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‘The Paradox of Dementia’

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Declaration

I certify that all material in this dissertation which is not my own work has been identified and properly attributed and that no material is included for which a degree had previously been conferred upon me. I have conducted the work in line with the BPS DCP Professional Practice Guidelines.

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Abstract

This qualitative study used semi-structured interviews to explore how 6 people talked about their difficulties before and after a dementia diagnosis. The Assimilation of Problematic Experiences Scale (APES) was used to analyse the data and describe participants' internal processes as they became increasingly aware of their problems. Assimilation analysis views successful therapeutic change as accepting and integrating an aspect of the self that had previously been denied, due to it being too painful. The findings of the study build on the research evidence that suggests that despite the enormity of its psychological implications individuals find ways of integrating a dementia diagnosis into their sense of self. This occurred within an oscillating progress; stepping in and out of awareness, illustrating the paradox of acceptance and denial. Social support was crucial in enabling participants to sustain a positive sense of self in the face of this adjustment.

A Narrative Review: The Subjective Journey of Receiving Dementia Diagnosis

Introduction

This review aims to evaluate the literature which explores the subjective journey of receiving a dementia diagnosis, taking into account the phases of assessment, diagnosis and early stages of the disease. It begins by looking at literature describing people's reactions towards diagnosis. Then, research which conceptualises awareness and sense of self is described. Finally, studies seeking to develop models explaining the psychological responses to the diagnosis are reviewed. The discussion synthesises the current understanding and indicates ideas for future research and practice.

The review focuses on qualitative literature derived from the viewpoint of those with dementia. It recognises the valuable evidence base, examining experience in other ways; quantitative approaches, cognitive testing and gaining others' perspective. This research has furthered the understanding of the disease, but consequently people with dementia have been seen as passive recipients and excluded from research (Pratt & Wilkinson, 2001).

Research looking at subjective experience has grown in recent years due to a number of developments. Advances in treatments which are effective in earlier stages have led to diagnosis being made earlier (Bamford *et al*, 2004; Watkins *et al*, 2006). Alongside these advances there has been a growth in person-centred approaches. In the late 1990's Kitwood's argued for a movement away from the medical model of dementia, claiming the experience of dementia arises not only from bio-medical phenomena but also from psychosocial factors

(Kitwood, 1997). This viewpoint represented a radical shift, highlighting the importance of the person with dementia rather than the disease process itself.

According to ICD-10 Classification of Mental and Behavioural Disorders (World Health Organisation, 2007), dementia is a progressive syndrome due to disease of the brain, with disturbance of multiple higher cortical functions (Langdon *et al*, 2007). Alzheimer's disease is the most common type of dementia and for simplicity, dementia and Alzheimer's are used inter-changeably throughout this review.

Narrative Method

This is a narrative review aiming to provide a comprehensive summary of the current literature on the subjective experience of receiving a dementia diagnosis. This method was chosen over a systematic review as the topic area requires the wider scope of a narrative review, in which less explicit methods are the trade-off for broader coverage (Green *et al*, 2001; Collins & Fauser, 2004). A narrative review with broad coverage and situational choices about the inclusion of evidence is a means of gaining an initial impression of a topic area. This way of reviewing the literature is a more uncertain process of discovery which allows greater flexibility to modify the boundaries of the search (Bryman & Bell, 2011). During this review databases were initially searched with prescribed search terms (see method section) however if articles then highlighted other relevant areas of study these could be legitimately followed up and included. Therefore relevant material was not lost within the strict rules of a systemic review (Collins & Fauser, 2004). It is recognised that this method is not replicable and may introduce author bias, as there are no clear rules of the search strategy and decisions about relevance and inclusion of studies are not explicit. However as this review aimed to generate an understanding of the

relevant background, knowledge and evolving concepts and not did not aim to answer a set research question or make firm conclusions about the evidence the narrative method felt appropriate.

Method

The databases Psy-Articles, CINAHL, Pubmed and Project Muse were searched during August 2010 and April 2012, using the search terms experience and diagno* (diagnosis) and assess* (assessment) with either dement* (dementia) or Alzheimer* (Alzheimer/s). References of the collected articles were scanned for additional relevant papers.

Results and quality of the review material

Thirty eight papers have been included and are summarised in Table 1 (Appendix 1). All but one of the papers employed qualitative approaches and all but two were published in peer reviewed journals. Fifteen studies interviewed people with dementia, the sample sizes ranged from six to thirty people (some additionally included carers). Ten of the studies discussed the characteristics and representativeness of participants. Four literature reviews were included, the number of papers in the reviews ranged from thirteen to fifty nine. All had explicit methodology and quality sections. Eleven discussion papers based on authors' previous research and/or case material or on others' writings were included. Two of these authors have dementia. Four studies take a case study approach. Two focused on conversational analysis and two followed clients as they progressed through therapy. Two studies used the transcripts of therapy/support groups for analysis. One study used focus groups. Only one study is included which used standardised measures. The literature is broadly categorised into four areas.

1. Reaction to diagnosis
2. Exploring awareness
3. Exploring the Self
4. Developing Models

Reaction to diagnosis

Following diagnosis people exhibit a range of emotional responses (Labarge *et al*, 1998; Pratt & Wilkinson, 2001; 2003; Snyder, 2001; Bryden, 2002; Sterin, 2002; Aminzadeh *et al*, 2007; Manthorpe *et al*, 2011).

Aminzadeh *et al* (2007) highlighted three categories of emotional responses; denial, grief and positive coping. They indicated a series of stages from not noticing, noticing and covering up, to noticing and revealing symptoms. Similarly Snyder (2001) used clinical material to highlight themes centring on trepidation, anticipating the future, change in self-concept and the value of humour and hope.

Studies indicate that how the diagnosis is disclosed impacts on emotional response. For example the term Alzheimer's was reported to be more associated with an initial negative response than other terms such as vascular dementia (Derksen *et al*, 2006; Landon, *et al*, 2007). Byszewski *et al*, (2007) found that a 'progressive' disclosure buffered the impact.

Notably from these papers, as well as negative responses there are also expressions of hope, humour and growth. The Manthorpe *et al*, (2011) review concludes that although there may be

short term distress, the majority of people do not experience long term negative effects on psychological health. This finding is in contrast to earlier work (Pearson, 1989, cited in Young, 2002) which reports several adverse responses and intense psychological after effects. Sterin (2002), who herself has dementia, concludes that people continue to cope, arguing that it is the powerful notion ‘of not having a mind’ that steals dignity, rather than the disease itself.

Exploring Awareness

A powerful representation of dementia is that ‘lack of awareness’ is symptomatic. It has even been misguidedly suggested that the disease and its effects have no meaning for and do not trouble the person with dementia. The person-centred care movement has challenged this view (Clare, 2002; 2003; 2012; Sabat, 2002a; 2002b; 2006; Cheston, 2005; Clare *et al*, 2005; Macquarrie, 2005; Vernooij-Dassen *et al*, 2006; Clare *et al*, 2012).

Clare’s work is based on phenomenological studies. She argues that apparent degrees of awareness can be viewed as adaptive psychological responses. Exploring the idea that personality types impact on awareness, she finds that people experiencing denial are more likely to have had high expectations of themselves before the onset of dementia. She proposes a model of conceptualising awareness as a coping response aimed at preserving the pre-existing self concept and adjusting to integrating new experiences into a changing self concept. She later extends this model to discuss the contribution of social factors to awareness, finding that communication within relationships and how the diagnosis was revealed impact significantly. She concludes that awareness must be viewed as the product of psychosocial processes interacting with cognitive impairments (Clare, 2003).

Clare *et al's*, (2005) follow up study demonstrated that participants had continued awareness of their difficulties, with individuals making varying evaluations of their memory problems. They explored coping styles and found an interaction between kinds of coping style and expression of awareness. Those with self-adjusting coping styles attributed their memory problems to dementia, whereas those with self-maintaining coping styles felt their memory had not worsened. In more recent work, Clare indicates that some aspects of awareness may be retained well into the later stages of the illness and that psychological and social factors account for a considerable proportion of the variance in discrepancy scores used to index awareness. Relevant factors include mood, self concept and personality (Clare *et al*, 2012). Clare (2010) argues for greater precision in distinguishing between different levels of awareness, suggesting three overlapping levels of awareness; online monitoring, evaluative judgments and meta representations. These complex levels not only require cognitive ability to make realistic evaluations about one's functioning and situation but also require emotional resilience and supportive environments.

Clare's models attempt to move beyond the notion of a direct relationship between impairment and awareness. These findings are supported by a number of other authors. Vernooij-Dassen *et al* (2006), tracked awareness over time. Rather than a diminution they found people showed a gradual understanding of dementia and the changes in their personal relationships.

Cheston's (2005, 2012, Betts & Cheston, 2011) work also supports this view. He applied the Assimilation of Problematic Experiences model (Stiles, 1999; 2001; Stiles *et al*, 1999) to the process of receiving a diagnosis. This model describes the processes by which painful experiences are assimilated into one's sense of self. He concludes that for a person with

dementia, apparent 'lack of awareness' may reflect the activation of self protective mechanism, initiated in an attempt to retain psychological equilibrium. Macquarrie (2005) also views awareness as a complex psychological response. She illustrates how participants simultaneously acknowledged and resisted aspects of their disease in order to maintain agency in the face of cognitive losses.

Exploring the Self

The dominant discourse that people with dementia suffer a loss of self informs both professional and lay understandings (Millet, 2011). This view presents problems as it can result in depersonalised treatment (Konto & Nagle, 2006). There is no widespread agreement on what self is and what its loss constitutes. Loss of self is frequently viewed in terms of reduced cognitive capacity, however if cognitive capacity alone is used as a determinant, the relevance of emotion, embodiment and a changing inner life to existence is denied (Millet, 2011). In Caddell and Clare's (2010) systematic review, they conclude that the majority of evidence points to the persistence of self. Many conceptualisations of preservation of self have been put forward (Sabat & Harre, 1995; Post, 1995; Sabat, 2002a; 2002b; 2006; Pearce *et al*, 2002; Caddell & Clare, 2010; MacRae; 2010; Millet, 2011).

Millet (2011) argues a model of self based on bio-phenomenology theory (von Uexkull, 1909, cited in Millet, 2011). This theory describes a 'life world' or 'directly experienced world'. Millets suggests that people continue to experience the world and create meaning in the presence of cognitive deterioration. He suggests affective responses (laughter, frustration) are indicators of an interior life which may not be determinable using cognitive criteria alone.

Sabat and Harre (1995) used case material to show that when conversations with people with dementia are based on the assumption that they have something meaningful to say their meaning can be understood. They highlight the importance of viewing people as capable of meaning and able to act intentionally. If this does not happen the person is in danger of being viewed as a non-person.

Supporting this viewpoint, Post (1995) describes how people are often seen as having the ‘then self’ who they were prior to the disease and a ‘now self’ which lives in the present. He argues this is misleading as people generally retain their ‘then self’ and uses case material to illustrate this. Pearce *et al*, (2002) interviewed men with dementia about managing their sense of self. Seven themes were identified (limited impact, normal memory loss, try harder, take a break, make the most of things, reliance on partner, medication and services). Strategies were described that enabled continued self identity.

Sabat talked about a tripartite conception of selfhood which may be affected by diagnosis such as dementia. ‘Self 1’ is the self of personal identity expressed through the indicial ‘I’, it is not reliant on others for existence and hence should not be damaged by dementia. ‘Self 2’ represents the sum total of the person’s cognitive and physical attributes past and present. When a person is diagnosed with dementia there is a danger this becomes the dominate feature of their ‘self 2’ resulting in many other intact and admirable attributes being rendered invisible (Sabat, 2002a). More recently Frazer *et al*, (2011) (exploring Sabat’s theory) found that participants sought to emphasise aspects of ‘self 2’ that might not be obvious on first acquaintance such as their creativity and resourcefulness.

Sabat's (2002a) third aspect of selfhood, 'self 3' concerns social identity. He describes how one can have a multitude of social identities, however to construct these the person must enjoy the co-operation of another. He argues that for people with dementia this becomes increasingly difficult as they are often perceived as confused and burdensome.

Other studies support this social link. Dalby *et al*, (2011) found that continuity in spiritual activities and involvement in existing communities helped maintain self integrity. Labarge *et al* (1998) found that people expressed an interest in building friendships but were concerned about their performance and the changes the diagnosis brings to relationships. Langdon *et al* (2007) indicated that people were acutely aware of how other people responded to them including their attempt to conceal true thoughts and their loss of social status. Individuals hoped that people would respond authentically helping them when necessary but as far as possible carrying on life as normal. They concluded that individuals are sensitive to the response of others and that this has a clear impact on their attempts to preserve a positive sense of self.

Reflecting the 'interactionist' premise that self arises from, and is sustained in, social interaction MacRae (2010) also indicates that participants' positive sense of self was sustained because their social experience was positive. All of these studies highlight that in contrast to a direct, causal relationship between neurological impairment and loss of self, selfhood is inherently social and therefore any loss is at worst caused by and at least mediated by social influences.

Developing Models

One way of conceptualising the experience of dementia is applying or developing models which seek to explain the psychological responses to being diagnosed and progressing through the disease (Pearce *et al*, 2002; Pratt & Wilkinson 2001; 2003; Cheston *et al*, 2004; Watkins *et al*, 2006, Harman & Clare, 2006). These models bring together the evidence exploring awareness, selfhood and the complex bio-psychosocial aspects to understanding dementia.

The Self-Regulating Model of Illness Behaviour (Leventhal *et al*, 1984, cited in Harman and Clare, 2006) provides a framework for understanding how threats to self-identity from chronic illness are managed. Harman and Clare apply this model to the field of dementia, proposing that on receiving a threat to health people attempt to manage the objective features and the emotional impact of the illness, by progressing through stages of awareness, coping and evaluation. Awareness develops as information derived from symptoms and social messages is compared to existing beliefs about health and health threats; the result is an illness representation. They conclude that this model assists in illuminating the experience of developing dementia and the self-regulation required between knowing one's prognosis and attempting to maintain a sense of identity. This model incorporates the ideas of self-identity as being social as the illness-representation is based on the social messages received.

Pratt and Wilkinson (2001; 2003) also propose a psychosocial model which operates on two axes. The first axis indicates the desire and/or ability to know the diagnosis, the second axis indicates the social context. This context refers to the combined influences of many factors including; the impact of family, medical practice and social stigma. According to the model people fluidly move across four quadrants depending where they are on each of the axes. The

‘detachment’ quadrant represents a combination of unsupportive context and a low ability/desire to know the diagnosis. The ‘distressed’ quadrant combines an unsupportive context and a strong ability/desire to know the diagnosis. Within the ‘maximizing’ quadrant the person seeks perspective about their dementia and has support. Within the ‘denial/decline’ quadrant the context will allow the person the right to denial. This model brings together the theories about selfhood and awareness as variable and social.

The Assimilation of Problematic Experiences (Stiles, 1999; 2001; Stiles *et al*, 1999) has been used as a means of understanding how in psychotherapy the meaning and experiences of events change for clients. A number of studies in this review (Cheston *et al*, 2004; 2005; 2012; Betts & Cheston, 2011; Watkins *et al*, 2006;) describe how this model provides a framework of thinking about fluctuating levels of awareness and how people ‘come to terms’ with a diagnosis of dementia. The central concern in the assimilation model is the processes by which painful or problematic experiences are gradually assimilated into people’s sense of self. These studies argue that due to the enormity of its psychological implications a diagnosis of dementia may constitute a threatening or painful experience, not easy to assimilate into the individual’s existing self. Therefore the process by which people ‘come to terms’ with a diagnosis of dementia can be construed in terms of the assimilation of a problematic experience. This research explores how clients diagnosed with dementia are able to assimilate the experience into self, using case material to show how clients move from originally ‘warding off’ or pushing away awareness of their problems to a position where they are able to define and have insight into their difficulties. These changing needs suggest that different therapeutic tasks may be required at different stages of the assimilation process. For example the task for clients at the early stages is to increase their problem awareness, however as they begin to assimilate the

threatening experience the task may be increased emotional expression. The model therefore highlights how others can help or hinder this process of assimilation.

All of the models attempt to bring together theoretical perspectives of understanding the experience of dementia and therefore include both inter-psychoic and interpersonal elements. These are useful in both suggesting change is possible and in describing how people cope with the direct and indirect effects of the illness.

Discussion

Individuals with dementia can present meaningful and insightful accounts which have informed clinical practice and research. It has been discovered that as well as experiencing feelings of shock, despair and fear people also express positive emotions such as anticipation, hope and continued enjoyment.

When beginning this review the aim felt simple; to explore the literature which examines the subjective journey of receiving a dementia diagnosis. However just as we find that the journey of dementia is not a one-way path to decline and despair, nor can the literature present a straightforward path to understanding subjective experience. The more we read and learn about the 'subjective' the more complex it becomes and we realise that the 'subjective' is not simply static but fluid and fluctuating. It is not solely inter-psychoic but also interpersonal. Individuals' experiences are constantly changing and based on the feedback and interaction with others. This raises the question of whether there is such a thing as independent subjectivity.

Studies which explore the 'subjective' as an expression of awareness find that lack of awareness is not symptomatic of the disease, but the product of psychosocial processes interacting with cognitive impairments. From this perspective awareness is thought to be variable, functional and social. People move through wavering stages of avoiding, exploration and understanding. This movement is enabled, hindered and explicitly entwined within individual environments, relationships and interactions.

Studies that have explored self-identity find that loss of self is not an inevitable consequence of the disease. Authors argue that, as well as being incorrect, this understanding has the potential to give rise to excess disability. Emerging from the accounts of those with dementia is an understanding that people can manage their identity, making sense of their illness and cope with the consequences. Self is not simply cognitive but involves emotion, embodiment and spirituality. Many factors lead to loss of selfhood. Identifying and changing these factors will reduce excess disability and improve quality of life.

