Title: How do Young People Experience and Make Sense of their First Experience of Hearing Voices? A Review of Current Theories and Research

Submitted in partial fulfilment of the requirements of the qualification of Doctorate in Clinical Psychology from School of Psychology, University of Exeter

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Regulations: Written to University guidelines

Word Count: 4000
(Excluding titles, references and appendices)
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Introduction

The intent of this review is to examine the current literature on the experience of hearing voices (HVs) within first-episode psychosis (FEP). Different theoretical explanations will be explored whilst accentuating the value of considering voice-hearing experiences from alternative perspectives, including the individual’s perspective and not solely the psychiatric and often pathologising position. The review will identify significant gaps in research literature, which has neglected views of young people who hear voices; particularly the impact HVs has on their sense of self at a crucial stage in identity and self-development (Adams & Marshall, 1996; Erikson, 1968). As the term ‘young people’ can refer to a broad age range, this review is specifically interested in people aged between 16 to 25 years of age.

The experience of HVs has been conceptualised in a number of ways within the scientific community; as an auditory hallucination (APA, 1994), a result of trauma (Bebbington et al., 2004; Read et al., 2005) or as a normal, although unusual, human experience (Bentall, 2004; Boyle, 2002; Johnstone, 2000). Experimental literature has often focused on the negative impact of voices and paid little attention to the subjective experience (Bentall, 2004; Boyle, 1990; Newton et al., 2007). The potential for psychosis to change or alter the person’s usual

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1 See Appendix 1.1: Search Criteria used to Ensure an Extensive Search of the Extant Literature
2 When referring to ‘identity’ in this review the intended meaning is taken from social psychological perspectives and relates to the continuity of the person’s psychological functioning, interpersonal behaviour, and commitments to roles, values and beliefs. In contrast, reference to the ‘self’ relates to a socially constructed construct of group membership and reflective awareness and self-regulation based on feedback from others within social contexts. These are clearly not simple definitions and reflect ambiguity and the lack of consensus over widely accepted definitions for these complex phenomena, but both are considered relational concepts.
3 HVs is the preferred phrase in this review as it does not pathologise the experience. ‘Auditory hallucinations’ will only be used when referring to the medical description of this experience. Similarly, the term ‘schizophrenia’ will be used cautiously and in moderation to indicate reservations about its validity as a diagnostic category.
way of understanding themselves, the world and their future has often been neglected and this devastation may be intensified when the individual is relatively young (Jackson et al., 1999).

**Literature Review and Context**

**Adolescence and Early Adulthood**

Adolescence is a transitional stage of physical and psychological development. The central tenet of adolescence, according to Rosenberg (1985), is the questioning of ‘who am I?’ Similarly, Erikson’s (1968) model of identity development proposes the key psychosocial task of adolescence is identity formation, often extending into adulthood. He identified this as a ‘normative event,’ consolidating identifications rooted in childhood into a coherent adult identity. Different selves are often rehearsed in exploring different roles; typically seen in young people becoming more autonomous; less dependent on family; and pursuing vocational aspirations (McGorry & Yung, 2003; Riedesser, 2004). The salience of peer relations typically increases in adolescence. Peers often sustain exploration of identity as young people try out new selves/roles (Drake et al., 2000; Mackrell & Lavender, 2004), and become a significant source of support, influence on attitudes, activities and emotional wellbeing (Lerner & Steinberg, 2004). Successful exploration at this stage can result in young people emerging with a strong sense of self and feelings of independence and control. Yet, the process is not automatic, not everyone achieves this synthesis and some may emerge insecure and confused about themselves and their future (Erikson, 1968).

**Selfhood**

Several basic tenets of social psychology have long informed understandings of identity formation and transformation (Goffman, 1959; Mead, 1968). Complex debates and
conceptualisations characterise the study of self and identity (Holstein & Gubrium, 2000; Lapsey & Power, 1988). Despite this, there are general domains of agreement about the social construction of selfhood and identity that are salient (Estroff, 1989). Mead’s (1968) notion of a relational self suggests self and other are inextricably linked; the self is constructed and maintained through social relations, thus social isolation usually fosters loss of self (Charmaz, 1983). As Estroff (1989) elucidates, others provide the contrast that permits definition of self – the object (out there, not me) defines the subject (in here, self). Furthermore, others reflect an image of ‘me’ back to ‘I’ (Mead, 1968). These processes provide an understanding of who we are and what categories we belong to. Reflexivity is the ability to reflect on our thought, speech and behaviour and how others may experience this. There are periods of self/other agreement and confirmation, and contexts of divergence. Feedback from others which is discrepant with inner experience contributes to renegotiation, development and changes to self. There are typically two facets to self: the private subject (a self known to self) and a public self (the person known to and identified by others). Yet, these domains must overlap as a lack of agreement between self and others about self may result in incomprehensibility of person, identified by Rosenberg (1984) as the hallmark of psychosis.

