

PORTFOLIO INCLUDING THESIS

VOLUME 1 OF 2

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Making Sense of a Diagnosis of Alzheimer's Disease: Partners' Experiences

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People with dementia are PEOPLE with dementia and not people with DEMENTIA. Critically discuss how the emphasis in this statement might influence working with this group of people psychologically.

Introduction: limitations of a purely biomedical approach to dementia

'The sadness of Maria's state affected me greatly. When the doctor said categorically that there was virtually no likelihood of her recovering mentally, I wanted to howl. In my mind I would question God's justice, and at times I wondered if I was justified in spending so much time and effort on a lost cause.' (Bernard Heywood, describing his initial reaction to his friend Maria's diagnosis of Alzheimers Disease; Heywood, 1994)

'Dementia' is a medical category which describes a 'widespread loss of mental function including memory loss, language impairment, disorientation, change in personality (e.g. increased irritability, anxiety, social withdrawal, loss of skills and impaired judgment), self-neglect, and behaviour which is out of character' (Department of Health, 2001). From a public policy perspective, dementia is perceived as the modern epidemic of later life (Bond & Corner, 2001). Approximately 600,000 people in the UK have dementia, and this number is projected to double by 2050, largely as a result of more people living into older age (Department of Health, 2001).

Given the large numbers of people affected by dementia and the significant psychological and social challenges that they, their relatives, and friends face in adjusting and coping with dementia, it is somewhat surprising that health services and mainstream society frequently respond within the confines of the biomedical paradigm. People with dementia tend to be construed as a 'victims' who have suffered a personal tragedy and loss of 'normality' as a result of the disease process (Oliver, 1986) with a consequent preoccupation with diagnosis, medication, and the search for a pharmacological or genetic cure or prevention.

It has been suggested, from a psychodynamic perspective, that the failure to adequately respond to the psychological needs of people with dementia has arisen from a need to distance ourselves psychologically from people with dementia. Kitwood and Bredin (1992) argue that people turn to biomedical explanations of dementia as a way of constructing a sense of order and objectivity to conditions such as dementia which otherwise induce anxiety and dread of '*frailty, dependency, madness, ageing, dying and death*'. As a society we tend to respond to conditions such as dementia by stigmatising and disempowering people because of behaviours that clearly challenge social norms (Johnstone, 2000). The relative lack of understanding of the condition and how to respond has helped to keep people with dementia in a powerless and socially excluded position in society (e.g. Sabat, 2001; Goldsmith, 1996). As Lubinski (1991) writes, '*elderly individuals with dementia are among the most devalued members of our society, regardless of their lifelong characteristics and contributions [...] individuals who once fitted into the mainstream of society [...] become marginal members within their own families and even more so within the larger social framework*' (p142).

Biomedical research has increased our knowledge of neuropathological processes, and has in recent years led to the availability of acetylcholinesterase inhibitor drugs which have been shown to be effective in slowing the decline in cognitive functioning in many people with dementia (Morrissey & Coakley, 1999).

However, authors such as Tom Kitwood (e.g. Kitwood, 1996; 1997) have challenged the dominance of the biomedical paradigm on the basis that empirical evidence does not support its (implicit) assumption of a simple direct causal relationship between neuropathology and dementia,

(i.e. neurological damage → cognitive change → symptomatic behaviour)

and the lack of insight such a framework brings in terms of helping people adjust and cope with dementia.

Cotrell and Schulz (1993) point out that there is an immense variability in the presentation and prognosis of people with dementia, a variability that cannot be explained by an understanding of neurology alone. Kitwood (1989) estimates that as much as 80% of the variance in

presentation of people with moderate to severe dementia is left unexplained by the description of brain pathology in post-mortem data. He also cites evidence of 'catastrophic decline' in some people, which is too rapid to be accounted for by changes in brain pathology, and 'reminiscence', whereby some people have been observed to regain some of their supposedly 'lost faculties', such as communication skills or task competence.

Although considerable resources continue to be directed towards biomedical research, the reality of a prevention or cure remains a distant hope (Clare & Woods, 2001). A more realistic expectation is that the range and efficacy of drug treatments will increase over the years, in a manner analogous to developments within the cancer treatment field 20 years ago (Morrissey & Coakley, 1999). However, with or without meaningful medical breakthroughs in the medical treatment of dementia, there is a clear need to develop our ability to respond effectively to the needs of people living with dementia and ensure that their quality of life is paramount. The biomedical paradigm offers little in this respect beyond the management of symptoms and 'troublesome' behaviours (e.g. Cheston & Bender, 1999).

Working psychologically with people with dementia: understanding and responding to subjective experiences and psychological needs

'the likely effect of limited information about the subjective experience of the disease is that treatable distress and excess disability may go untreated, remaining abilities and psychological resources underutilised, and means of coping and adaptation unfacilitated'

(Kasl-Godley & Gatz, 2000)

The *disability* model, whereby an individual's and others' responses to impairment can lead to 'excess disability' (Brody, 1971), has been widely adopted as a framework through which we can develop our understanding of dementia beyond the confines of the *organic disease* model. As Sabat (2001) explains,

'How we view the sufferer – as a human being whose sense of self, whose dignity, dispositions, pride, and whose ability to understand the meaning of situations and to act meaningfully, remain intact to some degree, on the one hand, or as 'demented',

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defective, helpless, and confused patient on the other – will affect ways in which we treat that person, which will, in turn, affect how the person behaves' (pviii).

Rather than interpreting the array of thoughts, feelings, and behaviours expressed by someone with dementia as *symptoms of a disease*, psychological approaches emphasise the importance of understanding them as understandable reactions to the experience of cognitive difficulties and the reactions of others in the social environment.

Holden & Woods (1995) reflect that the current state of research on positive, person-centred approaches to working with people with dementia, is such that theories and practice tend to develop in relatively unconnected ways, with the focus being on whether an intervention works rather than why. In an attempt to bridge such a theory-practice divide, social psychologists such as Tom Kitwood and Steven Sabat have proposed theoretical models which emphasise the *personhood* of someone with dementia, and which they argue are consistent, coherent, and testable. Central to their conceptualisation of dementia is that 'personhood' exists within, rather than without the context of social relationships, and describes a status bestowed by one person on another.

Kitwood (1993) proposed a biopsychosocial '*dialectical framework*' which integrates the social and personal aspects of dementia with the findings of biomedical research. He argued that there are five key factors that contribute to the manifestation of dementia in any individual. These are summarised below (Figure 1).

Figure 1: Five key factors contributing to the manifestation of dementia (Kitwood, 1993)

**Dementia = Personality + Biography + Health +
Neurological Impairment + Social Psychology**

Kitwood argued that the *presentation* of dementia arises from the complex interaction between all five factors, whereas the *progression* of the dementia depends primarily on the dialectical interplay between *neurological impairment* and *social psychology*. Thus the level and

expression of functional disability are determined to a large extent by the responses of others to the person with dementia.

From a social constructionist perspective, there are aspects of the individual's experience of the self, which are presented socially and publicly, that can be lost as a result of the ways in which healthy others position the person with dementia (Sabat, 2001). Kitwood argues that generally, people with dementia do not have strong internal defences against anxiety, and are thus extremely susceptible to social-psychological processes. Through his research into critical incidents and structured observation in care settings, Kitwood delineated 17 ways of interacting that are extremely damaging to people with dementia. He termed these '*malignant social psychology*'. Examples include disempowerment, labelling, infantilisation, intimidation, stigmatisation, outpacing, invalidation of the person's subjective experience, ignoring, withholding attention, psychological or physical exclusion, blaming, and disparagement (Kitwood, 1997). He viewed these characteristic ways of interacting as part of our cultural heritage, rather than as a deliberate attempt to undermine people with dementia.

Personal accounts and carer accounts of the experience of dementia add strength to Kitwood's argument that people with dementia can be particularly sensitive to malignant social psychology. For example, Bond & Corner (2001) present a carer's account of the effect of malignant social psychology on her husband, who had a lifelong passion for running,

'... a very good friend actually, they've been running for years together, came out and saw him last year and said 'right Dennis, I'm still running...I'll come and pick you up and I'll take you and I'll bring you back, give us a ring if you want to go'. So, I says 'Do you want to go?' 'Yes'. So I rang and told him he wanted to go and he never rang back and that really, really upset him. I don't think he ever got over that yet [...] I think he's frightened of getting let down again, you know ... he's frightened to trust again'
(p110)

Woods (1996a) reflects that there is an assumption within the research literature that there is a strong link between staff attitudes, morale, job satisfaction and burnout and behavioural change, and hence quality of the care provided. However, these links have not been clearly

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established due to a lack of studies which include observations of staff behaviour in addition to staff self-report measures, which are clearly open to bias. Such an approach within the learning disability literature has demonstrated a strong link between staff attitudes, staff behaviour, and levels of challenging behaviour in residential settings - staff training has been shown to be effective in changing attitudes and staff behaviour, particularly when directed at specific situations (McBrien & Candy, 1999). It is important to establish effective means of facilitating positive social psychology, evaluating approaches such as training for formal and informal carers, structured person-centred care practices, staff and carer support, and clinical audit tools such as dementia care mapping.

Mills (1997) provides evidence to support the view that with cognitive decline comes a fragmented sense of self, as revealed through the narratives of people with dementia. In line with Kitwood's model, she argues that others' knowledge of the person's life story can assist in holding the person's sense of self. Woods (2001) suggests that creating a life story book provides a tangible reminder of important aspects of self and offers the opportunity for others to communicate to the person with dementia that they remain valued and worthy of attention and interest.

Research by Thorne (2002) and Morgan & Woods (2002) found that interventions in which they developed life story books with people with mild-moderate dementia was often highly valued by their clients and carers. However, they found that some people with dementia reported finding the process cognitively too challenging or emotionally painful. Carers tended to report that such work facilitated the development of more close and supportive relationships with the person with dementia. Research by Coleman (1986) demonstrated wide differences between people with dementia in their attitudes to reminiscence, from valuing it highly to viewing it as intrusive. Such research reinforces the need for a person-centred approach, considering individual personalities and preferences, when offering therapeutic input. In the case of interventions such as developing life-story books, it would be helpful to evaluate whether it is the process or the finished product that is of most benefit to people with dementia. Could such books be developed with carers in several sessions rather than the far longer therapeutic programs (at least 12 sessions) described by the above authors? As Kasl-

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Godley & Gatz (2000) argue, research findings to date tend to demonstrate a convergence in outcomes and theoretical approaches, demonstrating the need to identify what it is about such programs that are of value to the individual.

Although there appears to be little formally documented evidence beyond residential or nursing care settings, it appears that malignant social psychology is also prevalent within the psychiatric services that people with dementia may come into contact with. For example, Cheston & Bender (1999) argue strongly that clinical psychologists are often guilty of malignant social psychology, particularly in their use of neuropsychological assessment procedures, which are often experienced as demeaning and by their nature reinforce people's sense of inadequacy. Authors such as Davies (1996) emphasise the importance of maintaining an awareness of the emotional impact of neurological assessments, whose results can be extremely helpful in terms of informing intervention strategies.

Woods (2001) argues that pre-diagnostic assessment counselling would be expected with other potentially devastating disorders, but is seldom offered prior to neuropsychological testing. One reason for this may be that diagnoses are often unclear and prognosis difficult to predict. Such uncertainty may also contribute to the fact that people with dementia are often not informed of their diagnosis. The (American) Alzheimers Association (2002) argues that it is a moral and legal right to be informed of one's diagnosis, so that people can begin the process of adjustment and planning for the future. In a study in which they interviewed 24 people with dementia about the impact and process of receiving a diagnosis, Wilkinson, Pratt, & Milne (2002) found that initial reactions included shock, fear, anger, depression but also relief and validation as the diagnosis gave them a sense of understanding reasons for their difficulties. Participants emphasised the importance of the need to be informed sensitively and to be offered follow-up sessions in which to explore the implications of the diagnosis and identify treatment and care options. Several participants described attempts to withhold diagnoses, for example *'I think it's an absolute disgrace, you should be told at the earliest moment [...] ignore it if you wish but it's your choice, it's not the doctor's choice, or the carer's choice'* (p37).

From their clinical observations, research into attachment behaviours (e.g. Miesen, 1992), and personal accounts of the experience of dementia, Bender & Wainwright (1998) present a model of how the ability of people with dementia to make sense of events affects their emotional, cognitive and behavioural responses to demands. They propose that, as the degree of neurological impairment increases, the way in which events are processed and responded to changes, with an increasing reliance on the non-verbal *safety system* as the ability to process and find meaning using the verbal/ conceptual *meaning system* deteriorates. Some of the more common emotional, cognitive, and behavioural responses are presented in figure 2 below.

Figure 2: Common psychological consequences of four levels of difficulty in processing events (adapted from Cheston & Bender, 1999)

State of information-processing system (increasing degree of neurological impairment)	Common effects on psychological functioning
1. General loss of information processing ability	<ul style="list-style-type: none"> - High levels of depression in many people as performance is compared to past functioning and found to be wanting - Decreased ability to empathise, which relies on complex information processing
2. Difficulty accessing the experiential and knowledge stores of the 'Meaning system' – loss of abstraction and richness of meaning abilities – increased triggering of safety system	<ul style="list-style-type: none"> - Uncertainty about sense of self - Loss of social self reported by others - Distorted perception of reality – bizarre explanations noted by others - Use of denial, blaming others, minimising as coping strategies - High levels of anxiety and insecurity resulting from over-dependence on safety system
3. Frequent triggering of safety system as meaning system extremely damaged (inability to draw on past experiences and knowledge)	<ul style="list-style-type: none"> - high levels of anxiety result from triggering of safety system - inattention, restlessness - behaviours such as wandering, repeated questioning, aggression to cope with anxiety - clinging to 'bizarre' explanations that offer reassurance - past memories of threat activated and applied to current situation (e.g. leading to accusations of physical or sexual abuse)
4. Loss of recognition subsystem of safety system	<ul style="list-style-type: none"> - low anxiety - high dependency on others - need for others to monitor and maintain safety

Cheston & Bender (1996) map out some of the negative feelings, emotions and burnt out states that are often experienced by people, particularly in the early stages of a dementing

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illness (figure 3). Research indicates that high levels of anxiety and depression (e.g. Reifler & Larson, 1990; Ballard et al, 1996) are experienced by people with dementia, leading to 'excess disability' which often goes untreated (Bird, 2000).

Figure 3: common negative experiences of the person with dementia (adapted from Cheston & Bender, 1996)

Feelings	Global states	'Burnt-out' states
Fears of abandonment, of being controlled, of humiliation	TERROR	DESPAIR
Sense of weirdness, of being imprisoned, of being excluded, of persecution		DEPRESSION
Panic	MISERY	VEGETATION
Grief		EXHAUSTION
Frustration at deficits and loss of abilities	RAGE	APATHY
Sadness at loss of familiar life		
Anxiety about being a burden	CHAOS	
Anger at dementia, at others reactions		
Feeling useless, worthless, bewildered		

There appears to be little research into the psychological treatment of depression and anxiety in people with dementia despite the high prevalence rates suggested by the above studies. Several case studies suggest that cognitive-behavioural therapy can successfully be adapted to help people in the early stages of dementia (e.g. Teri, 1996; Teri & Gallagher-Thompson, 1991). A greater body of research within the learning disability literature also supports the view that CBT can be successfully adapted when working with people cognitive impairments on difficulties such as anxiety, depression, anger management (Stenfert-Kroese, Dagnan & Loumidis, 1997).

If clinical psychologists are to take a truly person-centred approach to working with people with dementia, it is essential that researchers are committed to understanding experiences, meanings, intentions, and behaviours from the perspective of the person with dementia. Although the nature of undertaking research invariably means that participants' accounts cannot be truly independent of the interpretation that researchers place on those accounts (Bond & Corner, 2001), phenomenological approaches seem particularly suited to helping us develop an understanding of the experiences rather than the progression of dementia.

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Using such an approach, Clare (2002) conducted in-depth semi-structured interviews with 12 people with early onset Alzheimers Disease and used Interpretative Phenomenological Analytic techniques (Smith et al, 1997) to understand how people naturally attempt to cope with and adapt to the onset of dementia. She interviewed the respondents twice and also triangulated this data with interviews with partners as a means of increasing the reliability and validity of her data. She found that the majority of respondents attempted to cope with the onset of dementia using strategies that could be characterised as *self-protective*. This could involve attempts to hold on (e.g. by trying harder, sticking to previously held routines, using medication, or hoping for a cure) or compensate for emerging cognitive difficulties (e.g. by relying on their partner for tasks they could no longer manage or using memory aids and strategies). At the other end of the continuum, Clare found that some people attempted to cope using *integrative* responses. These could include developing a fighting spirit (e.g. I'll fight it as long as I can, gaining more information, talking about it, being useful, and focussing on the positives) or attempting to come to terms with it (e.g. balancing hope and despair, acceptance).

Clare's findings reflect those of Keady & Nolan (1995), who found that people's accounts of dementia included emotional reactions such as fear, anger and frustration, and a tendency to try to cover up their difficulties in order to protect themselves and their families using strategies such as denial, adaptive paranoia, confabulation, disinclination to go out, avoidance of others, and self-centredness. However the authors also reported being struck by the degree of acceptance and positive coping presented in the participants' accounts.

Although there is a lack of published evidence within the sphere of dementia research, there is a substantial body of research on the relationship between coping and adjustment to chronic illness. This indicates that denial or avoidance are common reactions to diagnosis, and that in the short term these can serve a protective function. However, in the longer term, denial tends to lead to poorer outcomes, one contributory factor being that the patient fails to monitor their health adequately (Edelmann, 2000). There is also evidence within the health psychology literature that emotion-focussed coping is negatively related to adjustment whereas problem-

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focussed coping is related to positive adjustment (Edelmann, 2000). It seems important that similar research questions are addressed with people with dementia, whose condition could be viewed as analagous but brings its own specific challenges to the individual and those around them. Such research could usefully guide the interventions that are offered to people with dementia to assist their ongoing coping and adjustment.

Therapeutic approaches to working directly with individuals, or groups of people in the early stages of dementia can be broadly categorised into approaches which aim to enhance and maximise the individual's cognitive functioning, and approaches which aim to enhance the individual's ability to cope with the emotional demands of living with dementia. Clare (2002) argues that, as people's needs and preferred coping strategies differ widely, that psychological interventions should be selected and adapted according to individual need rather than taking a prescriptive approach.

There is evidence that cognitive rehabilitation strategies such as reality orientation, the use of external memory aids, spaced retrieval, self-generated cues and strategies to improve encoding of information can lead to improvements in everyday functioning and limited improvements in ability to recall information (Clare & Woods, 2001). However, introducing such strategies is an intensive and effortful process with outcomes that tend not to generalise (Clare & Wilson, 1997; Woods, 1996b). Thus it is important that such strategies are directed towards the achievement of personally relevant and important goals.

According to Cheston & Bender's model (Figure 2), as cognitive abilities decline, people with dementia experience an increasing sense of loss of self which tends to be reinforced by others around them. As outlined earlier, there is some evidence to suggest that reminiscence and life story work can have therapeutic value in terms of helping carers to reinforce the person's sense of self and initiate more positive interactions

Discovering the inner, subjective experiences of people who lack insight or the ability to communicate insight adequately, is an important challenge for clinical psychology. As Stokes (2000; pp60) emphasises, *'just because the person loses insight, do not lose sight of the*

person'. Stokes argues that much of the challenging behaviour seen in the later stages of dementia is a result of poorly communicated need. He argues that it is essential to bear in mind fundamental psychological needs such as the need for safety, sociability, curiosity, and activity. Understanding that a person with dementia continues to have such fundamental human needs can lead to an understanding of the motivation for behaviours that can often appear bizarre and otherwise be interpreted as annoying or meaningless 'symptoms'.

Stokes (1996, cited in Stokes 2000) presents a case study of a man in the later stages of dementia, Mr D, who seemed intent on destroying the house and garden that he had once loved. Everyday Mr D was observed to go into the garden, dig up the flowerbeds and wheelbarrow as much soil as he could onto the lawn or into the house, where he would empty the contents, separating the soil from the rocks and stones. After separating these he would return the soil to the garden but keep the rocks and stones in the garage. Consequently the house became damp and dirty and his wife was finding it extremely difficult to cope with the situation. The response of services was to view this behaviour as a symptom of dementia and thus the recommendations were for sedation and/ or a move to residential accommodation. However, conversation with Mr D's wife, and attempting to take the perspective of Mr D, led to the conclusion that the behaviour was a means of Mr D meeting a psychological need for safety which was triggered by lasting memories of a personally traumatic time in the past when a gang of adolescents had thrown masonry through his shop window. Although Stokes reports that the behaviour remained unchanged, Mr D's wife became more tolerant and able to cope with her husband's behaviour.

The research literature contains several other such case examples of how treating a person with dementia as a PERSON can dramatically alter the course of their life, and opens up the options when considering how best to ensure a quality of life (Stokes, 2000). Attempting to understand the subjective experiences of people with dementia can be facilitated through a clear theoretical framework, sensitive research strategies, and taking the time to listen to the voices of people with dementia (Goldsmith, 1996).

The need for an integrated approach to helping people adapt and cope with dementia

The inter-relationship of cognitive, behavioural and emotional aspects of the person with dementia is complex and has received limited attention within the literature. Woods (2001) argues that it is essential to take an integrated approach, which allows the possibility that emotional responses are affecting cognitive functioning or are the root of challenging behaviour, for example. There is increasing recognition that people with dementia can benefit from direct psychological interventions to assist them in adapting to life with dementia, rather than indirectly through resources directed solely towards supporting carers .

Clare & Woods (2001) argue that psychological interventions should be offered within a biopsychosocial rehabilitation framework, with the aim of assisting people with disabilities to actively engage in maximising their functioning across a whole range of areas including physical health, psychological well-being, living skills, and social relationships. As Kitwood's model (Fig.1) indicates, these are all areas that interact to influence the course of the dementing illness. *Individual Programme Planning* (Woods & Britton, 1985) or *Goal Planning* (Barrowdough & Fleming, 1986), are examples of formalised approaches that have been shown to be partially effective in achieving these aims. Although the necessity of such an integrated approach is emphasised within the research literature, there has been a lack of (published) evaluations of such an approach.

In one such study, Romero & Wenz (2001) evaluated a four-week intensive residential treatment programme in Germany for 43 people with mild to severe Alzheimers Disease (median and mean MMSE score =14/30) and their relative-caregivers. The individualised, multidisciplinary rehabilitation programme incorporated: diagnosis and medical treatment for somatic, cognitive and psychopathological problems; training in the use of external memory aids; interventions aimed at maintaining the sense of self, such as psychotherapeutic support, systematic reminiscence (self-maintenance), validation therapy, art therapy, and the facilitation of satisfying everyday activities. The programme also offered psychotherapeutic and social support to caregivers with the aim of improving their resources for relating in a positive way with their relative.

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The programme was evaluated pre- and immediately post-intervention in terms of its aims, namely, to reduce patients' loss of confidence in social interaction, to reduce psychopathological symptoms such as depression, apathy, agitation and aggression, to facilitate participation in everyday life, and to improve caregivers psychological and practical resources for supporting the person with dementia. Moderate to large effect sizes were reported on measures of depression (Cornell Depression Scale, Alexopoulos, Abrams, Young & Shamoian, 1988), other psychopathological symptoms (Behaviour Rating Scale for Dementia, Tariot et al, 1995), and social behaviour (Nurses Observation Scale for Geriatric Patients, Spiegel et al, 1991). No significant change was observed in terms of memory and functional abilities using the above instruments. There was a significant reduction in caregiver depression - it is noteworthy that 48% of the sample had high levels of depression pre-compared with 15% post-intervention.

Due to the lack of a control group, it is unclear to what degree people's functioning improved for non-specific reasons such as attention, contact with others with similar difficulties, or relief from many of the stressful aspects of caring. In keeping with much of the published research with people with dementia, the outcomes for the person with dementia were based on caregiver and staff reports, and no attempt was made to formally document the experiences of the participants with dementia. As no formal observation was done by independent researchers, it is difficult to establish whether improvements in caregivers' own psychological wellbeing, their expectations, their desire to provide positive feedback, or to have felt that they were doing something helpful for their relative influenced their reports. It is also unclear how staff and relative reports reflected the subjective experiences of the person with dementia.

Challenges to a more person-focussed approach to working with people with dementia

'Simply knowing the person has dementia is remarkably uninformative in the face of such diversity, which demands an individualised response' (Woods, 1996;p577)

Key to working in a person-focussed way with people with dementia is the need to gain insight into the individual's subjective experiences and psychosocial needs. Theoretical frameworks such as that proposed by Kitwood (1996, see Figure 1) can helpfully guide the psychological assessment process. Various psychological intervention approaches have been discussed, with the emphasis that these should be offered according to the priorities, personality, and resources of the individual. As Clare (2002) emphasises, psychology services need to be flexible as people's needs change over time according to the difficulties they face, suggesting that there is a need for services to maintain an ongoing relationship with people with dementia.

Goldsmith (1996) reflects that there is a paucity of 'consumer-oriented' research within the dementia field as carers have traditionally been regarded by researchers as the 'consumer', rather than the person with dementia. He argues that, although the focus is slowly shifting, very little is known about the subjective experiences of people with dementia. There are clearly difficulties associated with establishing subjective experiences of people with dementia. The nature of cognitive impairment tends to result in difficulties communicating experience or lacking insight, and it is difficult to distinguish public and private accounts. However, Bond & Corner (2001) argue that it is weaknesses in dominant methodological approaches and a lack of theoretical rigour in health services research that mitigates against developing such an understanding, rather than any unique methodological challenges posed by work with people with dementia. They argue for a move away from positivist biomedical approach to more phenomenological approaches. Person-centred psychological interventions require person-centred evaluations, using outcomes of importance to people with dementia such as satisfaction or person-centred quality of life measures (e.g. Bond, 1999).

Although it is likely that medical advances will facilitate more optimistic and helpful social attitudes towards people with dementia, as has been the case with chronic illnesses such as

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cancer (e.g. Zeisel & Raia, 2000), Stirling (1996) argues that clinical psychologists should be proactively involved in deconstructing negative models of dementia and promoting more person-centred, coping focussed alternatives.

In a comparison of services for people with dementia in the UK and the Netherlands, Jones (2002) draws attention to the fragmented nature of services in the UK. She describes how clinical psychologists have been at the forefront of the 'Alzheimers café' movement in the Netherlands. Such café's have been developed in prominent places in the community and act as a place where people with dementia can access health, social, and voluntary services as well as have social contact with other people with dementia, their relatives and members of the local community. Jones reports that these projects have been immensely popular amongst people with dementia, and can be seen as a way of promoting positive social psychology and a person-centred approach to helping people actively adapt to and cope with some of cognitive and emotional demands of having a dementing illness. Adopting such a biopsychosocial framework which values the PERSON with dementia seems crucial in order to facilitate an improved quality of life and ability to cope with the challenges faced by people with dementia and their carers.

References

Alzheimers Association (2002): www.alz.org/PhysCare/Diagnose/disclosures.htm

Ballard,C., Boyle,A., Bowler,C., & Lindesay,J. (1996). Anxiety disorders in dementia sufferers. *International Journal of Geriatric Psychiatry*, 11, 987-990.

Barrowclough,C. & Fleming,I. (1986). Training direct care staff in goal planning with elderly people. *Behavioural Psychotherapy*, 14, 192-209.

Bird, M. (2000). Psychosocial rehabilitation for problems arising from cognitive deficits in dementia. In R.D.Hill, L.Bäckman & A.Stigsdotter Neely (eds), *Cognitive Rehabilitation in Old Age*, (pp249-269). Oxford: Oxford University Press.

Bond, J. (1999). Quality of life for people with dementia: approaches to the challenge of measurement. *Ageing & Society*, 19, 561-79.

Bond,J. & Corner,L. (2001). Researching dementia: are there unique methodological challenges for health services research? *Ageing & Society*, 21, 95-116.

Brody, E. (1971). Excess disabilities of mentally impaired aged: impact of individualised treatment. *Gerontologist*, 25, 124-33.

Carr,A. (2002). *The day to day lives of people with dementia – an insiders view*. Paper presented at the Annual Conference of the Psychologist's Special Interest Group in the Elderly, Winchester, July.

Cheston,R. & Bender,M. (1999). *Understanding Dementia: The Man with Worried Eyes*. London: Jessica Kingsley Publishers.

Clare,L. (2002). We'll fight it as long as we can: coping with the onset of Alzheimer's disease. *Aging & Mental Health*, 6 (2), 139-148.

Clare,L. & Wilson,B.A. (1997). *Coping with Memory Problems – A Practical Guide for People with Memory Impairments, their Relatives, Friends and Carers*. Thames Valley Test Company.

Clare,L. & Woods,B. (2001). Editorial: a role for cognitive rehabilitation in dementia care. *Neuropsychological Rehabilitation*, 11 (3/4), 193-6.

Coleman,P,G. (1986). *Ageing and Reminiscence Processes – Social and Clinical Implications*. Chichester: Wiley.

Cotrell,V. & Schulz,R. (1993). The perspective of the person with Alzheimer's Disease: a neglected dimension of dementia research. *Gerontologist*, 33(2), 205-211.

Roland Casson. University of Hertfordshire DClinPsy. Year 1 essay.

People with dementia are PEOPLE with dementia and not people with DEMENTIA. Critically discuss how the emphasis in this statement might influence working with this group of people psychologically.

Davies,S. (1996). Neuropsychological assessment of the older person. In R.T.Woods (ed.), *Handbook of the Clinical Psychology of Ageing*, (pp389-422). Chichester: Wiley.

Department of Health (2001). *National Service Framework for Older People*. Government Policy Document, DoH March 2001.

Edelmann,R.J. (2000). *Psychosocial Aspects of the Health Care Process*. Harlow: Pearson Education.

Goldsmith,M. (1996). *Hearing the Voice of People with Dementia: Opportunities and Obstacles*. London: Jessica Kingsley.

Heywood, B. (1994). *Caring for Maria: an experience of successfully coping with Alzheimer's Disease*. Shaftesbury: Element.

Holden,U. & Woods,R.T. (1995). *Positive Approaches to Dementia Care*. Edinburgh: Churchill Livingstone.

Johnstone, L. (2000). *Users and Abusers of Psychiatry*. London: Routledge.

Jones,G. (2002). *A Dutch perspective on British Clinical Psychology*. Presentation at the Annual Conference of the Psychologist's Special Interest Group in the Elderly, Winchester, July.

Kasl-Godley,J. & Gatz,M. (2000). Psychosocial interventions for individuals with dementia: an integration of theory, therapy, and a clinical understanding of dementia. *Clinical Psychology Review*, 20 (6), 755-782.

Keady,J. & Nolan,M. (1995). IMMEL: assessing coping responses in the early stages of dementia. *British Journal of Nursing*, 4(6), 309-14.

Kitwood,T. (1993). Towards a theory of dementia care: the interpersonal process. *Ageing & Society*, 13, 51-67.

Kitwood,T. (1989). Brain, mind & dementia: with particular reference to Alzheimers Disease. *Ageing & Society*, 9, 1-15.

Kitwood, T. (1996). A dialectical framework for dementia. In R.T.Woods (ed.), *Handbook of the Clinical Psychology of Ageing*, (pp267-282). Chichester: Wiley.

Kitwood,T. (1997). *Dementia Reconsidered*. Buckingham: Open University Press.

Kitwood,T. & Bredin,K. (1992). Towards a theory of dementia care: personhood and wellbeing. *Ageing & Society*, 12, 269-287.

Lubinski,R. (1991). *Dementia and Communication*. London: Decker.

Roland Casson. University of Hertfordshire DClinPsy. Year 1 essay.

People with dementia are PEOPLE with dementia and not people with DEMENTIA. Critically discuss how the emphasis in this statement might influence working with this group of people psychologically.

- McBrien, J. & Candy, S. (1999). Working with organisations, or: why won't they follow my advice? In E. Emerson, C. Hatton, J. Bromley & A. Caine (eds.), *Clinical Psychology and People with Intellectual Difficulties*, (pp 265-279). Chichester: Wiley.
- Miesen, B. (1992). Attachment theory and dementia. In G. Jones & B. Miesen (eds), *Care Giving in Dementia: Research and Applications*. London: Routledge.
- Mills, M.A. (1997). Narrative identity and dementia: a study of emotion and narrative in older people with dementia. *Ageing & Society*, 17, 673-698.
- Morgan, S. & Woods, R.T. (2002). *Life Review with People with Dementia: a Randomised Control Study*. Paper presented at the Annual Conference of the Psychologist's Special Interest Group in the Elderly, Winchester, July.
- Morrissey, M.V. & Coakley, A.L. (1999). *Alzheimer's Disease: Beyond the Medical Model*. Salisbury: Mark Allen Publishing.
- Oliver, M. (1986). Social policy and disability: some theoretical issues. *Disability, Handicap and Society*, 1(1), 5-18.
- Reifler, B.V. & Larson, E. (1990). Excess disability in dementia of the Alzheimer's type. In E. Light & B.D. Lebowitz (eds), *Alzheimer's Disease Treatment and Family Stress* (pp363-382). New York: Hemisphere.
- Romero, B. & Wenz, M. (2001). Self-maintenance therapy in Alzheimer's Disease. *Neuropsychological Rehabilitation*, 11(3/4), 333-356.
- Sabat, S.R. (2001). *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*. Oxford: Blackwell.
- Smith, J.A., Flowers, P., & Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. In L. Yardley (ed), *Material Discourses of Health and Illness* (pp68-91). London: Routledge.
- Stenfert-Kroese, B., Dagnan, D., & Loumidis, K. (1997). *Cognitive-Behavioural Therapy for People with Learning Disabilities*. London: Routledge.
- Stirling, E. (1996). Social Role Valorisation: making a difference to the lives of older people? In R.T. Woods (ed.), *Handbook of the Clinical Psychology of Ageing*, (pp389-422). Chichester: Wiley.
- Stokes, G. (2000). *Challenging Behaviour in Dementia – a Person Centred Approach*. Winslow Press.