In conclusion people with dementia have an active role as contributors to knowledge about the disease. Individuals can approach their diagnosis, allowing it to be relevant to them and accept it as part of them (Watkins *et al*, 2006). However for this to happen others must view them as competent, insightful and aware.

Critique

This review included a wide variety of papers which help to illuminate the views and experiences of people with dementia, however the quality of the studies was variable, with mainly small sample sizes. All but one of the studies relied on convenience samples, recruiting

from memory clinics, day hospitals or via advertisement, possibly biasing the samples with individuals confident and eager enough to participate in research. All participants also had capacity to consent and sufficient communication skills, therefore people with severe deficits were excluded. In addition it is important to note that although 38 papers have been included many of these were based on a small number of studies. For example both Clare and Cheston have published a range of papers from one research study and one therapeutic group respectively.

The current emphasis on developing models which seek to explain the psychological responses to being diagnosed and progressing through the disease are useful in their attempts to draw together the bio-psychosocial aspects to understanding dementia. However each emphasis has limitations. Clare's and Cheston's earlier work focuses on individual coping styles and personality traits in managing dementia. The emphasis is therefore on the individual with dementia, neglecting the role, importance and reasonability of the social environment. The importance of the social environment is included in Pratt & Wilkinson's, and Clare's more recent work, however the literature stops at concluding that the social context needs to be considered. More recent research into the importance of social identification (aligning oneself with a meaningful group) highlights the complexity of the interaction between one's self and their social context, especially during times of transition (Haslam *et al*, 2012). For example following diagnosis people with dementia may be invited to attend a support group however the developments in the social identification field suggest that continued social identity is more beneficial than joining new groups and being alienated to a group which has the psychological status as an 'out-group' can be damaging. Therefore developments in other social science fields can be applied and add to this field.

Implications for future research and practice:

- Whilst there is agreement that psychological, social and neurological processes underlay the experience of dementia, the ways in which they interact is unclear and is an important area for future investigation.
- There is a need to move to practices that have a ‘social’ understanding of dementia. It is recognised that a ‘supportive social environment’ enhances ‘awareness and wellbeing’. Studies exploring what a ‘supportive environment’ constitutes and how relationships and social identity impact on the individual have important implications for practice.
- More research now includes the ‘voice’ of people with dementia; further studies exploring experience at the later stages of the disease are required.
- As ‘lack of awareness’ is not an incidental aspect of clinical work with people with dementia, there is a need to develop therapeutic ways of supporting people to develop and sustain their understanding.
- Research into how people ‘adjust’ to their dementia diagnosis and what helps or hinders this process could inform therapeutic approaches.

Project development

This review has assisted in the development of the research project ‘The Paradox of Dementia’ This project is a qualitative study exploring of how people understand and adjust to receiving a dementia diagnosis. The project builds on the work of Cheston *et al*, 2004; 2005; 2012; Betts & Cheston, 2011 & Watkins *et al*, 2006. Exploring whether The Assimilation of Problematic Experiences (Stiles, 1999; 2001; Stiles *et al*, 1999) can be used to describe and further understand how people ‘come to terms’ with a diagnosis of dementia.

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Appendix One

Table 1: Summary of papers included in the review

Reference	Country	Participants	Methods	Key findings
Aminzadeh <i>et al</i> , 2007	Canada	30 patients (20 female/10 male) 30 carers	Qualitative interviews with patient & carer Follow up focus groups with carers Analysis of diagnostic appointments	People go through stages of emotional responses; not noticing symptoms, noticing & covering up, noticing & revealing.
Bamford <i>et al</i> , 2004	UK	n/a	Literature review (59 papers included)	Diagnostic disclosure is both inconsistent & limited. Perspectives of people with dementia are largely neglected.
Betts & Cheston, 2011	UK	n/a	Discussion paper, using previous case material and material from clinical practice	Apparent lack of awareness may reflect self-protective mechanisms.
Bryden, 2002	UK	n/a	Discussion paper	Counselling, psychodynamic therapy, CBT & rehabilitation may be helpful in coming to terms with a diagnosis.
Byszewski <i>et al</i> , 2007	Canada	30 patients (20 female/10 male) 30 carers	Qualitative repeated interviews (one week apart; focus group with carers one month later)	Most people prefer full disclosure of the diagnosis.
Caddell & Clare, 2010	UK	n/a	Literature review (33 papers included)	There is evidence for the persistence of self throughout the stages of dementia.
Cheston, 2005	UK	5 patients (3 female/2 male)	Analysis of psychotherapy group	A diagnosis of dementia may be shameful as it involves behavioural characteristics that are devalued.
Cheston, 2012	UK	n/a	Discussion paper, using previous case material	The assimilation of problematic experiences model is a useful framework for understanding change & awareness.

Reference	Country	Participants	Methods	Key findings
Cheston <i>et al</i> , 2004	UK	1 patient (male)	Case study from a psychotherapy group	People move from 'warding off' to a position of defining their problems & having insight.
Clare, 2002	UK	n/a	Discussion paper	Lack of awareness cannot fully be explained by biological factors.
Clare, 2003	UK	12 patients (3 female/9 males) 12 carers	Qualitative repeated interviews (2 interviews, 3 months apart) IPA	A model is presented which emphasises psychological factors in the construction of awareness.
Clare, 2010	UK	n/a	Literature review (13 papers included)	Environmental contexts & interaction influence awareness.
Clare <i>et al</i> , 2005	UK	12 patients (3 female/9 males)	Qualitative 1 year follow up interviews IPA	Expression of awareness interacts with coping styles.
Clare <i>et al</i> , 2012	UK	101 patients (54 female/47 males)	Longitudinal study using standardised measures	A bio-psychosocial approach to understanding awareness is required.
Dalby <i>et al</i> , 2011	UK	6 patients (5 female/1 male)	Qualitative interviews IPA	Highlights the importance of subjective experience of spirituality.
Derksen <i>et al</i> , 2006	Netherlands	18 patients (4 female/14 male) 18 carers	Qualitative repeated interviews (2 interviews, 10 weeks apart) Grounded theory	Diagnosis of dementia can be carried out without introducing stress for the patient & carer.
Frazer <i>et al</i> , 2011	UK	8 patients (females)	Qualitative interviews IPA	People engaged in reconstructing their sense of self using a variety of coping strategies.

Reference	Country	Participants	Methods	Key findings
Harman & Clare, 2006	UK	9 patients (4 female/5 male)	Qualitative interviews IPA	Self-regulation model of illness illuminates the experience of dementia.
Labarge <i>et al</i> , 1998	USA	11 patients	Analysis of a support group	People have an awareness of performance deficits & a wide range of emotional expressions.
Langdon <i>et al</i> , 2007	UK	12 patients (6 female/6 male)	Interviews (Qualitative) IPA	People were afraid of revealing their diagnosis to others.
Macquarrie, 2005	Canada	13 patients (4 female/9 male) 13 carers	Qualitative repeated interviews (2 interviews, 6 months apart) Thematic analysis	People simultaneously acknowledge & resist aspects of their disease.
MacRae, 2010	Canada	9 patients (2 female/7 male)	Qualitative interviews Thematic analysis	People with dementia can lead meaningful & purposeful lives.
Manthorpe <i>et al</i> , 2011	UK	n/a	Literature review (32 papers included)	People go through a transition from being a person to becoming a 'person with dementia'. Professionals need to provide tailored support.
Manthorpe <i>et al</i> , 2011	UK	27 patients (14 female/13 male) 26 carers	Qualitative interviews Thematic analysis	People go through a transition from being a person to becoming a 'person with dementia'. Professionals need to provide tailored support.
Millet, 2011	UK	n/a	Discussion paper	We need to move away from a view of dementia based on loss of self. Carers should be helped to understand the inner life.
Pearce <i>et al</i> , 2002	UK	20 patients (male) 20 carers	Qualitative interviews IPA	People manage their sense of self by balancing their prior sense of self against the need to reappraise & construct a new self.

Reference	Country	Participants	Methods	Key findings
Post, 1995	UK	n/a	Discussion paper	The 'then self' has stewardship responsibility within the journey into forgetfulness.
Pratt & Wilkinson, 2001	UK	24 patients (13 female/11 male)	Qualitative repeated interviews (2 interviews, 3 months apart)	Propose a psychosocial model for understanding the experiences of dementia.
Pratt & Wilkinson, 2003	UK	n/a	Discussion paper	Propose a psychosocial model for understanding the experiences of dementia.
Sabat, 2002a	USA	1 patient (female)	Case study	It is possible for a person with dementia to have a worthy sense of self.
Sabat, 2002b	USA	n/a	Discussion paper based on previous case material	An understanding of & sensitivity to the person with dementia is of paramount importance.
Sabat, 2006	USA	n/a	Discussion paper based on previous research	It is important to fully consider the effects of environmental factors that affect aging & memory.
Sabat & Harre, 1995	USA	2 patients (1 female/1 male)	Case studies	Symbiotic behaviour can be found in people with mild to moderate Alzheimer's.
Snyder, 2001	USA	n/a	Discussion paper based on previous research	Common themes are highlighted, experiencing symptoms, anticipating the future, changes in self-concept & the value of humour & hope.
Sterin, 2002	UK	n/a	Discussion paper or her own experience of dementia	People with a diagnosis of dementia are still able to cope with life.

Reference	Country	Participants	Methods	Key findings
Vernooij-Dassen <i>et al</i> , 2006	Netherlands	18 patients (4 female/14 male) 18 carers	Qualitative interviews (2 interviews, 10 weeks apart) Grounded theory	There is a gradual process about the realisation of what a dementia diagnosis means.
Watkins <i>et al</i> , 2006	UK	1 patient (male)	Case study	People move from a position of warding off to having awareness & insight.
Young, 2002	UK	24 patients 3 carers	Focus groups	Health professionals should treat people with dementia respectfully & encourage them to express themselves.

NB: To be succinct the terms patients & carers have been used to describe the participants. 'Carers' represents spouses, partners, family members & formal carers. 'Patients' represents people with dementia.

Major Research Project

The Paradox of Dementia

Abstract

This qualitative study used semi-structured interviews to explore how 6 people talked about their difficulties before and after a dementia diagnosis. The Assimilation of Problematic Experiences Scale (APES) was used to analyse the data and describe participants' internal processes as they became increasingly aware of their problems. Assimilation analysis views successful therapeutic change as accepting and integrating an aspect of the self that had previously been denied, due to it being too painful. The findings of the study build on the research evidence that suggests that despite the enormity of its psychological implications individuals find ways of integrating a dementia diagnosis into their sense of self. This occurred within an oscillating progress; stepping in and out of awareness, illustrating the paradox of acceptance and denial. Social support was crucial in enabling participants to sustain a positive sense of self in the face of this adjustment.

The Paradox of Dementia

Introduction

The traditional discourse that people with dementia¹ lose their minds, sense of self and are unaware of their difficulties has been challenged over recent years by the person centred care movement and research which includes the voice of people with dementia. Emerging from these accounts is an understanding that when provided with supportive environments people can manage their identity, make sense of their illness and cope with the consequences.

The powerful representation of people with dementia as being ‘unaware’ has been particularly challenged. Studies exploring awareness find that ‘lack of awareness’ is not simply symptomatic or static (Clare, 2002; 2003; 2012; Sabat, 2002a; 2002b; 2006; Cheston, 2005; Clare *et al*, 2005; Macquarrie, 2005; Vernooij-Dassen *et al*, 2006; Clare *et al*, 2012). Awareness is variable, functional and social. People move through wavering levels of avoiding, exploration and understanding. This movement is enabled, hindered and explicitly entwined with coping styles, self-identity, environments and interactions.

Whilst there is general agreement that awareness is the product of psychosocial processes interacting with cognitive impairments, the ways in which they interact and the effect they have on people’s capacity to talk about and ‘come to terms with’ their diagnosis is not clear. Further research exploring how people experience and manage the process of receiving a dementia diagnosis would further this understanding and have important implications for support and diagnostic practices.

¹ Alzheimer’s disease is the most common type of dementia and for simplicity, dementia and Alzheimer’s are used inter-changeably throughout the paper.

The Assimilation of Problematic Voices

The assimilation model of psychotherapeutic change (Honos-Webb & Stiles, 1998; Stiles, 1999; 2001; Stiles *et al*, 1999) is a transtheoretical model of the process of change involved in psychotherapy. It has been used extensively to understanding how during psychotherapy the meaning and experiences of events change (Cheston *et al*, 2004). This involves clients with mental health concerns such as post-traumatic stress (Varvin & Stiles, 1999) and the process of acknowledging loss associated with disability (Newman & Beail, 2002). It has also been applied to psychological intervention with people with dementia (Cheston *et al*, 2004, Watkins *et al*, 2006).

Dementia as a ‘problematic experience’

Due to the enormity of its psychological implications a diagnosis of dementia may constitute a threatening experience, not easy to assimilate into self (Cheston *et al*, 2004). Being diagnosed with dementia involves facing the terrifying inevitability of physical and mental deterioration, with no way of foretelling how the disease will progress. Dementia not only causes personal decline, it also undermines coping resources through its effects on cognition and behaviour, as well as on personal, social and occupational functioning (Kitwood, 1997). In many ways the process by which people ‘come to terms’ with a dementia diagnosis can be construed in terms of the assimilation of a problematic experience. A diagnosis is likely to be so threatening that the person would resist assimilation and ‘ward off’ any material related to the problematic experience.

The dialogical process of change

The assimilation model considers self as a community of voices (Stiles *et al*, 2002). Voices represent significant people, events and other constellations of experiences. The community of voices refers to an inherently multiple self that is multi-voiced with comfortable transitions among voices. Most experiences are unproblematic and are assimilated smoothly into the community; these are dominant voices. However some experiences that arise in events that are painful or frightening are not easily assimilated. In resisting assimilation these remain dissociated and may express as symptoms. These are non-dominant, problematic voices (Honos-Webb & Stiles, 1998; Stiles, 2001).

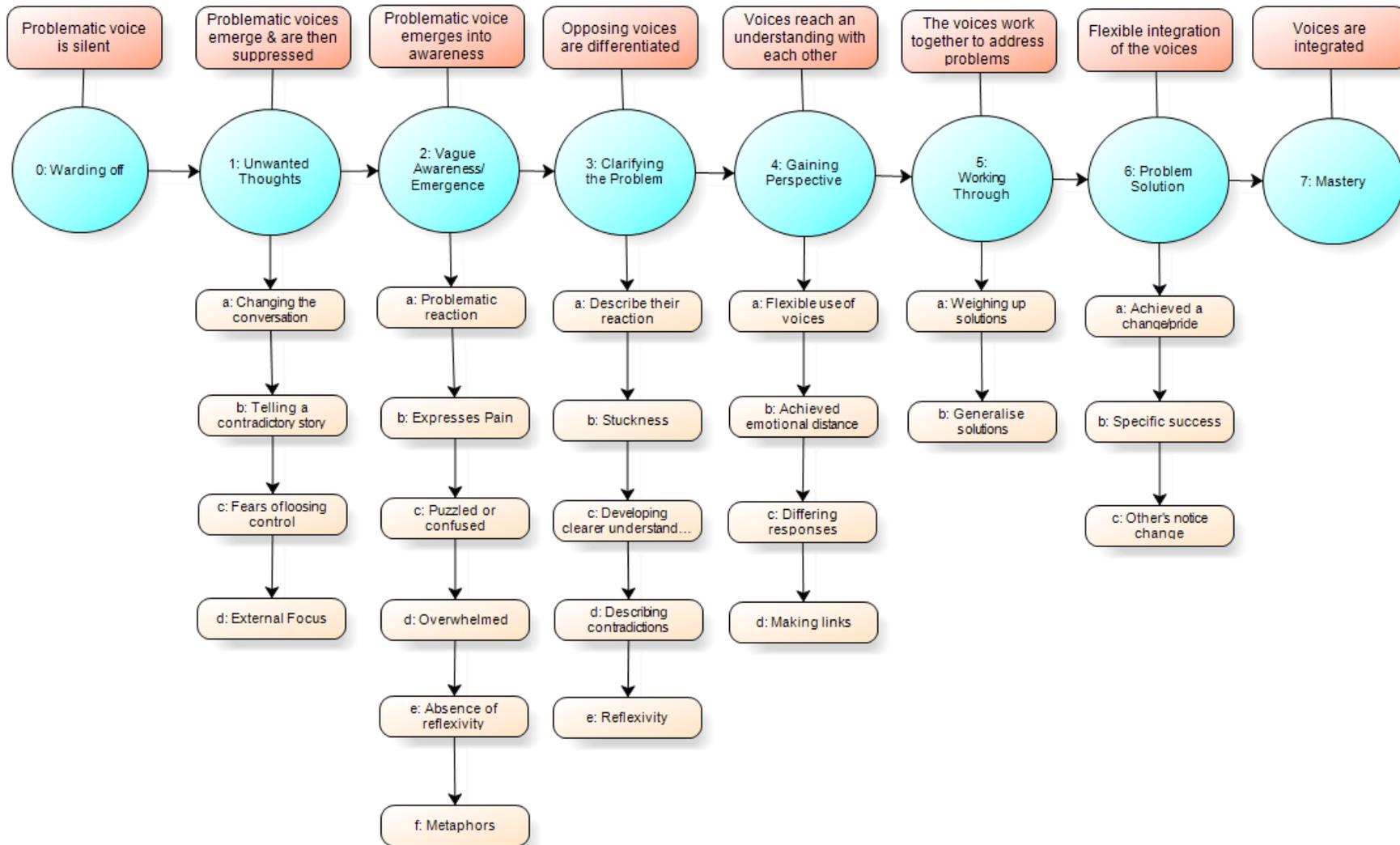
During assimilation, people come to experience problems differently through a dialogue between the voices. During this process an initially ‘warded off’ problematic voice finds expression and gains strength until it challenges the dominant community. Therapeutic change is viewed as mutual accommodation; the non-dominant and dominant community change as they develop shared understanding. The formally non-dominant voice joins the community, becoming an accepted aspect of one’s experience (Honos-Webb & Stiles, 1998; Stiles, 2001).