**First-Episode Psychosis (FEP)**

First-episode psychosis (FEP) often occurs during adolescence or early adulthood and some argue this can signify an assault on fundamental developmental processes leading to the acquisition of a sense of self, such as identity, social roles and social acceptance (Jackson *et al.*, 1999; Tarrier *et al.*, 2007).
FEP is often preceded by social and emotional difficulties from early adolescence (Poulton et al., 2000); and typically results in confusion, fear, depression, social isolation, stigma, disruption, and a sense of loss for future aspirations, in conjunction with attempts to cope with the uncertainties of adolescence/early adulthood (Kilkku et al., 2003). There is a high need for social support at this time, as quality of peer attachments and drawing on social support has been found to be strongly predictive of longer-term outcomes and adaptation to psychosis (Drake et al., 2000). Yet, often the stigma of mental illness and a voice-hearer’s potentially unusual, erratic or aggressive behaviour may lead friends to withdraw or the individual may isolate themselves (MacDonald et al., 2005; Mackrell & Lavender, 2004). Indeed, individuals experiencing psychosis have been found to have fewer social contacts (Buchanan, 1995), which can limit possibilities for positive validation of self (Charmaz, 1983). Furthermore, research suggests being labelled as mentally ill in adolescence/early adulthood may shape identity and affect psychosocial progression (Lally, 1989).

**Loss of Self in Psychosis**

The conception of psychosis as a disturbance to self and subjectivity is a long-standing area of interest within psychiatric literature (e.g. Laing, 1978); often described as a disruption to sense of self, sense of boundaries between self and others, and the ability to relate meaningfully to the world (Fabrega, 1989). Psychosis is often construed as a fragmentation where aspects of self no longer cohere or are no longer embedded in an intelligible history (Lysaker et al. 2002). This is in addition to altered experience of the world (Roe & Davidson, 2005) with personal agency often appearing to exist outside the self (Nelson et al., 2007). An identity crisis often results from feeling engulfed by the illness (Lally, 1989), trapped in ‘patienthood’ (Roe, 2001) and transformed into someone who is dysfunctional and devalued,
first by others and then by themselves (Estroff, 1989) creating a sense of isolation and rejection (Lysaker & Bell, 1995).

It has long been recognised that FEP tends to be the most frightening and shattering experience when compared with subsequent episodes (Ludwig, 1971). With time, experiences are no longer experienced as alien suggesting the person may incorporate psychosis into their sense of self. Minimal research has explored the impact of FEP on sense of self (Boydell et al., 2010; Hirschfield et al., 2005), fundamental to understanding distress and adjustment to FEP (Jackson & Iqbal, 2000). Trauma is commonly linked to development of psychosis, resulting from disturbing psychotic experiences, as well as from treatment itself (Gorell et al., 2004; Jackson et al., 2004). Dissociation, a symptom of trauma, involves troubling alterations in sense of self, which many argue is particularly acute in psychosis (Spitzer, 1990; Helmsley, 1998). Furthermore, understanding psychotic experience as coming from within, as opposed to being real, significantly challenges the concept of self (Jackson & Iqbal, 2000). This is particularly salient to FEP given young people have no pre-existing cognitive schema to use to make sense or guide adjustment (McGorry, 1995). Many ascribe damage and loss to former characteristics of self: the notion that self is invulnerable (Cullberg, 2006); control over self (Frith, 1992); behaving in ways inconsistent with one’s sense of self (Carlson & Dalenberg, 2000); optimism (Koivisto et al., 2003); competence (Lally, 1989); making oneself understood; and finding oneself in a subordinate role (Birchwood et al., 2002).