Roland Casson. University of Hertfordshire DCLinPsy. Year 1 essay.

People with dementia are PEOPLE with dementia and not people with DEMENTIA. Critically discuss how the emphasis in this statement might influence working with this group of people psychologically

Teri, L. (1996). Depression in Alzheimer's Disease. In M. Hersen & V. B. Van Hasselt (eds), *Psychological Treatment of Older Adults: an Introductory Text*, (pp209-222). Plenum.

Teri, L. & Gallagher-Thompson, D. (1991). Cognitive behavioural intervention for treatment of depression in Alzheimer's patients. *Gerontologist*, 31(3), 413-6.

Thorne, K. (2002). *The North Wiltshire life story project*. Paper presented at the Annual Conference of the Psychologist's Special Interest Group in the Elderly, Winchester, July.

Wilkinson, H., Pratt, R. & Milne, A. (2002). Do people with dementia want to know their diagnosis? *Signpost*, 6(3), 36-37.

Woods, R.T. (1996a). Institutional care. In R.T. Woods (ed.), *Handbook of the Clinical Psychology of Ageing*, (pp369-388). Chichester: Wiley.

Woods, R.T. (1996b). Psychological "therapies" in dementia. In R.T. Woods (ed.), *Handbook of the Clinical Psychology of Ageing*, (pp575-600). Chichester: Wiley.

Woods, R.T. (2001). Discovering the person with Alzheimer's Disease: cognitive, emotional, and behavioural aspects. *Aging & Mental Health*, 5 (Supplement 1), S7-S16.

Woods, R.T. & Britton, P.G. (1985). *Clinical Psychology with the Elderly*. London: Chapman & Hall.

Zeisel, J. & Raia, P. (2000). Nonpharmacological treatment for Alzheimer's Disease: a mind-brain approach. *American Journal of Alzheimer's Disease*, 15 (6), 331-340.

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**Critically discuss the concept of challenging
behaviour and the role of the clinical
psychologist in assisting with this**

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Introduction

'The psychologist as plumber: The plumber comes when called, equipped with a range of useful skills. This means appreciating that clinical psychologists working in complex organisational structures with vulnerable, devalued people are only needed if the skills they offer, the way they offer them and their ability and commitment to their work with a range of ordinary, down-to-earth people, dealing with some of the most intransigent problems in individuals, staff teams and organisations, are of the highest order.' (Clements & Rapley, 1996, cited in McBrien & Candy, 1998, p279) .

Putting any cynicism about whether this is really what plumbers do aside, Clements & Rapley (1996) contrast the above '*psychologist as plumber*' model with the '*affluent, exotic and irrelevant*' position that many clinical psychologists are seen to occupy. The focus of the essay will be on psychological work with adults with severe or profound learning disabilities. The aim is to consider the skills, knowledge and understanding that clinical psychologists can bring to work with this client group. The focus of the essay reflects the author's interest in understanding what constitutes effective consultation work as well as current experience of starting a placement in a specialist service for adults with severe learning disabilities and challenging behaviour.

Following a critical discussion of the concept of '*challenging behaviour*', some of the theoretical concepts available to understand and respond to such behaviours, and what the clinical psychologist has to offer in terms of such work will be considered. The influence of the evidence-based practice paradigm on such work will also be discussed.

What is 'challenging behaviour'?

Emerson and colleagues' (1988) definition of challenging behaviour dominates texts relating to challenging behaviour and people with learning disabilities. They define '*challenging behaviour*' as

'culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to and use of ordinary community facilities' (cited in Emerson, 1995; p4)

In a survey of services experiencing serious management problems in supporting someone with a severe learning disability, Emerson et al (1997) identified the following behaviours (Table 1) in 393 people in North-West England. Specific risk factors include being male, being between the age of 15-35, having a more severe learning disability, having additional sensory impairments, reduced mobility or specific communication impairment, and having autism (Emerson, 1998). Estimates of prevalence vary widely, from 30-60% of the population of people with severe learning disabilities, largely due to the wide range of definitions of the term by different researchers (Jones & Eayrs, 1993).

Table 1: Prevalence of specific forms of challenging behaviour among 393 people with learning disabilities (Emerson et al, 1997; cited in Emerson, 1998)

Behaviour	Shown by (%)	Behaviour	Shown by (%)
Non-compliance	54	Pulling others' hair	15
Hitting others	46	Biting self	14
Outbursts of temper	45	Pinching others	14
Repetitive 'pestering'	39	Hitting own body with hand	12
Destructive behaviours	35	Biting others	12
Verbal aggression	34	Scratching self	9
Repetitive screaming	28	Stripping in public	9
Over-activity	27	Hitting own body with objects	8
Hitting others with objects	24	Smearing faeces	7
Meanness/ cruelty	22	Eating inedible objects	7
Running away	21	Pinching self	7
Inappropriate sexual behaviour	18	Stuffing fingers in body openings	5
Hitting own head with hand	17	Excessive drinking	4
Hitting own head against objects	17	Pulling own hair	4
Scratching others	16	Regurgitating food	4
Theft	16	Teeth grinding	3

Kieman (1993) argues that, as '*challenging behaviour*' is socially constructed, it represents a totally heterogeneous category. '*Challenging behaviours*' range in terms of intensity, frequency, and chronicity, and describe the behaviours of people with profound to borderline learning disability. He argues that using a single term to describe such a broad range of problems makes it difficult to conceptualise using a singular theoretical framework. Emerson et al's (1997) survey does define behaviours explicitly. However, these behaviours would not necessarily be defined by people supporting the person as '*challenging*'. There is research evidence that behaviours that are seen as predictable, or not involving risk to others (e.g. self-injurious behaviour) are less readily defined by carers as '*challenging*' (Allen, 1999), and that behaviour which does not fit cultural stereotypes (e.g. violence by women) is more readily identified as a problem (Clements et al, 1995).

Parker et al (1995) argue that the identification and categorisation of problems is dependent on, if not created within language. The use of *'challenging behaviour'* to replace terms such as *'aberrant'*, *'disordered'*, *'disturbed'*, *'problem'*, *'dysfunctional'* has been adopted to encourage the reframing of *'problems'* as *'challenges to services'*. One of the logical consequences should therefore be that behaviour is relocated from an intra-personal to an interpersonal level, thus paving the way for a more contextually based understanding of problems. However, as Parker et al (1995) argue, notions such as *'challenging behaviour'* tend to be defined very vaguely within a cultural context, and don't necessarily represent the intended meaning to all who use them. Hastings and Remington (1993), for example, argue that services designed for *'people with learning disabilities and challenging behaviour'* fall into the trap of describing behaviour as a trait. They suggest that, paradoxically, the label is likely to restrict access to the community, and leave the individual with a long-lasting negatively-evaluated label.

Another implication of using *'challenging behaviour'* as a diagnosis is that it is used to justify the use of pharmacological approaches to control behaviour. In particular, antipsychotic medication tends to be used for its non-specific effects (Kiernan, 1993). In a survey of 500 people with learning disabilities living in residential accommodation, Robertson et al (2000) found extremely high rates of receipt of antipsychotic medication (56% in NHS residential campuses, and 27% in community based dispersed housing). This was in comparison with receipt of antidepressant medication in line with predicted rates of depression in the population. The results are in line with similar studies, which suggest that a label of challenging behaviour is associated with the use of medication to control, or 'treat' the behaviour. In addition to obvious concerns about the individual's human rights and consent issues (e.g. Arscott et al, 1999), the use of antipsychotic medication has been criticised on the grounds that there is little evidence to support its effectiveness in controlling behaviour, and the number of associated side effects (e.g. sedation, blurred vision, nausea, dizziness, weight gain, extra pyramidal side effects, and even death).

Parker et al (1995) argue that *'discourses of difference'* have historically served to regulate certain sectors of society in order to serve the interests of more powerful institutions. McBrien & Candy (1998) warn against taking the term *'challenging behaviour'* at face value as it may be used to meet a number of other hidden agendas, such as removing a disliked person from a service on the basis that they are unmanageable. There is considerable evidence that *'challenging behaviour'* is associated with placement breakdown (Emerson, 1998). On a more positive note, the label may be used for more positive reasons, such as gaining additional resources for someone whose needs are not being met.

Theorists such as Lacan (1977) have stressed the importance of considering the effect of culture on identity. People with severe and profound learning disabilities have been exposed to many shifts in societal responses to them over the years, from segregation to protection to education and treatment (e.g. Caine et al, 1998). After three decades of 'normalisation' principles dominating policy towards people with learning disabilities, a new agenda of 'inclusion' has emerged, as reflected in the recent government white paper (Department of Health, 2001). These shifts are likely to have been experienced at least in terms of the attitudes and behaviours of carers towards them, and the tasks that they are expected to do.

Rapley et al (1998) argue that one of the legacies of normalisation is that it is expected that people with learning disabilities will live an 'ordinary life' through attempting (or others attempting on their behalf) to conform and be invisible. Thus the tendency to isolate people whose '*challenging behaviour*' does not fit social norms (e.g. displaying unusual mannerisms, or behaving in a 'childish' manner). Culham & Nind (2003) argue that such attempts to eradicate visible difference is at odds with the types of empowerment strategies used by other devalued groups (e.g. ethnic minorities, women, gay, physically disabled) who tend to highlight difference and openly congregate. They argue that carers often see helping people with learning disabilities to gain social acceptance through hiding difference as a key duty which is carried out for the long-term good of the individual and people with a learning disability as a whole. The social inclusion movement, which views inclusion as a basic human right rather than as a privilege, could be seen as a challenge to this approach, as it relocates at least some of the responsibility for acceptance on society rather than the person with the learning disability. However, as Berry (2003) argues, people with learning disabilities are usually not afforded the choice of living on the margins of society rather than having to conform to some culturally determined norm.

A further issue relating to power is that the term '*challenging behaviour*' could be seen to place the individual with learning disabilities in a position whereby their interests are promoted at the expense of those of their carers. People with learning disabilities are often not seen as morally responsible for their behaviour, which tends to lead to carers tolerating challenging behaviour and becoming 'burnt out' (Kiernan, 1993). Of course, the assumption that people with learning disabilities lack moral awareness may also lead to paternalistic behaviours on the part of carers.

The argument so far has focussed more on where the boundaries of '*challenging behaviour*' lie, and how the use of the term is determined largely by the social and political context in which people with learning disabilities live. It could be argued that the use of the term '*challenging behaviour*' changes as

organisational and staff cultures evolve. Various alternative terminologies have been suggested in order to clarify these fuzzy boundaries. For example, Ephraim (1998) suggests the term '*exotic communication*' in order to encourage carers to see behaviour in terms of communication. Dockrell et al (1992) argue that 'challenging behaviour' encapsulates two distinct sets of behaviours – those which are '*dangerous*', and those that represent '*problems*' for carers (e.g. pestering, tantrums, verbal abuse). Although the use of language to reframe problems is an important consideration, a clear theoretical framework is also necessary in order to effectively understand and respond to people with '*challenging behaviour*'.

Theoretical framework

Behavioural approaches dominate assessment and intervention work with people with learning disabilities and challenging behaviour. Constructional approaches, which seek to use non-aversive contingencies to develop new behaviours and maintain existing positive behaviours, tend to be favoured above more traditional behavioural approaches which attempt solely to suppress or eliminate challenging behaviours. Several multi-component packages exist (e.g. LaVigna & Donellan, 1986; Zarkowska & Clements, 1994; Emerson, 1995) which emphasise the need for an in-depth functional analysis, attempting to identify immediate and broader ecological variables that affect a particular behaviour. Once the function of a behaviour has been identified (e.g. escape, reward, sensory stimulation, attention), intervention tends to consist of the development of a both proactive and reactive strategies to manage the behaviour. Proactive strategies aim to help the person develop more positive ways of communicating their needs and develop a repertoire of alternative but functionally equivalent skills. Reactive strategies aim to manage challenging behaviours and ensure the safety of the individual and others.

From an evolutionary perspective, people with severe and profound learning disabilities are at greater risk of stress due to their limited cognitive abilities, difficulties processing and appraising information, and a need for a structured and predictable environment and limited behaviour repertoires. Frequent and sustained stress may lead to permanent activation of biological response systems, leading to hard-wired maladaptive responses to even low levels of stress (e.g. Perry et al, 1995, cited in Janssen et al, 2002). Therefore, the emphasis on the development of a repertoire of coping skills and adaptive behaviours within the behavioural paradigm fits well with such a biological understanding and fits with dominant service culture that people with challenging behaviour should be seen as having long-term specialist needs if problems are not to re-surface.

A common criticism of behavioural approaches is that they are *'cold, sterile, simplistic, authoritarian, and dehumanising'* (Oliver & Head, 1993), although current emphases on functional and ecological analysis means that these criticisms are commonly 'brushed off' as outmoded. However, the behavioural literature is still littered with phrases which reflect the power imbalance between people with learning disabilities and those responsible for their care, and thus it is essential to consider whose interest intervening in the problem serves. For example, the aim of behavioural interventions is described by Hewett (1998) as *'helping the person with challenging behaviour learn how to behave'*. The fact that behavioural approaches have developed hand-in-hand with the normalisation movement means that the rationale for interventions are often not challenged if they fit with conceptualisations of the 'ideal home', the 'ideal carer', and the 'ideal client' (Clements et al, 1995). Authors such as Sinason (1992) argue that, although contemporary behavioural approaches emphasise the 'needs' of people with challenging behaviour, these tend to be defined in very mechanistic, 'male' terms, rather than in terms of emotions or relationships.

A further criticism is that, although there is considerable evidence within the research literature to demonstrate the efficacy of behavioural interventions, in practice there are multiple barriers to their successful implementation. These include staff attitudes and beliefs as well as wider organisational issues (Kushlick et al, 1997). Potentially treatable mental illness or physical factors are often not considered in functional analyses (Murphy & Holland, 1993; Ross & Oliver, 2002). Owens & MacKinnon (1993) argue that, even where a functional analysis is correct, its predictive ability may remain poor due to the numerous other variables that influence situations. They argue that even with the more 'hard' sciences, such as physics and astronomy, it is increasingly recognised that the chaotic nature of underlying processes limits the predictive value of theory. However, considering alternative models and theories which consider some of these 'chaotic' variables is likely to lead to improved formulation and intervention.

Guttman (1991) argues from a systemic perspective that in order to be meaningful, radical change is required within the system, otherwise one behaviour will simply be replaced by another. In a review of the literature on mediators of challenging behaviours, Allen (1999) concludes that little attention has been paid to factors such as the cognitive and emotional states of carers, reciprocal reinforcement systems, and the ecological and cultural systems under which interventions are introduced, limiting the success of such interventions.

Systemic approaches emphasise the need to reflect on beliefs and assumptions held by different people within the care environment, and to examine power issues, relationships, gender roles and so on (Campbell et al, 1991; Rhodes, 2003). In common with the behavioural approach, behaviour is seen as functional, although this is in terms of highlighting the fact that the organisation or family is stuck developmentally. The diversity of assumptions and beliefs within a family or organisation can be very divisive, and a systemic formulation allows these to be examined in depth. For example, in a series of in-depth qualitative interviews with care staff, Hastings (1995) found many factors within the organisational culture, such as the belief that behaviour should be controlled or managed rather than understood, led staff to respond inappropriately to challenging behaviour.

Wilcox & Whittington (2003) argue from a narrative perspective that the lives of people with severe learning disabilities are often very 'thinly' described by those who support them, often being based on dominant social, cultural, political and professional 'stories'. They argue that it is important to help carers deconstruct assumptions about the individual and develop a richer understanding of them as a person. A particularly important 'story' which is commonly told is that people with learning disabilities are fundamentally different from people without learning disabilities. Rhodes (2003) draws attention to the common 'story' of 'timelessness', whereby people with learning disabilities are seen as stuck, and therefore carers are unable to notice evidence of change or development. Without revising such 'stories', it is difficult to see how needs can be accurately identified and addressed. The behavioural approach, with its emphasis on technological approaches, may also serve to obstruct efforts to understand the person with the disability in more 'human terms'.

Unfortunately, there is little examination of carers' beliefs and attributions about learning disability and challenging behaviour within the research literature from such a perspective. Most of the literature has been located within the behavioural paradigm on the basis that unhelpful beliefs act as a barrier to the successful implementation of behavioural programmes. Allen (1999) reviews the research literature and reports that a consistent theme is that variables over which carers could exert some control (e.g. communication) are viewed as less likely causes of challenging behaviour than those over which they have little or no influence (e.g. internal factors and general environmental factors). Experimental evidence in the research literature supports the hypothesis that internal attributions of the cause of behaviours are associated with negative affect and high expressed emotion amongst carers, and low rates of involvement or helping behaviour with the person (e.g. Hill & Dagnan, 2002; Stanley & Standen, 2000; Dagnan et al, 1998; Cottle et al, 1995). Jones & Hastings (2003) found that care staff experienced less guilt when internal attributions about self-injurious behaviour were made.

In a large survey of care staff, Bromley & Emerson (1995) found that a significant proportion of care staff experience sadness, despair, anger, annoyance, fear and disgust in response to challenging behaviour. However, they often find it extremely difficult to talk about their own feelings relating to their work with people with severe or profound learning disabilities (Arthur, 2003). Arthur suggests that there is a tendency to suppress such feelings as they are seen to be incongruent with the role of carer. There is also a tendency for services to promote independence and practical skills whilst failing to address the emotional needs of people with learning disabilities (e.g. Reed, 1995). However, there is compelling evidence within the research literature to indicate that feelings of loss, separation, sadness, abandonment, rejection, anger and ambivalence are commonly experienced (e.g. Chaney, 1995; Arthur, 2003; Janssen et al, 2002; Szivos & Griffiths, 1992) and expressed in the form of challenging behaviour (Bihm et al, 1998).

Several authors have proposed more fundamental explanations based on psychodynamic theories to explain the tendency to suppress consideration of the emotional needs of people with learning disabilities. Beail (1994), for example, argues from a historical perspective that society has always dehumanised people with a severe learning disability. For example, in the middle ages a commonly held belief was that a child with learning disabilities came from the underworld in exchange for a normal child. The learning disability was believed to be a punishment for the sins of parents, or a result of sexual intercourse between the mother and the devil. The social policy of the Nazi regime amongst others involved an attempt to kill off disabled people, and Antonak et al (1995) found eugenic views still to be commonly held, particularly towards people with more severe learning disabilities. Sinason (1992) points out that carers, families and people with learning disabilities commonly hold these implicit beliefs, and that they have led to often dehumanising treatments (e.g. aversive techniques) that are presented in the form of 'treatment'. However, recent evidence in the research literature has challenged the view that people with severe or profound learning disabilities do not experience 'normal' human emotions. For example, Chaney (1996) demonstrated, using psychophysiological measures, that 35 participants with profound learning disabilities and challenging behaviour experienced stressful emotions despite the absence of overt signs of such emotions.

Symington (1992), a psychoanalyst working with people with learning disabilities, argues that we all treat people with learning disabilities with contempt, although it tends to exist below the level of awareness. He provides examples from his own practice to demonstrate this, for example, dressing more shabbily than with a normal client for a session, or being late for a session because 'they won't notice'. He argues

that it is a omnipotent ego structure, whereby the person with a learning disability is stuck at a developmental level where the mother is still seen as a functional object rather than a person in her own right, that leads to a paranoid ideation and god-like figure that cannot bear to be ignored and leads to exasperation from others in response and a desire to do them in. Symington argues that this automatic reaction is repressed at an interactional level but that feelings of contempt can lead to feelings of guilt and can lead to those involved in their care becoming crippled and ineffective or avoidant. This is supported by observational research which demonstrates that levels of interaction between staff and people with severe/ profound learning disabilities tends to be extremely low (e.g. Felce et al, 1995). Hastings & Remington (1994) observed higher levels of interaction with people with challenging behaviour compared with people without, although these still were very low.

Clegg & Sheard (2002) argue for a paradigm shift from focussing on developing autonomy of people with severe and profound disabilities to the helper-helped relationship and viewing emotional development from an attachment perspective where emotional maturity is seen not as a move to independence but from immature to mature dependence. In terms of theory, Berry (2003) argues that the ego functions of people with learning disabilities are especially vulnerable, in particular frustration tolerance, reality testing, and anticipation and that these should be developed in the context of relationships.

Experimental evidence indicates that people with learning disabilities are at much higher risk of developing insecure attachments (Janssen et al, 2002; Clegg & Sheard, 2002) and that they therefore find it difficult to form supportive relationships. There is evidence in the form of published case studies (e.g. Berry, 2003; Sinason, 1992) to suggest that focussing on the relationship with people with severe/ profound learning disabilities can lead to reduced challenging behaviour. Berry (2003) suggests that the significant decreases in challenging behaviour associated with developing a therapeutic relationship appeared to be at least partially mediated by staff noticing his efforts and becoming more confident in relating to the service user.

A major challenge of work with people with severe and profound learning disabilities is that of having to infer their needs, and the diversity of interpretations that this leads to. Grove et al (1999) argue that there is a need for more systematic strategies to collect evidence from a range of sources to support such inferences, and that they should be seen as a continuous rather than categorical variable. It has been argued that the behavioural paradigm provides a useful framework but that there are limitations to the understanding that other models can usefully address. The key message is that unless one is looking out for things one will not see them. For example, although people with severe learning disabilities

commonly suffer abuse, the impact of this tends not to be considered (White et al, 2003). Similarly, although people with severe learning disabilities could be considered at greater risk of mental illness than the normal population, potentially treatable mental illness is frequently not identified (Ross & Oliver, 2002). Although these are clearly difficult to identify in this population (Bicknell, 1994), by drawing on the range of approaches discussed above, it is likely that a more coherent understanding of how various 'factors' influence a person can be gained.

Role of the clinical psychologist

Clinical psychologists have much to offer in terms of understanding and responding to the needs of people with severe or profound learning disabilities and challenging behaviour. The emphasis in training on developing an understanding of problems from a range of theoretical perspectives, on gaining a lifespan developmental understanding of psychological needs, and on gaining a rich understanding of evidence based practice, are all key strengths in undertaking this task.

A clear association has been established between carers' difficulty understanding challenging behaviour and seeing the absence of a way forward, and the levels of stress that they report (Bromley & Emerson, 1995). There is also much evidence to indicate that carers' beliefs and emotions have a strong impact on their responses to challenging behaviour (Jones & Hastings, 2003). Therefore, a key role of the clinical psychologist is in helping families, staff, and organisations to understand the behaviour. This could be through consultancy, supervision to other professionals, training, staff support, or even direct work with the person with challenging behaviour. Various theoretical perspectives have been discussed, and these are of value in terms of formulating problems and identifying means of addressing them.

Clinical psychologists would be expected to have a good understanding and skills in working using the behavioural paradigm. However, it could be argued that challenging needs practitioners, whose training was established to 'plug the gap' of clinical psychology provision (Tizard Centre, 2003), are likely to have an equivalent or superior understanding of this approach. Therefore, adopting a purely behavioural approach is likely to be seen within the health service as an unnecessary waste of resources. However, a major limitation of the Tizard and similar training is its almost exclusive focus on behavioural models, and it has been argued that interventions often come 'unstuck' due to their lack of consideration of emotional, cognitive and systemic variables. Clinical psychologists should be in a strong position to help others develop a more psychological understanding of the needs of both people with learning disabilities and those who care for them. Although they may be wary of being seen to be sitting back and reflecting on problems, this is a strength in a culture where many other professionals are so focussed on 'doing'.

Although there is a danger that the clinical psychologist will be viewed as 'aloof', there are advantages of working from outside and joining the 'system'. Authors such as Campbell et al (1991) argue that taking an observer position opens up possibilities to question different assumptions, beliefs and goals within an organisation and develop an understanding of why they are finding it difficult to negotiate change. Clements et al (1995) argue that such a deconstruction of implicit as well as explicit practice and assumptions about the nature of learning disability/ challenging behaviour is necessary in order to improve the lives of people with learning disabilities. A solution-focussed approach, as described by Rhodes (2000), could also be helpful in terms of establishing a positive relationship with consultees. Such an approach emphasises the importance on focussing on the consultees own goals and then identifying a solution through a process involving noticing exceptions, strengths and resources that already occur. An obvious concern would be that such goals obstruct more 'important' issues from being addressed. However, a positive therapeutic relationship is clearly important if such goals are ultimately going to be met. Clinical psychologists often seem to feel under pressure to be 'doing something', and such a solution focussed approach highlights the power within the system to change rather than reinforcing powerless feelings, as may happen through a more directive 'expert' behavioural approach.

Research by Hatton et al (1999) indicates that staff often feel unsupported, and that this is related to stress and low satisfaction. This is particularly the case with challenging behaviour (Jenkins et al, 1997). Kushlick et al (1997) present a cognitive-behavioural approach for supporting staff, which could be viewed as personal development. They emphasise the fact that care staff are unlikely to be able to provide adequate care if their own needs are not being met. Their approach which focuses on staff identifying their own needs and draws parallels between these and the needs of their service users, seems to foster a more human understanding of people with learning disabilities, rather than seeing their needs as completely different. Kushlick et al (1997) also make the point that staff often experience the cognitive dissonance of knowing that new approaches are right but not feeling comfortable adopting new practices. They stress the importance of supporting staff through this process of change, and of reinforcing success. Evaluations of their program indicate that staff adopted more positive approaches to supporting people with challenging behaviour through a greater understanding of their own needs.

Arthur (1999) argues that staff consultation is an important therapeutic tool to enable staff to develop a greater understanding of residents' emotional lives and needs, to adopt a more 'listening, reflecting and interpreting' role instead of 'directing, advising and guiding'. He argues that the consultation process can help staff identify and talk about positive and negative feelings involved in their work (e.g. frustration,

anger, rejection, sadness) which often are repressed. Such feelings can provide important diagnostic information about the client (through transference and countertransference for example), prevent the feelings being expressed in maladaptive ways, and enable staff to receive understanding and support from colleagues. Implicit permission for such conversations often seems to be lacking in organisational cultures.

Although consultation has been shown to be an effective strategy for behavioural change, the general consensus within the research literature is that simply training direct care staff is not an effective strategy for change, and that such training needs to take place within a supportive organisational culture where there are clear opportunities for the modelling of positive approaches (Allen, 1999).

Although I have argued that clinical psychologists have much to offer, in practice it seems that they are frequently sidelined and seen as irrelevant (e.g. Ephraim, 1998; Clements & Rapley, 1996). Toogood (1993) argues that this is due to the way in which clinical psychologists present themselves, with a range of 'exotic' theories which leave others struggling to understand what perspective they are coming from. This was apparent in my work, where a leaflet about the clinical psychology department had been devised, with almost a page devoted to a detailed presentation of how qualified psychologists are, and further pages to a detailed description of theoretical models, without any indication of how these can be translated into assisting with problems. In addition, McBrien & Candy (1998) suggest that the clinical psychologist is often not perceived as a team player who is willing to share information, which means that they struggle to exert an influence. A further barrier is that clinical psychologist's influence is often weak in comparison with organisational culture (Allen, 1999). A reflexive self-awareness is thus essential if the clinical psychologist is to successfully negotiate these barriers and effectively assist with challenging behaviour.

Evidence and outcomes

'virtually all the work that has been undertaken in this area has been behavioural [...] this does not mean that we believe other approaches are invalid, simply that, to date, there is insufficient evidence to support their use in an 'evidence-based NHS'

Emerson, 1998; p127)

Although there is not space for an in-depth discussion of research and evidence, it is felt that it is an area that clinical psychologists have much to contribute. Emerson's (1998) argument above seems to serve the purpose of arresting development within the field until 'acceptable' evidence is generated.

However, as Davy (2002) points out, evidence based practice is a complex construct forged through the interplay of conflictual interests such as politics, professionalism, resource management, medical discourse, and collaborative ethics. A postmodernist perspective, as advocated by Laugharne (2002), takes the view that we should acknowledge the strengths and limitations of 'scientific evidence' and use it as a valuable source of information alongside other forms of evidence, such as the perspectives of users, carers, and purchasers (e.g. Thornton, 1997; Murphy et al, 1996). The use of meaningful outcomes applies to clinical work, where evaluating change should provide feedback to enable systems and individuals to evolve, as well as to policy development. The need for national initiatives to promote a more psychological understanding of the needs of people with learning disabilities/ challenging behaviour and their carers has been widely recognised (e.g. Kiernan, 1993). Although it lacks the influence of a national service framework, the white paper 'Valuing People' (Department of Health, 2001) offers some recognition of these issues. Clinical psychologists have a potentially important role to play in terms of contributing to policy development, and research is a potentially powerful source of influence.

Conclusion

To conclude, although there are many factors within the context of the lives lived by people with learning disabilities which can lead to clinical psychologists being sidelined, it has been argued that they have a potentially valuable role to play in helping carers and organisations develop a more psychological understanding and means of responding to the needs of people with severe or profound learning disabilities. There is a need to understand, yet look beyond the behavioural paradigm in order to achieve this.

References

- Allen,D. (1999a). Mediator analysis: an overview of recent research on carers supporting people with intellectual disability and challenging behaviour. *Journal of Intellectual Disability Research*, 43 (4), 325-339.
- Allen,D. (1999b). Success and failure in community placements for people with learning disabilities and challenging behaviour: an analysis of key variables. *Journal of Mental Health*, 8 (3), 307-320.
- Antonak,R.F., Mulick,J.A., Kobe,F.H. & Fielder,C.R. (1995). Influence of mental retardation severity and respondent characteristics on self-reported attitudes toward mental retardation and eugenics. *Journal of Intellectual Disability Research*, 39 (4), 316-325.
- Arcott,K., Dagnan,D., & Kroese,B.S. (1999). Assessing the ability of people with a learning disability to give informed consent to treatment. *Psychological Medicine*, 29, 1367-75.
- Arthur,A.R. (2003). The emotional lives of people with learning disability. *British Journal of Learning Disabilities*, 31, 25-30.
- Arthur,A.R. (1999). Using staff consultation to facilitate the emotional development of adults with learning disabilities. *British Journal of Learning Disabilities*, 27, 93-98.
- Beail,N. (1994). Fire, coffins and skeletons. In V.Sinason (ed), *Treating Survivors of Satanist Abuse*. London: Routledge.
- Berry,P. (2003). Psychodynamic therapy and intellectual disabilities: dealing with challenging behaviour. *International Journal of Disability, Development and Education*, 50 (1), 39-51.
- Bicknell,J. (1994). Learning disability and ritualistic child abuse. In V.Sinason (ed), *Treating Survivors of Satanist Abuse*. London: Routledge.
- Bihm,E.M., Poindexter,A.R. & Warren,E.R. (1998). Aggression and psychopathology in persons with severe or profound mental retardation. *Research in Developmental Disabilities*, 19 (5), 423-428.
- Bromley,J. & Emerson,E. (1995). Beliefs and emotional reactions of care staff working with people with challenging behaviour. *Journal of Intellectual Disability Research*, 39 (4), 341-352.
- Caine,A., Hatton,C. & Emerson,E. (1998): Service provision. In E.Emerson, C.Hatton, J.Bromley & A.Caine (eds.), *Clinical Psychology and People with Intellectual Disabilities*. Chichester: Wiley.
- Campbell,D., Draper,R. & Huffington,C. (1991). *A Systemic Approach to Consultation*. London: Karnac.
- Chaney,R.H. (1995). Psychological stress in people with profound mental retardation. *Journal of Intellectual Disability Research*, 40 (4), 305-10.
- Clegg,J. & Sheard,C. (2002). Challenging behaviour and insecure attachment. *Journal of Intellectual Disability Research*, 46 (6), 503-506.
- Clements,J., Clare,I. & Ezelle,L.A. (1995). Real men, real women, real lives? Gender issues in learning disabilities and challenging behaviour. *Disability and Society*, 10 (4), 425-435.

- Cottle,M., Kuipers,L., Murphy,G. & Oakes,P. (1995). Expressed emotion, attributions and coping in staff who have been victims of violent incidents. *Mental Handicap Research*, 8 (3), 168-184.
- Culham,A. & Nind,M. (2003). Deconstructing normalisation: clearing the way for inclusion. *Journal of Intellectual and Developmental Disability*, 28 (1), 65-78.
- Dagnan,D., Trower,p. & Smith,R. (1998). Care staff responses to people with learning disabilities and challenging behaviour: a cognitive-emotional analysis. *British Journal of Clinical Psychology*, 37, 59-68.
- Davy (2002). Evidence and Systemic Therapy.
- Department of Health (2001). Valuing People: a New Strategy for Learning Disability in the 21st Century. London: HMSO.
- Emerson,E. (1995). Challenging Behaviour: Analysis and Intervention in People with learning Disabilities. Cambridge: Cambridge University Press.
- Emerson, E. (1998). Challenging behaviour. In E.Emerson, C.Hatton, J.Bromley & A.Caine (eds.), *Clinical Psychology and People with Intellectual Disabilities*. Chichester: Wiley.
- Ephraim,G. (1998). Exotic communication, conversations and scripts – or tales of the pained, the unheard, and the unloved. In D.Hewett (ed.), *Challenging Behaviour – Principles and Practices*. London: David Fulton.
- Felce,D. (1993). Ordinary housing: a necessary context for meeting service philosophy and providing an effective therapeutic environment. In R.S.P.Jones & C.B.Eayrs (eds.), *Challenging Behaviour and Intellectual Disability: a Psychological Perspective*. Clevedon: BILD publications.
- Felce,D., Lowe,K. & Blackman,D. (1995). Resident behaviour and staff interaction with people with intellectual disabilities and seriously challenging behaviour in residential services. *Mental Handicap Research*, 8 (4), 272-295.
- Guttman,H.A. (1991). Systems theory, cybernetics and epistemology. In A.S.Gurman & D.P.Kniskern (eds.), *The Handbook of Family Therapy*, New York: Mazel.
- Grove,N., Bunning,K., Porter,J. & Olsson,C. (1999). See what I mean: interpreting the meaning of communication by people with severe and profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 12 (3), 190-203.
- Hastings,R.P. (1995). Understanding factors that influence staff responses to challenging behaviours: an exploratory interview study. *Mental Handicap Research*, 8 (4), 296-320.
- Hastings,R.P. & Remington,B. (1993). Connotations of labels for mental handicap and challenging behaviour: a review and research evaluation. *Mental Handicap Research*, 6 (3), 237-249.
- HastingsR.P. & Remington,B. (1994). Staff behaviour and its implications for people with learning disabilities and challenging behaviours. *British Journal of Clinical Psychology*, 33, 423-38.

