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**Perspectives on Living and Working with  
Dementia**

**by**

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**A thesis submitted in partial fulfilment of the  
requirements for the degree of  
Doctor of Clinical Psychology**

**University of Warwick, Department of Psychology  
and  
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## **Declaration**

I declare that this thesis is my own work and has not been submitted for any other degree at another university.

Chapters one and two have been written for submission to Aging and Mental Health. A copy of the instructions for authors wishing to submit papers for publication to this journal can be found in appendix 1. Instructions indicate that section headings and subheadings should not use numbering, indentation and bold or italic typeface. For ease of reading the thesis as a whole, however, these formats have been used within the papers as they are presented here.

Within chapter 2 all identifying features of the organisation in which the research was conducted and of the individual participants have been removed to maintain confidentiality.



## Summary

This thesis explores perspectives on living and working with dementia. Chapter one reviews the literature related to the experience of dementia and identity. Themes within theoretical and empirical papers are identified which contribute to an understanding of how the available information can be utilised to inform clinical work with people with dementia. It is argued that maintaining the integrity of a person with dementia's identity is possible and important for well-being, however, more research is needed to establish what 'identity work' should contain and when it should be delivered. Directions for future research are discussed.

Assessment and diagnosis have been identified as being difficult aspects of work by clinicians in areas of healthcare, such as oncology, and as crucial to the experience of clients with memory problems. Despite this, and the importance of understanding the experience of staff members to support recruitment, retention and staff well-being, research exploring the experience of clinicians of assessing and diagnosing clients within dementia services is lacking. Chapter two therefore uses interpretative phenomenological analysis to examine the experience of staff members who perform this role. Themes are identified that highlight the complex nature of this role and the conflicting aspects of it. Participants appeared to be trying to meet conflicting needs within the context of a progressive illness and service restrictions, which influenced their perceived effectiveness and caused conflict and stress. Clinical and service implications are discussed and suggestions for future research made.

Chapter three utilises the author's experience of completing the research presented in chapter two to reflect on tensions between the roles of researcher and clinician. How these roles can come into conflict with each other and the implications of this for the research process is explored.

## **Chapter one**

### **Literature Review:**

**'How can the Literature on Dementia and Identity Inform  
our Clinical Work?'**

**Word count: 8,484**

# **How can the Literature on Dementia and Identity Inform our Clinical Work?**

## **1.1 Abstract**

**OBJECTIVES:** Identity has been identified as a crucial part of the experience of dementia. This paper reviews literature related to identity and dementia and highlights clinical implications of this. **METHOD:** From a search of Medline and Psycinfo databases, 35 papers exploring identity and dementia were identified. **RESULTS:** Examination of these papers revealed four key areas for discussion; 'Critical Incidents', 'The Influence of Others', 'The Influence of Loss' and 'Preserving Identity'. **CONCLUSION:** Maintaining the integrity of a person with dementia's identity is possible and important for well-being, however more research is needed to establish what 'identity work' should contain and when it should be delivered.

## **1.2 Introduction**

Research indicates identity is a crucial part of the experience of dementia (Beard, 2004; Clare, 2002; 2003; Harris & Sterin, 1999; Husband, 1999; Sabat, 2002). Literature has debated whether dementia inevitably destroys identity (Killick, 2004), however, following a paradigm shift highlighting the uniqueness of each person with dementia and the importance of understanding the experience of dementia, emphasis has moved towards understanding the process and experience of the impact

of dementia on identity, rather than simply whether or not identity is retained (Harman & Clare, 2006).

This paper therefore reviews the literature related to the experience of dementia and identity, explores how this can inform clinical work and outlines the potential impact of 'identity work' on people with dementia.

### **1.2.1 What is Identity?**

Various perspectives exist regarding what constitutes identity and its component parts. This paper will not provide a comprehensive review of the different perspectives, rather, it will introduce the concept of identity and focus on how the term has been applied in literature related to dementia.

Within the philosophical literature, identity has been associated with conditions of consciousness, reciprocity, rationality, intentionality and ability to communicate (Perry & Connor, 2002). Identity has also been described as a multidimensional construct encompassing various constructs such as gender and ethnicity (Cohen-Mansfield, Parpura-Gill & Golander, 2006). Gillies and Johnston (2004) review different conceptualisations of identity concluding there are considerable consistencies regarding components of identity, highlighting continuity, self-awareness and distinctiveness of self concept as key themes.

Adams (2000) discusses dominant approaches to identity highlighting Widdicome's (1998) assertion that within social sciences the notion of identity is predominantly used in two ways. Firstly, to develop taxonomies and social structures (identity as groups, status or roles) and secondly, ascribed or acquired identities which are located within the social structure. Adams (2000) notes these approaches assume identity is an essential possession of either people or society and that a direct relationship exists between identity and social reality (in which an individual's identity is determined by their position in society). He highlights an alternative to these dominant views, stating identity can be conceptualised as arising out of discourse, "Rather than being an essential feature of an individual, identity is cast through meanings created within interaction" (Adams, 2000, p.796).

The importance of continuity has also been challenged, with Blustein (1999) suggesting the purpose of a theory of identity may not be to answer the question 'what is it for a person to persist over time?', rather to understand what it is that makes a set of experiences, actions and characteristics that of a given person and not somebody else. Blustein (1999) highlights psychological relatedness to others as being central in our survival as the 'same' person and discusses the narrative self-conception view of identity, which understands identity as being created by a self-conception in narrative form. Narrative approaches suggest identity is formed through mental processes, based on memories of the past and placed in relation to the present through narrative (Surr, 2006).

New experiences are integrated into our 'story' and selected experiences are reconstructed to achieve assimilation (Surr, 2006). Individuals therefore use narrative to construct a life history that validates identity (Shenk, Davis, Peacock & Moore, 2002). The concept of continuity is further developed by the 'communitarian view', that if individuals are unable to maintain their own psychological continuity, society can facilitate their recognition and validity as the same person (Blustein, 1999). Killick (2004) also emphasises the role of others, stating the concept of wholeness is reliant on interaction with the environment and others, in addition to having a concept of the past, present and future.

The language used by theorists varies within the literature, for example; 'identity', 'selfhood', 'subjectivity' and 'self'. Elliott (2001) provides a useful review of this area, suggesting terminological differences are not always significant given all represent concern with individual subjectivity. He notes, however, that attention has been paid to these different terms because they reflect historical and political traditions, "For example, it can plausibly be argued that the concepts of 'the self' and 'identity', though similar, are not coextensive, since there are forms of identity which are not based on the self, namely, forms of collective identity, such as nationalist identities" (Elliott, 2001, p.9).

Of particular relevance to the experience of dementia and identity is the suggestion that modern western philosophy separates mind and body,

positions the former as superior to the latter and places identity “as an exclusive privilege of the sphere of cognition” (Kontos, 2004, p.829), which holds importance for how identity may be experienced and interpreted within the context of dementia.

These approaches to identity can be observed within the literature related to dementia and identity.

### **1.2.2 Dementia and Identity**

Cheston & Bender (1999) state dementia has been placed within at least three contrasting frameworks, which are used here to understand perspectives regarding dementia and identity. Dementia has been represented as affecting either, an individual's brain, mind or social self (Cheston & Bender, 1999).

The ‘brains’ framework, originating from the biomedical model, has been dominant within the literature (Harris & Sterin, 1999) and “part of a popular discourse...widely disseminated through the...media” (Hinton & Levkoff, 1999, p.461). Dementia is conceptualised as a disease of the brain with losses defined in terms of “intellectual, linguistic and cognitive functioning arising directly from neurological impairment” (Cheston & Bender, 1999, p.204). Neurological changes are highlighted as fundamental in influencing identity, making it difficult for individuals to organise and sustain the self (Shenk et al, 2002) and maintain a unity of self-consciousness (Killick, 2004). Gillies and Johnston also highlight

this, stating that “Arguably, continuity relies on a rehearsal and accumulation of the past and the ability to find relevance for that past in the present” (2004, p.436).

This view highlights how continuity, self-awareness and distinctiveness of self-concept, identified above as central to many conceptualisations of identity, are challenged by cognitive decline. The term dementia derives from the Latin ‘de’ (out of) ‘mens’ (mind) and ‘ia’ (state of), meaning to be out of, or to have lost one’s mind (Herskovits, 1995) and conceptualisations such as these have contributed to a view that dementia causes an inevitable loss of identity, being “a disease that erodes and silences the familiar and known self” (Karner & Bobbitt-Zeher, 2005, p.554). In this representation of dementia “cognitive function is a central and defining characteristic of the self that is especially vulnerable to attack by the disease” (Herskovits, 1995, p.158) and the psychosocial context is ignored (Downs, 1997).

The ‘minds’ representation views dementia as a personal experience in which individuals struggle to establish meaning within the context of their experiences (Cheston & Bender, 1999). This framework acknowledges neurological influences, but highlights the impact of these changes on an individual’s ability to defend themselves against trauma caused by deterioration, with the view that as dementia progresses increasingly primitive defences emerge (Bender & Cheston, 1997). The clinical presentation of dementia is therefore “represented as a function of



neurological deterioration and psychological health” (Cheston & Bender, 1999, p.205). The interactions of a person with dementia are assumed to have meaning within this framework, which advocates this should be understood and psychosocial needs addressed.

Finally, ‘social selves’ places dementia within a social framework; individuals are seen within a social context, including a broader political context of definitions of appropriate behaviour (Cheston & Bender, 1999). This representation is based broadly on social constructionist ideas, which propose reality is socially constructed through human action and therefore emphasise the role of others in identity. It views dementia as an “interactive, interpersonal experience in addition to a physical condition” (Perry & O’Connor, 2002, p.55) where losses are seen in terms of both neurological changes and interpersonal relationships. The importance of social interactions is therefore highlighted, with these seen as more significant for identity than cognitive changes (Beard, 2004; Shenk et al., 2002). This framework acknowledges “the impact of progressive cognitive impairment, [while maintaining] a view of the person with dementia as an active agent in constructing his or her own sense of identity and emphasises that this process necessarily occurs within a social context” (Robinson, Clare & Evans, 2005, p.337).

Kitwood (1993) provides a model for this view, stating that social psychological experiences interact with neurology, influencing the impact

of dementia on identity. Personhood is seen as the result of interaction between factors including; personality, biography, neurological impairment, physical health and social psychology. Personality and biography are considered fixed, however Kitwood (1993) suggests an individual's physical health and social psychology surrounding them can be improved. A 'malignant social psychology' that depersonalises and invalidates individuals can therefore exacerbate cognitive decline and negatively influence identity, highlighting the relational nature of the concept (Kitwood, 1990; 1993).

Differing views therefore exist regarding how dementia influences identity, from the neurologically based view that identity declines as dementia progresses, to conceptualisations proposing a mediating influence of individual psychology and interactions with society. These conceptualisations, however, all acknowledge dementia does influence identity. It has been hypothesised that understanding this will have important implications for services regarding support for clients, training for staff and "in developing interventions that can enhance self-efficacy and adaptive coping" (Clare, 2002, p.139). It is also likely this understanding could contribute to helping carers (family members and paid staff), to understand the experiences of those for whom they care (Killick, 2004).

### **1.3 Methods - Search Terms and Procedure**

Search terms 'identity and dementia', 'self and dementia' and 'self-concept and dementia' were entered into Medline (1980-2006) and Psycinfo (1985-2006) databases. The search also requested papers published in English. Any relevant papers listed in the references of articles gained through the databases were also obtained. 35 papers were identified that explore the experience of dementia and identity. These fell into two main groups; six theoretical papers reviewing how identity relates to dementia and 29 empirical papers presenting results of research exploring dementia and identity. Of the empirical papers, three do not state the stage of dementia of participants, two present findings from research with participants in moderate-severe stages living at home and two papers include participants at all stages of dementia. Five present research with carers of people with dementia. The remaining 17 papers focus on either early stages of dementia (nine papers), or people in residential care (eight papers).

### **1.4 Results & Discussion**

References to identity and dementia were highlighted within each of the papers identified by the literature search. Papers discussed identity and dementia in relation to several areas, for example, ways in which other people may influence identity. Each of these was noted, revealing key areas relating to 'Critical Incidents', 'The Influence of Others', 'The Influence of Loss' and 'Preserving Identity'. These areas are not

mutually exclusive, but provide a structure for discussing this literature with reference to clinical implications.

#### **1.4.1 Critical Incidents**

Research identifies what Beard refers to as critical incidents, which are moments or experiences that “foster transformations of identity” and are crucial in understanding the experience of dementia and identity (2004, p.421). A frequently referred to critical incident was diagnosis (Beard, 2004; Bender & Cheston, 1997; Husband, 1999; 2000; Robinson et al., 2005; Saunders, 1998) with research suggesting that being told one has dementia and the diagnosis process itself are important for identity.

Bender and Cheston’s (1997) theoretical paper presents a three stage model of people with dementia’s subjective world, developed to highlight psychological as well as neurological processes involved. The authors acknowledge they do not comprehensively review the literature and offer little explanation of how the model was developed. They do, however, begin to highlight the impact of diagnosis on identity and, drawing on comparisons with other services such as HIV, draw attention to this as a valid and important point for support and psychological intervention.

Husband (1999) supports this, presenting three case studies of psychological therapy following diagnosis. These provide an in-depth view of the experience and beneficial effects of psychological therapy in mediating negative effects on identity, although no formal outcome

measure was utilised, only self-report. Individuals stated the effect of diagnosis on identity was critical, surpassing concerns about future care plans and that psychological therapy was beneficial in managing this (Husband, 1999). This was also a key finding of Husband's (2000) research which subjected notes from interviews with 10 recently diagnosed participants to content analysis and frequency counts. Both papers include relatively small samples from one geographical area making it difficult to generalise findings. They do, however indicate diagnosis may significantly influence identity and suggest this may be a key time to provide support.

Further to this, Beard (2004) and Robinson et al (2005) utilise more rigorous qualitative methodologies (grounded theory and interpretative phenomenological analysis (IPA) respectively) to explore psychological reactions to diagnosis. They support the idea of diagnosis as a 'defining moment' for identity, highlighting the importance of honesty, information and psychological support to help individuals make sense of their experiences and manage the impact on identity (Beard, 2004; Robinson et al., 2005). It has also been suggested that how and what information is presented at diagnosis has implications for identity, as individuals can only meaningfully integrate new circumstances if they have all the relevant information (Tappen, Williams, Fishman & Touhy, 1999).

Power imbalances in interactions with professionals may also compound the impact of diagnosis on identity. Professionals diagnose and refer

individuals to services they wish to access, while individuals are there to 'be diagnosed'. Saunders (1998) utilises interactional discourse analysis to analyse how 17 individuals undergoing neuropsychological assessment constructed their identities during assessment and suggests power imbalances create an even greater threat to identity as individuals with dementia are positioned as less powerful and more out of control.

The emphasis on diagnosis as a critical incident is possibly due to the focus of research, which specifically explores experiences of diagnosis and early stages of dementia. Other critical incidents are, however, identified within the literature relating to change, such as admission to residential care and changes in role (Beard, 2004; Cohen-Mansfield, Golander & Arnhem, 2000).

The literature therefore indicates that clinicians and services should use this information to help manage these critical incidents and support people through them. Diagnosis could be a key time for intervention, with a need for services that enable individuals to maintain some control and make sense of relevant information (Gillies & Johnston, 2004; Robinson et al., 2005; Saunders, 1998; Tappen et al., 1999). Gillies and Johnston suggest identity maintenance is influential in how individuals steer "a course through the disease trajectory" (2004, p.441), indicating the earlier this begins, the more beneficial it will be in enabling the individual to manage the impact of the illness.

### **1.4.2 The Influence of Others**

It has been suggested interpersonal relationships and social context are significant for identity (Kitwood, 1990; 1993; Kitwood & Bredin, 1992; Surr, 2006), with research suggesting social factors may mediate how individuals respond to dementia (Clare, 2003). Robinson et al's research with couples highlights this, suggesting the person with dementia and their partner are "constructing an individual and shared identity within a social context" (2005, p.337). Research also indicates people with dementia are aware of the role of others in constructing their identity and therefore have concerns about how they will be perceived and treated (Beard, 2004; Husband, 1999).

Literature relating to the influence of others is discussed in relation to four areas: 'Isolation', 'The label of dementia', 'Power in relationships' and 'Enhancing identity'. Each of these are outlined below.

#### **1.4.2.1 Isolation**

Literature suggests people with dementia can isolate themselves from social contact and be isolated by others, which influences identity.

Early theory based largely on clinical experience suggested social stigma was critical (Kitwood, 1990; Kitwood & Bredin, 1992). This has subsequently been supported by research (Sabat, 1998; 2002; Husband, 2000). Sabat's (1998; 2002) four case studies present data from conversations with people with dementia with whom the author

experienced long term relationships. These present in-depth pictures of participants' experiences, although it is difficult to generalise findings based on such small numbers. Husband's (2000) research further supports the role of social stigma, although this study again uses a small sample from one geographical area of the UK, raising questions about generalisability. Husband (2000) asked about fears and the effect of the diagnosis on 10 recently diagnosed individuals. They expressed concern about being treated differently by others and felt ashamed about their difficulties, frequently leading to withdrawal from social contact. Research suggests this can lead to reduced access to "a valued social identity" (Husband, 2000, p.546; Robinson et al., 2005), which also has implications for self-esteem (Husband, 2000); "Since selves are ordinarily situated in networks of social relationships, social isolation typically fosters loss of self" (Charmaz, 1983, p.176).

Kitwood (1990) and Kitwood and Bredin's (1992) papers also indicate that social isolation and devaluing of social identity occurs as people within the person with dementia's social network distance themselves and allocate them restricted social roles. Recent qualitative research supports this view. Shakespeare (2004) observes these processes in an analysis of the talk of people with dementia, while Gillies and Johnston (2004) present thematic findings from interviews with people with dementia, highlighting how they experience this distancing and restriction. Both papers present insights into these processes, however neither provides detail regarding data analysis or information about



participants, therefore making it difficult to judge the validity and generalisability of these claims. Bender and Cheston (1997) further suggest professionals may also distance themselves emotionally from the person with dementia, therefore restricting the number of safe places an individual can explore their experiences and begin making sense of these.

Clinical implications of the literature related to isolation therefore seem to include a need for interventions which promote social engagement. Robinson et al's (2005) exploration using IPA of reactions to diagnosis provides further empirical support for this, stating participants found maintaining social contact to be a useful coping strategy.

Professionals should also be aware of their role and that this may be of importance to someone who is socially isolated. As Charmaz suggests, "When a patient lives in social isolation, the relationship shared with the physician may assume extraordinary significance for the kind of self which that patient may possess" (1983, p.180). It may therefore influence their identity if a socially isolated person with dementia also experiences professionals as distancing themselves.

#### 1.4.2.2 The label of dementia

The literature indicates people with dementia are often seen in terms of their illness rather than as an individual and for older people this

compounds age-related stereotypes (Kitwood, 1990; Sabat, 1998; Saunders, 1998).

Shakespeare's (2004) analysis of people with dementia's talk in interactions indicates how the 'confused' aspect of their identity becomes seen as 'salient' and part of their core identity, negatively influencing their right to social participation and decision making. The idea that "malfunction dictates how we perceive and define the affected individual and which tends to override all other identity labels that might be attached" (Gillies & Johnston, 2004, p.437; Shenk et al., 2002) is significant for identity.