One study exploring the impact of FEP on young people’s sense of self was identified in a search of the literature. Geekie (2004) analysed recordings of 15 New Zealand FEP service-
users’ psychotherapy sessions using grounded theory and found three main constructs: authoring, ontological insecurity and epistemological uncertainty. ‘Authoring’ referred to participants’ foremost concern: trying to make sense of psychotic experiences by telling their own personal story rather than accepting a ready-made explanation. Geekie (2004) argues authoring is not solely a psychological process, but takes place in social contexts. Sharing efforts to author the experience helps come to terms with the experience, and provides a sense of personal agency and autonomy. Feeling silenced, invalidated or dismissed in efforts to author one’s own story was experienced by participants as damaging. ‘Ontological insecurity’ (a term used by Laing, 1960), was expressed in participant’s uncertainty about their sense of being in the world and the confusion resulting from FEP. ‘Epistemological uncertainty’ referred to participant’s uncertainty about their ways of knowing leading participants to doubt their own perceptions creating difficulty in distinguishing reality from ‘non-reality.’ This research was based on people between 20 to 37 years, excluding younger people’s views, and explored psychosis broadly rather than focusing on voice-hearing. There is a substantial need for further comprehensive exploratory studies of the subjective experience of HVs in FEP that are pertinent to the developmental stage of this group of people.

The Psychiatric Model

Within Western culture the dominant way of understanding the aetiology of HVs is psychiatric in nature; evident in how psychiatric discourse is privileged when discussions of HVs arise (Blackman, 2000). ‘Auditory hallucination,’ the medical terminology used to describe the ‘symptom’ of HVs, is considered the hallmark of schizophrenia (APA, 1994); understood as an organic brain dysfunction. However, many claim there is insufficient evidence for the validity of schizophrenia as a coherent disease entity and have attempted to comprehensively undermine use of this term (Bentall, 2004; Boyle, 2002).
Within the medical model there has traditionally been reliance on medication to remove voices with little discussion of the subjective meaning (Martin, 2000). Many argue the need to abandon symptom-based discourse and privilege experiences of voice-hearers (Boyle, 2002; Romme & Escher, 2000). Of the many explanations people hold for why they hear voices, illness is just one. Some argue medical explanations can result in people experiencing stigma, feeling marginalised by society, creating a taboo limiting the freedom voice-hearers have to speak about their experiences (Romme & Escher, 2000), which may exacerbate difficulties, delay help-seeking and hinder recovery (Rosenfield, 1997).

Research has challenged the belief that voice-hearing is a symptom of mental illness suggesting HVs is common within normal populations (Barret & Etheridge, 1992). Therefore, voice-hearing can be seen as lying on a continuum of experience, with those with a psychiatric diagnosis forming the most extreme end of the continuum (van Os et al., 2001). This research offers support for normalising voice-hearing experiences and suggests emotional responses to voices differentiate service-users from non-users (Romme & Escher, 1989; Sanjuan et al., 2004).

**Specialist Early Intervention for Psychosis**

Early Intervention Services (EIS) work with young people aged between 14 and 34 during the three year period following a FEP. EIS aim to raise awareness in an attempt to reduce stigma; improve earlier recognition, access and intervention; reduce psychological distress for both the individual and their family; promote recovery; and reduce wider psychosocial difficulties (Welsh et al., 2010). Rationale for intervening early is ‘duration of untreated psychosis’
(DUP) has been found to negatively affect outcomes of those impacted (Johannessen et al., 2007). A recent meta-analysis of 26 FEP studies indicated a mean DUP of approximately 2 years (Marshall et al., 2005). Identification is often made difficult by the confusing clinical diagnostic picture and behaviours that may be seen as ‘adolescent turmoil’ (Addington et al., 2007). More research is needed to increase understanding of factors precipitating and/or delaying help-seeking in FEP populations.

**The Experience of Hearing Voices**

Voices often present as a commentary of the individual’s behaviour or in a commanding and persecutory manner (APA, 1994). Typically voices are malevolent causing distress (Chadwick & Birchwood, 1994). Reactions to voices can change over time, possibly due to changes in voices, or the ability to cope with them (Romme & Escher, 1989). For some, voices can contribute positively by providing companionship, reassurance and guidance (Grimby, 1993; Romme & Escher, 2000).