- Hatton,C., Emerson,E., Rivers,M., Mason,H., Mason,M., Swarbrick,R., Kiernan,C., Reeves,D. & Alborz,A. (1999). Factors associated with staff stress and work satisfaction in services for people with intellectual disability. *Journal of Intellectual Disability Research*, 43 (4), 253-67.
- Hewett, D. (1998). Commentary: helping the person learn how to behave. In D.Hewett (ed.), *Challenging Behaviour – Principles and Practices*. London: David Fulton.
- Hill,C. & Dagnan,D. (2002). Helping, attributions and coping style in response to people with learning disabilities and challenging behaviour. *Journal of Learning Disabilities*, 6 (4), 363-72.
- Janssen,C.G.C., Schuengel,C. & Stol,J. (2002). Understanding challenging behaviour in people with severe and profound intellectual disability: a stress-attachment model. *Journal of Intellectual Disability Research*, 46 (6), 445-453.
- Jenkins,R., Rose,J. & Lovell,C. (1997). Psychological wellbeing of staff working with people who have challenging behaviour. *Journal of Intellectual Disability Research*, 41 (6), 502-511.
- Jones,R.S.P. & Eayrs,C.B. (1993). Challenging behaviour and intellectual disabilities: an overview. In R.S.P.Jones & C.B.Eayrs (eds.), *Challenging Behaviour and Intellectual Disability: a Psychological Perspective*. Clevedon: BILD publications.
- Jones,C. & Hastings,R.P. (2003). Staff reactions to self-injurious behaviours in learning disability services: attributions, emotional responses and helping. *British Journal of Clinical Psychology*, 42, 189-203.
- Kiernan,C. (1993a). Future directions for research and service development for people with learning disabilities and challenging behaviour. In C.Kiernan (ed.), *Research to Practice? Implications of Research on the Challenging Behaviour of People with Learning Disability*. Clevedon: BILD Publications.
- Kiernan,C. (1993b). Future directions. In R.S.P.Jones & C.B.Eayrs (eds.), *Challenging Behaviour and Intellectual Disability: a Psychological Perspective*. Clevedon: BILD publications.
- Kushlick,A., Trower,P. & Dagnan,D. (1997). Applying cognitive-behavioural approaches to carers of people with learning disabilities who display challenging behaviour. In B.Stenfert Kroese, D.Dagnan & K.Loumidis (eds.), *Cognitive-Behaviour Therapy for People with Learning Disabilities*. London: Routledge.
- Lacan,J. (1977). *The Four Fundamental Concepts of Psychoanalysis*. London: Hogarth.
- LaVigna,G. & Donellan,A. (1986). *Alternatives to Punishment: Solving Behavior Problems with Non-Aversive Strategies*. New York: Irvington.
- Laugharne, R. (2002). Evidence – the postmodern perspective. In S.Priebe & M.Slade (eds.), *Evidence in Mental Health Care*. Hove: Brunner-Routledge.
- McBrien,J. & Candy,S. (1998). Working with organisations, or: why won't they follow my advice? In E.Emerson, C.Hatton, J.Bromley & A.Caine (eds.), *Clinical Psychology and People with Intellectual Disabilities*. Chichester: Wiley.

- McDonnell, A. & Sturmey, P. (1993). Managing violent and aggressive behaviour: towards better practice. In R.S.P. Jones & C.B. Eayrs (eds.), *Challenging Behaviour and Intellectual Disability: a Psychological Perspective*. Clevedon: BILD publications.
- Murphy, G.H., Estien, D. & Clare, I.C.H. (1996). Services for people with mild intellectual disabilities and challenging behaviour: service-user views. *Journal of Applied Research in Intellectual Disabilities*, 9 (3), 256-283.
- Murphy, G. & Holland, T. (1993). Challenging behaviour, psychiatric disorders and the law. In R.S.P. Jones & C.B. Eayrs (eds.), *Challenging Behaviour and Intellectual Disability: a Psychological Perspective*. Clevedon: BILD publications.
- Oliver, C. & Head, D. (1993). Self-injurious behaviour: functional analysis and interventions. In R.S.P. Jones & C.B. Eayrs (eds.), *Challenging Behaviour and Intellectual Disability: a Psychological Perspective*. Clevedon: BILD publications.
- Owens, R.G. & MacKinnon, S. (1993). The functional analysis of challenging behaviours: some conceptual and theoretical problems. In R.S.P. Jones & C.B. Eayrs (eds.), *Challenging Behaviour and Intellectual Disability: a Psychological Perspective*. Clevedon: BILD publications.
- Parker, I., Georgaca, E., Harper, D., McLaughlin, T. & Stowell-Smith, M. (1995). *Deconstructing Psychopathology*. London: Sage.
- Rapley, M., Kiernan, P. & Antaki, C. (1998). Invisible to themselves or negotiating identity? The interactional management of being 'intellectually disabled'. *Disability & Society*, 13, 807-827.
- Reed, J. (1997). Understanding and assessing depression in people with learning disabilities: a cognitive-behavioural approach. In Kroese, B.S., Dagnan, D., Loumidis, K. (eds.), *Cognitive-Behaviour Therapy for People with Learning Disabilities*. London: Routledge.
- Rhodes, J. (2000). Solution-focussed consultation in a residential setting. *Clinical Psychology Forum*, 141 (7), 29-33.
- Rhodes, P. (2003). Behavioural and family systems interventions in developmental disability: towards a contemporary and integrative approach. *Journal of Intellectual and Developmental Disability*, 28 (1), 51-64.
- Robertson, J., Emerson, E., Gregory, N., Hatton, S., Kessissoglou, S. & Hallam, A. (2000). Receipt of psychotropic medication by people with intellectual disability in residential settings. *Journal of Intellectual Disability Research*, 44 (6), 666-676.
- Ross, E. & Oliver, C. (2002). The relationship between levels of mood, interest, and pleasure and 'challenging behaviour' in adults with severe and profound intellectual disability. *Journal of Intellectual Disability Research*, 46 (3), 191-197.
- Sinason, V. (1992). *Mental Handicap and the Human Condition: New Approaches from the Tavistock*. London: Free Association Books.
- Stanley, B. & Standen, P.J. (2000). Carers' attributions for challenging behaviour. *British Journal of Clinical Psychology*, 39, 157-168.

Symington,N. (1992). Countertransference with mentally handicapped clients. In A.Waitman & S.Conboy-Hill (eds.), *Psychotherapy and Mental Handicap*. London: Sage.

Szivos,S. & Griffiths,E. (1992). Coming to terms with learning difficulties: the effects of groupwork and group processes on stigmatised identity. In A.Waitman & S.Conboy-Hill (eds.), *Psychotherapy and Mental Handicap*. London: Sage.

Thornton,P.J. (1997). Consumer evaluation of a challenging behaviour support worker service for people with learning disabilities. *Clinical Psychology Forum*, 102 (4), 3-6.

Tizard centre (2003) www.kent.ac.uk/tizard/about.htm

Toogood,S. (1993). In D.Hewett (ed.), *Challenging Behaviour – Principles and Practices*. London: David Fulton.

White,C., Holland,E., Marsland,D. & Oakes,P. (2003). The identification of environments and cultures that promote the abuse of people with intellectual disabilities: a review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 16, 1-9.

Wilcox,E. & Whittington,A. (2003). Discovering the use of narrative metaphors in work with people with learning disabilities. *Clinical Psychology*, 21 (1), 31-35.

Zarkowska,E. & Clements,J. (1994). *Problem Behaviour and People with Severe Learning Disabilities: The S.T.A.R. Approach*. London: Chapman & Hall.

Small Scale Research Project
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A case study exploring staff views of a family therapy clinic within a Tier 3 Child & Family Consultation Service

Overview

This case study draws on interviews with staff, audit data, and participant observation to explore perceptions of the purpose and functioning of a recently established family clinic within a Tier 3 Child & Family Consultation Service in the South-East of England. There was general agreement within the service that the family clinic had developed an important and integral role within the CFCS. However, divergent views were expressed regarding the perceived purpose and functioning of the family clinic, which impact on the work that is done. Audit data provides some insight into the kinds of cases seen by the family clinic and outcomes, although this data was considered very limited in terms of understanding the complexity of processes involved. The findings are discussed within the context of service development.

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Introduction

There is considerable evidence that the number of children with *'troubled behaviour'* is increasing (Rutter & Smith, 1995), and that emotional and behavioural problems in childhood can have a significant impact on the child's life course. Evidence indicates that such problems are associated with poorer family relationships, educational problems, poor employment prospects, offending behaviour, social exclusion, difficulties in forming social and personal relationships, and physical and mental health problems in adult life as well as childhood (Kurtz, 1996; Buchanan, 2002).

Recent government policy initiatives have led to increased resources for child & adolescent mental health services (CAMHS) with the expectations that such services will expand (e.g. NHS Modernisation Fund, 1999), with a *'full range of evidence based treatment available'* (Department of Health, 2003). Systematic reviews of published research on the efficacy and effectiveness of various treatments (Carr, 2000; Fonagy et al, 2002; Barrett & Ollendick, 2004) indicate that systemic family therapy is an important component of such a vision, and its inclusion in Tier 3 CAMHS is supported by local NHS trust policy. The research evidence base indicates that a systemic family therapy approach can lead to improved functioning in child and families where there are complex difficulties such as child abuse or neglect, eating disorders, behavioural problems, ADHD, drug abuse and adjustment problems (e.g. Carr, 2000; Dallos & Draper, 2000).

This study aims to explore the views of different staff members about a recently established family therapy clinic within a multidisciplinary Tier 3 Child & Family Consultation Service (CFCS). The broad objective was to develop an understanding of how practice relates to the perceived remit of the family clinic, and perceptions of how practice should evolve in the future.

A case study approach, as described by Yin (2003), was adopted to guide data collection, following discussions with members of the CFCS about the purpose of the project. A case study strategy was considered appropriate to these ambitions in that it is suited to asking *'how'* and *'why'* questions (e.g. *how do perceptions differ within an organisation? how are decisions*

made to take on work with particular families? why does the clinic operate as it does?), relating to contemporary sets of events over which the investigator has little or no control. It facilitates the integration of various sources of data (in this case interviews, documentary analysis, participant observation, and previous audit data), which was considered helpful with an exploratory project where it was difficult to formulate clear research questions and hypotheses (Fitzgerald, 1999). Ferlie et al (1999) argue that the approach is also particularly suited to making sense within complex and dynamic organisational contexts.

A decision was made to limit the study design to seeking the views of CFCFS team members, rather than seeking feedback from other sources, such as the views of the families who had attended the clinic, referrers, or management (e.g. Carr et al, 1994; Chase & Holmes, 1990). This was for pragmatic reasons in that there was very limited time and resources available with which to conduct the project. Thus the analysis was based on the views of members of the clinic as well as those in the wider CFCS team, an audit of all the cases that have been referred to the family clinic, informal participant observation, and previous audits of the work of the CFCS and family clinic in a neighbouring CFCS service.

Background

The Child & Family Consultation Service (CFCS)

The CFCS is commissioned as a Tier 3 Child & Adolescent Mental Health Service, offering a *'specialist service for the more severe, complex and persistent disorders'* (Audit Commission, 1999), which require a multidisciplinary approach. Various assessment and intervention approaches are offered to individuals, couples, families, other professionals, and other agencies. Approaches include psychotherapy (psychodynamic, systemic, cognitive-behavioural), psycho-education, medication, parent training, environmental manipulation, counselling, and arts therapies. In addition to accepting cases of severe or enduring mental illness, cases with associated risk factors are usually considered appropriate. These include being in care, having a learning disability, physical disability, chronic illness or sensory impairment, having been sexually, physically or emotionally abused, or having a parent with significant mental health problems, substance misuse problems or a learning disability (Pearce & Holmes, 1994; Yates et al, 1999) – see Table 1 below. An audit of cases referred to the service from January to September 2002 (Hewitt, 2003) indicated that the most common reasons for referral were challenging behaviour, self-harm, depression and anxiety disorders, and cases frequently had co-morbid difficulties.

Table 1: Factors that increase the risk of mental health problems in young people (Pearce & Holmes, 1994; cited in Kurtz, 1996)

CHILD RISK FACTORS	FAMILY RISK SITUATIONS	ENVIRONMENTAL RISK FACTORS
Genetic influences Low IQ and learning disability Specific developmental delay Communication difficulty Difficult temperament Physical illness, especially if chronic and / or neurological Academic failure Low self-esteem	Overt parental conflict Family breakdown Inconsistent or unclear discipline Hostile and rejecting relationships Failure to adapt to child's changing developmental needs Abuse – physical, sexual, emotional Parental psychiatric illness Parental criminality, alcoholism and personality disorder Death and loss, including loss of friendships	Socio-economic disadvantage Homelessness Disaster Discrimination Other significant life events

The CFCS operates during office hours as a community-based multidisciplinary team. Referrals of 0-17 year-olds are accepted, and the team operates in a relatively affluent geographical area, covering a large town and some rural areas. The team comprises of two

full-time Social Workers (one of whom acts as team leader), a full-time Child Psychotherapist, a full-time Psychiatrist, two part-time Psychiatric Nurses, a part-time Clinical Psychologist, a part-time Educational Psychologist, a part-time Systemic Family Therapist, and four Admin Staff.

All referrals are discussed in a weekly team meeting (an audit by Hewitt in 2003 indicated that 55% of referrals to the service are accepted). Due to an increase in number and complexity of referrals over recent years, management have introduced a rating system to the CFCS teams within the trust (based on Yates et al, 1999), with the expectation that referrals will be rated for complexity, persistence and severity and those scoring above a cut-off point will be offered a service (see Appendix C). Those cases deemed appropriate for the service are prioritised, and allocated to a specific team member where someone is seen to have particular expertise. Other cases are taken from the waiting list by team members outside this forum. It was apparent through participating in such meetings that the formal system is not adhered to rigidly, as clinical judgment on a case by case basis is often considered more appropriate than the use of standardised procedures which are often not considered sensitive to the complexities and subtleties of the presenting problems.

Development of the family clinic

The family clinic has operated within the CFCS since January 2002. It was developed by two clinicians from a social work background - a systemic family therapist from a neighbouring CFCS in the same NHS trust and social worker who had moved from that team to the CFCS. Although never formally defined, the remit of the family clinic emerged from a '*complex case project*' that the two had piloted in the neighbouring CFCS. This involved a broadly systemic family therapy approach, based on the *Domains of Action Model* (Lang et al, 1990), to address the needs of families with complex issues in addition to the child's mental health, such as parental mental health difficulties, drug and alcohol problems, domestic and sexual abuse, often where multiple agencies are involved. Lang et al (1990) consider how it is possible for clinicians to adhere to the post-Milan systemic ideal of '*neutrality*' (Selvini et al, 1979) where professional codes of practice demand a clearly defined professional position (e.g. regarding sexual abuse, racism, neglect). The complex case project thereby aimed to promote shared responsibility with families by intervening with cases that would previously have been seen by social rather than mental health services.

The family clinic started operating in January 2002 following a complete refurbishment of the CFCS building. The refurbishment included the installation of a family therapy suite, comprising a room in which to meet with families, and an adjacent observation room fitted with a one way screen and video / audio links.

Staffing of the family clinic is fairly flexible in that different members of a core team work as therapist with different families. Typically one team member will work directly with the family as therapist, and the remaining team members work as a reflecting team from the observation room, sometimes offering feedback to the therapist privately, and sometimes having a reflecting conversation in front of the family (e.g. Andersen, 1987). There have been some changes in the core membership of the family clinic since its inception, with a greater degree of involvement by clinicians from outside the CFCS at the beginning. At the time that the interviews were conducted, the family clinic was staffed by two systemic family therapists (although one of the founding members was beginning to withdraw from the service), two social workers, an assistant psychologist, and a trainee clinical psychologist, and occasionally a third social worker. With the exception of the two systemic family therapists, the team members have little or no formal training in systemic family therapy. The clinic is supported by a member of the admin team, who deals with arranging appointments with families and correspondence from the clinic.

There is not a separate referrals system for the family clinic, and referrals to the CFCS are considered as to their suitability for the family clinic at the weekly CFCS team meetings. The CFCS waiting list is also screened for suitable cases by the two social workers, and discussed with the family clinic team separately. Appointments are offered to families considered suitable, usually after a telephone conversation from the clinician who is likely to work directly with the family. Families are given information about the approach and asked to sign a consent form to sessions being videotaped. The clinic is fairly flexible in terms of the frequency of sessions and which members of the family attend. There is capacity for one hour appointments to be offered to two families each week (one session).

Aims of the study

The aim of the study is to explore the perceptions that members of the family clinic and the wider CFCS have about the following:

Q1: the role of the family clinic within the CFCS

Q2: the impact of the family clinic

Q3: future development of the family clinic

Methodology and research design

Design

A case study design with supplementary audit data was adopted to address the above questions, with the family clinic as the 'case'. An embedded design was used, with the units of analysis including semi-structured interviews with staff, case records, the results of two previous service audits, and participant observation.

Data sources

The case study is based on data from four key sources:

1. Interviews with staff, addressing their views on three key aspects of the family clinic as outlined under 'Aims of the study' (see Appendix A for interview guide). All members of the family clinic team were interviewed, including admin staff (n=6). The views of all members of the CFCS team were sought, although time constraints, staff sickness, annual leave meant that it was only possible to interview 3 of the 9 non-family clinic team members. Notes were taken during and immediately after each interview regarding key themes and areas of interest to explore in future interviews. The interviews were recorded on audio-tape to aid the analysis. Interviews were not transcribed due to time constraints.
2. Audit of all cases offered at least one appointment by the family clinic since it began operating (although families had not necessarily attended). 37 case files were examined in total. A further 5 were not audited as case files had been sent on to other services if the child had moved out of the area, or had been held by other CFCS teams.

Demographic data, data relating to complexity factors (based on the CFCS screening criteria for considering new referrals), data relating to reason for referral, intervention, and outcome was recorded on data sheets devised for the study (see Appendix B). This data was entered onto a database (SPSS).

3. Informal participant observation as a trainee clinical psychologist on a five-month placement in the CFCS, which included attending team meetings, family clinic meetings, participating as a member of the reflecting team in the family clinic, as well as informal discussions with team members.
4. An audit of referrals to the CFCS between January and September 2002 (Hewitt, 2003), and an audit of the 'Complex Case Project' in a neighbouring CFCS (deFries & Herd), on which the family clinic was based.

Data analysis

A thematic analysis of interview data was conducted using a meaning condensation approach (Kvale, 1996), on the basis of interview notes and re-listening to audio-recordings of the interviews. The emergent themes are categorised in tabular form in the results section, with an indication of how frequently particular views were expressed.

A database was created for the purposes of analysing the audit data as a database was not kept by the family clinic (Appendix D). Data was analysed using SPSS and Excel computer packages to provide descriptive statistics.

Results

Q1: the role of the family clinic within the CFCS

Key issues emerging from the interviews included the following (see also Table 2):

1. The family clinic tended to be talked about within a developmental context, and was seen to have become an established and integral part of the CFCS service.
2. Family clinic and CFCS team members held implicit views about referrals appropriate for the family clinic, and these were fairly homogenous, although there is no explicit guidance or processes for allocating cases to the family clinic.
3. Views were expressed that the family clinic should focus on intervening with complex cases, particularly given the considerable time and technological resources involved. However, the view that a systemic family clinic approach is appropriate for a wide range of referrals where relational issues appear to be contributing to the problem was also widely held. Some suggested that both complex and more straightforward cases are / should be accepted, and that difficult issues often only emerge once a family has been seen. In comparison with other local family clinics, the cases were seen by some to be less complex. In relation to the above issues, audit data indicates the following:
 - With regards to legal status, there were far fewer cases involving criminal proceedings, police, child protection, and the care system compared with cases seen by the 'complex case project' (see Table 5).
 - The most common factors mentioned in the referral information (from referrer and family) were behavioural problems (26 cases – 70%), parental conflict / divorce (14 cases - 38%), school exclusion / refusal (8 cases – 22%), domestic violence (8 cases – 22%), and parental mental illness / substance abuse / alcohol abuse (8 cases – 22%). These figures are very high compared with cases referred to the CFCS (32%, 4%, 2%, 0.8%, unrecorded respectively), although the audit conducted by Hewitt (2003) does not provide information

about cases actually accepted (59% of referrals) by the CFCS and it seems likely that these issues are more prevalent in the clinic population.

- Two or more complexity factors were mentioned in the referral information of 86% of the cases seen. Due to a lack of data for earlier cases, complexity scores used by the clinic could not be utilised in this study.
 - Other agencies most commonly involved were educational support (e.g. behaviour support unit, educational psychology)(8 cases – 22%), social services (6 cases – 16%), and a Tier 2 family centre (14%).
4. Some confusion was expressed regarding allocation of cases – cases are sometimes allocated at the CFCS team meeting, sometimes cases on the waiting list are discussed by the family clinic team, and sometimes one of the family clinic team will take a referral from the waiting list and offer an appointment. It was not felt to be clear whether families are told that they are on a waiting list specifically for the family clinic, although several respondents suggested this would be preferable.
 5. It was felt that the family clinic rarely is included in a ‘package of care’, as is often the case in other local clinics. Other CFCS team members were involved in only 5 cases (14%) (Figure 4). 12 (32%) cases were stand alone, with a further 13 (35%) involving one other agency only (Table 4). It was unclear why such multidisciplinary / multi-agency working was relatively uncommon.
 6. It was noted that other CFCS team members rarely referred cases to the family clinic. Only 4 cases (11%)(Figure 2) were referred by other members of the CFCS - these were all by the psychiatrist or a member of the family clinic. It was unclear whether this was due to a reluctance to refer to the family clinic, or to a lack of need to do so. It may be that open communication and close working relationships within the CFCS team means that discussions about referring to the family clinic take place on an informal basis and decisions made not to refer.
 7. Members of the family clinic described their approach as broadly systemic, acknowledging the varying experiences of systemic training within the team. The approach was seen to involve conceptualizing families as systems connected to other

systems, understanding multiple perspectives and relational issues, not placing blame on any one part of the system, and considering gender, social, cultural issues and power differences.

8. Clinicians within the clinic described their approach as very open and transparent, whereas other members of the CFCS talked more in terms of the mystique and the perception that interpretations would be kept hidden from families.
9. Respondents often mentioned the considerable resources involved in operating a family clinic, and there was discussion of how these should best be utilized – for instance, the view was expressed that supervision and training elements should be integral to the approach in addition to clinical work.

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Table 2: Summary of views expressed regarding the perceived role of the family clinic within the CFCS

Views expressed (frequency – number of participants expressing view)
<p>Evidence-based practice and choice</p> <ul style="list-style-type: none"> • Core therapeutic treatment option (4) supported by evidence base (3) • Part of service provision strategy across county - expectation from management that every CFCS will offer systemic family therapy (4) – although the trust does not monitor what is being provided so may be significant differences between services (1) • Offering choice for service users (1)
<p>Process of allocating cases to family clinic</p> <ul style="list-style-type: none"> • Information in referral letter or family questionnaire indicates problems in relationships within family (3) - more effective to look for what does not fit rather than what does fit as most problems appropriate for a systemic approach (1) • Cases where child appears to be symptom of wider family problems (1) • Cases where difficulties are around relationships rather than psychiatric problems (2) although need to be flexible as somewhat arbitrary distinction (1) • Family clinic should be considered as part of a package of work with other CFCS members or other agencies (1) • 90% of cases allocated to family clinic can be predicted by non-clinician – decisions are usually clear-cut – little discussion in team meetings about different options (1) • Cases should be discussed with family clinic team before offering appointment, but not always possible due to time constraints and difficulties convening outside family clinic slot – some cases selected by one or two clinicians from the clinic rather than as a team(2) • Lack of clarity about how cases are allocated – unsure if families are told they are on waiting list for family clinic or a general waiting list (1) • Differences across different CFCS teams re: how cases are allocated (1) • Need for a balance between complex and more straightforward cases (2) – would need to do more marketing to attract enough complex referrals to fill family clinic slots (1) • Some cases are not appropriate for working without support of a team (1)
<p>Cases seen within family clinic</p> <ul style="list-style-type: none"> • Family clinic developed as service for more complex cases (e.g. difficult environmental context, abuse, domestic violence). Cases tend to be less complex than those seen in other family clinics locally, or tend to be more appropriate for social services (2) • Predominance of children with aggressive behaviour (1) domestic violence (1) • Cases where there is a need to look at the system (3) • Seem to be fewer cases where a package of help is offered compared with other local CFCS teams (1)
<p>Lack of referrals from or to other members of the CFCS</p> <ul style="list-style-type: none"> • We hardly get any referrals from within the CFCS team compared with other clinics (1) • Maybe discouraging inappropriate referrals has made people wary about making any referrals at all (1) • Tendency for clinicians to 'hold onto' cases once open to them (2)
<p>Clinical approach</p> <ul style="list-style-type: none"> • 'Eclectic' – depends on clinician's training (2) • Broadly systemic approach (4) – involving members of the system rather than the child only (4) looking for alternative ways of dealing with problems within family (1) thinking of families as systems connected to other systems, thinking about gender, social and power difference (1) • Different approach from family work without equipment (2) • Emphasis on multiple perspectives, not locating problem within child – non-blaming approach (3) • Very open and transparent approach (1)
<p>Roles beyond clinical work</p> <ul style="list-style-type: none"> • Role should include supervision and training as well as just seeing families – hard to justify use of clinicians' time and technological resources otherwise (2)
<p>Outsiders perceptions of 'what goes on' in the family clinic</p> <ul style="list-style-type: none"> • Observing team give feedback to families – families are observed interacting (2) although difficult to observe families as they won't behave naturally (1) • Managing transition and the role of terminology – 'family clinic workshop' helped family clinic establish a role alongside more psychodynamic approaches – feels as if systemic family therapy approach has become an established part of the service (1) • Perception that the approach is a 'bit cloak and dagger' (1). • As an outsider it is important that we have an understanding of what goes on so we can reassure families (1) / prepare them about what expect and what might be gained (2) • Individuals within the family clinic team are very dynamic – imagine they offer a very dynamic and forward thinking service (1)

Figure 1: Age by Gender of Cases Referred to the Family Clinic

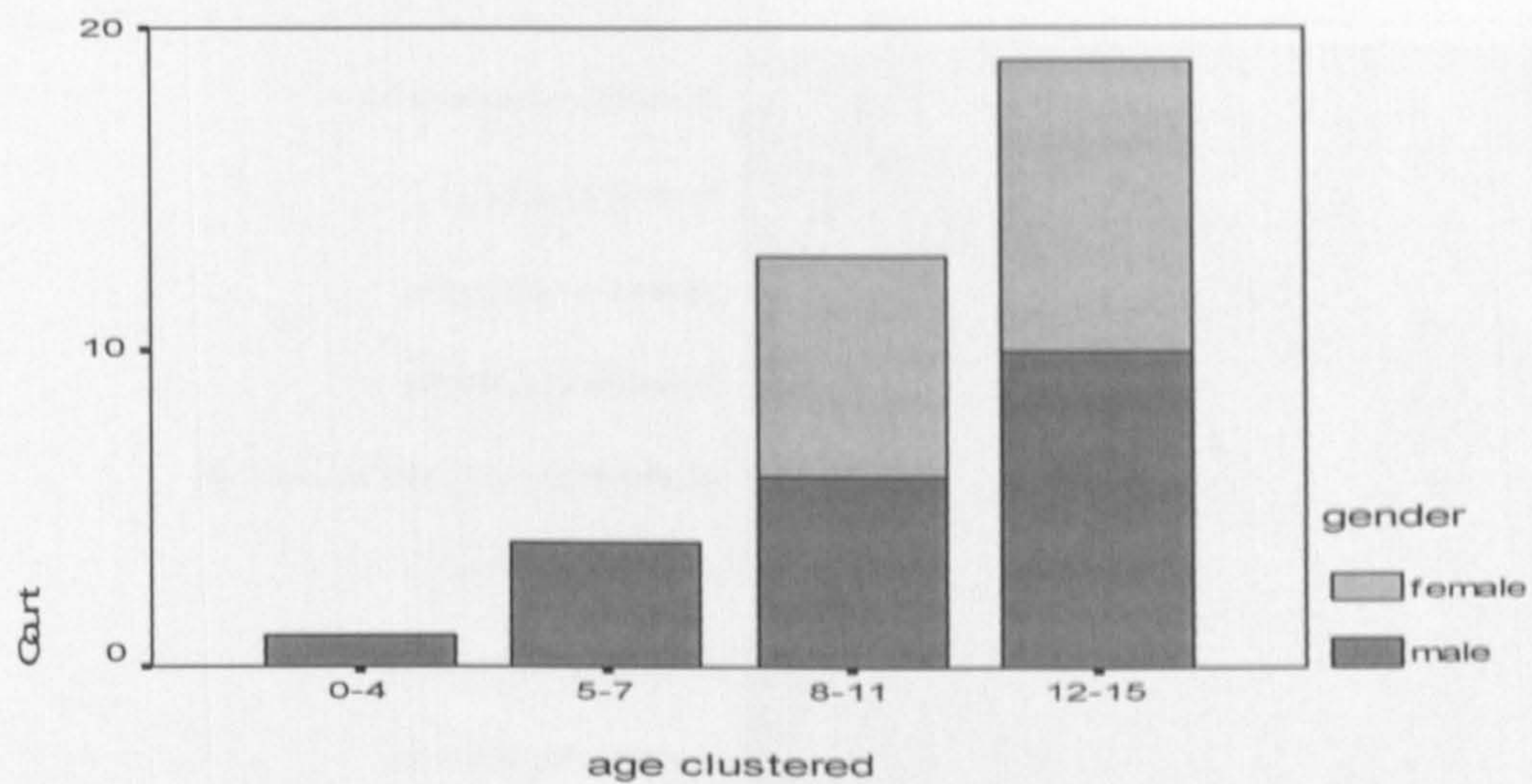


Figure 2: Source of Referral to the Family Clinic

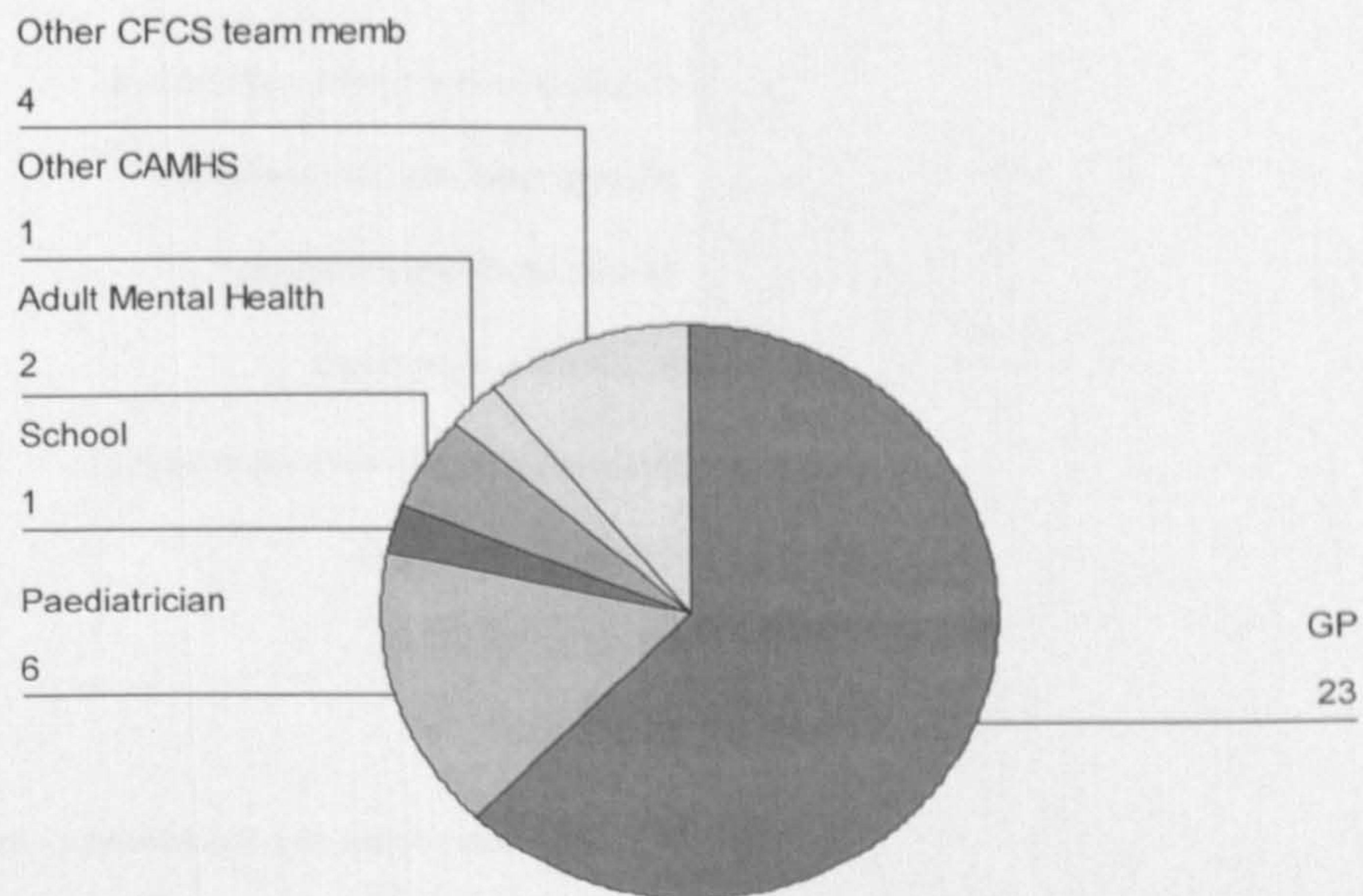


Table 3: Number of problems mentioned in referral information

Number of problems in referral information (complexity factors)	Number of cases (% of cases)
One	5 (14%)
Two	12 (32%)
Three	11 (30%)
Four	3 (8%)
Five or more	5 (14%)

