ethnography), as well as conflicting ones. Similar findings may be explained by similar approaches - using similar methods or influenced by similar theory - and should not automatically be assumed to indicate validity of individual studies or the credibility of particular studies.

Despite its concern to deconstruct *how* findings are reached as well as *what* conclusions are reached, it has been possible through meta-study to create innovative concepts and to expand existing ones. These should be valuable to practitioners and to policy makers. In addition, I contend that policy makers and practitioners will benefit from understanding both the theoretical frameworks that guide research, and those that are produced by them.

In particular, understanding the socio-cultural context of illness should help improve services through greater understanding of patient concerns and experiences. In addition, good theory provides explanations for the impact of decisions and practices.

A potential weakness of the current methods for the systematic review of qualitative research is how credible and valid it will seem to policy makers, especially those more familiar with the procedures for systematic review and meta-analysis of quantitative studies. These questions are difficult to address satisfactorily because they go to the heart of epistemological debates about truth, knowledge and our relationship to them as well as to understandings of how decisions, evidence-based or otherwise, are made;

*The world of policy-making is not one of transferable and enduring scientific truths, nor is it exclusively (or even predominantly) concerned with “what works.”*  
(Greenhalgh & Russell, 2005b)

### **7.3.3 Evidence-based decision making**

Decision-making is a dynamic process that involves consideration, re-presentation and interpretation of all sorts of “evidence”, despite the perception that meta-analysis of RCTs are the primary building blocks of reliable evidence. As the evidence-based medicine movement matures, it seems increasingly obvious and accepted that the technical “perfection” of the meta-analysed RCTs does not negate human processes and understandings. Patient narratives will continue to prove powerful and telling, and clinician experience persuasive, recognising that there are no neutral truths, particularly in policy-making where political truths are also served.

Unsurprisingly, though perhaps ironically, evidence based policy makers, apparent bastions of logical reasoning, are themselves susceptible to rhetoric and bias. Greenhalgh and Russell have noted how information that might be considered to be at the top of the evidence hierarchy can be displaced by rhetorical language, as was seen in the reframing of debates about “hip protectors” for osteoporotic falls through reference to the devices as “padded knickers” in discussion (Greenhalgh & Russell, 2005a). This may also be a concern because osteoporosis, like HMB, is predominantly a women’s health problem and that this school boy response could be seen as belittling such gendered concerns.

It may be worth remembering, however, that debates about how to establish validity are not solely the preserve of reviews of qualitative research. Some existing decision-making

tools, such as decision-analytic modelling, are technically highly numerate but suffer from similar concerns. Helpful comparisons can be made in terms of understanding how validity might be established in a decision-making context. Decision analytic models use computer simulations to compare the costs and benefits of treatment regimes in a particular population, using data from a range of sources, including the literature and expert opinion. They necessarily involve assumptions and simplifications of the real world situation. It has been said that while all models are likely to be wrong, some will be useful (Box, 1979).

In an HTA decision-making context, where models are usually developed by both an independent academic group and by the manufacturer of the drug being considered, these different parties invariably come to different conclusions with, predictably, results from the industry model usually suggesting better value for money from their drugs than the independent model. So how are decision makers to judge which is more likely to prove the most valid answer? One obvious response is to recognise the different positions of the researchers. In qualitative research, this reflexive acknowledgement of the researcher-constructed viewpoint is commonplace, as the researcher is recognised as a research tool. The amount of commercial interest involved in a drug company's results is likely to send messages of caution, if not ring loud alarm bells, to most aware readers. However, there is no guarantee that the academic model is free from false assumptions, inaccurate data, oversimplifications, misappropriations or other errors of judgement, construction or interpretation. In this sense there are similarities with the worlds of quantitative and qualitative research.

In their report on good practice, the International Society for Pharmacoeconomics and Outcomes Report (ISPOR) have suggested that independent models should be developed so that their results can be compared for validation purposes (Weinstein, O'Brien, Hornberger, Jackson, Johannesson, McCabe et al. 2003). However, it is acknowledged that identifying similarities might only prove that both are consistently wrong. Such a conclusion has parallels with the understanding within meta-study, which acknowledges that similar findings, and presumably syntheses, may be evidence only of similar approaches and methods. Models are also said to necessarily reveal the relationship "between assumptions and outcomes" (Weinstein et al., 2003). This too could be applied to qualitative research, where the steps of interpretation from participant quote to theme, and the way in which themes may be combined to produce theory, should be visible to the reader.

It has been suggested that validity might be considered by asking what a piece of work is valid for, rather than seeking absolute notions of validity. In this context, the included studies were useful for creating an overall picture of the research done in a particular area, and of allowing a synthesis of such findings that produced new knowledge.

The conclusions of my reviews are, it is hoped, meaningful in the subject area which is reassuring in the context of HTAs and other policy-making fora where requests for syntheses are likely to be topic based. The meta-ethnography of heavy menstrual bleeding (HMB) produced a detailed description of women's lay model of HMB. I felt that this lay model could allow women to understand how their concerns related to those described by others, as well as giving clinicians a framework for understanding the symptoms that concern women and their impacts. These aspects could be used to devise more patient centred outcomes, or condition specific quality of life measures for research assessing the effectiveness of treatments for HMB. In addition, the synthesis resulted in a model which attempted to explain the uncertainty women experienced in defining their bleeding as problematic, which could help to explain the varied behaviour between women with similar symptoms.

The meta-study for hysterectomy also produced results that depict the experience of hysterectomy as well as demonstrating the potential of meta-study. Reports from qualitative research in different countries and from different disciplines could be synthesised. On the whole, studies from health services and nursing backgrounds showed similar concerns. Sociological studies introduced macro level concerns which helped to situate women's concerns and misgivings about hysterectomy in their socio-cultural context. One study actually observed consultations and concluded that, in contrast to some perceived concerns, women were the drivers of consultations that led to hysterectomy and that they used a variety of strategies to ensure that they got the treatment they sought. This paper confirmed the importance of recognising the limitations of relying only on people's expectations, perceptions and recollections. It also raises interesting questions as to *why* the perceptions and recollections do not appear to be borne out by the observational findings which would be a potentially fruitful area for future research.

## **7.4 Key Areas for Future Research**

A number of potential areas for future research emerged. These include:

- The development and testing of appropriate women-centred outcomes for trials of treatment for HMB.
- Investigation of whether people's reports of what happens in health consultations matches what is observed. This could include an investigation into the ways in which women talk about their encounters with doctors, including whether reports of consultations related to gender-specific conditions are different to non gender-specific conditions.
- Reviews of qualitative research should be undertaken as part of the HTA process (and other policy-making arena) and their input evaluated.
- Continued research on the best strategies for searching for qualitative research reports is required. Alongside this, databases should also seek to standardise the language used to identify both primary qualitative research and their review.
- Research is needed to establish if, and how, missing studies through the searches influences a review.
- Studies should be undertaken that assess the differences between published reports from a research project and alternative write ups of the same research in the grey literature, such as project reports and thesis. The impact of these differences on the review and synthesis of such research should also be explored.

## **7.5 Conclusion**

This thesis has successfully addressed the aims outlined in Section 1.1. I have produced a unique review and comparative critical appraisal of the way in which different methods have described key stages of systematic review of qualitative research. I have used review of methods to produce a novel and comprehensive framework for good practice in reviews. This framework informed the two reviews that I undertook related to HMB, through which I produced innovative concepts based on the existing literature, which would be useful for researchers, practitioners and policy makers. Through these two reviews I have compared meta-ethnography alone and with the additional meta-method and meta-theory elements of meta-study. The ability of meta-study to unpack the procedures and theories that produce particular findings is key. In addition, I believe that it

constructs findings as well as deconstructs them. It emphasises the importance of theory in reviews.

Synthesis of qualitative research was possible and added both to understanding the topic areas, producing information that might have been useful to inform policy makers and medical practitioners, while also advancing knowledge about how such review and synthesis methods may be used which is of interest to researchers. Meta-study allows more flexibility and deeper analysis than meta-ethnography alone. Key in this is the ability to explore similar findings in the context of theoretical and methodological input into their development. In addition, there is the explicit ability to import concepts to use in the synthesis which are not found in the included papers. The downside of this is the added elements of interpretation that are involved which adds to the uncertainty about findings. In future studies I would want to be sure of the involvement of multidisciplinary teams in any synthesis.

Interest in, and acceptability of, qualitative research and its synthesis continues to grow and greater experience of working with the review tools in this environment is needed. PenTAG have recently won a contract to produce assessments of Public Health programmes for NICE. The call for proposals was explicit in wanting qualitative research to be part of this picture. While key challenges described in this thesis remain, greater understanding will be gained through the experience of undertaking more reviews.

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## 9 Appendices

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### 9.1 Search Strategy for Study Reports on HMB and Hysterectomy

Strategy for MEDLINE is

1. Findings.tw
2. Interview.tw
3. Qualitative.tw
4. 1 or 2 or 3
5. [Add subject specific search terms here]
6. 4 and 5

Line 5 for the HMB searches was:

Heavy menstrual bleeding OR menorrhagia.

Date	Database	Search terms	Hits	Obtained
4/2/04	MEDLINE	Hysterectomy [KW] plus the Grant strategy above	25	1
"	"	Menorrhagia or heavy menstrual bleeding [KW] plus the Grant strategy above	25	1 (repeat)
13/5/04	"	Rollerball OR TCRE OR thermal balloon OR microwave OR endometrial ablation PLUS grant strategy	56	0
4/2/04	PSYCHLIT	Hysterectomy [TI]	104	19 abs – 16 possibly useful
2	2	Menorrhagia or Heavy menstrual bleeding [ti]	28	2
4/2/04	BIDS	Hysterectomy [ti]	9	1 Entwistle
13/5/04	ASSIA 1987-present	Hysterectomy or endometrial [KW]	101	Elson x2 & case study, Dell 99
"	"	Hysterectomy [KW]	83	1
"	"	Hysterectomy [KW] plus the Grant strategy above	3	
"	"	Endometrial ablation [KW]	2	0
		Menorrhagia OR heavy menstrual bleeding [KW]	20	1 (O'Flynn and Britten)
13/5/04	AMED (Allied and Complementary Medicine) 1985	Hysterectomy	19	2
"	"	Menorrhagia or heavy menstrual bleeding	14	0
13/5/04	BNI (British Nursing Index)	Hysterectomy [KW]	139	
"	"	Menorrhagia or heavy menstrual bleeding [KW]	40	
"	"	Hysterectomy [KW] plus the Grant	1	1 but repeat

		strategy above		
“	“	Menorrhagia or heavy menstrual bleeding [KW] plus the Grant strategy above	2	0
13/5/04	Amazon online bookshop	Hysterectomy (in Books)	124	Sample only checked – mostly self help, or polemical
14/5/04	WHO website	Hysterectomy AND qualitative	9	1 (SA women's experience)
“	“	Menorrhagia AND Qualitative	4	0
14/5/04	Journal of Family Planning and Reproductive health Care	Hand-search online 2000; 26(2)+	0	0
14/5/04	Reproductive Health Matters	Handsearch online	0	0
7/6/04	Gender and Society	Handsearch online 1997 1(1)-14(6) 2000	0	0
7/6/04	Sociology of health and illness	Handsearch online 1997 19(1)- 2004 26 (2)	0	0

Finally, the bibliographies of qualitative studies already identified were examined. – three possibilities ordered re HMB.

13/5/04	CINAHL (Cumulative Index to Nursing and allied health literature) from 1982	Hysterectomy [KW] plus the Grant strategy above	8	2 (1 repeat)
“	“	Menorrhagia or heavy menstrual bleeding [KW] [KW] plus the Grant strategy above	1	0

Search hysterectomy 2 in Assia:

Jean Elson. H9ormonal Hierarchy: Hysterectomy and Stratified Stigma. *Gender & Society* 2003;17 (5): 750-770

### Search menorrhagia and HMB in Assia

Marshall, J. An exploration of women's concerns about heavy menstrual blood loss and their expectations regarding treatment. *Journal of Reproductive and Infant Psychology*; 1998; 16 (4): p.259-76

### Also 2 more

But already got (O'Flynn, Britten #28; Chapple #26)

### Hand-searching

Titles and abstracts in *Qualitative Health Research* from 1998; 8 (6) online.

1 previously identified title

## 9.2 Data extraction sheets for the study reports in the hysterectomy review

Complete citation:	Augustus CE, Beliefs and Perceptions of African American Women who have had Hysterectomy. Journal of transcultural Nursing 2002; 13 (4): 296-302
Author affiliation (discipline, institution)	RN, MSN-c Nursing, University of Louisiana PhD nursing student. Works in gynaecological surgery unit, Baton Rouge
Funding source	Not stated – part of PhD?
Acknowledgements	None
Period of data collection	Not stated
Location of study	Lafayette, Louisiana
Dates of submission and acceptance	Not stated
Publication type	Journal article
Mode of retrieval	E-search
Key words (given on paper)	Not stated
<p>This study used a qualitative, ethno-nursing, ethnographic design to identify cultural beliefs within the African American community related to hysterectomy. Three themes were derived from interviews with 30 women: African American cultural myths, fears, and sexual symbolism related to hysterectomy; benefits of hysterectomy that included freedom from pain and public embarrassment and freedom from risk of pregnancy; and improved self-esteem and sexuality. Results of this study indicate that there are negative connotations of hysterectomy in the African American community, which may cause some African American women to delay the procedure until they have no choice. Education and knowledge of cultural beliefs will enable health care providers to provide culturally sensitive and comprehensive care to African American women; it also will enable health care providers to instruct African American women to avoid unnecessary delay of hysterectomy.</p>	

### Stated research problem

Rates of hysterectomy vary. Some African American people seem to have string cultural negative beliefs relating to hysterectomy (refs Richter (2000), Bernard (1992)) however this is not well known in the health professions.

To explore the prevalence of negative beliefs surrounding hysterectomy in the African American community.

To determine if the age of women, marital status, level of education or religious belief played a part in these attitudes.

To see if women did in fact tell their friends and family.

To determine if women would recommend hysterectomy.

Major construct/ theory investigated (if applicable) (theoretical orientation)	Leininger's transcultural nursing model
Genre of study (note if stated genre fits design)	Transcultural ethnography. Content analysis
Nature of sample: No. Age Ethnicity Education  Other characteristics	30 Mean 49 African American 60% High School, 27% 1-2 yrs college, 13% 2-4 years college.  60% not married. 77% Baptists, 10% Methodists, 10% Full gospel, 3% Catholic. (All hysterectomised African American women by implication?)
General description of the research approach	FGD (6 groups, 2x3 women, 3x4, 1x5) Semi structured interviews (n=7)
Methodological orientation	Ethnographic content analysis.

### **Major findings**

All women had heard "old wives tales" about hysterectomy prior to surgery.

Themes:

#### **Myths, fears and sexual symbolism related to hysterectomy**

Fear of losing mate, their sexual desires and being sexually undesirable to men.

One woman travelled a long way for operation to keep it secret, including from partner.

African-American men say that women are not “whole” “stripped... you’re ruined”

Freedom from pain and embarrassment

Freedom from prior HMB causing public accidents, inability to wear white, planning around periods.

Much laughter when sharing these stories in the groups.

Improved sexuality and self-esteem

Most surprised and relieved that sexuality unchanged or better after hysterectomy.

Emotional burden continued as women remained aware of the emotional stigma of hysterectomy evidenced by decision not to tell others due to emotional burden of fear of abandonment and loneliness.

Women carried an invisible stigma, and felt not normal. “The strategy of secrecy the women used, as reflected in nondisclosure and concealment, is consistent with other individuals who are coping with a stigmatised identity and particularly a stigma that is not visible (Scambler 1998).”

All stated they would recommend hysterectomy to other African American women (reported in “Sample characteristics” not “results”)

Similar stories in groups vs individual interviews, although those wishing individual interviews seemed to carry a heavier emotional burden and more likely to cry.

Problem statement	Y
Statement of the phenomenon leads directly to the purpose of the study?	N
Purpose of research	
Clearly expressed?	Y
Significance of research problem clearly indicated?	Y
Research question	
Explicitly expressed?	Y
Evidence of flow from phenomenon?	N
Identification of assumptions?	
Identification of assumptions, preconceptions, presuppositions of researcher	N
Identification of theoretical framework?	Y
If yes, name framework (if it is not well known, include a description)	
Leininger's transcultural nursing model and ethnographic approach for investigating cultural beliefs and perceptions. This emphasises that diverse and common beliefs, values and life patterns of African American people should be taken into account by the health care provider.	
Theory of Cultural Care Diversity and Universality (Leininger) is directed at helping health care providers grasp the world of the clients and to use their viewpoints, knowledge and practices as the basis for making culturally congruent professional actions and decisions.	
Discussion sections interprets findings in terms of an "invisible stigma"	
Clarification of influence of theoretical framework	
Seen as appropriate because study reveals particular cultural belief is relevant to the experience of African American Women. Health care professional should be aware of these.	Y
Researcher credentials	
Documentation of researcher's discipline	
If yes, name it: Nursing research	Y
Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference)	N
Name of persons acknowledged by the authors and relationship: None	
Role of researcher	
Non-research relationship of researcher to participants?	
Evidence that the researcher has considered the effect of his/her presence on the research findings?	N
Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	N

<p>Sampling and participants</p> <p>Description of sampling procedure?</p> <p>Identification of inclusion criteria</p> <p>Discussion of attrition in longitudinal studies?</p>	<p>Y</p> <p>N</p> <p>NA</p>
<p>Data gathering strategy(ies)</p> <p>Clear description of data gathering procedures?</p> <p>If no, how could the description be improved?</p> <p>Description of gaining access?</p> <p>Discussion of time frame for data gathering?</p>	<p>Y</p> <p>NA</p> <p>Y</p> <p>N</p>
<p>Data analysis strategies</p> <p>Description of method(s) used?</p> <p>Identification of categories or common elements found?</p> <p>Report of participants' response to analysis?</p> <p>Data analysis presented in a clear framework (identification of central themes and categories)?</p> <p>Data presented in such a way that relationships between categories/ themes are clear?</p> <p>Analysis well supported by representative quotes/ findings?</p> <p>Provision of evidence as to how representative in the sample the various findings were?</p>	<p>Y</p> <p>Y</p> <p>N</p> <p>Y</p> <p>N</p> <p>Y</p> <p>Y</p>
<p>Conclusions, discussions, implications, suggestions for further study</p> <p>Identification of limitations of study? – small, non-randomised sample, mostly blue-collar workers. Most worked in the same facility.</p> <p>Discussion pertains to all significant findings?</p> <p>Interpretive statements correspond with findings?</p> <p>Examination of findings with existing body of literature?</p> <p>Clear indication of directives for future research?</p> <p>If yes, indicate directives identified.</p> <p>Larger study among African American men and women required to determined how education/ income/ and social class shape beliefs and attitudes</p>	<p>Y</p> <p>Y</p> <p>Y</p> <p>Y</p>
<p>Other considerations/ thoughts</p> <p>Questionnaire piloted with 4 women – no revisions.</p> <p>Paid participation.</p> <p>Snowball the most effective – first group, after initial reluctance, became project “allies” recruiting others to take part.</p> <p>Refs Richter and notes similar findings.</p> <p>Questions seem more appropriate to quant research and are not really answered.</p>	

Complete citation:	Bernhard, L.A. Black women's concerns about sexuality and hysterectomy SAGE 1985; 2 (2): 25-27
Author affiliation (discipline, institution)	PhD student nursing. University of Illinois, Chicago
Funding source	US Public Health Service Individual National Research Service Award and by a Gamma Phi chapter Clinical Nursing Award
Acknowledgements	None
Period of data collection	April 1984 – Feb 1985
Location of study	Chicago teaching Hospital.
Dates of submission and acceptance	NS
Publication type	Journal article
Mode of retrieval	Ref list
Key words (given on paper)	None
Abstract	None available.

### **Stated research problem**

Few studies have identified black women in research about hysterectomy. In two studies that do, findings about sexuality are generally positive but not identified by race.

Aims to determine the expectations that women have about the effect of hysterectomy on their sexuality, and the outcomes they experience.

Major construct/ theory investigated (if applicable) (theoretical orientation)	None
Genre of study (note if stated genre fits design)	Not stated – phenomenological?
Nature of sample: No. Age Ethnicity Education Other characteristics	37 black women (/63 total – prelim results, only black?) 35.5 yrs mean Black 73% completed high school or more. 43% single Half homemakers, remainder “pink collar” 86% protestant 1/3 had bilateral salpingo-oophorectomy
General description of the research approach	Three semi-structured interviews – on day of surgery, first post-op check-up and three months post-op.
Methodological orientation	Not clear. Thematic analysis

### **Major findings**

Concerns can be grouped into four:

#### **Personal physical attractiveness**

Primarily related to scar, also weight gain, “becoming masculine”, experiencing menopause/ becoming old

#### **Loss of womanhood**

*(my note – this is different from becoming masculine?)*

Loss of menstruation. Removal of “insides”.

#### **The ability to engage in sexual activity**

Concerned about possible lack of desire, or orgasm. “Feel different”, would change.

#### **Partner’s response**

An understanding that mean think women who have had hysterectomies are different, “not complete”. Fear they will leave.

15/34 of those with regular partners did not tell them they were having a hysterectomy (all white or Hispanic women told partners).

Linked to this anxiety or fear of pain on intercourse post-surgery. By end of study 60% had resumed intercourse. 8/22 indicated it was as good or better than before surgery, for the rest the first experience was not positive – “uncomfortable” or because not “relaxed”. Resolved after first few times.

Expectations influence outcomes – women’s fears come from external sources, other women/ partners.