Research has shown peoples’ relationships with voices often ‘mirror’ relationships in their social worlds (Mawson et al., 2010). In particular, a strong link has been found between past trauma and voice content (Romme & Escher, 2000).

**The Trauma Model**

Research has shown a high rate of traumatic histories in people who hear voices (Kilcommons & Morrison, 2005; Read et al., 2005). Many studies highlight the correlation between child abuse with development of voice-hearing (Bebbington et al., 2004; Janssen et al., 2004). People, often without psychiatric illness, may hear voices after suffering trauma;
individuals often hear voices following bereavement and combat veterans with a diagnosis of Post-Traumatic Stress Disorder (PTSD) often experience voice-hearing (Grimby, 1998).

The vulnerability-stress hypothesis (Nuechterlein & Dawson, 1984; Zubin & Spring, 1977) is a dominant model of psychosis based upon a biopsychosocial framework. The premise is individuals inherit or experience early trauma creating a vulnerability to psychosis that is triggered under stressful conditions (Smith et al., 1993). This hypothesis is criticised for privileging the biological and undermining other factors, such as stress, to merely being ‘triggers’ of underlying illness (Johnstone, 2007). Despite the abundance of research demonstrating a strong association between trauma and HVs, many who experience trauma do not go on to hear voices, and others without trauma histories do experience this phenomena. It is likely there are multiple pathways to HVs and currently little is known about the mechanisms by which trauma results in psychosis (Morrison et al., 2005). In trauma research, views of voice-hearers themselves have often been neglected, particularly views of young people whose trauma histories may be more recent.

**Quantitative Research**

Most psychiatric and psychological research has tended to utilise quantitative methods often proving useful in determining relational links between factors and likely causes of psychosis. For example, research using a range of scientific methodologies has recently established many social factors as significant risk factors for psychosis: mothers’ wellbeing during pregnancy; insecure attachment; early loss of parents; witnessing inter-parental violence; dysfunctional parenting; childhood abuse or neglect; bullying; high levels of racist or other forms of discrimination; and heavy marijuana use early in adolescence (Larkin & Morrison, 2006; Moskowitz et al., 2009; Read & Gumley, 2008). Yet, Strauss (1989) argues essential
information is lost in the process of systematically characterising individuals’ experiences on the basis of questionnaires or structured interviews. Quantitative approaches are often criticised as reducing meaningful experiences to meaningless symptoms, discounting context and having little relevance to informing therapeutic interventions (Romme et al., 2009).

**Qualitative Research**

Growing efforts to systematically study subjective experiences of voice-hearers have emerged using qualitative research (Harper, 2004; NICE, 2002). Quantitative methods based upon positivist methods of enquiry and realist assumptions, assume there is a single truth that can be measured using scientific methods (Smith, 2003). In contrast, qualitative research criticises such simplistic notions claiming there are multiple realities that are socially constructed and science is unable to depict underlying realities for all experiences (Salmon, 2003).

Conducting one of the first studies exploring subjective experiences of HVs, Romme and Escher (1989) found many Dutch voice-hearers from the general public were able to cope without psychiatric intervention. They used a range of explanations to make sense of their experiences, broadly grouped into two main categories: those viewing voices as arising from within the individual (mystical, psychodynamic/traumatic or parapsychological origins); and those viewing voices as caused by external factors (biological or spiritual origins). People appeared to transition through three phases to cope with voices: 1). The startling phase characterised by onset of voices and often experienced as frightening and confusing; 2). The organisation phase involving selection and communication with voices; 3). The stabilisation phase involving accepting voices as part of self and no longer perceived as overpowering, which appeared to facilitate coping. According to this model, people need to adopt a frame of
reference in order to attribute meaning to voices; otherwise they struggle to begin organising their relationship with voices. Based upon accounts of people with some success at coping; it is unclear if people who view themselves as unsuccessful at coping and/or are HVs for the first time would go through a similar transitional process. More research is needed to identify processes enabling progression through these phases; other research suggests greater complexity and a less linear process (Fenekou & Georgaca, 2009; Chin et al., 2009). Despite these limitations, the work of Romme and Escher (1989) has been influential in: normalising voice-hearing, stressing the need to respect people’s own explanatory frameworks for their experiences and developing the HVs Network.\(^4\)

**Voice-Hearer’s Subjective Accounts of their Experience**

Both within and outside the context of psychiatric services voice-hearers’ own accounts of their experiences are often considered delusional and evidence of a lack of insight (Baevan, 2012). Maher (1988) argues delusions are attempts to make sense of experience rather than ‘symptoms’ of illness. As the medical model leaves little space for individuals’ explanations of why they believe they are experiencing emotional distress, clinicians are often discouraged from discussing or considering these explanations (Coffey et al., 2004).