Sabat (1998; 2002) and Sabat and Collins (1998) highlight the social constructionist conceptualisation of individuals as possessing three forms of selfhood, which can be useful in understanding this process; Self 1 is the self of personal identity, Self 2 consists of physical and mental attributes and beliefs about these and Self 3 is comprised of the various social personae individuals construct in different social situations and requires cooperation of others. This model proposes Self 3 is vulnerable to the extent to which other people focus on 'dysfunctional' aspects of Self 2 (Sabat, 2002). Therefore, if an individual is treated as "defective" or "dysfunctional" they can only construct their Self 3 persona as "'dysfunctional Alzheimer's patient'" (Sabat, 2002, p.28), becoming increasingly defined by others in this respect.

Literature indicates health professionals may participate in, and perpetuate this process at different levels. Individually professionals may see and respond to, and encourage others to see and respond to, the person with dementia's interactions in terms of the disease label, as highlighted within American care settings by Tappen et al's (1999) results of conversational analysis of 45 conversations with people with dementia and Vittoria's (1998) year long ethnography. While Tappen et al's (1999) research excludes non-verbal residents, by utilising observational techniques Vittoria (1998) is able to include reflections on the experience of residents who are unable to articulate these.

At a broader level, theoretical papers that highlight conceptions of dementia and consequences of these (Downs, 1997; Herskovits, 1995) indicate that following diagnosis, society may understand an individual within the biomedical framework which displaces primacy of the self with the label of 'dementia', facilitates control over the individual and potentially misinterprets their actions or renders them meaningless. These experiences are echoed in research based on analyses of conversations with residents and observations of interactions within residential care (Kitwood, 1990; Sabat, 1998; Vittoria, 1998) and interviews with family members about the experience of 'caring' (Karner & Bobbitt-Zeher, 2005).

Culture has been highlighted as being important in how others understand dementia and therefore respond to the individual. Authors

suggest the privileged position of cognition in identity in Western culture, combined with the biomedical model's dominance, encourages others to interpret an individual's behaviour as resulting from dementia, rather than as purposeful (Bender & Cheston, 1997; Herskovits, 1995).

People with dementia may internalise these negative perceptions (Bender & Cheston, 1997) or be unable to maintain their sense of self in the face of them as it is suggested identity can only be developed and maintained within mutually respecting and trusting relationships (Kitwood & Bredin, 1992). Clinical implications of this literature therefore indicate health professionals need to examine their practice to address negative stereotypes they may convey and ensure they are relating to the individual rather than the label of dementia. It also seems to indicate a need for a broader approach to influence the perception of dementia more generally within services and society. Finally, if negative stereotypes are internalised, it may be beneficial to support individuals in acknowledging and challenging these.

#### 1.4.2.3 Power in relationships

Research suggests that due to the power imbalance within relationships and as a result of being seen in terms of the disease label, other people within the person with dementia's social context become able to position and represent who they are. As Cheston and Bender (1999) assert, the person with power within a relationship defines reality.

Adams (2000) suggests the relatively privileged position occupied by professionals and family enables them to construct the person with dementia's identity, particularly through discourse. This is supported by Clare (2003), who highlights how other people have the power to interpret the person with dementia's behaviour. Her research utilises IPA to analyse interviews with 12 people with dementia (24 interviews in total) and highlights how, by labelling attempts to manage threats to identity as an indication of lack of awareness, others position the individual as 'unaware', regardless of whether this is accurate. If individuals are deemed 'unaware' or 'incompetent' by others, this can then impede their right to participate in social situations, leading to increased isolation (Shakespeare, 2004).

Research analysing interviews with people with dementia and their carers has also found relatives may talk negatively about the person with dementia's memory loss and abilities, creating a threat to identity (Gillies & Johnston, 2004; Robinson et al., 2005). Family members in Gillies and Johnston's research perceived the person with dementia as having "reverted to an almost childlike, asexual role as their increasing dependence insidiously ate away at their previous status and sexuality" (2004, p.439). While Robinson et al's (2005) sample only includes nine people with dementia, who were all in contact with mental health services and their carers, Gillies and Johnston's (2004) research includes a larger sample of 20 people with dementia and their carers. These findings support the idea that perceptions of others may influence

how they position the person with dementia, resulting in a negative impact on identity.

Gillies and Johnston found relatives often talked about the person with dementia “in terms of objects or a problem which needed to be sorted out” (2004, p.440), feelings often accompanied by guilt. They suggest this perception can be understood in terms of Kitwood’s (1990; 1993) malignant social psychology, indicating if carers position the person with dementia in this way, they may respond to them in a way that further damages their identity (Gillies & Johnston, 2004).

Herskovits (1995) and Shakespeare (2004) refer to a common perception that people with dementia are unable to express themselves properly and therefore require a ‘translator’, resulting in others taking on responsibility for conversations, meaning components of identity become represented by others.

Being ‘represented’ by others can result in conflict for the person with dementia. Harman and Clare’s (2006) IPA study exploring illness representations of people with dementia, for example, identified tension between how participants wanted to position themselves and how others felt they should be positioned. This led to the person with dementia feeling excluded, stigmatised and betrayed (Harman & Clare, 2006). Again, it is hard to generalise from this small and relatively young sample of 9 people with dementia between the ages of 58 and 76 years

old, however, this research does provide an insight into the potential impact of this experience. Charmaz states this can be a disruptive and distressing experience as the representation others portray “can be so unexpected or jarring that they shake the very foundations of their self-concepts” (1983, p.181).

Findings of Cohen-Mansfield et al’s (2000; 2006) research also indicates others within residential care may have different perceptions to the person with dementia about their identity. These are among the few quantitative studies within this literature and explore the presence and importance of role identities for people with dementia in residential care and perceptions of staff and family. Utilising a role identities questionnaire (Cohen-Mansfield et al., 2000; 2006) the authors highlight differences in ratings given by the three groups. The authors suggest that these differences indicate staff and family may ‘represent’ the person with dementia inconsistently with their own self-conception and may also therefore provide care which negatively effects the resident’s identity (Cohen-Mansfield et al., 2006).

Clinical and wider implications therefore include a need for carers (family and staff), other professionals, services and wider society to recognise and address power imbalances that exist. Research indicates many people with dementia wish to be heard, to present their own identities and have this acknowledged and that individuals should be facilitated to

present their identity rather than family members or carers doing this on their behalf (Downs, 1997; Saunders, 1998).

It may also be worth considering literature identifying an association between the well-being of the person with dementia and that of family carers. From research exploring how spouses maintain their partner with dementia's identity, Perry and O'Conner (2002) suggest family-focused interventions may be beneficial in maintaining the person with dementia's identity.

#### 1.4.2.4 Enhancing identity

In addition to highlighting the negative influence of others, the literature also identifies ways in which relationships can enhance the person with dementia's identity.

Kitwood's (1993) theoretical paper, based largely on clinical experience, suggests 'others' have the potential to evoke and reassure 'selfhood' and bestow status. Surr's (2006) research supports this, with interviews with residents in care settings over two years indicating "the quality of interpersonal relationships is an essential component of preservation of self" (Surr, 2006, p.1721).

Research utilising observation and interviews suggests staff members can play an important role in enhancing identity (Graneheim, Norberg & Jansson 2001; Kitwood, 1990; Surr, 2006; Vittoria, 1998). Cohen-



Mansfield et al (2000; 2006) for example, suggest that if staff members' perceptions of identity resonate with the person with dementia's, care will be more appropriate for the individual and identity will be enhanced. The literature indicates the delivery of person-centred care (see Shenk et al., 2002) and 'communicative care' (see Vittoria, 1998) can provide a validating environment, enhancing the person with dementia's identity (Shenk et al., 2002; Vittoria, 1998). Both person-centred and communicative care emphasise the importance of social interaction, view people with dementia as individuals with unique experiences, attend to the whole person rather than simply meeting basic physical needs, try to 'enter their world' and aim to enhance personhood, or identity (Shenk et al., 2002; Vittoria, 1998). National Institute of Health and Clinical Excellence (NICE, 2006) guidance advocates the application of person centred care in dementia services.

While Perry & O'Connor (2002) state limited research exists regarding how identity is influenced by others outside the context of residential care, some qualitative research utilising interviews with carers and people with dementia has identified how a person with dementia's family can play an important role in maintaining identity (Gillies & Johnston, 2004; Karner & Bobbitt-Zeher, 2006; Perry & O'Connor, 2002; Robinson et al., 2005). While Gillies and Johnston (2004), Perry and O'Connor (2002) and Karner and Bobbitt-Zeher (2006) can be criticised for a lack of information about data analyses and participants and Robinson et al's (2005) sample is small and relatively homogenous, these studies

highlight the influence of the family context and its potential impact on identity. They also identify strategies family carers may employ to maintain the person with dementia's identity, such as using past knowledge of the person to interpret current behaviour, sustaining existing abilities and avoiding situations that may challenge identity (Gillies & Johnston, 2004; Karner & Bobbitt-Zeher, 2005; Perry & O'Connor, 2002; Robinson et al., 2005).

Some strategies identified by family carers involved elements of restriction or deception, for example, avoiding social situations that may threaten identity or covertly taking on more responsibility (Perry & O'Connor, 2002). It is difficult to evaluate the impact of these approaches, however it is possible some of these strategies could actually damage identity. Perry and O'Connor (2002) however, suggest that some participants were skilled at protecting the person with dementia without threatening their 'competent adult' identity.

The literature therefore indicates several implications for clinical practice. 'Others' can play an important role in enhancing the person with dementia's identity and authors suggest they have a responsibility to do this (Downs, 1997; Kitwood & Bredin, 1992; Shenk, 2002). Suggestions of how this may be achieved include employing communicative and person-centred care including individualised, meaningful activities (Cohen-Mansfield et al., 2000). Vittoria's ethnography (1998) highlights the benefit of a system that supports the delivery of care that enhances

personhood, such as resources (e.g. high staff to patient ratio) and support to find meaning in the person with dementia's interactions and act on this. It is also suggested information from family members should be heard and utilised, but that they and staff members may need support in enhancing the person with dementia's identity in truly beneficial ways (Cohen-Mansfield et al., 2000; Perry & O'Connor, 2002).

### **1.4.3 The Influence of Loss**

Authors have suggested people with dementia experience multiple losses, such as loss of roles, independence, relationships, self-worth, respect and memory (Bender & Cheston, 1997; Harris & Sterin, 1999). It is suggested these losses are difficult to cope with, may be one of the most difficult challenges in the early stages of dementia and impact on identity (Harris & Sterin, 1999; Robinson et al., 2005). Cheston and Bender's (1999) review of conceptualisations of dementia highlights that how loss is understood has changed, from a focus on neurology to an understanding that includes psychosocial factors.

Loss of control is particularly highlighted within the literature. Individuals expressed fear following diagnosis that they would no longer be listened to or involved in decisions, and resented losing control over their life (Husband, 1999; 2000; Sabat, 1998). Harris and Sterin's (1999) study interviewing people in the early stages of dementia and their carers highlights how loss of control can exacerbate that which may already be experienced by older people, especially if physical health problems limit

independence. It is important to note that one of these authors had recently been diagnosed with Alzheimer's Disease, which had prompted the research. While the authors state steps were taken to guard against any threat to validity this posed, an interview extract is included which appears to show the potential influence of the researcher's experience on the interview and, given that this researcher interviewed the participants with dementia separately as part of the research process, it may be that her experiences influenced the findings.

Surr (2006) and Cohen-Mansfield et al (2000; 2006) highlight how moving into and living in residential care can be experienced as a loss of control and threaten identity, particularly if individuals feel they have been forced into being cared for. They suggest that if residential care does not facilitate individuality, independence and choice, loss of control and a diminishing identity can be further exacerbated (Cohen-Mansfield et al., 2000; 2006; Surr, 2006).

Kitwood (1990) draws on clinical experience to suggest people with dementia also experience a loss of roles and skills, which undermines identity. Case studies provide support for this (Husband, 1999; Sabat, 1998; Sabat & Collins, 1998) and qualitative research analysing interviews with people with dementia also highlight the negative impact on identity of losing roles and skills (Husband, 1999; 2000; Gillies & Johnston, 2004). Individuals used phrases such as 'vegetable', and 'incompetent' to describe their current and future self, highlighting the

negative influence of these current and anticipated losses on identity (Husband, 1999). Gillies and Johnston (2004) assert that as people with dementia lose roles they lose sources of validation and status within their family, which for their participants resulted in feelings of 'being a burden', 'of no use' or 'rubbish'.

Surr (2006) and Cohen-Mansfield et al (2000; 2006) provide further evidence for the continuation of role and skill erosion in care settings, with individuals experiencing a decline in professional, family and personal role identities (Cohen-Mansfield et al., 2006). Role identities, which are integral in the construction of identity (Surr, 2006), are often not available within these settings (Cohen-Mansfield et al., 2000).

The literature identifies the influence of cultural values in the impact of loss, particularly loss of control and roles, on identity. Authors note that in Western societies meaningful productivity and autonomy are viewed as core components of identity and through the experience of dementia these may be transgressed, negatively influencing how an individual is perceived by others and their own views about their identity (Beard, 2004; Harris & Sterin, 1999; Herskovits, 1995; Hinton & Levkoff, 1999; Perry & O'Connor, 2002).

Authors have therefore highlighted the influence of loss on identity and the importance for clinicians of recognising this. Given the central role of loss in the experience of dementia, Robinson et al (2005) suggest

theories of loss may provide a helpful framework for conceptualising how individuals respond to changes following diagnosis. Husband (1999) reports how psychological therapy was used to support an individual with dementia to make sense of the meaning for them of not being able to perform some roles and integrating this into their identity. Research also suggests others in the individual's social context should attempt to understand their past and present role identities, use this to facilitate individualised activities that maintain and reinforce these (Cohen-Mansfield et al., 2000; 2006; Surr, 2006) and support the person with dementia to continue performing useful roles (Husband, 1999).

The literature relating to loss seems to indicate clinicians and services should enable individuals "to maintain identity in the face of losses imposed by dementia" (Harman & Clare, 2006, p.500), although these conclusions are drawn from reviewing conceptualisations of dementia and exploring the experience of people diagnosed with the disease and carers. None of these studies other than Husband's (1999) case studies, explore how we may maintain a person with dementia's identity in the early stages, or evaluate the process and any effect. Research regarding how this may be done in care settings is more available, with observations and interviews identifying good practice where identity appears to be enhanced. This has contributed to conceptualisations and theories that have led to the development of approaches such as person-centred care (Kitwood, 1990; 1993; Kitwood & Bredin, 1992; Vittoria, 1998).

It would seem important to enable the person with dementia to retain roles and stay in control of their life and decisions that affect them if that is what they want. Husband's (1999) research indicates having their views acknowledged and respected by professionals was incredibly important for participants' self-esteem and identity. Although this research consists of only three case studies with no formal outcome measurement, it supports the importance of control identified within the literature.

#### **1.4.4 Preserving Identity**

The literature also suggests people with dementia do not passively encounter a series of losses and are not solely reliant on others to enhance their identity. Themes of identity preservation are identified in much of the research (Beard, 2004; Clare, 2003; Cohen-Mansfield et al., 2000; 2006; Gillies & Johnston, 2004; Harris & Sterin, 1999; Robinson et al., 2005; Saunders, 1998) and, it is suggested in Beard's (2004) grounded theory study of the impact of diagnosis on identity construction, are crucial in understanding the experience of identity and dementia. Interviews with people with dementia indicate they are actively engaged in a conscious process of meaning making and identity preservation, attempting to maintain certainty about who they are (Beard, 2004; Gillies & Johnston, 2004; Harris & Sterin, 1999).

Research identifies strategies employed by people with dementia to combat changes and maintain their identity. Individuals attempt to

manage the impression they give to people and retain control; they focus on skills and roles they still retain, refer to past achievements in which they have pride, compare themselves favourably to others 'worse off' and at times use denial to preserve their 'pre-dementia' identity (Beard, 2004; Gillies & Johnston, 2004; Harris & Sterin, 1999). Each of these studies interviews participants at one point in time and two of the three (Beard, 2004; Harris & Sterin, 1999) include participants in the early stages of dementia. Gillies and Johnston (2004) provide no information about the severity of participants' dementia, but all are able to articulate experiences within an interview. Beard (2004) and Harris and Sterin (1999) suggest that as dementia is a process, longitudinal research may provide a more accurate picture of how and when these strategies are used.

The literature also suggests that individuals actively preserve their identity in the later stages of dementia and within residential settings, for example Cohen-Mansfield et al (2000; 2006) found most participants within residential care demonstrated some continuity of past role identities. Research demonstrates how people with dementia in care settings may construct life-stories that create continuity between past and current self, often using metaphor and which are crucial in their attempts to preserve identity (Surr, 2006). Participants in this in-depth, longitudinal research may not, however, be representative of individuals in residential care as all were articulate and able to discuss themselves and their lives (Surr, 2006). This study also does not explore any



change in identity maintenance during the research period, but uses information gained at each point in time to create an overall narrative of each participant's self.

Saunders' (1998) research uses interactional discourse analysis to examine transcripts of neuropsychological assessments and highlights how people with dementia made efforts to construct competent identities, often using metaphor, to maintain identity within this context. For example, participants represented the brain as a 'faulty part', allowing them to create distance "from the identity of an incompetent person by assigning agency or blame to one mere part" (Saunders, 1998, p.75). Little information is provided regarding data analysis, however this research seems particularly useful in highlighting processes that may be involved within these clinical situations and the author calls for more naturalistic research exploring similar situations (Saunders, 1998).

Some research has suggested that while people with dementia attempt to preserve their past identity they also try to integrate experiences created by dementia into a new identity. Clare and colleagues have completed several studies in this area (Clare, 2003; 2003; Harman & Clare, 2006; Robinson et al., 2005) with findings suggesting individuals may be engaged in a process of managing a changing identity. Each of these studies identifies a tension for people with dementia between maintaining their old identity (retaining a sense of being the same

person) and acknowledging and integrating the implications of diagnosis and changes experienced into a new identity. Robinson et al (2005) found that couples managed this process by engaging in a cyclical process of gradually noticing and making sense of the situation, while accepting this and their experiences. They suggest this may allow couples to maintain “continuity with each person's perceptions of the previous sense of self of the person with dementia, whilst gradually adapting these perceptions” (Robinson et al., 2005, p.344), thereby supporting them in achieving the balance between protecting their old identity and constructing a new one.

Each of these studies utilises IPA to explore the experience of people with dementia (Clare, 2002; 2003; Harman & Clare, 2006; Robinson et al., 2005). All participants are in the early stages of dementia, most having been diagnosed with Alzheimer's Disease and in contact with specialist services. While each study describes the procedure, analysis process and steps taken to protect the quality of the research, the homogeneity of the samples, a requirement of IPA (Smith & Osborn, 2004), may limit generalisability. This is not, however, the aim of IPA. Studies employing this methodology aim to understand the experience of participants, which may inform future research (Brocki & Wearden, 2006). It should also be noted that these cross-sectional studies are exploring a dynamic process and therefore longitudinal research may be of benefit in the future (Clare, 2003). Findings of Clare's (2002; 2003) research appear to be based on the same interviews with the same

participants and highlight how different themes can be developed from the same set of data.