“Ladner’s study [1971] of poor adolescent black women identified two factors as important to becoming women – menstruation and relationships with men. The women in this study know that they were first of these factors-, and the potential of losing the second could have an extremely strong effect on their feelings of being women” (p.26)

Problem statement	Y
Statement of the phenomenon leads directly to the purpose of the study?	N
Purpose of research	
Clearly expressed?	Y
Significance of research problem clearly indicated?	Y
Research question	
Explicitly expressed?	Y
Evidence of flow from phenomenon?	Y
Identification of assumptions?	
Identification of assumptions, preconceptions, presuppositions of researcher	N
Identification of theoretical framework	
Identification of theoretical framework?	N
If yes, name framework (if it is not well known, include a description)	
? not sure – I think that actually, Lader's study above about becoming a women seems key but this is not identified as a theoretical frame work.	NA
Clarification of influence of theoretical framework.	
Researcher credentials	
Documentation of researcher's discipline	Y
If yes, name it: Nursing	
Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference)	N
Name of persons acknowledged by the authors and relationship:	None
Role of researcher	
Non-research relationship of researcher to participants?	?
Evidence that the researcher has considered the effect of his/her presence on the research findings?	N
Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	N
Sampling and participants	
Description of sampling procedure?	Y/N
Identification of inclusion criteria	Y
Pre-menopausal women admitted to hospital for hysterectomy for benign conditions	
Discussion of attrition in longitudinal studies?	NA
Data gathering strategy(ies)	

<p>Clear description of data gathering procedures?</p> <p>If no, how could the description be improved? I think that this study reports on only the black women in a mixed race sample of 63, but not totally clear as this is also call a prelim study.</p> <p>Description of gaining access?</p> <p>Discussion of time frame for data gathering?</p>	<p>N</p> <p>Y</p> <p>Y</p>
<p>Data analysis strategies</p> <p>Description of method(s) used?</p> <p>Identification of categories or common elements found?</p> <p>Report of participants' response to analysis?</p> <p>Data analysis presented in a clear framework (identification of central themes and categories)?</p> <p>Data presented in such a way that relationships between categories/ themes are clear?</p> <p>Analysis well supported by representative quotes/ findings?</p> <p>Provision of evidence as to how representative in the sample the various findings were?</p>	<p>N</p> <p>Y</p> <p>N</p> <p>Y</p> <p>N</p> <p>N</p> <p>Y</p>
<p>Conclusions, discussions, implications, suggestions for further study</p> <p>Identification of limitations of study? –</p> <p>Discussion pertains to all significant findings?</p> <p>Interpretive statements correspond with findings?</p> <p>Examination of findings with existing body of literature?</p> <p>Clear indication of directives for future research?</p> <p>If yes, indicate directives identified.</p> <p>Research repeated among different socioeconomic groups, geographical locations, rural women.</p>	<p>N</p> <p>N</p> <p>?</p> <p>Y</p> <p>Y</p> <p>Y/N</p>
<p>Other considerations/ thoughts</p> <p>Poorly organised – no section headings – maybe due to age? This is prelim and there is, I think some overlap with the other paper by this author – some quotes look familiar.</p> <p>There is obvious link and overlap between last two categories but this isn't made clear although results under one could easily go in the other.</p>	

Complete citation:	Bernhard LA, Harris CR, Caroline HA. Partner communication about hysterectomy. Health Care for Women International 1997; 18: 73-83
Author affiliation (discipline, institution)	Nursing and women's studies, Ohio State University
Funding source	NIH
Acknowledgements	None
Period of data collection	N/S men interviewed mean 36 days after surgery
Location of study	Women in hospital after surgery Men in community later
Dates of submission and acceptance	5/10/95; 2/2/96
Publication type	Journal article
Mode of retrieval	E database
Key words (given on paper)	None
<p>Communication between marital partners about a woman's hysterectomy may be difficult and serve as a source of marital conflict. This study was conducted to determine marital partners' usual communication behaviors as well as what they communicated about hysterectomy with each other. Twenty-two educated Caucasian couples participated in the study. Individual, semistructured interviews were conducted with the women in the hospital following their hysterectomies and with their partners at a later time. Couples also completed the Primary Communication Inventory. Results showed that the couples had generally good usual communication. Couples reported that they communicated "everything" about the hysterectomy, but evidence (i.e., further questioning) showed that they communicated little. The authors discuss possible explanations for this apparent contradiction between perceived and actual communication behaviors.</p>	

### **Stated research problem**

- (a) How do partners experiencing hysterectomy usually communicate with each other?
- (b) What do partners communicate about the hysterectomy?
- (c) Are the communication behaviours related to hysterectomy similar to their usual communication behaviours?

Major construct/ theory investigated (if applicable) (theoretical orientation)	None stated (orientation is about marital communication). This situated in previous research about partner communications.
Genre of study (not if stated genre fits design)	Mixed methods.
Nature of sample: No. Age Ethnicity Education Other characteristics	22 couples Women 38, men 38.9 Caucasian All completed high school, 55% women, 73% men had degrees All had hysterectomies for non-cancer diagnosis and were premenopausal
General description of the research approach	Used the Primary communication Inventory – analysed descriptively.  Interviews recorded, transcribed, transferred to the Ethnograph. Constant comparison analysis to develop themes.
Methodological orientation	Non stated.  Elements of grounded theory (constant comparison method), but thematic analysis

### **Major findings**

“Communication is a symbolic process of sharing and creating meaning.”

Both men and women stated that they “talked about everything”, however, targeted questions about physical, emotional and sexual effects, revealed that little had been discussed. In particular, concerns from both sides were not usually discussed.

Where concerns were discussed, women were worried about anaesthetics, not waking up, dying in surgery.

In addition, some men did not say “hysterectomy” but “surgery”.

### **Women’s themes**

Deciding Women usually told men that doctors has said they needed it, or were tired of symptoms. Men rarely involved in decision-making.

Feeling supported through general positive comments “don’t worry” “everything will be all right”.

### **Men’s themes**

Avoiding feelings as do not want to appear vulnerable when women are vulnerable so minimise hysterectomy to reassure women all will be well.

Keeping out of it through telling themselves the decision was the woman's and the doctors – again self protection so no blame in the event of negative outcomes.

### **Couples' themes**

Wanting relief or getting over it Both partners able to describe the often distressing, symptoms that led to hysterectomy. Both wanted to get back to normal with surgery.

Planning for surgery logistics of planning around work, holidays etc.

Consequences such as infertility, menopause, initial lack of intercourse, not discussed in any detail.

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	Y
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	Y Y
Research question Explicitly expressed? Evidence of flow from phenomenon?	Y Y
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	N
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Clarification of influence of theoretical framework	N NA
Researcher credentials Documentation of researcher's discipline If yes, name it: Nursing and women's studies Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) Name of persons acknowledged by the authors and relationship: None	Y N/S
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	N Partial N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria Discussion of attrition in longitudinal studies?	N N NA
Data gathering strategy(ies) Clear description of data gathering procedures? If no, how could the description be improved? Description of gaining access?	Y N/A N

Discussion of time frame for data gathering?	Partial
Data analysis strategies	
Description of method(s) used?	Y
Identification of categories or common elements found?	Y
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	Y
Data presented in such a way that relationships between categories/ themes are clear?	N
Analysis well supported by representative quotes/ findings?	N
Provision of evidence as to how representative in the sample the various findings were?	Y
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study? – small sample, only 38% of the male partners of women initially interviewed (n=58) agreed to take part (22 couples used), long time between interviews with women and their partners , potential for social desirability bias. None of the 10 African American men invited agreed to take part.	
Discussion pertains to all significant findings?	N
Interpretive statements correspond with findings?	N
Examination of findings with existing body of literature?	N
Clear indication of directives for future research?	Y
If yes, indicate directives identified. - replication of research with larger, more diverse sample, investigate future of relationships related to communication around hysterectomy.	
Other considerations/ thoughts	
Refers to previous research but in the third person, not identifying it as her previous research!	
Clearly situates research questions in research of partner communication generally.	

Complete citation:	Bhavnani V, Clarke A. Women awaiting hysterectomy: a qualitative study of the issues involved in decisions about oophorectomy. BJOG 2003; 111: 168-174
Author affiliation (discipline, institution)	? Health Services Research Unit, LSHTM
Funding source	NHS R&D
Acknowledgements	Commissioner. I. Pell, J. Dowie, A. Coulter, M Sculpher, J. Teperi, R. Rosen = collaborators and steering group. Participants and peer reviewers.
Period of data collection	July 1998 – Dec 1999.
Location of study	6 hospitals in London and SE
Dates of submission and acceptance	N/S
Publication type	Journal article
Mode of retrieval	Database
Key words (given on paper)	N/S
<p>OBJECTIVE: Women awaiting abdominal hysterectomy have a further decision to take--whether or not to undergo a prophylactic oophorectomy. Prophylactic oophorectomy (removal of healthy ovaries) is commonly undertaken as an adjunct to hysterectomy to prevent ovarian cancer in women who are already having a hysterectomy for menorrhagia, fibroids or severe menstrual pain. It causes an immediate 'surgical menopause'--women no longer produce endogenous oestrogens and they are advised to take hormone replacement therapy (HRT). This descriptive study was undertaken as part of a larger pilot study. DESIGN: Qualitative interviewing study. SETTING: Hospital outpatient departments in southern England. SAMPLE: Women on waiting lists for hysterectomy for benign conditions. METHODS: In-depth semi-structured interviews were undertaken with 16 women awaiting hysterectomy to examine their views of prophylactic oophorectomy, menopause and HRT use. Interviews were transcribed. Nud*ist was used to organise the data. Analysis was undertaken by two researchers working independently who then met to agree themes. RESULTS: Women held treatment preferences both about the removal or retention of their ovaries and about subsequent HRT use. Many of the women did not want oophorectomy because of a dislike of a sudden menopause. Those who were planning to have an oophorectomy tended to have more severe symptoms. Some women were fearful of ovarian cancer--one woman described it as a 'silent killer'. A further theme was apparent in the discussion of ovaries as 'redundant' with further discussion of healthy versus problematic ovaries. Many women felt inadequately informed about their treatment options and were unaware of important longer term outcomes of oophorectomy such as an increased risk of osteoporosis or of coronary heart disease. CONCLUSION: It appears that many women emphasise the 'natural' when considering oophorectomy and the use of HRT. Women were uneasy both about a sudden menopause and about the risks of ovarian cancer. And although these women were all about to undergo surgery, they had experienced an apparent serious lack of information especially about long term risks and benefits on which they might base their decision.</p>	

**Stated research problem**

Available research about women’s views of menopause and HRT suggest that many women feel under-informed. However, little research about menopause, HRT has been undertaken among those who are anticipating hysterectomy or ovarian surgery rather than the well. Women were interviewed about their attitudes to hysterectomy, menopause, HRT and oophorectomy, and sources of information about them.

Major construct/ theory investigated (if applicable) (theoretical orientation)	Health Belief Model, and Comprehensive Model of Information Seeking (Johnson & Meischke,(2000)
Genre of study (note if stated genre fits design)	Framework approach to analysis. Discrepant cases. Interviewing continued until theoretical saturation occurred (? But all women responding were interviewed?)Thematic analysis.
Nature of sample:  No. Age Ethnicity Education Other characteristics	Systematic non-probabilistic sampling. Women on waiting list for hyst for benign reasons (ie not just HMB)  16 (/29 approached by letter)  Mean 45  NS  Higher education than average  75% in employment
General description of the research approach	Semi-structured interviews developed using literature review and HBM.
Methodological orientation	Framework method of analysis (Ritchie and Spencer, 1994)  Implicitly, elements of grounded theory “interviewing continued until theoretical saturation was reached” but they also say that there was a 50% response rate (discussion) – suggesting they interviewed all who agreed?  Double thematic coding “to increase validity”.  Coding concurrent with continued interviewing to allow adaptation to emergent themes.  Discrepant cases examined and discussed.  NUD*ST used.

**Major findings**

All women had an inclination for removal or preservation of their ovaries.

Preservers viewed them as healthy, unproblematic organs. Uneasy about menopause, but preferred a natural, normal menopause to early, medicalised menopause and HRT.

Removers viewed them as associated with risk of cancer, painful symptoms, redundant, and replaceable by HRT.

More information about oophorectomy and HRT wanted.

Theory – HBM – individual susceptibility to ovarian cancer and its seriousness, coupled with the risks and benefits of taking action and barriers to action influenced women's decisions.

“resourceful patient” (Muir Gray, 2002)

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	Y
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	Y Y
Research question Explicitly expressed? Evidence of flow from phenomenon?	N Y
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	N
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Clarification of influence of theoretical framework	Y HBM Y
Researcher credentials Documentation of researcher's discipline If yes, name it: Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) None Name of persons acknowledged by the authors and relationship: Commissioner. I. Pell, J. Dowie, A. Coulter, M Sculpher, J. Teperi, R. Rosen = collaborators and steering group. Participants and peer reviewers.	N None
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? No but note that being in hospital for interviews may elicit "orthodox" responses. Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	N/S N N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria Discussion of attrition in longitudinal studies?	Y Y NA
Data gathering strategy(ies) Clear description of data gathering procedures?	Y

If no, how could the description be improved?	NA
Description of gaining access?	Y
Discussion of time frame for data gathering?	Y
Data analysis strategies	
Description of method(s) used?	Y
Identification of categories or common elements found?	Y
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	N
Data presented in such a way that relationships between categories/ themes are clear?	Y
Analysis well supported by representative quotes/ findings?	
Provision of evidence as to how representative in the sample the various findings were?	Y
	Y
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study?	
– Transcripts not validated with participants. Women aware that study was about oophorectomy interviewed before operation – may already feel committed to particular action. Hospitals setting for interviews.	
Discussion pertains to all significant findings?	Y
Interpretive statements correspond with findings?	Y
Examination of findings with existing body of literature?	Y
Clear indication of directives for future research?	Y
If yes, indicate directives identified.	
- Research required in gynaecologists to see how short and long term benefits and risks are traded off, and how to convey that information to women.	
Other considerations/ thoughts	
- Undertaken as prior step before testing decision aids about prophylactic oophorectomy. Methods seem a bit muddled? Information needs seem to be more about the quality of information and discussion rather than quantity?	

Complete citation:	Chapple A, Hysterectomy: British National Health Service and private patients have very different experiences. 1995; 22: 900-906
Author affiliation (discipline, institution)	Nursing and Medical Sociology, Liverpool University
Funding source	Not stated
Acknowledgements	None
Period of data collection	1992-1993
Location of study	NW England
Dates of submission and acceptance	Accepted 11/1/95
Publication type	Journal article
Mode of retrieval	E-database
Key words (given on paper)	NS
<p>One in five women in the United Kingdom will have a hysterectomy by the time they reach the age of 65. This paper explores the experiences of women as they seek advice in outpatient clinics, as they go into hospital for surgery, and as they return home to convalesce. Differences in doctor-patient communication between private sector and National Health Service patients are discussed. The results of this study point to the inadequacy of current practice in providing information to patients about this potentially serious operation.</p>	

Do women having hysterectomies receive enough information (perhaps this is just an obsession of sociologists not ordinary women?) Exploratory research into the experience of women who had had, or avoided, hysterectomy. The title, rather than the introduction, highlights the interest in private vs NHS patient treatment.

Major construct/ theory investigated (if applicable) (theoretical orientation)	None
Genre of study (note if stated genre fits design)	Phenomenological (not stated)
Nature of sample: No. Age Ethnicity Education Other characteristics	28 (plus 13 pilot). Not clear if these are all used – 41 women also mentioned Not stated Not stated Half “well educated”, half left school at 16. (? N=41?) 8 seen privately, 20 NHS. Four additional interviews with women who avoided hysterectomy (myomectomy, EA, check ups) Note that some of this sample, n not given, had hysterectomy for malignancy
General description of the research approach	One in-depth interview. Not clear how/if structured
Methodological orientation	Not stated. Thematic analysis

### **Major findings (as discussed in paper, in order)**

Themes (underlined results are article headers)

#### **EXPERIENCES IN OUTPATIENT CLINICS**

– not enough information.

No consistent doctor, didn't always see a consultant.

Lack of sympathetic understanding.

Laparoscopy results delay there were delays in delivering results, or poor communication of results and no information or counselling for distressing findings.

Clinics are rushed.

A few women were very happy with the consultant's treatment of them.

PRIVATE PATIENTS' EXPERIENCE – positive about dialogue with consultant despite not learning much about alternatives or potential complications. No sense of rush. Invited to telephone between appointments. Good communication of results. Consistency of care with same consultant.

(note that quote on p. 902 is about choices about ovaries although this is not picked up in the paper).

### ADMISSION TO HOSPITAL

NHS patients waited a long time for an appointment. Difficulties changing consultant if wanted.

### Dr-patient relationships

*Concept* – organisational problems, such as long waiting lists, may have an adverse effect on dr-patient relationships. But not enough evidence to challenge Strong's (1977) "politeness ethic" (quoted Silverman 1987).

Private patients are seen quickly.

### THE HOSPITAL EXPERIENCE

More information available here than as an outpatient – written and from nurses.

One woman felt she was on a "conveyor belt" (direct quote) "battery hens"

Private patients had good experiences in hospital – good dr-pt communication and plenty of information, including leaflet provision and input from consultant, nurses, physio, anaesthetist.

### AFTER LEAVING HOSPITAL

Lack of communication after surgery, including some inaccurate advice from GPs. Easier for private pts to get help and advice.

Counselling offered to private patients.

Female drs are valued by some.

*(RG interpretation. Women want enough information about hysterectomy and good support and communication from their doctors. Women in the NHS perceive that they get this less than women treated privately. Waiting times may be very long in the NHS. Consultants are more consistent, and more available, and more likely to offer counselling in private care.)*

<p>Problem statement</p> <p>Statement of the phenomenon leads directly to the purpose of the study?</p>	Y
<p>Purpose of research</p> <p>Clearly expressed?</p> <p>Significance of research problem clearly indicated?</p>	Y Y
<p>Research question</p> <p>Explicitly expressed?</p> <p>Evidence of flow from phenomenon?</p>	Y Y/N
<p>Identification of assumptions?</p> <p>Identification of assumptions, preconceptions, presuppositions of researcher</p>	N
<p>Identification of theoretical framework</p> <p>Identification of theoretical framework?</p> <p>If yes, name framework (if it is not well known, include a description)</p> <p>Clarification of influence of theoretical framework</p>	N  Strong's (1977) "politeness ethic" mentioned in passing
<p>Researcher credentials</p> <p>Documentation of researcher's discipline</p> <p>If yes, name it:</p> <p>Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference)</p> <p>Name of persons acknowledged by the authors and relationship:</p>	N  None
<p>Role of researcher</p> <p>Non-research relationship of researcher to participants?</p> <p>Evidence that the researcher has considered the effect of his/her presence on the research findings?</p> <p>Evidence that the researcher has considered possibility of researcher bias or misinterpretation.</p>	N N N
<p>Sampling and participants</p> <p>Description of sampling procedure?</p> <p>Identification of inclusion criteria</p> <p>Discussion of attrition in longitudinal studies?</p>	N N NA

<p>Data gathering strategy(ies)</p> <p>Clear description of data gathering procedures?</p> <p>If no, how could the description be improved? How interviews were structured, what approach informed the research.</p> <p>Description of gaining access?</p> <p>Discussion of time frame for data gathering?</p>	<p>N</p> <p>N</p> <p>N</p>
<p>Data analysis strategies</p> <p>Description of method(s) used?</p> <p>Identification of categories or common elements found?</p> <p>Report of participants' response to analysis?</p> <p>Data analysis presented in a clear framework (identification of central themes and categories)?</p> <p>Data presented in such a way that relationships between categories/ themes are clear?</p> <p>Analysis well supported by representative quotes/ findings?</p> <p>Provision of evidence as to how representative in the sample the various findings were?</p>	<p>N</p> <p>Y</p> <p>N</p> <p>N</p> <p>N</p> <p>Y</p> <p>N</p>
<p>Conclusions, discussions, implications, suggestions for further study</p> <p>Identification of limitations of study? –</p> <p>Discussion pertains to all significant findings?</p> <p>Interpretive statements correspond with findings?</p> <p>Examination of findings with existing body of literature?</p> <p>Clear indication of directives for future research?</p> <p>If yes, indicate directives identified.</p>	<p>N</p> <p>Y</p> <p>Y</p> <p>Y</p> <p>N</p>
<p>Other considerations/ thoughts</p> <p>Methodological descriptions are weak, and the organisation of the findings lumpy – some headers are “private patients” while this group is discussed under other headers.</p>	

Complete citation:	Chassé, M.A. (1991) The experiences of Women having a hysterectomy in: The Illness Experience: dimensions of suffering. Morse & Johnson (eds)
Author affiliation (discipline, institution)	University of Alberta, Canada. Discipline not clear but supported by Nursing grant
Funding source	Alberta Association of Registered Nurses, Alberta Foundation for nursing research.
Acknowledgements	None
Period of data collection	NS
Location of study	A large US teaching hospital
Dates of submission and acceptance	NS but MA on which this was based published in 1988
Publication type	Book chapter
Mode of retrieval	Elsion reference list
Key words (given on paper)	None
<p>One of the strengths of using qualitative methods is that these methods allow the researcher to consider the context of the phenomenon as well as the phenomenon itself. Respecting the context of a phenomenon involves allowing the informants to tell the stories and share the experiences that they believe are relevant. Although Chassé was originally interested in the process of recovery following a hysterectomy, she soon discovered that her informants could not simply discuss their recoveries, rather they had to discuss all of the events surrounding the hysterectomy beginning with the exacerbation of symptoms and their first hunches that something was wrong. The informants could not separate their recoveries from the initial stages of the hysterectomy decision-making process because part of the recovery process involved resolving the issue of whether or not they had made the right decision when they consented to surgery. Chassé was sensitive to this fact and incorporated the rich data regarding pre-surgery decision-making into her analysis.</p> <p>(? Introduction not abstract?)</p>	

### **Stated research problem**

Hysterectomy is the most frequent surgical procedure in N. America, but the experiences of women are not well understood.

“Because of its fundamental role in reproduction, many social and personal values surround the uterus, and the removal of the uterus may have implications for a woman’s emotional and physical well-being”.

Major construct/ theory investigated (if applicable) (theoretical orientation)	Establishing the boundaries of normality as the basic psychological process by which women cope with hysterectomy.
Genre of study (note if stated genre fits design)	Phenomenology? (based on lived experience, but this is not explicit) feels like a narrative – accommodated as much of the story as possible.
Nature of sample:	
No.	10
Age	24-39
Ethnicity	-
Education	-
Other characteristics	9 married, 9 had children.
General description of the research approach	Interviews one and 3 months post-hysterectomy
Methodological orientation	

### **Major findings**

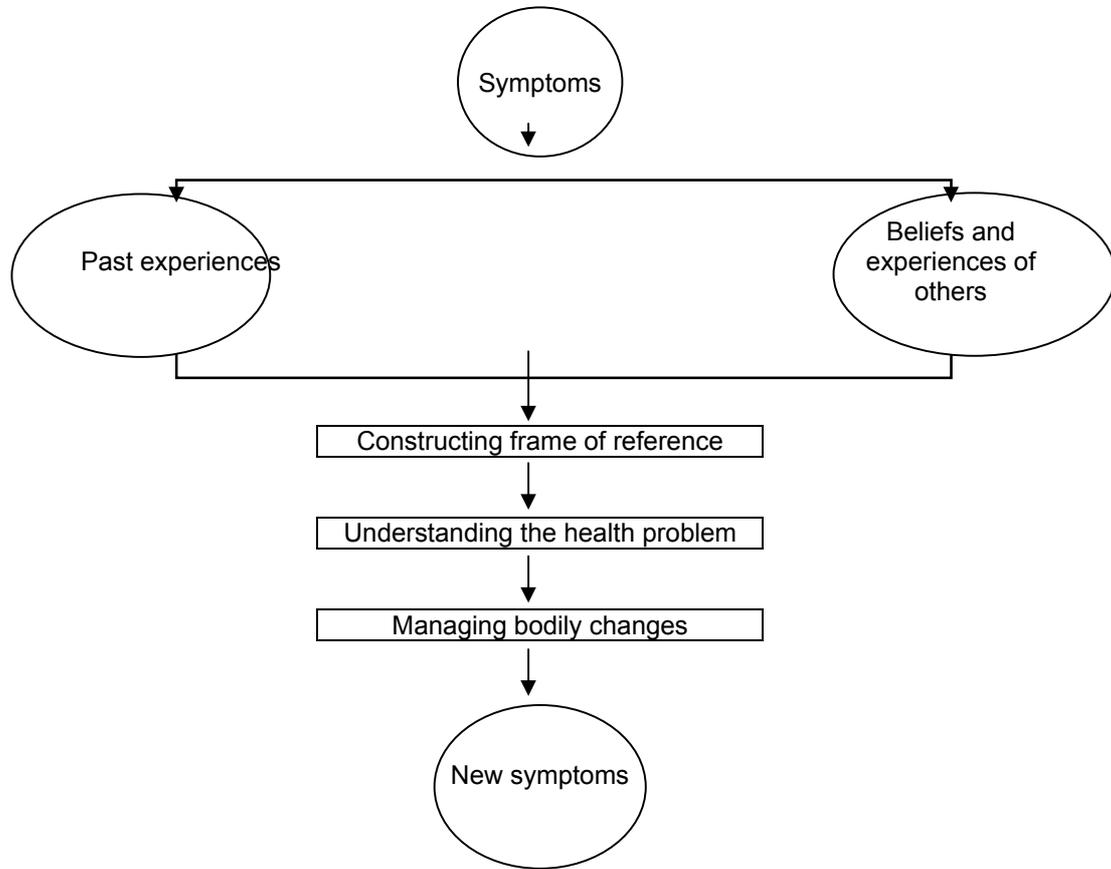
The experience of hysterectomy is composed of three interdependent stages, experiencing a disruption to the body, the struggle to preserve wholeness, and recovery:

Stage 1.	Experiencing a disruption	- Experiencing the problems - Perceiving a health problems - Learning to read the body - Evaluating the illness experience - Negotiating the medical management of the condition - Hysterectomy decision-making
Stage 2	Struggling to preserve self	- Managing the separation - Becoming a patient  - Observing the changes
Stage 3.	Recovering	- Adjusting to the changes  - Coming to terms with the hysterectomy

Through this process the woman established a frame of reference for *boundaries of normality* before during and after hysterectomy – establishing these boundaries of

normality was the basic psychological process by which women coped with symptoms and the experience of hysterectomy.