Figure 3: Problems Mentioned in Referral Information (No. and % of cases)

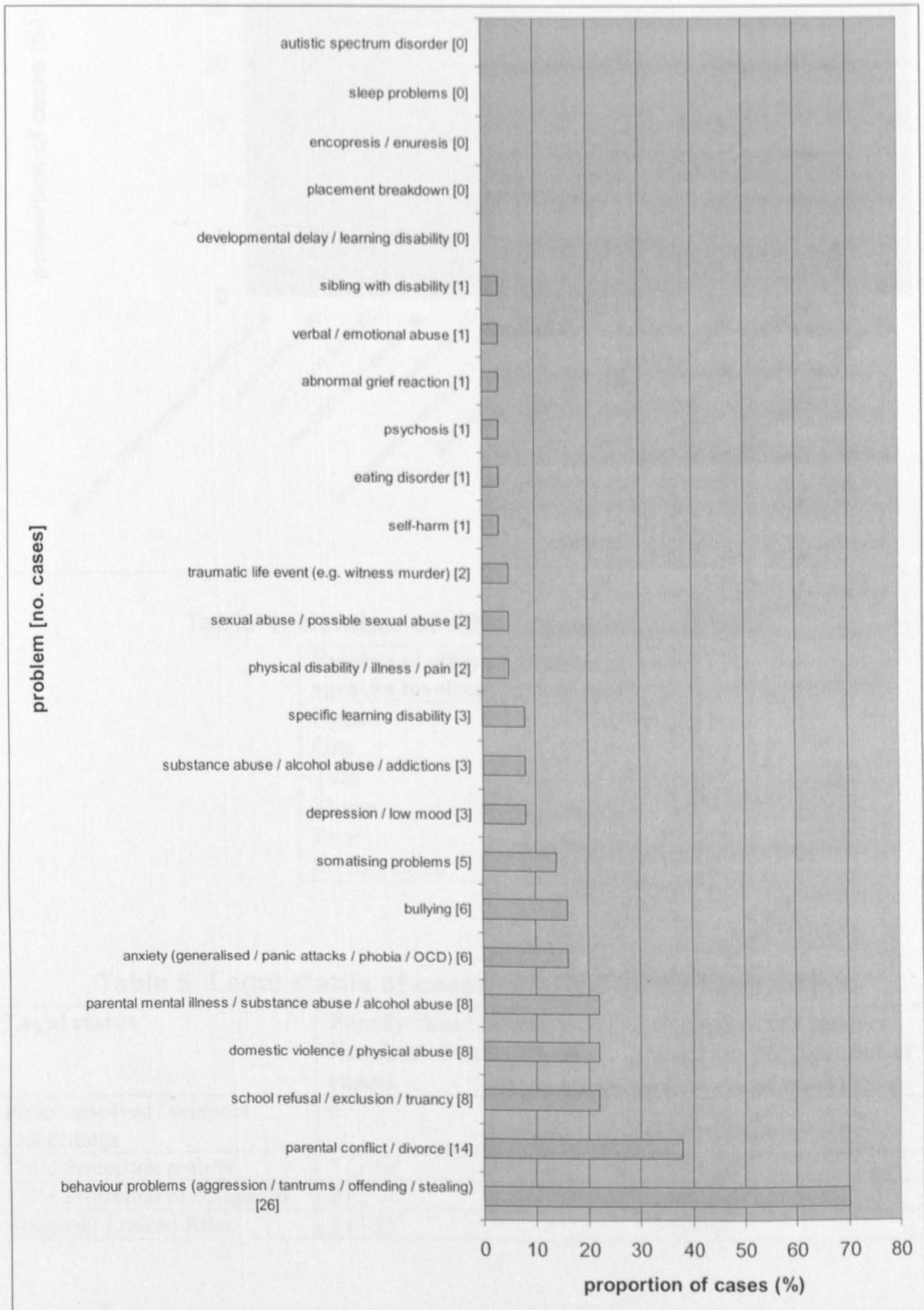


Figure 4: Other agencies involved (No. and % of cases)

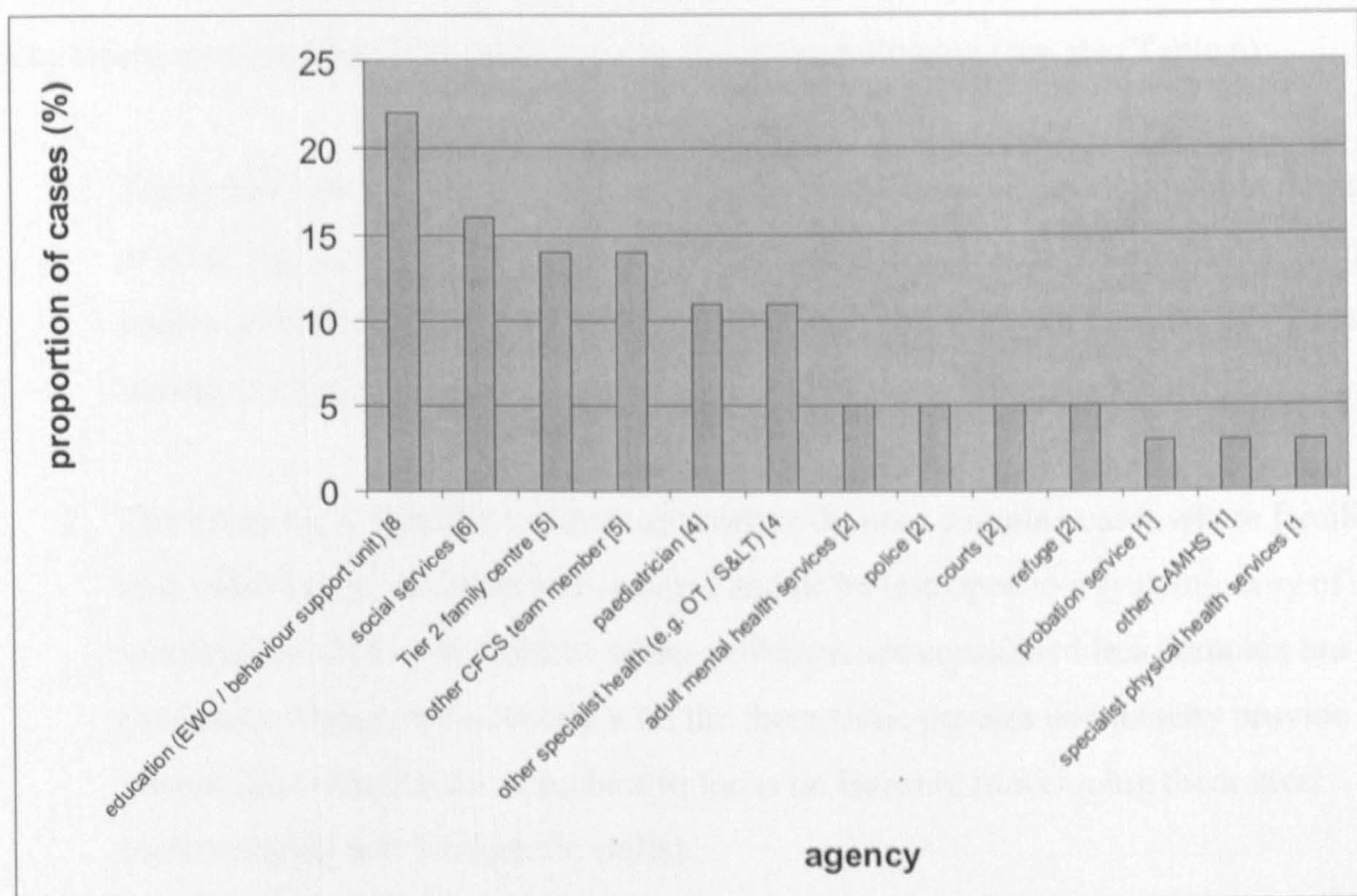


Table 4: Number of other agencies involved

Number of other agencies involved	Number of cases (% of cases)
None	12 (32%)
One	13 (35%)
Two	9 (24%)
Three	1 (3%)
Four	1 (3%)
Five or more	1 (3%)

Table 5: Legal status of cases referred to the family clinic

Legal status	Family clinic audit (n=37) Number of cases (% of cases)	Complex case project audit (n=36) Number of cases (% of cases)
Police involved / criminal proceedings	0	6 (17%)
Child Protection register	1 (3%)	4 (11%)
Child Protection investigation	2 (5%)	2 (6%)
Adopted / Looked After	2 (5%)	5 (14%)

Q2: the impact of the family clinic

Key issues emerging from the interviews included the following (see also Table 6):

1. The family clinic provides a useful context for professional development in terms of receiving feedback on clinical practice from colleagues, developing a theoretical understanding of difficulties, being more focused in work with families as well as having the opportunity to expand one's thinking about problems.
2. The dilemma of whether to focus on work with more complex cases where families may often cancel or not attend sessions and/or be less open to a systemic way of working, or work with families where problems are considered less complex but the family engage more readily with the therapeutic process and thereby provide greater opportunities for clinicians to focus on learning (developing theoretical understanding and therapeutic skills).
3. The introduction of the family clinic has helped broaden the CFCS team's thinking about the kinds of cases that should be seen within the CFCS.
4. There is the perception that there are many cancellations and that the strategy of admin phoning the family the day before an appointment is not entirely successful in that appointments can then not be offered to another family at such short notice, although it is helpful in that it does enable clinicians to be aware that a family will not be attending and thus make alternative plans. The audit data indicates that 12 (35%) of the families did not attend or cancelled at extremely short notice on at least one occasion. A cross-tabulation of number of DNA's by number of sessions attended (Table 7) indicates that families most likely to DNA were those who attended only one or two sessions, and that it was extremely rare for those who attended more sessions or no sessions to DNA.
5. In terms of outcome, it was felt to be very difficult to predict who will benefit from family therapy, and also how to judge a successful outcome. The audit data indicates that
 - 8 cases (22%) were ongoing at the time of the audit, 20 (54%) were closed after the family declined further appointments or DNA'd, 6 (16%) were closed mutually following discussion between the family and clinic, 1 (3%)

was referred to another agency, and 2 (5%) were referred on within the team (see Appendix E8).

- Most (74%) cases were open for 0-4 months.
- Most cases (87.5%) were offered appointments at intervals of 4 or more weeks (see Appendix E6).
- In terms of sessions attended, 7 (19%) families did not attend any sessions, 13 (35%) attended one or two sessions, 10 (27%) attended 3-5 sessions, with the rest (7 cases, 19%) attending 6-10 sessions (see Appendix E10).
- In terms of waiting time, 75% of families were offered an appointment within 18 weeks of referral (returning their questionnaire), with 28% of families being seen within 6 weeks of referral (see Appendix E3).

Table 6: Summary of views expressed regarding the impact of the family clinic

Views expressed (frequency – number of participants expressing view)	
On professional development	
<ul style="list-style-type: none"> Useful as learning / training experience (2) Useful for team members to get direct feedback on their practice from colleagues (1) Tend to work in a more focused and disciplined when working with a reflecting team – tend to 'go with the flow' otherwise (1) Working with a reflecting team helps broaden as well as focus thinking about a case – although anxiety provoking, having a reflecting team aids theoretical understanding (2) Dilemma of whether only to accept complex cases or to accept a balance of complex cases where families may often cancel sessions or not open themselves up to the process, and more straightforward cases where family clinic is not necessarily indicated but where they turn up for sessions, engage in process, and thereby offer opportunity for clinicians to develop skills and understanding (1) 	
Perceptions of family perspective	
<ul style="list-style-type: none"> Power issues - 'a bit cloak and dagger' – sense that one-way screen and use of video may undermine families (1) Lack of choice over intervention offered (1) Imagine a lot of thinking goes on / drinking a lot of coffee (1) 	
On multidisciplinary / multi-agency working	
<ul style="list-style-type: none"> Valuable opportunity to work as a team and think systemically about problems – do not have the opportunity in day to day work (1) Aids relationship with other local CFCS teams (2) Family clinic has had an impact on the culture of the CFCS in terms of broadening thinking about the kinds of cases accepted by the team (2) 	
Efficiency of the service	
<ul style="list-style-type: none"> There seem to be a lot of cancellations (2) Phoning families the day before appt helpful in terms of informing clinicians if family is not planning to attend, but does not leave time for an appointment to be offered to another family (2) Families are asked to confirm appointment 2 weeks before-hand, but the consequences of not doing so are not clear / not followed through – leads to wasted slots in family clinic. Difficult to judge as many families do not confirm but still turn up to appointment (1) 	
Effectiveness	
<ul style="list-style-type: none"> Difficult to predict who will benefit from family clinic – necessary for family members to be able to reflect on roles and relationships, to be curious – important that relationships have not broken down irrevocably (2) – important that families are able to tolerate technology and see the benefits (e.g. feeling reassured that a team is thinking about them) as outweighing the threats (1) Outcomes difficult to measure (2) 	

Table 7: Number of DNA's by number of sessions attended cross-tabulation

Number of DNA's * number of sessions attended Crosstabulation

Count		number of sessions attended										Total
		0	1	2	3	4	5	6	7	9	10	
Number of DNA's	0	5	1	3	6	2	1	3	2	1	1	25
	1		3	1	1							5
	2	2		3								5
	3		1	1								2
Total		7	5	8	7	2	1	3	2	1	1	37

Q3: future development of the family clinic

Key issues emerging from the interviews included the following (see also Table 8):

1. Current barriers to effective development of the family clinic service include transitions in personnel, not having a permanent family therapist post in the team which makes it difficult to take a long-term view on service development, and differences in opinion within the team about how or whether the service should develop its practice.
2. Several members of the family clinic felt that there should be a greater emphasis on development of systemic skills and understanding, which could be done more formally. It was felt that this could be incorporated into the session, as well as by making better use of cancellations. Others felt that this aspect of the clinic to be less important.
3. Several respondents felt that the clinic should attempt to identify ways of engaging more effectively with families. This could be through developing a system for requesting feedback on why families DNA or drop out of therapy, offering more flexible appointment times, preparing families better for what to expect, and by adopting a more open and transparent stance when having reflecting conversations.
4. Several respondents felt that efforts should be made to manage the clinic more efficiently given the resources involved. This could be through having a clearer system in place for dealing with families who do not confirm or cancel appointments, with advanced telephone reminders and clearer consequences of failing to inform the clinic that they will not be attending.
5. Several respondents felt that it would be helpful for CFCS team members to gain a clearer understanding of what goes on in the family clinic in order that they can communicate better with families about what to expect from accepting such an approach – this was felt to be the case both for potential referrers and for admin staff. Team meetings, direct observation, and presentations at practice workshops were all felt to be potential means of increasing awareness. Several respondents said that they felt that the family clinic team would be open to having observers but that they had not chosen to do so.

Table 8: Summary of views expressed regarding future development of the family clinic

Views expressed (frequency – number of participants expressing view)
<p>General comments about service development</p> <ul style="list-style-type: none"> • family clinic currently in a state of flux – development depends on who is around and who has the strongest voice (1) • difficulty of taking a long-term view re: service development when systemic family therapists employed only on short-term contracts (2) • feels like we talk too much at the moment about where we are going – we are all different and have to manage our differences (1) • should be taking on more complex cases (1) vs balance works well as it is (2)
<p>Clinical skills development</p> <ul style="list-style-type: none"> • More emphasis on development of theoretical understanding and skills development (4) • Continued emphasis on clinical work rather than theoretical and skills development (1) • Should make use of slots where families DNA rather than going off on our own (2) • Develop links with other agencies and consider strategy for dealing with issues of domestic violence (1)
<p>Engaging with families</p> <ul style="list-style-type: none"> • Consider alternative means of preparing families better for family clinic (2) • Understanding why families DNA or drop out of family clinic (2) • Imagine that families would want more flexible appointment times (1) • Should be more open with families by having reflecting conversations in front of them rather than privately as a team (1)
<p>Improving efficiency of the family clinic</p> <ul style="list-style-type: none"> • Understanding why families DNA (2) – current lack of formal feedback system from referrers makes it difficult to improve practice (1) • Families are treated with 'kid gloves' compared with, say, a GP surgery – the system should expect families to take more responsibility for their actions (e.g. DNA / cancel the day before) (1). Families should be made aware of how much time is being wasted if they DNA or cancel the day before an appointment (1). • Should follow-up families who have not confirmed appointment 2 weeks before so that appointment can be offered to another family where necessary – should not wait until the day before to phone family to check whether they are planning to attend – awareness that any system is not foolproof but would improve efficiency / capacity (2). • I wonder how time is used when families do not turn up (1)
<p>Improving CFCS team's understanding of 'what goes on' in the family clinic</p> <ul style="list-style-type: none"> • Would be useful for 'outsiders' to observe a session to better understand how the family clinic operates, what the aims are and the approach used for working with families. This understanding would help staff to communicate with families and provide some reassurance / information about what they are letting themselves in for (2). • Admin staff perceptions are as important as those of other clinicians as they are an important contact point for families (2). • Aware that family clinic team have offered for others to observe a session, but feel uncomfortable (1) have not taken up offer (1) • Would be useful for family clinic cases to be presented in mid-county practice workshops as a means of disseminating information and increasing profile of the family clinic (2)
<p>Multidisciplinary working</p> <ul style="list-style-type: none"> • Family clinic team should not hoard all the tea cups in the building (1) • Missing out on discussions as many conversations about cases seem to happen outside formal setting of family clinic (1)

Discussion and conclusion

Key findings, service implications, and emergent questions

General agreement was expressed by interviewees that the family clinic had developed an important and integral role within the CFCS, supported by research, and, to a certain extent, trust policy. However, divergent views were expressed regarding the perceived purpose and functioning of the family clinic, which may impact on the referrals received, and the work done within the context of the family clinic. This divergence in views appears to be reinforced by the fact that the remit of the service is implicit rather than explicit. For instance, although early development of the clinic was based on a complex case project based on systemic and social work principles, the clinic appeared to deal more broadly with cases referred to the CFCS where difficulties with family dynamics were highlighted in the referral information.

The issue of resources was highlighted by many respondents, and the need to make the most of the significant resources (personnel, technological etc) involved in providing the service. Many respondents highlighted the differences between work with families within and outside the context of the family clinic, where a reflecting team is not available. However, dilemmas were expressed regarding the function of the clinic, whether the emphasis should be on therapeutic work with families, training, supervision, professional development, multi-agency working, working with complex social problems or focusing on work with families who were more likely to embrace a systemic approach to resolving their difficulties (and hence providing more opportunities for meeting the training needs of the family clinic team). Although these are clearly not mutually exclusive, the disparity of views appeared to compromise the identity of the family clinic. It was inferred that this will impact on the types of cases referred to the family clinic, particularly if a proactive approach is not being made to attract certain types of referrals (e.g. from social services).

In terms of the organizational life cycle, the structure of the CFCS would appear to support innovation and change. Hall (2002) draws on the organizational research literature to suggest that organizations with high complexity in professional training, decentralization of power, low formalization, low stratification in the differential distribution of rewards, an emphasis on quality rather than quantity, and high levels of job satisfaction are associated with high levels of innovation, which all appear to be characteristics of the team. Factors highlighted in determining whether change will take place include costs involved in

introducing changes in practice, perceived benefits of change, perceived costs and risks of change, compatibility with existing practices, evidence-base for the new practice, whether innovation comes from within or outside the organization, whether things could return to how they were if the change is not successful, and how the development will affect the organization as a whole (Zaltman et al, 1973). Within this framework, some of the proposed innovations highlighted in the interviews involve minimal costs, such as attempting to reduce the number of wasted sessions through revising admin procedures relating to contacting families in advance of the session. Other proposed innovations are clearly more potentially costly to the team where a lack of consensus could result in change being construed in a negative as well as positive light by different parties.

The difficulty of judging what is a successful outcome was highlighted by several of those interviewed. Although audit data provides some basic information on outcome, a major shortcoming of this piece of work is that the views of families and referrers were not sought. This would have provided useful information into issues such as the perceived impact of attending the family clinic, perceptions of what was helpful or unhelpful, why families DNA, what is seen as a meaningful outcome, what families' experiences of the family clinic were. Such information would assist with service planning as well as evaluating the effectiveness of the service and any new innovations.

In terms of service implications, an attempt has been made to examine the function and functioning of the family clinic within the CFCS, highlighting some of the conflicts between individual needs and organisational life cycle, discrepancies between beliefs and actions, developmental stage of the organisation (Campbell et al, 1991). It is hoped that this piece of work will provide information that is of some use to the service both in terms of providing a current picture and to facilitate future service planning.

Several participants commented that taking part in the study has had an impact in itself by focusing attention on service issues and potential innovations. Firth-Cozens (1993) comments that such participation in audit often has an impact in terms of prompting reflection and team discussion, independent of the results. It was apparent from conducting the study that the team was already in the process of reflecting on their practice, and the study may merely have enhanced the process of making connections and hence facilitating change (Campbell et al, 1991).

In terms of improving practice, the case study is only one aspect of the range of methods available for improving clinical practice. Cape & Barkham (2002) review the research literature and conclude that multiple practice improvement methods (PIM)(see Figure 5, below) are more likely than single PIM's to impact on clinical practice and patient outcomes, particularly where they are owned by the service rather than imposed from outside. Clearly there is potential within the family clinic to expand the range of practice improvement methods available, for example through clinical audit (see Figure 6, below), monitoring outcomes through, for example, developing formal procedures for gaining feedback from families and referrers, introducing education, training, and supervision elements to clinical practice, although such developments would clearly take place within the constraints of day-to-day clinical practice.

Figure 5: Three-stage pragmatic model of practice improvement methods (Cape & Barkham, 2002)

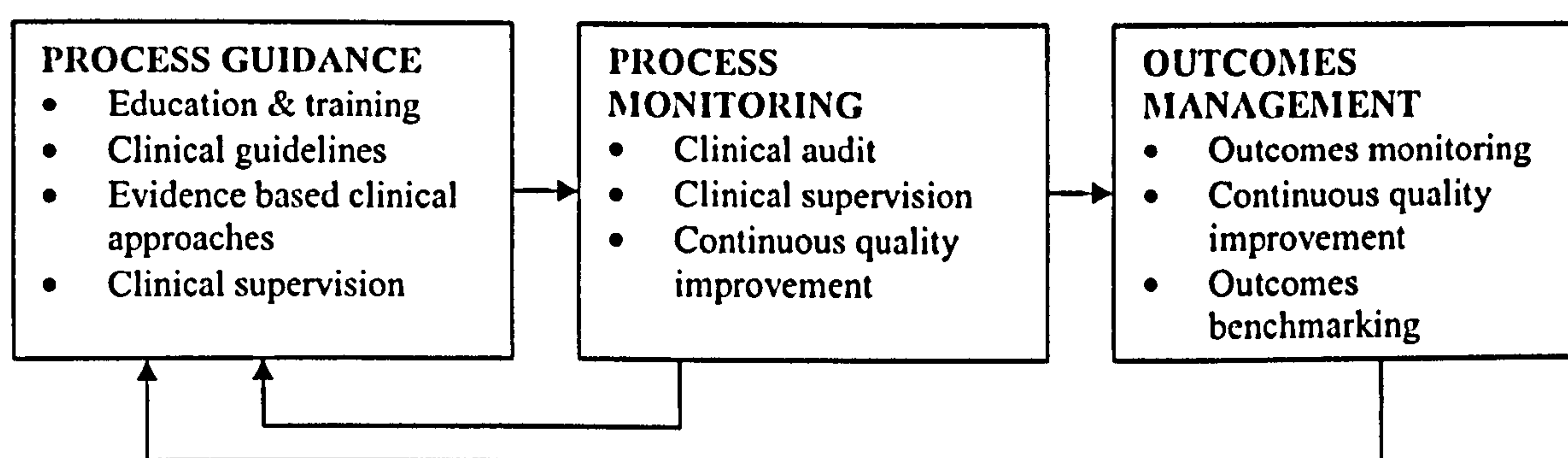
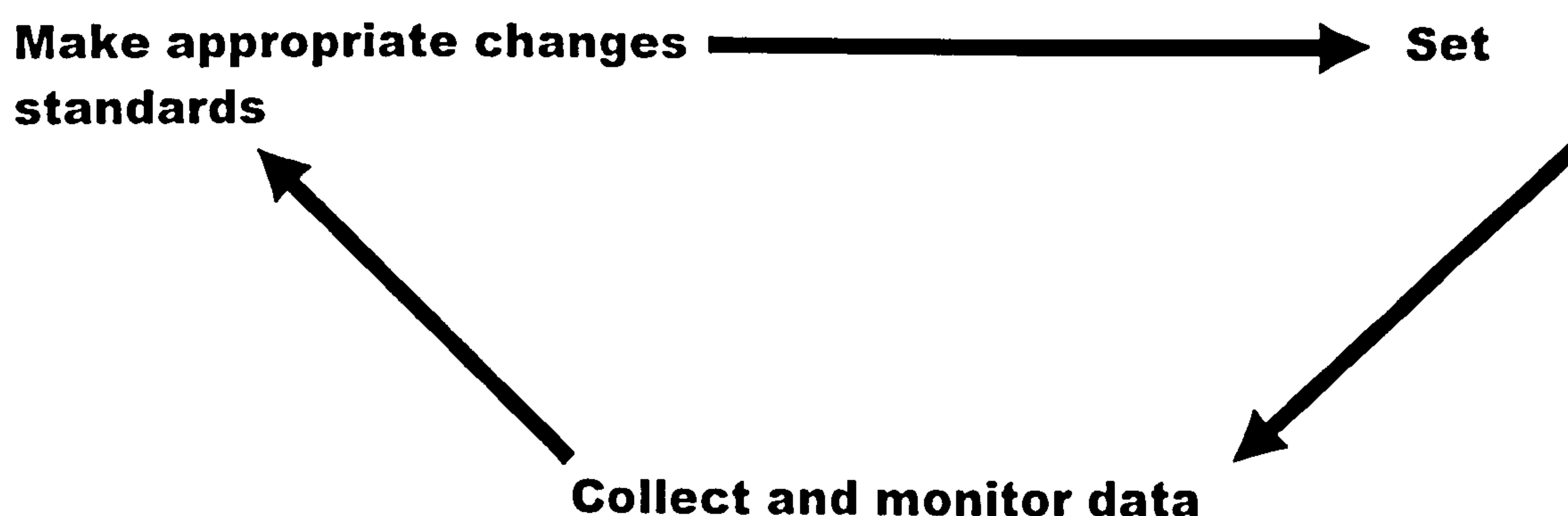


Figure 6: The simple version of the audit cycle (Firth-Cozens, 1993; p28)



Methodological considerations

In terms of validity of the findings, efforts were made to integrate multiple sources of evidence, although the validity of the findings reported could have been improved by requesting key informants to review this report prior to its submission. The results will be

presented to the family clinic and CFCS, although it is acknowledged that this phase should have been integrated more effectively into the process.

A further limitation is that the views of all members of the CFCS team were not included, due to difficulties gaining these views within the time constraints. In retrospect these views could have been canvassed through more creative means such as the use of questionnaires or telephone interviews. However, this report is considered to be merely part of a process rather than an end 'product' in itself.

The case could have been illuminated further by the inclusion of feedback from families who had attended the clinic. In terms of its significance, this case study is only considered significant at a local level rather than saying something of wider significance about services.

In terms of the audit data, it is acknowledged that these are of limited significance due to the difficulties of gaining comparable information about process and outcome from the casenotes. If these issues are considered important to the service, a system of monitoring process and outcome consistently across cases would need to be introduced.

Reflections on own learning

It is acknowledged that, in comparison to an 'ideal case study' (Yin, 2003), the current study is lacking, particularly in terms of the relative lack of explanation building and the absence of multiple cases. However, I considered it a useful learning experience and one that hopefully provides some useful information to the clinic. In retrospect, I would have spent more time developing the research questions and hypotheses with the family clinic team, and integrating theory / explanation building more fully into the data collection and analysis strategy. However, I recognise that this service related project has been conducted within strict time and resource constraints, and within the context of limited input on organisational theory, systemic principles, service development and work with organisations at this stage of clinical psychology training.

References

- Andersen, T. (1987). The reflecting team: dialogue and meta-dialogue in clinical work. *Family Process*, 26, 415-28.
- Audit Commission (1999). *Children in Mind: Child and Adolescent Mental Health Services*. London: Audit Commission.
- Barrett, P.M. & Ollendick, T.H. (eds.) (2004). *Handbook of Interventions that Work with Children & Adolescents – Prevention and Treatment*. Chichester: Wiley.
- Buchanan, A. (2002). Family Support. In D. McNeish, T. Newman, H. Roberts (eds.), *What Works for Children?* Buckingham: Open University Press.
- Campbell, D., Draper, R. & Huffington, C. (1991). *A Systemic Approach to Consultation*. London: Karnac.
- Cape, J. & Barkham, M. (2002). Practice improvement methods: conceptual base, evidence-based recommendations. *British Journal of Clinical Psychology*, 41, 285-307.
- Carr, A., McDonnell, D. & Owen, P. (1994). Audit and family systems consultation: evaluation of practice at a child and family centre. *Journal of Family Therapy*, 16, 143-157.
- Carr, A. (ed.) (2000). *What Works with Children & Adolescents? A Critical Review of Psychological Interventions with Children, Adolescents and their Families*. London: Routledge.
- Chase, J. & Holmes, J. (1990). A two-year audit of a family therapy clinic in adult psychiatry. *Journal of Family Therapy*, 12, 229-242.
- deFries & Herd. Outcome of Pilot Study of the Complex Case Project. Maldon Child & Family Consultation Service.
- Dallos, R. & Draper, R. (2000). *An Introduction to Family Therapy – systemic theory and practice*. Buckingham: Open University Press.
- Department of Health (2003). *Getting the Right Start: National Service Framework for Children: Emerging Findings*. HMSO.
- Ferlie, E., Wood, M., & Fitzgerald, L. (1999): Some limits to evidence based medicine: a case study from elective orthopaedics. *Quality in Health Care*, 8, 99-107.
- Firth-Cozens, J. (1993). *Audit in Mental Health Services*. Hove: Lawrence Erlbaum.
- Fitzgerald, L. (1999). Case studies as a research tool. *Quality in Health Care*, 8, 75.
- Fonagy, P., Target, M., Cottrell, D., Phillips, J. & Kurtz, Z. (2002). *What Works for Whom? A Critical Review of Treatments for Children & Adolescents*. London: Guilford Press.
- Hall, R.H. (2002). *Organizations – Structures, Processes, and Outcomes* (8th edition). Upper Saddle River, NJ: Prentice Hall.

Hewitt, A. (2003). *An Audit Examining the Appropriateness of Referrals to a Tier 3 Child and Family Consultation Service*. Small scale research project completed as part of University of Hertfordshire Doctorate in Clinical Psychology.

Kurtz,Z. (1996). *Treating Children Well: a guide to using the evidence base in commissioning and managing services for the mental health of children and young people*. London: The Mental Health Foundation.

Kvale,S. (1996). *InterViews – an introduction to qualitative research interviewing*. London: Sage.

Lang,W.P., Little,M. & Cronen,V. (1990). The systemic professional domains of action and the question of neutrality. *Human Systems: The Journal of Systemic Consultation and Management*, 1, 39-55.

NHS Modernisation Fund and Mental Health Grant for Child and Adolescent Mental Health Services (CAMHS) 1999 / 2000. Health Service Circular 1999/126 : Local Authority Circular (99) 22

North Essex Mental Health Partnership (2003). *Referral guidelines for Child & Family Consultation Services in North Essex*.

Rutter,M. & Smith,D. (1995). *Psychosocial Disorders in Young People*. Chichester: Wiley.

Yates,P., Garralda,M.E. & Higginson,I. (1999). Paddington Complexity Scale and Health of the Nation Outcome Scales for children and adolescents. *British Journal of Psychiatry*, 174, 417-423.

Yin,R.K. (2003). *Case study Research: Design and Methods (Third Edition)*. London: Sage.

Zaltman,G., Dunvan,R., & Holbek,J.(1973). *Innovations and Organisations*. New York: Wiley.