A description of assimilative change has evolved across a series of case studies (e.g., Field *et al*, 1994; Honos-Webb *et al*, 1998; Honos-Webb *et al*, 1999; Knobloch *et al*, 2001; Stiles *et al*, 2004) and is summarised in the Assimilation of Problem Experiences Scale (APES) (Figure 1). The scale has eight incremental levels through which problematic voices progress, called warded off, unwanted thoughts, vague awareness/acceptance, problem statement/clarification, understanding/insight, working through, problem solution, and mastery². The emotional quality of the different levels is central. As the problematic voice is gradually assimilated, the person

² See Appendix 1a: The Assimilation of Problematic Experiences Scale

experiences a parallel sequence of emotional reactions, from being oblivious, to experiencing the content as painful, then as problematic but less distressing (Cheston *et al*, 2004). In later levels, as the voice is accepted, solutions are tried out, confidence grows and satisfaction is gained (Newman & Beail, 2002).

Figure 1. The Assimilation of Problematic Experiences Scale (Based on Honos-Webb *et al*, 1998).



More traditional analysis methods were considered for use in this project (Interpretative Phenomenological Analysis, Grounded Theory). However as in addition to being a validated analysis strategy APES, has been applied as a useful clinical research tool and as such as has high clinical relevance (Stiles, 2001; Wilson, 2011). When being used in this way the therapist identifies each problematic experience and assesses the degree to which the problem has been assimilated by the client. They use this as the starting point to help the client move to the next level of assimilation and to measure the level of change during the therapeutic process (Stiles, 2001). The APES is unobtrusive in that it allows progress to be monitored as part of the therapeutic dialogue as opposed to the use of clinical measurement instruments (Wilson, 2011). APES attempts to bring together process and outcomes in psychotherapy and recognises the dynamic nature of change as involving both cognition and affect (Varvin & Stiles, 1999).

Aims

This study explores whether the APES can be used to further the understanding of how people experience, understand and manage the process of receiving a dementia diagnosis. The specific aims were:

1. To use APES to analyse discourse of people before and after an assessment at a memory clinic.
2. To explore whether the problematic and dominant voices can be heard and tracked in the discourse.
3. To explore if there are changes in levels of assimilation (e.g. are there changes in the relationships between the problematic and dominant voices).

Method

A qualitative, explorative method was chosen using assimilation analysis. Data was collected through semi-structured interviews. Interviews were held at two time points, shortly after participants' initial appointment at the clinic and 6 weeks after their diagnostic appointment. Repeated interviews were required to gather comparable data to explore the question of whether there are changes in levels of assimilation. NHS Ethics Committee (South West REC 4), Avon and Wiltshire Research and Development Consortium and the University of Exeter ethical approval was received³.

Recruitment

Potential participants were recruited from an memory service. The researcher initially met with practitioners to discuss the research; e.g. the number of participants required and anticipated time frames. It was agreed that practitioners (nurses and psychologists) would discuss the research with individuals who met the study's criteria during their initial appointment. The following inclusion/ exclusion criteria were observed:

Inclusion

- Patient undergoing a dementia assessment.
- Capacity to consent to all aspects of the study.
- Relatively unimpaired communication skills.
- Can talk about their difficulties sufficiently to engage in an interview.

Exclusion

- Has a history of pre-morbid mental health needs or risks highlighted.

³ See Appendix 4c: Ethical Approval Letters

As interviews were conducted at a time of increased vulnerability, everyone had the option of having support at the interview. This idea was recommended by a service user group who were consulted about the research⁴. After discussing the research with prospective participants, practitioners gave them an information sheet⁵ and verbal consent was gained for their details to be passed on. The researcher telephoned prospective participants to explain the research and answer questions. Verbal consent was gained before arranging a convenient time and place to meet. All willing participants who could be recruited in the timeframe of this research and who fit the inclusion criteria, 7 men and 3 women, all Caucasian and British born⁶ were included in the study and initially interviewed, however only 6 of the participants were interviewed a second time⁷. The recruitment to this study was constrained by a number of issues. Firstly, the memory service was undergoing a service re-design resulting in staff being anxious and strained and finding the recruitment an additional pressure. Secondly, the diagnostic appointments were delayed meaning that two of the participants did not receive their diagnosis within the time frame of this research.

Data Collection

Interviews took place at participants' homes. The researcher again explained the studies purpose, emphasised that the research was independent of the clinic and that participation was entirely voluntary. Informed written consent was gained⁸. Simultaneously the researcher made a decision about the individuals' current capacity to consent and documented this⁹.

⁴ See Appendix 2a: Additional information on service user consultation

⁵ See Appendix 5a: Participant information sheet

⁶ See Appendix 2b: Additional participant information

⁷ Of the four participants not interviewed a second time, 2 refused their second interview and 2 had not had their diagnostic appointment within the time frame of this research.

⁸ See Appendix 4a: Consent form

⁹ See Appendix 4b: Additional information on capacity

A semi-structured interview schedule was developed to gain insight into individuals' experience of their difficulties; it was used for both interviews¹⁰. Interviews took place between August 2011 and February 2012. Interviews were recorded and transcribed verbatim. Of the 10 participants, 6 agreed to be interviewed a second time, 2 declined their second interview and 2 had their diagnostic appointments postponed and therefore could not be interviewed within the research timeframe¹¹. Prior to the second interview the researcher had been contacted by the memory service to let them know the individual had attended their diagnostic appointment, so was ready for their second interview. However they were not told the individuals' diagnosis. This was in order to allow the interview dialogue to develop without any prior assumptions.

Data Analysis

The data was prepared according to the criteria and guidelines from the Stiles' group which have been published in several studies (Honos-Webb & Stiles, 1998; Honos-Webb *et al*, 1999; Knobloch *et al*, 2001). This procedure is comprised of five steps.

1. Familiarisation and indexing: Required intensive exposure to the transcripts, making systematic notes to locate passages concerning topics of interest.

2. Identifying and choosing themes: Involved identifying themes for further detailed analysis. In this context a 'theme' related to the over-arching subject of cognitive loss, changes in roles, relationships and affect.

¹⁰ See Appendix 5b: Interview schedule

¹¹ The data from the four participants who were only interviewed was analysed. Appendix 3a: Extended findings, details the analysis and findings from these four interviews.

Extracting passages: Entailed extracting passages that included potential markers. Markers are identifiable events in discourse that recur throughout the transcripts that indicate important phenomena. Passages relating to the themes being analysed were collated. This process of extracting passages was particularly important, as it was these which were rated as markers of assimilation. Therefore the primary researcher performed the initial extraction, however a proportion of transcripts (20%) were analysed by the field or supervisors to ensure consistency.

4. Rating passages: Involved rating passages that had been extracted. Before completing these ratings, considerable training and preparation was required. The manual for rating assimilation (Honos-Webb *et al*, 1998) includes guidelines for rating passages, a description of the markers and a guide to prioritising markers. The field supervisor was competent in using the manual, however the primary researcher required training.

Material collected from clinical practice and previous research (Wakins *et al*, 2006) was utilised as training material. Both researchers rated passages independently and then discussed their ratings, focusing on areas of disagreement. This allowed the primary researcher to become competent in using the model and for discussion of how experiences of receiving a dementia diagnosis mapped onto the scale.

During this period it became apparent that using the original manual was labour intensive, due to its dense descriptions. Therefore as part of the primary researcher's training, extracts from the 'dementia related' material were gathered to illustrate each of the levels and markers of assimilation relevant to dementia. From this a 'decision guide' was developed to use when

making assimilation ratings¹². This ‘decision guide’ preserved the structure of the original makers system. Ratings were completed independently by the researchers using this guide.

Rating the extracts according to the coding frame is a deductive approach, in that the model guides the analysis. Extracts which could be coded according the framework were included in the analysis, however extracts that did not fit the existing structure could not be included. This methodology was chose as this project is theory driven in that it aims to explore whether APES could be used analyse discourse and explore whether the problematic and dominant voices can be heard and tracked. However it is recognised that this strategy results in inevitable data loss and prevents theory emerging from the data.

5. Analysis of markers: Began by establishing whether the use of the markers-based system of rating assimilation was internally valid. Thus the level of agreement between researchers across each interview set was calculated. Subsequent analyses involved looking at the overall and individual levels of assimilation and whether there had been a change between the first and second interviews.

Inter-rater reliability

To ensure consistency of the interpretations an independent checking process was used. Assimilation ratings were completed independently by the researchers. The findings were also discussed with both supervisors.

¹² See Appendix 2c: Decision Guide

Findings

As this study is concerned with exploring changes before and after diagnosis the data from the four participants who were only interviewed once have not been included in analysis¹³. The following section therefore presents findings from the six participants interviewed twice. The first part describes the number of extracts drawn from the interviews and the level of agreement between the coding. The second part focuses on what the findings indicate about overall levels of assimilation. The third part explores individual participants' changing levels of assimilation and the changing relationship between the problematic and dominant voice.

Coding Analysis

From the initial 6 transcribed interviews, 120 extracts were drawn and coded. Coding was completed independently. Researchers coded in agreement 51% of the time. Following this researchers met to discuss coding and resolve disagreements, finding 3 reasons for discrepancies:

1. They had coded different parts of extracts,
2. Systematic errors, for example consistently coding level 2a rather than 3a,
3. Some extracts could not be coded.

Discussion took place about which part of extracts constituted a marker and which of the extracts could or could not be coded using the 'decision guide'. It was decided that some extracts did not contain enough detail or were too ambiguous to be coded. When making their ratings each of the researchers had provided confidence ratings (from 1 to 5). It was agreed that when confidence

¹³ As this study is primarily concerned with exploring changes before and after diagnosis the data from the four participants who were only interviewed once have not been included in the main analysis. Appendix 3a: Extended findings, details the analysis and findings from these four interviews.

ratings were 2 or below these extracts would be removed as they could not be reliably coded. Once it was clear which part of an extract constituted a marker and which extracts could be coded the disputed extracts were then re-rated and extracts which could not be coded removed. This resulted in 97 extracts of which 96% were coded in agreement. Only these extracts have been included in the analysis.

From the six second interviews (after diagnosis) 124 extracts were drawn and coded. The researchers coded in agreement 75% of the time, indicating that initial inconsistencies between coding had been resolved. The researchers again met to discuss discrepancies. Once 14 extracts which could not be coded had been removed from the analysis 110 remained, all of which were coded in agreement.

The high level of agreement between the researchers coding indicates that APES can be used to reliably analyse the discourse of people undergoing a dementia assessment. The problematic and dominant voice was heard, tracked and coded independently by the researchers.

Overall levels of assimilation

The overall levels of assimilation are illustrated in figures 1 and 2. During the first interviews participants' levels of assimilation ranged from level 0 (warding off) to level 4 (understanding and gaining perspective). The majority of extracts (44%) were coded at level 3 (clarifying the problem). During the second interviews levels of assimilation ranged from level 1 (unwanted thoughts) to level 6 (problem solution). The majority of extracts (40%) were coded at level 3.

During both interviews the most common level of assimilation is level 3. This percentage remains stable across the interviews. At this level people can name their problem and describe how it makes them feel without being caught up in the emotion of the moment. In other words both voices are articulated and they may feel stuck between these different ways of approaching dementia. Given the timings of the interviews it is perhaps not surprising that ‘clarifying the problem’ is the most common level. Participants are at a stage in which they are directly faced with ‘figuring out what is wrong’ by the very process of assessment and diagnosis. Interestingly participants were ‘clarifying the problem’ before receiving their diagnosis indicating they were, in part already aware of their difficulties and likely prognosis.

Differences can be seen between the spread of the additional levels pre and post diagnosis. Whereas in the initial interviews levels 0 to 4 are observed in the second interviews levels 1 to 6 are attained. During initial interviews the majority of extracts (not coded at level 3) are coded at lower levels (41%). During the second interviews the majority of extracts (not coded at level 3) are coded at higher levels (33%), indicating participants achieved higher levels of assimilation during the second interviews. Thus, following diagnosis participants are talking about their problems differently.

Figure 2: The assimilation of problematic experiences framework and the number of items coded at each level from the six initial interviews.

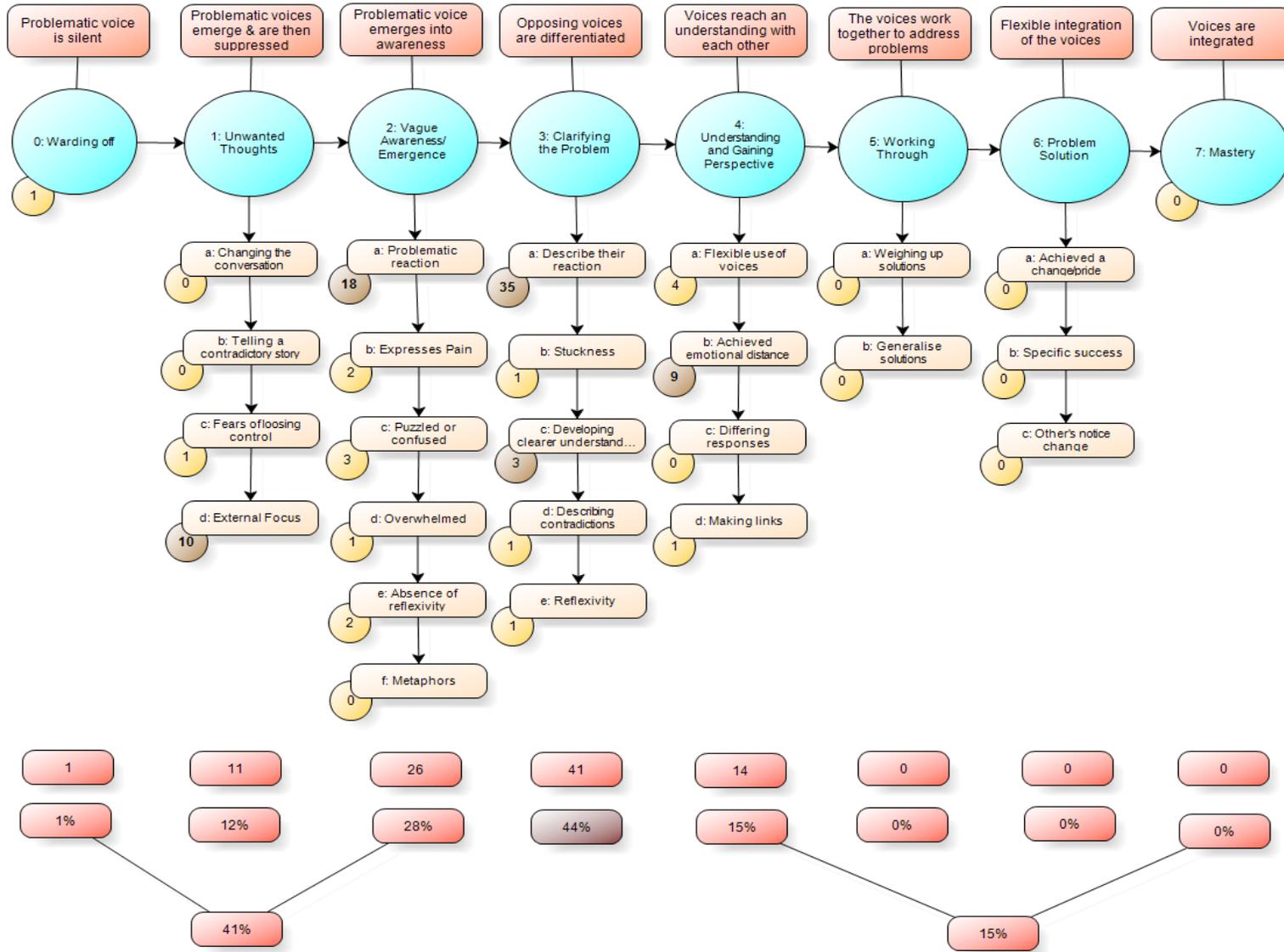
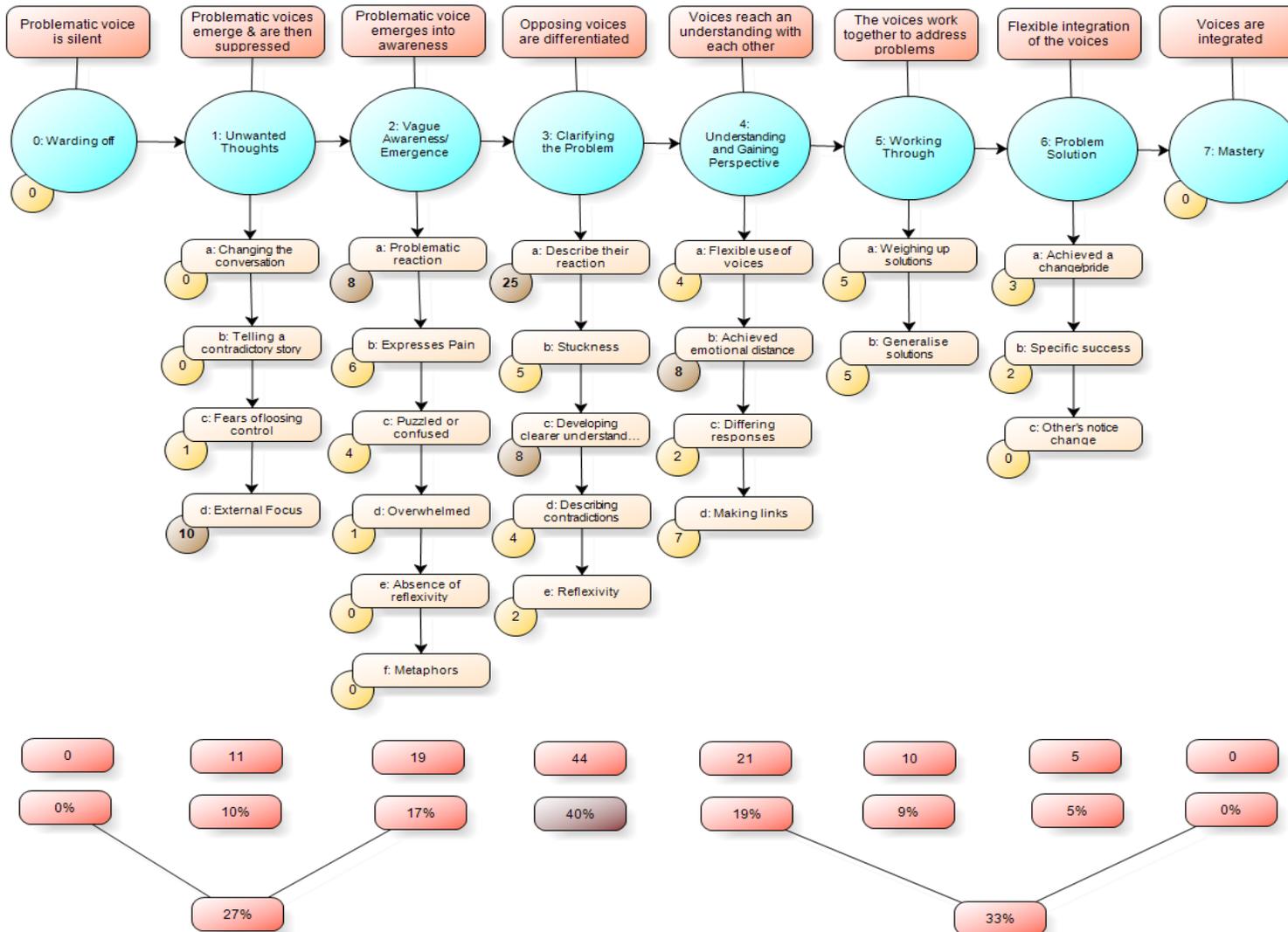


Figure 3: The assimilation of problematic experiences framework and the number of items coded at each level from the six second interviews.