**Figure 17 : Establishing the boundaries of normality**



Through this, they attempted to retain in control of their bodily changes, and to protect self esteem. See Figure 17, women understood their symptoms through their own past experiences and talking to friends. Boundaries of normality were repeatedly revised.

#### Stage 1 Experiencing a disruption

*Experiencing the symptoms* largely pain and bleeding (detailed table of symptoms), but also weakness, fatigue, shortness of breath, swelling, headaches and lack of emotional control. Concern about impact of these symptoms on lifestyle (sexuality, work, domestic responsibilities, anxiety about birth control).

*Perceiving a health problem* health problems can be ignored if 4 conditions are met: symptoms are few, they were consistent and predictable, they did not alter life-style in unacceptable ways, they could be justified as normal in female life cycle.

Become problematic if new symptoms appeared or symptoms changed or they could not control symptoms.

*Learning to read the body* Recognising the symptoms as indicating they are ill through evaluating symptoms, triggers, trying to find relief, information seeking. Often involving a “wait and see” period. Involvement of others, including Drs, at this phase and testing of self-medication. (See Figure 20). This included *learning to recognise cycle, activity, event, and combination triggers*.

*Evaluation of the illness experience* Coping influenced by interactions with others. Generally women confidants were more understanding and empathetic because they shared experiences and may offer possible remedies or strategies. Lacking significant women made it difficult to cope. Husbands’ ability to support and discuss the problem was important and varied. Impact of this is seen in Figure 18.

**Figure 18 : Influence of significant others on women’s coping**

		Accessibility of supportive women	
		+	-
Husband’s	+	Adjusted	Isolated
Recognition of Illness	-	Limited adjustment	Distressed

Those who consulted a Dr were seeking confirmation and a label as well as solutions. Most women had little success in early encounters because “their doctors did not acknowledge the impact of the illness on their lives”. Dr and husband acceptance became increasingly important (**Figure 19**).

**Figure 19: Influence of spouse and physicians on women’s coping and view of illness**

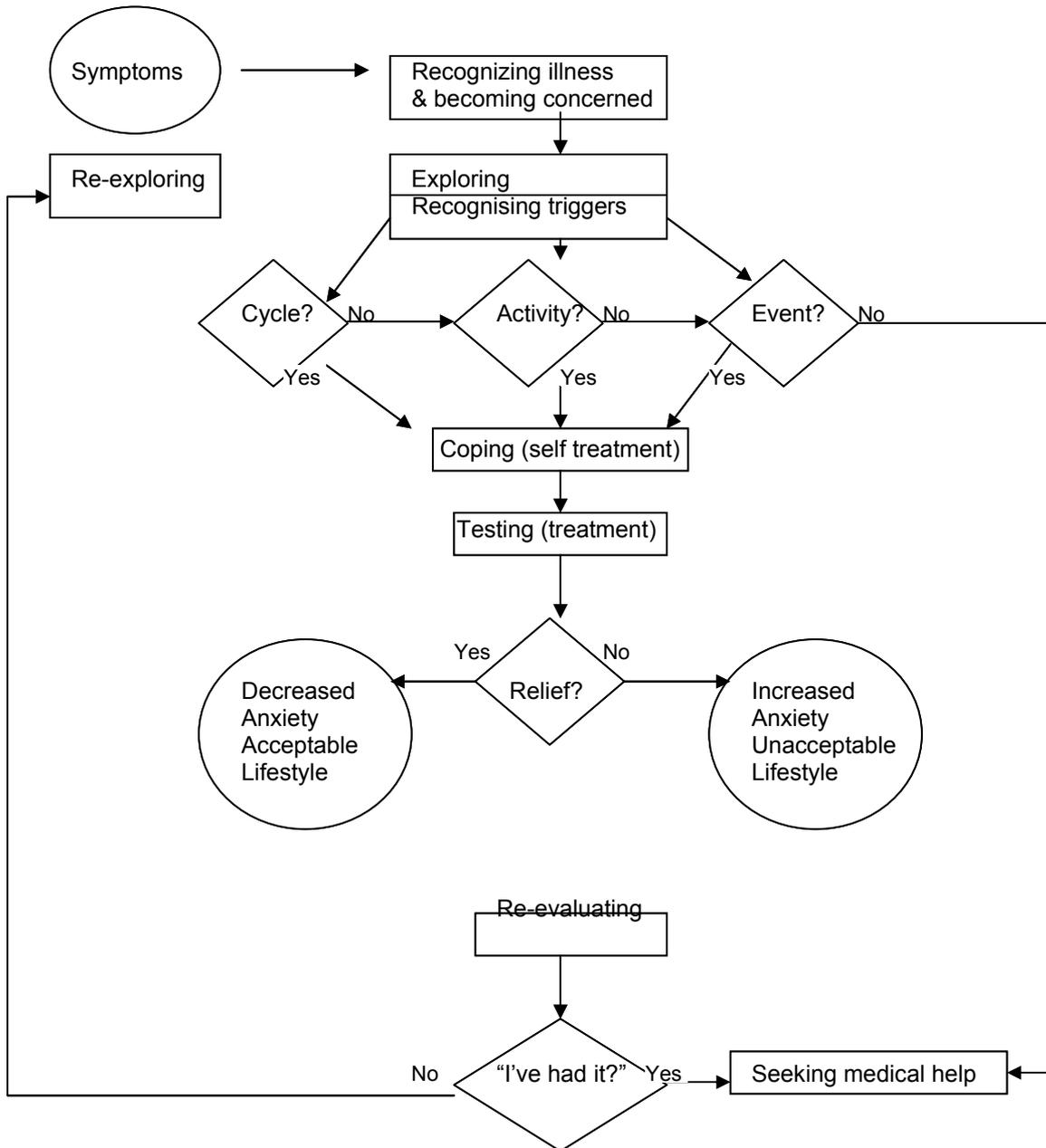
		Physician’s acknowledgement of illness	
		+	-
Husband’s recognition of illness	+	Confirmed illness	Doctor hopping
	-	Attempted to convince spouse	Doctor hopping/ distressed

*Negotiating the medical management of the condition* Medical identified as different from lay illness management strategies. Women felt disadvantaged approaching physicians who they perceived as having privileged knowledge about the body and controlled access to medication. Whiles some were assertive in consultations, most acquiesced to doctor’s decisions. As in many cases, investigations revealed no underlying benign cause, women started to worry about cancer. Initial suggestions of hysterectomy, which was presented as the last possible treatment available, were often felt to be overwhelming, women were shocked and disbelieving. Most Drs expressed a preference for retaining ovary/ies if possible, although reasons not always understood by women.

*The hysterectomy decision-making process* This varied greatly – decision made by Dr and husband (felt not to consider her feelings), decision made alone, joint with partners, assisted by husbands and Drs. Ability to cope with symptoms, and acknowledging that no

more children were desired was often the deciding factor, if future children had been desired, the decision was painful. Some husbands worried the surgery would affect their wives sexually. Other worries included losing a body part, and fear of the dangers of surgery itself.

**Figure 20: Learning to read the body**



**Stage 2: Struggling to Preserve Wholeness**

*Managing the separation* Preparing for hospital stay by trying to minimise disruption on husbands and children, providing practical and emotional support for family. Usually preparing husband to by clarifying “aspects of family routines such as their children’s extracurricular activities”(!), leaving frozen meals etc.

*Becoming a patient* Assuming the patient role in hospital which involved loss of control (few opportunities to initiate, select or orchestrate events) and sense of fragmentation (health professionals concentrate on illness/organs, rather than on whole person). Comfort depended on knowledge of hospital rituals (such as usual medical procedures) and mastery (understanding and ability to use) of medical language.

**Figure 21: Women’s perceptions of the patient role**

		Mastery of medical language	
		+	-
Knowledge of the purpose of results <sup>i</sup>	+	Collaborative	Resistant
	-	Acquiescent	Isolated

Women preferred to have someone there when they were examined – a female nurse, or their partners.

Concern about the surgery focused on: reaction to anaesthesia, how health care professionals would handle the body, possible cancer, extent of removal and remaining organs. Long term concerns were mental, emotional, and sexual changes, hormonal instability, and changes in relationships with others.

Immediate post-op experiences were physically intense – pain, vomiting, nausea – a leaving women feeling vulnerable. Altered sleep patterns and other effects of painkillers such as sense of unreality “changed the natural rhythm” of their bodies and number their ability to self-assess. Some preferred pain to side effects. Effects of pain killers also affected their ability to process and recall information given in the post-op period.

Uncontrolled bleeding and bladder infections the most common complications of surgery, which bleeding causing buy far the most concern.

As symptoms subsided and women became more able to carry out daily activities without assistance, they felt able to relate to their bodies in a normal fashion.

*Observing the changes* the finality of hysterectomy was considered – permanent removal of symptoms and ability to function better at work and home, but grief also. Grief related to many aspects – loss of the womb but also infertility, loss of intimacy with partners.

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<sup>i</sup> I think this is a typo in the paper – should be “ritual” not “results”

Women wanted more details about how the operations went and what had physically happened to them.

“The informants thought they were less than ordinary women when they thought health professionals and others were indifferent to their situation.”

Written information about what to do on returning home was generally not seen as helpful because no opportunity for exchange of information. Women appreciated being told to listen to their bodies, as this promoted ordinary behaviour to promote recovery.

**Stage 3: Recovering**

*Adjusting to the changes* Initial physical limitations managed through frequent rest, re-establishing bowel and bladder activity, appropriate nutrition, gradual increase in activity, and delegation of tasks. Healing was measured through comparing bodily response compared to others, their own previous state, testing their tolerance and reaction to activities. Concentrated on specifically affected physical areas (such as incision pain) or behaviour – resumption of normal sleep, bowel and bladder habits.

Mostly positive, with gradual improvement. Negative experiences where they were unable to re-establish normality, especially if there was pressure to re-establish roles. Home demands, especially from young children, were difficult to delegate. Other delegated tasks might not be done as they would wish leading to frustration over lack of control. Easier to go back to work outside the home as this was generally not resumed until later. Recovery pattern impacts on women’s assessment’s about whether or not they were right to choose hysterectomy.

Resuming sexual activity was a source of anxiety as they had 6 weeks to worry about it. Those who had close relationship with physician more likely to trust her/his assurances about post-hysterectomy sex lives. Some physical differences were noted on resumption of sex, although most said fears were unfounded.

Follow-up visit to physician allowed women to hear results of any tissue analysis and abnormalities. This allowed women to feel they had made the right decision. If uterus was “normal” this may cause doubts.

*Coming to terms with the hysterectomy* achieved through evaluating recovery and seeking evidence that surgery was the right decision. See matrix below Figure 22. One woman left feeling “out of control” and said she didn’t “feel like a woman”.

**Figure 22 Women’s perceptions of the hysterectomy**

		Recovery	
		+	-
Input on decision-making	+	Snapped back	Out of control
	-	Satisfied	Depressed

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	Y
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	N Y
Research question Explicitly expressed? Evidence of flow from phenomenon?	N Y
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	NA
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Clarification of influence of theoretical framework	N NA
Researcher credentials Documentation of researcher's discipline If yes, name it: Not clear – funded through nursing grant Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) Name of persons acknowledged by the authors and relationship:	N None
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	NS N N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria: women having hysterectomy in the previous month, repeated at 3-months post-hysterectomy Discussion of attrition in longitudinal studies?	N Y N
Data gathering strategy(ies) Clear description of data gathering procedures? If no, how could the description be improved? No details at all are given	N

Description of gaining access?	N
Discussion of time frame for data gathering?	N
Data analysis strategies	
Description of method(s) used?	N
Identification of categories or common elements found?	Y
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	Y
Data presented in such a way that relationships between categories/ themes are clear?	N
Analysis well supported by representative quotes/ findings?	N
Provision of evidence as to how representative in the sample the various findings were?	N
Conclusions, discussions, implications, suggestions for further study	No
Identification of limitations of study? –	
Discussion pertains to all significant findings?	N
Interpretive statements correspond with findings?	Y/N
Examination of findings with existing body of literature?	N
Clear indication of directives for future research?	N
If yes, indicate directives identified.	
Other considerations/ thoughts	
Intended direction of research changed during the course of undertaking. As it is, there is very little about recovery, compared to establishing reasons for hysterectomy.	
The matrices offer some theories of why women have positive and negative experiences through the process. Mostly this reads as a narrative account. There are a lot of unsupported assertions although space may be an issue.	

Complete citation:	Dell, P. (2000) Deconstructing the hysterectomised woman. In Women's health Contemporary International Perspectives
Author affiliation (discipline, institution)	NS
Funding source	NS
Acknowledgements	Father, editor J. Ussher, Dr H. Malson and Dr I. Anderson for comments and S. Papargiannidou for conducting interviews.
Period of data collection	NS
Location of study	Thessalonika, Greece
Dates of submission and acceptance	NS
Publication type	Book chapter
Mode of retrieval	
Key words (given on paper)	None
Abstract	None

### **Stated research problem**

"Contemporary (biomedical) research into women's experience of hysterectomy, as with research on the natural menopause....reproduces classical constructions of non-reproductive women as pathological, without considering the complex ways in which these more modern (biomedical) discourses act as "social practices that systematically from the object of which they speak (Foucault, 1972)."

Socio-historically, woman has been constructed as "reproductive body". The uterus is a potent signifier of women's emotional well being and sexuality. Associations of menstruation with toxicity, and uterus with hysteria and other mental health problems. "The normalization of the female body based entirely on its fecundity".

"Biomedical (and other) understandings of the possible experiences of hysterectomy are limited by the patriarchal conflation of "woman" with her (apparently) biologically determined "feminine role..... such that post-surgery loss of the uterus *signifies* loss of "femininity" and "womanhood"."

"researchers and women alike should take note of recent critiques of the modernist concept of the (essential) "woman" as guaranteed by her (reproductive) body."

"To view menorrhagia as predominately a medical problem when for two-third of women such blood loss is within the normal range says more about society's regulation of the female body than it does about concern for her health."

The research aims to both explore the materio-discursive construction of hysterectomised woman and explore the range of meanings it might sustain.

Major construct/ theory investigated (if applicable) (theoretical orientation)	The “hysterectomised woman” is a materio-discursive production.
Genre of study (note if stated genre fits design)	? Discourse analysis
Nature of sample: No. Age Ethnicity Education Other characteristics	10 40-52 ? white European? “Well educated” “Middle class”, “traditional families”.
General description of the research approach	Interviews
Methodological orientation	Foucauldian, post-structuralist, Materio-discursive

### **Major findings**

“Women and their gynaecologists constructed women’s bodies firmly within the biomedical model of anatomical cause requiring surgical intervention: the women’s symptoms being constructed as a signifier of disease by both parties rather than, for example, part of the natural process of aging.”

The gendered body is constructed as diseased due to its bleeding, and this has several consequences:

- the experience of illness draws attention to the body: foregrounding “inescapable embodiment”
- This body changes the sense of self simultaneously empowered to act (operate) and disempowered (hand over to medical authority).
- Body as diseased is a shock – provokes fear and anxiety.

Deciding to have a hysterectomy “is not so much about exercising informed choice but rather is seen as a necessity to regain control over a body discursively constructed as diseased by reason of its bleeding.”

Before seeing the Dr, none of the interviewed women described feeling ill, only bloody.

Given this construction, there is a possibility of the hysterectomised body being constructed as healthy and free from symptoms and potential cancer. Researchers should be encouraged to elucidate the positive aspects of women’s experience.

<p>Problem statement</p> <p>Statement of the phenomenon leads directly to the purpose of the study?</p>	Y
<p>Purpose of research</p> <p>Clearly expressed?</p> <p>Significance of research problem clearly indicated?</p>	Y Y
<p>Research question</p> <p>Explicitly expressed?</p> <p>Evidence of flow from phenomenon? HMM not sure – phenomenon part of general feminist concern about the way woman has been constructed in patriarchal socio-medical discourses</p>	Y Y/N
<p>Identification of assumptions?</p> <p>Identification of assumptions, preconceptions, presuppositions of researcher</p>	N
<p>Identification of theoretical framework</p> <p>Identification of theoretical framework?</p> <p>If yes, name framework (if it is not well known, include a description) Foucauldian structuralism</p> <p>Clarification of influence of theoretical framework</p>	Y Y
<p>Researcher credentials</p> <p>Documentation of researcher's discipline</p> <p>If yes, name it:</p> <p>Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) yes in terms of theoretical home.</p> <p>Name of persons acknowledged by the authors and relationship: Father, editor J. Ussher, Dr H. Malson and Dr I. Anderson for draft comments and S. Papargiannidou for conducting interviews.</p>	N
<p>Role of researcher</p> <p>Non-research relationship of researcher to participants?</p> <p>Evidence that the researcher has considered the effect of his/her presence on the research findings?</p> <p>Evidence that the researcher has considered possibility of researcher bias or misinterpretation.</p>	NS N N
<p>Sampling and participants</p> <p>Description of sampling procedure?</p> <p>Identification of inclusion criteria</p> <p>Discussion of attrition in longitudinal studies?</p>	N N NA
<p>Data gathering strategy(ies)</p> <p>Clear description of data gathering procedures?</p> <p>If no, how could the description be improved? No details of methodology at all are given here.</p>	N

Description of gaining access?	N
Discussion of time frame for data gathering?	N
Data analysis strategies	
Description of method(s) used?	N
Identification of categories or common elements found?	N
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	N
Data presented in such a way that relationships between categories/ themes are clear?	N
Analysis well supported by representative quotes/ findings?	Y
Provision of evidence as to how representative in the sample the various findings were?	N
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study? –	N
Discussion pertains to all significant findings?	Y
Interpretive statements correspond with findings?	Y
Examination of findings with existing body of literature?	Y
Clear indication of directives for future research?	Y
If yes, indicate directives identified. Researchers to focus on positive experiences.	
Other considerations/ thoughts	

Complete citation:	Dell P, Papagiannidou S. Hysterical talk? A discourse analysis of Greek women's accounts of their experience following hysterectomy and oophorectomy. J Reproductive and Infant Psychology 1999; 17 (4): 391-404
Author affiliation (discipline, institution)	Psychology Dept. University of East London.
Funding source	NS
Acknowledgements	Author's father
Period of data collection	Not stated
Location of study	Thessalonika, Greece
Dates of submission and acceptance	Submitted 7/4/98 Accepted with revisions 18/2/99
Publication type	Journal article
Mode of retrieval	E-search
Key words (given on paper)	None stated
<p>Women's experiences following hysterectomy have typically been understood from a medical perspective as a series of endocrinological, physiological and psychiatric symptoms which may require therapeutic intervention. Such an understanding is limited because it does not acknowledge that the experience is embedded within socio-political practices which have historically produced and sustained the human body. This article draws on feminist post-structuralist theory to examine ways in which experience following hysterectomy is constituted in relation to patriarchal and medical discourses. It is based on the transcripts of interviews with 10 Greek women, all of whom had had hysterectomies accompanied by oophorectomies for benign conditions. Discourse analysis indicated that central to understanding the meaning(s) of hysterectomy is the cultural production and regulation of hysterectomy as an embodied experience separated from and alien to the self. More particularly, for some women the whole body is pathologised as uncontrollable; for others it is the absence of uterus and ovaries themselves which denotes both absence of control and loss of femininity. Not all constructs, however, were negative. For some, hysterectomy liberated the body from the mark of "other" and, it is argued, offered a point of resistance to patriarchal discourses which privilege women with reproductive capacity as complete and sexual.</p>	

### **Stated research problem**

"This study explores how the historico-cultural discourse produce ways of "being" hysterectomised"

Hysterectomy for benign conditions is common. "While there is no reason for women to suffer gynaecological problems unnecessarily, the iatrogenic nature of the effects of surgery is a matter for concern as are the consequences of an early menopause and infertility." Medical and psychiatric literature over the past 50 years has tended to

approach the “post-hysterectomised women” as though she is a distinct clinical entity – a syndrome, corroborated by scientific measures of endocrine, physiology and psychiatric profiles as depressed, asexual and “hysterical”. The production of this hysterectomised body has been understood in terms of the individual, rather than as embedded in medical discourses - “social practices that systematically form the objects of which they speak (Foucault)”.

Those who “successfully cope” with aftermath of surgery conceptualised as having the appropriate expectations, psychological skills, and social support. However, this:

1. Leaves those who do have problems pathologised as psychologically vulnerable, or culturally pre-determined, without acknowledging the power relations that sustain these systems of categorisation.
2. Encourages the view that hysterectomy is a suitable tool to treat a variety of “women’s problems.”
3. Reproduces the classical construction of “woman” as intimately linked with her uterus, “hysteria”.

“In patriarchal societies, the feminine role emphasises satisfactory sexual functioning, fertility and childcare.” Although women may feel less pressured to adopt this role in recent years, this “feminine role” is not an unproblematic unified category, but a discursive site that sustains complex and contradictory meanings.

Central to understanding the meaning of post-hysterectomy/ oophorectomy experience is the “cultural production and regulation of the gendered body.”