Research therefore indicates individuals with dementia are engaged in efforts to manage their identity and several clinical implications can be drawn from this. The literature highlights potential benefits of using stories about the past to facilitate continuity and maintain competent identities (Bender & Cheston, 1997; Surr, 2006) and the importance of providing opportunities to maintain role identities (Cohen-Mansfield et al., 2000; 2006; Husband, 1999; Surr, 2006).

Findings suggest people with dementia may use metaphor to construct and present their identities and it would seem important that clinicians recognise and understand this. It would also seem important that clinicians are aware of the processes people with dementia may be going through and tensions they may be experiencing between maintaining their old identity and constructing a new one, and that support is offered to facilitate this process. It seems individuals employ coping strategies to protect their identity and services should perhaps work with these rather than simply labelling someone as unaware because they use denial as a defence. It may therefore be helpful to use information in the literature about strategies individuals naturally use in order to help services develop to support these.

### **1.5 Impact of 'Identity Work'**

Implications of the literature for clinicians and services have been highlighted in the previous sections. Here, the potential impact of 'identity work' for people with dementia is outlined.

Romero and Wenz (2001) assert that experiences which violate identity cause negative emotions and comment that if individuals are unable to integrate new experiences into their prior self, they can experience shame, depression and aggression. Based on this assumption, conceptualising self as a cognitive schema and the premise that behavioural disturbances are partly caused by incompatibility in "individual's actual experiences...and self-based expectations and preferences" Romero and Wenz's (2001, p.335) Self-maintenance therapy (SMT) aims to maintain a "sense of personal identity, continuity and coherence in patients" with dementia (Romero & Wenz, 2001, p.335) (for a description of SMT see Romero & Wenz, 2001). It is interesting to note the outcome measures presented are measures of mood (of the person with dementia and their carer) and of behavioural disturbance (person with dementia) and improvement is demonstrated in each of these (Romero & Wenz, 2001). The authors do acknowledge it is difficult to establish a causal relationship between SMT and mood, for example carer's mood may be influenced by the person with dementia's affect and behaviour (Romero & Wenz, 2001). Interpretation of results is further complicated as carers rate the person with dementia's mood, which may not be accurate and any improvement could reflect an

improvement in the carer's mood rather than an improvement for the person with dementia.

Romero and Wenz (2001) suggest their findings support the idea of a relationship between identity and mood and demonstrate benefits of working to support identity. Identity, or self, is not, however measured making it difficult to conclude whether SMT actually facilitates 'self-maintenance' and whether this was the element of the residential course that contributed to improvement in affect and behaviour.

Other literature does also support the assertion that maintaining identity is important for well-being. Bender & Cheston comment that depression is the most commonly reported affective response to dementia with individuals experiencing a "profound existential sense of emptiness" (1997, p.518) when simply anticipating damage to identity. Robinson et al (2005) found all participants experienced hopelessness at some point following diagnosis, while some participants in Harris and Sterin's (1999) research 'gave up' attempts to maintain identity and others found it difficult just 'getting through the day'.

People with dementia in other research also expressed anger, frustration, embarrassment, humiliation and despondency associated with the experience of threats to identity and efforts to maintain it (Beard, 2004; Harris & Sterin, 1999; Husband, 1999; 2000; Sabat, 2002; Tappen et al., 1999). It is also suggested individuals use denial to cope with the

impact of dementia on their identity when it is unsafe to explore their experiences (Clare, 2003; Harris & Sterin, 1999).

We should also be aware of a number of therapeutic approaches used with older people and the role they play in identity. Approaches such as reality orientation, validation therapy and resolution therapy, developed through the philosophical shift towards addressing the person with dementia as an individual, are thought to improve care; however evaluation of the impact of these therapies and their relationship with identity is limited (Heason, 2005). Bender and Cheston (1997) suggest that approaches such as these that highlight each individual's identity and focus on the emotional content of experience, should be part of general care and not limited to specific programmes in care settings.

### **1.6 Future Research**

Whilst there have been a number of studies in this area, there remain several gaps in knowledge regarding the experience of dementia and identity and clinical implications of this. Here, some suggestions for future research are made to begin to address some of these gaps.

Firstly, the concept of identity may need to be more clearly defined and measured. Terms such as 'personhood', 'self', 'selfhood' and 'identity' are used interchangeably within the literature and definitions are often not provided. It would seem important to understand clearly what is meant when these terms are used, in order that research can be

compared and clinically applied. It has been suggested more quantitative research is needed to operationalise and measure the term (Cohen-Mansfield et al., 2000). Cohen-Mansfield et al (2000; 2006) have developed a tool for measuring salience of role identities over time, however, conclude that "The complexity of the construct of identity explains the...inconsistencies of constructs described in the literature" (Cohen-Mansfield et al., 2006, p.746).

It should be noted most participants in the research are white, European or American older people with dementia, often Alzheimer's disease. It seems important therefore, particularly given the relevance of social context, for research to explore the experience of identity and dementia with individuals from different countries, cultures, ethnic backgrounds and ages. The predominance of Alzheimer's disease may be expected given prevalence rates of different dementias (Alzheimer's Society, 2007), however, it could be of interest to explore the impact of other dementias on identity.

The literature suggests supporting identity around diagnosis may be beneficial to people with dementia then and in the future. Given this and an increasing focus on early diagnosis perhaps we should, as Clare (2002) suggests, be working towards developing interventions to support individuals at this time.

Future research could explore components of 'identity work', how these influence identity and the benefits, or otherwise of this. While research exploring the experience of people with dementia and carers and conclusions from theoretical papers indicate potential benefits of supporting identity and how this may be done, research that evaluates 'identity work' is lacking, particularly in the early stages of the disease. It may therefore be helpful to use information from the literature to develop interventions and to assess the effectiveness and benefit of 'identity work', for example, does 'identity work' help individuals cope with the onset and progression of dementia? Also to consider whether it is appropriate to support people at all stages of dementia at the same time given Romero & Wenz's (2001) findings indicating this was distressing for people in the early stages of the disease.

Much of the literature calls for more research to gain the views of people with dementia and the importance of using this to understand how best to support identity (Beard, 2004; Cohen-Mansfield et al., 2006; Downs, 1997; Harris & Sterin, 1999). Cohen-Mansfield et al (2000) suggest that while identity is preserved in the later stages of dementia, an individual's ability to communicate this is impaired and state it is important to increase understanding of the experience of identity in the later stages of dementia, even if only through the views of family members. Existing research also appears to focus on either the earlier or later stages of dementia, longitudinal studies may therefore be useful to explore the process of the influence of dementia on identity. This research may also



help to identify other critical incidents, evaluate whether 'identity work' is beneficial and at what stage.

It should be generally noted that the majority of the current literature utilises qualitative methodologies, which range in rigour and that this should be considered when undertaking any future research.

### **1.7 Conclusions**

Individuals encounter many experiences during the course of dementia that threaten identity, including interactions with services and clinicians that are disempowering and stigmatising. Research indicates that people with dementia can be enabled to manage these threats and to find a way of integrating experiences into their identity, potentially having a beneficial effect on well-being. More research is needed to establish what 'identity work' should contain and when it should be delivered. Whether professionals actively work with the impact of dementia on an individual's identity, however, they should at least be aware of the potential they have to threaten it and work in ways that reduce this threat. Approaches to enhance identity within institutions, such as person-centred care, could also be applied to family and outpatient settings. Most people with dementia do not live in residential care (Gillies & Johnston, 2004) therefore, as Cheston and Bender assert, "Waiting to intervene until the person with dementia is confined to an institution...is leaving matters almost too late" (1999, p.207).

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## **Chapter two**

### **Empirical Paper:**

**'What is the Experience of Staff Members of the Assessment and  
Diagnosis of People Presenting with Memory Problems?'**

**Word count: 8,589**

# **What is the Experience of Staff Members of the Assessment and Diagnosis of People Presenting with Memory Problems?**

## **2.1 Abstract**

OBJECTIVES: 'Breaking bad news' has been identified in some areas of health care as a difficult aspect of health professionals' work, which is related to staff well-being and client experience. Assessment and diagnosis has also been identified as a critical incident for people with memory problems. This research therefore aimed to explore staff members' experience of assessment and diagnosis of people with memory problems. METHOD: Interviews with ten health professionals were conducted and analysed using interpretative phenomenological analysis. RESULTS: 18 subordinate themes were identified, which could be clustered into four superordinate themes ('What Helps me do my Job', 'What Hinders me Doing my Job', 'Things that are Difficult', 'Impact on Self and Coping'). Conflicts (a fifth superordinate theme) between themes were also identified. CONCLUSION: Participants appeared to be trying to meet conflicting needs within the context of a progressive illness and service restrictions. This influenced their perceived effectiveness and caused conflict and stress.

## **2.2 Introduction**

### **2.2.1 The Experience of Staff Members in Dementia Services**

It could be argued that working with people with dementia, and older adults in particular, raises unique issues for mental health service staff.

They are working with an incurable, progressive disease and encounter issues such as aging, physical and mental ill health, loss of independence and distress (Roberts, 1994). Clinicians working in this field also do not know whether they will face this themselves in the future.

Bender and Cheston state "with no other client group are carers, health professionals and therapists forced to confront so many issues that potentially involve such enormous personal power" (1997, p.562), while Rick and Warner (1994) comment talking to clients about a progressive, incurable disease can be distressing for doctors. More recently, Marzanski (2000) suggests doctors may attribute their own hopes and fears to clients, thereby responding less well to individuals' wishes.

It is important to understand staff members' experience in order to support recruitment, retention and staff well-being; also in the light of some literature and anecdotal reports indicating a relationship between how clinicians perform their role and clients' experience (Salander, 2002).

Literature has explored the impact on staff of working with people in the later stages of dementia (Brodaty, Draper & Low, 2003), however, research with staff working with people in the early stages of dementia is lacking. Research that does exist focuses on whether individuals should be told their diagnosis, whether this information is provided and who else

it is shared with (Monaghan & Begley, 2004; Whitehouse, Frisoni & Post, 2004). More recently there have been calls for research exploring the *process* of disclosure (Bamford, Lamont, Eccles, Robinson, May & Bond, 2004).

### **2.2.2 The Experience of “Breaking Bad News”**

‘Bad news’ has been defined as “any information likely to alter drastically a patient’s view of his or her future” (Buckman, 1984, p.1597). The diagnosis of dementia can therefore be viewed as ‘bad news’. Breaking bad news has been described as a “complex communication task” (Baile, Buckman, Lenzi, Glober, Beale & Kudelka, 2000, p.302) and a “difficult and complex” part of clinicians’ work (Ptacek, Ptacek & Ellison, 2000, p.216). Buckman (1984) suggests breaking bad news is difficult for several reasons including; fear of blame, of not knowing the answers, of showing emotion and fears about clinicians’ own health and mortality.

‘Breaking bad news’ has therefore been identified as potentially difficult for clinicians. Dickson, Hargie, Brunger and Stapleton highlight this, stating “patient experiences of the...encounter are mirrored in the difficulties evidenced among health professionals who break bad news” (2002, p.325). Simpson and Bor (2001) identify some feelings professionals may experience while breaking bad news, including anger, fear, grief, anxiety and helplessness.

Research suggests breaking bad news influences clinician well-being (Ptacek, Fries, Eberhardt & Ptacek, 1999). Ptacek et al (2000), for example, found clinician stress lasted up to three days, suggesting this may negatively affect the clinician and could influence subsequent client interactions. They suggest research should identify factors that contribute to clinicians' discomfort during these encounters to provide better support to enhance their experience and that of clients (Ptacek et al., 2000).

The relationship between clinician and client experience has been explored in research highlighting the importance of how clinicians break news. Dickson et al note patients often find the encounter "unsatisfactory, threatening or frightening, above and beyond the effects of the news itself" (2002, p.325), supporting suggestions that breaking bad news influences patient well-being, coping and relationship with services (Ptacek et al., 1999; Salander, 2002).

This process is therefore important for the clinician and client. Extensive research exists exploring how this should be done (Simpson & Bor, 2001), however, little is known about how professionals perceive these transactions and experience the process (Dosaniyh, Barnes & Bhandari, 2001; Ptacek et al., 2000).

Research also focuses mainly on doctors, often excluding other health professionals involved in breaking bad news (Dunniece & Slevin, 2000; Farrell, 1999).

### **2.2.3 The Experience of Clients in Dementia Services**

A philosophical shift has led to challenges of biomedical conceptualisations of dementia and an increasing recognition that dementia occurs within a biopsychosocial context (Clare, 2003), creating individual meaning and experience. This has led to research exploring individual meaning and experience and calls for person centred care (e.g. Kitwood, 1997). This research has identified the diagnosis of dementia as critical for individuals (Pratt & Wilkinson, 2001) and a “defining moment” in people’s lives (Beard, 2004, p.421); diagnosis brings people “face to face with their own aging, decline and vulnerability” (Beard, 2004, p.416).

As in other areas of health, how clients experience assessment and diagnosis influences their approach to care and treatment in the short and long term (Wilkinson & Milne, 2003). How the diagnosis is given and how prepared individuals are has been identified as crucial for younger people (Beattie, Daker-White, Gilliard & Means, 2004) and presumably, therefore, also for other individuals with dementia.

#### **2.2.4 This Research**

Current health policy focuses on early detection and service provision in the early stages of dementia (Audit Commission, 2000; 2002; National Institute for Health & Clinical Excellence (NICE), 2006) and states that the treatment of dementia “always involves explaining the diagnosis to the older person and any carers” (Department of Health, 2001, p.98). Research has identified the assessment and diagnosis process as being critical in how individuals understand and experience dementia (Beard, 2004; Beattie et al., 2004; Clare, 2003; Pratt & Wilkinson, 2001). In other health care areas research also highlights the impact of assessment and diagnosis on staff, their work with clients and clients’ experience in the long and short term. Despite this, there is a lack of research exploring clinicians’ experience of assessment and diagnosis in dementia services.

This research therefore aims to identify important, shared elements of staff members’ experience of assessment and diagnosis of memory problems/ dementia. It aims to understand how some of the important issues for clinicians may impact on how they engage with this process and to identify service implications.

### **2.3 Methods**

As the focus of the research is the lived experience of this phenomenon, a qualitative methodology was utilised. Interpretative Phenomenological Analysis (IPA), a psychological research method that allows individual’s

psychological worlds to be explored (Willig, 2001), is an appropriate method for understanding subjective responses to, and meanings of, phenomena (Clare, 2003). Shaw notes that as IPA facilitates understanding and exploration of the “meaning and significance” of individuals’ experiences within their cultural context, research findings can be useful in informing health care policy and practice (2001, p.51). Smith and Osborn also suggest IPA is “especially useful when one is concerned with complexity, process or novelty” (2003, p.53). IPA was therefore selected as an appropriate research method.

This research employed a cross-sectional design, interviewing each participant once. IPA uses a form of purposive sampling in that an homogenous as possible group of potential participants are identified as suitable for inclusion given the research question (Smith & Osborn, 2004). In the case of this research this consisted of staff members from one National Health Service (NHS) Mental Health Trust in the UK who were involved in assessment and diagnosis of people with memory problems.

### **2.3.1 Procedure**

Ethical approval was obtained from an NHS Local Research Ethics Committee (appendix 2) and the Research and Development Department for the NHS Trust (appendix 3) in which the research was conducted. Information sheets (appendix 4) were disseminated to staff members involved in assessing and diagnosing people with memory



problems and interested individuals contacted the researcher to discuss participation. A meeting was arranged with each participant at their place of work where informed consent was gained (appendix 5) and a semi-structured interview, lasting between 40 and 60 minutes, was conducted and audiotaped. Open-ended questions and reflection were used to facilitate discussion, the purpose of interviews being to encourage participants to tell their stories in their own way (Clare, 2003). In line with Smith's (1995) recommendations, the interview schedule (appendix 6) was devised by determining the overall question and establishing broad themes to cover within this, then developing questions. This was trialled with a colleague and used to guide each interview without dictating its exact course (Smith, 1995). A pilot interview was conducted, following which no substantial changes were made to the interview schedule or process and this data was included in the research. Interviews were transcribed verbatim and analysed using IPA methodology by the researcher. Participants were informed about support services available should the interview raise any difficult issues.

### **2.3.2 Guidelines for Qualitative Research**

Elliott, Fischer & Rennie's (1999) 'evolving guidelines' for reviewing qualitative research are not intended to be definitive or used as a "rigid 'checklist'" (Elliott et al., 1999, p.224), however, they offer useful guidance for considering issues of good practice for qualitative research. Each guideline is outlined below.

### 2.3.2.1 'Owning one's perspective'

Authors should "specify their theoretical orientations and personal anticipations" (Elliott et al., 1999, p.221).

IPA has its roots in a phenomenological tradition, viewing individuals as interpreting and formulating their own understanding of the world, rather than perceiving an objective reality (Brocki & Wearden, 2006). A phenomenological approach within psychology focuses on individual's experience of events or phenomenon, rather than attempting to generalise or produce an objective statement about them (Beard, 2004). IPA assumes individuals interpret and attribute meanings to events, which shape how these are experienced (Brocki & Wearden, 2006). It aims to capture meanings and experiences to better understand "*what it is like* to live a particular moment or situation" based on an individual's description (Willig, 2001, p.63).

The phenomenological analysis of an individual's description of an experience or phenomenon is necessarily an interpretation of this description. This highlights IPA's connection to the interpretative, or hermeneutic tradition as it recognises and makes explicit the central role of the researcher in the process (Brocki & Wearden, 2006). IPA is reflexive in that it acknowledges the researcher's thinking, beliefs and assumptions in this process (Clare, 2003). Results of analysis are therefore a co-construction as the researcher engages with the data (Willig, 2001).

Symbolic interactionism also influenced the philosophical roots of IPA. This movement emphasises the importance of meanings individuals' ascribe to events, suggesting these can only be accessed through a process of interpretation (Smith, 1996).

The author has worked in services providing assessment and diagnosis of memory problems (although not performing this role), which influenced the decision to undertake the research. Prior to data collection, the author wrote about these experiences and kept a journal throughout the research process to record her thoughts, beliefs, values and assumptions. The author believed this role could be complex and demanding in practical and emotional terms.

#### 2.3.2.2 'Situating the sample' - Participants

Information should be provided that aids the reader in "judging the range of persons and situations to which the findings might be relevant" (Elliott et al., 1999, p.221).

Of a potential 85 participants, 10 female clinicians participated (a response rate of 11.76%); four Community Psychiatric Nurses, two Clinical Psychologists, two Support Workers, one Day Hospital Nurse and one Occupational Therapist. Length of experience in assessment and diagnosis of people with memory problems ranged from three months to 20 years (mean length of experience 5.48 years). Seven

participants worked within community teams and three at memory clinics within day hospitals.

None of the participants' roles included giving a diagnosis of dementia, however, 6 of the participants were sometimes present when this was given and provided 'pre-assessment counselling', which involves raising the possibility of dementia with clients. All participants were involved in the assessment process and 're-telling' the diagnosis after clients had been formally given this by a doctor, which may include answering questions and providing them with more information regarding what the diagnosis means.