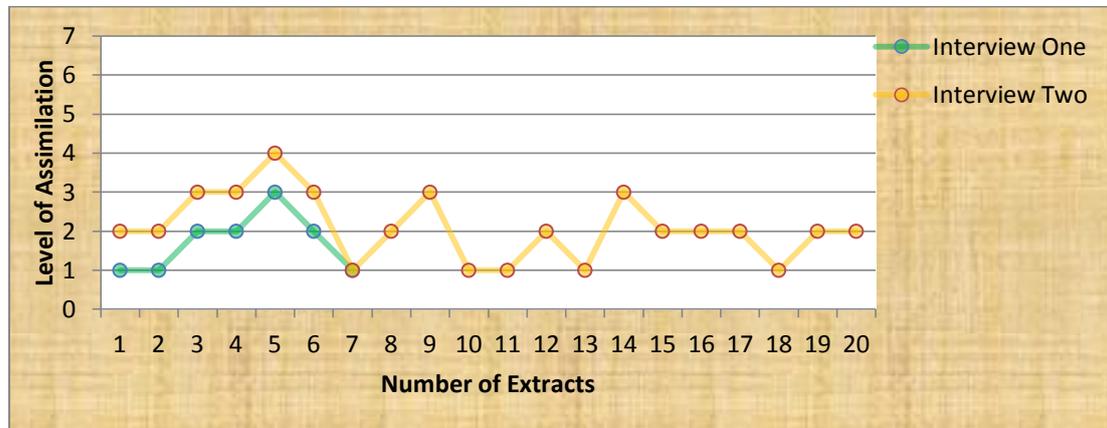
Individual levels of assimilation

Although group analysis indicated changes in levels of assimilation it does not capture the unique experiences or the individual changing relationships between the problematic voice (PV) and dominant voice (DV). Therefore subsequent analysis explores individual levels of assimilation. This account is structured participant by participant to stay closely connected to their experiences and to present a clear picture of individual changes¹⁴. Graphs are provided to show a visual illustration of assimilation as interviews progress. The level of assimilation is indicated in brackets following the quotation.

¹⁴ Pseudonyms have been used and other identifying information has been removed. For ease of reading, throughout the quotations, the omission of material not central to this analysis is indicated using square brackets. Ellipses are used to indicate pauses in the flow of speech. Repeated words or utterances have been removed unless relevant.

1. Henry

Figure 4: A graph showing the number of extracts drawn from Henry's interviews and the level at which they were coded:



First interview: During the first interview Henry answered more questions about what he enjoys doing, than those about difficulties, resulting in fewer extracts for coding. His reluctance to talk about his difficulties is typical of the lower levels of assimilation. Although the PV is emerging into awareness, as he acknowledges his difficulties, the DV is strong, and he states '*he is not worried and that he can always use a diary*' (level 1). He distracts from challenging topics by changing the subject (a marker of level 1). At times he expresses frustration, but the association between this and his difficulties is not explicit.

'I wasn't very happy about it I have to say ... I mean we've got to go next week, for a brain scan [] but I'm not very happy about it to be quite honest' (level 2).

The focus of Henry's attention is external to the self; problems are located 'out there' rather than in his subjective experience. He maintains this external focus by telling stories about the PV '*fear of deterioration*' but not explicitly relating these to himself.

Second interview: During the second interview this pattern of 'warding off' continues. Henry's responses indicate the dominant community's resistance to the PV; part of him wants to know about his diagnosis yet another part does not. When asked if he knows what is causing his problems; he replies, '*No, not at all, nobody has said a word []. It hasn't bothered me an awful lot*' (level 1). However his partner suggests that he has chosen to 'forget or ignore' his Alzheimer's diagnosis and he replies,

'I think you've got to have a positive attitude in life and if you are told you have got this and that you automatically, I think, mentally decide, I haven't, but I agree that my memory is not what it used to be' (level 2).

Henry indicates his apparent 'lack of awareness' is a defence against the pain of deterioration. Although more forthcoming in this interview his main focus stems from his distress at the loss of his driver's licence. Painful affect is evident, as he becomes caught up in the moment of the emotion, the hallmark of level 2.

'It worries me when you get a lot of these medical people, oh you shouldn't be doing this, and should you be driving now, those sort of questions that you don't really want to know about []. I mean I have never thought that I shouldn't be driving, and quite frankly I don't want to stop' (level 2).

Henry feels disempowered by the professionals' recommendations, he wants to deny what is happening, but they don't allow it. In addition to the loss of his licence its removal is damaging to his sense of self, as a person capable of making autonomous decisions.

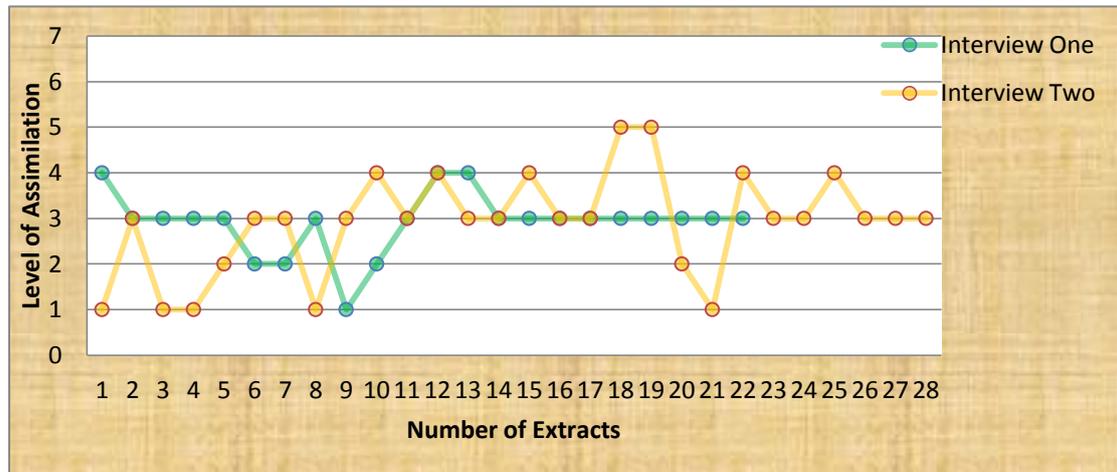
At times the PV has more expression and the voices reach an understanding with each other, *'I don't want to admit that my memory is becoming a little bit difficult [] it's not easy to accept'* (level 4). However, the DV re-asserts and dismisses material relevant to the PV.

'If you start worrying yourself too much, I can't do this and I can't do that it affects your whole attitude to life and I don't want to do that []. I have got to an age now where other people are saying, you can't go there, and you can't do this, well that's absolute nonsense' (level 1).

Henry embodies the internal dialogue between the PV and the DV he is *'not going to wave the white flag'*; he is not going to submit to the problem. Henry's interviews demonstrate the complexity of 'awareness'. His capacity to discuss his illness varies over the course of the interview, he approaches and retreats from awareness, illustrating the central nature of ambivalence.

2. Jill

Figure 5: A graph showing the number of extracts drawn from Jill's interviews and the level at which they were coded:



First interview: Jill lingers at ‘problem clarification’ for most of the initial interview. Although there are times when she indicates her performance ‘*is not of concern*’ (level 1) for the most part she articulates the PV; her frustration at something being wrong.

‘Simple things like when I’m talking to somebody, I forget something silly, that I should have known, it’s embarrassing. I used to go out with the ladies from work [] I didn’t say nothing, but then I had to say something, I said, well my memory, they said it’s alright, don’t worry’ (level 3).

Her forgetfulness creates social problems, she describes attempts to disguise her difficulties, she feels differentiated from others, no longer ‘*fitting in*’.

Jill can circumscribe the application of the DV or determine situations in which the PV is more appropriate for guiding behaviour (a marker of level 4). She discriminates between the voices rather than unthinkingly reacting from the dominant perspective.

'When I'm talking to somebody now with my memory I get halfway through and think, oh what was I going to say? And that's embarrassing. I've done that a few times, but if they're quite happy, good people I talk to them, tell them what's wrong. I've got to otherwise they think I'm barmy you know' (level 4).

The importance of others acceptance is crucial. Not only is she adjusting to her difficulties she is grappling with how she will be judged by others.

Second interview: At the beginning of the second interview Jill's husband reports that she has been diagnosed with Alzheimer's. Jill then oscillates between 'warding off' the PV, *'I haven't found any problem with it'* (level 1) and allowing it to gain strength until both voices are heard.

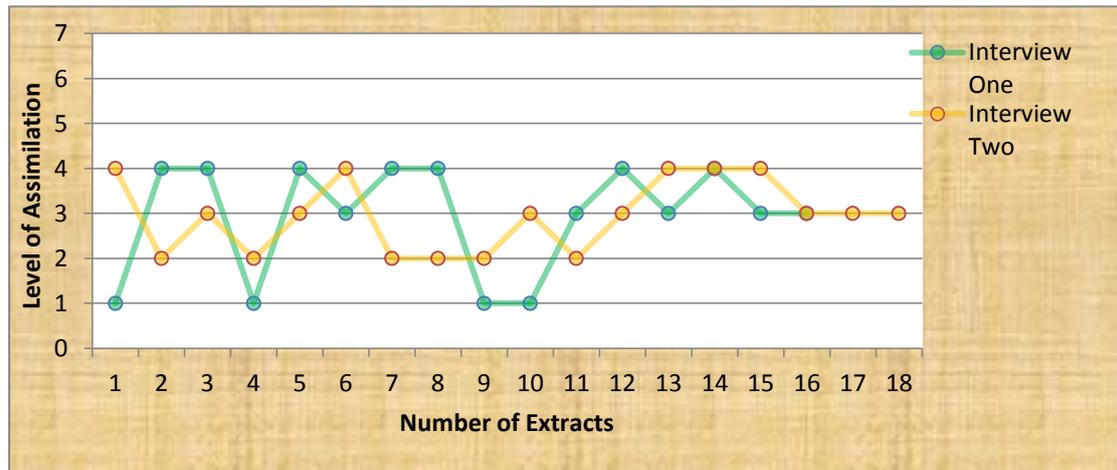
'I've told most of our family, as long as they accept it, I don't mind now, I've got used to that word you know, as long as it doesn't get any worse that's what I worry about, you can't tell if it gets worse or not, they don't know what causes it really do they?' (level 3).

Both interviews are characterised by advancing and retreating from 'problem clarification'. That is, the opposing voices are differentiated and expressed. However during the second interview more frequent and higher levels of assimilation are

observed, as voices reach a mutual understanding. Jill's capacity to assimilate the PV is interconnected with her social world. She talks about the importance of others acceptance, in assisting her to cope with her diagnosis.

3. Jim

Figure 6: A graph showing the number of extracts drawn from Jim’s interviews and the level at which they were coded:



First Interview: The relationship between the PV and DV in Jim’s initial interview is erratic and changeable. Dialogue varies between negotiation and understanding to the PV being suppressed. For example, when Jim cannot recall his children’s names, he acknowledges ‘*this is his problem*’ but then quickly moves away from the discussion avoiding the discomfort this causes (level 1). When asked about how he was referred to the clinic Jim talks about the history of his difficulties.

‘I’ve had memory problems for quite a long while, even when I was teaching, say we were doing a Dickens novel, there’d be kids in the class, they could advise me who was Mr so and so, what did Mr so and so do, and they would tell me, I didn’t know. I began to realise that as head of English you can’t say that I don’t read (laughs), but in fact I was not and still am not a good reader, because of my memory problems’ (level 4).

As Jim talks about his difficulties, the PV is expressed. However, when asked, about the possible causes of his problems he replies, *'I don't concentrate, I don't always listen properly. I think those are the main reasons why in my particular case, my memory is letting me down'* (level 1). He again 'wards off' the PV, maintaining a powerful determination that nothing is wrong.

Second interview: During his second interview this oscillating process continues, however in contrast to the initial interview, the PV is never suppressed. Throughout the interview Jim has difficulties with word finding. Sometimes he is clearly troubled by this, *'what's the word? Oh S oh S oh, this is terrible, oh I have let myself down []*. *Oh I wish I had never started this''* (level 2). However at other times he is able to talk about this difficulty, without becoming irritated or overwhelmed by it.

"I have an awkward facilities with words now []. I think the hesitation I'm having with the words, with you, I don't think they actually reflect the actual state of my competence, I don't do myself justice (level 4).

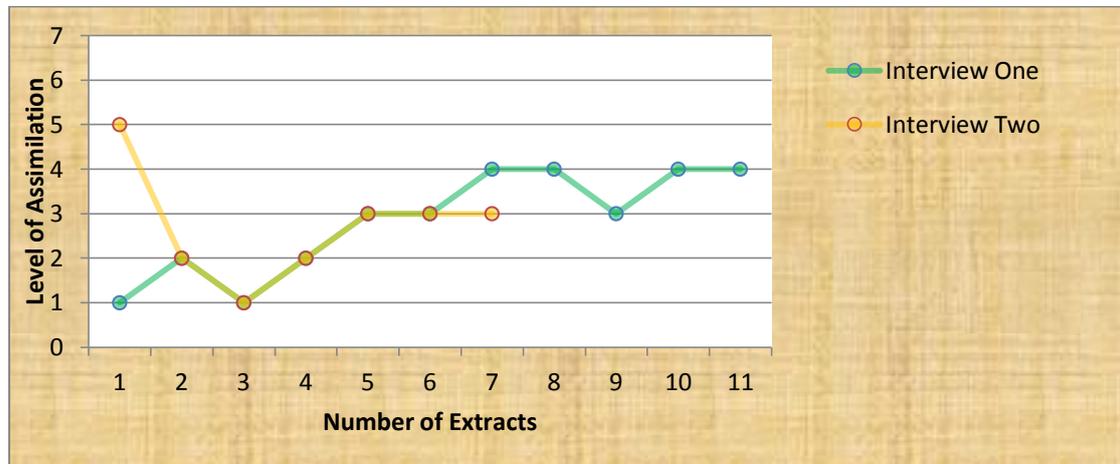
Much of the second interview centres on Jim's distress regarding losing his driver's licence. Although Jim is able to reflect on his difficulties this becomes more problematic for him when applied to the impact they have on his driving ability.

'I don't think I am fooling myself, I am now the learner driver now, I don't feel I am driving too fast []. I don't think I worry about getting anywhere or worry about where we are supposed to be going' (level 2).

Throughout both interviews an ebbing and flowing pattern is observed. That is, the dominant community tolerates, accepts and then rejects the PV. At times, Jim is aware of his problems *'I used to be quite hot on memory, it suddenly seems ever since [] we retired, that's gradually grown on me that my memory isn't what it was'* (level 4). At other times he appears unconcerned *'it's not something I've worried about'* (level 1). There is ambivalence between persevering with his problem and 'warding it off', illustrating that 'awareness' is a complex process neither static nor distinct.

4. Doris

Figure 7: A graph showing the number of extracts drawn from Doris’s interviews and the level at which they were coded:



First interview: Doris’s initial interview is characterised by gradual assimilation. At the beginning the PV emerges, but is not clearly formulated, she describes her difficulties as ‘*mixing things up*’ (level 1). Doris tells stories that point to the PV ‘*brain deterioration*’ but these are not clearly described. She talks about her history of Transient Ischaemic Attacks but the association between these and her current problems is not explicit. During the interview however, the dialogue changes and the PV is heard.

‘We’re meeting for a meal and I thought I’d drop the bombshell then, I don’t want to do it, I don’t know how they’re going to react []. I’ve warned them, I’ve told them that I’m going for a head scan [] they know something’s happening, cos I thought well it’s no good to sort of say, I don’t know myself what’s going to happen’ (level 4).

Both voices are present, conflicting sets of ‘feelings or wants’ can be heard (I don’t want to tell my friends but they need to know).

Second interview: During the second interview Doris begins at the higher level of assimilation describing problem solving efforts, *‘I have started doing crosswords to try and help’* (level 5) but when asked about the cause of her problems she becomes puzzled, *‘whether it was anything to do with the brain I don’t know, that’s the only thing I can think of’* (level 2).