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Appendix A: Interview topics

- *role of the family clinic*
- *what cases should be seen*
- *how are decisions made to see a family*
- *what is being offered clinically? (therapeutic approach)*
- *how could the service be improved? clinically /admin wise*
- *what does the service do well*
- *pathways into family clinic*
- *name of service*
- *who would you refer to family clinic?*

Appendix B: Audit data coding sheets

Category	Information from file	Code
Referred Child -name - age at referral - gender		
Legal status (CP register, adopted, looked after, investigation etc)		
Agencies involved (ss, other health, legal, other team members etc)		
Referrer (GP, SS, paediatrician, school etc)		
Referral problem -main reason - other information in referral letter / family questionnaire		
Who was seen in family clinic? (parents, child, other agencies, other family etc)		
Input - date referred - date questionnaire returned - date 1 st appt - date last appt - date closed - dates of sessions - dates of DNA / last minute cancellations		
Outcome - (ongoing, closed, referred on, declined input, moved from area etc)		

Appendix C: CFCS complexity/ referral criteria (North Essex Mental Health Partnership, 2003; based on Yates et al, 1999)

Psychosis / borderline states	5
Deliberate self-harm	5
Severe anxiety	4
Severe isolation and withdrawal	4
Depression	4
Obsessive Compulsive Disorder	4
Severe reaction to trauma	4
Eating disorders	4
Severe somatising disorders	4
Under 9's with conduct disorder / severe aggressive behaviour	3
Hyperkinetic disorder	3
Prolonged adjustment difficulties (e.g. abnormal grief reactions)	3
Clinical presentations complicated by neuro-developmental factors (e.g. autistic spectrum) and / or physical health difficulties (e.g. diabetes)	3
Family relationship problems with associated severe distress and symptomatology in the child	3
Adolescent conduct disorder	2
Sleep disorders	1
Simple soiling / wetting problems	1
Normal distress related to parental divorce	1
Normal distress related to bereavement	1
Substance abuse	1
Offending behaviour	1
For the following circumstances and factors additional weighting is allocated	
Duration of problem > 6 months	1
Excluded / refusing / out of mainstream school / school action plus	1
Looked After child	1
Child Protection Register	1
Adult mental health issues including domestic violence, parental substance misuse, parental physical ill health and bereavement	1
Medical illness / disability	1
Learning disability	1
More than one main problem area	1

*** SCORE ALL PROBLEM AREAS**

*** A MINIMUM SCORE OF 4 IS REQUIRED TO BE ACCEPTED BY THE CFCS**

Appendix D: Database categories (SPSS)

Code

Gender:

1. Male
2. Female

Age (years):

Referrer:

3. GP
4. Paediatrician
5. social services
6. school
7. A&E
8. Refuge
9. Health Visitor
10. Parent / child
11. Adult mental health
12. School support – EWO / Educational Psychology / Behaviour Support
13. other CAMHS
14. Other specialist health services
15. Other CFCS team member

Agencies involved

1. Paediatrician
2. Social Services
3. Adult Mental Health
4. Police
5. Educational support
6. Courts / Probation service
7. Tier 2 family centre
8. Refuge
9. Other health specialist
10. Other CAMHS
11. Other CFCS team member/s

Reasons for referral

1. behavioural problems (aggression, tantrums, stealing, offending etc)
2. self-harm
3. depression / low mood
4. anxiety (generalised, panic attacks, phobia, OCD)
5. parental conflict / divorce
6. developmental delay / learning disability
7. physical disability / illness / pain
8. bullying
9. sexual abuse / possible sexual abuse
10. school refusal / exclusion
11. placement breakdown
12. encopresis / enuresis
13. eating disorder
14. sleep problems
15. autistic spectrum disorder
16. domestic violence / physical abuse
17. psychosis
18. traumatic life event
19. somatising disorders

20. abnormal grief reactions
21. substance abuse / alcohol / addictions
22. parental mental illness / substance abuse / alcohol abuse
23. verbal / emotional abuse
24. specific learning difficulties
25. sibling with disability / significant health problems

Legal status

1. CP register
2. CP investigation
3. adopted
4. police involvement
5. criminal proceedings
6. looked after

Who seen

1. immediate family in household
2. parents only
3. other agencies
4. other family
5. parent no longer part of household
9. not seen

Outcome

1. ongoing
2. family closed
3. mutual closed
4. referred on to other agency
5. referred on to other CFCS team member

Frequency sessions offered

1. weekly
2. fortnightly
3. three weekly
4. four weekly
5. 5 or more weekly

Appendix E: Descriptive statistics – SPSS output

Appendix E1: Legal status

legal status

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	CP register	3	8.1	37.5	37.5
	CP investigation	4	10.8	50.0	87.5
	Adopted	1	2.7	12.5	100.0
	Total	8	21.6	100.0	
Missing	System	29	78.4		
Total		37	100.0		

Appendix E2: who seen in clinic

	who seen in clinic 1
	Count
immediate family	30
not seen	7

Appendix E3: time on waiting list (weeks)

time on wait list (weeks)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	2	3	8.1	8.3	8.3
	4	1	2.7	2.8	11.1
	5	2	5.4	5.6	16.7
	6	4	10.8	11.1	27.8
	7	1	2.7	2.8	30.6
	8	2	5.4	5.6	36.1
	11	1	2.7	2.8	38.9
	13	4	10.8	11.1	50.0
	14	1	2.7	2.8	52.8
	17	3	8.1	8.3	61.1
	18	5	13.5	13.9	75.0
	19	3	8.1	8.3	83.3
	21	2	5.4	5.6	88.9
	22	1	2.7	2.8	91.7
	28	1	2.7	2.8	94.4
	30	1	2.7	2.8	97.2
	38	1	2.7	2.8	100.0
	Total	36	97.3	100.0	
	Missing	System	1	2.7	
Total		37	100.0		

Appendix E4: length of time case open

Statistics

length of time case open (months)

N	Valid	27
	Missing	10

length of time case open (months)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	4	10.8	14.8	14.8
	1	3	8.1	11.1	25.9
	2	4	10.8	14.8	40.7
	3	2	5.4	7.4	48.1
	4	7	18.9	25.9	74.1
	6	1	2.7	3.7	77.8
	7	1	2.7	3.7	81.5
	8	2	5.4	7.4	88.9
	11	1	2.7	3.7	92.6
	15	1	2.7	3.7	96.3
	17	1	2.7	3.7	100.0
	Total	27	73.0	100.0	
Missing	System	10	27.0		
Total		37	100.0		

Appendix E5: number of sessions attended by family

Statistics

number of sessions attended

N	Valid	37
	Missing	0

number of sessions attended

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	7	18.9	18.9	18.9
	1	5	13.5	13.5	32.4
	2	8	21.6	21.6	54.1
	3	7	18.9	18.9	73.0
	4	2	5.4	5.4	78.4
	5	1	2.7	2.7	81.1
	6	3	8.1	8.1	89.2
	7	2	5.4	5.4	94.6
	9	1	2.7	2.7	97.3
	10	1	2.7	2.7	100.0
	Total	37	100.0	100.0	

Appendix E6: Frequency of sessions offered

Statistics

frequency of sessions offered

N	Valid	32
	Missing	5

frequency of sessions offered

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	3	4	10.8	12.5	12.5
	4	20	54.1	62.5	75.0
	5	8	21.6	25.0	100.0
	Total	32	86.5	100.0	
Missing	System	5	13.5		
Total		37	100.0		

Appendix E7: Number of DNA's / last minute cancellations

Statistics

Number of DNA's

N	Valid	37
	Missing	0

Number of DNA's

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	25	67.6	67.6	67.6
	1	5	13.5	13.5	81.1
	2	5	13.5	13.5	94.6
	3	2	5.4	5.4	100.0
	Total	37	100.0	100.0	

Appendix E8: Outcome

outcome

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	ongoing	8	21.6	21.6	21.6
	family closed	20	54.1	54.1	75.7
	mutual closed	6	16.2	16.2	91.9
	referred on to other agency	1	2.7	2.7	94.6
	referred on within team	2	5.4	5.4	100.0
	Total	37	100.0	100.0	

Appendix E9: Crosstabs – number of DNA's by number of sessions attended

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Number of DNA's * number of sessions attended	37	100.0%	0	.0%	37	100.0%

Number of DNA's * number of sessions attended Cros

Count		number of sessions attended					
		0	1	2	3	4	5
Number of DNA's	0	5	1	3	6	2	1
	1		3	1	1		
	2	2		3			
	3		1	1			
Total		7	5	8	7	2	1

Appendix E10: length of time case open (months)

Statistics

length of time case open (months)

N	Valid	27
	Missing	10

length of time case open (months)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	4	10.8	14.8	14.8
	1	3	8.1	11.1	25.9
	2	4	10.8	14.8	40.7
	3	2	5.4	7.4	48.1
	4	7	18.9	25.9	74.1
	6	1	2.7	3.7	77.8
	7	1	2.7	3.7	81.5
	8	2	5.4	7.4	88.9
	11	1	2.7	3.7	92.6
	15	1	2.7	3.7	96.3
	17	1	2.7	3.7	100.0
	Total	27	73.0	100.0	
Missing	System	10	27.0		
Total		37	100.0		

Appendix F: Content analysis of interview data

Appendix F1: Summary of views expressed regarding the perceived role of the family clinic within the CFCS

Views expressed (frequency)
Evidence-based practice and choice <ul style="list-style-type: none">• Filling a niche within the service – offering a different therapeutic approach (1) (5) a core treatment option (3)(7)• Consistency across services in the county (1) expectation from management that every CFCS will offer systemic family therapy (3) – but the trust does not monitor what is being provided so may be significant differences between services (8)• Offering choice for service users (1)• Expectation by funders that systemic approach will be offered by the service (1) Systemic family therapy model an important role within the team – supported by evidence-base (5)(3)(7)
Process of allocating cases to family clinic <ul style="list-style-type: none">• Information in referral letter or family questionnaire indicates problems in relationships within family (1)(3)(5)• More effective to look for what does not fit rather than what does fit as most problems appropriate for a systemic approach (7)• Cases where child appears to be symptom of wider family problems, abuse cases (5)• Cases where family clinic makes up part of a package of work with other CFCS members or other agencies (3)• 90% of cases allocated to family clinic can be predicted by non-clinician – decisions are usually clear-cut – little discussion in team meetings about different options (4)• Cases should be discussed with family clinic team before offering appointment, but not always possible due to time constraints and difficulties convening outside family clinic slot – some cases selected by one or two clinicians from the clinic rather than as a team(1)(7)• Lack of clarity about how cases are allocated – unsure if families are told they are on waiting list for family clinic or a general waiting list (3)• Differences across different CFCS teams re: how cases are allocated (3)• Need for a balance between complex and more straightforward cases (7)(8) – would need to do more marketing to attract enough complex referrals to fill family clinic slots (7)• Dilemma of whether only to accept complex cases or to accept a balance of complex cases where families may often cancel sessions or not open themselves up to the process, and more straightforward cases where family clinic is not necessarily indicated but where they turn up for sessions, engage in process, and thereby meet training needs for therapists (8)
Cases seen within family clinic <ul style="list-style-type: none">• Historical development in work with complex cases (difficult environmental context, abuse, domestic violence etc). Cases tend to be less complex than those seen in other family clinics locally, or tend to be more social services end of the spectrum (3)• Predominance of children with aggressive behaviour (6)• Seem to be a lot of cases of domestic violence which is not mentioned in referral information (7)• Cases where difficulties are around relationships rather than psychiatric problems (1) although need to be flexible as both could be appropriate and somewhat arbitrary distinction (3)• Cases where there is a need to look at the system (3)• Seem to be fewer cases where a package of help is offered compared with other local CFCS teams (3)• Some cases are not appropriate for working with without support of a team (7)
Lack of referrals from or to other members of the CFCS <ul style="list-style-type: none">• We hardly get any referrals from within the CFCS team whereas in other local clinics there are lots of internal referrals (7)• Maybe discouraging inappropriate referrals has made people wary about making any referrals at all• Tendency for clinicians to ‘hold onto’ cases once open to them (1)• Aware that could refer to family clinic if need arises but have not done so (5)

Clinical approach

- Eclectic – depends on training of clinician – most do not have training in systemic family therapy (1) we're not all singing from the same hymn sheet in systemic therapy (3)
- Broadly systemic approach (3) (1)(7)(8) – involving members of the system rather than the child only (6) looking for alternative ways of dealing with problems within family (6) thinking of families as systems connected to other systems, thinking about gender, social and power differences (8)
- Family work with vs without equipment (3)
- Multiple perspectives, not locating problem within child – does not 'blame' the child (4)(6)(7)
- Observing team – feedback given to families – families there to be observed (4)
- Useful to understand different perspectives, and in particular to understand the child's perspective (5)
- Very transparent approach (3)

Role beyond clinical work

- Role should include supervision and training as well as just seeing families – hard to justify use of time and technological resources otherwise (8)

Outsiders perceptions of 'what goes on' in the family clinic

- My guess is that people won't have much understanding of what goes on within family clinic (7)
- Managing transition and the role of terminology – 'family clinic workshop' helped family clinic establish a role alongside more psychodynamic approaches – feels as if systemic family therapy approach has become an established part of the service (3)
- Perception that the approach is a 'bit cloak and dagger' (2).
- Difficult to observe families due to lack of natural behaviour (4)
- Perceptions of staff 'outsiders' influences how they communicate with families about the family clinic (2)
- Individuals within the family clinic team are very dynamic – imagine they offer a very dynamic and forward thinking service (5)

Appendix F2: Summary of views expressed regarding the impact of the family clinic

Views expressed

On professional development

- Useful as learning experience (6)
- Useful for team members to get direct feedback on their practice from colleagues (1)
- Tend to work in a more focused and disciplined when working with a reflecting team – tend to 'go with the flow' otherwise (1)
- Working with a reflecting team helps broaden as well as focus thinking about a case – although anxiety provoking, having a reflecting team aids theoretical understanding as well as considering alternative perspectives (1)
- Provides useful clinical material for training courses (1)
- Dilemma of whether only to accept complex cases or to accept a balance of complex cases where families may often cancel sessions or not open themselves up to the process, and more straightforward cases where family clinic is not necessarily indicated but where they turn up for sessions, engage in process, and thereby meet training needs for therapists (8)

Perceptions of family perspective

- Power issues - 'a bit cloak and dagger' – sense that one-way screen and use of video may undermine families (2)
- Lack of choice over intervention offered (2)
- Imagine a lot of thinking goes on / drinking a lot of coffee (5)

On multidisciplinary / multi-agency working

- Valuable opportunity to work as a team and think systemically about problems – do not have the opportunity in day to day work (8)
- Aids relationship with other CFCS teams in area as clinicians join family clinic from these teams (5)
- Family clinic has had an impact on the culture of the CFCS in terms of broadening thinking about the kinds of cases accepted by the team (7)
- Don't always feel included in discussions as they take place outside family clinic forum (6)

Efficiency of the service

- There seem to be a lot of cancellations (6)
- Phoning families the day before appointment helpful in terms of informing clinicians if family is not planning to attend, but does not leave time for an appointment to be offered to another family (2)
- Families are asked to confirm appointment 2 weeks before-hand, but the consequences of not doing so are not clear / not followed through – leads to wasted slots in family clinic. Difficult to judge as many families do not confirm but still turn up to appointment (2).

Effectiveness

- Difficult to predict who will benefit from family clinic – necessary for family members to be able to reflect on roles and relationships, to be curious – important that relationships have not broken down irrevocably (3)(7) – important that families are able to tolerate technology and see the benefits (e.g. feeling reassured that a team is thinking about them) as outweighing the threats (8)
- Outcomes difficult to measure (6)

Appendix F3: Summary of views expressed regarding future development of the family clinic***Views expressed*****General comments about service development**

- family clinic is in a state of flux at present – development depends on who is around and who has the strongest voice (7)
- difficulty of taking a long-term view re: service development when systemic family therapists employed only on short-term contracts (7)(8) team should have a permanent family therapist post (8)
- feels like we talk too much at the moment about where we are going – we are all different and have to manage our differences (7)
- should be taking on more complex cases (8)

Clinical skills development

- More emphasis on skills development – more opportunities for discussion / role play of specific intervention strategies / questioning techniques – time management issues (1)(6)(3)
- Seeing families is more important than developing theoretical understanding (7)
- More structured opportunities for team to consider systemic ideas in-depth within the family clinic morning (3) should make use of slots where families DNA rather than going off on our own (8)
- Would be interested in thinking about how best to support families with issues of domestic violence given the large numbers of cases seen – need to liaise with services such as refuge (7)

Engaging with families

- Possible that families could be better informed about service, although unsure whether practice could be improved as efforts are made to engage with families before the first appointment (1)
- Understanding why families DNA or drop out of therapy (1)
- May be helpful to meet with families outside context of family clinic as way of engaging them in a less threatening manner (1)
- Families often seem unclear about who should be attending (4)
- Imagine that families would want more flexible appointment times (7)
- Should be more open with families by having reflecting conversations in front of them rather than privately (8)

Improving efficiency of the family clinic

- Understanding why families DNA (1, 2) – currently lack of feedback from referrers makes it difficult to improve practice (1)
- Families are treated with 'kid gloves' compared with, say, a GP surgery – the system should expect families to take more responsibility for their actions (e.g. DNA / cancel the day before) (2). Families should be made aware of how much time is being wasted if they DNA or cancel the day before an appointment (4).
- Should follow-up families who have not confirmed appointment 2 weeks before so that appointment can be offered to another family where necessary – should not wait until the day before to phone family to check whether they are planning to attend – awareness that any system is not foolproof but would improve efficiency / capacity (2) (4).
- I wonder how time is used when families do not turn up (5)

Improving team's understanding of 'what goes on' in the family clinic

- Would be useful for 'outsiders' to observe a session to better understand how the family clinic operates, what the aims are and the approach used for working with families. This understanding would help staff to communicate with families and provide some reassurance / information about what they are letting themselves in for (2) (1).
- Admin staff perceptions are as important as those of other clinicians as they are an important contact point for families (2).
- Aware of family clinic offer for other team members to observe a session, but feel uncomfortable (2) have not taken up offer (5)
- Would be useful for family clinic cases to be presented in mid-county practice workshops – would be a good way of disseminating information and increasing profile of the family clinic (5) (3)

Multidisciplinary working

- Seems as if all the tea cups in the building end up in the family clinic observing room – they should not leave them lying around! (5)
- Missing out on discussions as many conversations about cases seem to happen outside formal setting of family clinic (6)

Seeking professional opinion and receiving a diagnosis of Alzheimer's disease: partner's experiences

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WORD COUNT = 4904 words, excluding references

Seeking professional opinion and receiving a diagnosis of Alzheimer's disease: partner's experiences

Overview

Published research relating to partners' evolving perception of the person with dementia is reviewed, with a focus on the process leading up to and receiving a diagnosis of Alzheimer's disease. A constructivist / social constructionist framework has been adopted when presenting the literature, with an emphasis not only on professional, social and cultural discourses, but on how such understandings are used by individuals to make sense of their personal experiences.

A comprehensive search for relevant literature was carried out, and is outlined in Appendix A. Although the diagnosis of '*Alzheimer's disease*', with its characteristically gradual onset, forms the focus of the review, other forms of dementia have not been excluded. Similarly, although the focus is on '*partners*' of people with dementia, research involving other relatives and friends has not been excluded.

Introduction

Alzheimer's disease is the most common form of dementia and has a high prevalence amongst the elderly population, with risk increasing significantly with age. It is a medical category which describes a progressive and '*widespread loss of mental function including memory loss, language impairment, disorientation, change in personality (e.g. increased irritability, anxiety, social withdrawal, loss of skills and impaired judgment), self-neglect, and behaviour which is out of character*' (Department of Health, 2001).

It has been estimated that there are 600,000 people in the UK with Alzheimer's disease at present, a figure which is expected to double by 2050 as the population ages and older people live longer (Department of Health, 2001).

Making sense of Alzheimer's disease: the biomedical paradigm

The biomedical paradigm dominates professional, research and societal efforts to understand Alzheimer's disease. Its core assumption is that there is a direct causal relationship between neuropathological change in the brain and the progressive cognitive, behavioural and psychological deterioration associated with dementia. Current biomedical emphases are on delineating the impact of neurofibrillary tangles and neuritic plaques in the brain, and understanding familial and genetic transmission (Chung, 2000).

Neuropsychological research has also focussed on mild cognitive impairment and whether it represents normal ageing or an early stage of dementia (e.g. Morris et al, 2000), a development which could be interpreted as the medicalisation of old age. The hope is that in the future a medical or genetic cure will be identified, and the analogy is often made with the cancer care field 20 years ago.

A critique of the biomedical paradigm

The biomedical paradigm has come under increasing criticism over recent years from authors writing from a constructionist perspective (e.g. Kitwood, 1997; Sabat, 2001; Harding & Palfrey, 1997; Cheston & Bender, 1999; Bender, 2003). A key criticism is that there is very little empirical evidence to support the assumption of a simple direct causal relationship between neuropathology and dementia. For example, Kitwood (1989) estimated that as much as 80% of the variance in presentation of people with moderate to severe dementia is left unexplained by the description of brain pathology in post-mortem data. He also cites evidence of '*catastrophic decline*' in some people which is too rapid to be accounted for by neuropathological change, and '*rementia*' whereby some people are observed to regain supposedly lost skills.

A social constructionist perspective

A major criticism of the biomedical paradigm is that it implies a sense of hopelessness in that there is no sense of how to intervene beyond the currently available cholinesterase inhibitor medications. In response to these criticisms, Kitwood (1996) developed a 'dialectical framework' whereby dementia is seen as arising from a complex interaction of neurological impairments, physical health, personality, critical life events, and the social psychology surrounding the individual. This disability model (as opposed to disease model) is presented in Figure 1, below.

Figure 1: Five key factors contributing to the manifestation of dementia (Kitwood, 1996)

$$\mathbf{Dementia = Personality + Biography + Health + Neurological Impairment + Social Psychology}$$

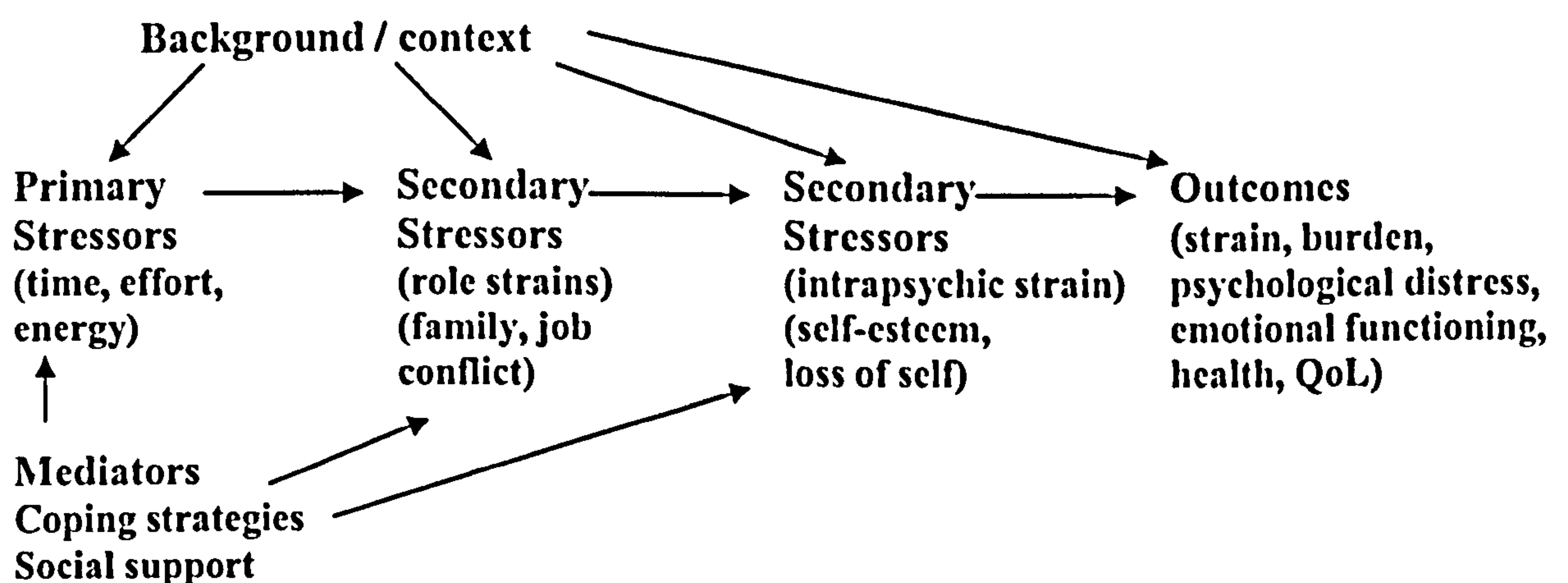
The research evidence in support of Kitwood's model is outlined by Kitwood (1997), Harding & Palfrey (1997), Cheston & Bender (1999), and Bender (2003). From this perspective, it follows that the understanding that partners develop to explain the difficulties experienced by the sufferer will have a major impact on the course of the illness, for example through malignant social psychology (Kitwood, 1997). The limited

social discourses about dementia means that ways of construing a person with dementia may be very restricted (Harding & Palfrey, 1997; Bodily, 1994).

Alzheimer's disease and its impact on relative caregivers

Alzheimer's disease places heavy practical, physical and emotional demands on caregivers, the majority of whom are relatives (Bosanquet, 2001). Research over the past decade on the impact of caregiving on relatives, has been conducted predominantly within the stress-process framework (Figure 2, below), and is summarised by Zarit & Edwards (1999) and Gootlieb & Wolfe (2002). High rates of depression, anxiety, physical and emotional strain have been associated with this population, although people adapt very differently to apparently similar situations. Being a female carer, having a poor relationship prior to the onset of dementia, and contending with more behavioural disturbances have been found to be related to increased strain and distress. Use of approach (rather than avoidant) coping strategies, maintaining a sense of self, and receiving informal support have all been associated with reduced levels of psychological distress. A key criticism of much of the research is that due to its cross-sectional, correlational nature, dynamic associations between the elements of the model have not been convincingly demonstrated. In addition, most of the research is on coping with the later stages of dementia, which may provide a very different challenge compared with earlier difficulties.

Figure 2: Stress-process framework (Pearlin et al, 1990, in Zarit & Edwards, 1999; p161)



The importance of beliefs and attributions as mediators has been demonstrated in several studies, which have explored links between attributions and burden (e.g. Levy et al, 2000), expressed emotion (e.g. Tarrier et al, 2002), abuse (Decalmer & Glendenning, 1997), and other behaviour which has the effect of dehumanising the individual (e.g. Kitwood, 1997). Caregiving is clearly a very complex, multi-faceted issue for researchers to explore in a way that does not construe caregiving in an overly mechanistic and negative way.

Researchers such as Farran (1997) have promoted an existential paradigm for understanding caregiving, which focuses on meaning and understanding the positive as well as negative aspects of undertaking such a role.

The diagnosis of Alzheimer's disease: the role of memory clinics in the NHS

Historically, the NHS has taken a predominantly reactive rather than proactive approach to service provision, with very little support available to people with mild to moderate dementia and their relatives, and 90% of public spending being on institutional care (Bosanquet, 2001).

However, recent policy initiatives (e.g. National Service Framework for Older People, Department of Health, 2001) emphasise the need for early identification and treatment of Alzheimer's disease. Memory clinics, specialist outpatient based assessment and diagnostic services for people with early presentation of cognitive impairments and dementia, have proliferated in recent years and play an important role in this vision (Phipps & O'Brien, 2002). Traditionally, these services were developed to facilitate research (Wright & Lindsay, 1995), and continue to fulfil this role. Evidence suggests that local service provision varies widely (Lindsay et al, 2002), and could include assessment, investigation, diagnosis, information-giving and cholinesterase inhibitor medication treatment. Surprisingly there is a lack of guidance from the National Institute of Clinical Excellence and the National Service Framework as to how memory clinics should operate clinically (Phipps & O'Brien, 2002). Supporting caregivers appears to be a low priority in terms of service provision (Bender, 2003; Woods, 2001). Reviews of caregiver interventions indicate that the majority of research has been on interventions to support relatives caring for people in the later stages of dementia rather than at the time of diagnosis (Pusey & Richards, 2001; Cooke et al, 2001; Thompson & Spilsbury, 2003).

Literature review: aims and theoretical framework

The review focuses on the research literature relating to how partners make sense of their experiences living with someone with memory problems, how they come to consult with health professionals, how such consultations influence their understanding, and how a diagnosis of Alzheimer's disease impacts on the way they construe their partner's 'illness'. Such an understanding of partners' perspectives is essential if services are to be in a position to respond appropriately to their needs (e.g. Chung, 2000) at the time of diagnosis and thereby facilitate effective coping strategies.

A social constructionist / constructivist position has been adopted. The author's particular interest is in how individuals assimilate social, cultural, and professional discourses and construct identity, rather than on how such discourses themselves develop. The aim of the review is to provide an overview of the literature and current debates, rather than providing an in-depth theoretical and methodological critique.

Deciding to seek the opinion of health professionals

Despite the strong association between '*not knowing how to interpret what is happening*' and caregiver burden and strain (Wilson, 1989), it has been suggested that many people live with dementia without seeking a diagnosis. On the basis of case register data and morbidity survey estimates (in Camberwell, London), Cooper & Fearn (1998) estimated that only 1 in 7 people with moderate to severe dementia living in the community had received a formal diagnosis.

A number of authors have emphasised the difficulties experienced by sufferers and informal caregivers in differentiating memory problems associated with normal ageing from potential dementia, particularly where the onset is gradual (e.g. Knopman et al, 2000). In a retrospective survey of 528 family caregivers of people diagnosed with dementia, Wackerbarth & Johnson (2002) found that the mean time from first noticing symptoms to seeking a diagnostic assessment was 22.4 months, although clinical experience suggests this is often much longer (e.g. Keady & Gilliard, 1999).

In an influential qualitative (grounded theory) study of 20 caregivers of people with dementia, Wilson (1989) developed a stage model of the lived experiences of relative-caregivers. She emphasised the notion that caregivers' efforts are always directed at minimising the negative impact of dementia. She identified a process of '*noticing*', '*discounting or normalising*' using rational explanations for the observed changes, and '*suspecting*' or realising that the problem is serious before the '*search for explanations*' or an official diagnosis.

Qualitative interview research by Orona (1990), Willoughby & Keating (1991) and Keady & Nolan (1995) indicates that both partners and sufferers tend to cope initially by denying that there is a significant problem, keeping difficulties hidden, or finding strategies and explanations which emphasise normality. This fits with psychodynamic explanations, for example by Hagberg (1997), who argues that perception of cognitive change is mediated by factors such as personality, ego-strength, defence mechanisms, and self-concept, in the context of past experiences. Clare (2000, 2002), found from in-depth interviews with people with early-stage dementia and their partners, that reactions, explanations, and emotional responses reflected a tension between the '*need to put on a protective coating*' in order to maintain the prior self-concept, and the need to '*spend time in the depths*' in order to confront the changes and allow them to be integrated into the self-concept.

Several researchers have focused on the decision-making process to seek an assessment of cognitive difficulties. These are summarized in Table 1 (below).

Table 1: Summary of studies investigating the decision-making process to seek an assessment of cognitive difficulties

Authors	Methodology / approach	Key findings	Country
Connell & Gallant (1996)	Survey of spouse caregivers of people with a diagnosis of dementia (n=233)	Perceived barriers = availability, knowledge of, and responsiveness of specialist services Perceived benefits = rule out other causes of memory difficulties, access to information, help access to treatment trials, enables to plan for future.	USA
Boise et al (1999)	Survey of spouse caregivers of people with diagnosis of dementia	Barriers / most common reasons for delay in seeking assessment = lack of information about dementia, belief that symptoms are a normal part of ageing, feeling overwhelmed by their situation, not knowing who to ask.	USA
Wakerbarth & Johnson (2002)	Survey of relative-caregivers of people with a diagnosis of dementia (n=528)	Most prevalent barriers = perceiving problems as a normal part of ageing, perceiving strong risks for undertaking assessment (e.g. impact of diagnosis on their life, worry about family members reaction). Most commonly reported benefits = confirming a medical problem, enabling access to treatment.	USA
Werner (2003)	Survey of convenience sample of adults in community without cognitive difficulties (mean age 64) about intentions to seek cognitive assessment in response to vignettes (n=186)	Tendency to underestimate risk of developing dementia except where there was family history. Used the Health Belief Model to identify perceived benefits, barriers and cues to action. Perceived barriers = strongest predictor of decision to seek assessment, particularly belief that there is no treatment for dementia, and not feeling able to cope with a positive answer.	Israel

These studies focus on the cognitive, emotional, and practical factors influencing the decision making process. Limitations include the use of cross-sectional research designs which do not view decision making as a process, and which provide no evidence of a relationship between intention and action. In addition, they do not include the perspective of the person experiencing cognitive problems, although Werner (2003) asked participants to 'put themselves in the shoes of someone with memory problems'. Furthermore, the samples could be seen as skewed to include those who actually sought professional opinion at the expense of those who did not. Levy et al (2000) argue that there are cross-cultural differences in seeking help from professionals, with far fewer people from ethnic minorities seeking a diagnosis of dementia.

However, the results of these studies do echo findings from earlier qualitative studies which highlighted the cognitive, emotional and practical barriers faced by people when

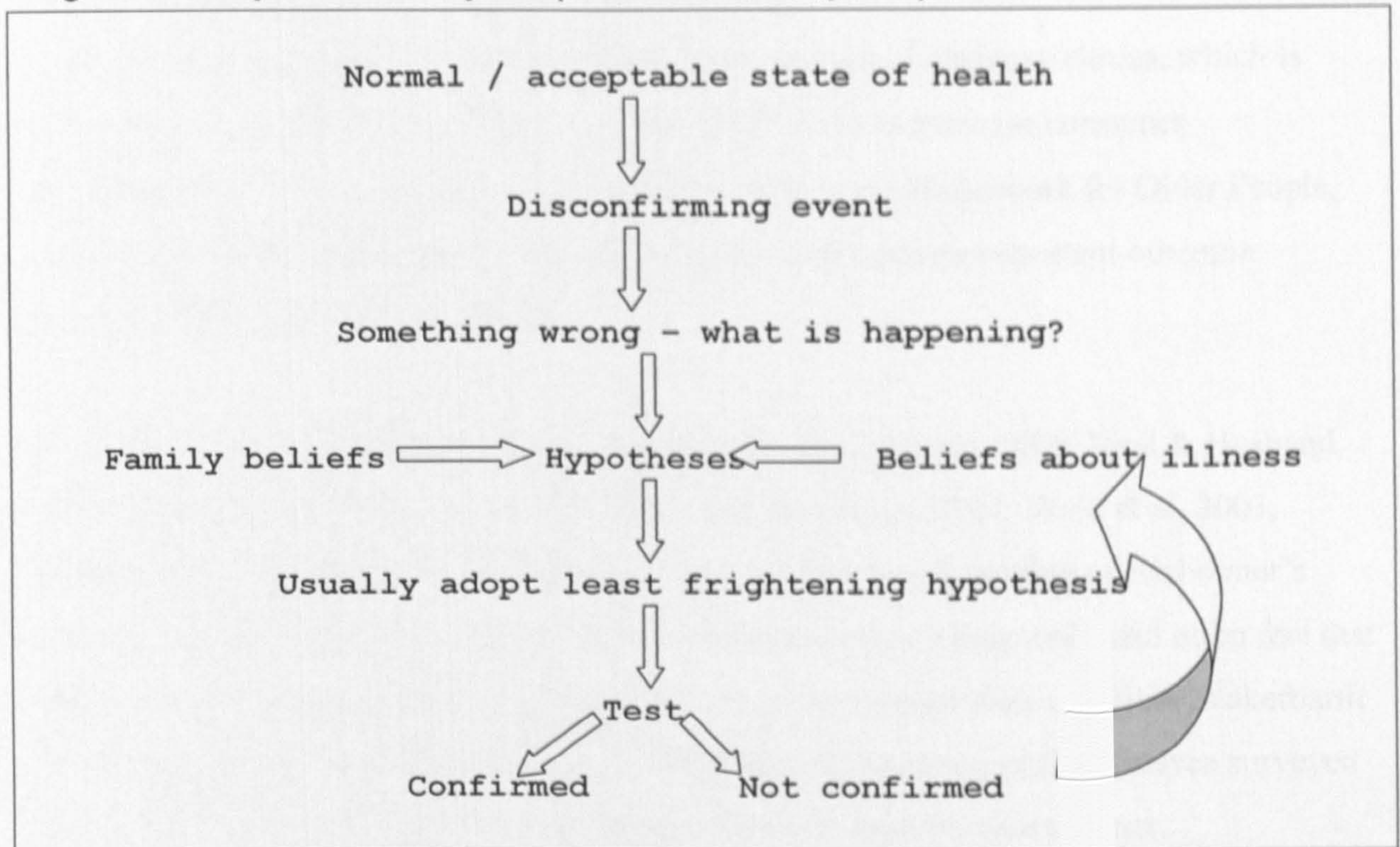
deciding to seek an assessment, particularly difficulties differentiating normal ageing from potential dementia, and the need to maintain normality in the face of contrary evidence.