#### 2.3.2.3 'Grounding in examples'

Elliott et al (1999) suggest examples should be provided to illustrate the analytic procedure, understanding developed and support the validity of research. Quotations are provided here to ground themes and an extract of a transcript in appendix 7 helps illustrate the analytic procedure.

#### 2.3.2.4 'Providing credibility checks'

To check the credibility and validity of the research, the analysis of each transcript and categorisation into themes was reviewed by a colleague of the author (Elliott et al., 1999). Themes and categories were also checked by the research supervisor who is experienced in the application of IPA. Notes regarding how the analysis developed over

time were kept and included in the 'checking' process, as indicated by Smith, Jarman & Osborn (1999).

#### 2.3.2.5 'Coherence' - Data analysis

The understanding developed should be "represented in a way that achieves coherence and integration while preserving nuances in the data" and "fits together to form a data-based story/ narrative, 'map', framework, or underlying structure for the phenomenon or domain" (Elliott et al., 1999, p.222-223). IPA aims to allow integrated themes to emerge, while preserving the detail of the meaning of individual accounts (Brocki & Wearden, 2006).

As IPA assumes a link between self-report and underlying cognition, analysis aims to identify thinking and beliefs about the phenomenon under investigation (Willig, 2001). Transcripts were analysed systematically using an idiographic approach, where analysis begins with particular examples and works towards developing a more general categorisation or theory (Smith et al., 1999) thereby allowing the meaning of participants' experiences to inform this development.

The first transcript was read, re-read and emerging themes identified and labelled, which were then clustered into groups with a shared meaning or hierarchical relationship (Smith et al., 1999). Reference was constantly made to the transcript to ensure themes and connections between them were reflected directly in the account (Smith et al., 1999).

Subsequent transcripts were analysed using the master-theme list from the first transcript. Instances of these themes and new themes were identified. Again, these were checked against each transcript to ensure they appeared directly within each account. This allowed a progressively integrated list of themes and clusters of themes to be constructed. A list of master-themes was therefore developed that “captures the quality of the participants’ shared experience of the phenomenon under investigation” (Willig, 2001, p.58).

#### 2.3.2.6 ‘Accomplishing general Vs. specific research tasks’

Research should state whether its aim is to gain a general understanding of a phenomenon or of a specific instance or case and the sample should be suitable for this purpose with limitations made clear (Elliott et al., 1999). This research aims to explore the experience of these participants of assessing and diagnosing people with memory problems, limitations of the sample are addressed in section 2.8 (Limitations).

#### 2.3.2.7 ‘Resonating with readers’

The research should stimulate “resonance in readers...meaning that the material is presented in such a way that readers...judge it to have represented accurately the subject matter or to have clarified or expanded their appreciation and understanding of it” (Elliott et al., 1999, p.224).

## **2.3 Results**

Participants described their experiences of assessing and diagnosing people with memory problems. 18 subordinate themes were identified, which were clustered into four superordinate themes: 'What Helps me to do my Job', 'What Hinders me doing my Job', 'Things that are Difficult' and 'Impact on self and coping'. Analysis also revealed conflicts between themes, creating a fifth superordinate theme ('Conflict'). Appendix 8 contains further quotations to ground each theme.

### **2.4.1 What Helps Me to Do My Job**

Participants identified important skills and elements of their role that enabled them to work in ways they felt benefited clients. The number of participants whose transcript contained each theme is stated in brackets next to theme headings. The number next to each quotation is the participant identifier.

#### **2.4.1.1 Awareness of the clients' experience (10)**

Participants demonstrated awareness of clients' experience, particularly related to testing and clients' anxieties about the assessment process and possible outcome. This enabled participants to respond to clients' emotional and practical needs, however also created difficulty for participants, which is discussed later.

Participants highlighted the importance of recognising the impact of the process on clients and responding to this:

(10) *“sometimes people are shocked that their answers, that “oh my goodness, I don’t know the year”, you can see the trouble on their face and really as a clinician is having the skills to work with that anxiety and those emotions”*

(4) *“people are often quite, nervous about going through something like that...so there’s quite a role there in helping people to feel as comfortable as they possibly can...allowing them to have quite a lot of ownership over the process”*

#### 2.4.1.2 Empathising as a means of understanding what people want (9)

Participants used empathy to understand clients’ experiences. They used ideas about what they would want from services to guide their practice and expressed hoping for experiences and outcomes for clients they would want for themselves.

(2) *“there are those kinda thoughts about what if this happens to me...how scary that would be”*

(5) *“I can really see why they’re frightened”*

#### 2.4.1.3 Individualising care appropriate to level of need (10)

Participants identified the importance of seeing each client as an individual, of respecting individual wishes and meeting these without judging. Again, this was presented as an aspect of participants’ skills



enabling them to respond to clients' needs, thereby enhancing their experience.

*(2) "every referral, every assessment session, every feedback session, is very different 'cause it has to be, tailored to the individual"*

*(10) "a lot of people recently have not wanted to know [their diagnosis] and you've got to respect that choice"*

*(1) "some people are quite happy managing on their own with just the occasional visit to the memory clinic and there's other people need more support and that varies at different periods of time"*

#### 2.4.1.4 The role of experience and confidence (10)

Participants felt that as their experience of assessment and diagnosis increased, their confidence and skills developed, enabling them to feel more comfortable with the process and work in an increasingly beneficial way for clients.

*(8) "you get more experienced at it, you see similar reactions, you start to learn the different ways to help people and how to react and the best things you can do"*

*(3) "it's still hard to initiate that conversation really, but once you've done a few times, you get a feel for how people react, you get to understand"*

*where people are coming from...I suppose that's it, I feel safer doing it now because I've got used to it"*

## **2.4.2 What Hinders Me Doing My Job**

Participants discussed factors they felt hindered how well they could do their job and meet clients' needs. Themes reflect elements external to participants, such as service limitations, rather than internal characteristics or skills.

### **2.4.2.1 Who is the client – working with families and systemic needs (8)**

Participants noted clients' families were often involved in assessment and diagnosis and have their own needs and expectations of services, which are often different to that of the client. This creates situations that are difficult to manage as participants attempt to acknowledge everybody's needs while primarily respecting the wishes of the referred client, which hinders participants in performing their role as well as they would like.

*(4) "it was the family's wishes that were driving the assessment and I found very, very difficult because it was about who's my client, where do I sit in relation to the person themselves and to the family and there were some conflicting needs during that assessment"*

*(6) "that is the most difficult, I saw someone recently and the wife desperately wanted some sort of name... if she could just have, well*

*look it's most probably Alzheimer's, then I kind of think she could read a little bit and think, "no, we can't talk about it getting better, we can talk about managing it", but I can't because he doesn't want a diagnosis"*

#### 2.4.2.2 Impact of service restrictions (9)

Participants identified service restrictions as limiting how well they could perform their role and negatively influencing clients' experience and service. Participants were frustrated at not being able to offer clients sufficient time, support, resources and continuity of relationships.

*(2) "having so many locums over such a short period of time, I think is...just really inappropriate, almost verging on unethical...how can you go through quite a emotional process like assessment and feeding back when you've got lots of different people, you know, for somebody who's got memory problems anyway, coming and constantly seeing a different person its not ideal"*

*(7) "you sometimes become like a robot, and that sounds awful, but ...you might have had like 6 all in one go and you're repeating the same thing to them"*

#### 2.4.2.3 Lack of guidance/ feedback on job (7)

This theme reflects a desire by participants to perform well, but the uncertainty many had about whether they achieve this. They noted a lack of feedback about their performance meant they could not address

areas of practice that need improvement and were concerned about whether they were doing a satisfactory job.

*(1) “apart from the families who the majority are just bloody grateful you turned up, there’s nobody telling me if my instinct or intuition is well off, I could be really off the mark and not know it, just ‘cause they’re grateful I turn up”*

*(6) “I try to get feedback from the person I’ve talked to, I guess that’s not always viable, ‘cause sometimes they’re just grateful that you’ve been, so it’s not always a good measure”*

### **2.4.3 Things that are Difficult**

This superordinate theme refers to aspects of assessment and diagnosis participants identified as being personally difficult.

#### **2.4.3.1 Honesty (10)**

Participants felt a responsibility to be honest, provide clients with information about possible consequences of assessment and explanations for their experiences. Honesty was difficult as participants could feel reluctant to discuss potential implications of a diagnosis, however they often felt uncomfortable about not being honest.

*(6) "I couldn't rule it out, but I couldn't say it was, because on one visit that wouldn't be enough, and he was quite relieved at that, but I came away thinking, "it's dementia" and that kind of feels a little bit, dishonest"*

*(10) "that can be difficult to say, but sometimes it's important to get that information to the family for the benefit of the person that you're working with"*

#### **2.4.3.2 Talking about dementia (for the first time) (10)**

Many participants felt raising the possibility of dementia and giving the diagnosis were difficult situations. Participants felt the consequences of discussing dementia were different for each client and their families, with some experiencing relief and others huge distress.

*(4) "For some people it comes as a relief as well; it's not always a horrific thing to hear"*

*(4) "in some ways what we do is we say "well, now they've got a diagnosis there's a whole world of support services that open up to people", and yes, it is true, at the same time that does not take away the devastating impact for somebody, that's one aspect I find extremely difficult"*

*(2) "it does feel really awful, like you're giving someone a, kind of, a terminal illness"*

#### 2.4.3.3 Letting people down/ being unable to help (10)

Participants expressed a sense of letting people down when they felt unable to help in the way clients' required, for example, when participants were unable to give a diagnosis or clients could not be prescribed acetylcholinesterase inhibitors ('cognitive enhancer' medication).

*(4) "it can be a very difficult experience not to be able to give an answer to somebody as well, because that's what people are hoping to get from you"*

*(3) "that feels a bit like you've let them down although I don't think they see that, it's just your perception, 'cause you can't provide anything positive for them" (if not prescribed medication)*

*(9) "that just puts you down a bit, that you know, 'damn, I can't help'"*

#### 2.4.3.4 Thinking about the future (8)

Being aware of what the future may hold for clients created difficult feelings. Participants discussed working with clients in the later stages of dementia and how they are aware of these experiences when working with clients during assessment and diagnosis.

*(7) "when you look at the whole picture sometimes, it does look bleak, because you're working with these clients and you know their future,*

*because I've seen clients who are so poorly on the ward previously...it's hard isn't it? 'cause you, um, you meet people and you know what their outcome will be and it's not a very nice outcome"*

*(8) "with a lot of these clients there is no light at the end of the tunnel"*

#### 2.4.3.5 Dealing with distress and sadness (10)

Participants all referred to the impact of working with distress and sadness and the effect of this on their own emotional well-being.

*(3) "It's upsetting when people get upset"*

*(9) "it's horrible, really horrible" (when clients are upset)*

*(7) "it can be quite depressing to be honest sometimes, you know, having to see people so poorly and relatives so upset, it can get depressing"*

#### 2.4.3.6 What I do Causes Distress (5)

Some participants felt their role could be counterintuitive to what health professionals should do. Participants were aware the process could be distressing for clients and experienced dilemmas regarding balancing the needs of the service (how much information is necessary to make a diagnosis) and the client (wanting to understand what is happening for them but finding the process distressing). Despite the fact participants

could make positive interventions with clients, assessment and diagnosis can be distressing for clients and being part of that could be difficult for participants.

*(8) “our natural abilities, that we want to look after people and it goes against the grain when you’re putting people in difficult situations...goes against what you would normally do, which is...do what you can to relieve that distress, whereas actually you’re causing the distress”*

*(2) “when somebody’s struggling and having to make that decision, should I stop here, but then if I stop here I haven’t quite got the whole assessment finished, therefore the results might be a bit skewed, so it can be quite difficult”*

#### **2.4.4 Impact on Self and Coping**

This superordinate theme contains themes related to the impact of assessing and diagnosing people with memory problems on participants. Participants described a variety of ways of coping and some identified contextual aspects that made coping with the impact of their job more difficult.

##### **2.4.4.1 Self-containment and self-reflection (10)**

Participants accepted difficult aspects of their roles as ‘part of the job’. They seemed aware of the impact of the job on them and felt an



expectation they should be able to contain this and continue to perform their role in a professional manner.

*(8) "It's part of the job and in some respects you just have to ride it through"*

*(4) "sometimes they're very difficult feelings to hold, so there's a challenge in maintaining an awareness of those difficult feelings to ensure that you're able to hold those to allow you to continue to provide what you ought to be providing"*

#### 2.4.4.2 Protecting self – professional and personal boundaries (10)

Developing an emotional detachment from the work and not 'taking work home' were identified as strategies participants employed to prevent themselves becoming overwhelmed by the impact of the emotional content of their work.

*(8) "you get practised at detaching yourself, I try very hard not to take work home and it's something that you have to learn to do, otherwise you'd never sleep"*

*(7) "I've been working in this type of field for quite a good few years and I've seen lots of different cases, I suppose that it sounds hard but I suppose you do get used to it"*

#### 2.4.4.3 Importance of peer support (9)

The majority of participants identified peer support as crucial in enabling them to perform their role, both when with clients and following appointments.

*(4) “what I find quite useful is in the immediacy, to come back and talk to some of my colleagues”*

*(2) “when we had somebody here who’d been working with us for years we’d got quite a, banter of how to feedback and how to support each other as well...but there are times when you’ve just finished with a client and the other person’s gone and you’re just left there thinking ‘oh, that was awful’ and not any time to kind of, debrief really”*

#### 2.4.4.4 Lack of formal support/ training (5)

Participants discussed feeling unsupported by the Trust in which they work and highlighted a lack of training regarding how to conduct assessments and feedback diagnoses with clients with memory problems. These factors made coping with the job and its impact on them more difficult to manage.

*(1) “there’s instances occurred that have been quite distressing, and however much this Trust say that they have things in place to help you with stress it’s b\*\*\*\*\*t, so, if you’re sensible then you find things that will ease that for you”*

(2) *"I don't think there's any kind of formal training around feeding back"*

#### 2.4.4.5 Doing something positive – job satisfaction (6)

Job satisfaction seemed to occur mostly when participants felt they were able to do something positive (such as provide medication) or felt they had used their clinical skills to benefit a client. Experiencing job satisfaction enabled participants to cope with the demands of their job.

(3) *"I wouldn't say I enjoy it, but I enjoy the whole experience of doing it, 'cause I feel it's an important step that brings people into our service and often that's something that people remember more than anything"*

(9) *"if the patient was started on medication, they're keeping stable, then yeah, that makes the job altogether satisfying"*

#### 2.4.5 Conflict

Conflicts emerged through the analysis of participants' transcripts and development of the subordinate and superordinate themes. These highlight how, during the course of their work, participants experienced dilemmas regarding the role they perform and the interests of, and impact on, themselves, their clients and the wider system within which they work. Conflicts between subordinate themes that emerged were: 'Individual need versus Service restrictions', 'Empathising versus Protecting myself' and 'Honesty versus Causing distress and maintaining hope'.

#### 2.4.5.1 Individual need Vs Service restrictions (8)

The impact of service restrictions created conflict for participants as this caused frustration that, although they could identify individual's needs, they might be unable to meet them. This could create a sense of having let their client down and frustration with the system in which they work. Participants also described feeling uncomfortable with the assessment and diagnosis procedure established in their team, which may not be flexible in responding to individual need.

*(8) "it's something we have to do, but I'm more interested in how they are and how they're functioning, rather than what their score is on the flipping Mini Mental State, but that's part of the process that we have to do"*

*(9) "Just not offering all the services that we may be able to provide is a down side to the job, 'cause I think that would affect the client, definitely"*

#### 2.4.5.2 Empathising Vs Protecting myself (9)

Participants all had an awareness of clients' experiences and most used empathy to facilitate the delivery of effective services. They also, however, reflected on a need to protect themselves from feeling 'too much' and allowing the work to become overwhelming. This would appear to be a difficult balance, being open and responding to clients' emotional experiences to a degree that is helpful for clients, but not too draining for the professional.

(4) *"I think that's another potential outcome of having been involved in processes for quite a long time, you kind of run the risk of stopping feeling 'cause the feelings that you have can be quite difficult at times. I think we kind of, well I know that I sort of wax and wane a little bit with that and if I feel at all that I'm starting to become a bit unconcerned about things then I might take that to my supervision"*

#### 2.4.5.3 Honesty Vs Causing distress and maintaining hope (7)

A conflict emerged between feeling a responsibility to be honest with clients, but wanting to protect them from the distress this information could cause. This develops the idea of the importance of being honest with clients, within the context of a potential diagnosis of a progressive illness. The idea that being honest with clients may potentially take away any hope could feel difficult and counterintuitive to participants' instinct of wanting to help.

(1) *"it's a real relief to people to be diagnosed with a Vascular Dementia rather than Alzheimer's. I suppose it's one of the things that I haven't...It just seems cruel if they're getting that relief to say "well, in the end it's not going to make a difference, the progress and the outcome's gonna be pretty similar""*

(10) *"that can be quite difficult...you try and put a positive spin on it as much as you can, saying, "you're mom's doing really well now, we don't know the progression, she could stay at this level for a long, long time""*

(7) *“it’s hard, ‘cause you can’t tell anyone with memory problems that it’s going to get better”*

## **2.5 Discussion**

Themes identified resonate with literature regarding the experience of clients in dementia services and that of clinicians who ‘break bad news’ in other services.

### **2.5.1 What Helps Me to Do My Job**

Consistent with research exploring clinicians’ experiences of breaking bad news, awareness of clients’ experience and empathy allowed participants to identify individual need. Empathy has been identified as important in encounters professionals felt were effective (Dickson et al., 2002) and it is suggested guidelines for the diagnosis encounter be applied flexibly (Baile et al., 2000). It is also consistent with research in dementia services suggesting clients want to be treated as individuals (Wilkinson & Milne, 2003) and recommendations that disclosing information should be patient led (Bamford et al., 2004; Pratt & Wilkinson, 2001; Rice & Warner, 1994).

Experience facilitated the process, enabling participants to feel confident about their ability to manage difficult situations and respond to clients’ needs. While research highlights that experience can facilitate confidence (Dickson et al., 2002; Dunniece & Slevin, 2000; Simpson & Bor, 2001), others warn experience may also be associated with a

decrease in the use of compassionate communication skills (Ptacek et al., 1999; Sise, Sise, Sack & Goerhing, 2006). Therefore, while clinicians may feel more comfortable, it is possible clients' experiences may not actually improve.

### **2.5.2 What Hinders Me Doing My Job**

These themes highlight how external factors could reduce participants' ability to effectively perform their role. Most participants discussed how working with families meant they often had to acknowledge and manage conflicting needs, which resulted in participants feeling their ability to identify and meet the referred individual's needs could be compromised. This echoes findings in other areas of health care suggesting working with families increases the level of stress experienced while breaking bad news and makes interactions more difficult to manage (Catalan, Burgess, Pergami, Hulme, Gazzard & Phillips, 1996; Dickson et al., 2002). Research suggests this is difficult because professionals recognise the client's and family's needs and want to acknowledge and meet these, which can be a complex task if they are different or conflicting (Simpson & Bor, 2001).