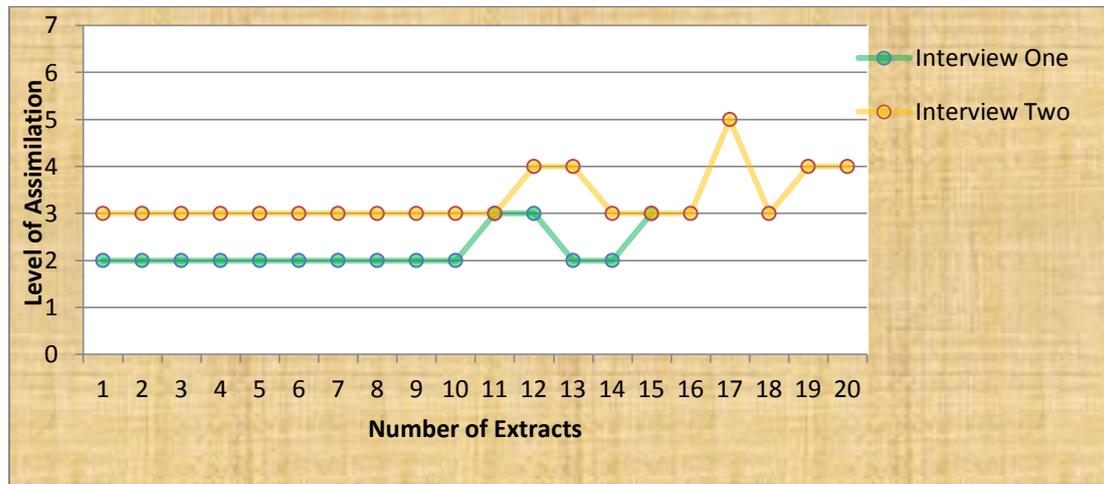
The PV is emerging into sustained awareness. Doris is able to describe both the sense of something being wrong, but also other aspects of herself. She is engaged in noticing how she is reacting to the PV, this takes the form of ‘yes ... but...’ statements, a marker of level three.

‘The memory clinic order the scan and the doctor has said that it was, you know it wasn’t bad not to worry about but that apparently there is blood vessel damage in the front, which is the memory part which is down to the strokes’ (level 3).

Except for an initial assertion of the PV in the second interview, during both interviews the PV gains strength and expression. That is, she appears unaware of her difficulties but as the conversation progresses the dialogue reveals that she is ‘aware of’ and is ‘clarifying’ her problems.

5. Geoffrey

Figure 8: A graph showing the number of extracts drawn from Geoffrey's interviews and the level at which they were coded:



First interview: For most of Geoffrey's initial interview the dialogue remains stable, the PV is emerging into awareness. Geoffrey is struggling to integrate the problematic material resulting in negative emotions, the hallmark of level two.

'That's quite upsetting when you're trying to think of something and it's not there anymore []. I mean, I used to have quite a sharp brain, things that I do at work now, I've got to really think about, where the icons [] for the, software that I use, which is disturbing, I mean I'm not that old really' (level 2).

Towards the end of the interview this painful affect associated with loss of abilities alleviates. Although he continues to express conflicting feelings in contrast to previous material there is emotional distance. He shifts from talking 'out of the' DV to being able to talk 'about the' DV.

'Cos you can't think of the words what have you to say, maybe if you're chatting to somebody it takes you that much longer to have a conversation because you can't think of the words to say so you withdraw' (level 3).

He describes how withdrawing protects him from the shame of struggling to find words. His responses indicate the '*disturbing*' nature of his difficulties and the impact they are having on his abilities and sense of self worth.

Second interview: During Geoffrey's second interview the dialogue again remains stable, this time the opposing voices are differentiated and he is beginning to make sense of his problems (level 3).

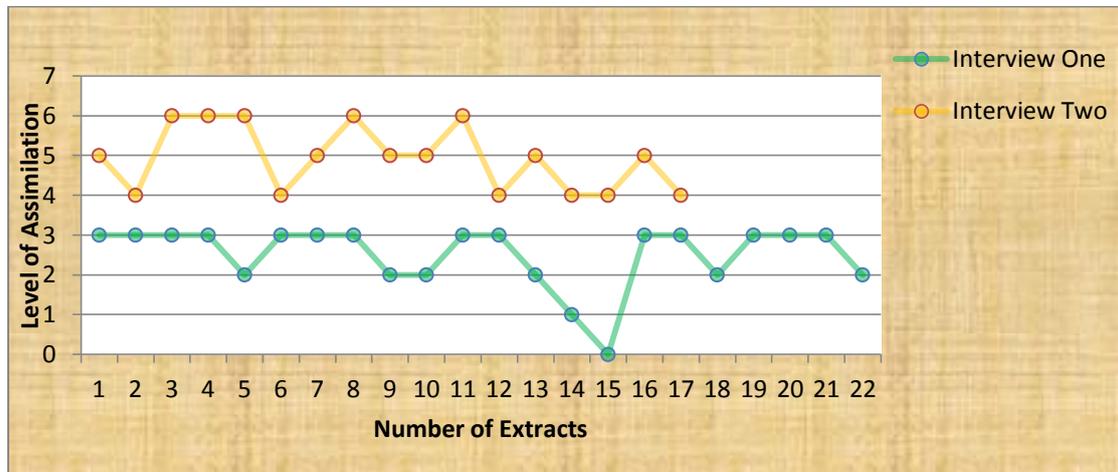
'I have to think about where the icons were on the desktop, for a particular function of a program and I thought that was unusual because normally that would just be second nature' (level 3).

In contrast to the similar passage from the initial interview, his narrative is calmer. Both voices can be heard and have equal weighting. As the interview progresses, the voices begin to reach an understanding with one another and he describes ways of managing his problems, '*I've told them my memory isn't as good as it was and I do have problems recalling things so they'll have to make allowances for it, they were quite understanding'* (level 4).

During both interviews the dialogue remains stable. In the first interview the PV is emerging into awareness. During the second it has gained expression, the voices are differentiated and the PV is consistently and more clearly heard. Rather than a gradual diminution of awareness, Geoffrey's interviews indicate an increased understanding of what his illness means to him. This results in him beginning to identify different perspectives to his problems.

6. Len

Figure 9: A graph showing the number of extracts drawn from Len's interviews and the level at which they were coded:



First Interview: For most of the first interview Len was engaged in a process of ‘stepping back’ and gaining clarity about his problems. His affect is negative but manageable; not panicky, a marker of level 3. The voices are differentiated and both heard.

‘I belong to an organisation []. I used to organise their dinner and dances, but I’ve resigned from that position because I found that, like memory loss, I’m not like, well everybody will tell you I was very finicky, everything had to be right, a hundred percent, but with this going on, I said, I’ve got to stand down and somebody else must take over so, I quietly dropped out of that one’ (level 3).

There is a sense of self slipping away, of losing meaningful roles. Len expresses doubt and uncertainty about giving up roles that belong to his ‘former self’. He describes ‘quietly dropping out’ indicating an avoidance of judgment. There are times

in which the PV loses strength and is suppressed, for example when asked about the cause of his difficulties Len is placed in a position of having to directly confront his problems, this is threatening and he ‘wards off’ the material, *‘I haven’t given that a thought to be honest with you but I just put it down to just getting old’* (level 0).

Second interview: A considerable shift is apparent in Len’s second interview. The voices are working together to address problems. He talks about having made changes in how he understands his life and his dementia and has found partial solutions to his problems (a marker of level 5).

‘Whereas before I always took the lead in things (wife) has almost taken over that role now and for the first time in our married life I’m doing what I’m told, no, but seriously she’s been my right arm, as I say the rules have changed, I’m not as dominant [] and I’m just grateful that she was here to help me out’ (level 5).

Len has tried out new strategies and describes changes, resulting from accepting and integrating the PV. There is an acceptance of increasing dependency and an appreciation of the support he has received.

‘I mean I tried to cover up [] yeah, you try to cover up and swear blind that you haven’t been told, you know, what you have been told and eventually you accept the reality that you’re not right and I think that took a long time for me to recognise it, but I’m glad that it happened, you know I’m glad that it was brought to people’s attention’ (level 6).

Len's capacity to assimilate the PV is entwined with his social support. He initially used denial as a way of coping. However when others provided feedback he begins to take on board what was happening, indicating the importance of others in moderating self.

'There are people that I can talk to [] our eldest daughter is a nurse so she's conversant with sorts of things our second daughter has been involved with old people so she's got a grounding in that, they're all very supportive and our son he's a brick, so yeah the family have supported us though the problem' (Level 5b).

Len's dialogue indicates increasing understanding of his difficulties and of his ability to be able to reflect back and on times when he was not able to integrate or accept the PV.

'I think that if people know, they understand, but if you hide it as I did, first going, they get frustrated with you, so if I was advising someone, if they found themselves in the situation I found myself in, I think you've got to be open with people and they may understand instead of thinking oh that silly old fool is losing his marbles' (level 5).

Len acknowledges the difficulties of concealing his problems and the importance of understanding and acceptance in coping with the fear associated with being judged as losing cognitive faculties. Len's interviews provide an opposing picture to the traditional view of dementia as resulting in a gradual diminution of awareness. His experience demonstrates the process and importance of assimilation; in accepting and

integrating a previously denied aspect of self, he achieves a sense of pride and accomplishment.

Discussion

As with previous research (Cheston, 2005; 2012; Macquarrie, 2005; Vernooij-Dassen *et al*, 2006; Betts & Cheston, 2011) rather than finding a diminution in awareness, participants in this study generally showed a gradual understanding of their difficulties. In conceptualising dementia as a ‘problematic experience’ this study represents ‘awareness’ as the product of dialogue between dominant and problematic voices. The higher levels of assimilation found during the second interview indicated that the problematic voice had gained more expression as participants began to assimilate the diagnosis.

However each dialogue was unique, there were no predictable, direct or linear patterns. Participants approached, talked about and adjusted in varying ways, supporting the findings from Cheston (2012) that assimilation is social, personal and variable. Despite many different experiences, there were also some commonalities of ‘coping’ observed. These patterns indicate how people begin to ‘adjust’ to their diagnosis and illuminate what helps or hinders the process of assimilation. Two interlinking processes were found:

1. The centrality of ambivalence: oscillating in and out of awareness
2. The importance of acceptance and support

The centrality of ambivalence. Participants’ dialogues fluctuated through the levels. For Jim, Henry, Len and Jill these fluctuations took notable shifts through the levels with them making sudden gains and then regressing to earlier levels. Although Geoffrey and Doris showed a more linear progression, ‘warding off’ was still observed. This approaching and retreating from awareness, illustrates the paradox of

acceptance and denial which has been observed in other studies. Macquarrie (2005) found that participants simultaneously acknowledged and resisted aspects of their disease in order to maintain agency in the face of cognitive losses. Pearce *et al* (2002) found that denial appeared to be part of a cyclical process of slowly turning to face the situation, rather than accepting it immediately.

This oscillating process is akin to that of the attachment processes in the ‘strange situation’. In this sense, ‘warding off’ equates to the ‘safe base’ from which participants venture and explore their difficulties. When this becomes too painful they retreat to a comfortable position of ‘not knowing’. Thus ambivalence (wanting, not wanting to know) regulates the pain and stress of facing the diagnosis with the need for safety and security. This association between dementia and attachment theory is not new. Miesen (1993) claimed that Alzheimer’s disease can be considered a ‘strange situation’, in which ever increasing experiences of feeling ‘insecure’ leads to the activation of attachment behaviours.

Rather than finding a direct relationship between impairment and awareness, this study supports the work of Clare (Clare, 2002; 2003; Clare *et al*, 2005; Clare 2010; Clare *et al*, 2012), who argues for a more sophisticated understanding. This study finds that awareness is not simply cognitive but is profoundly emotional. It is not static or distinct, rather people approach and retreat from awareness, enabling them to gradually face their difficulties.

Understanding 'awareness' as fluctuating and adaptive has important implications. Firstly, if awareness is not 'fixed or distinct' the use of short interviews, questionnaires, or comparing a person's understanding (for instance of the extent of their memory problems) with some external record for measuring awareness is misleading (Cheston, 2012). In this study, when the participants were asked about the cause of their problems they all 'down played' the severity, explanations included old age and laziness. If taken at face value these responses could indicate 'lack of insight'. This could then be viewed as symptomatic of the condition, rather than as an ebbing and flowing pattern of understanding.

Adopting the assimilation of problematic experiences model places the duality of people with dementia about knowing and not knowing within the context of research into how people generally assimilate problematic material. Processes involved in mediating awareness are not a response to neurological impairment but either wholly or partially the same as those that mediate awareness of any traumatic event (Cheston, 2012). 'Lack of awareness' is therefore not an incidental part of working with people with dementia and there is a need to ensure, just as with other diagnoses (e.g. HIV, cancer), individuals are provided with opportunities to express their feelings and make sense of what is happening to them.

The role and importance of acceptance and support. Research exploring dementia's impact on selfhood concludes that 'self' cannot be seen in isolation. Self is inherently social, dependant on others feedback and co-operation (Sabat 2002a; 2002b; MacRae, 2010). This becomes difficult for people with dementia who are

often perceived as confused or burdensome (Sabat, 2002). This study supports these findings. All participants talked about withdrawing to protect themselves from shaming judgments. As found in Langdon *et al* (2007), participants were sensitive to others' responses and these impacted on their attempts to preserve a positive sense of self. Jill and Len particularly described how their families' acceptance was instrumental in their willingness to 'face up to' their difficulties, which supports Pratt and Wilkinson's (2003) model which claims that supportive social contexts permit individuals to approach the diagnosis. People who have a strong sense of worth which is not dependent on what they do, but concerns who they are, are likely to do better (Cheston, 2012). This can be seen in Len's interview as he accepts that he can no longer do his old activities, but realises the importance, pleasure and value in being a husband, father and grandfather. Therefore it appears the process of 'adjusting' to dementia is tied up in social interaction. Accepting and valuing environments are likely to ease the process of assimilation.

Conclusion

In exploring whether the APES can be used to further the understanding of how people experience and manage the process of receiving dementia diagnosis, this study builds on the research evidence suggesting that people are able face the terrifying inevitability of deterioration and begin to 'come to terms' with the diagnosis. In addition, the findings begin to illuminate what makes this adjustment possible. Although each participant uniquely approached their diagnosis, some common aspects of coping were observed. All participants ventured in and out of awareness, gradually and partially 'adjusting' to their diagnosis, rather than facing it 'head on'. Social support and acceptance were crucial in enabling participants to sustain a positive

sense of self in the face of this adjustment. As participants began to assimilate the problematic voice there was a reduction in negative affect and they were more able to identify different perspectives to their problems.

Implications

- In dementia assessment, diagnostic and support practices ‘awareness’ should be viewed as a functional, fluctuating process entwined with social environments. Therefore many of the current tools which assess ‘awareness’ are misleading. Tools need to be developed, sophisticated enough to account for this variability and social influence.
- People with dementia should be provided with support to make sense of their illness and to help increase and sustain awareness. It is not enough for services to focus simply on diagnosis. Just as with other health conditions, pre and post diagnosis counselling/ support should be available.
- Families, carers and care homes should be advised of the importance of social feedback, and supported to ensure they can help the person to continue to feel accepted and valued in the face of their dementia diagnosis.

Limitations

This paper primarily focused on the finding that people have fluctuating awareness. It touches on the importance of social support; however this finding needs to be elaborated further. This can be done by re-visiting the data and focusing on the many extracts which indicate the importance of social context which have not been the focus of this paper. In addition to this employing an additional analysis strategy would add to the findings. APES involved coding the data to an existing framework, as

opposed to allowing themes to emerge from the data. This method resulted in some inevitable data loss. Reflecting on the interviews and analysis an interesting observation that was not captured by APES was the importance of the participants' partners in directing the dialogue. At times individuals would be 'facing up to' or talking about their difficulties and their partner would assert that 'there was thing wrong' or 'nothing to worry about', thus acting as the DV. Discourse Analysis would be an appropriate way of analysing the texts to further explore this observation as it is a method which explores the hidden motivations and underlying structures behind social interactions.

Further limitations stemmed from time constraints and the study design. Firstly researchers coded the extracts at two time points shortly after each interview set. This meant they knew which interview the extracts came from, possibly biasing the coding. Secondly four of the participants were not interviewed a second time. These interviews would have enhanced the overall analysis. Thirdly the repeat interview design meant that the participants were familiar with the interview questions and process as well with the researcher. This may have resulted in them being 'more at ease' and honest during the second interview, influencing the findings. Finally the focus on people whom had been recently diagnosed meant that they had not yet experienced severe cognitive deterioration. The findings about functional, variable awareness may have been different of the study had interviewed people further on in the disease progression, this would be an valuable area for future development.

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Appendices

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Appendix 1: Expended Introduction

Appendix 1a: Assimilation of Problematic Experiences Scale (APES)

APES level	Content	Affect
0. Warded off	Unformed, unaware avoidance	Minimal affect reflecting successful avoidance
1. Unwanted thoughts	Emergence of thoughts associated with discomfort	Unfocused strong emotions (e.g. anxiety, fear, sadness) which are more salient than the content
2. Vague awareness/emergence	Problematic experience is acknowledged and uncomfortable associated thoughts are described	Affect focused on acute psychological pain or panic
3. Problem statement/clarification	Clear problem statement	Negative but manageable
4. Understanding/insight	Problematic is formulated within schema including clear connective links	Curiosity of affect, with mixed pleasant recognitions
5. Application/working through	Working on current problem with reference to specific problem solving efforts	Business like, positive/negative affect linked to outcomes
6. Problem solution	Success with a specific problem	positive satisfaction linked to accomplishments
7. Mastery	Generalisation is through habitual use of problem solution in new situations	Neutral (i.e. this is no longer something to get excited about)

Adapted from Newman and Beail (2002)

Appendix 2: Expanded Method

Appendix 2a: Additional Information on Service-user Consultation

People with dementia were consulted to provide guidance on the interview schedule, the participant information sheet and the appropriate conditions for the study. This consultation was organised by the trusts, service user involvement officer. The researcher met a group of 6 people with dementia who attended a day service. The aims and rationale of the research were explained and then the people then reviewed the consent form and the participant information sheet. The interview schedule was then piloted on the group. Following this they made a number of suggestions and the following items were introduced:

- To offer the participant the option of having their partner or a supportive person present at the interview
- To offer a break during the interview
- Adjustments to the participant information sheet were made in-order to shorten it.