Note that recent literature has tended to shift away from the womb onto the ovaries as the most potent signifier of women’s emotional well-being and sexuality (dysfunctional hormones now constructed as the cause of women’s madness).

Major construct/ theory investigated (if applicable) (theoretical orientation)	“contemporary research into women’s experience following hysterectomy has reiterated the classical construction of infertile woman as pathological...without considering the complex ways in which these more modern discourses are themselves productive of the ‘hysterectomised woman’.”
Genre of study (note if stated genre fits design)	Discourse analysis
Nature of sample: No. Age Ethnicity Education Other characteristics	10 40-52 Greek (?white Caucasian) “Well educated, at least to secondary level” Hysterectomies took place 1-12 yrs prior to interview All had hysterectomies with oophorectomy 9/10 married with children. 2 in employment
General description of the research approach	Semi-structured interviews approx 40 minutes. Transcribed in Greek, translated for article
Methodological orientation	Feminist post-structural Foucauldian analysis

Discourse analysis shows a “concern with both written and spoken language” understood as being constitutive of psychological reality – “the active labour of making things mean” (Hall, 1982).

## **Major findings**

### **The pathologized body**

Post-hysterectomy experienced as “a collection of bodily symptoms” (including emotional reactions), separated from mind, beyond the control of the woman herself and alien to her. This pathologised body is diseased and uncontrollable – but may be eased by medical intervention (HRT – paradoxically, an iatrogenic regulation).

Adoption of medical regulation not unproblematic, particularly where medical opinion differs. Example shows “choice” between future cancerous and future hysterectomised body.

### **Body as incomplete/ asexual commodity**

Uterus metonymically signifies whole women- idea of both as a commodity (worn out, how long it would last.)

As the uterus is a cultural signifier of women's sexuality and fertility, its presence is "normalising" and its absence is felt, most intensely immediately post-operatively.

The hysterectomised / oophorectomised body can be conceptualised as an oestrogen-deficient body discursively constituted as unfeminine and libido-less, non desirable which provokes anxiety. This regulates women where the discourse is internalised and sexuality experienced in a negative way.

Potential for the scar to become fetishised as a signifier of lack of femininity.

Status as hysterectomised/ oophorectomised may be hidden.

### **Body as liberated by hysterectomy**

Positive experiences where hysterectomy was seen as liberating the body from the constraints of menstruation which marked them as polluting, diseased or unhygienic and "other" to men. Freedom from taking measures to avoid pregnancy, from HMB. Bleeding constituted as problematic, unclean so its removal liberating and puts women back in control of her body.

The body did not necessarily feel ill prior to surgery, only bloody. Excess bleeding signifies an "excess" of femininity paradoxically making women feel unfeminine and asexual.

Liberation discourses may be seen as sites of resistance that should be encouraged as an antidote to prevailing negative discourses of femininity and sexuality.

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	N
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	Y Y
Research question Explicitly expressed? Evidence of flow from phenomenon?	Y N
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	Y
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Foucault Clarification of influence of theoretical framework Used as the framework and mechanism for enquiry and analysis – to explore how hysterectomy “is imbricated in particular knowledge domains and <i>how</i> those who are hysterectomised subjects are regulated but the materio-discursive practices extant within those domains.”	Y Y
Researcher credentials Documentation of researcher’s discipline If yes, name it: Psychology Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) Feminist, post-structuralist Name of persons acknowledged by the authors and relationship: father, Prof A Woollett and 2 anonymous reviewers for comments on previous draft, Dr Aggouridakis and Dr Gerorganas for information about Greek medical practice.	Y
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? Considers that generational gap may lessen the usual power imbalance between interviewers and interviewees Evidence that the researcher has considered possibility of researcher bias or misinterpretation. Although upfront about political agenda driving the research so not needed?	N Y N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria	N N

Discussion of attrition in longitudinal studies?	NA
Data gathering strategy(ies)	
Clear description of data gathering procedures?	Y
If no, how could the description be improved?	
Description of gaining access?	N
Discussion of time frame for data gathering?	N
Data analysis strategies	
Description of method(s) used?	Y
Identification of categories or common elements found?	N
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	Y
Data presented in such a way that relationships between categories/ themes are clear?	Y
Analysis well supported by representative quotes/ findings?	Y
Provision of evidence as to how representative in the sample the various findings were?	N
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study? –	N
Discussion pertains to all significant findings?	Y
Interpretive statements correspond with findings?	Y
Examination of findings with existing body of literature?	Y
Clear indication of directives for future research?	Y
If yes, indicate directives identified.	
Elucidate more positive discourses that free women's bodies, subjectivities and experiences from medical and patriarchal regulation.	
Other considerations/ thoughts	
Note some cross over with other included paper by same author.	

Complete citation:	Elson, J. Am I still a woman? Hysterectomy and Gender Identity. 2004. Temple University Press, Philadelphia
Author affiliation (discipline, institution)	Medical Sociology
Funding source	Doctorate funding Brandeis University Graduate School of Arts and Sciences, Graduate grant prize for Research in Women's studies, Brandeis University.
Acknowledgements	
Period of data collection	1997-1999
Location of study	Urban area, New England, USA
Dates of submission and acceptance	Not applicable
Publication type	Book
Mode of retrieval	Ref in journal article by same name
Key words (given on paper)	NS
Abstract	NA

### **Stated research problem**

Uterus and ovaries carry great cultural and personal significance. The uterus has no male equivalent and has historically been particularly considered synonymous with "woman". It occupies a central role in women's body image, social and gender roles. When these organs are surgically removed, women may find themselves feeling "defeminised". However, this is often not considered by individuals until they are faced with a crisis such as hysterectomy/ oophorectomy which gives them the opportunity to contemplate the meaning in the context of female identity.

Social constructionists (symbolic integrationists) argue that gender is created through interpersonal interpretation of action. It is not the property of individuals but is produced through situational performance. Traditional explorations of the rules of such gender(ed) performance have focused on those who transgress these social rules – transsexuals, transvestite, "intersex" people or others with different chromosomal or hormonal characteristics. "My intention in undertaking the current study was to explore the phenomenon of gender identity by studying individuals who have undergone surgical removal of their uteruses (hysterectomy) and/or ovaries (oophorectomy), a far more ordinary experience".

Elson finds social constructionism the most useful approach for the study, however she notes limitations, in that it does not fully describe embodied experience. "Feminist sociology has tended to be particularly "somatophobic" because women's bodies have

been the basis for biological determinism (Soelman, 1988)". Interviewed women oscillated between woman as sex (biology) and woman as gender (social and cultural perspectives). She aligns herself with embodied sociology, attempting to link lived experience and cultural representation and emphasises the former "the body is not totally constructed by social discourse or socialization processes, nor does it exist completely independently of these."

Other theories of sex and gender – biological essentialist, cultural essentialist and performance theories – are also discussed. Elson suggests that the women interviewed struggled with lay versions of these theories following hysterectomy.

An experience of illness perspective, focusing on the subjective understanding of what it is like to have a condition, is also taken. Illness is experienced as an attack on embodied selfhood, not just a physical attack – to change embodiment is to change identity (Turner, 1992). Illness as a biographical disruption.

### **Aim**

"to explore how – whether they perceived loss, stability or enhancement – participants dealt with the possible contradictions in gender identity presented by absent sexual reproductive organs"

Major construct/ theory investigated (if applicable) (theoretical orientation)	Gender identity is a constructed, flexible concept. Hysterectomy may challenge this identity causing them to reflect, perhaps for the first time, on what makes them a woman.
Genre of study (note if stated genre fits design)	Grounded theory (data analysis as on-going process, constant comparative analysis, development of themes)
Nature of sample: No. Age Ethnicity Education Other characteristics	44 24-69 (mean 38.9) 36 European American, 5 Latina American, 3 African American  27 bi-lateral salpingo-oophorectomy (bs-o) 3 separate hysterectomy and oophorectomy. 2 did not know if ovaries were removed. 0-60 years had passed since surgery. 23 married, 11 divorced, 6 single, 4 other Children: None 16 One 3 Two 13 Three 7 Four + 5 Straight 39 Lesbian 4 Bisexual 2  Self reported class: Homeless 1 Working class 8 Lower class 4 Lower middle class 4 Middle class 17 Upper middle class 10

General description of the research approach	Open-ended, semi-structured interviews lasting 90-180 minutes largely conducted in their own homes, workplaces or other private location. Recorded and transcribed. Field notes also taken. Emphasis on “lived experience”. Author encouraged narratives that were self directed, these included information about menarche, child birth etc.
Methodological orientation	Grounded theory  But also uses Foucauldian analysis I introduction/ and aligns herself with social constructionist theories of gender.  States that an ethnographic approach is most suitable for her purposes (help!)  Feminist research

Not that ERT is used for estrogen replacement therapy – often give for those with hysterectomies and avoiding in natural menopause as some evidence that ERT on its own may increase the risk of uterine lining cancer which is avoided by including progesterone in HRT.

### **Major findings**

(underlining indicates subheadings in the chapters)

Gender identity may be disrupted by hysterectomy. The following aspects are more likely to lead to such disruption:

- Bs-o oophorectomy,
- Women who were still fertile prior to surgery (regardless of whether they had already given birth)
- Straight women who feared diminished sexual attractiveness and who did not have supportive partners
- Women who perceived negative changes in sexual response
- Women who believed they had no control over decisions to undergo surgery

On the whole, women’s narratives reinforced the binary nature of cultural gender, and still identified as women post-surgery, which they valued. Agency is required to stretch the traditional biological definitions of woman to encompass them. A few women saw themselves as operating in alternative identities – neuter, liminal.

(biological markers – current breast and previous uterus/ ovaries were valued, no woman referred to her chromosomes to show she was woman. Personality markers – sensitivity, motherliness, kindness etc – also referred to.) Further, women created gender identity through selecting certain behaviours and appearances. It has been suggested that social

interactionism is not compatible with biological essentialism. However, cultural essentialism, whereby women perform according to a cultural essence, is demonstrated here. The more extreme understandings of gender performance (Butler) are not borne out as these women ground their experience in former biological fact.

The study lends support for simultaneous use of biological and social perspectives on the body. Participants merged biological, cultural and social rationales for gender identity post-hysterectomy.

Women's bodies are culturally constructed as inherently unstable and defective, requiring close monitoring and control. For some women, they believed that gynaecological problems were not the root cause of the pain/ bleeding, but that doctors looked there first, leading to hysterectomy. Because hysterectomies are common, women often know many relations and friends who have previously had one – hysterectomy as a kind of “inherited curse”.

Constructions of female bodies as objects experienced by women generally, and particularly as gynaecological patients. Women may also view their wombs as a separate object, not part of the self, especially if it is seen as a threat. Women experience extreme objectification if they have not been involved in decision-making (for eg hysterectomy performed at exploratory surgery). Some women believed that men are more cavalier towards them and their wombs/ovaries as they don't have them, but insensitivity was also reported about female doctors (medical socialisation stronger than gender socialisation.)

#### Constructions of female bodies as powerless

Some women felt powerless regarding possible treatment options because they were not offered, or because previous conservative treatments had failed and they felt they had run out of options. Severe symptoms were felt to demand hysterectomy. Some women felt normality could only be returned through hysterectomy and there was some anger at negative attitudes towards hysterectomy, and other people who felt hysterectomies were only performed on women “bamboozled by the medical establishment.”

Others felt that although they had chosen hysterectomy, they were not fully aware of the consequences physically, including side effects, or emotionally. Complications of surgery led women to re-examine their previous decision. Elson suggest that “elective” surgery may be so from the perspective of the doctor, but not by the woman. Statements that the removed organ was “normal” were not experienced as reassurance, but caused women to question the operation.

At best, hysterectomy may only be a constrained choice.

#### Hormonal hierarchy

Gynaecological surgery prompts women to consider the meaning of their wombs and ovaries. Ovaries carry greater symbolic meaning with hormones, especially oestrogen seen as central to femininity, femaleness.

Women perceive stigma is associated with gynaecological surgery (Goffman) and create (social construction) a stratified, “hormonal hierarchy” depending on whether all, some or none of their ovaries are removed. Retaining (part of) their ovaries allowed women to

continue to identify with “biologically normal” women who had not had gynaecological surgery and dis-identify with women who had ovaries removed. For this reason, women valued menstrual “waxing and waning” of hormones, including potentially PMS symptoms. This allows them to dis-identify with the stigma of hysterectomy and “pass as a “normal” woman.”

In the land of the blind man, the one-eyed man is king Women with one retained ovaries a little lower on the hormonal hierarchy than those who retains all, some asked to leave me a little piece and these women still felt higher than those who had oophorectomy, who they pitied.

Decisions regarding removal of ovaries are key – the uterus may be identified with childbearing primarily, whilst ovaries produce the sex hormones (especially oestrogen) that constitute sexual difference. Castration is really the proper way to describe removal of the ovaries, as they are the female gonads. Failure to name it so leaves women unprepared to deal with physical consequences of surgery. While hysterectomy often undertaken due to symptoms, ovary removal is often prophylactic.

Taking “everything” (or “all”) was often used to describe the removal of ovaries.

They also wanted “normal”, “natural” menopause. Elson notes that women who have hysterectomy without oophorectomy may have earlier menopause, and that women may be disappointed about this as they didn’t seem aware of it.

Some women who had bs-o had later regrets especially if they had agreed to it but were not fully aware of the impact – surgically induced menopause.

### **An “Ovary Prosthesis?” The meanings of estrogen replacement therapy**

(a note on language – some prefer HT rather than HRT as the latter implies that there is a lack that required treatment and re-labels menopause as a deficiency disease).

Medicalisation of natural menopause in common with other natural stages of women’s lives such as pregnancy, menstruation and childbirth. Women’s health activists have resisted these definitions of post-menopausal women as past their prime, no longer functional etc. which they regard as methods social control, and some self help books (*RG note I think this is written before recent scares about HRT and increased risk of coronary problems*).

Women having bs-o (=25% of US women) may be poorly served by the emphasis on menopause as normal.

Medically induced problems are acknowledged as potentially different, even by women’s groups usually critical (genuine “replacement” therapy in young women), although some participants still felt the need to justify their decision to take HT.

Elson suggests that the justifications for using hormone therapy for women with surgically induced menopause is subtly different to those used by women who go through natural menopause.

### **Gender related rationales for taking ERT**

#### **ERT as a strategy to recover control of the hormonal body**

Women perceive their bodies as under the control of hormones. Losing control of their hormones through ovarian surgery means they feel out of control and HRT is required for bodily “regulation”. Vaso-vascular menopausal symptoms – hot flushes, sweats etc particularly troublesome and may be more “sudden, frequent and physically devastating” in sudden, surgically induced menopause. These may make the otherwise invisible stigma of surgery, visible (Goffman)

#### ERT to secure youth and femininity

These women did not wish eternal youth or turning back the clock, but rather wished to experience appropriate youth while they were young, and not feel old before their time (“prune up”).

Retaining or regaining femininity through taking oestrogen. Some difficulty in this, for example where participants felt ERT resulted in weight gain, itself unfeminine. Also, taking a pill is potentially a reminder of the stigma of missing ovaries.

#### **“Resisters”, “stoics” and “martyrs”: the decision not to take hormones**

Only one woman fully resisted hormone therapy, she was older at 49 than most participants at time of hysterectomy.

Women on the whole were not aligned with those advocating resisting ERT – quite critical of “toughing it out”, being miserable, “martyrs”.

They therefore inverted the cultural concept that avoiding medication is a virtue.

#### Catch-22: possible long term benefits and risks of ERT.

#### Medical control and medical uncertainty

Participants were aware of “controversies” about long term health risks with ERT, minor (breast tenderness, fluid retention, migraine) and serious (breast cancer, heart disease). Benefits are also carried – prevention of osteoporosis, lowering cholesterol, prevention of vaginal atrophy.

Most felt the choice was up to them and used a variety of formal (doctors, medical research, women’s groups advice) and informal (friends and relations) sources of information before making it.

Advice could be ambiguous and confusing though, Drs often had different opinions, and women found uncertainty about risks and benefits difficult to deal with, and “a more crucial problem than medical control”.

#### Recent research regarding HRT and the Implications for ERT

*(RG note – this section feels like an add-in to the PhD work?)* Reports HERS study increased coronary risk results with HRT (but not with ERT?). This increases the uncertainty with ERT.

#### A “balancing act”: Weighing the risks and benefits

In the absence of certain medical evidence, most women preferred to take ERT. Decisions may be made on the basis of retaining or regaining femininity instead.

### **“Badge of femininity”? Menstruation**

(note – I’ve just taken scant notes for these 2 chapters – this one about periods and the next about childbearing, as focus of my interest is hysterectomy)

The association between menstruation and gender identity identified in previous research. Culturally, menarche marks initiation into womanhood. “Normal” women menstruate.

Menstruation as a connection to other females shared rhythms

Cessation of menstruation and gender identity Some previous researchers have suggested that menopause is problematic for women, who may have doubts about their womanhood.

Participants perceptions of menarche as a measure of female normality All participants identified menarche as the point at which they recognised they were female, and became a woman, and were normal.

Age at menarche affected attitude – unwanted early, wished for if late.

Connection with other females Women felt closer to female friends and relations at menarche, including bonding over the “mess”.

Recognition as females by fathers and sometimes support (over mothers’ objections) in terms of types of sanitary protection worn.

Negative aspects of menstruation as initiation into womanhood Embarrassment, awkwardness and rules for female behaviour/ social restriction/ taboos.

Entry into adult sexualization and fertility along with womanhood – marks them as “dangerous” sexual beings.

Missed aspects of menstruation:

Use of menstrual cycle as a regulator of their daily lives, rhythm, connection, internal calendar.

A feeling of connection to other women, “member of the club”, shared confidences and commiseration (helped if still have ovaries, PMS)

Redeployment of menstruation for their own emotional needs. For rest, assertiveness or bitchiness (an escape from usual cultural expectations)

Relief as Primary Reaction in the context of previous pain and bleeding.

Quality of life better without periods Most did not miss them – freedom from symptoms and restrictions

Female suffering as normal Excess blood and pain dismissed as “just part of being a girl” and this view internalised by some for themselves, and other women.

Disassociation with menstruating women Feeling of pity for them, and deliberate disassociation from.

**“Women’s Work”? Motherhood and Gender Identity** Culturally expected that all women must mother. Most women interviewed shared this vision. Hysterectomy severs the link, even if they had not intended to have (more) children. Infertility was felt as a threat to gender identity. This was felt regardless of whether they believed that maternal desire was natural or socially constructed.

Infertility and female Identity “Infertility can produce feelings of failure that precipitate... “identity shock.” Has been suggested that this may be particularly so in childless women undergoing hysterectomy. The research showed that, despite social changes that place value of women in roles other than mothering, women themselves placed importance on childbearing.

#### Women’s Reactions to loss of Fertility

No Regrets: some childless women With few exceptions, hysterectomy triggered “emotional gender crisis” because of the importance that women placed on the ability to reproduce. (My note – high number of childless women in the sample?) For the resolutely childless, hysterectomy let the “off the hook” of social and familial pressures.

Previously acknowledged regrets; some childless women For some, they had come to terms with childlessness for other reasons prior to hysterectomy.

No regrets: some women with biological children Most felt, like their childless peers, regret at not being able to have more. Some, including a catholic woman, were glad that the possibility of further children had been removed.

The despair of childless women Most “distraught” they were now infertile, women had “a substantial sense of loss” both personal and in the face of perceived societal expectations. “fertility had destroyed the core of her gender identity”, the ability to reproduce seen as the key separation between men and women. Women may feel a sense of “otherness” of being neither male nor female. Some found it difficult to join in “cultural fertility rites” such as baby showers, and felt that there was no space for or recognition of their negative feelings, sensitivity or pain around the pregnancy, and babies of other women. Hospitals housed women recovery from hysterectomy and women giving birth in close quarters and this was felt to be insensitive.

Those they perceived as “inadequate mothers” triggered anger and pain.

Inability to produce his child leading to insecurity due to the fear that partners may leave them – “inadequate as wives”.

Closing the final door Women feel strongly reproductive ability as a *potentiality*, a choice that was part of self-image.

Images used such as “crossing a bridge”, “chapter closing”, “the final dotting of the ‘i’”. this was the source of emotional grief for many.

“Women who have hysterectomies are forced to confront the end of their fertility not only before they are “psychologically ready” but before they are “*sociologically ready*.” This latter refers to the perception of life stage and where a woman sees herself in terms of her

age cohort – if friends and family still bawled to become pregnant, this is a painful reminder of premature loss. Paradoxically, existing children may also serve as a reminder, and may not mitigate against the grief, even if they had decided not to have more children.

Looking backward with regret is common with people with chronic illness (ref Corbin and Strauss, 1987) women undergo “*accounting reviews*” which re-evaluate past failures and successes in life, which can no longer be made right, such as miscarriages, abortions, relationships. Some felt guilt and blamed hysterectomies on past actions, or reframed them as cause for remorse (eg putting off childbearing due to careers, deciding to stay with or leave partners). For some participants, this was especially true for “life choices they had previously made that did not conform to a traditional feminine lifestyle”. This may be reinforced by other’s insensitive comments.

#### Restoring order/ Regaining control

Learning to Live with Infertility As other research has noted, there may be an exaggerated notion of control in our view of reproduction, when in reality, social and biological processes interfere with individual control. Individuals may be shocked if they can’t control reproduction as expected. Infertile women may see themselves as “not yet pregnant” and this option is removed by hysterectomy.

Restored/reconstructed Motherhood Motherhood was the “preferred identity” for many participants, they therefore tried to reconstruct this through roles as godchildren, stepmothers, aunts, cousins, fostering, caring for young people or adoption. Although for many the experience of pregnancy and childbirth is not one they see as replaceable.

Empty space Emotional and physical emptiness resulting from hysterectomy. Perception that they have an “empty hole” within. Symptoms of emptiness/ absence – “cavity”, “vacuum”, “nothingness”, “black hole”. Belief that this led to physical bowel and bladder symptoms. Women want to understand how the “void” is filled. See the absence as physical evidence they are no longer whole women. “No longer a woman, just a shell.”

One woman likened her post hysterectomy self to a transsexual as she had no uterus. Her previous bearing of children provided reassurance that she was still a woman.

Reproductive organs experienced as integral to their sense of self.

#### **“Feel like a woman”? Sexuality and gender identity**

Sexuality, like gender, is culturally constructed. Any physical effects of gynaecological surgery are mediated through social interpretation. Diverse effects were felt.

#### Woman as sexual object

##### Importance of sexual attractiveness

Current contemporary American norms suggest that recognition through men’s sexual desire is an important component of straight women’s gender identity. Attractiveness requires that women conform to ideals about physical perfection. Hysterectomy interrupts this. Lesbian and bi-sexual women interviewed were less affected by these concerns.

Standards for women’s attractiveness were identified as youthful appearance, slim figure and physical flawlessness all of which were thought to be threatened by hysterectomy

("dry-up like a prune," gaining weight after surgery, or being left with damages protruding abdominals) The scar carried a symbolic meaning, use the term "bikini cut" implies interest in maintaining a particular type of physical attractiveness. Some women resented Drs' indifference to the disfiguring nature of the scar, and felt they were made to feel vain or frivolous for their preferences about it's position. Others were concerned that doctors were too concerned about the scar – particularly telling women they could be belly dancers if the scar was minimal.