Participants also identified service restrictions as creating stress and undermining their ability to meet clients' needs. Several papers identify this as important in how clinicians feel about encounters with clients. Sufficient time with clients has been highlighted as an important factor in breaking bad news encounters clinicians identified as effective (Dickson

et al., 2002; Dunniece & Slevin, 2000) and a shortage of time (to prepare, with the client and to process the emotion afterwards) making the situation more difficult (Catalan et al., 1996; Dosaniyh et al., 2001; Simpson & Bor, 2001). Dosaniyh et al (2001) suggest having no time to process information can result in clinicians feeling that clients are on an 'assembly line', echoing some participants' experiences above. The frustration felt by participants about service restrictions and concern about the impact on clients seems justified, given research suggesting shortage of time with professionals, waiting for appointments and little continuity of contact with staff negatively influences clients' experiences (Pratt & Wilkinson, 2001; Ptacek et al., 1999; Salander, 2002; Simpson & Bor, 2001).

Most participants felt a lack of guidance and feedback meant they were unable to gauge how effectively they were doing their job. Sise et al (2006) note this is an important problem as feedback is rarely available for physicians regarding breaking bad news, while Dickson et al (2002) found uncertainty about how a patient had understood information given contributed to clinicians' feeling an interaction had been ineffective.

### **2.5.3 Things that are Difficult**

Participants discussed the difficulty of feeling obliged to be honest with clients but reluctant to be 'too honest' and the complex issue of discussing dementia with clients. A key issue for participants was feeling they had let people down when they were unable to help, provide



answers or services they felt would be beneficial. Dosanjh et al's (2001) research echoes this, with medical residents stating that having something tangible to offer patients helped when breaking bad news. Dickson et al (2002) suggest clinicians feel responsible for clients, creating difficult feelings when they experience powerlessness regarding their care.

Further to this, and of particular relevance to dementia, research also indicates breaking bad news is especially difficult when limited prospects for a cure exist, increasing feelings of discomfort, stress and inadequacy (Baile et al., 2000; Dosanjh et al., 2001). Again, clinicians' concerns are reflected in clients' experience for whom a connection exists between treatment and hope (Salander, 2002). Bamford et al highlight this; stating clients within dementia services felt being given an answer, or diagnosis, to explain their experiences could be beneficial and identified not receiving a definite diagnosis as being "confusing, upsetting and difficult to interpret" (2004, p.165). Feelings of helplessness may therefore be experienced by both clinician and client (Farrell, 1999).

Thinking about the future was difficult as most participants had worked with people in later stages of dementia and knew what clients' futures could hold. Participants also found it difficult to witness and respond to clients' distress and sadness. Dealing with patients' emotions has been identified as "one of the most difficult challenges of breaking bad news" (Baile et al., 2000, p.306) often causing stress and distress for the

clinician (Dosanih et al., 2001; Schildmann, Cushing, Doyal & Vollmann, 2005; Simpson & Bor, 2001). How clinicians cope with this is important. Not only does clinician's health affect the quality of services they deliver (Simmons & Nelson, 2001), but having opportunities to express distress and fears around diagnosis is important for people with dementia (Bamford et al., 2004; Wilkinson & Milne, 2003).

Participants found working in a 'helping profession' while being part of a process that causes distress difficult, creating ambiguity about their role (Simpson & Bor, 2001). It has been suggested professionals feel responsible for patients' reactions (Simpson & Bor, 2001) and do not want to hurt them (Salander, 2002). This is supported by reports that doctors who believed their patient experienced substantial stress during a transaction, themselves experienced greater stress for longer than doctors who reported less stress in their patients (Ptacek et al., 1999). The nature of this relationship is not addressed, however this does suggest the process is affected by the individuals involved and how they perceive the 'bad news'. As Baile et al (2000) highlight, receiving unfavourable medical information does not inevitably cause psychological distress. For clinicians however, "giving information which is probably some of the most painful to be received" (Farrell, 1999, p.109) is a potential source of difficulty.

#### **2.5.4 Impact on Self and Coping**

Participants accepted difficult aspects of their role as part of their job and felt it was important to maintain awareness of this and contain it. This has been identified as important for clinicians and clients and as being difficult in other services (Buckman, 1992; Schildmann et al., 2005; Simpson & Bor, 2001). Participants also described coping by detaching themselves from the emotional content of their work, by maintaining personal and professional boundaries. Sonographers identified this as essential to protect themselves and the quality of their work, particularly as they had no 'recovery time' between patients (Simpson & Bor, 2001).

Dosanih et al (2001) suggest peer support may alleviate clinicians' need to detach themselves to an extent that negatively impacts clients and participants identified this as crucial in coping with the impact of their role. Again, this is consistent with research suggesting peer support during and after breaking bad news is vital in maintaining well-being (Dickson et al., 2002; Simpson & Bor, 2001; Wakefield, Cocksedge & Boggis, 2006). Half of participants felt that while they experienced significant support from colleagues, they were unsupported by the Trust and training for this role was inadequate. They therefore felt they had to find ways to cope, rather than relying on support to be provided.

Positive aspects of participants' roles centred around being able to 'do something' for clients and seemed to contribute to participants' ability to cope with job demands. Again, research identifies this as helping other

clinicians cope with the impact of breaking bad news (Simpson & Bor, 2001).

### **2.5.5 Conflict**

'Conflict' reflects dilemmas that occur during assessment and diagnosis and demonstrates how each theme can exist separately within participants' experience, however, when they come into conflict they can increase distress. Participants were frustrated by the limitations of services, which they sometimes felt did not best meet clients' needs. Not only do participants therefore recognise needs they are unable to address, they are working within systems they feel could make the process more difficult for clients.

Participants needed to experience empathy with clients but also to protect themselves. Communicating news "in ways that are beneficial to the recipient – or at least cause no additional harm – and yet do not negatively influence...doctors themselves" has been identified as a difficult element of breaking bad news (Ptacek et al., 1999, p.114) that adds to the complexity of interactions (Simpson & Bor, 2001). It has been suggested experiencing and demonstrating empathy involves "briefly brushing against personal mortality" (Dunniece & Slevin, 2000, p.616) and participants seemed to need to balance being open to clients' emotional experiences with being able to contain this. Farrell suggests this creates a "feeling of emotional incongruence" (1999, p.102), where the clinician adopts an empathic style while remaining unmoved.

Interestingly this appears to reflect clients' experiences of a tension "between 'putting on a protective coating' and 'spending time in the depths'" (Clare, 2003, p.1023), to cope with a diagnosis of dementia.

Participants were also aware of conflict between the responsibility to be honest and wanting to protect clients from distress and maintain hope. This has been ranked as the most important additional stressor in delivering bad news (Tesser, Rosen & Tesser, 1971, cited in Baile et al., 2000) and referred to as "perhaps the greatest challenge for all involved in communicating bad news" (Farrell, 1999, p.104), raising "the dilemma of how to give hope when the situation is bleak" (Baile et al., 2000, p.302). Hopefulness has been identified as critical for quality of life (Kim, Kim, Schwartz-Barcott & Zucker, 2006; MacLeod & Carter, 1999), while hopelessness has been associated with feeling helpless, useless and with depression (MacLeod & Carter, 1999). Research indicates professionals' hope and hopelessness can influence similar feelings in clients (Cutcliffe, 2006) and recipients of 'bad news' prefer it is "delivered...with some measure of hope" (Ptacek et al., 1999, p.114).

Research with people with dementia indicates clinicians should be honest (Bamford et al., 2004) "however challenging or painful" (Wilkinson & Milne, 2003, p.304) if that is what the client wants and guidance states clients should be given information about the course and prognosis of their dementia (NICE, 2006). This would therefore seem to be a critical issue for clinicians, particularly when hope tends to

be associated with cure or the absence of disease progression (McLeod & Carter, 1999). Working with diseases such as dementia has therefore led to calls for hope to be re-conceptualised as dynamic and framed in terms of what might be accomplished rather than focussing on 'cure' (Baile et al., 2000; Carter et al., 1998).

Again, it should be noted participants' attempts to balance honesty and hope are reflected in accounts of people with dementia who engage in a process of "negotiation aimed at reaching a balance between hope and despair" (Clare, 2003, p.1025) while accepting the reality of the diagnosis.

It is also important that while much existing literature focuses on breaking bad news as a one-off encounter, participants here discussed assessment and diagnosis as a process for all involved. This echoes Salander's (2002) findings, that people with cancer describe diagnosis as an interaction between themselves and health services from detection of symptoms to the present: "From the patient's perspective, "bad news" was far more than passively receiving a single verbal message, far more than a moment of communication that divided time into "before" and "after". Rather than an *event*, "bad news" is better described as a *process*" (Salander, 2002, p.729).

## **2.6     Conclusions**

### **2.6.1    The Experience of Staff Members in Dementia Services**

Analysis of interviews with clinicians involved in assessing and diagnosing people with memory problems revealed five superordinate themes. Participants seemed aware of their own needs and experience and that of clients and their families. They appeared to be trying to meet all these, often conflicting needs, within the context of a progressive illness and service restrictions, limiting their perceived effectiveness. This causes conflict, distress and stress. Participants identified ways of coping with the impact of their work, however, they can only employ strategies available within this context.

It seems likely clients' experiences will be influenced by the dynamics of the work for clinicians. If we do not understand staff members' experiences we will be unable to support them adequately to enhance their experience and that of clients. The shift in conceptualisations of dementia leading to calls to understand individual experience and provide person-centred care would therefore seem to be usefully replicated with clinicians.

### **2.6.2    The Experience of "Breaking Bad News"**

This research supports suggestions that diagnosis is a process and, while doctors may give the formal diagnosis, other clinicians are involved throughout. This research also identified aspects of the clinician and clients' journeys that mimic each other, with both experiencing similar

feelings at similar points, highlighting the potential for transferential processes.

## **2.7 Clinical and Service Implications**

It would seem there is a need for training and feedback to ensure professionals do not have to rely on experience and guesswork to evaluate and develop their competence. “Effective communication, particularly when giving bad news, requires training and ongoing performance evaluation to ensure successful completion. Experience alone may not be enough to ensure...[clinicians] are effective communicators” (Sise et al., 2006, p.216). It would also seem helpful for training to explore how to establish what each client wants from services, ways of working with them through the process and clients' likely responses to this.

Being involved in the assessment and diagnosis of people with memory problems raises complex issues. It is therefore important clinicians can manage these in a way that allows them to continue to perform their role effectively.

Organisations have a responsibility to staff and to be aware that how they perform their roles impacts on clients. This suggests services should support staff members to do their jobs effectively. Research exploring the application of psychodynamic models to organisations suggests institutions develop ‘organisational defences’ such as



structures and practices, to defend staff from the anxiety caused by the primary task of the organisation (Bain, 1998; Hyde & Thomas, 2002; Menzies, 1960; Roberts, 1994); "Like individuals, institutions develop defences against difficult emotions which are too threatening or painful to acknowledge" (Halton, 1994, p.12). For example, Menzies (1960) identified defences associated with nursing in hospitals, such as depersonalising the patient, being busy and not having continuity of contact, which protect staff from getting 'too close' to patients and therefore experiencing anxieties generated by working closely with suffering and death. These defences may offer short term relief, however, the source of anxiety is not removed or resolved (Hyde & Thomas, 2002).

It has been suggested staff members within health services have to deal with their own emotional responses to situations and feelings such as anxiety and depression projected onto them by patients (Hyde & Thomas, 2002; Moylan, 1994). Findings here support this, with participants' emotional responses mirroring that of people with dementia in other research. Analysis also identified conflict between being open to clients' emotional experiences and protecting themselves from this, which Hinshelwood & Skogstad (2000) identify as common within mental health service staff.

Service culture would therefore appear to be critical. Organisations should acknowledge the complexity of this work and encourage

reflection and support from peers and management. If training draws attention more closely to clients' experience, clinicians will need support in working with this and making sense of their own responses. Staff members need helpful defences to enable them to cope with anxieties caused by their work (Moylan, 1994). Participants noted the helpful role of peer support and supervision, which may be developed to facilitate tolerating feelings projected onto them by clients, expressing feelings experienced in response to the work and helping 'work through' this (Halton, 1994; Hyde & Thomas, 2002; Obholzer, 1994). This could facilitate "a culture of support...and containment of their anxieties" (Hinshelwood & Skostad, 2000, p.166).

Research in other areas of health care suggests clinicians need their emotional needs to be acknowledged and supported (Simpson & Bor, 2001), which is made difficult by cultures where "time for reflection is seen as an extravagance" (Dosaniyh, 2001, p.202). Heginbotham particularly notes providing a containing environment seems to be "extraordinarily difficult for mental health services to achieve" (1999, p.257).

While this psychoanalytic view of organisations does not provide a flawless explanation of clinicians' experiences it can be useful in understanding some of the issues facing staff, how to better support them in performing their roles, and what may be important for change (Bain, 1998; Halton, 1994).

## **2.8 Limitations**

A limitation of qualitative research is that constructing an interview schedule influences the outcome of the research (Brocki & Wearden, 2006). Guidelines were followed to construct the interview schedule (Smith, 1995), however, and this can be helpful in highlighting the researcher's assumptions prior to data collection (Smith, 1995).

Interpretation of data is restricted by participants' ability to articulate their thoughts and the researcher's ability to reflect and analyse (Brocki & Wearden, 2006). The clinical supervisor for the research was Head of Older People's Psychology in the Trust (although she was not made aware of who participated), which could have influenced how open participants were. The analysis was also conducted by a relatively inexperienced IPA researcher, however, the researcher was supervised and steps described above taken to guard against threats to reliability and validity.

Smith and Osborn (2003) suggest there is no 'right' sample size in IPA, with published research including samples of one to 30 (Brocki and Wearden, 2006). Brocki and Wearden (2006) highlight the emergence of smaller samples within IPA (although do not state what constitutes 'small'), with large data sets potentially losing subtle detail of meaning. Elliott et al's guidance suggests qualitative research should achieve "coherence and integration while preserving nuances in the data" (1999,

p.222-223) and it is suggested the information gained from the sample here was able to do this.

The sample included different professionals of different levels working in different contexts with older and younger adults. Samples within IPA tend to be broadly homogenous and it is possible this sample was not homogenous enough. Themes were identified across participants' accounts however, demonstrating elements of shared experience.

Another weakness in the sample was the lack of males and doctors. All members of staff were invited to participate and no males or medical staff contacted the researcher. Doctors are heavily involved in diagnosing people with memory problems and it may limit generalisability that they are not represented. The overall response rate of 11.76% was also poor and raises questions about how representative and therefore generaliseable these findings are, given that only a small percentage of staff members chose to take part.

Sample size and composition may therefore limit the generalisability of findings. The primary aim of IPA is, however, not to make claims for larger populations, rather to understand participants' experience, which may subsequently lead to generalisations in future research (Brocki & Wearden, 2006).

## **2.9 Future Research**

Future research could explore whether themes identified are present in other groups of clinicians (different professions, gender, Trusts) and represent a more common experience of this role. This should include consideration of how to improve response rates. It may also be helpful to conduct longitudinal research to observe processes as they evolve over time.

Research exploring how to best train and support clinicians and provide performance evaluation would also be helpful. Given research highlighting the relationship between how clinicians break bad news and clients' well-being, it may also be beneficial to identify mutually helpful elements of the process. Further to this, research exploring transferential processes may help clinicians to identify and work with these.

Finally, research exploring organisational defences of services providing assessment and diagnosis for people with memory problems may contribute to an understanding that helps facilitate change.

## **2.10 Summary**

Assessment and diagnosis in dementia services involves managing different needs within a context that limits how clinicians can meet these. Participants identified factors which helped and hindered them when performing their roles, difficult elements, conflicts that arise and how

they cope. How clinicians manage their experiences would seem to influence their well-being and that of clients and it is therefore hoped this paper contributes to our understanding of training and support needs of staff within these services.

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## **Chapter three**

### **Reflective Paper:**

#### **'Exploring Tensions between Researcher and Clinician Roles'**

**Word count: 3,147**



## **Exploring tensions between researcher and clinician roles**

### **3.1 Introduction**

As part of the requirements of my training to be a clinical psychologist I completed research exploring staff members' experiences of the assessment and diagnosis of people who present to services with memory problems, using Interpretative Phenomenological Analysis (IPA), a qualitative research method. Throughout this process I sometimes experienced tension between the role of robust researcher and my training as a clinician as the two roles came into conflict with each other, particularly in my relationship with participants.

Training to be a clinical psychologist involves developing counselling and clinical skills through teaching and practical experience gained through clinical placements. The doctorate in clinical psychology course covers the development of assessment and formulation skills to understand clients' presenting problems and how to work with these using a variety of intervention approaches, such as cognitive behavioural therapy and psychodynamic models. Trainee clinical psychologists also learn how to evaluate their clinical work. Training includes the development of research skills and provides practical experience of applying these through coursework requirements and the completion of clinically based research that forms part of a final thesis (British Psychological Society, 2002).

Tensions created for researchers about what their role should be within different situations while conducting qualitative research can lead to stress and confusion (Dickson-Swift, James, Kippen & Liamputtong, 2006) and conflict between the role of 'counsellor' and 'researcher' has been particularly noted within the literature as being difficult to manage (Rowling, 1999). This paper will therefore use my experiences as a trainee clinical psychologist completing research to explore conflicts that may emerge between the role of researcher and clinician during the research process and the effect of this.

### **3.2 The Interview Process**

Guidance regarding IPA suggests that the interview schedule should be used only as a guide for the interview (Smith, 1995) rather than dictating its course and that participants should be encouraged to tell their own story in their own way (Clare, 2003). IPA recognises and emphasises the role of the researcher in the analysis of interview transcripts and refers to the development of themes as a co-construction between the participant and the researcher, with the researcher interpreting what the participant says (Willig, 2001). It has been suggested, however, that this co-construction could begin prior to analysis as the researcher and participant co-construct the participant's story during the interview, with Poindexter, for example, suggesting that interpretation does not simply begin after an interview but is "an omnipresent force while the talk is being constructed" (2003, p.405).

In their review of the use of IPA in health psychology, Brocki and Wearden (2006) state that there is little guidance regarding how much influence the interviewer should have over the course of the interview, for example, should they interpret what is being said as the interview proceeds and should these interpretations be shared with the participant? "Is the interviewer intended to be passive and to do their work primarily at the interpretative stage or might the interviewer influence the account given through active listening, prompting and encouraging further disclosure on selected topics?" (Brocki & Wearden, 2006, p.91).

How the researcher may influence each participant's construction of their story within the interview was an important consideration for me during the research process. When conducting interviews, as indicated in literature regarding qualitative research methods I tried to establish rapport with participants (Hubbard, Backett-Milburn & Kemmer, 2001) and encourage them to tell their story about their experiences. Both the role of researcher and clinician require the use of similar skills to establish rapport with clients or participants, such as displaying empathy and using listening skills (Dickson-Swift et al., 2006). This, however, created a tension for me between these two roles; as a clinician I wanted to respond to participants' stories in a way that would, perhaps, be different to how a researcher would respond.

Managing this tension between these roles seems to be important as the response received from the researcher by the participant during the interview may encourage them to expand on a particular experience or thought they may have otherwise not discussed further. I therefore had to recognise that how I responded to the participants' stories could influence how they were constructed and use my skills as a researcher, rather than clinician to facilitate this process.