Rather than focussing solely on relatives or the sufferer, Bender (2003) emphasises the process of negotiation between relatives and sufferer to explain their cognitive difficulties and hence arrive at a course of action. He argues that partners often experience considerable unease or guilt about talking publicly about these difficulties as it will result in a loss of face for the sufferer.

Husband's (2000) research provides insight into how the difficulties faced by the sufferer may influence the decision making process. She asked 10 people recently diagnosed with dementia, '*what are you most worried about in relation to the diagnosis?*', and found that the commonest fears expressed related to other people finding out (and hence being pitied, laughed at, talked about or humiliated), letting oneself down in public (appearing stupid, boring, embarrassing, incompetent), and increasing disability (needing help from strangers, being a burden to family, having to enter an institution), and not being listened to.

Bender (2003) draws on personal construct theory to argue that sufferers and relatives enter into an explanation cycle whereby they look for evidence to confirm or disconfirm explanations for the difficulties, generally starting with the least frightening option. Of course both may be working through different belief cycles in the process of trying to make sense of a possible illness, and this may represent a source of conflict. Bender argues that this process may serve the purpose of gradually adjusting to loss.

Figure 3: Explanation cycle (Bender, 2003;p183)



Although Bender's (2003) model fits with attribution research literature by assuming that people tend to look for a single attribution for bad events (e.g. Morris & Larrick, 1995), research by Levy et al (2000) indicates that caregivers often develop multiple attributions for dementia, which may fit better with the current state of scientific and lay knowledge.

What is apparent from the research literature reviewed is that by the time people are referred to memory clinics, it is highly likely that they will have considered a range of explanations for their difficulties but found insufficient evidence to support those explanations fully. Psychodynamic theories in particular suggest that these efforts may serve a self-protective function and may facilitate adjustment to loss. The following section will focus on relatives' experiences of memory clinics and whether the experience helps in terms of finding an explanation and adjusting to their difficulties.

Relatives' experiences of memory clinics

There is scant research literature on relative's experiences of memory clinics, which is surprising given NHS policy initiatives over recent years to increase consumer involvement in service development (e.g. National Service Framework for Older People, Department of Health, 2001), with satisfaction being seen as an important outcome measure (Phipps & O'Brien, 2002).

Findings within the research literature (e.g. Gilliard & Gwilliam, 1996; Heal & Husband, 1998; Holroyd et al, 2002; Marzanski, 2000; Van Hout et al, 2001; Wald et al, 2003, Werner, 2001) suggest that caregivers often have a poor understanding of Alzheimer's disease, frequently feel unsupported following disclosure of a diagnosis, and often feel that they are lacking important information to help them to manage their situation. Wakerbarth & Johnson (2002) highlight the sense of abandonment that many of the relatives surveyed felt as their initial expectations of accessing additional support were not met.

Such findings may reflect the emphasis of memory clinics as a diagnostic rather than treatment service. Authors such as Woods (2001) have argued for the need for pre- and post-diagnostic counselling as would be offered for other medical conditions, although research indicates that this is rarely provided (Lindesay et al, 2002). Although much has been written about 'doctor-patient communication' and how to break bad news, particularly with regard to cancer (e.g. Brewin, 1996; Davis & Fallowfield, 1991; Faulkner, 1998), very little attention has been paid within the dementia research literature to understanding patients' experiences of the diagnostic process. Nolan et al (1996) and Bender (2003) observe that relatives tend to be treated as partners to health professionals at the diagnostic stage, and it is only as 'burden' increases in the later stages of caregiving that they are recognised as having their own needs.

Although authors writing from a constructionist perspective (e.g. Mishler, 1997; Harding & Palfrey, 1997) have argued that consultations with health professionals are a place where reality is co-constructed, there is a dearth of research on this topic in the field of dementia care. In terms of process, the overwhelming focus of the research literature is on the ethical debate about whether a diagnosis should be disclosed to the sufferer (e.g. Bachman et al, 2000; Heal & Husband, 1998; Johnson et al, 2000; Maguire et al, 1996; Pucci et al, 2003).

Although rarely provided in memory clinics, Moniz-Cook et al (1998) evaluated the

impact of a home-based program (UK, 6-12 hours) offering information about diagnosis and prognosis, reinforcement of coping strategies, crisis prevention advice, and memory management interventions to people newly diagnosed with dementia and their relatives. They found, compared with a control group who were offered treatment as usual (a diagnosis and generic written advice), improved wellbeing (assessed using the Beck Depression Inventory, General Health Questionnaire [GHQ], Hospital Anxiety Depression Scale), less likelihood that the relative had been institutionalised, and better memory functioning at 18 month follow-up.

In a randomised control trial of the impact of a memory clinic in Australia offering assessment, diagnosis, information, and counselling, Logiudice et al (1999) found that relative-carers attending the clinic had a greater quality of life and increased social interaction at 12 month follow-up compared with those who had not attended a clinic. However, they found no difference in terms of morbidity (GHQ), carer burden (Zarit family interview) or carer knowledge of dementia (Dementia Knowledge Test), suggesting that a diagnosis and intervention had little impact on coping.

To conclude, there is some evidence that memory clinics have the potential to facilitate adaptation and coping by relatives, although little to suggest how disclosure might be most effectively handled by professionals. Certainly, evidence suggests that many relatives are not satisfied with the services they receive in memory clinics. The following section will consider how receiving a diagnosis and contact with specialists impacts on the way in which relatives construe their own and the person with dementia's difficulties.

Impact of a diagnosis of Alzheimer's disease on relatives' construal of the person with dementia

Receiving a diagnosis of Alzheimer's disease is a turning point in the course of the illness for many people (e.g. Nolan et al, 1996; Taraborelli, 1993), and the least researched aspect of the caregiving 'career' (Zarit & Edwards, 1999). Orona (1990) describes diagnosis as an 'existential coordinate' for many relatives. In essence, it is a time where the relative is compelled to reconstruct their idea of the past and the future in terms of the current understanding.

There is a distinct lack of research on the impact that receiving a diagnosis of dementia has on relatives. Qualitative studies by Morgan & Laing (1991) and Clare (2002) focus on the emotional impact and coping strategies used by relatives in the six months following diagnosis, and Candey (2001) focuses on the transition in identity of relatives from 'spouse' to 'caregiver'. However, there is little published research on how a diagnosis impacts on relatives' perceptions of identity of the person with dementia. Several papers are reviewed on lay models of dementia, and these provide insight into how the diagnosis itself might influence such perceptions.

Lay models of dementia

Chung (2000) makes the observation that, in contrast with other illnesses, few attempts have been made to understand lay models of dementia. She argues that standards of care and communication between professionals and families have been compromised as a result of the lack of publicly available lay accounts which prevents a dialogue between lay and professional understandings as would occur within fields such as cancer care. Askham (1995) also suggests that the dominance of the biomedical paradigm within institutional, professional, and voluntary sector settings means that caregivers' construal of dementia may be a very private experience as their understanding may be invalidated within such settings.

Askham (1995) interviewed 106 informal caregivers (offering care for more than 7 hours per week) of people recently (past 12 months) diagnosed with dementia about how they perceive and describe the condition. The research was conducted in an inner-London borough and a market town in the south of England. The ways in which participants' construed the condition were found to be enormously diverse, although they could be organised into a number of key categories.

Askham found that an explanatory strategy used by a quarter of respondents was to make comparisons with a more familiar condition such as normal ageing, childhood, functional mental illness or physical illness. For example *'she's getting old, her memory's going, just like mine will go at times'*, *'he's just going into his second childhood, so you have to treat him like a child'*, or *'I think it's emotional – he's imaging people in the room, because he's lonely, he's missing my mother'* (p107). A further quarter of respondents, who tended not to be partners but children and other relatives, construed the condition very narrowly, as *'going senile'*, or *'losing her memory'*. These explanations therefore excluded the complex, diverse, or unpredictable nature of the condition and there was little elaboration of responses in the interviews. Less common were explanations which referred to medical or professional understandings which were gained through contact with health professionals or by seeking additional information from voluntary organisations.

People's accounts of the condition were located along a number of key parameters, such as normal-abnormal, orderly-unpredictable, simple-complex, illness-not an illness. Many of the respondents seemed to be drawing on various explanatory models to make sense of the complex presentation of the condition. For example, one participant felt symptoms could be due to old age, dependency, or loneliness: *'I think it just came with age really.///My father used to wait on her hand and foot; he made the rod for us really///and a lot of it is being on her own'* (p110).

Askham (1995) suggested that one of the key reasons for the diversity in understanding of dementia could be a lack of information that relatives have about the condition. This hypothesis has been investigated by several researchers (e.g. Connell & Gallant, 1996; Roberts & Connell, 2000; Werner, 2001). The findings have been inconsistent. In contrast with Connell & Gallant and Werner's findings, Roberts & Connell found relatives to be relatively knowledgeable about Alzheimer's disease, although their sample was skewed in favour of young, highly educated, high SES relatives. This may mean that they are more confident about accessing the information available within the public domain (e.g. internet) and may be more demanding consumers within the healthcare system.

Of course, even where knowledge, which the above studies defined strictly within the bounds of the biomedical paradigm, is relatively good, caregivers may not necessarily adopt this explanation of their situation. Chung (2000), from a grounded theory research

into lay interpretation of dementia, concluded that the biomedical paradigm did not help many of the participants to make sense of their lived experiences. Chung interviewed 18 family caregivers in Hong Kong (who were all accessing services), and found that although many caregivers had been told that dementia is a kind of brain degeneration, this did not fit their lived experiences of relatively inconsistent behaviours and functional behaviours from one day to the next. Alternative explanations were developed through linking the current condition to past medical history, critical life events, particularly those resulting in loss of others or loss of role, and supernatural beliefs. For example, *'I had thought of taking him to temples and asked monks to rid him of the evil spirits, but my children stopped me from doing so and volunteered to take him for medical consultation. Although he received a diagnosis, I still think his illness has something to do with evil spirits'* (p374).

Chung (2000) emphasises the central importance of 'illness stories' (e.g. Blaxter, 1993), which place ill health in the context of the individual and his or her life history, and relates it to wider themes of the society and the culture, in caregivers construal of their situation. Such stories are seen as meeting caregivers' need for meaning and gaining a degree of control over their situation. Hinton & Levkoff (1999) provide a good review of the sociological and anthropological research literature on the construct of dementia.

Hinton & Levkoff (1999) investigated the narrative structure of these illness stories across different ethnic groups, with an interest in how biomedical discourse is interpreted, communicated, discussed and adapted locally to fit the lived experiences of caregivers of people with dementia. They used a narrative approach to analyse in-depth interviews with African-American, Chinese-American, Irish-American, and Latino-American family caregivers living in Boston (USA). Three different story types were identified.

First, narratives of Alzheimer's as a disease that erodes the core identity of a loved one through deteriorating minds were used by all four ethnic groups. Hinton & Levkoff argue that this view is shaped by professional and popular discourses of dementia as a kind of 'social death', which crosses ethnic boundaries within American society. The remaining two story types emphasise the importance of alternative cultural stories as resources available for individuals to understand the condition.

Second, a subset of the Chinese caregivers drew on traditional Chinese notions of ageing

and health. They emphasised how families manage confusion and disability as an expected part of growing old (thereby removing the stigma), focussing on the moral fibre of families. For example, *'she is like a machine, there is a missing part. It is not a crazy machine [...] it is old age. These are changes for old people'* (p462), or *'in Chinese there is a saying "when an person gets old, he changes into a baby". The elder will change into a baby. When people get old, the mind will regress. They don't know what they are doing'* (p465). Interviews with Chinese healthworkers indicated that they saw little point in burdening Chinese families with a stigmatising diagnosis with little hope of cure, preferring to withhold diagnosis from families until the decision to institutionalise them was being considered.

Third, a subset of the Latino caregivers placed the onset of the illness in the context of stories about tragic losses, migration, loneliness and family responsibility in old age. Although these caregivers had adopted the biomedical label, they placed the condition along a continuum of psychosocial distress, serving the function of de-stigmatising the condition.

Levy et al (2000) also conducted an in-depth cross-cultural analysis of relative's (mostly children rather than partners) illness attributions, focussing on their relationship to caregiver burden. Attributions were categorised by content analysis of interview transcripts, and are presented in Table 2 (below).

Table 2: Definitions and examples illness attributions held by caregivers of a relative with dementia (Levy et al, 2000; p217)

Age	Normal ageing caused the dementia. (<i>'senility is part of growing older'</i>)
Bad Luck	Bad Luck caused the disease. (<i>'Many bad events happened to her, including getting sick. It is not like she went looking for them, they just occurred'</i>)
Bad Medicine	A bad medical experience caused the dementia (<i>'if that incompetent doctor hadn't messed up her labour, she wouldn't have become sick'</i>)
Body	A problem with a part of the body other than the brain caused the dementia (<i>'the arthritis and confused nerves caused the illness'</i>)
Brain	A change in the brain caused the dementia (<i>'the illness is due to her brain shrinking'</i>)
Childhood	A regression to childhood caused the dementia (<i>'in old age he started to become a baby again'</i>)
Diet	A bad diet caused the dementia (<i>'she ate so many fatty foods she became senile'</i>)
Disease	A chronic disease, such as Alzheimer's disease caused the dementia (<i>'she slowly developed Alzheimer's disease'</i>)
Divine retribution	A punishment from God caused the dementia (<i>'I think God decided to make him sick'</i>)

Environment	An environmental factor caused the dementia (‘The full moon made her crazy’)
Genetics	Genes caused the dementia (‘It’s no wonder he got sick. All of his siblings had the same illness’)
History	A distressing event caused the dementia (‘after her oldest son passed away, that’s when she really started getting worse. I mean, worse from the sickness’)
Immigration	Immigration to the USA caused the dementia (If only we had stayed in China she would never have become sick’)
Lack of social support	A lack of social support caused the dementia (‘She started to become sad and confused when her children and grandchildren withdrew. She needed their love to keep well’)
Stress	Psychological stress caused the disease (‘the agitation that came from losing her job led to the disease’)
Stroke	A stroke caused the dementia (‘a series of mini strokes led to the disease’)
Venting	A pattern of not venting emotions caused the dementia (‘if she let her emotions out, it would never have happened’)

They found that on average, and contrary to much research using attribution theory which suggests that caregivers tend to seek a single explanation, four attributions were held by each relative. Those with more attributions, and a greater number of internal and temporary attributions were rated as experiencing higher levels of burden. The authors suggest that holding fewer attributions allows relatives to be more focussed on searching for help that fits their perceived needs. Clear cultural differences were observed, particularly that white relatives held far more biomedical attributions, and far fewer attributions related to a lack of social support, reflecting the dominant culture of the USA. Comments by an African-American (1) and Chinese-American (2) relative illustrate these differences (p223):

‘there would be people [in Arkansas] who would reminisce with you...you could just sit and think and talk about the past...and there would be people around and it would be no big deal. It’s a big deal in cities where people live in isolation’(1)

‘Chinese people seem to be clear-minded, even when they are dying [...] in China I never felt this was prevalent, and I’ve never met any elderly who suffered from this. I also know that because of the tension and stress from living in America: if it’s long term the condition is more likely to be induced’ (2)

Askham (1995) also found that for some respondents in the UK, the biomedical label did not fit their construal of what ‘illness’ is. For example, ‘well, it’s not an illness – she’s perfectly fit- and it’s not like she can’t look after herself- and it’s not as if she were mad or anything...’ (p111). She suggests that people may develop an understanding of the condition in a way that accords with their own self-image or the type of relationship they have with the sufferer. For example, if they have, or would like to have a relationship characterised by nurturing or caring, then it makes sense for them to construe the condition as illness or childlike. Of course, this is also influenced by how the sufferer presents

themselves, and the caregiver's emotional response to cognitive and behavioural difficulties, as discussed earlier in the review. Askham also emphasises how the caregiver's context influences the accounts they develop about the condition. For example, if the caregiver no longer wishes to continue the caregiving role, then they are far more likely to see the problem as medical than someone who wishes to continue until the end.

The research literature on lay beliefs suggests that the biomedical disease model is only one of many explanations used by relatives to understand their situation. This diversity of beliefs seems to reflect the current scientific uncertainty about the causes of dementia, and reflects debates between the medical, sociological, psychological and anthropological research communities.

Conclusion

It is apparent from the literature reviewed that the process of recognising that there is a problem, finding an acceptable explanation, and deciding to seek help from mental health services is a complex one which involves a combination of cognitive, emotional and social processes. The diversity of explanations of dementia held by relatives, many beyond the bounds of the biomedical paradigm, reflects the current scientific status of dementia whereby the biomedical model dominates but is not well supported empirically or clinically. The diversity of beliefs fits well with Kitwood's (1993) biopsychosocial model of dementia which emphasises the complexity of factors contributing to the presentation and course of dementia.

Levy et al (2000) argue that, as most existing interventions for relative-caregivers have failed to have a significant impact on caregiver burden, it is essential to develop a better understanding of lay beliefs in order to develop more effective person-centred interventions. A clear association has been demonstrated between relatives' attributions and their own / the patient's physical, cognitive and emotional wellbeing, and thus this is an important area to study.

However, there is a dearth of literature on relative's perceptions of dementia, particularly around the time of diagnosis. There is also scant research literature on their experiences of memory clinics, which is surprising given their potential to influence the course of the dementia. The question of how relatives use consultations with professionals in memory clinics to develop their understanding of the problem has not been investigated. Nor has the meaning of the label 'Alzheimer's disease' and the impact of labelling on relative's perceptions and behaviour.

Nolan et al (1996) observe that there is an overemphasis within the research literature on the burdens and difficulties of caregiving using deterministic models of how caregivers manage rather than attempting to capture the complexity and uniqueness of caregiving. They argue that there is a need for a longitudinal temporal perspective with a focus on transition points, such as receiving a diagnosis. Adopting a narrative approach to understanding the psychological and social processes involved in the generation of illness meanings may be a particularly appropriate means to address some of these gaps in the research literature.

References

- Askham, J. (1995). Making sense of dementia: carer's perspectives. *Ageing and Society*, 15, 103-114.
- Bachman, D.L., Wagner, M.T., DePalma, M., Spangenberg, K.B., Hendrix, S.A. & Perlman, D.J. (2000). Caregiver attitudes about patients told they have Alzheimer's disease after truth disclosure. *Journal of Clinical Geropsychology*, 6 (4), 309-313.
- Bender, M. (2003). Explorations in Dementia – theoretical and research studies into the experience of remediable and enduring cognitive losses. London: Jessica Kingsley.
- Blaxter, M. (1993). Why do victims blame themselves? In A. Radley (ed.), *Worlds of illness: Biographical and cultural perspectives on health and disease*. London: Routledge.
- Bodily, C.L. (1994). Ageism and the deployment of 'age' – a constructionist view. In T.R. Sarbin & J.I. Kituse, *Constructing the Social: Inquiries in Social Construction*. London: Sage.
- Boise, L., Morgan, D.L., Kaye, J. (1999). Delays in the diagnosis of dementia: perspectives of family caregivers. *American Journal of Alzheimer's Disease*, 14, 20-26.
- Bosanquet, N. (2001). The socioeconomic impact of Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 16, 249-253.
- Brewin, T. (1996). *Relating to the Relatives – Breaking Bad News, Communication & Support*. Abingdon: Radcliffe Medical Press.
- Candey, L. (2001). Women's understandings of their relationship with their husband in the early stages of his gradual onset dementia. University of East Anglia: unpublished DClinPsy thesis.
- Cheston, R. & Bender, M. (1999). *Understanding Dementia – the man with worried eyes*. London: Jessica Kingsley.
- Clare, L. (2000). Cognitive rehabilitation in early-stage Alzheimer's disease: learning and the impact of awareness. Open University: Unpublished PhD thesis.
- Clare, L. (2002). We'll fight it as long as we can: coping with the onset of Alzheimer's disease. *Ageing & Mental Health*, 6 (2), 139-148.
- Chung, J.C.C. (2000). Lay interpretation of dementia. *International Psychogeriatrics*, 12 (3), 369-377.
- Connell, C.M. & Gallant, M.P. (1996). Spouse caregivers' attitudes toward obtaining a diagnosis of a dementing illness. *Journal of the American Geriatric Society*, 44, 1003-1009.
- Cooke, D.D., McNally, L., Mulligan, K.T., Harrison, M.J.G. & Newman, S.P. (2001). Psychosocial interventions for caregivers of people with dementia: a systematic review. *Ageing & Mental Health*, 5 (2), 120-135.
- Cooper, B. & Fearn, R. (1998). Dementia care needs in an area population: case register data and morbidity survey estimates. *International Journal of Geriatric Psychiatry*, 13,

Davis,H. & Fallowfield,L. (1991). Evaluating the effects of counseling and communication. In H.Davis & L.Fallowfield (eds.), *Counselling and Communication in Health Care*. Chichester: Wiley.

Decalmer,P. & Glendenning,F. (1997). *The Mistreatment of Older People*. London: Sage.

Department of Health (2001). *National Service Framework for Older People*. Government Policy Document, DoH March 2001.

Farran,C.J. (1997). Theoretical perspectives concerning positive aspects of caring for elderly persons with dementia: stress / adaptation and existentialism. *The Gerontologist*, 37 (2), 250-256.

Faulkner,A. (1998). *When News is Bad – a Guide for Health Professionals*. Cheltenham: Stanley Thornes.

Gilliard,J. & Gwilliam,C. (1996). Sharing the diagnosis: a survey of memory disorders clinics, their policies on informing people with dementia and their families, and the support they offer. *International Journal of Geriatric Psychiatry*, 11, 1001-1003.

Gottlieb,B.H. & Wolfe,J. (2002). Coping with family caregiving to persons with dementia: a critical review. *Aging & Mental Health*, 6 (4), 325-342.

Hagberg,B. (1997). The dementias in a psychodynamic perspective. In B.M.L.Miesen & G.M.M.Jones (eds), *Care-giving in dementia: research and applications Volume 2*. London: Routledge.

Harding,N. & Palfrey,C. (1997). *The Social Construction of Dementia*. London: Jessica Kingsley.

Heal, H.C. & Husband,H.J. (1998). Disclosing a diagnosis of dementia: is age a factor? *Aging & Mental Health*, 2 (2), 144-150.

Hinton,W.L. & Levkoff,S. (1999). Constructing Alzheimer's: narratives of lost identities, confusion and loneliness in old age. *Culture, Medicine & Psychiatry*, 23, 453-75.

Holroyd,S., Turnbull,Q. & Wolf,A.M. (2002). What are patients and their families told about the diagnosis of dementia? Results of a family survey. *International Journal of Geriatric Psychiatry*, 17, 218-221.

Husband,H.J. (2000). Diagnostic disclosure in dementia: an opportunity for intervention? *International Journal of Geriatric Psychiatry*, 15, 544-547.

Johnson,H., Bouman,W.P. & Pinner,G. (2000). On telling the truth in Alzheimer's disease: a pilot study of current practice and attitudes. *International Psychogeriatrics*, 12 (2), 221-229.

Keady,J. & Gilliard,J. (1999). The early experience of Alzheimer's disease: implications for partnership and practice. In T.Adams & L.C.Clarke (eds), *Dementia Care: Developing Partnerships in Practice* (pp227-256). London: Balliere.

- Kitwood, T. (1989). Brain, mind and dementia: with particular reference to Alzheimer's disease. *Ageing & Society*, 9, 1-15.
- Kitwood, T. (1993). Towards a theory of dementia care: the interpersonal process. *Ageing & Society*, 13, 51-67.
- Kitwood, T. (1996). A dialectical framework for dementia. In R.T.Woods (ed.), *Handbook of the Clinical Psychology of Ageing*, (pp267-282). Chichester: Wiley.
- Kitwood, T. (1997). *Dementia Reconsidered – the person comes first*. Buckingham: Open University Press.
- Knopman, D., Donohue, J.A. & Guterman, E.M. (2000). Patterns of care in the early stages of Alzheimer's disease: impediments to timely diagnosis. *Journal of the American Geriatric Society*, 48, 300-304.
- Levy, B., Hillygus, J., Lui, B. & Levkoff, S. (2000). The relationship between illness attributions and caregiver burden: a cross-cultural analysis. *Journal of Mental Health and Ageing*, 6 (3), 213-225.
- Lindesay, J., Marudkar, M., vanDiepen, E. & Wilcock, G. (2002). The second Leicester survey of memory clinics in the British Isles. *International Journal of Geriatric Psychiatry*, 17, 41-47.
- Logiudice, D., Waltrowicz, W., Brown, K., Burrows, C., Ames, D. & Flicker, L. (1999). Do memory clinics improve the quality of life of carers? a randomised pilot trial. *International Journal of Geriatric Psychiatry*, 14, 626-632.
- Maguire, C.P., Kirby, M., Coen, R., Coakley, D., Lawlor, B.A. & O'Neill, D. (1996). Family members' attitudes towards telling the patient with Alzheimers disease their diagnosis. *British Medical Journal*, 313, 529- 531.
- Marzanski, M. (2000). On telling the truth to patients with dementia. *Journal of Medical Ethics*, 26, 108-113.
- Mishler, E.G. (1997). The interactional construction of narratives in medical and life-history interviews. In B.L.Gunnarsson, P.Linell, B.Nordberg (eds), *The Construction of Professional Discourse*. Harlow: Addison Wesley Longman.
- Moniz-Cook, E., Agar, S., Gibson, G., Win, T. & Wang, M. (1998). A preliminary study of the effects of early intervention with people with dementia and their families in a memory clinic. *Ageing & Mental Health*, 2 (3), 199-211.
- Morgan, D.G. & Laing, G.P. (1991). The diagnosis of Alzheimer's disease: spouse's perspectives. *Qualitative Health Research*, 1 (3), 370-387.
- Morris, J.C., Storandt, M., Miller, P. (2000). Mild cognitive impairment represents early stage Alzheimer's disease. *Archives of Neurology*, 58, 397-405.
- Morris, M. & Larrick, R. (1995). When one cause casts doubt on another: a normative analysis of discounting in causal attribution. *Psychological Review*, 102, 331-55.
- Nolan, M., Grant, G. & Keady, J. (1996). *Understanding Family Care*. Buckingham: Open

University Press.

Orona,C.J. (1990). Temporality and identity loss due to Alzheimer's disease. *Social Science and Medicine*, 10, 1247-1256. Reprinted in: A.Strauss. & J.Corbin (eds) (1990) *Basics of qualitative research: grounded theory procedures and techniques*. Sage.

Phipps,A.J. & O'Brien,J.T.O. (2002). Memory clinics and clinical governance – a UK perspective. *International Journal of Geriatric Psychiatry*, 17, 1128-1132.

Pucci,E., Belardinelli, Borsetti,G. & Giuliani (2003). Relatives' attitudes towards informing patients about the diagnosis of Alzheimers disease. *Journal of Medical Ethics*, 29, 51-54.

Pusey,H. & Richards,D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging & Mental Health*, 5 (2), 107-119.

Roberts,J.S. & Connell,C.M. (2000). Illness representations among first-degree relatives of people with Alzheimer's disease. *Alzheimer Disease and Associated Disorders*, 14 (3), 129-136.

Sabat, S.R. (2001). *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*. Oxford: Blackwell.

Sullivan,K. & O'Conor,F. (2001). Should a diagnosis of Alzheimer's disease be disclosed? *Aging & Mental Health*, 5 (4), 340-348.

Taraborrelli,P. (1993). Exemplar A: becoming a carer. In N.Gilbert (ed), *Researching Social Life*. London: Sage.

Tarrier,N., Barrowclough,C., Ward,J., Donaldson,C., Burns,A. & Gregg,L. (2002). Expressed emotion and attributions of carers of patients with Alzheimer's disease: the effect on carer burden. *Journal of Abnormal Psychology*, 111 (2), 340-349.

Thompson,C. & Spilsbury,K. (2003). Support for carers of people with Alzheimer;s type dementia (Cochrane Review), *The Cochrane Library*, Issue 2, 2003.

Van Hout,H.P.J., Vernooij,M.J.F.J., Hoefnagels,W.H.L. & Grol,R.P.T.M. (2001). Measuring the opinions of memory clinic users: patients, relatives and general practitioners. *International Journal of Geriatric Psychiatry*, 16, 846-851.

Wackerbarth,S.B. & Johnson,M.M.S. (2002). The carrot and the stuck: benefits and barriers in getting a diagnosis. *Alzheimer Disease and Associated Disorders*, 16 (4), 213-220.

Wald,C., Fahy,M., Walker,Z. & Livingston,G. (2003). What to tell dementia caregivers – the rule of threes. *International Journal of Geriatric Psychiatry*, 18, 313-317.

Werner,P. (2001). Correlates of family caregivers' knowledge about Alzheimers disease. *International Journal of Geriatric Psychiatry*, 16, 32-38.

Werner,P. (2003). Factors influencing intentions to seek a cognitive status examination: a study based on the Health Belief Model. *International Journal of Geriatric Psychiatry*, 18, 787 –794.

Willoughby, J & Keating, N. (1991). Being in control: the process of caring for a relative with Alzheimer's disease. *Qualitative Health Research*, 1 (1), 27-50.

Wilson, H.S. (1989). Family caregivers: the experience of Alzheimer's disease. *Applied Nursing Research*, 2 (1), 40-45.

Woods, R.T. (2001). Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects. *Aging & Mental Health*, 5 (supplement 1), S7-S16.

Wright, L.K. (1991). The impact of Alzheimer's disease on the marital relationship. *The Gerontologist*, 31(2), 224-237.

Zarit, S.H. & Edwards, A.B. (1999). Family caregiving: research and clinical intervention. In R.T. Woods (ed.), *Psychological Problems of Ageing*. Chichester: Wiley.

Appendix A: Literature Search Strategy

A comprehensive search for relevant literature (published books / journal articles / theses) was carried out using the following computerised databases:

- **Psychinfo**
- **Medline / PubMed**
- **NHS National Research Register**
- **Health Management (Kings Fund / Department of Health)**
- **SIGLE (grey literature)**
- **Cochrane Library**
- **Internet search using Google**
- **Alzheimer's Society and Alzheimer's Association websites**

From 1980 until December 2003

Using the following search terms:

- **Alzheimer's disease / dementia**
- **Carer / caregiver / relative / partner / spouse/ husband / wife / child***
- **Experience / subjective experience**
- **Meaning**
- **Belief / attitude / labelling / attribution / appraisal / perception**
- **Identity / role**
- **Caring / caregiving / relationship**
- **Transition / loss**
- **Adjustment / coping / mental health**
- **Diagnosis / diagnostic disclosure**
- **Memory clinics**
- **Coping / stress**
- **Psychological support / intervention**

Further literature has been identified since through an iterative process of identifying literature from the references obtained.

Further papers were identified by conducting a citation search of key papers using Web of Science citation search engine.

Making Sense of a Diagnosis of Alzheimer's Disease: Partners' Experiences

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Abstract

Objectives

This study aimed to explore the personal experiences and meanings that people develop in response to their partner being diagnosed with Alzheimer's disease, and how these inform the ways in which they cope with and manage their situation in the early stages.

Method

In-depth interviews were conducted with four women whose partners had received a diagnosis of early-stage Alzheimer's disease from specialist services within the past six months. Interpretative Phenomenological Analysis was used to identify themes running within their accounts.

Results

Three key themes *emerged* from the analysis: '*Receiving confirmation of a diagnosis of Alzheimer's disease*', '*Making sense of the diagnosis*' and '*Staying on an even keel*'. '*Receiving confirmation of a diagnosis of Alzheimer's disease*' came at the end of a chain of events for participants. By the time they had been through the process of searching for an explanation for their husband's cognitive difficulties and consulted with professionals, most had half-expected a diagnosis, although it provoked some strong emotional responses. They described a range of strategies to '*make sense of the diagnosis*', including making social comparisons, interpreting professional and social discourses about Alzheimer's disease, making comparisons with previous phases of their life, and attempting to understand and empathise with their partner's experience. The core theme that emerged from participants' accounts was an emphasis on '*staying on an even keel*' and protecting their partners' sense of competence and selfhood. They engaged in a range of idiosyncratic *intra-personal and inter-personal adjustments* to achieve this goal, including re-evaluating their life story and re-defining themselves or their partners as 'old', re-defining social boundaries to avoid social stigma, and subtly taking on an increasingly powerful position within the relationship in a way that their partners would not be aware of.