The scar is a "stigma signal" that may draw attention to their identify, a sign of lack of wholeness. Negative reactions from men were anticipated, especially among African-American women. (she refs Bernhard here)

Practically, women worried about splitting stitches and vulnerability of the scar.

#### Greater availability as a sexual object

Due to removal of the threat of pregnancy.

"Whether woman was stigmatised for becoming "sexless" or "oversexed", the common theme is that both stigmas are cultural consequences of women's perceived role as sexual objects".

Sexual frequency as a cause of hysterectomy? Believed in a couple of accounts.

Childhood sexual abuse and hysterectomy 7/44 women (16%) told interviewer they had been sexually abused a children. Some previous research has suggested a link between early sexual trauma and gynaecological surgery. One woman reported a dr suggesting this as a reason for hers.

#### Woman as sexual subject

Sexual response Disagreement between medical profession (also some within the medical profession) and women's health advocates about negative affects of hysterectomy on women's sexual desire and response. Four possible areas affected: libido (mental and physiological drives), arousability (capacity to be aroused – emotional and physical), genital tissues response, capacity for orgasm. However, most women did not feel their sexuality had changed.

Changes in vaginal configuration Women nervous about resuming sex after surgery because they didn't know what physiological changes may have occurred (shortened vagina, pain, "looser", "tighter").

Changes in vaginal lubrication Some found HRT helped, or used additional lube.

Changes in orgasm "the sex to me is not the same."

Hormonal changes: simple hysterectomy vs bilateral salpingo-oophorectomy Previous studies have not distinguished sufficiently between hysterectomy and bs-o. Many participants found HRT/ ERT helped with physiological problems after bs-o, regardless of age.

Battle over the cervix A few women tried to assert their right to keep their cervix. Their battles "are emblematic of misunderstandings and miscommunications between

gynecologists and their patients regarding sexual response.” Some felt they had to fight the medical assumption that avoiding cervical cancer was most important with their feeling that the cervix was involved crucially in their experience of orgasm. This was difficult and embarrassing to talk to doctors about. Some felt there was a gender difference – women’s groups said cervix was involved, (male) medical establishment said it wasn’t. The ability to talk, negotiate extent of operation helped women feel in control. Those who didn’t and found sex altered after cervix removed “felt impotent both literally and figuratively.

“Just different” either physically or emotionally.

Improved sexual feelings especially if conditions such as fibroids and HMB had hampered sex life before. Absence of fear of pregnancy, and so avoid taking contraception, which may also have been problematic, also beneficial. “they took out the cradle, but not the playpen.”

Dearth of information for lesbians.

A post-hysterectomy revelation regarding sexuality One woman experienced the hysterectomy as a rape. Became angry with the male doctors. Eventually came out as a lesbian. She explained this by saying that she had never felt like a woman and that the hysterectomy had helped her to face this about herself./

### **Biographical work and impression management: maintaining and reclaiming gender identity**

Many, but not all, participants found maintaining or reclaiming their gender identities was problematic. Regardless of sexuality, the quality of intimate relationships is the most significant factor in how successful they were at this. Emphasising the interaction between biological and social factors in the preservation of gender identity.

Use framework of “stigma potential” e.g. Scambler, 1984 distinguishes between *enacted* stigma (resulting from the discrimination of others) and *felt* stigma (shame induced by belief that they deviate from some social norm). Women believing that hysterectomy was stigmatising undertook *biographical work* and *impression management* to maintain or reclaim their identity as women, internally and socially respectively.

Biographical work (Corbin and Strauss, 1987 re chronic illness) Review, maintenance, repair and alteration of biography in order to regain control. For e.g. reclaiming “nurturing” aspect of selves in face of no longer being able to bear children, or taking HRT.

Other strategies included redefining what to meant to be a woman, - looking at ways of defining gender outside of the biologically determined.

Impression management (all participants did this)

Presenting an appropriate gendered image (Goffman 1959) presenting particular images of self to others. Often “sincere attempts to show others who we “really are” (RG note – camp?) Kessler and McKenna, 19987. Moreover, repeated performance may “ossify” these identities into true selves.(Blumstein, 1975)

Passing (Goffman 1963) Goffman distinguishes between discredited stigma – physically obvious to others and discreditable stigma, which may be hidden, allowing people to “pass” as “normal”. This is very possible as most social/ cultural signs of femininity are

external, not internal. Several “prettifying” (my term) strategies are described – hair, make-up, feminine clothes.

Information control with potential heterosexual partners, due to perception they would believe her to be “not a woman” and that sex would not feel the same, and they may be rejected. Other women agonised about whether to tell potential lovers, torn between fears of negative attitudes while also thinking they probably couldn’t tell the difference. (note all ethnic groups)

Alternatively, women might chose to inform (= telling with an objective, Gramling and Forsyth, 1987) to get special status, or admit the lesser of two stigmas. An example given where a women tells her supervisor to explain why she feels she might not be performing her best.

Role of intimate partners the quality of this relationship was the most significant factor in how successfully women maintained the gender identity.

Supportive partners serve as a “protective circle” (Goffman, 1963), but the main work is done by the persons themselves (Corbin & Strauss 1987). All the lesbian interviewees and many of the straight ones had supportive partners – emotional and practical support was valued and helped to maintain gender identity.

Fear of rejection many women had not discussed their apprehensions about surgery with partners because disclosure might initiate their own doubts. They are therefore unable to reap the benefits of full support. (quoted Bernhard’s study with men here about possibility that men may feel unmanned by sex with a hysterectomised woman.)

Rejecting partners Several women had partners who did not offer support, were not aware of the impact or were outright rejecting – seeing them as not really a woman, and anticipating inability to satisfy them sexually, seeing the surgery as an attack on their masculinity. The is emotionally damaging.

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	Y
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	Y Y
Research question Explicitly expressed? Evidence of flow from phenomenon?	Y Y
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	Y/N/NA
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Embodiment, social construction, Experience of illness perspective. See above for more detailed description. Clarification of influence of theoretical framework Although there are a number of imported concepts throughout the book, and it is not always clear, despite the label of grounded theory, whether these were used as analytic lenses, or illustrations after analysis.	Y Y
Researcher credentials Documentation of researcher's discipline If yes, name it: Medical sociology Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) Feminist orientation. This book started out as a thesis. Name of persons acknowledged by the authors and relationship: Family, Peter Conrad and Shulamit Reinharz, supervisors, Stefan Timmermans & Catherine Kohler Reissman, on dissertation committee, dissertation writing group, friends, Michael Ames & Janet Francendese at Publishers, funding grants and fellowships Brandeis University Graduate School of Arts, Women's studies program Brandeis University, American Association of University Women. Women who were interviewed.	Y
Role of researcher Non-research relationship of researcher to participants? But probably none Evidence that the researcher has considered the effect of his/her presence on the research findings? Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	NS N N
Sampling and participants Description of sampling procedure? Convenience sample - personal contact and snowballing	

<p>primarily. Adverts in community locations resulted in few additional participants. Purposive sampling for lesbian/ women and low income population.</p> <p>Identification of inclusion criteria</p> <p>US women who had hysterectomy +/- oophorectomy for benign conditions</p> <p>Discussion of attrition in longitudinal studies?</p>	<p>Y</p> <p>Y</p> <p>NA</p>
<p>Data gathering strategy(ies)</p> <p>Clear description of data gathering procedures?</p> <p>If no, how could the description be improved?</p> <p>Description of gaining access?</p> <p>Discussion of time frame for data gathering?</p>	<p>Y</p> <p>Y</p> <p>Y</p> <p>Y</p>
<p>Data analysis strategies</p> <p>Description of method(s) used?</p> <p>Identification of categories or common elements found?</p> <p>Report of participants' response to analysis?</p> <p>Data analysis presented in a clear framework (identification of central themes and categories)?</p> <p>Data presented in such a way that relationships between categories/ themes are clear?</p> <p>Analysis well supported by representative quotes/ findings?</p> <p>Provision of evidence as to how representative in the sample the various findings were?</p>	<p>Y</p> <p>Y</p> <p>N</p> <p>Y</p> <p>Y</p> <p>Y</p> <p>Y</p>
<p>Conclusions, discussions, implications, suggestions for further study</p> <p>Identification of limitations of study? –</p> <p>Discussion pertains to all significant findings?</p> <p>Interpretive statements correspond with findings?</p> <p>Examination of findings with existing body of literature?</p> <p>Clear indication of directives for future research?</p> <p>If yes, indicate directives identified.</p>	<p>N</p> <p>Y/N</p> <p>Y/N</p> <p>Y/N</p> <p>Y/N</p> <p>Y/N</p>
<p>Other considerations/ thoughts</p> <p>She suggests that previous qualitative research (refs ENDOW studies and Dell) is based on existing medical or psychological perspectives, and “does not include comprehensive sociological perspectives, nor does it investigate the meanings of the diverse gender implications of gynaecological surgery”.</p>	

Complete citation:	Fleming, V. A Case study of one woman's experience. J Adv Nursing 2003,44(6): 575-582
Author affiliation (discipline, institution)	Prof of Midwifery, school of nursing, Glasgow Caledonian University
Funding source	NS
Acknowledgements	None
Period of data collection	Not stated
Location of study	UK
Dates of submission and acceptance	26-11-02 16-7-03
Publication type	Journal article
Mode of retrieval	E-database
Key words (given on paper)	Hysterectomy, case study, doubts, pain, nursing, midwifery
<p>Background. There are many published qualitative studies in the large volume of literature about hysterectomy documenting themes common to the majority of participants, such as social support, feelings of illness and wellness, pain and resumption of normal life rather than events which were unique or exceptional. Aim. This study explores the meaning of the experience of abdominal hysterectomy for one woman. Methods. Single client case study method was used. An overview of case study is presented and the rationale for its selection as an appropriate methodology for this study given. The participant and her 'significant others' are introduced. Findings. Four major themes relating to the participant's experience were identified: doubts and justifications, pain, embodiment and sense of betterness. These are discussed in relation to the participant, the research literature and nursing and medical practice. Conclusion. Highlighting the case of one woman and analysing her experience as a single case study has produced a depth of material not previously available in other studies. The findings should be of use to staff working in gynaecological nursing, but could also be used in the education of nursing and midwifery students</p>	

### **Stated research problem**

Hysterectomy is common. Previous research focuses on alternatives to traditional approaches to hysterectomy (medical), hospital stay, including information needs, follow up care (nursing). Qualitative research develops thematic analysis about experience of hysterectomy –identifying the common, rather than the exceptional. This study aims to “grasp the essence” of the phenomenon.

Aim – to explore the meaning of abdominal hysterectomy for one woman.

Major construct/ theory investigated (if applicable) (theoretical orientation)	None – explicitly grounded in findings.
Genre of study (not if stated genre fits design)	Hermeneutic phenomenology
Nature of sample: No. Age Ethnicity Education Other characteristics	Case study - 3 interviews, 3hrs, 48 hrs, 4 days and 6 weeks postop with woman undergoing hysterectomy. Two interviews each with consultant, nurse and partner. One group interview.  Woman was 35, an RN and feminist.
General description of the research approach	Case study using unstructured interviews, transcribed, and analysed using NUDIST software.  Analysis – texts examined to find “expression that reflected the fundamental meaning of the text as a whole” then every sentence examined to “expose its meaning for understanding” facilitating theme development. Also each sentence related to meaning of whole text and so sense extended. Selection of passages representing shared understanding to appear in report.
Methodological orientation	Phenomenology

### **Major findings**

4 main themes – doubts and justifications, pain, embodied experience, sense of betterness.

#### **Doubts.**

Doubts of woman about medical necessity for surgery – trivialising own experience, & hoping to find pathology. Needing to be in control. These dismissed or not seen by others interviewed.

#### **Pain.**

Immediately post-op – difficulty using the PCA which was not reported by notes. This not revisited in subsequent interviews. Immediate experience of pain physical, later moved to an emotional level due to revelations that at a appendectomy 20 yrs previously, a fallopian tube and ovary had also been removed – unknown to her.

Embodiment.

Changing perceptions of body through experience - disassociation from body about technical aspects of care, but moving to a need for "therapeutic touch" later – nurse provided reflexology & massage. Warmed dr's hands.

Sense of betterness.

Physically well but emotional hurt and angry about previous experience.

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	Y
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	Y Y
Research question Explicitly expressed? Evidence of flow from phenomenon?	Y Y
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	Y
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Clarification of influence of theoretical framework	N NA
Researcher credentials Documentation of researcher's discipline If yes, name it: Nursing Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) See above about interpretation of phenomenological research. Name of persons acknowledged by the authors and relationship:	Y None
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	N N N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria Discussion of attrition in longitudinal studies?	NA
Data gathering strategy(ies) Clear description of data gathering procedures? If no, how could the description be improved?	Y NA

Description of gaining access?	Y
Discussion of time frame for data gathering?	N
Data analysis strategies	
Description of method(s) used?	Y
Identification of categories or common elements found?	Y
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	Y
Data presented in such a way that relationships between categories/ themes are clear?	N
Analysis well supported by representative quotes/ findings?	Y
Provision of evidence as to how representative in the sample the various findings were?	NA
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study? –	N
Discussion pertains to all significant findings?	Y -
Interpretive statements correspond with findings?	integrated
Examination of findings with existing body of literature?	Y
Clear indication of directives for future research?	Y
If yes, indicate directives identified.	N
Other considerations/ thoughts	

Complete citation:	Groff JY, Mullen PD, Byrd T, Shelton, AJ, Lees E, Goode J. Decision-making, beliefs, and attitudes toward hysterectomy: a focus group study with medically underserved women in Texas. Journal of Women's health and Gender Based Medicine. 2000;9:39-50
Author affiliation (discipline, institution)	Director of Research – Family Practice and Community Medicine. Health Science Centre Medical school, School of Public health, Center on Aging all at University of Texas, Houston.
Funding source	Centre for Disease Control
Acknowledgements	Prevention Research Centres Program, National Centre for Chronic Disease Prevention and health Promotion, the Office of Women's Health, Centres for Disease Control and Prevention, the Women's Health Initiative Community Prevention Study, National Heart, Lung and Blood Institute, National Institutes for health. Community Partners, and clinic staff in participating clinics.
Period of data collection	Ns
Location of study	Texas USA
Dates of submission and acceptance	NS
Publication type	Journal Article
Mode of retrieval	E-database searches
Key words (given on paper)	-
<p>Variations in hysterectomy rates have been associated with assorted physician and patient characteristics, and the disproportionate rate of hysterectomies in African American women has been attributed to a higher prevalence of leiomyomas. The role of women's beliefs and attitudes toward hysterectomy and participation in decision-making for medical treatment has not been explored as a source of variance. The purposes of this qualitative study were to explore these constructs in a triethnic sample of women to understand beliefs, attitudes, and decision-making preferences among underserved women; to facilitate development of a quantitative survey; and to inform development of interventions to assist women with such medical decisions. Twenty-three focus groups were conducted with 148 women from community sites and public health clinics. Thirteen self-identified lesbians participated in three groups. Analysis of audiotaped transcripts yielded four main themes: perceived outcomes of hysterectomy, perceived views of men/partners, opinions about healthcare providers, decision-making process. Across groups, the women expressed similar expectations from hysterectomy,</p>	

differing only in the degree to which dimensions were emphasized. The women thought men perceived women with hysterectomy as less desirable for reasons unrelated to childbearing. Attitudes toward physicians were negative except among Hispanic women. All women expressed a strong desire to be involved in elective treatment decisions and would discuss their choice with important others. Implications for intervention development include enhancing women's skills and confidence to evaluate treatment options and to interact with physicians around treatment choices and creation of portable educational components for important others.

### **Stated research problem**

Hysterectomy rates are high in the US and variable. Rates among African American women are higher than among white women. The role of patient factors, such as attitudes or involvement in decision-making, in this variation has not been investigated.

Attitudes are correlated with, and predict, behaviour.

“Could racial variation in hysterectomy rates result, in part, from (sub)cultural differences in beliefs and attitudes about hysterectomy?”

Overt involvement in decisions about medical treatment has been shown to influence patients' choices and outcomes. There is a known link with socioeconomic status (SES).

“Exploring decision-making processes of women of varied race/ ethnicity and SES is important in attempting to understand patients' roles in medical care choices, such as elective hysterectomy.”

“Purpose of this study was to elicit what women belonging to three racial / ethnic groups (African-American, Hispanic and low-income white) expressed as important criteria and processes for making decisions about hysterectomy”.

Ultimately this would be used to develop instruments to measure attitudes.

Major construct/ theory investigated (if applicable) (theoretical orientation)	None
Genre of study (note if stated genre fits design)	NS
Nature of sample: No. Age Ethnicity Education Other characteristics	148 NS inclusion 30-65 African American (n=38), Hispanic (n=73), White (n=24) NS One lesbian FGD (n=13)
General description of the research approach	23 Focus groups
Methodological orientation	? thematic analysis

### **Major findings**

Findings are organised by group characteristics – ethnicity or sexuality. Findings were largely similar, but different in emphasis.

Women rarely distinguished between hysterectomy and removal of ovaries.

#### **African Americans:**

*Perceived outcomes:* Many knew women who had hysterectomies to relieve bleeding and pain, often from fibroids. Therefore seen as a positive as relieves symptoms, saves on buying sanitary products, negates need for contraception.

Negative comments about scar and facial hair, “body dries up” but treatable with HRT. Some thought loss of natural hormones was unfavourable. Varied views on impact on sexuality, but often dependent on partner.

*Views of partners:* Hysterectomy rendered women “not whole” – less interested in sex and less desirable. “Like falling into an empty hole”. Women stated that men could not tell if they had hysterectomy and their negative attitudes would not prevent them having one.

*Opinions about healthcare providers:* Preferred female doctor. General distrust of doctors, lack of respect, too quick to surgery, especially for African-American women. Possible financial motivations. Hysterectomy as genocide.

*Decision-making process:* Get multiple medical opinions and ask for information on alternatives. Many preferred uterus only removal (which they called “partial” hysterectomy). Opinions of women who had previously had hysterectomy would also be important, also relatives, husbands and prayer.

#### **Hispanics:**

*Perceived outcomes:* Many negative ideas about effects – especially depression, sadness, crying. Lack of sexual desire, vaginal dryness. Sadness about lost fertility. Concern about “hollow” space left by removal of uterus.

Positives – no periods, no chance of pregnancy. Relief from gynaecological conditions not mentioned.

*Views of partners:* men would see them differently, “not “useful” as women”, “no longer a woman”. Related to removal of uterus physically, not necessarily about childbearing. This was seen as generally true for men, but not for their women partners.

*Opinions about healthcare providers:* care better in the US than Mexico because Drs can be sued. But care in Mexico more holistic.

*Decision-making process:* Multiple Dr opinions – to get most information. Likely to do what Dr recommended. Consult relatives and husbands.

#### Non-Hispanic whites:

*Perceived outcomes:* Emphasised physical effects on woman’s body. Used their experience of ops such as C-section to describe hysterectomy outcomes related to the operation, scar, anaesthesia, recovery. Therefore vaginal hysterectomy preferred to abdominal . Financial implications if off work to receiver.

Negative physical effects included weight gain and excess body hair. Emotional impact both positive (“emotionally calm, like a spayed dog”) and negative “go crazy” “grouchy”. Most felt biggest influence would be emotional state before surgery.

Benefits – no need for contraception, no more menses, no risk of pregnancy.

*Views of partners:* Negative –“like falling into an empty hole”, thought men more likely to cheat on these partners, and to suspect women as now free from pregnancy. Men likely to be unsupportive.

*Opinions about healthcare providers:* Negative views. Drs motivated by money. Poor communication, “talked down to” women, especially poor women. Preferred women Drs. Wanted multiple opinions.

*Decision-making process:* Wanted rationale for surgery, and options. Inputs from friends, family, husbands, Ministers.

#### Lesbians:

*Perceived outcomes:* Benefit – freedom from periods, so activities such as swimming easier and better sex lives. Imagined for straight women freedom from unplanned pregnancy also a benefit. But some felt giving up the ability to have children could be emotionally difficult.

Main negative, physical loss of part of oneself. Also mood swings and need for HRT.

*Views of partners:* Supportive. One women said she would feel less desirable.

*Opinions about healthcare providers:* Ambiguous about gender preference. Second opinion important. Negative experiences around sexuality common. Drs seen as too quick to offer surgery and motivated by profit.

*Decision-making process:* Wanted to be in charge of their own decision-making and would research it themselves. Consult “knowledgeable others”. Seek second medical opinion. Involve partners.

Findings used to develop questionnaire – both topic and wording (e.g. “Loss of femininity”, replaced with “feeling less of a woman”). Whether differences in groups are the result from racial differences will be investigated in the quantitative phase of the study.

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	Y
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	Y Y
Research question Explicitly expressed? Evidence of flow from phenomenon?	Y Y
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	N
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) I'm not sure, question guide "based on a decision-making framework" Clarification of influence of theoretical framework	N NA
Researcher credentials Documentation of researcher's discipline If yes, name it: not clear from institute Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) none Name of persons acknowledged by the authors and relationship: Grant body, community partners, clinic staff.	N
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? In the sense that moderators were matched for language and ethnic identity. Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	NS Y N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria Women who had NOT had hysterectomy Discussion of attrition in longitudinal studies?	Y Y NA
Data gathering strategy(ies) Clear description of data gathering procedures?	Y

If no, how could the description be improved?	NA
Description of gaining access?	Y
Discussion of time frame for data gathering?	N
Data analysis strategies	
Description of method(s) used?	Y
Identification of categories or common elements found?	Y
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	Y
Data presented in such a way that relationships between categories/ themes are clear?	N
Analysis well supported by representative quotes/ findings?	Y
Provision of evidence as to how representative in the sample the various findings were?	Y
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study? –	N
Discussion pertains to all significant findings?	Y
Interpretive statements correspond with findings?	Y
Examination of findings with existing body of literature?	Y
Clear indication of directives for future research?	N
If yes, indicate directives identified. But used to plan quant survey.	
Other considerations/ thoughts	
Groups facilitated by women of the same ethnic group, native Spanish speakers spoke this in their group – transcript analysed in Spanish and then translated.	
They state that there was time for questions after the interviews, and women were given written info about considering hysterectomy. Information about anatomy and the procedure was given as part of this.	
After the first few interviews., three groups of lesbians were added, because men's views generated a lot of discussion "to explore whether this represented women's perceptions of males or sexual partners".	
Focus group discussion guide is given – 13 questions were grouped around "Knowledge and experience", "Beliefs and attitudes", Decision-making process".	
Codes used in analysis are also given (NUD*IST assisted):	
General attitudes to hysterectomy (positive, negative, neutral or not specified), hysterectomy definition, hysterectomy indication, effects of hysterectomy and / or oophorectomy (positive, negative, neutral or not specified), alternatives to hysterectomy, men's and partner's perceptions of women with hysterectomy, hormone replacement therapy effects (positive, negative, neutral or	

<p>not specified), HRT indications, alternatives to HRT, healthcare providers, menopause – nonsurgical, sources of health information, decision-making process, involving others in decision-making.</p> <p>The division of results by group rather than theme is awkward -0 makes it more difficult to see similarities and differences – there seem to be lots of similarities – differences mostly in emphasis?</p>	
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Complete citation:	Kinnick V, Leners, D. The Hysterectomy Experience: An ethnographic study. Journal of Holistic Nursing 1995; 13 (2) 142-154
Author affiliation (discipline, institution)	Both associate professors at the School of Nursing, University of Northern Colorado. RN qualifications
Funding source	Not stated
Acknowledgements	None
Period of data collection	NS
Location of study	NE Colorado
Dates of submission and acceptance	NS
Publication type	Journal article
Mode of retrieval	E-search
Key words (given on paper)	None
<p>Women who undergo a hysterectomy typically experience preoperative symptoms that severely affect quality of life. The purpose of this study was to understand the hysterectomy experience from the informants' perspective. The research design chosen was ethnography. Research aims included (a) describing the quality of life before hysterectomy, (b) understanding the decision-making process involved in having a hysterectomy, (c) describing the knowledge base women have about hysterectomies, (d) describing concerns and fears about hysterectomies, (e) making comparisons before and 3 months after the hysterectomy, and (f) discovering what advice women give each other about hysterectomies. Ethnographic interviews were conducted and analyzed according to the Spradley method. The informants provided researchers with valuable advice for professionals caring for women who elect to undergo a hysterectomy.</p>	

### **Stated research problem**

Traditionally, hysterectomy has been associated with depression, although recent studies have shown that only pre-operative depression is the only predictive variable of post-operative depression. The authors found no qualitative research about hysterectomy.