Nunkoosing (2005) notes the number of occasions on which a participant has commented that they had 'not thought about that before', suggesting that the time, space and interaction within the interview has facilitated a new, or different perspective about their experience to enter their consciousness; "The interviewer does not just collect data, as if picking daisies; he or she colludes with the interviewee to create, to construct stories" (Nunkoosing, 2005, p.701). It seems possible that the stories constructed by an individual and researcher may be different to those that could be constructed by an individual and clinician. As Dickson-Swift et al (2006) highlight, if the participant is gaining therapeutic benefit from an interview, they may raise 'deeper' personal issues, which can then not be addressed within this context.

Tensions therefore arose for me within the interview process. Similar skills are required by the clinician and researcher to establish rapport, but the consequences and purposes of this are different for each. Participants construct their stories within the interview process and how

these develop may be influenced by their interactions with the person interviewing them. Whether this person is a 'researcher' or 'clinician' may affect how these stories are constructed and what response the participant receives.

### **3.2.1 The Relationship with Participants and my Role**

The development of new perspectives by participants was something that I was aware of during the research process. Several times during interviews I wondered about how the participants may be experiencing the interview process and what this would be leaving them with after the interview ended. Some participants did develop new perspectives during the process of the research interview, commenting that they had not thought about their experiences in a certain way until then, or had not realised something about the impact of their experiences on them until that point, in the process of discussing them with me. For example, when talking about the lack of support she felt from the organisation in which she worked, one participant commented "it's only just by talking about this now that it's making me realise, yeah, that is actually just what it's like".

One participant also became distressed during the interview while talking about a client with whom she had experienced a particularly close relationship. At these moments I felt uncomfortable that the participants had given their time and talked openly about their experiences and that this may have left them with difficult thoughts or

feelings. The participant information sheet did highlight that we would be discussing participants' experiences of their role and that support would be available afterwards through the Trust Staff Support Service should they need it. How could participants know, however, what this process may reveal to them about their experience of their job and its impact on them as neither the interviewer or the interviewee know exactly what will be discussed prior to the interview (Nunkoosing, 2005).

Hubbard et al (2001) refer to the relationship between the researcher and respondent as 'parasitic' and suggest that establishing rapport allows the interaction to at least feel equal to the researcher. For me, I sometimes felt the opposite, that by establishing rapport I was encouraging the participant to share more of themselves and their experiences and wondered about whether this process was potentially exploitative (Nunkoosing, 2005). This tension possibly reflects a difference in the purpose of the researcher and clinician and is referred to by Dickson-Swift et al (2006), who highlight suggestions that the purpose of a 'research interview' is to gain information to help the researcher, whereas a 'therapy interview' is for the clinician to listen to the client with the aim of helping the client in some way. The clinician is, perhaps, trained to work towards facilitating change and 'helping the client' in a more immediate way than the researcher who is accustomed to facilitating change in the much longer term following the publication and dissemination of findings. This may therefore have contributed to my concerns about taking too much from the participants; a researcher

without clinical training may be more used to the length of the process of facilitating change through research.

My relationship with some of the participants and what they chose to discuss within the research interview may have been directly influenced by my trainee clinical psychologist role. In some ways, this may have helped to establish rapport as I was seen as a 'fellow clinician' and enabled the participants to feel comfortable in talking openly to me, an important part of qualitative research (Dickson-Swift et al., 2006). It may, however, have inhibited some people who may have discussed more with a 'stranger', who was not involved in their area of work (Rowling, 1999). Being a clinician completing research with other clinicians could also create an alliance or feeling of responsibility to participants that may not be present if research is conducted by an academic with no clinical role.

The tension between researcher and clinician roles was particularly highlighted for me by one of the participants who stated several times during the interview that she disliked formal supervision and much preferred to discuss her experiences informally with peers. Throughout the interview she appeared quite guarded and seemed to be careful about what she 'gave away'. As soon as the interview ended, however, and the recorder was switched off she began to talk about how there was a strong history of dementia in her family and that her job can be difficult as it provides a glimpse for her of what her future may hold. This

was difficult for me as the interview had formally ended, but she was now discussing information that was incredibly relevant to my research. Had she just been inhibited by the formal interview situation or had this raised issues for her that she now wanted to discuss and should I be the person with whom she did this? We did talk about this briefly and I felt unsure about my role in this conversation, was she talking to me as a colleague, a researcher or a therapist and how was it appropriate for me to respond?

I therefore sometimes experienced confusion about what I should do in situations, was I a researcher there to collect data about participants' experiences or a trainee clinical psychologist who may respond very differently to participants' distress and realisations?

Dickson-Swift et al (2006) note that researchers with dual training can find it difficult to maintain boundaries between their roles, so that a researcher who is a trained counsellor, or in my case a trainee clinical psychologist, experiences difficulty in stepping out of their 'therapeutic' role and into that of researcher. This conflict regarding the relationship with participants is also highlighted by Rowling, whose journal extract emphasises this dilemma and the impact of it on the researcher, "I had let someone down – that the 'I' as a researcher had opened up some issues – but the 'Counsellor I' had, mindful of my research role, not reached out to help" (1999, p.172).



Rowling's (1999) sense of letting participants down resonates with my own experiences. Throughout the process I felt a responsibility to individuals who gave their time and shared their experiences with me to portray their experiences in a way that would resonate with them and be of use in developing the services in which they work. This sense of responsibility also led me to think about the power the researcher holds to present participants' experiences, "the opportunity to treat their...[stories] as 'data', to judge them, to draw conclusions about their lives" (Poindexter, 2003, p.402) and how this conflicts with training as a clinician that emphasises how judgements should not be made about those with whom you are working (e.g. Egan, 2002).

My training to be an empathic clinician encouraged me to be aware of the experience of participants and I therefore felt concern for them and guilt about the potential impact of the research process on them. Feeling guilt about participants' experience of the research has, however, also been identified as difficult to manage by other researchers (Hubbard et al., 2001). I also experienced feelings of responsibility to the participants and as a trainee clinical psychologist their experiences resonated with me in a way that they perhaps would not have done with a researcher who was not also a clinician. As a robust researcher, however, I had to manage these feelings to ensure that they did not bias the research process.

The role of researcher and clinician both provide a space for an individual to talk about their personal stories with someone who wants to listen to them and require similar engagement skills to facilitate this process, such as establishing rapport, as discussed above. Dickson-Swift et al (2006) therefore emphasise the danger of crossing the boundary between research interview and therapy, particularly when researchers are not trained therapists. This warning indicates that researchers without therapeutic training also experience empathy and emotional involvement with participants and difficulty in managing this boundary. They have been reported as experiencing confusion about whether, as researchers, they can (or should) avoid being placed in a therapeutic role by participants (Dickson-Swift et al., 2006). Hubbard et al (2001) also warn that without adequate training and support, researchers may 'over-empathise' with participants, leading to self-disclosure that may be inappropriate and not for the benefit of the participant.

These experiences have therefore highlighted for me the importance for researchers of recognising tension between roles, how these may influence the research process and having support in dealing with them. I kept a journal, which helped me to identify and reflect on some of these experiences, I also had access to peer support and research supervisors with whom I could discuss these issues and who conducted credibility checks on the data to ensure these tensions did not influence the process of analysis. Through my experiences in conducting interviews

and my relationships with the participants, I would agree with Rowling (1999), who suggests that researchers should have access to training and supervision that enables them to reflect on and cope with these issues.

### **3.3 Thinking about the system**

This research began by aiming to explore individual clinician's experiences. Through the course of data analysis wider issues emerged such as the impact of service restrictions, working with an incurable disease and how organisational defences may protect clinicians against the anxiety caused by this. This emphasised for me the context within which I, and other individuals providing clinical services, work and made me think about the influence of wider systems on service delivery and the experience of clinicians and clients.

This process has also encouraged me to think about how the researcher themselves may be influenced by the system they are researching. I experienced feelings of helplessness, hopelessness and frustration during these interviews. I sometimes worried about taking too much from the participants and having to leave them without support they may need and experienced conflict about the balance between hearing their story without becoming too involved in it. These feelings were also experienced by participants in relation to their work with clients. Analysis of the interviews with participants highlighted the potential presence of transference processes between clinicians and clients and

the feelings I experienced during these interviews made me consider the potential role of transference within the research interview and how this may influence the interview process and data analysis.

Hubbard et al (2001) identify research which recognises the influence of transference in research interviews; that powerful feelings experienced by the participant may be transferred onto the researcher. They indicate that the emotion experienced by the researcher can hold an interpretative function as it can provide insight into the experience of the participant (Hubbard et al., 2001; Rager, 2005). Hubbard et al (2001) therefore warn that if researchers negatively experience participants' emotions and consequently avoid them, they may be closing down a way of understanding the world. It would therefore seem important that researchers are aware of these processes.

Here, my experiences as a trainee clinical psychologist enabled me to identify these processes and manage them within the interview situations; my training as a clinician in this context therefore helped me to perform the role of a robust researcher.

### **3.4 The Impact on the Researcher**

Completing this research emphasised for me the importance of recognising the experience of staff members and supporting them to cope with the impact on them of their work. It also brought to my attention the experience of researchers, especially regarding the tension

that may exist between roles they hold and the possible value of supporting them in similar ways.

It has been noted in the literature that while participants' experience of taking part in research has been explored and their welfare is protected, there is a lack of understanding about the impact of research on the researcher and that this is often ignored (Dickson-Swift et al., 2006; Hubbard et al., 2001; Rager, 2005; Rowling, 1999). As discussed above, researchers can experience difficult feelings, confusion and conflict while completing research. If researchers are not able to understand their own feelings and the impact of the research on them, there is a danger that these will negatively influence the research process and the researcher (Hubbard et al., 1999; Knowles, 2006; Rager, 2005). For example, it can be difficult observing someone who is distressed, or attempting to control their feelings and Hubbard et al (2001) warn that some researchers may avoid establishing rapport in order to avoid the difficult experience of dealing with participants' emotions. These feelings may also become overwhelming, leading to the potential for 'researcher burnout' particularly when exploring 'sensitive topics' such as grief and loss (Dickson-Swift et al., 2006) and may negatively influence an individual's ability to perform their role of robust researcher.

Authors suggest there is a lack of guidance regarding how researchers could be supported in understanding and managing conflict between

roles, their emotional reactions to participants and the research (Hubbard et al., 2001). There does, however, appear to be agreement that formal support (such as individual and group supervision) should be available alongside informal peer support (Dickson-Swift et al., 2006; Hubbard et al., 2001; Rager, 2005; Rowling, 1999). Other authors identify the role of a research journal in providing information about the researcher's emotional reactions and acting as a form of 'debriefing' (Rager, 2005; Rowling, 1999) and suggest that models of group psychotherapy may help research teams in addressing issues (Corden, Sainsbury, Sloper & Ward, 2005). My experiences have emphasised for me how important this support could be for researchers and the influence it may have on them, their research and those who participate in it.

This experience has also raised the question for me of who should complete research, particularly interviews or fieldwork. It seems the researcher may be part of complex processes and experience difficult feelings during interactions with participants and that not recognising and understanding these could have a negative impact on the researcher and the research. Dual training (for example, as a trainee clinical psychologist and researcher) may create tension during the research process, however, this may also enable the researcher to recognise and manage some of the complex processes during data collection. Researchers would therefore seem to need training and support to be able to manage these processes within interviews. If the

researcher does not have these skills and feels that they respond badly in a situation they can experience distress, their professional identity can be undermined and the research may be influenced (Hubbard et al., 2001).

### **3.5 Conclusions**

Tension may exist for researchers who have dual training as clinicians. Similar skills, such as developing rapport, are required for some aspects of both of these roles, their purpose is, however, different. How a researcher and clinician may respond to distress and the development of perspectives by the participant/ client may also be different. These tensions may create difficult feelings for the researcher and has potential to influence the research process. It may also be, however, that aspects of therapeutic training and experiences may actually facilitate the role of robust researcher by enabling individuals to identify and manage aspects of the interview situation, such as their emotional responses to the participant's story.

It would seem important that individuals who conduct research are supported to recognise and understand these tensions, processes and experiences and the impact on them, in order to protect both themselves and the quality of the research process. "What is required is compassionate analysis which intertwines the researcher's and participant's emotions, as long as the emotions do not interfere with 'real

listening” (Rowling, 1999, p.177), which it seems may be facilitated by the careful balancing of the researcher and clinician roles.



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## **Appendix 1.**

### **Guidelines for authors submitting papers to Aging and Mental Health**

## [Journals Listings](#)

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**\*\*\*Note to Authors:** please make sure your contact address information is clearly visible on the **outside** of all packages you are sending to Editors. \*\*\*

**Aging and Mental Health** welcomes original contributions from all parts of the world on the understanding that their contents have not previously been published nor submitted elsewhere for publication. We encourage the submission of timely review articles that summarize emerging trends in an area of mental health and aging, or which address issues which have been overlooked in the field. Reviews should be conceptual and address theory and methodology as appropriate. All submissions will be sent anonymously to independent referees. It is a condition of acceptance that papers become the copyright of the publisher. **Books for review** should be sent to Dr Chris Gilleard, Psychology Department, Springfield Hospital, Tooting, London SW17 7DJ, UK.

### **Manuscripts**

**Aging & Mental Health** is moving to an electronic submission system and has a new editorial e-mail address: [amh@ucl.ac.uk](mailto:amh@ucl.ac.uk).

All editorial correspondence, including manuscripts for submission should be sent to **Professor Martin Orrell** at [amh@ucl.ac.uk](mailto:amh@ucl.ac.uk) or **Professor Dan G. Blazer** at [blaze001@mc.duke.edu](mailto:blaze001@mc.duke.edu). Word format is preferred. General enquires can be sent to [m.orrell@ucl.ac.uk](mailto:m.orrell@ucl.ac.uk). Books for review should be sent to **Professor Murna Downs**, Bradford Dementia Group, School of Health Studies, University of Bradford, Bradford BD5 0BB, UK.

If submission by email is not possible, four complete copies (with electronic copy on disc) can be submitted to either Editor: Professor Martin Orrell, Department of Mental Health Sciences, University College London, Wolfson Building, 48 Riding House Street, London W1W 7EY, UK, or Dan Blazer, J. P. Gibbons Professor of Psychiatry, Duke University Medical Center, School of Medicine, Box 3005, Durham, NC 27710, USA.

All submissions should be in the style of the **Publication Manual** of the American Psychological Association (4th edition, 1994). Papers should be typed on one side of the paper, double spaced throughout (including the references), with margins of at least 2.5 cm (1 inch). All pages must be numbered.

The first page should include the title of the paper, first name, middle initial(s) and last name of the author(s), and for each author a short institutional address, and an abbreviated title (for running headlines within the article). At the bottom of the page give the full name and address (including telephone and fax numbers and e-mail address if possible) of the author to

whom all correspondence (including proofs) should be sent. The second page should repeat the title and contain **an abstract of not more than 200 words**. The third page should repeat the title as a heading to the main body of the text.

**Structured abstracts:** The main text should be preceded by a short structured abstract, accompanied by a list of keywords. The abstract should be arranged as follows: Name of author(s); title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.

**Key words:** A list of 3-6 keywords should be provided. Words already used in the title should be avoided if possible

The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content. Within the text section headings and subheadings should be typed on a separate line without numbering, indentation or bold or italic typeface.

#### Electronic Submission

We prefer email submissions only - in Microsoft Word format. Do not save your files as "text only" or "read only".

#### **References**

References should follow APA style. All publications cited in the text should be listed following the text; all references listed must be mentioned in the text. Within the text references should be denoted by the author's name and year of publication in parentheses, e.g. (Woods, 1995) or (Mansell & McGill, 1995) or, if there are more than two authors, (Gallico *et al.*, 1986). Where several references are quoted consecutively within the text the order should be alphabetical, e.g. (Elford & Sherr, 1989; Folkman, 1992). Similarly, where several references are quoted within a single year, the order should be alphabetical (Mansell & McGill, 1995; Woods, 1995). If more than one paper from the same author(s) and year is listed, the date should be followed by (a), (b) etc., e.g. (Blazer, 1995a).

References should be listed at the end of the paper in alphabetical order, typed in double spacing. Responsibility for the references and their verification against the original documents lies with the author(s).

References should be listed on a separate sheet(s) in the following standard form, capitalisation and punctuation:

a) for periodical articles (titles of journals should not be abbreviated):

WOODS, B. (1995). Dementia care: progress and prospects. *Journal of Mental Health*, 5, 115-124.

b) for books:

NORMAN, A. (1987). *Aspects of ageism*. London: Centre for Policy on Ageing.

c) for chapters within multi-authored books:

ROBERTSON, I. T. (1994). Personality and personnel selection. In C. L. COOPER & D. M. ROUSSEAU (Eds.), *Trends in organizational behavior* (pp. 75-89). Chichester: Wiley.

#### **Units of measurement**

All measurements must be cited in SI units.

#### **Illustrations**

All illustrations (including photographs, graphs and diagrams) should be referred to as Figures and their position indicated in the text (e.g. Fig. 3). Each should be submitted on a separate sheet of paper, numbered on the back with Figure number (Arabic numerals) and the title of the paper. The captions of all figures should be submitted on a separate sheet, should include keys to symbols, and should make interpretation possible without reference to the text.

Figures should ideally be professionally drawn and designed with the format of the journal (A4 portrait, 297 x 210 mm) in mind and should be capable of reduction.

#### **Tables**

Tables should be submitted on separate sheets, numbered in Arabic numerals, and their position indicated in the text (e.g. Table 1). Each table should have a short, self-explanatory title. Vertical rules should not be used to separate columns. Units should appear in parentheses in the column heading but not in the body of the table. Any explanatory notes should be given as a footnote at the bottom of the table.

#### **Proofs**

Proofs will be sent to the author nominated for correspondence. Proofs are supplied for checking and making essential typographical corrections, not for general revision or alteration. Proofs must be returned (by air mail or fax if overseas) within 72 hours of receipt.

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## **Appendix 2.**

**Local Research Ethics Committee (NHS) approval**



17 May 2006

Miss Anna Buckell  
Trainee Clinical Psychologist  
Coventry & Warwick Universities  
Clinical Psychology Department  
George Eliot Building  
Coventry University, Priory Street  
CV1 5FB

Dear Miss Buckell

**Full title of study:** An exploration of the experience of staff members who are involved in the assessment and diagnosis of people presenting with memory problems.  
**REC reference number:** 06/Q2706/13

Thank you for your letter of 21 April 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

#### 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 as revised.

#### Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

#### Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application	Parts A + B	28 February 2006
Investigator CV	-	28 February 2006

Protocol	1	28 February 2006
Covering Letter	-	28 February 2006
Letter from Sponsor	-	23 January 2006
Interview Schedules/Topic Guides	1	28 February 2006
Letter of invitation to participant	1	28 February 2006
Participant Information Sheet Staff	2	21 April 2006
Participant Consent Form	1	28 February 2006
Response to Request for Further Information	-	21 April 2006

### Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

### Statement of compliance

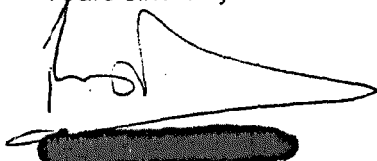
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q2706/13

Please quote this number on all correspondence

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

Yours sincerely



Chairman

Email:

Enclosures:

Standard approval conditions

Copy to:

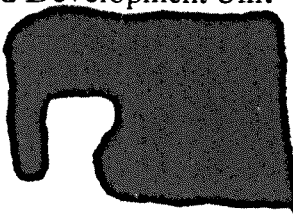
Coventry and Warwick Universities  
 Doctorate Course in Clinical Psychology, George Eliot Building  
 Coventry University, Priory Street  
 Coventry  
 R&D Department for NHS care organisation at lead site

SF1 list of approved sites

## **Appendix 3.**

**NHS Trust Research and Development Department approval**

Research and Development Unit


Tel: 

Ms Anna Buckell  
Trainee Clinical Psychologist  
George Eliot Building  
Coventry University  
Priory Street  
Coventry  
CV1 5FB

27<sup>th</sup> July 2006

Dear Ms Buckell,

**Re: "An exploration of the experience of staff members who are involved in the assessment and diagnosis of people presenting with memory problems".**

Thank you for returning your completed Trust Research Application Form for the above project. This research has now been approved by the Director of Research & Development and we have notification of a favourable ethical opinion. You may therefore commence the work.