Conclusions

The results are discussed in relation to current clinical debates about the ethics and practicalities of diagnostic disclosure as well as how services can better engage with and respond to the psychosocial needs of family caregivers in the early stages of dementia.

1 Introduction

1.1 Overview

Care-giving in dementia has been described as one of the most stressful and disruptive events in the family lifecycle (Zarit & Edwards, 1999), requiring both partners to adapt to significant losses in terms of intimacy, communication, socialisation, control, roles and relationships (Loos & Bowd, 1997). A clear association has been demonstrated between care-giving and chronic stress, mental and physical ill health and disability (Gottlieb & Wolfe, 2002). The stress-process paradigm has dominated research efforts to understand how family caregivers cope, and has been influential in the design and development of services to support caregivers. However, it is argued that it has a number of key limitations in terms of understanding the complexities, dynamics and individual differences in how people cope, which has resulted in services that frequently do not meet the needs of family caregivers and are associated with low rates of uptake (Nolan, Ingram & Watson, 2004).

It is argued in the present thesis that the personal meanings that partners develop in order to make sense of Alzheimer's disease (AD) in the early stages has a potentially huge impact on the experiences of the person with dementia and degree of disability experienced, as well as on partners' experiences, but that partners' experiences are little understood. Without a rich, nuanced and dynamic understanding of the complexity and diversity of partners' experiences, it is argued that services will not be in a position to respond effectively to their needs, a need which has been highlighted in recent policy documents (e.g. Department of Health, 2001).

The present thesis reports on a qualitative (interpretative phenomenological analysis) study into the experiences of partners whose husband had recently been diagnosed with Alzheimer's disease, reflecting a lack of in-depth research in this field as highlighted by a number of authors (e.g. Bamford *et al*, 2004; Bender, 2003; Coleman, 1999; Nolan *et al*, 2004). In particular, the aims were to gain insight into how partners make sense of the diagnosis, and how the personal and idiosyncratic meanings that they develop relate to ways in which they cope with their situation. It is anticipated that developing a better understanding of the psychological manoeuvres employed by partners in situations of change and loss could inform current ethical and practical debates about diagnostic disclosure, as well as how services can respond more effectively to the needs of family 'caregivers' in the early stages of dementia.

1.2 Partners' experiences and NHS context of care-giving in dementia

There are an estimated 600,000 people in the United Kingdom with Alzheimer's disease (AD), and it has been predicted that this figure will double by 2050 (Department of Health, 2001) as people live further into older age. The majority of long-term care of people with dementia takes place in the community, with an estimated 85% of home care being provided by family, and in particular partners (Whitlatch, 1998), consisting of an average 60 hours per week undertaking a supportive role (Haley, 1997). A survey by Stoller and Cutler (1992) indicated that fewer than 10% of care-giving spouses received help from outside the household.

A number of researchers have argued that partners frequently take on the role as care-giver unquestioningly as a consequence of dominant societal discourses about care-giving being a natural role (particularly for women), a basic feature of identity, a moral obligation and an extension of the parenting role and orientation to the family (e.g. Candey, 2001; Caron & Bowers, 2003; Kirsi, Hervonen & Jylha, 2000), as well as a lack of viable alternatives (O'Connor, 1999). A clear association has been established between care-giving and stress, burden, negative mental health consequences such as depression, and poor physical health (e.g. Gottlieb & Wolfe, 2002; Schultz *et al*, 1995; Zarit & Edwards, 1999).

The NHS has traditionally relied on family to take the burden of care, taking a reactive rather than proactive approach to meeting the needs of people with dementia, with 90% of spending being on institutional care for people in the later stages of dementia (Bosanquet, 2001). However, the recent National Service Framework for Older People (Department of Health, 2001) has highlighted the need to better support family care-givers. Nolan *et al* (2004) comment that carers have moved from the margins of social policy to 'centre stage', albeit seen as a resource, with an implicit aim being to 'keep carers caring' and thus avert a potentially overwhelming burden on the NHS and social services.

Care-giving for a partner with dementia is frequently referred to in the research literature as a 'career'. However, to date research has predominantly focussed on the later stages of dementia, with relatively little known about care-giving in the early stages (Morgan & Laing, 1991; Pearce, Clare & Pistrang, 2002; Pearlin *et al*, 1990; Zarit & Edwards, 1999). This is of serious concern in that services that better reflect the needs of caregivers cannot be effectively developed without fully understanding what those needs are (e.g. Nolan *et al*, 2004).

1.3 Understanding partners' experiences of dementia: a paradigm shift to focus on personal meanings

1.3.1 Limitations of stress-coping, attribution theory and labelling perspectives on understanding partners' experiences

The stress-process framework (e.g. Aneshensel, Pearlin & Schuler, 1995; Pearlin *et al*, 1990) has dominated research efforts to understand how partners cope with care-giving in dementia. In order to understand how people adapt very differently to seemingly similar circumstances, the stress-process framework operationalises coping as a process by which individuals use cognitive or behavioural strategies to manage stressful internal and external demands. Thus it focuses on individual differences in the appraisal of a situation and personal coping resources.

Although research using this framework (reviewed by Gottlieb & Wolfe, 2002; Schulz *et al*, 1995) has provided important insights into some of the factors, such as an emotion-focussed coping style and lack of social support, associated with negative outcomes such as depression, subjective burden, and declining physical health, it also has a number of key limitations. First, it has been associated with a preoccupation by researchers and policy makers with negative and pathological aspects of care whilst neglecting positive aspects (e.g. Nolan *et al*, 2004). Second, it has been criticised for being a very mechanistic, cognitive, linear, and rational approach, viewing meaning as an important coping resource (rather than as an outcome), but neglecting the subtleties of how meaning evolves over time and context (Farran, 1997). Third, much of the research has been criticised on methodological grounds, for example an over-reliance on cross-sectional research design and a huge diversity in outcome measures (Gottlieb & Wolfe, 2002). Nolan *et al* (2004) comment that the stress-coping paradigm and the associated pursuit of 'gold standard' quantitative research has led to services that are insensitive to individual need and thus tend to be rejected by carers.

The ways in which people construe a mental illness have been associated with a range of important behaviours and responses by patients, carers, professionals and social environment (Lobban, Barrowclough & Jones, 2003). Clare and Woods (2001), writing about the basis for effective cognitive rehabilitation in dementia, draw attention to the importance of minimising excess disability and the development of a malignant social psychology within the person's family system and social environment. Kitwood's (1997) dialectical model and social constructionist theory (e.g. Harding & Palfrey, 1997; Sabat, 2001) have been influential in highlighting the impact of social attitudes on the course of dementia. For example, Kitwood's

observational research within institutional care settings with people with advanced dementia highlighted a wide range of behaviours by care staff that were seen to inadvertently disempower and devalue the person with dementia (Barnett, 2000).

Similarly, Tarrier *et al* (2002) investigated the association between the attributions that carers make and their interactions with the person with dementia. They found that carers with high levels of expressed emotion (EE) made more attributions that were personal and controllable by the person with dementia for negative events, and over-involved carers were found to make more attributions of the patient's behaviour to causes external to the patient and internal to themselves. Research has demonstrated a clear association between high levels of EE (e.g. criticism) by carers of people with Alzheimer's disease and lower psychological well-being, poorer patient-carer relationships, lower marital intimacy, and higher levels of carer strain and burden (Tarrier *et al*, 2002).

Although little is known about the experiences of people with dementia at home (Norman *et al*, 2004), it seems reasonable to anticipate that similar processes would be evident in the interactions between people developing cognitive difficulties and their families, before, during and after it becomes labelled as 'dementia' (Clare & Shakespeare, 2004).

From a social labelling theory perspective, a *diagnosis* of AD has a potentially huge impact on social perceptions of the person with dementia, potentially leading to stigmatisation and exclusion (Walker *et al*, 1994). Wadley and Haley (2001) found that a label of Alzheimer's disease in the context of inappropriate behaviour by an older person generally elicited greater compassionate attitudes such as sympathy, less blame, and more willingness to help, although these could also result in helping behaviour that disempowers the individual with dementia. Their research was with college students rather than family members caring for a person with dementia, and there has unfortunately been little other research using this paradigm in the dementia field.

To conclude, evidence suggests that there is a strong association between not knowing how to interpret what is happening and caregiver strain and burden (Bonnano *et al*, 2004; Wilson, 1989), and that the stress-process framework is limited in its capacity to provide insight into such personal meanings. The way in which partners construe Alzheimer's disease has a significant impact on their own adjustment and on the degree of disability experienced by their

partner, and evidence suggests that the well-being of both partners is highly correlated (Forbat, 2004).

1.3.2 Meaning-making perspectives on the diagnosis of Alzheimer's disease: an overview of constructivist, existential, social constructionist and narrative paradigms

'each of us is actively involved, or implicated in construing, or attempting to make meaningful, our experience of the world – which includes our experience of ourselves, of others, and of all those features, objects, and mental processes that make up our lived reality.'

(Spinelli, 1996; p181)

Although there are differences between the theoretical positions, constructionist, constructivist, narrative and existential perspectives, all view meaning as the basis for understanding human action. We respond not to events themselves but to the meaning that those events have for us. In order to theoretically position the study reported on in this thesis and the remainder of the literature reviewed, a (necessarily) brief overview of these theoretical positions and how they enhance our understanding of events such as the onset or diagnosis of dementia follows. For more in-depth overview of these theoretical perspectives, see Ashworth (2003), Burr (1995), Harding and Palfrey (1997), McLeod (1997) and Rosen (1996).

From a personal construct theory (constructivist) position, Kelly (1955) viewed people as personal scientists, positing that we are continuously interpreting and re-interpreting events throughout our lives in order to make sense of our past, present and future. He posited that we draw on a complex hierarchical and personal system of bipolar constructs (e.g. good / bad), developed through individual experiences of the world, to make sense of our experiences and the future. Kelly (1955) viewed psychological development as a never ending cycle of validation and invalidation in response to events. Events that invalidate some of these constructs, or disconfirm expectations (such as developing memory problems or receiving a diagnosis of dementia) are experienced as stressful, making the individual psychologically vulnerable, as well as representing an opportunity for growth. A range of uncomfortable emotions, such as anxiety or guilt, are experienced when our constructs do not help us to predict events.

Whilst defining the individual as a *perceiver* rather than *conceiver* of the world (Ashworth, 2003), the existential-phenomenological paradigm, as outlined by Spinelli (1989, 1996) and

duPlock (1994) also posits that we all experience an innate drive to make our experiences meaningful, in order to protect us from the deep-rooted anxiety and sense of isolation associated with meaninglessness. When confronted with novel life events or situations, we seek meaning by making comparisons with things where we already have a meaning, or by trying to find some functional purpose for the event / situation. In our efforts to avoid existential angst, we often end up adopting a passive position, seeking out the security of external truths, permanent meanings, and statements from on high regarding the true purpose of our lives. Difficulties may occur when we define our identity along certain fixed characteristics, attitudes, or patterns of thought which, when experientially confronted by evidence to the contrary or with experiences that expand the meaning they have given themselves, they reject or disown the evidence in order to maintain their fixed meaning rather than re-shape or extend the meaning.

Rather than focus on the idiosyncratic, personal and individual way in which meanings are constructed by individuals, social constructionist approaches suggest that meanings are constructed socially. These approaches focus on how our meanings and realities are shaped and constrained by history and culture (e.g. Bruner, 1990; Gergen & Gergen, 1984). Burr (1995) identifies four basic assumptions of the social constructionist position: a critical stance to taken-for-granted knowledge; historical and cultural specificity; knowledge is sustained by social process; knowledge and social action go together. It follows that research from a social constructionist position focuses on the social construction of realities, such as the construct 'Alzheimer's disease', and how these are maintained by moral, political or pragmatic rather than epistemological or ontological precepts (Cromby & Nightingale, 1999).

Writers from both constructivist (e.g. Botella, 2004; Neimeyer, 2004; Viney, 1993) and social constructionist (e.g. Bruner, 1990; Gergen & Gergen, 1984; Miller, 2000) positions have focused on the centrality of narrative in providing meaning to our lives, other people, and the world. Narratives provide directionality, connectedness, coherence, and allow us to anticipate the future (Gergen & Gergen, 1984), mediate between culture and the beliefs, desires and hopes of persons, allow us to make sense of unusual or threatening events, and allow us to consider how things might be different (Bruner, 1990). According to Miller (2000; p310) "as actors we are able, through narrative construction and reconstruction, to impose some order, some intelligibility on events retrospectively... ultimately the continuous narrative account provides unity in an individual's life from birth to life to death".

The onset of chronic illness, such as dementia, has been conceptualized in terms of biographical disruption, and the role of narrative reconstruction has been recognized as an important process in order for people to make sense of such events (e.g. Mathieson & Stam, 1995; Miller, 2000; Riessman, 1990).

1.4 The social construction of 'Alzheimer's disease'

Dementia has been defined as a global deterioration in mental functioning (Lishman, 1987), with Alzheimer's disease representing the most common form of dementia in older age. It is a medical category which has come into widespread usage since the 1970's, describing a progressive and "widespread loss of mental function including memory loss, language impairment, disorientation, change in personality (e.g. increased irritability, anxiety, social withdrawal, loss of skills and impaired judgment), self-neglect, and behaviour which is out of character" (Department of Health, 2001). Alzheimer's disease is characterized by an insidious onset, and gradual but progressive decline in mental functioning, from mild impairment where the individual is still able to manage independently to severe dementia where continual help and support is required. Epidemiological research has indicated that it is typically 8-10 years from diagnosis to death (Karlsson *et al*, 1998), and prevalence increases greatly with age, from 1% of those aged 60-69 to 50% of those aged 90 and above (Fratiglioni, 1998).

Although it can only be confirmed post-mortem, a provisional diagnosis of Alzheimer's disease is typically made by medical practitioners on the basis of clinical assessment of social and behavioural functioning, brain scans and information on cognitive functioning (e.g. Folstein, Folstein & McHugh, 1975; Morris, 1999). A particular difficulty faced by clinicians in many cases is in distinguishing dementia from depression, with approximately 10% of cases diagnosed as organic dementia later being re-diagnosed as depression (Desrosiers, 1992).

From a neuroscience perspective, Alzheimer's disease is associated with enlargement of the ventricles and sulci of the brain, reflecting brain shrinkage, senile plaques, neurofibrillary tangles and granulovascular degeneration, tending to produce disconnection between different regions of the brain, although many of these markers are also associated with old age (Morris, 1999). A reduction in neurotransmitter activity has also been observed, and this discovery has led to the development of cholinesterase inhibitors.

However, the scientific validity of the construct 'Alzheimer's disease' is challenged by authors writing from a social constructionist position (e.g. Cheston & Bender, 1999; Harding & Palfrey, 1997; Kitwood, 1997; Sabat, 2001). They view the diagnosis as an arbitrary and historically / culturally bound construct, dictated by the needs of a society which needs to believe in it. Key criticisms include the assumption of a simple direct causal relationship between neuropathology and dementia on the basis of limited and questionable empirical evidence; evidence of 'catastrophic decline' in some cases which is too rapid to be accounted for by neuropathological change and 'reminiscence' whereby some people are observed to regain supposedly lost skills; and a lack of explanatory or predictive power of the diagnosis for a condition with an extremely wide-ranging presentation and prognosis.

It has been argued that the dramatic increase in funding for neuroscientific research into dementia that resulted from this paradigm shift has been successful to an extent in that understanding of the neuropathology, biochemistry and genetics of dementia has increased, along with the development of cholinesterase inhibitors which have been associated with positive outcomes in terms of slowing decline in cognitive abilities, global functioning and activities of daily living (e.g. Forette & Rockwood, 1999; Melzer, 1998).

Authors such as Kitwood (1997), however, have argued that the paradigm shift also resulted in a relative neglect of attempting to understand and respond to the social and psychological causes and impact of dementia (see Table 1). In response, Kitwood developed a dialectical bio-psycho-social framework, in which dementia is construed as resulting from complex interactions between biological, social and psychological processes (Figure 1). Table 1 illustrates the practical impact of both biomedical and biopsychosocial discourses, which emphasise technology and personhood respectively. It is argued that these have a significant impact on the type of care received at the time of diagnosis (Section 1.5.1).

Although psychologically-based interventions based on the disability framework have been developed in dementia care, observations of clinical practice indicate that they are rarely offered within the dominant medical framework of dementia care (Clare & Woods, 2001) which privileges the fatalistic view that there is little one can do to intervene beyond the use of medication. However, the impact of pharmacological approaches is limited at present, and, although the hope is for progress in a similar way to progress in the cancer care field 20 years previously, this situation is unlikely to change in the near future (Bosanquet, 2001).

Figure 1: Kitwood's bio-psycho-social framework (Kitwood, 1997)

$$\text{Dementia} = \text{Personality} + \text{Biography} + \text{Health} + \text{Neurological Impairment} + \text{Social Psychology}$$

Table 1: Competing cultures of dementia care (adapted from Kitwood, 1997; p136)

Old Culture (biomedical framework)	New Culture (biopsychosocial framework)
<p>General view of dementia The primary degenerative dementias are devastating diseases of the central nervous system, in which personality and identity are progressively destroyed</p>	<p>Dementing illnesses should be seen, primarily, as forms of disability. How a person is affected depends crucially on the quality of care.</p>
<p>Ultimate source of knowledge In relation to dementia, the people who possess the most reliable, valid, and relevant knowledge are the doctors and brain scientists. We should defer to them.</p>	<p>In relation to dementia, the people who possess the most reliable, valid and relevant knowledge are skilled and insightful practitioners of care.</p>
<p>Emphasis for research There is not much that we can do positively for a person with dementia, until the medical breakthroughs come. Hence much more biomedical research is urgently needed.</p>	<p>There is a great deal that we can do now, through the amplification of human insight and skill. This is the most urgent matter for research.</p>
<p>What caring entails Care is concerned primarily with such matters as providing a safe environment, meeting basic needs (food, clothing, toileting, warmth, cleanliness, adequate sleep etc) and giving physical care in a competent way.</p>	<p>Care is concerned primarily with the maintenance and enhancement of personhood. Providing a safe environment, meeting basic needs and giving physical care are all essential, but only part of the care of the whole person.</p>
<p>Priorities for understanding It is important to have a clear and accurate understanding of a person's impairments, especially those of cognition. The course of a dementing illness can be charted in terms of stages of decline.</p>	<p>It is important to have a clear and accurate understanding of a person's abilities, tastes, interests, values, forms of spirituality. There are as many manifestations of dementia as there are persons with dementia.</p>
<p>Problem behaviours When a person shows problem behaviours, these must be managed skilfully and efficiently.</p>	<p>All so-called problem behaviours should be viewed, primarily, as attempts at communication, related to need. It is necessary to seek to understand the message, and so to engage with the need that is not being met.</p>
<p>Carer's feelings In the process of care the key thing is to set aside our own concerns, feelings, vulnerabilities etc and get on with the job in a sensible, effective way.</p>	<p>In the process of care the key thing is to be in touch with our concerns, feelings, vulnerabilities etc and transform these into positive resources for our work.</p>

1.5 Partners' experiences of a diagnosis of 'Alzheimer's disease'

1.5.1 NHS context

There is evidence to suggest that a large majority of cases of Alzheimer's disease are undiagnosed, even in the more advanced stages (Cooper & Fearn, 1998). However, the need for early identification and treatment of Alzheimer's disease has been emphasised in recent government policy initiatives (e.g. Department of Health, 2001). Memory clinics, specialist outpatient-based assessment and diagnostic services for people with early presentation of cognitive impairments and dementia, have proliferated in recent years and play an important part in this vision (Phipps & O'Brien, 2002). Diagnosis is also made by medical practitioners in other settings, and evidence suggests that local service provision varies widely (Lindesay *et al*, 2002). Surprisingly, there is a lack of guidance from the National Institute of Clinical Excellence and the National Service Framework as to how these services should operate clinically (Phipps & O'Brien, 2002), although memory clinics have been criticised for being overly medical in their approach (Moniz-Cook *et al*, 1998).

Authors writing from a constructionist perspective (e.g. Harding & Palfrey, 1997; Mishler, 1997) have argued that consultations with health professionals are a place where 'reality' is co-constructed, but there is little research on how the process of diagnostic disclosure is managed by health professionals, or how such consultations influence the illness experience (Good, 1995).

Most of the research literature on diagnostic disclosure has focussed on the ethical debate about whether, rather than how a diagnosis should be disclosed to the patient (see Literature Review section). Bamford *et al* (2004) highlight the dilemma for health professionals between ensuring that patients are well informed about their condition (Department of Health, 2002) and the uncertainty associated with diagnosis and prognosis, as well as the right for patients not to know. From their review of the research literature, Bamford *et al* (2004) conclude that a large proportion (20-53%) of medical practitioners, particularly in primary care, experience difficulties in disclosing a diagnosis, often avoiding using the term 'dementia' or 'Alzheimer's disease'.

Although there is a growing emphasis on providing psychosocial interventions such as pre- and post-diagnostic counselling, support groups, cognitive rehabilitation, and advice / support to partners in the early stages of care-giving (Clare, 2002; Moniz-Cook *et al*, 1998), services are severely lacking in comparison with areas such as cancer-care (e.g. Bender, 2003; Nolan *et al*, 2004; Woods, 2001). Research on the effectiveness of psychosocial interventions for caregivers has been reviewed by several authors (Brodaty, Green & Koschera, 2003; Cooke *et al*, 2001; Pusey & Richards, 2001; Thompson & Spilsbury, 2003). These authors all conclude that there is a lack of empirical evidence to support the view that interventions to support family caregivers are of quantifiable benefit, although qualitative results indicate that interventions are often perceived as helpful (Brodaty *et al*, 2003). Nolan *et al* (2004) argue that research has tended to use crude outcome measures such as delaying institutionalisation and reducing burden rather than using personally meaningful outcomes. In order to develop effective and personally relevant interventions, there needs to be a better understanding of the coping strategies naturally used by partners (Clare, 2002) as well as understanding of what constitutes a personally relevant outcome of intervention (Nolan *et al*, 2004).

1.5.2 Partners' experiences of seeking professional opinion and coping with a diagnosis of Alzheimer's disease

Published research relating to the process of deciding to seek professional opinion is reviewed in the Literature Review section. This literature indicates that there is often a considerable delay in coming to the attention of services as people adjust naturally to the difficulties that arise and tend to use cognitive strategies to normalise their situation and avoid an inevitable sense of loss associated with a diagnosis (e.g. Bender, 2003; Wilson, 1989).

Consumer satisfaction is viewed as a key outcome within current NHS culture. A number of authors have found that although people tend to express satisfaction with professionals involved in disclosing a diagnosis, they are frequently dissatisfied with the feedback they receive. In particular the vagueness of diagnostic information, lack of information and advice regarding future management, a lack of support and inadequate follow-up procedures (e.g. Gilliard & Gwilliam, 1996; Heal & Husband, 1998; Holroyd, Turnbull & Wade, 2002; Marzanski, 2000; Sweetman & Davies, 2002; Van Hout *et al*, 2001; Wald *et al*, 2003, Werner, 2001).

The research literature base on the impact of a diagnosis on partners and coping in the early stages of dementia is extremely limited. In a qualitative study of coping during the period shortly after diagnosis, Morgan and Laing (1991) found that all of those interviewed expressed uncertainty and a sense of helplessness, and they categorised partners according to whether they were 'coming to terms' with the diagnosis and grieving losses, or 'hanging on' despite feeling overwhelmed with an increasing number of responsibilities. Morgan and Laing (1991) argue that the strategies used were dependent on the relationship before the onset of dementia, and that those who had had a relationship characterised by conflict, unequal power relations and a lack of intimacy were struggling significantly with the role strain associated with trying to hang on. Although her emphasis was on the person with dementia, Clare (2002, 2003) used a qualitative approach to explore the strategies used by people with dementia and their partners to adjust and cope, and found in most cases that coping strategies were focussed on holding onto a sense of self and normality, rather than accepting losses and integrating the diagnosis with their identity.

1.5.3 Meaning making: the influence of lay, professional and cross-cultural discourses about Alzheimer's disease

Research relating to socio-cultural discourses that relatives refer to in constructing an account of their situation is reviewed in the Literature Review section, and summarised in table 2.

Authors such as Bodily (1994) and Harding and Palfrey (1997) argue that there are limited socio-cultural discourses about dementia within the UK leading to limited ways of construing a person with dementia. Various authors argue that this lack of publicly available lay models means that partners' construal is often a very private experience in order to avoid invalidation in public medicalised arena (Askham, 1995; Chung, 2000) and shame in social contexts (Adams & Sanders, 2004).

Table 2: Summary of research studies on lay discourses on dementia

Author/s	Aims / Methodology / no. of participants / country	Key findings
Askham (1995)	To understand how family caregivers perceive and describe dementia. Content analysis of qualitative interviews. N = 106 family caregivers (diagnosis in past 12 months). UK (inner-London / market town)	Accounts divided into several categories based on several parameters: 1. Normal – abnormal 2. Orderly – unpredictable 3. Simple – complex 4. Illness – not an illness ¼ of participants made comparisons with more familiar conditions such as normal ageing, childhood, functional mental and physical illness. ¼ used narrow construal – going senile / losing their memory.
Chung (2000)	To understand how family caregivers make sense of AD. Grounded theory. N = 18 family caregivers. Hong Kong.	Tendency for a limited knowledge of dementia. Searching for meaning seen to be associated with an attempt by family to gain control of the disease process. Tendency to be dismissive of biomedical explanation, favouring explanations related to past medical history, critical life events, and supernatural beliefs.
Clare & Shakespeare (2004)	To identify what discourses dyads draw on to construct and co-construct an account of dementia. Conversation Analysis. N = 10 married couples in early-stage dementia. UK.	Dyad drew significantly on discourses of ageing, lack of stimulation, distinguishing long-term from short-term memory. Only one of the 10 couples drew on a medical discourse to construct an account of their situation.
Hinton & Levkoff (1999)	To understand how biomedical discourse is interpreted, communicated, discussed and adapted across different ethnic groups. Narrative analysis of illness stories. N = not stated! USA (African-American, Chinese – American, Irish-American, Latino-American groups)	Caregivers drew on biomedical explanations and other cultural discourses to construct personal meanings. Three key story types identified: 1. stories about Alzheimer’s disease as a disease that erodes the core identity and deteriorates their minds (across all ethnic groups) 2. stories that emphasise how families manage confusion and disability as an expected part of growing old (Chinese) 3. stories which place AD in the context of tragic losses, loneliness and family responsibility (Latino)
Levy et al (2000)	In-depth cross-cultural analysis of relative caregivers’ illness attributions. Content analysis of interview transcripts. N = 40 USA.	Illness attributions (cause of dementia) held by caregivers of a relative with dementia: Normal ageing, Bad luck, Bad medical experience, Problem with a part of the body other than brain, Change in the brain, Regression to childhood, Bad diet, Disease (e.g. Alzheimer’s), Divine retribution, Environmental factors, Genetics, Personal history, Immigration, Lack of social support, Psychological stress, Stroke, Not venting emotions.

1.5.4 Impact of a diagnosis of Alzheimer's disease on caregiver identity

Several researchers have focussed on the impact of the early stages of dementia on caregiver identity, although none of these have focussed on the impact of the diagnosis itself. Charmaz (1987) proposes that when people develop chronic illnesses, their former social and personal identities and future plans are threatened as a result of the physical, social, psychological and financial consequences of the illness. Individuals enter into an implicit or explicit process of creating new identities that represent new goals, assumptions and hopes. Over time they may reduce their aspirations, instead aiming for less preferred identities. It could be postulated that a similar process occurs for partners in response to dementia.

Zarit and Edwards (1999) comment that following diagnosis, partners find themselves increasingly positioned by others in a care-giving role. There is also a tendency to position themselves in such a role, through feelings of obligation, reciprocity, continuing a family tradition, mutual concern, marital closeness, social captivity, intimacy and love (Farran, 1997).

O'Connor (1999) interviewed partners care-giving in dementia, examining the discourses they drew on relating to care-giving. She found that partners tended to reject the term 'caregiver', viewing care-giving as a logical extension of the marital relationship, with the assumption that there was little 'choice' about adopting the role if one wished to be construed as 'caring'. This mandate was seen to be legitimated by the perception that a partner is the most logical and qualified person to take on the role, and that accepting outside help constituted abandonment to a less good option, thereby representing a personal failure or deficiency. Wives that were interviewed tended to see their aim as preserving the relationship, whereas husbands emphasised qualities related to maintaining independence. Those who viewed care-giving as a public duty and contribution that should be recognised tended to feel invalidated by their actual experiences. O'Connor (1999) uses this data to explain why partners tend not to request the support of outside services, due to the risks of being invalidated as a competent and caring partner.

Bender (2003) argues that there are a number of potentially positive aspects of construing oneself as a caregiver. These include the acquisition of a clear role, the acquisition of social status in terms of being construed by society as 'saintly', the acquisition of clear rights, clarification of difficulties, and thereby relief from uncertainty, relief from anxiety leading to

the opportunity to activate effective coping strategies, and increased power as a carer of a very ill person.

Meuser and Marwit (2001) conducted focus groups with partners in the early stages of dementia care-giving and found that the individual and group discourses reflected less use of denial, a strong sense of togetherness, acceptance of present circumstances, and a sadness about loss but not a desire to hold onto the past, resistance to institutionalisation, and a focus of loss on shared rather than individual experiences. However, in a qualitative analysis of older partners' reactions to bereavement, Golsworthy and Coyle (1999) found that shame and self-criticism were common reactions to not being able to meet these socio-cultural discourses of being a 'saintly coper'.

Although she interviewed people in the later stages of care-giving, Orona (1990) found that a key concern for partners was that they were losing access to their own identity as their partner lost the ability to bear witness to their shared history, particularly as they directed an increasing proportion of their energy to the role of primary caregiver.

Candey (2001) focuses on wives' acquisition of a caregiver identity in the early stages of dementia, providing evidence from in-depth interviews and repertory grids that partners integrate previous caring roles flexibly to define their role and identity as caregiver. In a conversational analysis of how partners negotiate the impact of forgetting in the early stages of dementia, Clare and Shakespeare (2004) found that partners positioned themselves in varying ways in relation to the 'problem', from denying its existence to defining their current situation as being the memory problem. Typically they found that partners positioned themselves through discourse as 'helpers', trying to promote a sense of equality, minimising emotional responses, and minimising the sense that their position had shifted. Perry and O'Connor (2002) also found that preserving personhood was a guiding directive for spouses caring for a partner with dementia, through strategies to maintain continuity, sustain existing competencies, protect the partner from incompetence, and strategise public encounters.

To conclude, research supports the view that the onset of dementia impacts significantly on partners' social and personal identities, and that although the role of 'carer' has positive social connotations, there is little element of 'choice' about adopting the role, which can lead to significant loss to other aspects of one's identity as the dementia progresses.

1.6 Research questions

It has been argued in this review of the literature that there is a need for a much more in-depth understanding of the experiences of partners coping in the early stages of Alzheimer's disease if services are to evolve to better meet their needs, both in terms of diagnostic disclosure and support following a diagnosis. Understanding the psychological manoeuvres employed by partners at this time of change and loss has been severely neglected within the research literature, at the expense of large scale quantitative studies that fail to capture the complex, dynamic and individual psychological and social strategies employed by partners (e.g. Bamford *et al*, 2004; Bender, 2003; Coleman, 1999; Levy *et al*, 2000; Nolan *et al*, 2004).

In response to the gaps identified in the research literature, the aim of the study is to address the following questions:

1. What sense do participants make of their partners' diagnosis of Alzheimer's disease?
2. What psychological and social strategies do participants employ in order to make sense of their partners' diagnosis of Alzheimer's disease?
3. How do the meanings that participants arrive at relate to the ways in which they cope with and manage their situation?

2 Methodological approach

2.1 Research approach

'The aim of qualitative research is to understand and represent the experiences and actions of people as they encounter, engage, and live through situations. In qualitative research, the researcher attempts to develop understandings of the phenomena under study, based as much as possible on the perspective of those being studied.'

(Elliott et al, 1999; 216)

A qualitative approach was considered most appropriate to addressing the research questions, given the exploratory nature of the study, the focus on personal meanings, and the limitations of the research evidence base. This is in contrast with a quantitative approach which aims to test hypothesized relationships or causal explanations, measuring the degree of

generalisability across samples (see Figure 2 for a comparison of qualitative and quantitative approaches). The aim of this particular study was to use in-depth, semi-structured interviews to explore the experiences of a small but well defined sample in detail, whilst remaining cautious about generalizing to the wider population (Flowers *et al*, 1997).

Interpretative Phenomenological Analysis (IPA) (e.g. Smith, Flowers & Osborn, 1997; Smith & Osborn, 2003) was identified as the preferred methodology for several reasons. First, its fit with the aims and constructivist / constructionist philosophy of the study. Second, as a novice qualitative researcher, the availability of texts containing structured and detailed guidance for conducting an IPA study (e.g. Smith & Osborn, 2003; Willig, 2001) was considered particularly helpful in the learning process. Third, the availability of supervision by a researcher experienced in the use of IPA was considered essential. IPA has been used to address a wide range of issues in health and clinical psychology, including a number of studies on experiences of the early stages of dementia (Clare, 2002, 2003; Pearce, Clare & Pistrang, 2002), and experiences of bereavement and loss (Golsworthy & Coyle, 1999).