Study aims are:

- a) To describe QoL before hysterectomy
- b) To understand decision-making process around electing to have a hysterectomy.
- c) To describe the knowledge base women have before surgery.
- d) To describe concerns and fears women have about hysterectomy
- e) To make comparisons about life before and 3 months after the hysterectomy
- f) To discover advice that women would give to others about hysterectomy.

“An explanation of the cultural phenomenon of experiencing hysterectomy was proposed to help understand the hysterectomy from the perspective of the lived world of women who undergo surgery.”

Major construct/ theory investigated (if applicable) (theoretical orientation)	none
Genre of study (note if stated genre fits design)	States ethnographic but not sure what it is about the interview that make it this – seems to be semi-structured interviews with guide. No field element.
Nature of sample: No. Age Ethnicity Education Other characteristics	6 All in their 40s NS NS 5/6 employed, 2 nurses.
General description of the research approach	Interviews 3 months after elective hysterectomy.
Methodological orientation	Ethnographic (“study of culture.... from an emic or “native” position”).  Ethnographic analysis (Spadley 1979.) Data transcribed into the Ethnograph computer program. 2 researchers analysed.

**Major findings** organised around 5 domains and 15 associated themes – 3/5 related to anticipation of surgery, 2/5 expressed reflections of experience and aftermath. Organised about one central theme =

“From resourceful endurance to unexpected relief”.

**Domain 1: Miserable**

*Gush* experience of heavy bleeding

*Bloating* discomfort and negative impact on self-image

*Chronic discomfort* pain experienced, sometimes for years before surgery. In some cases extent not realised until after surgery.

*Bitchy* impact of physical symptoms.

## Domain 2: Talked to others

*Do it* Many people consulted, consistent advice to go ahead, usually those who had had hysterectomy – reassurance of right decision.

*Negative things* usually from those with second hand information about complications, HRT.

## Domain 3: Not knowing what to expect

*Scared me* General concerns about surgery (anaesthesia, pain etc.), specific concerns about impact of hysterectomy physically and psychological outcomes. One informant had seen a TV show and read a book about how unnecessary hysterectomies are “and it just about scared me to death”.

*Sources of information* Information about hysterectomies in the lay media were largely about why women shouldn't have one. Dr information sheets too general. Would prefer structured consultation to give full details of intended procedure.

*Surprises* Not prepared for – the degree of post-op pain, being shaved before surgery, having to get up and walk immediately after. 3 had panic attacks afterwards. One nurse described this as an “out of uterus experience”, not uncommon.

## Domain 4: Outcomes

*Changes* Mostly very positive – removal of pre-op symptoms.

*No less a woman* All said this was so, all had finished childbearing.

*Sex* 5/6 said sex the same or better – freedom from unwanted pregnancy. One woman felt “totally exhausted” and attributed this to HRT.

## Domain 5 Caring support

*There for me* Attending appointments. Practical help with household tasks after surgery. Checking they ate and slept during recovery period.

*Getting to know me* Lacking from most primary physicians, better with nurses. Women valued being treated as human being – taking time to get to know them, calling them by name, finding out how they felt.

*Caring for self* “related to choices made by the respondents to help give them control over their experience and to help make it more positive”. Who knew and accompanied them, made plans for home life and recovery.

(“media that sensationalise the unnecessary hysterectomies that women have historically been pressure into probably have a direct influence on women's delaying surgery longer than necessary, even when there are tremendous physical problems.”)

Define hysterectomised women as a “subculture” from whom the medical profession can learn.

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	Y
Purpose of research Clearly expressed? But not all answered – no advice women would give to others? Significance of research problem clearly indicated?	Y N
Research question Explicitly expressed? Evidence of flow from phenomenon?	Y Y
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	N
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Clarification of influence of theoretical framework	None NA
Researcher credentials Documentation of researcher's discipline If yes, name it: Both are RNs with academic positions on the school of nursing, university of N., Colorado Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) Name of persons acknowledged by the authors and relationship:	Y N None
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	NS N N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria Discussion of attrition in longitudinal studies?	Y N NA
Data gathering strategy(ies) Clear description of data gathering procedures? If no, how could the description be improved? Description of gaining access?	Y Y

Discussion of time frame for data gathering?	N
Data analysis strategies	
Description of method(s) used?	Y
Identification of categories or common elements found?	Y
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	Y
Data presented in such a way that relationships between categories/ themes are clear?	N
Analysis well supported by representative quotes/ findings? Very short, often single word examples given	N
Provision of evidence as to how representative in the sample the various findings were?	Y
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study? –	N
Discussion pertains to all significant findings?	Y
Interpretive statements correspond with findings?	N
Examination of findings with existing body of literature?	N
Clear indication of directives for future research?	Y
If yes, indicate directives identified. Need to do more research about impact on sex as only 3 months since operation here.	
Other considerations/ thoughts	
Interview guide supplied.	
I'm not clear that hysterectomised women represent a "subculture"?	

Complete citation:	Lees, E, Shelton AJ, Groff, JY. Beliefs and attitudes of Middle aged lesbians about Hysterectomy. J of the Gay and Lesbian Medical Association 200; 5 (1): 3- 10
Author affiliation (discipline, institution)	MPH, Baylor School of Medicine, PhD, University of Texas – Houston School of Public Health, MD, PhD University of Texas – Houston School of Medicine
Funding source	Prevention Research Centres Program, National Center for chronic Disease prevention and health Promotion, and the Office of Women’s Health, Center for disease Control and Prevention; and the Women’s health Initiative Community Prevention Study, National Heart Lung and Blood Institute, National Institutes for Health.  Part of ENDOW
Acknowledgements	Commissioners and the Monroe Counselling Centre.
Period of data collection	NS
Location of study	Not stated but assume Texas
Dates of submission and acceptance	Not stated
Publication type	Journal article
Mode of retrieval	E-journal
Key words (given on paper)	Homosexuality, female; hysterectomy; attitudes, women.
<p>Objective: The aim of this study was to identify the beliefs and attitudes of lesbians aged 30–65 years regarding hysterectomy. Design: This qualitative study comprised 12 lesbians in three focus groups, utilizing a semistructured guided discussion technique based on qualitative application of Multiattribute Utility Theory. Participants were chosen to represent various stages of decision-making, and women who had undergone a hysterectomy were excluded from the study. Setting: All sessions were conducted in a Houston health clinic serving the lesbian community. Measurements: Transcripts were analyzed using Nonnumerical Unstructured Data Indexing Searching and Theorizing (NUD*IST). Results: Major categories, comprising multiple themes, were perceived outcomes of hysterectomy, help-seeking, and experiences with the physician or with the medical establishment. The lesbians in the study revealed both positive and negative outcomes of hysterectomy on sexuality. Loss associated with hysterectomy was perceived as physical, emotional, and ontological. Partner support emerged as a salient outcome. There were varying attitudes toward the use of hormone replacement following hysterectomy. For the lesbians, being in charge of decisions concerning their bodies was crucial, and they would seek information from a number of sources, including two or more physicians, before making a decision</p>	

regarding hysterectomy. Although the women reported negative experiences with physicians, these experiences were not related to the physician's gender or sexual orientation. Conclusion: While being sensitive to the needs of lesbian patients, physicians also must keep in mind that hysterectomy is an individual decision.

**Stated research problem**

As lesbians usually receive healthcare in medical settings with their heterosexual counterparts, their particular needs may be overlooked. Hysterectomy is of concern as both partners may be affected, and one study found lesbians 2.5 times the number of hysterectomies as bisexuals. It has been posited that this is related to less concern about fertility. There has been little research about lesbians' attitudes to elective gynaecological care.

Major construct/ theory investigated (if applicable) (theoretical orientation)	None
Genre of study (note if stated genre fits design)	NS. Broadly phenomenological
Nature of sample: No. Age Ethnicity Education Other characteristics	12 30-65 (mean 43.1) 5 African American, 1 Hispanic, 6 White. Mean 17 years education. 9 employed, 2 on public assistance for health care Self identified lesbians ½ had been advised to have a hysterectomy.
General description of the research approach	3 focus groups
Methodological orientation	Study questions derived using the Multiattribute Utility Theory (MAUT) to "elicit perceived outcomes in individuals". Use content analysis (ref Zemke and Kramlinger, 1986) on NUDIST for themes not elicited specifically by question in the guide.

**Major findings**

Many findings are similar to those with straight women. Three main themes: "perceived outcomes of hysterectomy" encompassing sexuality, resolution of sexual abuse, emotional impact of loss, partner support, impact on health. "Help-seeking" including control, use of multiple opinions, resources for research, communication with friends and family, barriers to seeking information. "Experiences with the physician or with the medical establishment" including a broad range of individual experiences.

Predominant theme = “desire to be in control of the situation and their bodies”.

### **Perceived outcomes of hysterectomy**

*Sexuality* Freedom from menstruation seen as sexually liberating. Periods an emotional and “messy” inhibitor to sex. Benefit to partner as well as self. Speculation that as penetration less important in sexual relations, impact may be less for gay than straight women.

Others saw hysterectomy negatively – loss of uterus affects “femaleness” or “sexual identity” – this latter seen as a problem for others, not themselves..

#### *Resolution of sexual abuse*

Uterus and menstruation associated with abuse for some participants. One women identified both abuse and hysterectomy as “castration”.

*Emotional impact of loss* Relates to loss of physical self, “staying whole”, or a less definable “loss” beyond the physical – psychological, emotional. Other women thought otherwise. Some thought concern about reproductive capacity may be more a concern for straight women.

*Partner support* Anticipated more support than for other sorts of surgery, and better support provided by female, over male partners – better empathy and understanding of bodies. Acceptance of whatever decision made.

*Impact on health.* Need for HRT a strong negative factor.

### **Help-seeking**

*Control* Consensus that being informed allowed them to be in charge of their bodies.

*Use of multiple opinions* See more than one doctor as an information gathering strategy.

*Resources for research* medical libraries and literature used. As well as TC, internet, magazines.

*Communication with friends and family* used as another source of information and personal experience.

*Barriers to seeking information.* Some women referred to who would not consult for fear of disclosing sexuality. Generally lack of access to information for people. Access even more difficult due to lower socio-economic status, gender and sexuality. Preventative care especially often not accessed.

### **Experiences with the physician or with the medical establishment**

Generally critical of approach to hysterectomy – to eager to perform especially in the past. Women’s vigilance brining numbers down.

Reported unsatisfactory encounters unrelated to gender or sexuality.

Felt that information was sometimes withheld.

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	Y
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	Y Y
Research question Explicitly expressed? Evidence of flow from phenomenon?	Y Y
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher – although there is an assumption that the reports of lesbians may be different.	N
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Clarification of influence of theoretical framework	N NA
Researcher credentials Documentation of researcher's discipline If yes, name it: not clear, in medical school Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) none Name of persons acknowledged by the authors and relationship: See above – commissioner.	N
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? Only in that the facilitators were female and the lead lesbian. Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	N N N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria Discussion of attrition in longitudinal studies?	N Y NA
Data gathering strategy(ies) Clear description of data gathering procedures? If no, how could the description be improved? Description of gaining access?	Y Y

Discussion of time frame for data gathering?	N
Data analysis strategies	
Description of method(s) used?	Y
Identification of categories or common elements found?	Y
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	Y
Data presented in such a way that relationships between categories/ themes are clear?	N
Analysis well supported by representative quotes/ findings?	Y
Provision of evidence as to how representative in the sample the various findings were? Some	Y/N
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study? – small sample, not generalizable. Higher than expected number of women had been suggested hysterectomy.	
Discussion pertains to all significant findings?	Y
Interpretive statements correspond with findings?	Y
Examination of findings with existing body of literature?	Y
Clear indication of directives for future research?	Y
If yes, indicate directives identified. – Further investigation into the association of sexual violence and hysterectomy.	
Other considerations/ thoughts	
All three authors also among those on Groff et al (2000) in which 3 focus groups of a total 13 lesbians were included. Is this different? They reference it, but only to remake a statement that attitudes are best assessed in those who have not had a hysterectomy as this would influence recollections of decision-making – a statement made in the Goff et al 2000 paper as well, but references to another paper!	
I would add to limitations that the women were recruited through a local lesbian professional group and fliers in a health centre in the city's gay community.	

Complete citation:	Marchant-Haycox S, Salmon P. Patients' and Doctors' Strategies in Consultations with Unexplained Symptoms. Interactions of Gynaecologists with Women Presenting Menstrual Problems. Psychosomatics 1997; 38 (5): 440-450
Author affiliation (discipline, institution)	Department of Psychology University College , London & University of Liverpool.
Funding source	NS
Acknowledgements	Participating gynaecologists. Dr Carl May for discussion of data, Dr C Dowick for comments on a draft.
Period of data collection	1995
Location of study	NS – hospitals with high numbers of menstrual dysfunction consultations. UK.
Dates of submission and acceptance	Received 5/6/96, revised and accepted 6/11/96.
Publication type	Journal article
Mode of retrieval	E-database
Key words (given on paper)	NS
<p>Patients commonly receive invasive investigation and treatment for subjective symptoms, but little is known about how this decision is reached. Therefore, the authors audiotaped the interactions of gynaecologists with 88 patients presenting menstrual problems without confirmed physical pathology. From these, eight interviews that led to hysterectomy were chosen for detailed qualitative analysis, together with eight of those leading to other responses. Dialogues leading to hysterectomy were characterized by a framework dictated by the patient. She presented deteriorating subjective symptoms and psychosocial distress in a way that placed responsibility on the gynaecologist. She imposed a biomedical model on the dialogue, which entailed presentation of an anatomical cause and a surgical solution, with criticism of conservative treatments. Interviews leading to conservative responses were, by contrast, characterized by a strategy whereby gynecologists established authority by confirming their ability to "look inside" the woman's uterus and see that it was normal. The results suggest a novel view of consultation in the absence of physical pathology. The patients and doctors in this study were opponents who used specific strategies to assert authority by emphasizing contrasting areas of expertise: knowledge of subjective symptoms vs. the inside of the body. The use of these strategies helps to explain whether hysterectomy is chosen as a response to menstrual problems in the absence of pathology.</p>	

**Stated research problem**

Treatment is often provided in the absence of objective signs or symptoms. Patients may not be helped, and could be harmed. It is therefore important to understand how decisions are made about physical treatment of subjective symptoms. Previous studies have concentrated on Dr influence in the consultation and the patient impact has been neglected (traditionally seen only in terms of compliance).

Aims:

1. To add to existing ways of understanding dr-pt interaction by delineating components of patient presentation and surgical response whereby either party might influence the other
2. To propose a theory, grounded in an account of such interaction that would explain why patients receive one clinical response or another. This theory should be amenable to testing quantitatively.

Major construct/ theory investigated (if applicable) (theoretical orientation)	See below
Genre of study (note if stated genre fits design)	Grounded theory
Nature of sample: No. Age Ethnicity Education Other characteristics	16 (/88 total) NS NS NS Sample included those with dysmenorrhoea or menorrhagia .
General description of the research approach	Consultations were watched and audio-taped. Initial testing of account on 6 transcripts, then additional 10 until "this method became unfruitful" (?=saturation)
Methodological orientation	They do a "editing-analysis style" – "in which the aim is to allow theory to arise from a thematic analysis of the scripts. Not clear if or how this differs form grounded theory – Strauss also referenced. A case study of pone interview is also presented so that the manner and sequence of strategies for patient influence is shown.

### **Major findings**

"The clinical decision is negotiated by material other than the symptoms."

THEORY = “In the absence of organic signs, patients and doctors use strategies that we have described to exert their influence toward opposite ends: disengagement (sought by the doctor) and engagement to the point of surgery (sought by the patient).” These strategies use aspects that they alone have access to – view inside the uterus (Dr) & subjective experience of symptoms and their effect (patients.) Their interaction is therefore one of opponents rather than collaborators.

Adding to the theory of Shorter described above, patients can additionally exploit an additional dimension of responsibility – culpability. Conservative procedures may contribute to deterioration, adding a moral, to the existing professional, responsibility to the patient.

#### CONSULTATIONS THAT LED TO CONSERVATIVE TREATMENT:

Gynecologists personalized report of normality ie that the uterus was normal, often stated because Dr had looked at it giving them personal authority.

#### Gynecologists’ Models of normality

*The inadequacy of the categorical model of normality* Discordance between symptoms reported and Drs assurances of normality (this disregards the patients symptoms).

*Ambiguous Models of normality* Ambiguity is descriptions (e.g. “Your womb is perfectly normal. Very slightly enlarged.”) Such ambiguity likely to be problematic for the patient.

*“Lay” models of normality* Drs sometimes use lay rather than medical models of explanation. Identifying which symptoms “don’t mean anything” and which do and can be treated – a dualist view which gives the gynecologist the authority to separate meaningful/genuine from meaningless/ unreal, pains.

A machine based model identifies none serious problems (“needing “finer control”) – and therefore still treatable, although non-serious. Although as all women are different, the effects of treatment cannot be predicted. (Note – this section unclear)

#### Patients’ reference to external authority

No Dr cited literature of another person as authority. Patients did this a lot – both for literature and individuals.

#### Treatment decision

If Dr has eliminated pathology, usually no, or non-invasive treatment chosen. Involvement in a clinical trial made Drs wish to explore all the options with the Pt.

#### CONSULTATIONS THAT LED TO HYSTERECTOMY

Frequently show the patient’s power over the doctor.

#### Symptom presentation

*Deterioration* Failure to improve, or deterioration since last consultation, especially expansion of area of pain.

*Psychosocial distress* Negative impact of symptoms of emotions, social lives & employment. This technique in particular helps the patient to take control of the consultation, placing responsibility on the Dr for these aspects as well as medical needs.

*Danger* “I don’t think I can go on” and allusions to excessive use of pain-killers.

Patients’ Biomedical Explanatory model.

Locating symptoms in gynaecological domain. In some cases, the patient takes control of the medical model. A wish to “stop it” leading to request for hysterectomy. No attempt by Drs to normalise symptoms or offer models.

Criticism of available treatments

Prior treatments criticised as ineffective, or even worsening symptoms.

Patients reference to external authority

“my daughter actually says to me if you don’t get it [hysterectomy] done soon she’ll wheel me to the theatre and do it herself” (this statement is given an external reference?)

Treatment decision

Often Dr asks what should be done and patient responds with hysterectomy, in some cases after eliminating alternative treatments. One consultation showed Dr pressure to patient reluctance.

CASE STUDY OF A CONSULTATION LEADING TO HYSTERECTOMY: THE COORDINATION OF PATIENT STRATEGIES

This presents in detail a sequenced consultation comprising the elements above:

Symptom presentation: deterioration and psychological distress.

Patient’s explanatory model.

Treatment decision

Criticisms of conservative treatment

Patient’s reference to external authority

<p>Problem statement</p> <p>Statement of the phenomenon leads directly to the purpose of the study?</p>	Y
<p>Purpose of research</p> <p>Clearly expressed?</p> <p>Significance of research problem clearly indicated?</p>	Y Y
<p>Research question</p> <p>Explicitly expressed?</p> <p>Evidence of flow from phenomenon?</p>	Y Y
<p>Identification of assumptions?</p> <p>Identification of assumptions, preconceptions, presuppositions of researcher</p>	N
<p>Identification of theoretical framework</p> <p>Identification of theoretical framework?</p> <p>If yes, name framework (if it is not well known, include a description)</p> <p>? Discussion states “evidence for the process that Shorter has proposed from an historical analysis: that medicine loses control of models that pass into lay discourse about health and illness and that patients use these models to locate their problems within the domain of professional responsibility of doctors.”</p> <p>Clarification of influence of theoretical framework</p> <p>This is introduced in the discussion, but paper also referenced in first =sentence of the article.</p> <p>They also claim to be doing grounded theory.</p>	Y       N
<p>Researcher credentials</p> <p>Documentation of researcher’s discipline</p> <p>If yes, name it: Psychology and other author not stated.</p> <p>Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference)</p> <p>Name of persons acknowledged by the authors and relationship:</p> <p>Participating gynaecologists. Dr Carl May for discussion of data, Dr C Dowick for comments on a draft.</p>	Y
<p>Role of researcher</p> <p>Non-research relationship of researcher to participants?</p> <p>Evidence that the researcher has considered the effect of his/her presence on the research findings?</p> <p>Evidence that the researcher has considered possibility of researcher bias or misinterpretation.</p>	NS N N
<p>Sampling and participants</p>	

Description of sampling procedure?	Y
Identification of inclusion criteria	Y
Discussion of attrition in longitudinal studies?	NA
Data gathering strategy(ies)	
Clear description of data gathering procedures?	Y
If no, how could the description be improved?	NA
Description of gaining access?	Y
Discussion of time frame for data gathering?	N
Data analysis strategies	
Description of method(s) used?	Y
Identification of categories or common elements found?	Y
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	Y
Data presented in such a way that relationships between categories/ themes are clear?	Y
Analysis well supported by representative quotes/ findings?	Y
Provision of evidence as to how representative in the sample the various findings were?	Some
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study? –	N
Discussion pertains to all significant findings?	Y
Interpretive statements correspond with findings?	Y
Examination of findings with existing body of literature?	Y
Clear indication of directives for future research?	N
If yes, indicate directives identified.	NA
Other considerations/ thoughts	
Only the gynaecologists, not the women receive acknowledgement.	
Sampling used a random sample of those going on to have hysterectomy, from a purposive, consecutive sample of women consulting. Plus 8 transcriptions form consultations that led to more conservative management, also chosen at random. No details about how the random selection occurred.	
Selective analysis – didn't analyse in detail Drs attempts to clarify previous tests and consultations.	
A quote apparently from a patient, and a header (Case study) are given references – not clear what this means.	
The tone of the discussion seems to disapprove of women who hold their doctors responsible	

for the psycho-social as well as physical aspects illness? Also of patient commandeering medical models	
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Complete citation:	Mingo C, Herman CJ, Jasperse M. Women's stories: Ethnic variations in women's attitudes and experiences of menopause, hysterectomy and hormone replacement therapy. J Women health and gender based Medicine 2000; 9: S27-38
Author affiliation (discipline, institution)	Dept. Epidemiology, Dept. Internal Medicine & the Navajo Division of health. New Mexico. Discipline not clear – one Dr, with public health qualification.
Funding source	Centre for Disease Control and Prevention. Part of ENDOW
Acknowledgements	Commissioners.
Period of data collection	Jan 1996 – March 1997
Location of study	5 locations in New Mexico, USA
Dates of submission and acceptance	Not stated
Publication type	Journal article
Mode of retrieval	E database
Key words (given on paper)	Not given.
<p>To increase understanding of women's midlife changes, 23 focus groups were held to investigate the possible ethnic variations in attitude toward and experience with menopause, hysterectomy, and hormone replacement therapy (HRT) in non-Hispanic white, Hispanic, and Navajo women in New Mexico. The medical definition of menopause, no menstrual bleeding for 12 months, did not coincide with the women's definition of menopause as the hormonal fluctuations they experienced before, during, and after any change in their menstrual cycle. More women reported having to fight to have a hysterectomy than having one unnecessarily. Women complained about the lack of information and preparation prior to having a hysterectomy and expressed dissatisfaction with doctor-patient communication, but they were satisfied with their hysterectomy because they felt better after the surgery. Although women in the study reported that menopause and hysterectomy are seldom discussed openly, they all participated freely in the storytelling focus groups. The most traditional women, primarily rural Navajo and newly immigrated Latina, related few or no menopausal symptoms with natural menopause or after hysterectomy. Many of these women had not even heard of HRT. Many women who had been prescribed HRT expressed dissatisfaction with the side effects and dosage. Unsupervised tinkering with the dosage was the rule rather than the exception. The study revealed that women are much more alike than they are different. Traditional women in all ethnic groups had more in common with each other than they did with the least traditional women in their own ethnic group.</p>	

### **Stated research problem**

No real description of problem to be addressed.