Research suggests voice-hearers (in clinical and non-clinical samples) show a strong tendency towards psychological and spiritual explanations over biological ones (Romme et al., 2009). Psychological explanations include effects of interpersonal trauma, dissociated parts of self and abnormal cognitive processes such as a failure to attribute internal mental

\(^4\) The HVs Network is an anti-psychiatry movement that aims to normalise and move away from a medical, pathologising understanding of HVs. This movement has led to the development of service-user support groups across Europe.
states to self, all of which are supported by scientific literature (Bentall, 2004; Lataster et al., 2006). In contrast, spiritual explanations include communicating directly with God or ancestors, and possessing psychic abilities (Bidois, 2012). Biological explanations include alluding to brain dysfunction and effects of drugs (Beavan, 2012). Cockshutt (2004) suggests many voice-hearers find sole medical explanations of little value because they overlook the reality of voices, invalidating the experience.

A study by Jones et al. (2003) found 20 service-users’ and non-users’ beliefs about voices clustered into six distinct factors. Seven took the positive spiritual perspective, regarding voices as a blessing; four related voices to personal life experiences; three used resigned pessimist perspectives, troubled by voices, believing therapy would not alleviate their distress; two took a pragmatic perspective of voices, believing they were able to communicate with spirits; three felt passive to forces they believed caused voices (spiritual possession and neurochemical imbalances); finally, two took mental illness perspectives believing voices need controlling with psychiatric treatment. This study showed the diversity and complexity of beliefs about HVs, but as participants were aged between 27 to 75 years, experiences of young voice-hearers were not captured.

**How do Young People Make Sense of HVs?**

Research with young voice-hearers has primarily focused on long-term outcomes of adolescent-onset psychosis (Escher et al., 2002; Gillberg et al., 1993; Hollis, 2000). Minimal research has explored young people’s subjective attempts to make sense of this experience; in a search of the literature only one study attended to the subjective explanations that young people use to understand their experiences. Newton et al. (2007) evaluated a cognitive behavioural group intervention for 17 and 18 year old voice-hearers; seen as a place to share
experiences, provide support and normalise experiences. Participants also described personal understandings of HVs, which could be classified into two distinct groups: those adopting agentic explanations where they felt able to exercise some agency over voices (illness, brain dysfunction or sensitivity to stress); and those ascribing passive explanations without agency (external sources, such as other people, supernatural forces or spiritual entities). Findings are consistent with studies with adults, stressing the importance of feeling able to exert control over voices (Romme & Escher, 1989; Vaughan & Fowler, 2004); but provide little information about processes by which young people make sense and adapt to HVs.

**Recovery**

Research into recovery from psychosis has identified a central role for the experience of self. Crucial components in this process are: re-establishing a sense of identity, finding meaning in life, negotiating selfhood, and developing a more active sense of self (Andresen et al., 2003; Dilks et al., 2010). Roe and Davidson (2005) conclude authoring one’s life story is integral to recovery and reconstructing a sense of self. Ridgeway (2001) analysed first-person accounts and found common transitions: moving from despair to hope, withdrawal to engagement, passive adjustment to active coping, and to reclaiming a positive sense of self, meaning and purpose. McGlashan (1987) described a continuum of recovery styles ranging from ‘integration’ to ‘sealing over.’ An integrative style allows individuals to accommodate psychotic experiences into their life context; whereas sealing over involves treating psychosis as separate from self and minimising its impact. Whilst these qualitative models provide rich details involved in adaptation, they fail to account for differences between those who remain overwhelmed by psychosis, and those who adjust well (Braehler & Schwannauer, 2012).
Other research has focused on how the high prevalence of emotional difficulties amongst individuals with psychosis might compromise adaptation (Birchwood, 2003). Negative appraisals of psychosis, such as feeling entrapped, lacking control, feeling ashamed and excluded, have been linked to increased anxiety (Gumley et al., 2004) and depression (Birchwood et al., 1993). Furthermore, post-psychotic depression has been linked to increased suicidal thinking, risk to self and others, poorer quality of life, mental functioning and family relationships (Birchwood et al., 2000; Conley, 2009). Further research is needed to identify factors which both facilitate and hinder adaptation.