Please note that the Trust's approval of this research is given on the understanding that you are aware of and will fulfil your responsibilities under the Department of Health's *Research Governance Framework for Health and Social Care*, including complying with any monitoring/auditing of research undertaken by the Research & Development Unit.

Please do not hesitate in contacting the Research & Development Unit should you require any advice or support on any aspect of your project. When contacting us it would be helpful to quote our reference number for this project: 788.

With best wishes  
Yours sincerely,

*PP - C. Coope*

  
Research Manager

**MENTAL HEALTH NHS TRUST**

**APPROVAL**

In conducting this research I agree to abide by the policies and procedures of  
Mental Health NHS Trust.

I am aware of and will fulfil my responsibilities under the  
Department of Health's Research Governance Framework for Health and Social Care,  
including complying with internal and external monitoring of my project.

Name of applicant: ANNA BUCKELL

Signature: *Anna Buckell*

Date: 26/05/2006

Name of supervisor\*/manager: DR AMANDA GATHERER

Signature: *Amanda Gatherer*

Date: 26-5-06

\*Supervisors from Universities/non [redacted] staff are asked to complete the  
declaration overleaf

Approved by the Research Programme Lead:

*[Signature]*

Date 27/6/06

Approved by the Director of R&D on behalf of

*[Signature]*

Professor [redacted] Director of R&D

Date 13/7/06

## **Appendix 4.**

### **Participant Information Sheet**

August 2006

Dear Staff Member,

**What is the experience like of assessing and diagnosing people  
who present with memory problems?**

I am currently conducting research exploring the experience of staff members who are involved in the assessment and diagnosis of people who present with memory problems and am looking for members of staff from within this Trust to participate.

If you are interested in finding out more about this research, I have enclosed an information sheet that describes the study and what participation would involve. It also contains my contact details should you have any further questions about this study.

Thank you for your time.

Yours faithfully,

Anna Buckell  
Trainee Clinical Psychologist  
Coventry and Warwick Universities

Enc:

## **What is the experience like of assessing and diagnosing people who present with memory problems?**

**You are being invited to take part in a research study. Before you decide to take part it is important that you know why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me if there is anything that is not clear, or you would like more information. Take time to decide whether you wish to take part.**

**Thank you for reading this information sheet.**

### **What is the purpose of the study?**

The study is looking at what staff members' experiences are of being involved in assessing and diagnosing people who present with memory problems.

Some research has been done to evaluate the experience of clients going through this process. Research exploring staff members' experiences is, however, lacking. This study will therefore aim to identify what the key issues are for staff involved in this process.

### **Why am I been approached?**

Members of staff who are involved in the assessment and diagnosis process for memory problems have been invited to take part in this study. I am hoping to speak to about 15 people about their experiences.

### **Do I have to take part?**

It is up to you whether or not you take part in the study. If you do decide to take part you will be asked to sign a consent form, which you will be given a copy of to keep. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

No other member of staff within the Trust will be informed whether or not you have participated.

### **What will happen to me if I decide to take part?**

You will be asked to take part in one interview that will last for approximately one hour. This will be arranged at a time that is convenient to you and will take place at a Trust property of your choice. After the results have been collated, you will be offered another chance to meet with me to discuss these.

### **What do I have to do?**

You do not have to do anything else, other than take part in one interview.

### **What are the possible disadvantages of taking part?**

There is a possibility that some of the issues raised during the interview may be difficult. If this is the case, you would be able to access support from the Trust Staff Support Service via the Trust Intranet.



### What are the possible benefits of taking part?

Taking part in this research will help to develop an understanding of what it is like to be involved in assessing and diagnosing clients with memory problems. This would highlight what some of the important issues are for staff involved in this process.

Hopefully, this understanding will help to develop a focus on what the needs are of staff involved in this process. This will hopefully also benefit clients receiving this service, as any changes in staff support in the future should benefit their experience.

### Will my taking part in this study be kept confidential?

All information that is collected about you and your experiences during the course of the research will be kept strictly confidential.

No-one other than myself will know who has taken part in the study. Nicky Bradbury (Head of Psychological Services for Older People) is supervising the research, but she will not know who has participated in it.

The interview that you take part in will be audiotaped and transcribed by me. Both the tape and transcription will be kept in a locked box. Neither will be identified as being yours.

The results from the research will be written up as a report. This will be submitted as part of a Doctorate course in Clinical Psychology and may be submitted for publication. You will receive a copy of this, as will Nicky Bradbury. All information within this report will be fully anonymised. You will not be identifiable in the report.

You should also be aware, as with any research with staff members in the NHS, in the unlikely event that any issues were raised that had an impact on your ability to work, the researcher would be obliged to speak to a manager.

### Who is organising and funding the research?

The research is being supported by Coventry and Warwick Universities and is being completed as part of the requirements of the Doctorate course in Clinical Psychology.

### Who has reviewed the study?

The Local Research Ethics Committee and the Trust's Research and Development Department have reviewed and approved the research.

### Who should I contact for further information?

If you have any questions or would like further information, please contact me:

#### **Anna Buckell**

Trainee Clinical Psychologist  
Doctorate Course in Clinical Psychology  
George Eliot Building  
Coventry University  
Coventry  
CV1 5FB

**Tel: 024 7688 8328**  
**Fax: 024 7688 8328**

Thank you for your time and for considering taking part in this research. If you would like to participate, please complete the opt-in box below and return this page to me in the enclosed stamped addressed envelope. I will then contact you to arrange a convenient time for us to meet.

**What is the experience like of assessing and diagnosing people who present with memory problems?**

I have read the information about this research and am interested in taking part:

Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Please contact me on the telephone number below to arrange a meeting at a time and location that is convenient for me:

Telephone Number: \_\_\_\_\_

## **Appendix 5.**

### **Consent Form**

[version 1, 28.02.06]  
Study Number: 06/Q2706/13  
Patient Identification Number for this trial:

CONSENT FORM

Title of Project:           An Exploration of the Experience of Staff Members who  
                                  are involved in the Assessment and Diagnosis of People  
                                  Presenting with Memory Problems

Name of Researcher: Anna Buckell

- |  | Please initial<br>box:  |
|--|---|
| 1. I confirm that I have read and understand the information sheet dated 21.04.06 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <div style="border: 1px solid black; width: 80px; height: 40px; margin: 0 auto;"></div> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my employment or legal rights being affected.  | <div style="border: 1px solid black; width: 80px; height: 40px; margin: 0 auto;"></div> |
| 3. I give my permission for the interview I take part in to be audiotaped and transcribed.   | <div style="border: 1px solid black; width: 80px; height: 40px; margin: 0 auto;"></div> |
| 4. I understand that individuals supervising this research will look at the transcription of my interview, but that I will not be identifiable to these individuals.   | <div style="border: 1px solid black; width: 80px; height: 40px; margin: 0 auto;"></div> |
| 5. I agree to take part in the above study.  | <div style="border: 1px solid black; width: 80px; height: 40px; margin: 0 auto;"></div> |

Name of Participant	Date	Signature
Researcher	Date	Signature

## **Appendix 6.**

### **Interview Schedule**

## **Interview Schedule**

### **Experiences of the Job**

What part of the assessment/ diagnosis process does your job involve & what is this experience like?:

- What does your role involve in terms of the assessment and diagnosis of people with memory problems?
- Raising the word 'dementia' with clients and their families:
  - Do you have to do this – has it been mentioned prior to your contact?
  - How do you approach this with clients/ families? – do you?
  - How do you feel when this is raised?
- Are all clients given a diagnosis?
  - How do you feel if you are un/able to give the client a diagnosis?
- What is it like to tell someone, or be with them when they are told, that they have memory problems/ dementia?
  - Your feelings/ reactions
  - Other professionals' feelings/ reactions
  - Is this ever discussed in the staff team?
  - Best/ worst things about giving someone a diagnosis
- What are the good things/ difficult things about your role

### **Support**

How do you deal with the clients' reactions?:

- What is it like for you to be present?
- Support systems?
- Support available within staff teams?
- Recognition within staff teams of the potential for impact of this work?
- What would be helpful?

### **Personal Experience/ Views**

What would be important to if you were going through this process?:

- Attitude of staff
- Services available
- Support available

## **Appendix 7.**

### **Extract of transcript**

65 18 and they can be saying "well there's nothing wrong with my memory, why am I here?" and that can be quite  
66 difficult,

67 AB Mmm

68 18 a, trying to, you know, in a tactful way explain to people that there are difficulties and that the family have  
69 noted difficulties, but you don't want to put the family in a difficult position by saying what, what they've told  
70 you, that they might want have told you on the quiet and they don't want to know, you get caught up in this  
71 network of, you know bits but you can't tell different people what you know,

72 AB Yeah

73 18 in particular the client and that, I find that very difficult, trying to explain to them why they're here, we have  
74 people coming thinking they're coming to have their feet done and I think sometimes the relatives may not  
75 always tell them the complete truth,

76 AB Mmm

77 18 they just want to get them here because they've got concerns, they want to get them here, they want to get  
78 them seen, they'll tell them any old story in order to get them here and then you'll, you go to do an  
79 assessment and they want to know "why are you asking me these questions? There's nothing wrong with  
80 my memory" and that can be quite difficult,

81 AB Mmm

82 18 so it can be quite, and also when you're doing, when you're doing the testing and you can see the  
83 recognition on the client's face that they're not able to answer questions that they know are fairly simple  
84 straightforward questions

It's like  
for the client

Who's my client?

- whose side  
am I on?  
keeping secret  
family vs client  
needs.

Who's my client?

1  
- who wants the  
assessment  
- who has what  
needs - which  
are more important  
- How balance these

Awareness of  
impact on client  
of client's  
experience  
(or testing)

difficult to  
explain why  
you have  
network of  
secrets  
Diff. info  
from family

relatives not  
always honest  
the client

difficult  
to answer  
client's ques.

can  
be difficult  
for clients



Teaching can be distressing for client + participant

147

clients we want to help them to be able to cope with what's going on

85 AB Mmm  
86 I8 and they get quite distressed by that that's, 'cause basically you get to the point where you just want to say  
87 "forget it, let's", you know, 'cause you can see that they're becoming distressed, but unfortunately from a lot  
88 of respects we have to finish it 'cause it's for their benefit but that's quite difficult. —  
89 AB Mmm yeah, so you're kind of, you can see that, that test you're doing with someone is making them  
90 distressed, but at the same time you have to  
91 I8 You need to do it because it's going to be beneficial to them  
92 AB Mmm  
93 I8 in the long run if we can reassess and show that there are difficulties, I mean, we might be able to, to help  
94 them,  
95 AB Mmm  
96 I8 but it's not, it's not always a very pleasant experience, depending on what people's problems are, you get  
97 some people who'll come along and answer the questions quite happily even if they have got quite severe  
98 difficulties  
99 AB Mmm  
100 I8 it's, their, their insight is less so they they're not quite as bothered, but people who've got a little bit more  
101 insight into their problems can find it quite distressing and so from your point of view, you know, our natural  
102 abilities, that we want to look after people, want to make, be nice to people  
103 AB Mmm  
104 I8 and it goes against the grain when you're putting people in difficult situations.

Impact on the experience - dealing with distress

↑  
Individuals respond differently  
↓

I'm causing distress  
What I do is  
— process is distressing to clients  
causing the distress

↑  
Individuals respond differently  
↓  
if they're distressed it's more difficult to impact on them  
if dealing with distress

— goes against the grain  
causing distress  
What I do causes distress

on the  
making the  
business  
difficult

105 AB Mmm, yeah it's kind of, I suppose the opposite of what you would

106 I8 Goes against what you would normally do, which is, if anybody's becoming distressed you'd go, what you'd

107 normally do is do what you can to relieve that distress,

108 AB Mmm

109 I8 whereas actually you're causing the distress, so

110 AB Yeah

111 I8 that can be quite difficult.

112 AB And you mentioned about people not always really knowing why

113 I8 why they're

114 AB they've been, why they've come to the clinic, what's, what's that like for you?

115 I8 Because usually when we take somebody to do the assessment you would want to first say, you know, "do

116 you know why you're here today?", 'cause I wouldn't go into a long ream of questions about their memory,

117 and they'll say "no, not really, me daughter bought me" and you say, "well, um, are you having problems

118 with your, have you been having any problems with your mem", "no, no no, my memory's fine", so you

119 know, you sort of have to go "well, that's why you're here, because we feel that there may be some

120 difficulties and we need to look at that" and they'll be "oh, there's nothing the matter with, there's nothing

121 the matter with me", um, and you sort of get caught up sometimes because, like I say, the family are in the,

122 in their own, the, the client's interests have got them there under false pretences

123 AB Mmm

What I do causes distress  
(Goes against what a professional would do) (Difficult thing / part of experience)

Respond to individual  
main difficulty in case  
(gauge what they're coming from)

honesty (have to be honest, but difficult - "sort of have to go")

Who is my client?  
(family want assessment)  
Does client?  
(whose needs - trying to balance price & all?)

148 Why  
and the  
more  
understand  
the motive  
coming from

My have  
interests  
client's need  
difficult

My have  
interests  
= "Caught up"

## **Appendix 8.**

### **Quotations to ground themes**

## **What Helps Me To Do My Job**

### **Awareness of the clients' experience (10 participants)**

(2:692-705) *"it's actually really intimidating to have someone doing an assessment on you and to test you, and I think that where, wherever possible try and encourage, you know, people who are new to that, whether it's a trainee, or whatever, um, t, to go away with an assessment with a friend or partner and practice it, and, and see how uncomfortable it can feel to be, you know, to be questioned and tested and that, and it's horrible and I think going through that process is really important, to put yourself in the client's shoes who's going to be even more anxious because they've got, probably a memory problem and coming in somewhere new, it's mental health, you know, all those kind of issues that, that are, you know, weighted with it."*

(7:297-299) *"you've got other, the other clients who can get very angry, um... you can understand that as well, because they think that they haven't got a problem, so, and some of the questions on, like say the Mini Mental do seem a bit bizarre"*

(9:159-168) *"they usually get distressed around the assessments, while we're doing the assessments, but every time before I start the assessment, I always ask them "if there's anything you wa, if you feel uncomfortable at anything or you don't want to do it, let me know and I will stop the test" 'cause it's only fair on them isn't it? You can't carry on the test if they're in a state, and I'll, I keep saying that, 'cause while*

*they're carrying out the test you can see how the individual is, you know how they're responding to the test and the body language gives a lot away as well don't they? So, I always try and reassure them while doing the test, "are you okay, do you want me to carry on?" and if the, the response is positive then I'll carry on."*

*(6:278-281) "I think the way we give a diagnosis and the way we handle that information is really important I've certainly seen people who've been to out-patients and had the information and it can be fairly brutal"*

*(6:39-41) "balancing I suppose some more positive aspects of them as a person, with, in areas of deficit I suppose, hopefully they feel more at ease with that, you're not there to kind of rubbish their whole persona really, which is very important for them."*

### **Empathising as a means of understanding what people want (9 participants)**

*(2:292-306) "I suppose I would be putting myself in their shoes and thinking I would want to see the same person, so that they'd know my history, they'd know a bit about my background or my concerns or what I'm like or my vulnerabilities or whatever, than having to come and see somebody new each time, you've got to have a quick scan of the notes, or probably doesn't look at them that thoroughly and then, you know, prescribe or then, you know, does that and then go and see somebody else again, a different person, um. I think it's quite important really, but I,*

*I'm thinking that from my own perspective as well, that if it was me, or one of my relatives, I'd want to see the same person each time, I wouldn't want to be seeing lots of different people who, um, particularly when it is such an emotional subject like that"*

*(3:443) "I treat people as if, how I would want to be treated"*

*(5:212-214) "it is frightening and it does make you think about things, and I feel really it, you know, I often feel, "how would I like my mom to be treated"? And, probably that's the way I go about it really"*

*(1:156-161) "it's like when I do the Mini Mental States, I've had quite a few people tell me that they can see that I'm willing them to get the answer and, you know, I don't believe in all that hocus pocus, but I do, I am in my head, shouting the answer at them, you know?"*

*(1:301-305) "you would never want it for yourself anyway would you, not to know who you are, not to recognise your family, not to (...) know where you are or be able to make yourself a cup of tea, yeah, so you sympathise with that"*

*(5:188-191) "and then, you've got other people where they have actually got the problem and really are embarrassed to admit that they've got problems with their memory um, and the fear that comes with knowing*

*that you're losing your memory in that, they might not stay the way they are, they may deteriorate and, I can understand that"*

**Individualising care appropriate to level of need (10 participants)**

*(2:73-81) "then I always sort of, like, try and check with them what they perceive to be the cause of their memory difficulties, just to see where they're coming from really, um, and a lot of people might sort of say, um, "oh it's just down to my age", or "I'm sure it's my age", or, you know, and occasionally people will, will say, "well I am worried if it's dementia, I'd like to know now if there's anything I can do about it now", so it, it's quite good to get a, kind of a footing of where they're coming from as early on a possible, I think that, that helps with the assessment process and then kind of like the feeding back"*

*(3:28-42) "every assessment is different...Even though you've got common themes, which, which is good and makes it interesting and varied really. Keeps people as individuals, doesn't it? Lump people all as a memory assessment, it's not, it's a person with memory problems 'cause they're all individual"*

*(1:408) "some people want the diagnosis, some don't, it's just individuals"*

*(2:214-217) "it's going to be quite difficult to feedback because she doesn't really want to, to hear that, and she'll probably hear it but then*

*her own coping mechanisms and denial will need to come in and will come in, and we'll need to respect that"*

*(5:121-124) "sometimes that's all people want from me is to be er, you know, a port of call where they give advice and name the resources that they can tap into, but other times I'm the emotional aspect of support, um, and help them validate their feelings and express their feelings"*

*(6:372-373) "when someone's been given the diagnosis, sometimes they do just need to get on with it"*

#### **The role of experience and confidence (10 participants)**

*(3:50) "It's definitely experience that gives you that comfort zone"*

*(2:622) "Some of it is just about having experience in doing it I suppose"*

*(3:24-26) "I have to say I feel fairly comfortable with it because I've been doing it for so long"*

*(3:139-140) "I don't find it hard to do it, I did in the beginning, I did find it hard and which way was the best way to do it"*