Aim: to gain an understanding of the ethnic variations in women's attitudes and experiences of menopause, hysterectomy and HRT.

Major construct/ theory investigated (if applicable) (theoretical orientation)	Not given
Genre of study (note if stated genre fits design)	? Focus on experiences but using ethnographic interview techniques, and focusing on story-telling (narrative).
Nature of sample: No. Age Ethnicity Education Other characteristics	156. Mean age 59, Navajo, 40 Hispanic, 49 White Not stated 10 groups (74 people) naturally menopause, 12 groups hysterectomies, 1 mixed group with both (all Navajo) Groups further divided by ethnicity.
General description of the research approach	23 Focus groups. Bilingual facilitators used.
Methodological orientation	Open-ended ethnographic interview techniques. Women shared stories in a round robin style.

## **Major findings**

### **Menopause: starting at the beginning**

Stories usually began with onset on menses.

Difficult to get information about menopause, friends and family reluctant, embarrassed to talk about it.

### **Participants attitude toward and experience with health care providers**

Health care providers legitimise only a few menopausal symptoms, and women felt many of their concerns were dismissed. But acknowledged that it is hard to neatly define and fix the problem of menopause.

### **Hysterectomy: surprising stories**

Many had to “fight to have their surgery” despite long term and serious pain or excessive bleeding. Waned the minimal removed possible “I wish she’d been a little more sensitive to why I wanted to keep an ovary.”

But women very satisfied if main problem solved by surgery even if there were side effects. Not informed about the impact of hysterectomy on menopause.

It is inappropriate and insensitive to put these women in with post-partum women in hospital because of “trauma” associated with loss of fertility.

Women with less severe symptoms saw surgery as a drastic option to be avoided – through waiting, herbs, acupuncture, diet and exercise.

HRT: the jury is still out

No unanimous view about HRT, “when HRT worked it was wonderful; when it did not work, it was awful.” Note also that women “tinker” with their prescriptions – not taking them continuously, cutting pills in half etc.

CONCEPT Women from different ethnic backgrounds are more alike than different. (?My query – necessarily since they had to self define as menopausal to take part?) The experiences of women from Navajo and Hispanic/Latino groups vary according to how isolated they are from their traditional lifestyles. Women with more traditional diet, exercise, social support, language and healthcare lifestyles are less likely to experience menopausal symptoms. Meanwhile, whites have always associated hot flushes and craziness with menopause.

Women felt they knew their own bodies and wanted healthcare providers to “respectfully listen”.

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	N
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	Y N
Research question Explicitly expressed? Evidence of flow from phenomenon?	Y Y
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	N
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Clarification of influence of theoretical framework	N NA
Researcher credentials Documentation of researcher's discipline If yes, name it: Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) They prefer to use ethnographic interviewing rather than prescribed questions and prompts because of diversity of ethnicity and language within groups. Allows most natural and authentic way of speaking. Name of persons acknowledged by the authors and relationship: Commissioners – Prevention Research Centres Program, National Centre for Chronic Disease Prevention and health Promotion, and the Office of Women's health Initiative Community Prevention Study, National Heart, Lung and Blood Institute, National Institutes of Health.	N
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	N N N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria Discussion of attrition in longitudinal studies?	N Y NA

Data gathering strategy(ies)	
Clear description of data gathering procedures?	Y
If no, how could the description be improved?	NA
Description of gaining access?	Y
Discussion of time frame for data gathering?	Y
Data analysis strategies	
Description of method(s) used?	Y
Identification of categories or common elements found?	Y
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	Y/N
Data presented in such a way that relationships between categories/ themes are clear?	N
Analysis well supported by representative quotes/ findings?	Y
Provision of evidence as to how representative in the sample the various findings were?	N
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study? –	N
Discussion pertains to all significant findings?	Y
Interpretive statements correspond with findings?	Y
Examination of findings with existing body of literature?	N
Clear indication of directives for future research?	N
If yes, indicate directives identified.	NA
Other considerations/ thoughts	
Much of this is untransformed data.	
Hysterectomy only a small part of the study focus.	

Complete citation:	Richter DL, Kenzig MJ, Greaney ML, McKeown RE, Saunders RP, Corwin SJ. Physician-Patient Interaction and Hysterectomy Decision-making: The ENDOW study. American Journal of Health Behaviour 2002. 26 (6): 431-441
Author affiliation (discipline, institution)	Department of Health Promotion, Education and Behaviour; Dept of Biostatistics and Epidemiology; Geriatric Education; University of S. Carolina, University of San Francisco.
Funding source	National Centre for Chronic Disease Prevention & Health promotion, and the Office of Women's Health. Centre for Disease Control and Prevention, and the Women's Health Initiative Community Prevention Study, National Heart Lung and Blood Institute, National Institutes of Health.
Acknowledgements	Commissioners
Period of data collection	NS
Location of study	2 locations in S. Carolina
Dates of submission and acceptance	NS
Publication type	Journal Article
Mode of retrieval	E-database
Key words (given on paper)	NS
<p>Abstract</p> <p>OBJECTIVE: To investigate physician-patient communication in the context of hysterectomy decision-making. METHODS: A series of 17 focus groups with African American and white women (n=82) between the ages of 30 and 65 were run. Personal interviews with physicians (n=7) also were conducted. Transcripts were analyzed using NUD*IST software and note-based techniques. RESULTS: For both patients and physicians, the optimal physician-patient interaction would be for the physician to provide plain, usable information to the patient allowing the patient to make the hysterectomy decision. CONCLUSIONS: The current state of physician-patient interaction represents collaboration but not a shared approach approximating the deliberative model.</p>	

### **Stated research problem**

Hysterectomy rates vary. "As hysterectomy is most often an elective procedure, the decision-making process a woman goes through when considering a hysterectomy is

important.” A physician’s communication style and interaction with patients may influence their decision-making.

Aim: “To investigate women’s perceptions of the role of the physician in hysterectomy decision-making and to examine the physician-patient communication in the decision-making process. Women’s definitions of optimal physician-patient communication were also examined.”

Major construct/ theory investigated (if applicable) (theoretical orientation)	Described interactions were assessed against Emanuel & Emanuel’s styles of patient-physician interaction (paternalistic, informative, interpretive, deliberative)
Genre of study (note if stated genre fits design)	Broadly phenomenological? Looking for themes in descriptions of medical encounters
Nature of sample: No. Age Ethnicity Education  Other characteristics	Convenience  28 with hysterectomy, 54 without.  30-65 (hyst group older)  63% African American, 32% other, 5% other  11% <12 <sup>th</sup> grade (all hyst. Group); 28% hyst, 39% not - 12 <sup>th</sup> grade; 11% hyst 30% not - college grad; 21% g-hyst, 11% not – Graduate school; Unknown 10%.  61 hyst, 65% not – married/ living with partner. 47% hyst, 67% not employed. 46% had incomes of \$10K-\$35K.  7 physicians performing hysterectomies were also interviewed.
General description of the research approach	17 FGDs – separately for African-American, Caucasian, hysterectomised and non-hysterectomised women. Each n=9 to n=3.  7 interviews with gynaecologists
Methodological orientation	

### **Major findings**

Recurrent themes are reported.

Physician as information provider delineating options, outcomes, what to expect post-operation and alternatives.

Importance of the nature of physician-patient communication usually satisfactory. African American women more likely to say they didn't communicate well, or create an atmosphere conducive to communication (which needed time, being put at ease, given space to ask questions, familiarity with physician, physician who listens, using language that was comprehensible to them, feel that the interaction is personal). Feeling that low educational status was used as an excuse not to provide full information as it was assumed they would not understand.

Physician's role in actual hysterectomy decision-making not primary Role should be limited to information giving. In a minority of groups, women felt the doctor should have a more important role as they had the medical facts.

Necessity of a second opinion For peace of mind, or due to inherent distrust ("Doctors are cut-happy").

(themes from Dr interviews – optimal physician-patient interaction was assumed; physician as information provider; patient as decision maker regarding physician recommended hysterectomy; physicians unwilling to perform hysterectomy at the patient's request.)

Interactions closely approximate the "informative model" listed below, although both women and physicians express a wish for partnership (= deliberative model). Viewing drs simply as information providers precludes the development of a relationship on both sides and this may feed women's distrust, and leaves drs with little reason to invest in patient relationships if they are just seen as providers of information (" a human book or an interactive computer").

*Concept* – 4 styles of physician-patient interaction have been posited (ref Emanuel & Emanuel JAMA 1992). Deliberative suggested as the ideal. –

- Paternalistic – Physician as guardian performing the procedures that they deem to be in the patient's best interest without reference to their desires.
- Informative – the patient is in complete control – physician is a source of information.
- Interpretive – Physician as counsellor, examines and interprets patient's values, and provides treatments that best fit their values.
- Deliberative – Patient control, while physician provides information and helps apply it to the patient's values.

Problem statement	Y
Statement of the phenomenon leads directly to the purpose of the study?	N
Purpose of research	
Clearly expressed?	Y
Significance of research problem clearly indicated?	Y
Research question	
Explicitly expressed?	Y
Evidence of flow from phenomenon?	Y
Identification of assumptions?	
Identification of assumptions, preconceptions, presuppositions of researcher	N
Identification of theoretical framework	
Identification of theoretical framework?	Y/N
If yes, name framework (if it is not well known, include a description) ? Examine descriptions through Emanuel's, 1992 models of physician-patient relationship although this doesn't seem to influence themes/ concepts in analysis.	N
Clarification of influence of theoretical framework	
Researcher credentials	
Documentation of researcher's discipline	N
If yes, name it: Its not clear – multi authors in various departments (including health promotion, education and behaviour, Biostatistics, geriatric education, Health Education etc) so not clear exactly how discipline would be defined.	
Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) none	
Name of persons acknowledged by the authors and relationship: Commissioners (see above)	
Role of researcher	
Non-research relationship of researcher to participants?	
Evidence that the researcher has considered the effect of his/her presence on the research findings?	N
Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	N
Sampling and participants	
Description of sampling procedure?	Y
Identification of inclusion criteria	Y
Discussion of attrition in longitudinal studies?	NA

Data gathering strategy(ies)	
Clear description of data gathering procedures?	Y
If no, how could the description be improved?	NA
Description of gaining access?	Y
Discussion of time frame for data gathering?	N
Data analysis strategies	
Description of method(s) used?	Y
Identification of categories or common elements found?	Y
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	Y
Data presented in such a way that relationships between categories/ themes are clear?	N
Analysis well supported by representative quotes/ findings?	Y
Provision of evidence as to how representative in the sample the various findings were?	Y for some
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study? –	N
Discussion pertains to all significant findings?	Y
Interpretive statements correspond with findings?	Y
Examination of findings with existing body of literature?	Y
Clear indication of directives for future research?	N
If yes, indicate directives identified.	
Other considerations/ thoughts	
Participants not paid – check other ENDOW reports.	
“Themes were said to be related and important if they were mentioned more than one time across the groups”	

Complete citation:	Richter DL, McKeown RE, Corwin SJ, Rheaume C, Fraser J. The role of Male Partners in Women's Decision-making Regarding Hysterectomy. J Women's Health and Gender Based Medicine, 2000; 9 (2): S51-25
Author affiliation (discipline, institution)	Dept Health Promotion & Education, and Dept. Epidemiology & Biostatistics, School of Public health, University of South Carolina.  Dept. Health and Kinesiology, Georgia Southern University.  Armstrong Atlantic State University, Georgia
Funding source	Centre for Disease Control and Prevention. Part of ENDOW
Acknowledgements	Commissioners.
Period of data collection	NS
Location of study	2 coastal South Carolina counties
Dates of submission and acceptance	NS
Publication type	Journal article
Mode of retrieval	E-journal
Key words (given on paper)	NS
Abstract	<p>Although hysterectomy is a frequently performed surgical procedure, little is known about how women make decisions regarding hysterectomy. This report details the women's perceptions of male partners' knowledge and attitudes about hysterectomy and the role women expect or allow men to play in their decision-making process. Seventeen focus groups were conducted with a total of 82 African American and Caucasian women aged 30-65 years in two coastal counties of South Carolina. Transcripts were coded and analyzed using the nonnumerical unstructured data indexing searching and theory building (QSR NUD*IST) software program. Results indicate that women perceive men to be not well informed or knowledgeable about hysterectomy, to be concerned about the quality of sexual relations after hysterectomy, and, in some cases, to be neutral about hysterectomy. African American women reported that men hold more negative perceptions about hysterectomized women. Caucasian women stressed men's inability to understand what a woman is going through and men's concern with the hysterectomy's effect on their own egos. Nonhysterectomized women felt that men would be more bothered by a surgical procedure that left more visible effects (such as mastectomy). These women defined a limited role for men in their decision-making regarding hysterectomy, consisting of discussion and offering of support/sympathy, but they reserved the actual decision for themselves. In a few instances, women accorded men a role in the hysterectomy decision based on a religious interpretation of marriage. Intervention programs are recommended that target women and their partners together, using hysterectomized women and their partners as peer educators.</p>

### **Stated research problem**

Hysterectomy rates vary, suggesting professional uncertainty about its appropriate use. This means that patient preferences are important and it is therefore important to determine how women make decisions about having surgery, and what roles other people play in this process. The role of men has received little previous attention, and it is unclear how women perceive men's views.

The aim of this study was to examine women's decision-making regarding hysterectomy. In particular, this article focuses on how women perceive men's knowledge and attitudes about hysterectomy and how women define men's role in their decision-making process regarding hysterectomy.

Major construct/ theory investigated (if applicable) (theoretical orientation)	Theory of Reasoned Action (Fishbein & Ajzen, 1994) informed the 13 item FGD guide.
Genre of study (note if stated genre fits design)	
Nature of sample: No. Age Ethnicity  Education  Other characteristics Recommended hysterectomy	Convenience sample  82 30-65 African-American (63%), Caucasian (32%), Native American (1%), other/missing (4%) 4% < 12 <sup>th</sup> grade, 35% 12 <sup>th</sup> grade, 16% > 12 <sup>th</sup> grade 19% college graduate or higher 77% married or steady partner. 31%
General description of the research approach	17 FGD (4-6 in each) <sup>i</sup>
Methodological orientation	not sure!  NUDIST used. Codebook developed, multiple readers to develop/pilot this on 3 transcripts, themes coded.  Themes "related and important" if they were mentioned more than once across the groups.

### **Major findings**

- Themes across all groups (headers identified as themes in the paper here underlined):

#### **Sexuality and childbearing**

Women thought men had concerns about the quality of sex post-hysterectomy.

Positive for women that they no longer had to worry about contraception.

Concept women are "not whole", "less of a woman", "something wrong" after hysterectomy. This seems to be related to their reproductive capacity.

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<sup>i</sup> Although this is not clear as it is stated that in 3 groups the audio recording failed and that this affected 8 total participants. Perhaps a typo - should be 18?

### Men's lack of information

Men are not informed about hysterectomy.

### Hysterectomy a neutral issue

For some men, hysterectomy is not a significant issue – the wellbeing of the woman being paramount (unless the man still wanted to have children).

- 3 themes found additionally in African-American groups (hysterectomised and non-)

### Negative perceptions/terms

Men superstitious about hysterectomy – believed old wives tales (these are not specified in the paper...). Terminology used by men was undermining of women's self esteem – "bottomless pit" "dry hole" "mute" "empty shell". Less able to give and receive sexual pleasure, and no longer capable of reproduction.

### Men unable to discern hysterectomy

Physically, men are not able to tell if a woman has had a hysterectomy, however, some men are "obsessed with the thought of it" and this can lead to the end of a relationship.

### Women may not inform men of hysterectomy

- 4 themes found more strongly in white groups (hysterectomised and non-)

### Men unable to understand

Lack of information and knowledge among men mean they do not understand what a woman is going through.

### Mood swings

Men find it hard to cope with mood swings associated with hysterectomy and menopause.

### Effect on the male ego

Hysterectomy affects male egos or self concepts – feel they are both getting old. For some men, there is a conflation of women's sexual and reproductive selves.

### Men relieved

If hysterectomy relieves women's previous suffering.

- Additional theme among non-hysterectomised groups (white and African American)

### Visibility/ invisibility of effects

Important to men that hysterectomy leaves a woman externally intact (apart from the scar in abdominal procedures) – compared to, for example, mastectomy.

- Men's role in decision-making (common across ethnic groups, and hysterectomised or not)

### Male partner as sounding board

All wanted to talk to partners and get input from them.

### Sympathy and support

Practical support, such as accompanying them to the doctors, or verbal support, sympathy and understanding were desired.

### Men do not make the decision

Male partner was one source of support among many – friends, family, media – and the decision was the woman's alone. A few women involved men more strongly, based on a religious interpretation of bodies belonging to each other in marriage.

Problem statement	
Statement of the phenomenon leads directly to the purpose of the study?	Y
Purpose of research	
Clearly expressed?	Y
Significance of research problem clearly indicated?	Y
Research question	
Explicitly expressed?	Y
Evidence of flow from phenomenon?	Y
Identification of assumptions?	
Identification of assumptions, preconceptions, presuppositions of researcher	N
Identification of theoretical framework	
Identification of theoretical framework?	Y
If yes, name framework (if it is not well known, include a description) Theory of reasoned action	Y
Clarification of influence of theoretical framework	
Researcher credentials	
Documentation of researcher's discipline	
If yes, name it: Dept health promotion and education, Dept of epidemiology and biostatistics, school of public health, University of S. Carolina.	Y
Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference)	N
Name of persons acknowledged by the authors and relationship: Commissioners – Prevention Research Centers Program, National Centre for Chronic Disease Prevention and health Promotion & Office of Women's Health, Centres for Disease Control and Prevention & the Women's Health Initiative Community Prevention Study, National Heart, Lung and Blood Institute, National Institutes of health.	
Role of researcher	
Non-research relationship of researcher to participants?	NS
Evidence that the researcher has considered the effect of his/her presence on the research findings?	N
Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	N
Sampling and participants	
Description of sampling procedure?	Y
Identification of inclusion criteria	N
Discussion of attrition in longitudinal studies?	NA
Data gathering strategy(ies)	

Clear description of data gathering procedures?	Y
If no, how could the description be improved?	-
Description of gaining access?	N
Discussion of time frame for data gathering?	N
<b>Data analysis strategies</b>	
Description of method(s) used?	Y
Identification of categories or common elements found?	Y
Report of participants' response to analysis?	N
Data analysis presented in a clear framework (identification of central themes and categories)?	Y
Data presented in such a way that relationships between categories/ themes are clear?	N
Analysis well supported by representative quotes/ findings?	Y
Provision of evidence as to how representative in the sample the various findings were?	Y
<b>Conclusions, discussions, implications, suggestions for further study</b>	
Identification of limitations of study? – Non random sample in a single state.	
Discussion pertains to all significant findings?	Y
Interpretive statements correspond with findings?	Y
Examination of findings with existing body of literature?	Y
Clear indication of directives for future research?	Y
If yes, indicate directives identified. Need for research to determine what influences decision-making about hysterectomy, and research with men directly for their perceptions and beliefs,	
<b>Other considerations/ thoughts</b>	
ENDOW study	

Complete citation:	Webb, C. Women as Gynaecological Patients and Nurses. Feminist Practice in Women's Healthcare.
Author affiliation (discipline, institution)	Not stated – nurse and lecturer. Sociological training.
Funding source	NS
Acknowledgements	None
Period of data collection	NS
Location of study	NS
Dates of submission and acceptance	NA
Publication type	Book chapter
Mode of retrieval	Ref list
Key words (given on paper)	None
Abstract	None

### **Stated research problem**

Pre-op

How do women prepare for their operation?

Post-op

Where their expectations fulfilled? Who had actually given help and support?

If hopes unfulfilled had this led to disappointment? Do needs change?

Also interviewed gynae. nurses about how they make sense with the way women may be treated in gynae wards.

In addition, the author drew on her own experiences as a patient in a gynae. ward.

Major construct/ theory investigated (if applicable) (theoretical orientation)	Feminist
Genre of study (not if stated genre fits design)	Phenomenological (but not stated as this – broadly feminist research about experiences)
Nature of sample: No. Age Ethnicity Education Other characteristics	25 women 3-4 wks pre and 3 months post-hysterectomy plus 25 women post-hysterectomy only.  30 female gynaecology nurses.
General description of the research approach	Interviews – 25 before and after hysterectomy, and 25 only after hysterectomy.
Methodological orientation	Not stated

### **Major findings**

Pre op women had concerns that they had not been able/ did not feel able to discuss with doctors. Including partner's understanding about ability to continue with housework. Also ways of coping in hospital with pain, vomiting, use bedpan and protect stitches. They wanted to use author as source of info for this.