Appendix 2b: Additional Participant Information

A table is provided with additional participant information and the exact timings of the interviews. Pseudonyms for each participant have been applied throughout to protect anonymity and other identifying information has been removed.

Participant	Gender	Age	Person present at the interview	Date of First Interview	Date of Second Interview	Diagnosis
Henry	Male		Partner	16 th September 2011	16 th January 2012	Alzheimer's
Geoffrey	Male		Wife	6 th July 2011	1 st September 2011	Dementia
Jim	Male		Wife	8 th August 2011	17 th February 2012	Dementia
Jill	Female		Husband	26 th August 2011	16 th January 2012	Alzheimer's
Doris	Female		Husband	6 th September 2011	11 th January 2012	MIC
Len	Male		Wife	7 th September 2011	17 th February 2012	Alzheimer's
Fergus	Male		Wife	5 th August 2011	n/a	Dementia
Adam	Male		Wife	15 th September 2011	n/a	MIC
Mike	Male		n/a	7 th July 2011	n/a	Unknown
Maggie	Female		n/a	7 th July 2011	n/a	Dementia

Appendix 2c: Decision Guide (Adapted from the APES scale Honos-Webb *et al*, 1998)

**HOW TO USE THE MARKERS OF ASSIMILATION IN DEMENTIA
CODING FRAME:
DECISION GUIDE**

Level 0. Warding off

Does the person actively avoid discussing dementia and subjects related to dementia and does not recognise dementia or the problems associated with dementia as having relevance in their life. For instance by attributing problems to something other than dementia, such as ageing or physical health problems?

Affect (mood) is minimal as the person is successfully avoiding the problem.

Then consider a rating of level 0

Level 1. Unwanted thoughts.

Does the person acknowledge that they experience an aspect of dementia such as memory loss, but avoids discussing this? For instance

- a. By changing the conversation
- b. Or by telling a contradictory story
- c. Or by describing or referencing fears of losing control, being mad or abnormal
- d. Or alternatively, locates the existence of dementia elsewhere by either
 - talking about other people and not themselves as having dementia
 - describing dementia (or an aspect of dementia) only indirectly (e.g. as "it" or "the problem") and avoid using terms such as "dementia" or "Alzheimer's disease"
 - limits the problems they face to some areas without this being explicitly or implicitly associated with dementia, and asserts that other areas of functioning are unimpaired or that they can be easily overcome
 - or otherwise minimizes the significance of this

The relevance of the passage may be confusing as the problem (i.e. dementia, its treatment and assessment) may be talked around rather than named.

Affect (mood) involves stronger negative feelings such as anxiety, fear, anger and sadness.

Then consider a rating of level 1

2. Vague Awareness and Emergence

Is the person in **distress**, and this distress seems to come from some internal conflict relating either to dementia (or a variant of this such as Alzheimer's disease) or to a primary symptom of dementia, and in talking seems to be **caught up in the moment of the emotion**

- a. If the person expresses feelings of **sadness, depression, worry or anxiety**.
- b. Or is **angry** or **irritated** about some aspect of dementia (including treatment and assessment).
- c. Or if the person seems **puzzled or confused** about what is happening to them.
- d. Or if the person seems to feel **overwhelmed** and feels that things are getting worse.
- e. The person may tell stories that point to the problem (dementia) but these are **not clearly described**.
- f. The person uses **metaphors** to talk about their difficulties.

Affect (mood) is strong they are in psychological pain or panic.

Then consider a rating of level 2

Level 3. Clarifying dementia as the problem

Does the person acknowledge the existence of a problem **and** attributes this to or recognize that this is caused by a specific problem or illness (such as dementia)?

- a. and **describe or talk about** their reaction to this (e.g. feeling upset, silly, angry or trying to cover up for mistakes) without being caught up in the emotion of this, and **also** without being able to identify a way out of this problem. Or **describe mixed feelings** about the dementia ("yes But")
- b. The person appears **'stuck'** and sees no way out.
- c. Is person is **developing a clearer understanding** of the problem (for example asking questions about the problem or being curious about the problem in order to aid their understanding)

- d. The person is **describing contradictions** the person (for example saying that their short-term memory is fine but their long-term memory poor or pointing out instances where they can do things, and other instances when they can't)
- e. The client realises that they have had **difficulty previously recognising the problem** (dementia) (for example they might say they used to put their poor memory down to age, or simple did not want to think about it)

The affect (mood) is negative but manageable (not panicky)

Then consider a rating of level 3

Level 4. Understanding and gaining perspective

Does the person acknowledge the existence of a dementia or a central aspect of dementia such as a memory problem and is also able to describe how this makes them feel, or how they react to this (but is able to stand back from their feelings)? And

- a. Either identify instances or situations where their feelings differ in intensity or their problems are more or less acute
- b. Or otherwise show that they have achieved some emotional distance from the dementia, rather than being overwhelmed by it (e.g. through use of humour, making a joke or laughing)
- c. Or between how they respond to some aspects of dementia and others areas of their life or other areas of dementia
- d. Or make links between the past and the present, or comparing themselves with others in a worse position

The affect (mood) is mixed there is a tone of relief in addition to distress.

Then consider a rating of level 4

Level 5. Working through (developing strategies)

Does the person acknowledge the existence of a dementia or a central aspect of dementia such as a memory problem and recognise that the dementia cannot be cured, but can be managed. They can point out exactly what needs to change/ get worked on.

- a. The person is weighing up attempts at a specific or partial solutions to the problem (e.g. taking or considering taking medication, activities such as support groups, supporting the Alzheimer's society or challenging stigma). They **also** describe being optimistic or hopeful or otherwise indicate they

have a positive affect either about their future or because of something that they are doing.

- b. They are able to generalise their new found (partial) solutions to varying problems and areas of life. Or if the person is able to find some way of acknowledging deterioration, and the prospect of further change, but with explicitly describing some acceptance.

The affect (mood) is positive, business like and optimistic.

Then consider rating as level 5

6. Problem solution (noticing change)

Does the person acknowledge that they have a dementia, and has achieved a successful solution for a specific problem.

- a) They talk about feeling that they have achieved a **change** in their life in living with the dementia that they feel positive about. They are proud of their solution and /or changes
- b) They see a change in their **understanding of what is happening to them** or they talk about another aspect of **change in their relationships with others**
- c) The person comments on how **others have noticed that they have changed**

Affect (mood) is positive satisfied, proud of accomplishment

Then consider rating at level 6

7. Mastery

The person is able to integrate dementia into the whole of their life. Dementia is acknowledged and recognised but no longer defines them as a person. It is recognised as something that has changed them and the emotional aspects of that change for themselves and others is also recognised.

The person is successfully uses their new solutions in new situations.

Affect (mood) is positive but no longer excitable.

Appendix 2d: Reflectivity Statement

Reflexivity Statement

According to Rice and Ezzy (1999) qualitative researchers should continually take stock of their actions and role in the research process and subject these to the same critical stance as the rest of the data. As a result this section will provide some of the author's reflections on their actions and roles in terms of both the research content and process.

Content: This project was shaped by my theoretical stance on knowledge and how we can obtain knowledge. I personally believe that our understandings and experiences are largely socially constructed, in this sense I take a constructionist epistemology stance. I believe that knowledge is a representation of the world influenced by what people (e.g. researchers', scientists, Politicians' the media) chose to observe, how they interpret it and crucially the stories they tell about what they have found. This belief has had a number influences on this project. Most obviously I chose a qualitative research method exploring people's experiences. I would find it very difficult to accept an argument about experience unless the people whose experience is understudy have been included in the research. During the interviews there were times when partners suggested that the account given by the person with dementia was not accurate or misleading. This did not matter to me as it was the experience from the perspective of the person with dementia I was interested in rather than trying to futilely achieve an accurate, factual account of the process of assessment and diagnosis.

Secondly this stance impacts on my beliefs about knowledge as power. I believe that those that create knowledge gain the most power. Doctors are architects of medical

knowledge and control what is defined as an illness or not. Although I would not dispute that dementia is an illness with a number of organic changes and symptoms, I believe a purely biomedical account of dementia is harmful. It frustrates me that the importance of the person's social environment, opportunities for interpersonal interaction and emotional needs are neglected in our society's narrow focus on cognitive decline. This frustration inspired this project and I acknowledge that it will have influenced me during the design, delivery, analysis and writing of this project.

Process: During the interviews I was aware of the possible distress of participants and their partners. I did not want to unnecessarily cause upset or disturbance. Therefore I was initially tentative with my questioning. Although the questions remained the same, the tone and surrounding 'small talk' changed according to how I felt participants and their partners were managing the discussion. I observed that at times when participants became painfully upset that their partner or I acted as the 'dominant voice' of everything is ok in an attempt to rescue them and ourselves from the distressing discussion. Although I aimed not to do this as I was aware this influenced the dialogue, personally this was difficult for me especially as it became apparent that I was often the first person to have mentioned dementia as a possibility to them. I believe that this observation about others acting as the 'dominant voice' makes an interesting area for further study and I plan to revisit my data with this in mind for a future paper.

Appendix 3: Extended Findings

Appendix 3a: Findings from the four interviews excluded from the main paper

The following section presents the extended findings from the interviews. As the main study was primarily concerned with exploring changes before and after diagnosis the data from the four participants who were only interviewed once was not included in the main analysis. This extended section details the analysis and the findings from these four interviews and contrasts and compares it with the overall analysis. The first part describes the number of extracts drawn from the interviews and the level of agreement between the researchers' coding. The second part explores the impact the four additional interviews have on the overall analysis. The third part looks at 4 participants' levels of assimilation and the changing relationship between voices.

Analysis of Coding

The percentage of coding agreement remains stable with or without the data from the four participants only interviewed once; illustrated in figure 10.

Figure 10: The number of extracts drawn and coded from the interviews and the percentage of coding agreement between the researchers.

	Number of Extracts initially drawn	Percentage coded in agreement	Extracts remaining following resolving disagreements	Percentage coded in agreement
Total 10 initial interviews	192	51.5%	161	94%
6 participants interviewed twice	120	51%	97	96%
4 participants interviewed once	72	52.5%	64	92%

Assimilation Models

Figure 11 presents the assimilation of problematic experiences framework and the number of items coded at each level from the 10 initial interviews. This illustrates that that during the first interviews participants' levels of assimilation ranged from level 0 'warding off' to level 4 'understanding and gaining perspective'. The majority of extracts (43.5%) were coded at level 3 'clarifying the problem'. Figure 12 is the same model presented in the main paper (page 46), and includes only the data from 6 participants that were interviewed twice. Again levels of assimilation ranged from level 0 'to level 4. The majority of extracts (44%) were coded at level 3 'clarifying the problem'. This indicates that the removal of the four participants did not alter the overall findings.

Figure 11: The assimilation of problematic experiences framework and the number of items coded at each level from the total 10 initial interviews (before diagnosis).

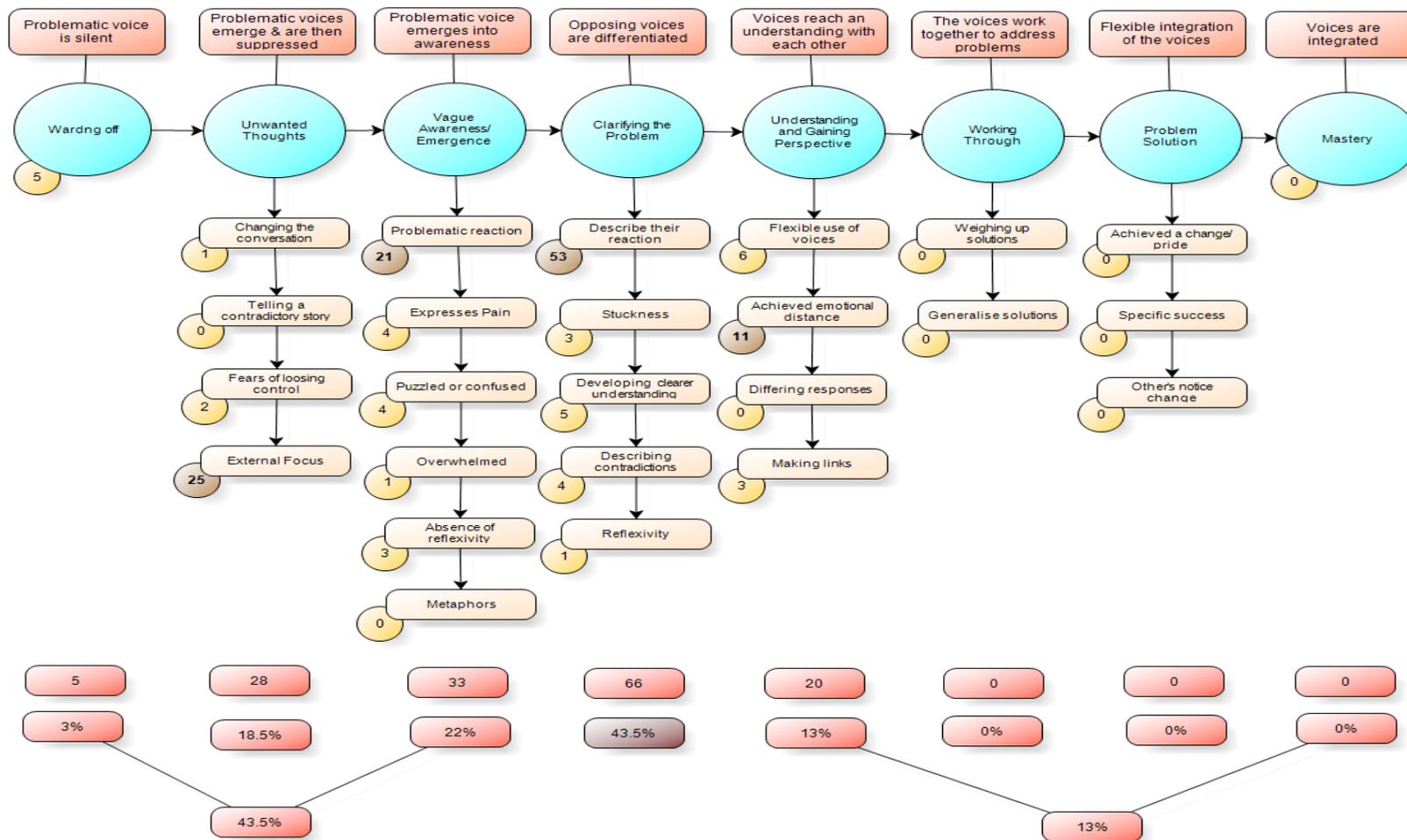
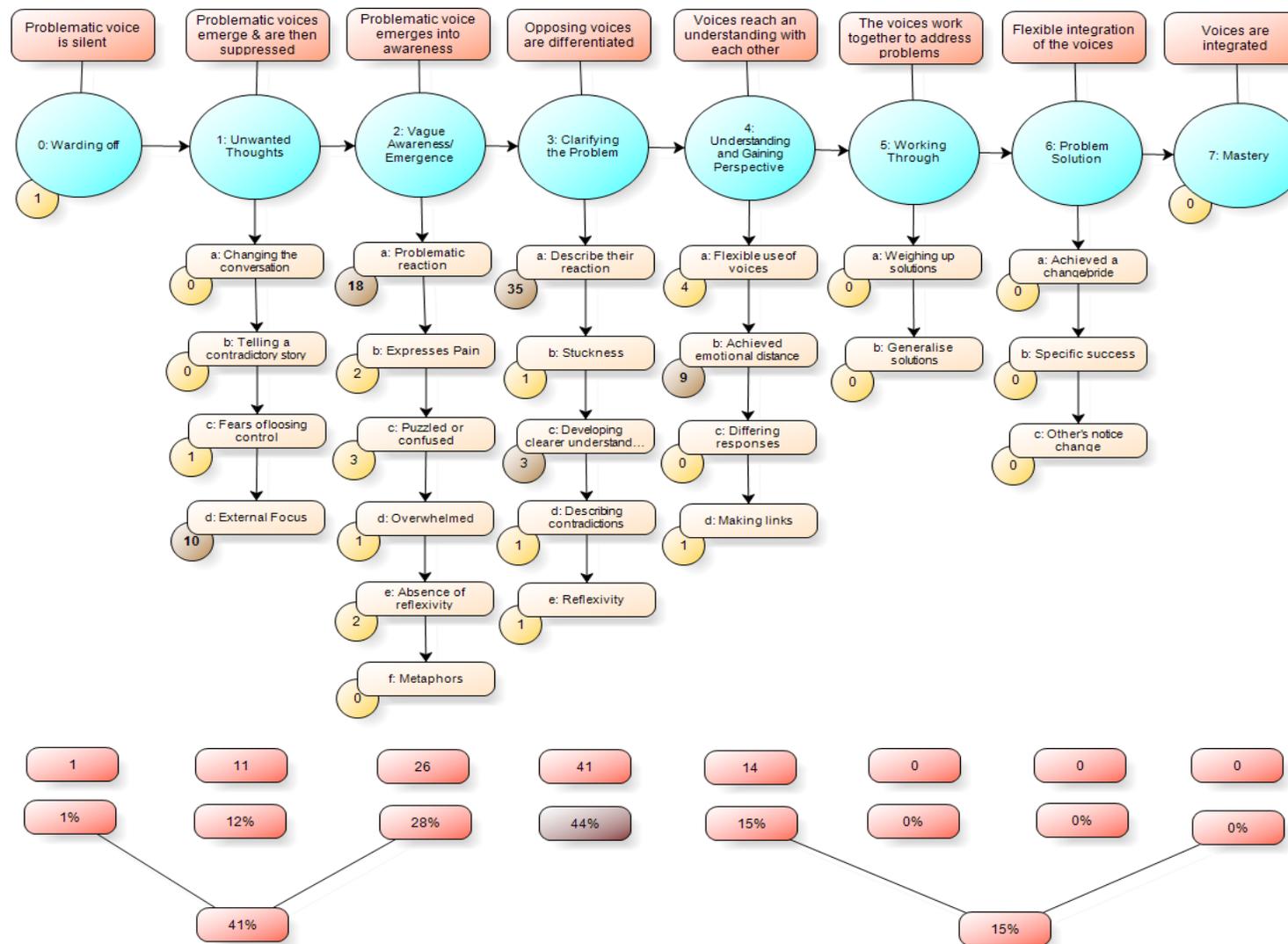


Figure 12: The assimilation of problematic experiences framework and the number of items coded at each level from the initial interviews (before diagnosis) excluding the data from the four participants that were only interviews once.