*(7:66) "I think over the years you get used to these cases"*

*(5:317-319) "through the years it's probably made me more skilled at the assessments and more sensitive at the assessments"*



*(5:329-330) "I suppose, like in any job really, if you take on board all things that are happening around you and you reflect it should make you a better practitioner really shouldn't it?"*

### **What Hinders Me Doing My Job**

**Who is the client – working with families and systemic needs (8 participants)**

*(2:196-198) "I have had it where, um, the client hasn't wanted to hear any feedback, but the carer knows, and that's really awkward, 'cause the carer knows what the diagnosis is 'cause the client has said "I'm happy for that", but the carer's saying, "I can't do anything without them knowing what it is"*

*(10:463-465) "that can be quite challenging to say, "okay I'm listening to what you're say, I'm hearing what you're saying, but I need to hear what your mom's saying or your dad's saying or your wife" or something like that"*

*(8:65-71) "they can be saying "well there's nothing wrong with my memory, why am I here?" and that can be quite difficult, a, trying to, you know, in a tactful way explain to people that there are difficulties and that the family have noted difficulties, but you don't want to put the family in a difficult position by saying what, what they've told you, that they might want have told you on the quiet and they don't mom to know, you get*

*caught up in this network of, you know bits but you can't tell different people what you know"*

*(8:140-143) "you'll get the situation where you'll have um, the family wanting them to be seen, but then saying they don't want, "we don't, we don't want them to know if they've got, um Alzheimer's, we don't want them to know" so how are we supposed to do this assessment and this testing and come up with a diagnosis, but not actually feed it back to the client?"*

*(10:87-93) "sometimes it's a surprise for them what that person has, you know, the extent of the problems they are having, and are really quite shocked so sometimes when you're working with the hus, you know you've got, you know you're working with somebody and the wife's in the room, you've not only got that person's you know the shock and upset and anxiety you've also got their relative's, you know, anxiety and upset as well to deal with."*

#### **Impact of service restrictions (9 participants)**

*(3:525-526) "you don't get that opportunity, the way things are now you don't get that opportunity to be, to work, for that length of time with someone"*

*(2:451-456) "I did put a business case together, but it was kind of dismissed because I needed some funding for, like a venue and*

*transport, the usual kind of frustrations I think that you get that you might have these ideas, but the actual ability to put them into practice can be curtailed by other people who hold, you know the powers that be as it were, so that, that's quite frustrating"*

*(5:13) "we've got such a waiting list with our memory clinic"*

*(10:68-69) "when I first came to the job and time pressures and things you felt as if you had to swoop in and take away the information"*

*(7:330-336) "A not so good thing is having to, to sometimes always be aware that there's other people all waiting and not having as much time as, as I would like, say, if you spend say twenty minutes with a client and then they're chatting away to you happily and then, you know, you're thinking, "right, I'm going to have to, er, go now, but how do I", and you can get a little bit edgy thinking "all those people out there are waiting for me as well" and you've got that inside your head, but then I think, "well, it's too bad, they'll just have to wait", so there's that side"*

*(8:462-466) "when I first started we had the full staff team and we had fewer clients and now there's more clients, less staff, more pressure"*

*(6:479) "'cause our, um, team is kind of shrinking, it's easier just to go out and do it on your own" (assessments)*

*(10:140-144) "you're aware of the time pressure, you know you've got so many people to see, but also for the people, well, "you've come, well we've answered all your questions, we want an answer now we don't want you taking weeks because it's just dragging these feelings out""*

*(5:62-64) "in my last job there was also actually a reluctance to give the diagnosis of dementia, simply because care homes through that time were not taking people with the label of dementia"*

#### **Lack of guidance/ feedback on job (7 participants)**

*(1:602-603) "you've got nothing to judge it by, whether you're doing a good job, or a crap job, or an indifferent job"*

*(6:73-77) "It's usually, I find it, the person I'm talking to just kind of like, "oh yeah, yeah" and I'm never really sure how much of that they take in you know, invariably there's family there and things, that, I find that quite difficult to work out how they feel about it personally and what, what sort of an impact it might have."*

#### **Things that are Difficult**

##### **Honesty (10 participants)**

*(1:330-332) "its bringing things up for people to consider that they might not have considered, that if you carry on down this line, these are other issues that you're gonna to have to consider as well. And some people*

*decide to drop it at that stage" (making aware of possible consequences of diagnosis e.g. stop driving)*

*(4:79-84) "another area of challenge is um raising the words at times, and bringing those um, brining the idea of dementia into somebody's consciousness. Because, if it's not there then you could argue that somebody's not giving informed consent because they don't fully understand what the purpose of the assessment is"*

*(5:159-163) "I think its right to be honest with people as to why you're there rather than being quite sly about that you've come because they've got memory problems and, "oh I've only come for a chat, the G.P. sent me", I don't think that's right, I think it's, it's ethically right to say why you've come and because I feel they have, you know, it's their right to know why you've come and so that 's the way I go about it."*

*(3:207-215) "I have to say, I have given diagnoses of what I feel, if that's what I've been asked "what do you think"? and you, and people don't always want to be put off "well I'm sorry, but I can't say that because it's not my role". I do actually give an opinion of what I think's going on and again I see that as quite important"*

*(5:240-245) "I try to give the educational side of things, because that's important in um, you know especially if somebody's got something like vascular dementia, um, and they're smoking and they're drinking still*

*and I think it's important to educate them, you know, and then they can make an informed decision about how they want to progress, so I do do that and I will give them um, the Alzheimer's books um, "I've got Dementia" and the fact sheets and things like that because if you had another disease you'd be told and you'd be informed so I don't see anything different about dementia"*

**Talking about dementia (for the first time) (10 participants)**

*(2:98-101) "it is very hard but I always feel that I need to bring to bring it up because it would feel so much worse if it hadn't been discussed at the beginning and then they have the assessment, they have got a diagnosis and then you're get, you're giving them this diagnosis"*

*(3:102-103) "a lot of the time, in my experience, I've found that's what people want to talk about, but they don't want to say it"*

*(6:59-60) "I would say, "well have you thought about what might the problems be", and very often people will say, "no", because they don't want to be the one to, to bring up the 'D' word"*

*(3:123) "It's a bad word isn't it, dementia?"*

*(7:101) "dirty work" (giving the diagnosis)*

*(7:192) "told that thing" (referring to being given a diagnosis of dementia)*

(3:247-248) *"You know, this is what somebody doesn't, they're asking you, but they really don't want to hear it, but you're telling them"*

**Letting people down/ being unable to help (10 participants)**

(7:48-51) *"sometimes it hard if the relatives start asking questions or if the client starts asking questions and obviously you can't start saying "oh I think you've got this, that or the other", you have to just try and say, "well, we'll do this assessment now and in a few weeks the Doctor will explain it to you a bit more""*

(10:135-139) *"you're in that person's home, you are that face of that service, you know, "you've asked me all these questions and you've rumbled all these emotions, now what are you going to do about it"? And that can be, I mean, "Oh dear", you feel quite terrible saying, "well I've got all this information, I'm going to take this away, 'cause I can't give you any answers yet", and I'm leaving this family in absolute bits, you know"*

(2:441-442) *"we've got a number of carers' groups and the Alzheimer's Society run them as well, but there's very little we provide for the person who, who has just been given a diagnosis"*

(8:404-408) *"you just feel as though you're just leaving people and you know, floating with, there's very little else you can do. So, it's not frustrating, 'cause there's nothing else I can do, but you just feel as*

*though you're not, you know, I wish there was more I could do, but you can't."*

### **Thinking about the future (8 participants)**

*(2:107-100) "it's horrible, um...but probably because, um, maybe I know more of what to expect having worked with people with varying degrees of dementia and working with their families as well, so maybe I'm carrying a lot of that kind of negative, um, experience of dementia, the, er, really difficult, um, side of it." (talking about giving diagnosis)*

*(7:361-362) "they're not going to be able to enjoy their life as they ever had and they are going to get very poorly"*

*(5:205-206) "you know, the, the people in the very, very advanced stages of dementia, I don't think anybody on earth would want to be like that, nobody"*

*(5:321-327) "because I know what could be coming and what could happen and you know I've worked in continuing care and things like that and I know what happens in the later stages, for some people, and that, the, the, there is a possibility that that might be that person one day"*

### **Dealing with distress and sadness (10 participants)**

*(2:105) "I hate doing it, I hate it" (giving a diagnosis)*



*(10:102-104) "you've got to be prepared for, I think sometimes when I first er qualified I was quite shocked really at people, I wasn't quite prepared for the, for peoples' emotions you know that are tied up with these things really"*

*(7:292-293) "that's hard as well really because if you've got someone who's very tearful and they realise what's going on and you know what their future is going to be like, that, that can be a bit upsetting"*

*(8:520) "we can't give them any hope really and that is, that, that is, that is difficult"*

*(7:367) "It's hard to keep positive sometimes"*

### **What I do Causes Distress (5 participants)**

*(9:37-42) "some of the questions that are actually on this Mini Mental, I get the feeling I'm asking them silly questions and they're probably feeling stupid 'cause they always seem to get in a mutter then or, you know, look down and start crying, I've had a lot of experiences like that, which isn't pleasant at all"*

*(9:446-455) "it's just seeing them in a terrible state, you just, things, it just makes you think that, 'why are you doing this job', you know you, you've just made that person cry by doing this test, that's really the down*

*side to it, I, I just think 'why am I sitting here doing this, should go out and work in a shop or something'"*

*(5:185-188) "I found that, you know, if you do something like the Mini Mental with them they feel that you're taking the mick out of them and it's a joke, you know, and become quite offended by it" (if deny they have memory problems)*

*(8:82-88) "when you're doing, when you're doing the testing and you can see the recognition on the client's face that they're not able to answer questions that they know are fairly simple straightforward questions and they get quite distressed by that that's, 'cause basically you get to the point where you just want to say "forget it, let's", you know, 'cause you can see that they're becoming distressed, but unfortunately from a lot of respects we have to finish it 'cause it's for their benefit but that's quite difficult."*

*(10:34-38) "sometimes people get "oh, why are you asking me these silly questions", you know, 'what's the day', 'what's the time' and er, you know 'what's the day, the season' and things like this, um, you know, 'what's a watch', um, you know, 'do you know this?' and it's a pencil and people can, and I can feel a bit um, you know, uncomfortable sometimes asking that"*

*(8:500-503) "to be perfectly honest, we don't want to put ourselves in that position, whereby we're asking people to fail to such an extent, 'cause it's just uncomfortable for everybody"*

### **Impact on Self and Coping**

#### **Self-containment and self-reflection (10 participants)**

*(1:309-314) "always at the back of your mind you've got, you're there because you're helping them make a decision about something really aren't you and, um, trying to support them, so there's no, you know and it's not going to do them any good if you're sitting there crying alongside them, it's not a help"*

*(9:440-443) "that can be a bit upsetting, but like I say, you've just got to try and do your best at it, try not to let it get to you, just carry on"*

*(9:369-375) "It can put you down, yeah, it can put you down um, but I try not to let it get to me, it's the best thing really isn't it? Just try and be a professional as you can about it" (when clients haven't got access to services that would help them)*

*(1:459) "I suppose, largely accept it as part of the job" (feelings of disappointment when someone does have a dementia)*

*(2:625-626) "you, to a degree, as an individual need to be able to be open and recognise issues"*

*(5:426-427) "if somebody's distressed you can find yourself becoming distressed, even if you might not show it because you've got to be professional"*

*(6:273-277) "I couldn't carry on doing my job without really, really, really sound clinical supervision (laughs) you know I just couldn't, it would be so un-professional and so un-safe and so un-safe for me as well 'cause I'd just be taking all this stuff home and things so I'm a real big campaigner of supervision"*

*(10:181-184) "having time for yourself to reflect, you know, within yourself, erm, giving yourself that time to reflect on er, how you were with that person, that family, could you have, if, if there was strong emotions that were coming through from that person, from yourself, er, how did I, how did I handle that and how would I in the future?"*

**Protecting self – professional and personal boundaries** (all participants)

*(1:491:500) "I suppose its just that I've taken time out to develop different hobbies, things that I enjoy, that are relax, well, that I find relaxing anyway, and that they're absorbing, it, it's...it's not just a job, you're not just do, you know, your whole life is not just doing a job, um, and I suppose at times when I've been doing this, it, sort of like, the job, you know, doing this job has been, taken over a bit, you know, get tired*

*and irritable after a while, and I suppose over time I've taken time out to make sure that it's not, and, and just put other things in place."*

*(7:369-370) "otherwise you get focused in what's going to happen to the clients and think 'well I can't do this job anymore'" (just go along with each day/ dealing with emotional impact on me)*

*(8:543) "I suppose we're quite well practised at detaching ourselves"*

*(3:328) "my attitude's always trying to be positive, stay on the positive side really"*

#### **Importance of peer support (9 participants)**

*(2:653-656) "I do think your staff team, the staff support though is really, really important, feeling comfortable with people that you work with, to be able to, I, you know, discuss impact of assessment, or whatever, working with people with, dementia"*

*(3:416-419) "you get a lot of input really from different angles it's quite, it's quite interesting – put the world to rights (laughs)... but it's nice 'cause you know you can bring something up, people will understand what you're saying"*

*(8:438-444) "I think it's beneficial working in a, in a, like if you were doing a memory clinic and there was just you doing the assessments and you*

*hadn't got your team around you, I think if you had times when you were dealing with people who were upset and stuff and you didn't have, you didn't have anywhere, anybody to, it's just nice to go out and say "oh, that was really, that was really sad", you know it's just nice to be able to talk, and I don't know whether if you didn't have that, whether it would make the job a bit harder"*

*(10:156-163) "I think that I'm fortunate to be in good teams with people that are very experienced, you know years of experience, far more than me, that, that, you know can er, you know, can talk to when you come in, informal supervision you know you come in, put your bag on the table and, "phew I've just been there and had all these", you know and even the most experienced nurses and therapists and things do that still, um, so you have that immediate you know, talk to"*

#### **Lack of formal support/ training (5 participants)**

*(2:170) "there's kind of expectations you just get on with it I suppose"*

*(2:485-492) AB "what do you think about staff in the service, do you think that they're kind of supported and cared for?"*

*I2 No, not at all, no, I really don't think so, I think that um, the only that would come would be perhaps through peer support, that's no kind of formal way, you know, there's nothing around training or anything, um, no, I think that's a really interesting question"*

(2:628-634) *"the Trust at the moment it's just, it just feels like it's a bit of a "get on with it" kind of state of play at the moment, regardless of, of what people are feeling, you just have to get on with it and do it, keep plodding on really. I think that is effecting moral, effecting people"*

(1:596) *"training is definitely lacking" (assessment and diagnosis of dementia)*

**Doing something positive – job satisfaction (6 participants)**

(3:235) *"it makes me feel like I've done my job" (giving a first possible diagnosis)*

(5:137) *"That's the bit I like is the bit using my, my um, my skills"*

(9:249-259) *"you get a sense of satisfaction that you're doing you're job right really, you know it's rewarding to actually put a smile on someone else's face even if, you know they've got problems and they're crying or what, and you're able to talk to them, but just, just seeing them smile's nice it's pleasant, good feeling yeah, it's rewarding that it just makes you think, you know, even if you're not enjoying that particular job, you know, carrying out those assessments, it's worth doing 'cause you're making someone else just to be a bit comfortable, yeah it's nice."*

*(8:54-56) "so we can sort of give people support regarding their memory difficulties and looking at ways that they can get into, feed into services in the community to help support them through those difficulties."*

*(10:307-308) "so we're saying, "we're not just going to leave you now, we're going to look at ways to help you and strategies to help""*

*(10:378-387) "the stage I worked with people at previously, people have worked through their loss they've, ah, people have worked with their feelings generally and it hasn't come as a huge shock because everyone has sort of braced themselves for it really um, so there's no huge surprises, still difficult to hear, but there's not, but at this stage that I'm working at now in the community setting people have only had sort of memory problems for a short while um, the working with those people and their feelings it's new to them and it's just like a shock, as, as professionally it's quite rewarding, because you can actually er, have some positive intervention erm, and you can see that intervention is assisting that person, whereas my role before is pretty much assessment and saying, "that person's not safe", or, you know, things like that"*



## **Conflict**

### **Individual Need Vs Service Limitations (8 participants)**

*(2:133-135) "sort of wanting to stay with them even longer but having to sort of go through the process of, it's an appointment and finishing and kind of moving on really." (after diagnosis)*

*(4:107-128) "I guess I've got a very strong view that, if somebody is able to give informed consent and they say they don't want to carry on with the process then that should be respected, that view isn't always shared, erm, between all professionals there's a more of a, I guess perhaps what I would call a paternalistic view about erm, well, "things are going to get worse anyway, so... you need to go through this, through this assessment", for want of a better way of describing it, so that can be a challenge as well, what to do when somebody says they don't want to carry on and how to communicate that to, erm, other professionals"*

*(2:309-316) "I think it's too easy to get into, um...a bit of a habit, or being overwhelmed and just by seeing so many people with memory problems that you actually forget what the impact is of having an assessment or a diagnosis, or coming here, or, you know, coming into mental health services, what that must be like for somebody. You kind of, you, it might be easy to get just soaked up into it that you forget to stand back and see it actually from the client's perspective"*

(7:431-432) *"it's not very quality time sometimes with these clients 'cause there's so many of them filtering through"*

### **Empathising while Protecting Myself (9 participants)**

(7:67-68) *"you do get used to it, unfortunately, I don't know whether that's a good thing or a bad thing"*

(6:169) *"I suppose to some extent it's easy to be a little bit blasé about it"*

(6:270-270) *"again that's where the clinical supervision comes in so I'm not kind of over empathic"*

(4:432-437) *"AB So for you there's a balance between, I suppose the importance of feeling but in a way that you're able to contain?"*

*I4 Yes, and feel um, as comfortable as I can with it"*

(9:231-233) *"I feel upset for them, but I try and remain professional at the same time you know, try not to get too emotionally involved or anything like that"*

### **Honesty Vs Causing Distress and Maintaining Hope (7 Participants)**

(8:256-259) *"you sort of don't want to say too much about later stages because, you know, they've got enough to cope with at the time and you don't really want to paint a really black picture, say "things are going to*

*get worse, they're going to get much worse and it's going to end up like this", you have to sort of let that progress naturally"*

*(8:616-620) "as much empathy as you've got, you've got with them, it's your job and there comes a point where it's what you have, that's what you have to do, regardless of the consequences, or how the person feels about it, you've got a professional responsibility and that's your job and you've got to do it" (having to be "up front" with people about their memory problems)*

*(10:286-291) "ultimately you've got to be truthful with people haven't you? You know, if they're asking you the questions and, it can be really difficult to tell people, you know and highlight, people say, "what sort of p, you know, 'cause obviously you work in this field, you work with people in different stages of dementia, you know, what sort of things do you see" and you've got to be truthful but then, you, you know, you're giving that person that information, you've got to expect, you know the, how that person's feeling"*

*(10:275-277) "I've had people actually say to me, "well, thank goodness I've not got Alzheimer's", 'cause they've been diagnosed with vascular dementia and they see it as, "oh thank goodness" and that can be quite difficult really um, about, oh, you know, it's quite similar, talking about the process and things"*

(8:286-288) *"although I know what's coming, not try to think about that with them"*