**Concluding Comments and Future Directions**

The purpose of this review was to critically review research into the psychological phenomena of voice-hearing; highlighting studies which explored subjective aspects of HVs, whilst identifying the significant gap in the literature where experiences of young people with FEP should be acknowledged. Furthermore, there is a long-standing assumption that psychosis disrupts sense of self; yet little research has explored this with young people at a time when identity is crucial.

Research has contributed towards exploring how people make sense of HVs, but has focused on adult samples despite literature suggesting young people’s difficulties may be more distressing and long-term outcomes most vulnerable in this period (Birchwood, 1999). Adults may have had more time to formulate more coherent belief systems about their voice-hearing experiences than young people. EIS base interventions on research carried out with adults raising questions about whether it is possible to generalise results to young people who hear voices (Newton et al., 2007). Young people have tended to be excluded due to diagnosis-led approaches to research. Bentall (1990) advocates research focusing on specific difficulties,
and argues for more beneficial clinical applications if professionals can better understand phenomena such as voice-hearing rather than clusters of symptoms labelled ‘schizophrenia.’

Newton et al.’s (2007) study identified explanations young people may use to make sense of voice-hearing experiences. However, there is a need for further exploration and to explore the process by which young people are able to make sense. Geekie’s (2004) research revealed the impact of psychosis on young peoples’ sense of self, yet neglected adolescents and did not look solely at the experience of HVs.

In order to better understand voice-hearing in young people, the proposed study aims to pay greater attention to the impact HVs has on young peoples’ sense of self, the way in which they make sense of their experiences, and the process by which they come to do this.

A method that seems particularly suitable for this area of study is interpretative phenomenological analysis (IPA); a qualitative approach that aims to explore in detail the processes by which participants make sense of their experiences within their personal and social worlds (Smith & Osborn, 2008). Grounded theory was also considered as a qualitative methodology, but was excluded because the emphasis here is on developing an understanding of individual experience, rather than developing an overarching theory (Smith & Osborn, 2008). Discursive approaches were similarly excluded as this study is not seeking to explore how experiences are constructed within language specifically, but how they are recounted in personal experience.
The research question of particular interest in this study is:

How do voice-hearing experiences impact on young peoples’ sense of self and how do they make sense of this experience?
References


Appendices

Appendix 1: Literature Search Strategy 41
Appendix 1: Literature Search Strategy

Method

Identification of Relevant Studies

To search for relevant literature a search was conducted using the ISI Web of Science, PsycINFO and PubMed databases.

Search Terms

As the review focuses upon the experience of hearing voices (HVs) in first-episode psychosis (FEP), specifically the impact this has on sense of self in young people, the search strategy used a combination of terms to reflect these elements. The search terms used initially were as follows:

1. “Psychosis” AND “first-episode”
2. “Psychosis” AND “first-episode” AND “voices”
3. “Psychosis” AND “first-episode” AND “auditory hallucinations”
4. “Psychosis” AND “first-episode” AND “self”
5. “Psychosis” AND “first-episode” AND “qualitative”
Inclusion/Exclusion Criteria

The results were limited to papers published in English. A qualitative review of titles and abstracts was conducted to eliminate irrelevant studies. A further qualitative review of reference lists of the collated articles was carried out to identify additional relevant papers.

Organisation of the Review

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<thead>
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<th>Search Term</th>
<th>No. of Papers Found</th>
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Removing duplicates from the searches, a total of 46 papers were found. Of these, 40 were identified as relevant following qualitative review and a further 10 were selected as from reviewing reference lists.
Figure 1. Flow Diagram showing the Flow of Citations Reviewed during the Course of the Literature Review

- 10,747 records identified through database searching
- 21 additional records identified through others sources

Inclusion criteria applied and duplicates removed

- 10,689 records excluded
- 61 full-text articles assessed for eligibility
- 5 full-text articles excluded, with reasons

- 34 studies included in qualitative synthesis
- 22 studies included in quantitative synthesis