Post op. Experiencing recovery.

Overwhelmingly glad they had the operation.

Not clear about what had happened at operation (why still have PM symptoms – ovaries still in tact)

Lack of information problematic. Want detailed info about how their bodies work, what to expect about treatments impact on physical and mental health, their family and working lives, complications, how to build up activities post-op.

### **Social support**

Many women (26/40 who had a male partner) did not know his opinion of the operation. Half each of the remaining had made positive or negative remarks about it.

Many women (20/50) had no particular confidante, 11 no sympathetic family either.

People who had a confidante found this a great source of comfort.

Advice not to be active in recovery was overprotective and not welcome as women wanted to control their own recovery.

Many “old wives’ tales” were in circulation about hysterectomy – facial hair, weight gain, going off sex, not satisfying male partners sexually, up to a year of recovery, depression.

Authors suggests that these relate to historical practices relating to operation and recovery and will change as practice changes.

CONCEPT old wives tales are not irrational myths, but are based on actual experiences. Old doctors tales have a different status – published in medical journals, privilege psychological and psychoanalytical outcomes. This suggests that depression is related to “castration anxiety” and penis envy in hysterectomised women unable to get substitute penis through bearing a male child. (p.103)

Author states that depressed women often have physical (complication) complaint, not psychological one.

“old wives’ tales’ usually have a validity based on women’s actual life experiences, whereas ‘old doctors tales’ often appear like myths and fantasies.

#### Personal experiences of being a gynaecology patient

“were like a caricature of the sexist male expert doctor putting down the emotional woman”. Physical reactions dismissed as psychological, doctors didn’t know who she was, concerns about AEs dismissed, weight gain trivialised.

#### Being a gynaecology nurse

Nurses felt that gynaecological disorders were special, and that women were concerned about “loosing their womanhood” post-hyst, although they could not define what this meant.

(my note – nurses assume that womb and reproduction are key aspects of womanhood, femininity).

Lack of training to offer psychological support (my note – this contradictory since she previously says most concerns are practical not psychological.

“Many recounted incidents... in which they felt that men doctors had humiliated women patients or not taken their problems seriously.” (p.108)

“the male-dominated ‘health’ system which inhibits women nurses and patients from sharing their knowledge and problems and acting together to change things for themselves.” (p.109)

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	Y
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	Y Y
Research question Explicitly expressed? Evidence of flow from phenomenon?	Y Y
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	Y
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Clarification of influence of theoretical framework	Y Feminist NA
Researcher credentials Documentation of researcher's discipline If yes, name it: Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) Name of persons acknowledged by the authors and relationship:	Y Nursing None
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	Y Y N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria Discussion of attrition in longitudinal studies?	N N NA
Data gathering strategy(ies) Clear description of data gathering procedures? If no, how could the description be improved? Nature of interviews not clear – unstructured?	Y

Description of gaining access?	Y
Discussion of time frame for data gathering?	N
Data analysis strategies	
Description of method(s) used?	N
Identification of categories or common elements found?	N
Report of participants' response to analysis?	Y
Data analysis presented in a clear framework (identification of central themes and categories)?	N
Data presented in such a way that relationships between categories/ themes are clear?	N
Analysis well supported by representative quotes/ findings?	Y
Provision of evidence as to how representative in the sample the various findings were?	N
Conclusions, discussions, implications, suggestions for further study	
Identification of limitations of study? –	N
Discussion pertains to all significant findings?	
Interpretive statements correspond with findings?	N
Examination of findings with existing body of literature?	Y
Clear indication of directives for future research?	Y
If yes, indicate directives identified.	N
Other considerations/ thoughts This study reports details of the research itself, more than the findings which are presented elsewhere.	
I like the focus of how female nurses situate themselves within patriarchal structures, the way nurses have to use “feminine wiles” (Florence Nightingale!) to get round these structures – such as Webb does for her research.	
She uses her position as a feminist researcher to supply additional information, and answer the question of the women she speaks to pre operatively. Offers this as likely to produce more valid results because it legitimises both the social encounter of the interview making the research a cooperative enterprise, with conscious raising part of the legitimate process. Also more ethical than the “smash and grab raid” approach.	
P. 104 – she suggests that her research has the impact of lessening hostility (compared to postop interviewees only) but increasing criticism – because she raised their hopes?	

<p>(Note p. 98 – Webb's expectation is that hysterectomy will not involve oophorectomy – is this correct?)</p>	
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Complete citation:	Williams RD, Clarke AJ. A qualitative study of Women's hysterectomy experience. Journal of Women's Health and Gender-based Medicine. 2000. 9 (sup. 2) S15-S25
Author affiliation (discipline, institution)	Dept. of Graduate Studies, School of Nursing, University of Alabama
Funding source	Centres for Disease Control and Prevention (Part of ENDOW)
Acknowledgements	Commissioners
Period of data collection	NS
Location of study	SE USA
Dates of submission and acceptance	NS
Publication type	Journal article
Mode of retrieval	E-database
Key words (given on paper)	NS
<p>Abstract</p> <p>The purpose of this qualitative study was to elicit women's perceptions of their experiences with hysterectomy, oophorectomy, and surgical menopause. Focus group and individual interviews were used to obtain data from a sample of southern urban women who had had hysterectomies for benign reasons. Of the 38 women who participated, 22 were African American and 16 were Caucasian, the mean age was 48 years, and most were low to middle income. Findings revealed that biophysical, psychosocial, and spiritual domains were important in the decision to have a hysterectomy. For many, the choice to have a hysterectomy was a last resort and was viewed as a technique that could relieve a myriad of symptoms. Although most participants described the hysterectomy experience as positive, they expressed a variety of concerns from diagnosis through recovery. Participants expressed a need for information about women's gynecological health for themselves and their male partners. African American women expressed a need for change in attitudes and beliefs in the black community about women undergoing hysterectomy. Many spouses, brothers, uncles, and other African American male friends were nonsupportive, and a few women revealed that they had not told a new partner about the surgery. The findings have implications for women's healthcare providers. Provider training and education are needed that integrate biophysical care of women with the psychological, sociological, and spiritual domains. Efforts must be directed to the community to enlighten men and families about hysterectomy by dispelling myths and providing current health information related to women's gynecological health and alternatives to, indications for, and types of hysterectomy.</p>	

### **Stated research problem**

Despite the frequency of hysterectomy, little is known about how women who have the procedure experience it.

Aim – to elicit women’s perceptions of the experience of hysterectomy, oophorectomy and surgical menopause.

Major construct/ theory investigated (if applicable) (theoretical orientation)	
Genre of study (note if stated genre fits design)	NS but broadly phenomenological language of experience, phenomenon.
Nature of sample: No. Age Ethnicity Education Other characteristics	38 30-76 (mean 48) 22 African American, 16 Caucasian Half had some college to graduate education, all finished high school. Low to middle income.
General description of the research approach	5 interviews among those requesting this rather than take part on the 5 FGDs.
Methodological orientation	Analysis through Miles and Huberman

**Major findings**

Described as 3 “separate patterns of response” – decision-making; outcomes - a continuum of responses; perceptions of male response.

Decision-making based on risks and benefits of surgery with variables from biophysical, psychological, sociological, and spiritual domains.

Biophysical - sometimes for a numbers of years, mostly pain & bleeding. But also fatigue, malaise, headache, pelvic pressure, bladder problems, infections and constipation. Most had tried to avoid surgery using other treatments or lifestyle changes. Not clear if women expect these latter symptoms to be cured by hysterectomy.

Psychological – a range of emotions associated with symptoms – mood swings, nervousness, irritation, depression. Relief about making the decisions to have a hysterectomy, and fear about making the wrong decision, or dying in surgery, were also reported.

Social – seeking and sharing information and gathering support from family, friends, co-workers and healthcare providers as well as books magazines and the internet. Caucasian women more likely to talk to co-workers than African American women. African- American women talk to male relatives, while Caucasian talk to female friends and relations. Few healthcare providers gave information about alternatives to hysterectomy, some even refused to discuss it.

Spiritual – low income and African American women most likely to say they prayed or meditated to help them come to the right decision, conquer fears and ask for a speedy recovery.

Outcomes – a continuum of experience From very positive to very negative, about the surgery and about HRT. Very positive experiences associated with well-controlled post-operative pain and bleeding, also freedom from symptoms, pregnancy and cancer fears and gains in sexuality. Healthcare also influenced experience. Negative experiences associated with loss of childbearing ability, concerns about sexuality, and fear of HRT. Long term complications also associated with negative experiences.

Physician recommendation for HRT varied. Women had little understanding of HRT.

Despite previous studies focussing on it, there was little mention of depression post-hysterectomy.

Perceptions of male responses For most only positive attitudes of male partners were reported, this expressed as supporting whatever decision she made, and wanting what was best for her. Partner support regarded as more important than family support.

Most negative accounts were from African American women. They felt that hysterectomy threatened their relationships. Negative attitudes appeared to be related to the loss of reproductive capacity. Some women therefore preferred not to reveal they had had a hysterectomy. Women felt men were ill-informed about women's bodies and hysterectomy and needed educating. Women also unaware of different procedures, HRT, specific risks and benefits.

*Concept* – imported from Braithwaite (1981). "Black males have historically associated fertility (as an aspect of virility) control with feelings of powerlessness, attitudes about the value of children, and fear of racial genocide, whereas black women relate controlling fertility with economics and a desire to control their own lives." (S-23) Therefore development of healthy relationships between black men and women are compromised.

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	Y
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	Y Y
Research question Explicitly expressed? Evidence of flow from phenomenon?	Y Y
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	N
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Clarification of influence of theoretical framework	N NA
Researcher credentials Documentation of researcher's discipline If yes, name it: Nursing Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) Name of persons acknowledged by the authors and relationship: Prevention Research Centers Program, National Centre for Chronic Disease Prevention and Health Promotion & the Office of Women's Health, centres for Disease control and prevention, & the women's health initiative community Prevention Study, National Heart, Lung and Blood Institute, National Institutes of Health.	Y N
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	NS N N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria Discussion of attrition in longitudinal studies?	N N NA

<p>Data gathering strategy(ies)</p> <p>Clear description of data gathering procedures?</p> <p>If no, how could the description be improved? They state they use the methods off Miles and Huberman – but this sourcebook contains many tolls for analysis. More detail would have been helpful, or an alignment with a particular tradition.</p> <p>Description of gaining access?</p> <p>Discussion of time frame for data gathering?</p>	<p>N</p> <p>N</p> <p>N</p> <p>N</p>
<p>Data analysis strategies</p> <p>Description of method(s) used?</p> <p>Identification of categories or common elements found?</p> <p>Report of participants' response to analysis?</p> <p>Data analysis presented in a clear framework (identification of central themes and categories)?</p> <p>Data presented in such a way that relationships between categories/ themes are clear?</p> <p>Analysis well supported by representative quotes/ findings?</p> <p>Provision of evidence as to how representative in the sample the various findings were?</p>	<p>N</p> <p>Y</p> <p>N</p> <p>Y</p> <p>N</p> <p>Y</p> <p>Y</p>
<p>Conclusions, discussions, implications, suggestions for further study</p> <p>Identification of limitations of study? – Implications should be confined to African American and Caucasian women, most with some college education.</p> <p>Discussion pertains to all significant findings?</p> <p>Interpretive statements correspond with findings?</p> <p>Examination of findings with existing body of literature?</p> <p>Clear indication of directives for future research?</p> <p>If yes, indicate directives identified.</p> <p>Spiritual care is an underdeveloped area in healthcare – further research needed.</p> <p>Studies needed to understand women's decisions for hysterectomy and how this influences their physical and emotional health.</p>	<p>N</p> <p>Y</p> <p>Y</p> <p>Y</p> <p>Y</p>
<p>Other considerations/ thoughts</p> <p>Some women preferred to be interviewed alone rather than in a group. No comment is made about the similarity or difference of topics covered in these individual compared to the group interviews.</p> <p>Little conceptualisation.</p> <p>Why "patterns" not "themes"?</p> <p>This assumes emotional = psychological.</p>	

Complete citation:	Wood PJ, Giddings LS. The symbolic experience of hysterectomy. Nursing Praxis in New Zealand 1991; 6 (3): 3-7
Author affiliation (discipline, institution)	Both RGON, Christchurch Poly & Auckland Institute of Technology, NZ
Funding source	NS
Acknowledgements	None
Period of data collection	1987
Location of study	NZ – questionnaire distributed through NZ Women’s Weekly
Dates of submission and acceptance	NS
Publication type	Journal Article
Mode of retrieval	E-search
Key words (given on paper)	None
Abstract.	None

**Stated research problem**

The womb “carries with it symbolic ideas about womanhood”, and its removal also has symbolic significance.

Major construct/ theory investigated (if applicable) (theoretical orientation)	Because the uterus has symbolic value as a symbol of womanhood – its removal also carries symbolic significance.
Genre of study (note if stated genre fits design)	NS Textual analysis? – this is an analysis of the written qualitative answers in a survey distributed in a women's magazine.
Nature of sample: No. Age Ethnicity Education Other characteristics	987 responded to questionnaire 25-84 Most Pakeha (ie non-indigenous NZers) NS Some had hysterectomy as long as 40 years previously.
General description of the research approach	Questionnaire distributed in the NZ Woman's Weekly. Women attached letters to these which were analysed here.
Methodological orientation	Not clear – “Themes which have symbolic significance” were identified.

### **Major findings**

4 themes with symbolic significance:

#### **Uterus: Reshaping Womanhood**

Uterus has symbolic meaning - feelings of sadness, loss, grief over uterus loss, loss of periods, “loss of womanhood.” Images relate to loss of ability to have (more) children.

For some “a hysterectomy was a release”, especially if had experienced HMB. Uterus “boggy” “soggy” “redundant”.

#### **Sexuality: redefining sexual Experience**

Redefined positively (for about 1/3) improved relationship or feeling,

Some found sexual desire lessened “personally I have always felt akin to a castrated animal”. Some Drs maintained that sexuality unlikely to be important at their age.

Some male partners reacted badly post-hysterectomy – felt physically different, or no longer approached the women sexually. May lead to separation.

“Sexual relationships assumed symbolic power within relationships” Strong focus on sex in Dr attitudes, and emphasis on heterosexual sexuality and its resumption – one reported “tightening up the vagina, which should please my husband”.

#### **Power: Retrieving control**

Through entering the healthcare system, women forced to relinquish power. Different ways were found of retrieving control - decision-making about hysterectomy (my note – can't actually see strategies about how they regained power here.) – where they felt pressured or rushed, women felt angry. Impersonal nature of (largely male) healthcare system, treating hysterectomy as routine, added to perceived powerlessness. “I was treated like a naughty, ungrateful little girl who didn't appreciate what this wonderful doctor was doing for her”. Analyst suggested use of the term “little girl” related to the symbolic association with uterus and womanhood (my note – doesn't hold water? She has her uterus at the time of this comment?)

Those who managed to participate in the decision-making, had more positive experiences.

#### Lifeforce; Reclaiming Energy

Hysterectomy allowed women to, eventually, reclaim energy, although many felt very ill immediately after the operation. Symbolically, there is no longer a physical focus on the body, especially if HMB had been a problem. Ability to wear light coloured clothes.

Problem statement Statement of the phenomenon leads directly to the purpose of the study?	N
Purpose of research Clearly expressed? Significance of research problem clearly indicated?	N N
Research question Explicitly expressed? Evidence of flow from phenomenon?	N N
Identification of assumptions? Identification of assumptions, preconceptions, presuppositions of researcher	N
Identification of theoretical framework Identification of theoretical framework? If yes, name framework (if it is not well known, include a description) Removal of the uterus has symbolic significance Clarification of influence of theoretical framework	Y N
Researcher credentials Documentation of researcher's discipline If yes, name it: Nursing Any other pertinent information about the researcher (e.g. methodological preference, conceptual preference) Name of persons acknowledged by the authors and relationship:	Y NS None
Role of researcher Non-research relationship of researcher to participants? Evidence that the researcher has considered the effect of his/her presence on the research findings? Evidence that the researcher has considered possibility of researcher bias or misinterpretation.	NS N N
Sampling and participants Description of sampling procedure? Identification of inclusion criteria Discussion of attrition in longitudinal studies?	N N NA
Data gathering strategy(ies) Clear description of data gathering procedures? If no, how could the description be improved? No details given about how qualitative data were collected or analysed.	N N

<p>Description of gaining access?</p> <p>Discussion of time frame for data gathering?</p>	<p>Y</p> <p>N</p>
<p>Data analysis strategies</p> <p>Description of method(s) used?</p> <p>Identification of categories or common elements found?</p> <p>Report of participants' response to analysis?</p> <p>Data analysis presented in a clear framework (identification of central themes and categories)?</p> <p>Data presented in such a way that relationships between categories/ themes are clear?</p> <p>Analysis well supported by representative quotes/ findings? Some – good quotes but some don't seem top support the themes (eg loss of womanhood) and others seem to also contain additional information not discussed.</p> <p>Provision of evidence as to how representative in the sample the various findings were?</p>	<p>N</p> <p>Y</p> <p>N</p> <p>Y</p> <p>N</p> <p>?</p> <p>N</p>
<p>Conclusions, discussions, implications, suggestions for further study</p> <p>Identification of limitations of study? –</p> <p>Self selected through the survey methods, hysterectomy significant in their lives, may not be representative.</p> <p>Discussion pertains to all significant findings?</p> <p>Interpretive statements correspond with findings?</p> <p>Examination of findings with existing body of literature?</p> <p>Clear indication of directives for future research?</p> <p>If yes, indicate directives identified.</p>	<p>Y</p> <p>NA</p> <p>N</p> <p>N</p> <p>N</p>
<p>Other considerations/ thoughts</p> <p>The article has no methodological details (such as how many questionnaires were distributed, how many included qualitative data and how this was elicited.) Also no details of how it was analysed.</p> <p>The qualitative data is published elsewhere.</p> <p>Given the way it was conducted and the age range – hysterectomies could have taken place a long time previously, and in many HC systems. No details are provided.</p> <p>I'm not sure that the "loss of womanhood" theme flows from the quotes.</p>	

### 9.3 Illustration of Study Findings Translated into the Chassé framework

Stage	Chassé labels	Garside label	Headers used in study reports
1,1	<u>Experiencing a disruption</u> Evaluating the illness experience	Justification for hysterectomy	Wanting relief or getting over it (Couples) (Bernhard et al., 1997) Miserable (Gush, Bloating, Chronic discomfort, Bitchy)(Kinnick & Leners, 1995) Menopause: starting at the beginning(Mingo et al., 2000b) Mood swings(Richter et al., 2000)
1,1		Valued support	Feeling supported (Women) (Bernhard et al., 1997) Caring support (There for me, Getting to know me, Caring for self ) (Kinnick & Leners, 1995) Sympathy and support(Richter et al., 2000) Social support(Webb, 1986)
1,2 ,3	<u>Experiencing a disruption</u> Negotiating the medical management of the condition	Experiences of the dr-pt relationship	Dr-patient relationships(Chapple, 1995) Opinions about healthcare providers (Groff et al., 2000) Experiences with the physician or with the medical establishment(Lees et al., 2001) Participants attitude toward and experience with healthcare providers(Mingo et al., 2000b) Physician as information provider(Richter et al., 2002) Importance of the nature of physician-patient communication(Richter et al., 2002) Physician's role in actual hysterectomy decision-making not primary (Richter et al., 2002) Necessity of a second opinion(Richter et al., 2002)
1,4	<u>Experiencing a disruption</u> Hysterectomy decision-making	Decision-making process	Deciding (Women) (Bernhard et al., 1997) Decision-making process(Groff et al., 2000) Talked to others (Do it, Negative things )(Kinnick & Leners, 1995) Help-seeking (control, use of multiple opinions, resources for research, communication with friends and family, barriers to seeking information)(Lees et al., 2001) Men do not make the decision(Richter et al., 2000) Decision-making(Williams & Clarke, 2000)
1,4		Men's understanding of hysterectomy	Men unable to discern hysterectomy(Richter et al., 2000) Men unable to understand(Richter et al., 2000) Men relieved(Richter et al., 2000)

St ag e	Chassé labels	Garside label	Headers used in study reports
1,4		Men's role in decision-making	Concerns about Partner's response(Bernhard, 1985) Views of partners(Groff et al., 2000) Effect on the male ego(Richter et al., 2000) Perceptions of male responses(Williams & Clarke, 2000) Avoiding feelings (men) (Bernhard et al., 1997) Keeping out of it (men) (Bernhard et al., 1997) Male partner as sounding board(Richter et al., 2000) Men's lack of information(Richter et al., 2000)
2.2	<u>Struggling to preserve self</u>  Becoming a patient	Concerns about impact of hysterectomy (pre surgery, or non-hysterectomised women)	Myths, fears and sexual symbolism related to hysterectomy(Augustus, 2002) Concerns about Personal physical attractiveness(Bernhard, 1985) Concerns about loss of womanhood(Bernhard, 1985) Concerns about the ability to engage in sexual activity(Bernhard, 1985) Doubts(Fleming, 2003) Sexuality and childbearing(Richter et al., 2000) Negative perceptions/terms(Richter et al., 2000) Uterus: Reshaping Womanhood(Wood & Giddings, 1991) Sexuality: redefining sexual experience(Wood & Giddings, 1991) Perceived outcomes(Groff et al., 2000)
2.2	<u>Struggling to preserve self</u>  Becoming a patient	Women's experiences in hospital	Experiences in outpatient clinics(Chapple, 1995) Laparoscopy results delay(Chapple, 1995) Embodiment(Fleming, 2003)
2.3	<u>Struggling to preserve self</u>  Observing the changes	Stigma	Women may not inform men of hysterectomy(Richter et al., 2000) Visibility/ invisibility of effects(Richter et al., 2000)
3.1	<u>Recovering</u>  Adjusting to the changes	Recovering and experienced outcomes	After leaving hospital(Chapple, 1995) Sense of betterness(Fleming, 2003) Outcomes (Changes, No less a woman)(Kinnick & Leners, 1995) Perceived outcomes of hysterectomy (sexuality, resolution of sexual abuse, emotional impact of loss, partner support, impact on health)(Lees et al., 2001) Experiencing recovery(Webb, 1986; Webb, 1989; Webb, 1986) Outcomes – a continuum of experience(Williams & Clarke, 2000) Lifeforce; Reclaiming Energy(Wood & Giddings, 1991) HRT: the jury is still out(Mingo et al., 2000b) Power: Retrieving control(Wood & Giddings, 1991)

St ag e	Chassé labels	Garside label	Headers used in study reports
3.2	<u>Recovering</u>	Outcomes: Relief of symptoms	Freedom from pain and embarrassment(Augustus, 2002) Pain(Fleming, 2003)
3.2 19	Coming to terms with hysterectomy	Outcomes: Impact on sexuality	Improved sexuality and self-esteem(Augustus, 2002), Hysterectomy a neutral issue(Richter et al., 2000)