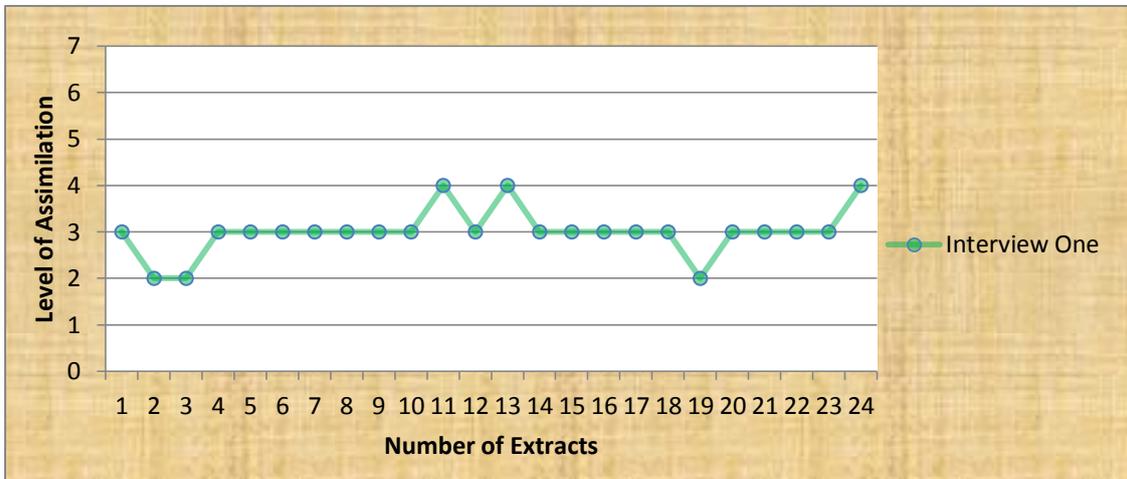


Individual levels of assimilation

As described in the main analysis the group findings do not capture the unique experience each participant brought to the analysis. Although their stories have not been included in the main paper each of the excluded participants offered valuable insight and added to the overall understanding of how people begin to adjust to a dementia diagnosis. The following account is structured participant by participant to stay closely connected to their experiences and to allow exploration of the individual changing relationships between the problematic voice (PV) and dominant voice (DV).

7. Mike

Figure 13: A graph showing the number of extracts drawn from Mike’s interview and the level at which they were coded:



First interview: For the most part Mike remains at the assimilation level of ‘clarifying the problem’ (level 3). The emerging problematic voice is differentiated and expressed but not yet accepted into the community of voices, this is indicated by his feelings of confusion.

‘I keep forgetting, things [] as I said, I sit here for hours trying to analyse myself and the more I think about it the more I just go asleep, I just sort of nod off. I find that if I’m concentrating on something, I just fall asleep, brain just shoos [] than all of a sudden I look up at the clock and I think well that can’t be right [] and I turn the tele on and I realise this is night time not day time, yes it’s weird. It’s sort of very hard to explain, very hard to explain. It’s like it’s frustrating for me but also and it’s hard to explain’ (level 3).

Mike is able to talk about the impact that his memory problems are having on him. Mixed feelings emerge, he describes both the sense of something being wrong, and

also another aspect of himself, feeling that he needs to try harder, or do something differently.

'It's strange [] I don't know what' wrong I have sat here many a time for many hours trying to figure it out [] you know it just can't. I think I have thought of so many things [] I think it got worse, over this last couple of months it's got worse, you know, with the going out and the forgetting, yes, that's got worse' (level 3).

As with the other participants Mike oscillates between the levels. He occasionally becomes caught up in the emotion and painful affect is evident.

'I've written on all the exams [] I can show you everything but again it don't mean nothing now, it's like sometimes I want to burn it cause it doesn't mean nothing no more [] I feel worthless or whatever cause I can't do the things any more' (level 2).

At other times Mike the PV gains more expression and there is negation between the voices.

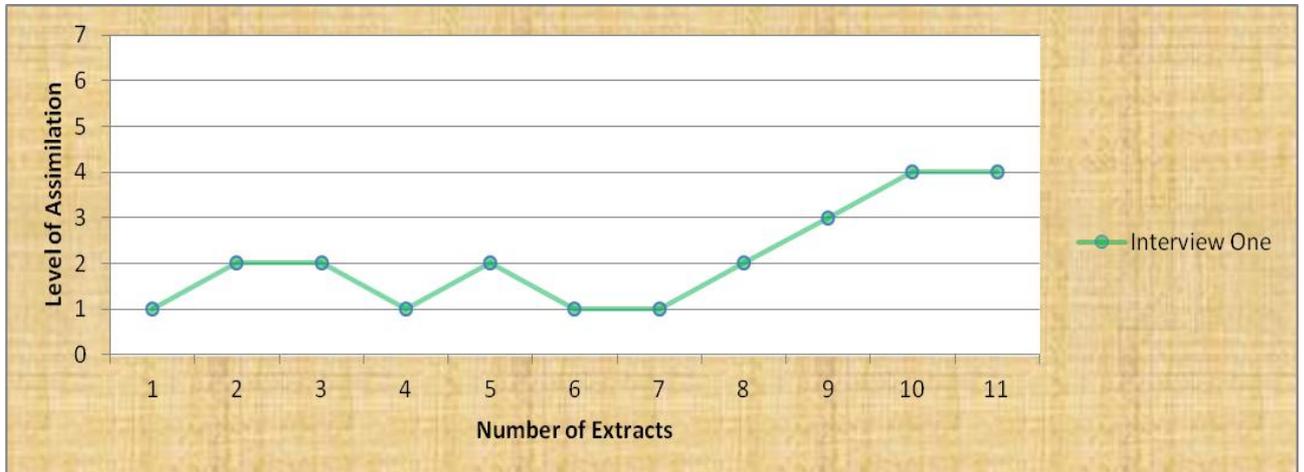
'I think well look, I might not look ill, but I know I am because I know I can't' do things that I used to be able to do, and when I try to do things it gets frustrating' (level 4).

For the most part, Mike appears stuck as he tries to understand what is happening to him. Although he remains at the 'problem clarification' stage for the most part, the

findings from his interview add to overall picture of ebbing and flowing awareness at times he regresses to level 2 and at times achieves a level 4. Unfortunately Mike did not receive his diagnostic appointment within the time frame of this research so was not interviewed a second time and the outcome of his assessment is unknown.

8. Adam

Figure 14: A graph showing the number of extracts drawn from Adam's interview and the level at which they were coded:



First interview: For the majority of his interview Adam remained at the lower levels of assimilation. He minimises the significance of his difficulties when talking about whether others have noticed his memory problems, *'I don't think there's been any cause for them to be aware of it, if I mentioned it they might have said oh yeah, I'm sure nobody at the moment does'* (level 1). He tells a story which points to the problematic voice but the problem is located 'out there' rather than in his own subjective experience, *'funny enough, one of my cousins, actual fact, has got a problem, he's been diagnosed with dementia of some sort'* (level 1). At times the PV emerges into awareness this is confusing and results in painful affect.

'I had been forgetting things and more importantly which annoyed me most I was getting confused when I wanted to do something and you've got it in the wrong order or you think oh god what do I do next sort of thing' (level 2).

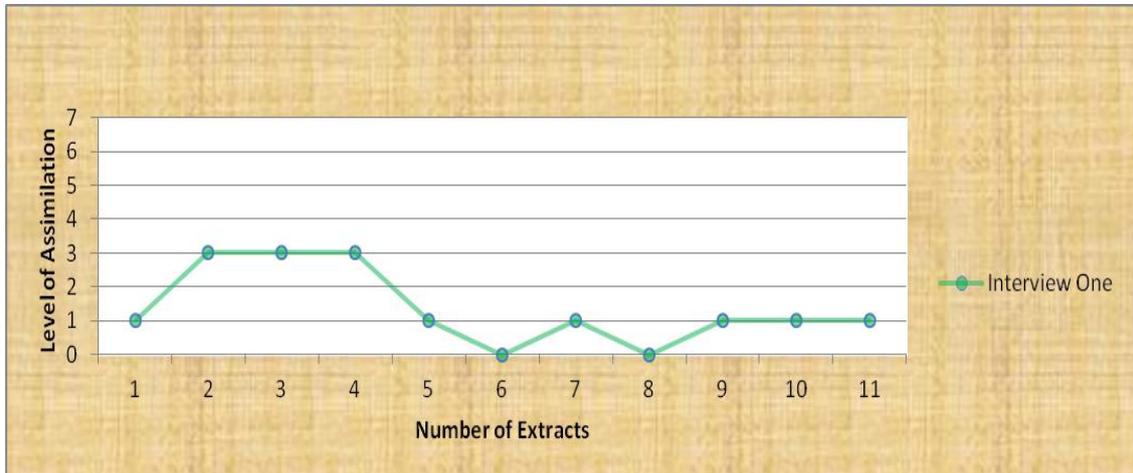
Towards the end of the interview Adam shows a gradual assimilation. The PV is emerging into sustained awareness, differentiated and begins to negotiate with the DV. When asked about the impact of his memory problems he talks about how his relationships and social situation buffers the affects, without denying that there is a problem.

'I suppose you tend to jog along as you are until somebody comes along like you are and asks a question like that, (laughs). I suppose it's bound to make a difference to a degree, obviously, but in the situation I am, with the family, people I know and the lifestyle we have, it hasn't impacted greatly' (level 4).

As with Len and Jill the findings from this interview highlight the importance of a supportive social environment. He talks about his sons being particularly supportive and *'keeping an eye on him'* without mentioning that they need to do this. This supports the idea that people sensitive to the responses of others. Adam understands his sons changing responses towards him even through this is not explicitly discussed. Adam did not receive his diagnostic appointment within the research timeframe so was not re-interviewed.

9. Maggie

Figure 15: A graph showing the number of extracts drawn from Maggie’s interview and the level at which they were coded:



First interview: For the most of the interview Maggie avoids or trivialises material relating to the PV. ‘Perhaps you don’t notice it yourself, but, I thought if somebody had lost their memory or was losing their memory, they’d be a lot worse than I am’ (level 1). When confronted directly about her experience the PV surfaces and she talks about the difficulties she is having.

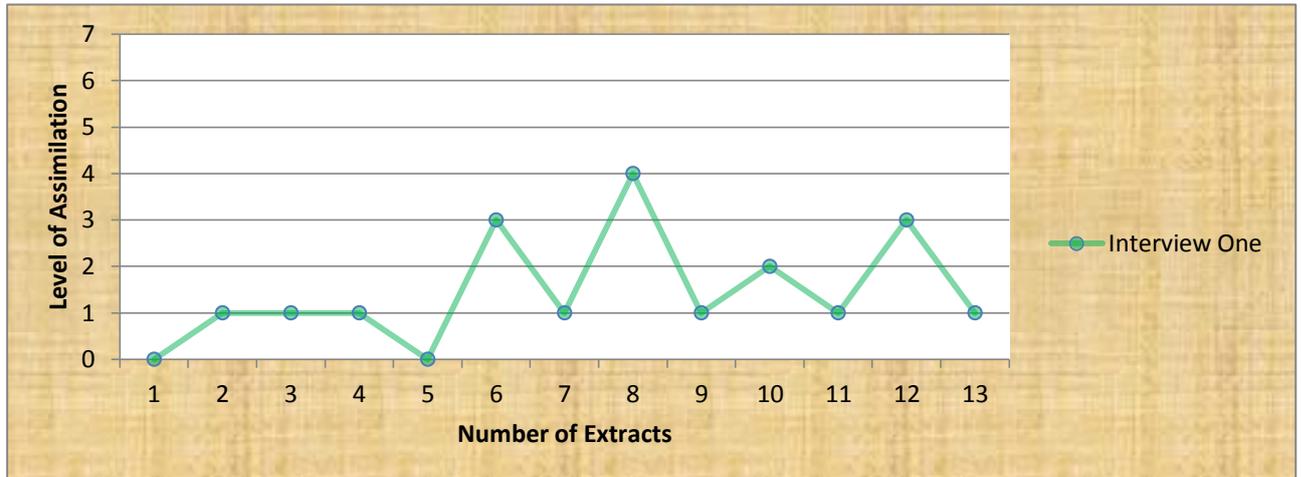
“It’s silly little things like this morning, I looked at your letter just to make sure you know time and everything and I can’t find the thing now, (laughs), I must of put it somewhere so safe []. I thought well I had it this morning, I think that’s the sort of thing” (level 3).

However for the most part the DV prevails and there is strong determination that nothing is wrong ‘well I’m not really aware of it’ (level 1), ‘I just put it down to old age’ (level 0). Although the PV is not entirely suppressed; she at times talk about and

is aware of her difficulties. Too much acknowledgment is profoundly frightening so the DV asserts and she retreats to neutral ground. Maggie decline to be interviewed a second time, given her difficulty in assimilating the problematic material her diagnosis of dementia is likely to have been devastating for her.

10. Fergus

Figure 16: A graph showing the number of extracts drawn from Fergus's interview and the level at which they were coded:



First interview At the beginning of the interview the possibility of dementia as being relevant as an explanation for the his problems is minimised and Fergus attributes his difficulties to less threatening causes, *'One of my problems is see, I'm Dyslexic'* (level 0). When asked about the cause of his memory problems the DV asserts there is nothing wrong, *'well it could possibly be all the pills'* (level 0).

However as the interview progresses the relationship between the PV and DV changes and becomes more erratic. The dialogue varies between negotiation and understanding to the PV being suppressed. For example when asked if he is worried about the possibility of having dementia the PV emerges into sustained awareness and he clearly names his problem.

'Well I think its dementia, for if I'm getting memory loss []. I'm wandering is there any way I can start to strengthen my own memory, see what I mean, try and get it into my head more' (level 3).

However he then moves away from the conversation and changes the subject to neutral ground, *"can I make a suggestion, cup of tea"* (level 1). The dialogue fluctuates between the problematic, dementia-related experiences, being pushed away and him being able to acknowledge both the PV and his reactions to it. The responses indicate his internal struggle; moving into awareness which is profoundly painful so retreating to more neutral ground. Given his difficulties in 'accepting' and 'integrating' the PV his diagnosis of dementia is likely to have been devastating for him possibly reflecting why he declined to be interviewed a second time.

Extended findings summary

The removal of the data from the four participants only interviewed once from the main analysis, does not alter the overall results (e.g. agreement between researcher coding and overall levels or ranges of assimilation). The exploration of the 4 participants' levels of assimilation and the changing relationship between the PV and DV adds to the overall findings. As found in the main paper each dialogue (experience of assimilation) was unique, there were no predictable, direct or linear pattern. Participants' dialogues fluctuated through the levels with them approaching and retreating from awareness.

Appendix 4: Ethical Documentation

Appendix 4a: Consent form



A research Study looking at how People Experience,
Understand and Talk about their Memory Difficulties.

Consent Form

Please put your initials in the boxes if "yes"

I have read the information sheet (version 4: 28/02/2011) about the study. I understand what the study is about and have had the chance to ask questions.	
I understand that it is my choice about whether I take part in the study or not and that it is ok to withdraw from the study at any time.	
I agree to be interviewed by the researcher about my memory difficulties.	
I understand that the interviews and transcripts may be listened to or looked at by the researchers supervisor's to ensure the researcher is conducting the research according to ethical guidelines and good practice guidelines.	
I agree to my GP being informed that I am taking part in this study. (this is not necessary for participation in the project)	

If you agree to take part, please sign below:

Signature..... Date.....

THANK-YOU!

Researcher's statement of capacity.

To give valid consent a person must be able to:

- Understand and retain the information.
- Communicate their choice.
- Understand the risks/benefits, alternatives and consequences.
- Weigh up the information to make a decision.

(Mental Capacity Act 2005)

Statement of capacity:

- I have explained the research study and interview process using the information sheet.
- I have explained the right to withdraw from the study.
- I have explained the risks and benefits to the study.
- I believe that the participant has capacity to consent to all aspects of this study.

Signature..... **Date**

NB: If the participant has shown little response to the information or has not demonstrated a basic understanding of proposed interview and research, then consent is not valid as capacity is not present. The interview must therefore be terminated.

Appendix 4b: Additional Information on Capacity

The Mental Capacity Act 2005 (DOH, 2005)¹⁵ indicates that every adult has the right to make his or her own decision and it assumed that they can unless proved otherwise. The act also recognises that some people may have difficulties making decisions some or all of the time. This could be because they have:

- a learning disability
- dementia
- a mental health problem
- a brain injury
- had a stroke

This study's inclusion criteria stipulated that all participants must have, 'capacity to consent to all aspects of the study'. The clinician's at the memory clinic only broached potential participants who they felt had capacity. Following this the researcher contacted potential participants by telephone and talked to them about the research, again keeping in mind the question of capacity. However it was recognised that due to their memory problems individual participant's capacity to consent may fluctuate, therefore at the start of each interview the researcher made a decision about the individuals' current capacity to consent to the interview at that time and documented this (see appendix 4a).

¹⁵ Department of Health (DOH) (2005). *The Mental Capacity Act*. Retrieved from: www.legislation.gov.uk/ukpga/2005/9/contents (Accessed 21.04.20112).

When assessing if the participant had capacity to consent to the interview and take part in the study the researcher considered:

- did the person understand the decision and why they needed to make it (did they want to be interviewed and take part in the research)
- did the person understand what might happen if they did or did not make this decision (that they had a choice to take part and if they chose not to take part that this would not affect their treatment)
- could they understand and weigh up the information relevant to this decision
- could they clearly communicate their decision

If they felt the participant did not have capacity to consent to the interview and/or the research at that time the interview would have been terminated. However this did not occur with any of the participants.

Appendix 4c: Ethical Approval Letters

Miss Emma Lishman
Trainee Clinical Psychologist
Taunton & Somerset NHS Trust
University of Exeter
School of Psychology
Washington Singer Laboratories
EX4 4QG

Research and Development
Avon & Wiltshire Mental Health Partnership NHS Trust
Blackberry Hill Hospital
Blackberry Centre
Manor Road
Fishponds
Bristol
BS16 2EW
0117 378 4269
Charlotte.hook@awp.nhs.uk

24th March 2011

Dear Miss Lishman

A qualitative study using the markers of assimilation of problematic voices technique: looking at how people talk about their memory problems before and after an assessment at a memory clinic.

AWP Ref: 0717S

Start date: 24th March 2011 **End date:** 30th September 2012

Thank you for the R&D application for the above project, this has been reviewed by the R&D Office and I am very pleased to be able to confirm that your project has been given **PERMISSION TO PROCEED**. It was considered that for this particular R&D project, that permission could be given without the need for additional review of scientific quality by the R&D group, as the project is part of a formal educational qualification, with formal academic supervisor Dr Janet Smithson. Permission is on the condition of your supervisor having reviewed and approved formally your protocol.

Please note that the University of Exeter will be the 'Sponsor' for this project. Please let me know immediately if this is not the case.

In addition:

- **Trust permission is given subject to the appropriate NHS research ethics committee review and favourable opinion. The R&D Office has received this confirmation dated 16th March 2011.**
- Numbers of recruited staff and service users should be notified to the AWP research and development office as required.
- If there are any changes to the study protocol (version number 3 dated 21st December 2010) then please ensure that a revised protocol is immediately forwarded to the AWP R&D office with the amendments highlighted, together with confirmation that the amendments have been favourably reviewed by the appropriate research ethics committee.
- Consideration needs to be given to ensuring patient confidentiality and to ensuring that informed consent for the participants' involvement in the research is initially made by the direct clinical team. This will also need you to ensure that you do not see any patient identifiable information or records prior to full consent being given. Please read the enclosed AWP information on confidential data.

Chair
Felicity Longshaw

Headquarters
Jenner House, Langley Park, Chippenham. SN15 1GG

Chief Executive
Laura McMurtrie

- If the end date changes from that shown above then please inform me. Trust permission will cease on the end date above, whereby you will be requested to submit a final governance report. Please contact me to discuss and request any extension.
- Please ensure that both you and your supervisor are aware of the Department of Health's Research Governance Framework (available from the Internet: <http://www.dh.gov.uk/assetRoot/04/01/47/57/04014757.pdf>), Trust Intranet and the R&D Office.

The R&D office is required to monitor the progress of all research in the Trust under the Department of Health's Research Governance Framework. Therefore we will need to contact you in due course with a request for governance reports of progress. If you have any questions about any of the above, or if I can be of any other assistance then please feel free to contact me.

Yours sincerely



Charlotte Hook
Research Governance Facilitator



National Patient Safety Agency

National Research Ethics Service

South West 4 REC

Whiteflans
Level 3, Block B
Lewin's Mead
Bristol
BS1 2HT

Tel: 0117 342 1328
Fax: 0117 342 0445

16 March 2011

Miss Emma Lishman
Trainee Clinical Psychologist
Taunton and Somerset NHS Trust
University of Exeter
School of Psychology
Washington Singer Laboratories
EX44QG

Dear Miss Lishman

Study Title: A Qualitative Study using the Markers of Assimilation of Problematic Voices technique: Looking at how People Talk About their Memory Problems Before and After an Assessment at a Memory Clinic

REC reference number: 11/H0102/8

Thank you for responding to the Committee's request for further information on the above research.

The further information was considered in correspondence by a sub-committee of the REC 14 March 2011. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/H0102/9

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr David Evans

To: Emma Lishman
From: Cris Burgess
CC: Dr Janet Smithson
Re: Application 2010/208 to Ethics Committee
Date: 25 March 2012

The School of Psychology Ethics Committee met recently and your NHS Local Research Ethics Committee application and approval were reviewed. In line with our procedures, your project is now de facto approved.

The agreement of the Committee is subject to your compliance with the British Psychological Society Code of Conduct and the University of Exeter procedures for data protection (<http://www.ex.ac.uk/admin/academic/datapro/>). In any correspondence with the Ethics Committee about this application, please quote the reference number above.

I wish you every success with your research.

Yours sincerely,



Cris Burgess
Chair of School Ethics Committee

Appendix 5: Schedule, Letters and Information

Appendix 5a: Participant Information Sheet



A research Study looking at how People Experience, Understand and Talk about their Memory Difficulties.

INFORMATION SHEET FOR PARTICIPANTS

We would like to invite you to take part in a research study which will tell us how people talk and feel about their memory problems as they are going through an assessment at the memory clinic.

Before you decide to take part it is important for you to understand *why* the study is being done and *what* it will involve. This information sheet contains this information so please read it carefully.

Please Ask us if there is anything you don't understand or if you want more information. Take time to decide whether or not you want to join in.

Thank you for reading this!

Why are we doing this study?

We want to find how people with memory problems talk and feel about their difficulties as they are undergoing an assessment at a memory clinic. This is so we can learn new ways of helping people as they go through this process.

This research study also forms part of the researcher's training to become a clinical psychologist.

Why have I been asked to take part?

You have been asked if you want to take part because you are undergoing an assessment at the memory clinic.

What are we asking you to do?

If you agree we will pass on your name and telephone number to the researcher Emma Lishman, who will then contact you by telephone to arrange a time and place convenient to you to meet for an interview. If you have changed your mind about taking part when she calls you this is fine just tell her you no longer want to take part.

The interview will ask about your memory problems and your thoughts and feelings about them. A second interview will then take place once you have completed the assessment at the clinic. The interviews will be audio-recorded and will last for around 1 hour.

Do I have to take part?

You do not have to take part in this study and this would not affect the medical care you are receiving from the memory clinic.

If you decide to take part but change your mind later, this is fine we can cancel the interview and destroy any information you have already given us.

If you decide not to take part or decide to withdraw at any time, this will not affect the standard of specialist medical care that you will receive.

Are there any disadvantages of taking part in this study?

We understand this may be a difficult time for you. Some of the interview questions may remind of things that upset or sadden you.

However in the unlikely event you should become distressed the interviewer will talk this through with you or we can arrange follow-up contact with a clinical psychologist.

Benefits of joining in

There are no specific benefits for you in taking part in this study. However if we understand more about how people feel and think about going through the memory clinic assessment process, we may be able to offer help to people undergoing the same process in the future. We can do this by telling professionals who work in memory services about what you have told us. We aim to publish our results in journals and talk about

our results at conferences. This should ensure professionals consider the view point of people with memory problems in their work.

What happens when the research study stops?

After the study stops, you will continue to access the memory service as you would have done. You will not be contacted again for this study.

However you will be offered a finished copy of the project or a summary of the project by the researcher, which would be sent to you at a later date.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any point and this will not affect the care that you are receiving at the memory clinic. We will destroy any information you have given us if you would like to withdraw from the study.

Will my details be kept private?

It is very important that all the information you give us is completely private. We will write down the things that you say from the audio-recording and take out any details linking the recording to you so that nobody will know that it was you. We may use small bits of what you say when we report the study, but the quotes will be completely anonymised so nobody will know it was you. The recording will be encrypted and password protected (so no-one else can listen to it). The copy of what you said in the interview (the transcript) will be linked to you via a code. All personal details or lists that could identify you will be kept secure in locked cabinets in locked offices. With your permission we will let your General Practitioner (G.P) know that you are taking part in the research but will not pass on anything you tell us.

Consent

We have to be absolutely certain that you are happy to join in this study, so before the interview starts Emma Lishman (the researcher) will ask you to sign a consent form. Even if you do sign the forms, you will be free to withdraw at any point. Just tell Emma if this is the case. Whether or not you wish to participate, you will continue to receive the same care from the memory clinic.

What will happen to the results of the study?

This study will give us information about the how people feel about their memory problems whilst undergoing a memory assessment. We aim to publish these results in journals to help other people working with people with memory problems to provide the best service they can.

What should I do if I have a problem with this study?

If you have any problems with this study, you can contact the researcher Emma Lishman on...

You can also contact xxx or xxx from the clinical team at

You can also complain to the NHS in the usual way if you were not happy with the study through the Patient Advice and Liaison services (PALS) on 01249468261

Who is organising and funding the study?

This research is organised by a Trainee Clinical Psychologist at the University of Exeter. They are supervised by a Consultant Clinical Psychologist who works within NHS older adult mental health services and a Social Psychologist from the University of Exeter.

Will I need to pay to be part of this study?

No

Ethical Approval

The study has been approved by the National Research Ethics Service, South West 4 REC (11/H01012/0)

T: 0117 3421335

Email uhb-tr.SouthWest4@nhs.net

Contacts / Further Information:

THANK YOU for taking the time to read this information sheet

Appendix 5b: Interview Schedule

Interview Schedule

My name is xxx and I am a Trainee Clinical Psychologist at Exeter University. I have asked to interview you today as I am aware that you are going through an assessment at the memory clinic at xxx and my research is trying to understand people's experiences of their memory problems. The interview should take about an hour. But if you need to stop for any reason please let me know. Some of the questions may cause you to feel upset, I hope this won't happen but if it does we can stop at anytime. (To the partner/ support: you are also free to stop me if you feel this is appropriate or provide comfort if required). I shall be recording the interview, this so I can remember everything you say later on. However everything you tell me will be completely anonymous. You won't be identified and we never pass on any personal information about you or your family to anyone else. Are you happy about this? (*Information sheet to be read and Informed consent letter and form to be signed*)

Thank you very much for agreeing to talk to me.

Do you have any questions?

Interview

I am going to start by asking you some questions about your life in general.

1. Who do you live with?

Can you tell me their names/ is it just the two of you

2. Can you tell me a bit about your family?

How often do you see them? Do they live close by?

3. What things do you enjoy doing?

4. Have the things you enjoy doing changed over the past year?

5. What do you do in an average week?

Ok well perhaps you could tell what you have done this week/ the main things you have done this week

6. Have there been any changes in your life in the past year?

I am now going to ask you some questions about yourself

7. Thinking about yourself, I would like you to give me as many different answers as you can to the question? Who am I?

So for example...a mother/ father, job role

8. What qualities do you think of when you think of yourself?

If can't come up with any speak to the carer and then see if they agree

9. What are your main roles?

10. Have any of these roles changed in the past year?

11. Do you think you have changed at all in the last year?

I am now going to ask you some questions about your memory problems

12. Can you tell me how you came to be referred to the memory clinic?
13. Whose idea was this?
14. Had there been any incidents or slips when you (or others) noticed that your memory was not so good?
15. Are other people more worried than you are? Who has been the most worried about your memory?
16. Have you just been referred about your memory, or are there any other concerns?
17. What are your feelings about going to a memory clinic?
18. What was the actual experience of the memory clinic like?
19. Was it what you thought it might be?
20. Have any other assessments carried out/ (e.g. a scan, blood tests)
21. Do you know what the next step in the process might be?

I am now going to ask you some general questions about memory problems

22. There can be lots of different causes of memory problems has anyone mentioned to you what might be causing your difficulties?
23. Sometimes people who go to the clinic are worried that they'll be told that they have an illness like dementia or Alzheimer's disease – is this something that you'd thought about?
24. Are worried about this?
25. Is this something that you try and keep from other people?
26. Is there anyone you can talk to about this?
27. What does dementia or Alzheimer's disease mean to you?
28. What do you think might be the cause dementia or Alzheimer's disease?

I am now going to ask you about some questions about other people

29. How have other people around you reacted to the memory problem?
30. Have there been any changes in your relationships recently?
31. How do you think society feels about older people?
32. How do you think society feels about peoples with dementia or Alzheimer's disease?

Is there anything else you feel you would like to tell me about your memory problems? Or anything this interview has made you think of?

Thank-you very much for talking to me it had been very useful.

Appendix 6: Dissemination Plan

Appendix 6a: Dissemination

Dissemination Plan

1. A version of the report will be sent to all participants that are interested.
2. An oral presentation regarding the findings of the study will be given to the Memory Service during the summer months.
3. The primary researcher attended the trusts 'service user engagement meeting' in September 2011 to feedback the preliminary findings of the initial interviews. This meeting was attended by people representing different parts of the older people's service across the trust. The aim was to share information/good practice and to ensure that service user engagement was happening across the trust.
4. This paper will be submitted for publication in the journal, *Dementia: The International Journal of Social Research and Practice*. This journal acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families (see appendix 6c: guidelines for submission)
5. Elements of the findings are being presented by the primary researcher and field supervisor in June 2012 at the BPS, PSIGE conference: 'Working systemically in older people services' (see appendix 6b: conference poster).
6. The presentation for the PSIGE conference will be written up as a paper for the PSIGE newsletter for the October 2012 publication. The title for this paper is, 'The paradox of dementia: meaning making before and after receiving a diagnosis of dementia'.

These methods allow for the research to be disseminated to an extensive audience including those involved in the study, those directly involved in the service and to a wider audience interested in gaining insight into the subjective experience of receiving a dementia diagnosis

Appendix 6b: Conference Poster



Bristol CPD Event 2012

Programme

Friday June 15th – CPD Day – Ashton Court Mansion

Working systemically in older people's services

9.30 – 12.30: Eleanor Anderson, Glenda Fredman, Eleanor Martin, Alison Milton and Penny Rapaport: 'Systemic practice with older people: Collaboration and community'.

12.30 – 1.30: Lunch

1.30 – 2.40: PSIGE AGM

2.40 – 3.00: Paul Whitby: Title tbc.

3.00 – 3.40: Marion Dixon & Liz Curtis: 'Reflections on training staff in systemic approaches for everyday practice'.

3.40 – 3.55: Break.

3.55 – 4.15: **tbc**

4.15 – 4.45: Rik Cheston and Emma Lishman: 'The paradox of dementia: meaning making before and after receiving a diagnosis of dementia'.

4.45 – 5.00. Close



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Clinical Psychology

Appendix 6c: Guidelines for Submission

Notes for Contributors

1. The aim of the journal is to publish original research or original contributions to the existing literature on social research and dementia. When submitting papers for consideration, please attach a letter confirming that all authors have agreed to the submission, and that the article is not currently being considered for publication by any other paper or electronic journal.
2. Each paper submitted, if considered suitable by the Editors, will be refereed by at least two anonymous referees, and the Editors may recommend revision and re-submission.
3. *Length of papers.* Brief articles should be up to 3000 words and more substantial articles between 5000 and 8000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length. Please also supply an abstract of 100-150 words, and up to five keywords arranged in alphabetical order.
4. When submitting a paper for consideration, our preferred method of receipt is as an electronic version and as a Microsoft Word document. This should be sent via email attachment to one of the Editors outlined in Note 18, together with a separate covering letter. If this is not practicable, please supply one paper copy and the article on a PC-compatible disk (containing text and all illustrations). Rejected papers will not be returned to authors.
5. Your typescript (written in English) needs to be typed using double spacing on one side only of white A or US standard size paper, with generous left and right-hand margins.
6. Your title page should give: one first name as well as the surname and any initials for each author; a maximum of four degrees/qualifications for each author and the current relevant appointment only; authors' accurate postal addresses; daytime telephone numbers, and fax and email numbers.
7. *Quotations.* Lengthy quotations (over 40 words) should be displayed and indented in the text.
8. American or UK spellings may be used. Please use single quotation marks. Dates should be in the form '9 May 2000'. Delete full stops/periods from 'USA' and other such abbreviations.

9. If the paper is accepted for publication, a copy of the final version will be required as either an email attached Microsoft Word document, or on disk in a PC-compatible format. The author is responsible for ensuring that the final version of the article matches exactly the one required by the Editors.

10. *Tables.* You should present tables in your manuscript typed double-spaced on separate sheets and containing only horizontal rules. Each table needs a short descriptive title above it. Column headings should clearly define the data presented. If necessary, suitably identified footnotes should be included below. Take care to include all the units of measurement. The table needs to be cited in the text.

11. *Figures.* Line drawings should be presented as camera-ready copy on glossy paper (b/w, unless to be reproduced - by arrangement - in colour) and, if possible, on disk as EPS files (all fonts embedded) or TIFF files, 800 dpi - b/w only. For scanning, photographs should preferably be submitted as clear, glossy, unmounted b/w prints with a good range of contrast or on disk as TIFF files, 300 dpi.

12. *References in the text* should be presented in American Psychological Association (APA) style, i.e. the author's name and year of publication in brackets, together with the page numbers, e.g. 'As Kitwood (1997, pp 40-41.) has observed', or, in a more general reference: 'Kitwood (1997) appears to be saying ...'

13. *Reference list.* The references should be listed alphabetically in full at the end of the paper, typed double-spaced for ease of editing, in the following style.

14. *Language and terminology.* Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. dements). Language that might be deemed sexist or racist should not be used.

15. *Abbreviations.* As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

16. The corresponding author will receive page proofs for checking. Twenty-five free offprints will be sent to the corresponding author, and each of the co-authors will receive a free copy of the journal.