Figure 2: Contrasting qualities of qualitative and quantitative paradigms (Roberts, 2000)

QUALITATIVE	QUANTITATIVE
Personally meaningful	Generally measurable
Contextualised	Controlled
Relational	Reproducible
Inductive	Deductive
Evocative	Highly probable
Pluralistic	Standardised
Imaginative	Logical
Lateral	Linear
Amusing	Informational
Private	Public
Intimate	Detached
Humanistic	Scientific
Individualistic	Epidemiological
Constructed	Analytical, dissected
Performative	Observational
Symbolic	Theoretical
Wisdom	Knowledge
Practice	Research

IPA is a recently developed and still evolving approach to qualitative research. It is grounded within a realist ontology, in that there is assumed to be a chain of connection between account, cognition, and behaviour (Willig, 2001). The approach is *phenomenological* in that it is assumed that what a participant says has some ongoing significance for them and that there is a relationship, albeit not necessarily a transparent one, between what they say and the constructs that they hold. It is also *interpretative* in that it is recognized that meanings are seen to be negotiated within a social context (Smith, 1995). In order to “explore the participant’s view of the world and to adopt, as far as possible, an ‘insider’s perspective’” (Smith, 1996; 264), the IPA approach acknowledges that the researcher must engage in an interpretative dialogue with the data. Thus the analytic account is seen to be a joint product of reflection and co-construction by both participant and researcher (Smith *et al*, 1997).

Although there is an emphasis on developing an understanding of participants’ experiences, IPA can also involve analysis at a critical level, analyzing interviews by asking questions such as ‘what is the person trying to achieve here?’, ‘is something leaking out that wasn’t intended?’, or ‘do I have a sense of something going on here that maybe the participants themselves were less aware of?’ (Smith & Osborn, 2003). Consistent with the constructivist approach outlined in the Introduction, IPA is philosophically rooted in symbolic interactionism, with its interest in how meanings are constructed by individuals (Smith, 1996). However, as Clare (2003) points out, IPA is also consistent with discursive understandings.

The research approach adopted here draws both on constructivist and social constructionist traditions, as outlined in the Introduction. As Elliott *et al* (1999; 217) put it, “to take into account matters such as history, language and context that relativise the knowledge gained to the individuals and situations studied and to those doing the enquiry”. As outlined in the Introduction, the analytic approach is informed by narrative texts (e.g. Gergen & Gergen, 1985; Miller, 2000; Riessman, 1993), given the emphasis within the qualitative research literature reviewed on locating the experiences and significance of a diagnosis within the context of the individual’s and the couple’s ongoing life story. Thus the research approach adopted in this study is consistent with the current paradigm shift within qualitative research towards epistemological eclecticism, encompassing both the real and the constructed (e.g. Larkin, 2004; Spencer *et al*, 2003).

Although there are many similarities between IPA and Grounded Theory in terms of theoretical background and analytic procedures, authors such as Willig (2001) have argued that IPA represents a more psychological (rather than sociological) approach. It was therefore considered better suited to gaining insight into individual participant's worlds, rather than attempting to build a 'theoretically saturated' (Strauss & Corbin, 1990) account of the social processes that account for the phenomena under investigation. Given the practicalities and constraints of undertaking research as part of a doctoral training in clinical psychology, IPA was seen as a realistic means by which to achieve the aims of the study.

2.2 Reflexive considerations

Qualitative researchers accept that it is impossible to separate the practicalities of research from the theoretical frameworks and assumptions of the researcher (Edwards & Ribbens, 1998), and IPA literature emphasises the co-constructed nature of participants' accounts (e.g. Smith, 1995). However, the researcher's self reflective attempts to 'bracket' existing theory and their own values can facilitate efforts to understand and represent their informants' experiences and actions more adequately than would otherwise be possible (Elliott *et al*, 1999; Yardley, 2000).

In this case, the researcher's interest in undertaking the research arose both through family experiences of dementia and old age, experiences as a trainee psychologist involved in memory clinic assessments and co-facilitating a memory skills group for people in the early stages of dementia. Both resulted in an interest in how people managed to retain a strong sense of humour and resilience in response to a potentially devastating condition. This is in the context of a wider interest in how people use a diagnosis to inform their coping. A presentation by Miesen (2002) on the flourishing Alzheimer's café movement in the Netherlands acted as a catalyst to undertaking this research, as it highlighted the responsibility and possibility for services to respond creatively to negative social attitudes about dementia and old age and create a context for positive social experiences and support for people with dementia and their partners. Thus a strong directive for doing the research was to add to the body of research literature that can inform service development.

3 Method

3.1 Design

A cross-sectional qualitative research design was employed, using Interpretative Phenomenological Analysis (IPA) (Smith, 1995, 1996; Smith & Osborn, 2003; Smith, Osborn, & Jarman, 1997, 1999) to analyse verbatim transcripts of in-depth, semi-structured interviews.

3.2 Participants

3.2.1 Recruitment strategy

In keeping with the philosophy of IPA research, the aim was to recruit a relatively small and homogenous sample from which generalisations to other groups of caregivers could be considered (Smith, 1995, 1996; Smith & Osborn, 2003; Smith *et al*, 1997). In this case, the aim was to recruit a group of partners of people who had been assessed within specialist services and recently received a diagnosis of 'probable Alzheimer's disease'.

Considerable difficulties were experienced recruiting a sufficient number of participants within the limited timescale available. This meant that the recruitment strategy was revised several times. Initially, partners were invited to participate where a diagnosis of 'probable Alzheimer's disease' had been disclosed within the past two months. The basis of specifying this two month period was that it would facilitate more immediate accounts of participants' experiences around the time of diagnosis, rather than relying on retrospective accounts.

However, this period was subsequently extended to six months post-diagnosis (a criterion used by other qualitative researchers in this field e.g. Candey, 2001; Clare, 2002, 2003; Morgan & Laing, 1991; Pearce *et al*, 2002).

Furthermore, although the initial aim was to approach participants through a memory clinic, on the basis of projections made in conjunction with a recent audit of the service (Sweetman & Davies, 2002), advice from clinicians working in the service, and high recruitment rates among this population reported by Clare (Clare, 2002, 2003), few potential participants could be identified in this way. Therefore, recruitment was broadened to recruiting through the associated Old Age Psychiatry department and a local branch of the Alzheimer's Society.

As dictated by Local Research Ethics Committee (LREC) protocol, potential participants were approached indirectly, through the psychiatrists responsible for the patients' care and through a case-worker at the local Alzheimer's Society. A clinical psychologist from the service was involved in coordinating research by several trainee psychologists who were recruiting through the old age psychiatry department, and assisted in terms of identifying suitable participants. The researcher also attended as many of the psychiatrists' weekly outpatient clinics as possible in order to prompt them with recruitment. Recruitment packs, consisting of a detailed information sheet and reply form (with stamped addressed envelope) indicating whether the person wished to take part in the research (and if so, consenting to being contacted directly by the researcher), were offered either in person or by post to potential participants. Those who agreed to participate were then contacted either by telephone or letter, on the basis of their stated preferences, and an interview arranged. Participants' GP's were informed of their participation and sent an information sheet describing the project where consent was given to do so.

In total, at least 17 recruitment packs were sent out or handed directly to potential participants. Of these, four people agreed to take part in the study.

3.2.2 Sample

Smith and Osborn (2003) suggest that 5-6 participants is generally a reasonable sample size for an IPA study, enough to examine similarities and differences, but not be overwhelmed by data. However, due to the considerable difficulties in the recruitment phase, as highlighted previously, only four participants could be recruited to the study within the limited time available. The difficulties experienced are detailed in the Critical Review section, and methodological implications considered in the Discussion section. It is argued that, as the emphasis of the research was on gaining rich and in-depth accounts of individual experiences rather than on constructing a theoretical account of the phenomena encountered, four participants were considered sufficient.

Participants were recruited from a region of Essex with a mainly white British population of 120,000 people living in urban and rural settings, ranging from deprived to extremely affluent. The area is served by a multidisciplinary mental health team for older people, including two consultant psychiatrists (and their specialist registrars) and two clinical psychologists. A memory clinic operates for one day a week staffed partly by members of this department. As

with most memory clinics, the primary function is as a diagnostic service, with medication being the intervention in the majority of cases, although with an increasing emphasis on psychosocial intervention (Sweetman & Davies, 2002). The area is also served by an active branch of the Alzheimer's Society, which provides outreach and day services as well as information and advice.

All the participants had attended the memory clinic and had the diagnosis disclosed by a psychiatrist in outpatients within the past three weeks to six months. They were all female, married, retired (all had previously been employed), white British, aged from their late-60's to their mid-80's, and three had adult children. Three of the husbands were in their 80's and one in his late 60's, and all had been prescribed cholinesterase inhibitor medication. Only one of the four couples was in contact with the local Alzheimer's Society.

3.3 Ethical Considerations

Ethical approval for the study was granted by the West Essex Local Research Ethics Committee (LREC), and relevant documentation is appended in Appendix A.

In terms of confidentiality, data is held securely as outlined within the Data Protection Act. Consent to record interviews on audiotape was sought, on the basis that on completion of the study, transcribed tapes would be returned to participants or destroyed. Participants were informed that verbatim quotes might be recorded in the thesis and subsequent publications, with the premise that any identifying information would be removed from any such quotes.

In terms of informed consent, a written information sheet was provided to potential participants orienting them to the purpose and nature of the research, and outlining confidentiality and anonymity arrangements (Appendix B). Participants were made aware (both in writing and verbally) that they could withdraw from the study at any time, refuse to answer particular questions without explanation, and that their decision would not affect their partner's care. A consent form (Appendix B) was signed by participant and researcher prior to the initial interview. The issue of whether to seek the consent of participants' partners was considered, but it was felt that as the focus of the interviews was on participants' experiences, partners' consent was unnecessary and would have invalidated the right for participants to be considered as individuals in their own right.

The nature of the study meant that potentially distressing issues were discussed. Participants were made aware that they could decline to answer particular questions or follow particular lines of enquiry. Clearly, as in clinical practice, every attempt was made to be sensitive to the needs of participants to avoid potential harm. It should be noted that researchers addressing similar issues using qualitative methodology have commented that participants have valued the opportunity to describe their experiences and discuss issues/ concerns that they may not have felt able to discuss with family or friends (e.g. Candey, 2001). Participants were asked prior to the study whether they wanted their GP to be sent an information sheet describing the study. A supervisory team was available should concerns be raised about a participant's mental health during the course of the interviews, and it was agreed that participants would also be encouraged to approach their GP. Information packs on Alzheimer's disease and local services were also made available to participants.

The issue of fatigue was considered, and the researcher was observant of signs of fatigue. Participants were made aware before the interviews that they should indicate if fatigue was an issue, and were made aware that the interview could be continued on another occasion if necessary. However, this was not an issue in the interviews that were conducted.

A written summary of the results was sent to participants and comments invited as a means of establishing credibility of the analysis and of debriefing participants.

3.4 Procedure

The procedure is summarised in Figure 3, below.

3.4.1 Interviews

Three of the four participants elected for the interviews to be conducted in their homes. The fourth participant was interviewed in the psychology department as she did not wish for her husband to be aware that she was participating in the research (as he refused to acknowledge the diagnosis). Interviews lasted between 50 and 120 minutes. Before starting the interviews, participants were asked to read through and sign a consent form (Appendix B), and any questions about the process were addressed. Interviews were recorded on audio-tape, from which transcripts of the interviews were made by the researcher.

An interview schedule (Appendix C) was used flexibly by the researcher. The schedule was used as a framework to guide the interview but after the opening question, the interviewer followed the participants' train of thought rather than imposing a structure. The schedule was developed to address the research questions, and to ensure sufficient levels of depth, nuance, detail and vividness to the interview material (Rubin & Rubin, 1995). In developing the interview schedule, research literature, previous clinical and personal experience, discussions with psychologists working in the field, and guidance on the development of interview schedules (e.g. Kvale, 1996; Rubin & Rubin, 1995; Smith, 1995; Smith *et al*, 1999) were used. A pilot interview was conducted with the partner of a wife who had been diagnosed with Alzheimer's disease several years previously, and feedback from this interview process was used to refine the schedule. In line with the iterative nature of the research process, the interview schedule was revised between interviews in order to incorporate unexpected or interesting directions pertinent to the interview questions.

Guidance on qualitative interviewing technique was followed to facilitate sufficient levels of depth, nuance, detail and vividness in interviewee's accounts (e.g. Kvale, 1996; Rubin & Rubin, 1995; Smith, 1995; 1999). An interview feedback sheet (Appendix C) was completed after each interview to increase reflexivity, focussing both on content and process issues. For example, how participants presented their narratives, unexpected issues and themes, and the interviewer's experience.

Interviews were transcribed by the interviewer from audio-tape as soon as possible after the interviews. Audio tapes were re-listened to after the initial transcription to ensure accuracy and nuance had been captured. Emotional content, non-verbal communication was incorporated into the transcripts where this was felt to be particularly pertinent. Transcription notation is summarised at the beginning of the Analysis section. The interviewer's experience is discussed in the Critical Review section.

3.4.2 Data analysis

The qualitative interview data was analysed using Interpretative Phenomenological Analysis, as described by Jonathan Smith (Smith, 1995, 1996; Smith *et al*, 1997, 1999; Smith & Osborn, 2003). The aim of the systematic analytic process was to produce a list of themes and relationships between themes that provide insight into participants' experiences. These are illustrated with verbatim quotes in the Analysis section. Guidelines for assessing the quality of

qualitative research (Elliott *et al*, 1999; Lincoln & Guba, 1985; Smith, 1996; Spencer *et al*, 2003) were used to guide the process, as was supervision from an experienced IPA researcher.

3.4.2.a Analytic procedure

Interviews were analysed after each interview on a case-by-case basis. On completion of the set of interviews, these individual analyses were then compared and integrated to produce the 'analysis', in line with the idiographic IPA approach.

On completion of an interview, the transcript and audio-tape for that participant were listened to and read several times. To ensure close consideration of all the interview material, the transcript was initially coded on a line by line basis, before adopting a broader perspective. In order to develop the analysis, the wide right-hand margins of the transcripts were divided into two columns.

The left-hand column was used to note initial responses to the interview material, making notes on anything that appeared relevant or interesting with regards to the research questions. The framework proposed by Rubin and Rubin (1995) to promote active engagement with the interview material was followed. They propose looking out for (i) core ideas and concepts (unusual phrases / terms, frequently repeated nouns, opposites, core ideas); (ii) stories (engaging with what the participant is communicating; (iii) and themes. This stage of the process involved summarising key concepts used by the participant, narratives, preliminary interpretations of and associations to the material, possible links to theory, and possible connections with other parts of the interview. In addition to the IPA literature and dementia research, several narrative psychology texts (Gergen & Gergen, 1984; Miller, 2000; Riessman, 1993) were found to be helpful in the analytic process in terms of looking more broadly at the structure and function of particular narratives.

The right-hand column was used to document emergent theme titles. These were labelled using key words or phrases that captured the essence of what the participant was felt to be conveying. An attempt was made to use words or phrases used by the participants themselves, in keeping with the phenomenological nature of IPA.

A list of emergent themes (from the right-hand column) was then produced for that participant, along with brief descriptions and references (page and text unit number) to illustrations of the themes in the transcript.

Connections between these themes were made, grouping those that appeared to be inter-related. This was a constant iterative process of going between the list of themes and the transcript, as well as consulting memos. Mind maps (Buzan, 1995) were used to facilitate a more creative and exploratory process of making connections between themes. Superordinate themes were identified to connect the themes that had been grouped together. This stage of the process involved more interpretation, drawing on existing theoretical and research literature and clinical / personal experience, as outlined in the Introduction section.

On completion of case-by-case analyses, a thematic analysis was completed for the group, as described by Macran, Stiles and Smith (1999). The lists of themes for each case were examined for commonalities and differences. Themes which appeared to cluster were checked against the original transcripts. Supervision was used to examine, elaborate or refine the consolidated list and examine alternative groupings and possible broader domains. As suggested by Smith *et al* (1997) and Willig (2001), a list of master themes and their constituent subordinate themes was drawn up for the group, with identifiers to locate from where in the transcripts these themes were identified (see Appendix F).

Memos were used throughout the analytic process to document the development of the researcher's thinking, and these were categorised as 'code notes', 'theoretical notes', or 'operational notes' (Strauss & Corbin, 1990). Examples of these are included in Appendix E. These were an essential part of the iterative analytic process, and form part of the audit trail that demonstrates the analytic process from interviews to the Analysis section.

3.4.2.b Writing up

Writing-up began after the analysis of the first three interviews. This was felt to be a less than ideal situation, as it had been hoped that writing-up would follow the completion of the analysis. However, as Smith *et al* (1999) comment, the division between analysis and writing up is an arbitrary one, in that analysis continues during the writing stage.

Verbatim quotes were selected from the interview transcripts that illustrate the emergent themes in an accurate, convincing and hopefully vivid way (Rubin & Rubin, 1995). Extracts were selected from a theme-by-theme list of interview extracts (see Appendix F for examples). The themes presented in the Analysis section represent the key themes pertinent to answering the research questions (see Appendix F for a complete list of themes).

3.4.2.c Reliability and Validity issues

Several key references aided consideration of issues relating to the reliability and validity: Cabinet Office guidance on assessing the quality of qualitative research (Spencer *et al*, 2003); guidelines on the publication of qualitative psychological research (Elliott *et al*, 1999); a discussion of validity and reflexivity in qualitative research (Smith, 1996); and the widely quoted guidelines by Lincoln and Guba (1985) on establishing 'trustworthiness' of qualitative research. Table 3, below, summarises the steps taken to ensure 'trustworthiness'.

Table 3: Steps taken to address issues relating to 'trustworthiness' of the data and analysis (Lincoln & Guba, 1985)

Naturalistic Criteria (scientific equivalent)	Steps taken within study to address 'trustworthiness'
Credibility (Internal Validity) i.e. truth value	<ul style="list-style-type: none"> • Member Validation • Checking understanding with participants within interview context • Triangulation • Independent auditor to ensure that analysis makes sense • Peer review • Personal reflection on personal, cultural and political values, interests, influences (through research diary, supervision) • Considering and documenting alternative interpretations of interview data, and looking for exceptions within data
Transferability (Generalisability) i.e. applicability	<ul style="list-style-type: none"> • Consideration of (published) research literature and other relevant accounts, and how the Analysis fits with existing data • Consideration of sample characteristics and the contexts in which the research was undertaken, and thus limitations in transferability • Inviting experts from within the dementia care field to comment on the analysis (written report to members of the department, Alzheimer's Society) and presentation to the memory clinic team
Dependability (Reliability) i.e. consistency	<ul style="list-style-type: none"> • Audit trail – checked by supervisor and by auditor (clinical psychologist) independent of the study. Example of the audit trail is appended (Appendix D, E, F)
Confirmability (Objectivity) i.e. neutrality	<ul style="list-style-type: none"> • Audit trail (Appendix D, E, F) • Documenting reflexive considerations through research diary and memos, and supervision (i.e. relationship between researcher and the researched) • Presenting sufficient evidence to support the analysis in the Analysis and Appendix. Distinguishing data from analysis.

Member validation provides an opportunity for participants to comment on the analysis (Smith, 1996). The model for this was taken from Macran *et al* (1999), in that themes were summarised for participants on an individual basis with a brief description and illustrative excerpts. A summary of the findings of the study was also provided. These were sent to participants and feedback invited. This was done more for ethical reasons in terms of ensuring that participants were made aware of how interview material was used and also giving some feedback. Shaw (2004) comments that although member validation is currently in vogue in qualitative research, it is hampered by a number of concerns, in particular relating to whose account this is, and who holds the power to include or exclude interpretations. Smith (1996) also comments that members may find it difficult to question interpretations freely as a response to dynamics whereby the researcher is perceived as a more powerful person. Checking understanding and preliminary interpretations was also done within the context of the interviews, which was felt to be a more democratic process.

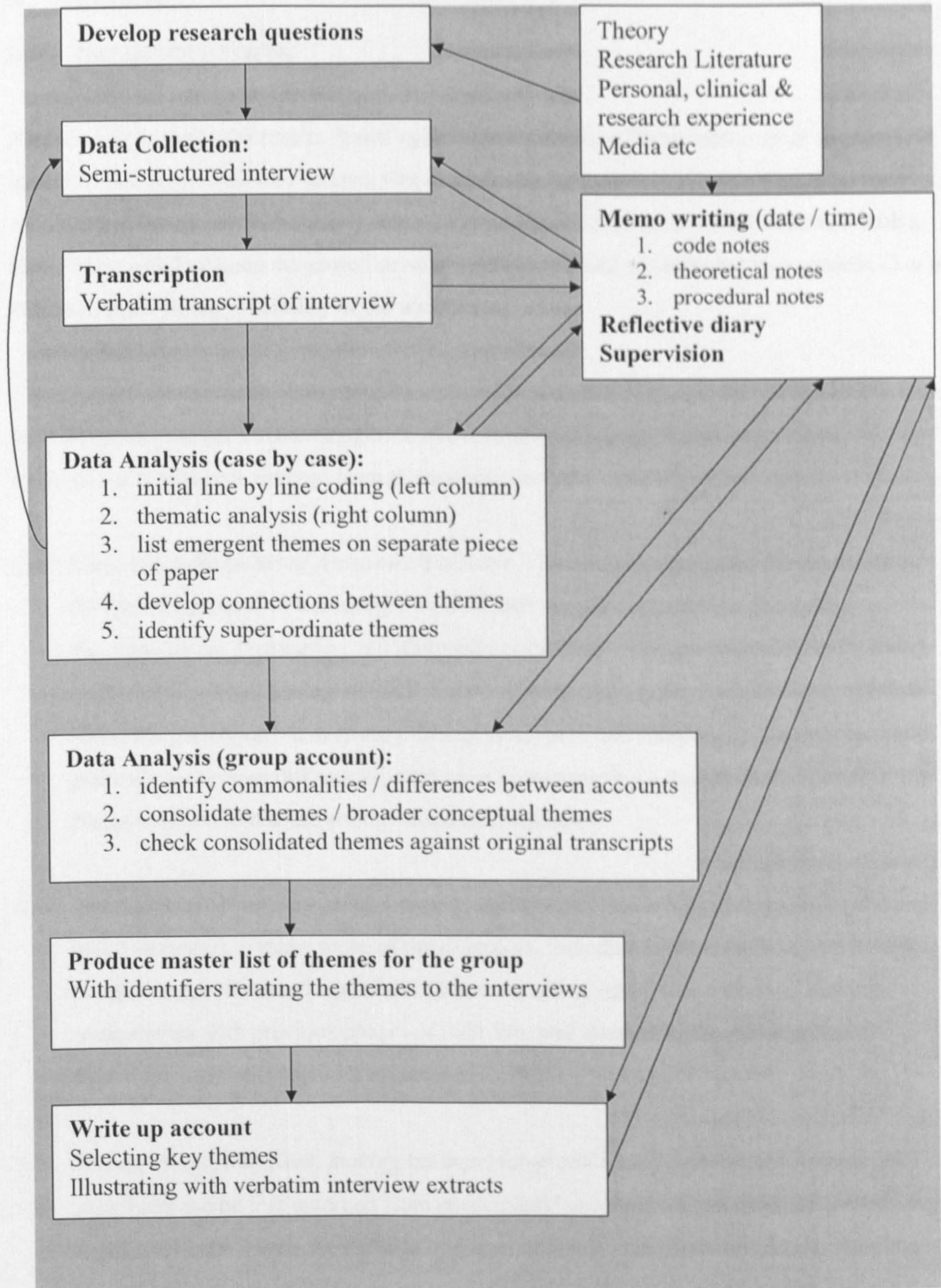
Triangulation was sought in terms of informally discussing the experiences of 'experts in the field' (professional and non-professional). As Smith and Osborn (2003) comment, the aim of an IPA study is for theoretical rather than empirical generalisability, with success being defined in terms of readers being able to make links between the findings of an IPA study, their own personal and professional experience, and the claims of the existing literature.

A further means of establishing credibility as well as transferability of the analysis was by inviting experts from within the dementia care field to comment on the analysis. This was done through providing a written report to members of the Psychiatry and Psychology departments for older people and Alzheimer's Society.

Yin (2003) emphasises the importance of ensuring that others are able to follow an audit trail from the initial data to the final report. An audit trail is provided in the Appendix for the first interview done with participant 4, including a transcript of a section of the interview with coding, examples of memos relating to the analysis, and the final list of themes relating to the transcript. Documentation for Participant 4 was audited by a clinical psychologist independent of the research, who commented that the analysis represented a fair reflection of the interview, and the whole process was guided by supervision from an experienced IPA researcher, who was able to comment on trustworthiness of the process as well as help the researcher consider alternative interpretations of the data.

Although IPA does not theorise reflexivity (Willig, 2001), it was seen as an important issue, in terms of considering how the personal, cultural, and political values, interests, and influences on the researcher impact on the analysis, as well as how the context of the research and the need for the participant to present a particular story impact on the account (e.g. Miller, 2000; Smith, 1996). These issues were considered within the context of supervision, a research logbook, and memos, and are discussed in the Discussion and Critical Review sections (as well as Section 2.2. of the thesis).

Figure 3: Summary of procedure



4 Results

4.1 INTRODUCTION

This chapter presents the results, based upon an Interpretative Phenomenological Analysis, of in-depth interviews with four women whose husbands had, prior to the interviews, recently received a diagnosis of Alzheimer's disease. Verbatim extracts from a pilot interview with a man whose wife had been diagnosed several years previously are included in Appendix G as a means of establishing credibility of the analysis.

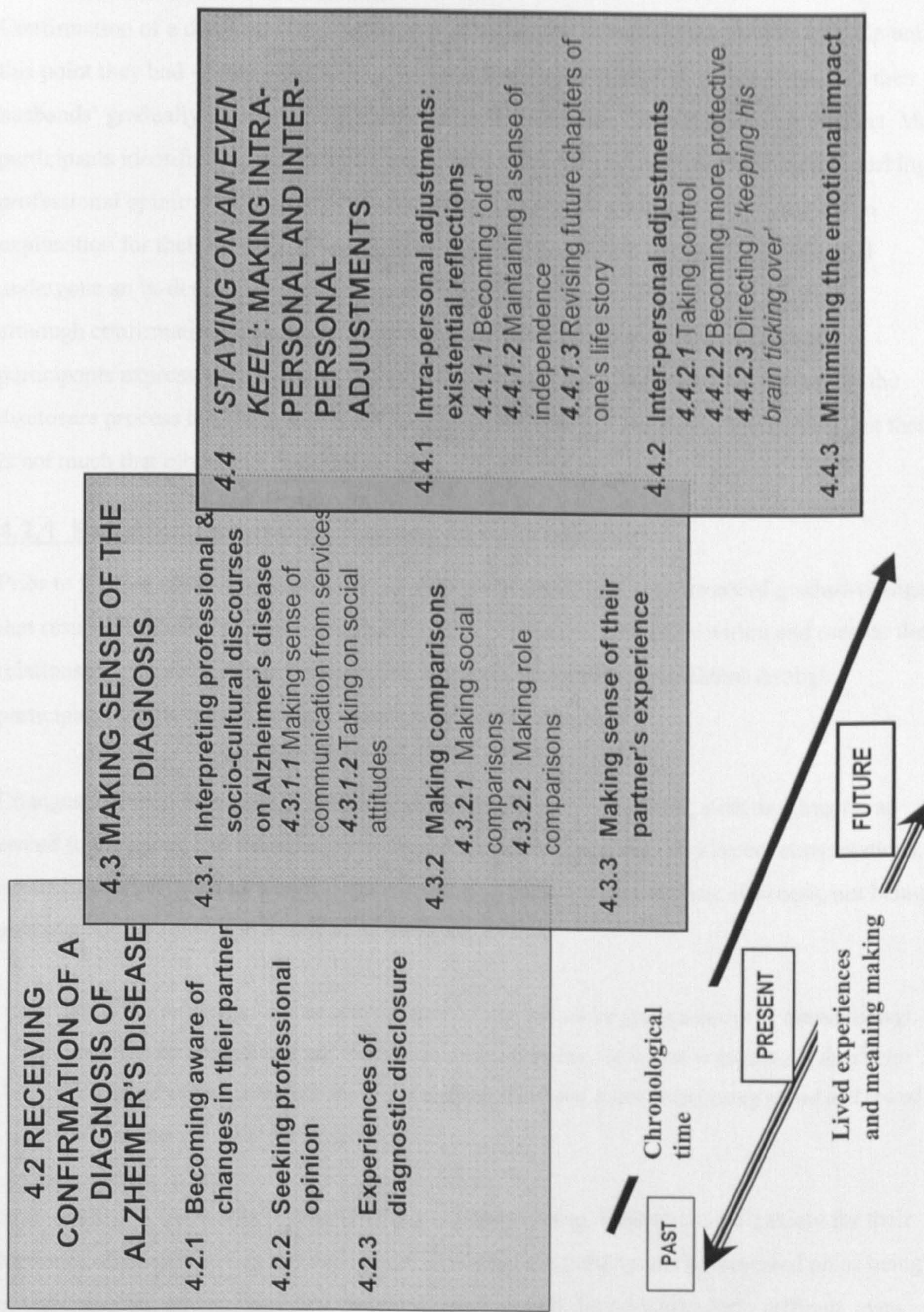
The analysis reveals the meaning-making processes and strategies used by participants to cope following their partner's recent diagnosis of Alzheimer's disease. Three key themes, summarised in Figure 4, emerge from the analytic process:

1. *Receiving a diagnosis of Alzheimer's disease.* The participants placed the diagnosis at the end of a process of becoming aware of their husband's cognitive difficulties to searching for an explanation and ultimately consulting with professionals. So receiving confirmation of a diagnosis of Alzheimer's disease came at the end of a chain of events where the participants had already started to adapt to and compensate for their husbands' gradually increasing difficulties, with most half-expecting a diagnosis. Despite this, the diagnosis provoked some strong emotional responses.
2. *Making sense of the diagnosis.* The participants described a range of psychological and social strategies to make sense of the diagnosis, including making social comparisons, interpreting professional and social discourses about Alzheimer's disease, making comparisons with previous phases of their life, and attempting to understand and empathise with their partner's experience.
3. *Staying on an Even Keel: making intra-personal and inter-personal adjustments.* A significant theme that emerged from participants' accounts was an emphasis on '*staying on an even keel*' (given the feelings of uncertainty and lack of control surrounding the future) and protecting their partners' sense of competence and identity. They engaged in a range of idiosyncratic intra-personal and inter-personal adjustments to achieve this goal. These include: (a) re-evaluating their life story and re-defining themselves or their

partners as 'old'; (b) re-defining social boundaries to avoid social stigma; and (c) subtly taking on an increasingly powerful position within the relationship in a way that their partners would not be aware of. Although the process clearly had an emotional impact, participants tended to minimise this and adopt a 'you just have to get on with it' approach to coping.

Together these three themes represent a sequence from becoming aware of a problem, through receiving and reacting to a professional diagnosis of that problem, to strategies for coping with an expected future with a spouse with Alzheimer's disease. The themes, and their component parts, are further explored in the remainder of this chapter. The analysis is illustrated with verbatim interview extracts that demonstrate each of the themes (see Appendix H for a summary of the notation used).

Figure 4: Summary of Analysis



4.2 RECEIVING CONFIRMATION OF A DIAGNOSIS OF ALZHEIMER'S DISEASE

Confirmation of a diagnosis came at the end of a chain of events for the participants. Up until this point they had - often unconsciously - been accommodating and compensating for their husbands' gradually increasing difficulties. This only became clear to them in retrospect. Most participants identified an incident that triggered a re-evaluation of their situation and seeking professional opinion. By the time they had been through the process of searching for an explanation for their husband's cognitive difficulties, consulted with professionals, and undergone an in-depth memory clinic assessment, most had half-expected a diagnosis, although confirmation provoked some strong emotional responses. Although all the participants expressed satisfaction with the contact they had with health professionals, the disclosure process left them with a sense of uncertainty about the future and a sense that there is not much that others can do to help.

4.2.1 Becoming aware of changes in their partner

Prior to making contact with services, all four participants had been aware of gradual changes that resulted in their husband experiencing difficulties managing roles within and outside the relationship. However, these changes had been accommodated to an extent through participants tacitly adjusting their own ways of doing things.

Changes included increasing forgetfulness in everyday life situations, such as going on an errand to the shops and forgetting why they were there, forgetting very recent conversations, making mistakes, such as wearing mismatching or back-to-front clothes, slowness, not being able to stick at things, and a lack of motivation.

He keeps on saying 'are we going today?', I say 'no, we're going tomorrow' (sounds weary), and then he'll laugh and say 'where are we going today, we've got to go and see the doctor', you see, it seems as though there is something there and it just keeps going round and round all the time. (Mrs B)

Such confusion frequently resulted in repeated questioning, frustration and anxiety for their husbands. Aggression was a characteristic that all of the participants commented on as being out of character, and an issue that many, although not all, found particularly difficult, even where it was reframed as 'frustration'.

It started I suppose ... uh, three or four years ago, when I noticed that he was, um, losing his cool occasionally, which is something he's never done (...) but no big deal, you know I'm not a person to make a big deal out of most things. (Mrs C)

All four participants emphasised deteriorating skills in the context of previously important aspects of their husband's identity, in particular qualities such as intelligence, an excellent memory, being a brilliant mathematician, taking responsibility as the decision maker for the couple, and being socially skilled. Although all participants were able to drive, with Mrs B and Mrs D emphasising how much they enjoy driving, all had assented to traditional gender roles over the course of the relationship, whereby their husband was seen as the 'driver'. The development of difficulties with driving was therefore seen as a key threat to his identity.

The difficulties that their husbands were experiencing were gradually accommodated by participants in a way that enabled husbands to continue their lives with minimal frustration.

He goes around and gets the paper every morning, and he was going around there not giving in the [newspaper] coupons which I had, and so um, now I do it on a Monday and he just goes in there and collects the paper, they give it to him because they've got the coupons and things there ... it's so much easier, I mean, easier for them and easier for [husband]. So I try, what it amounts to, is to be just one jump ahead all the time. (Mrs A)

Although these day-to-day difficulties were experienced by participants as subtle changes, all made the point that outsiders would not notice and would see their husbands as 'normal'. This position was maintained even in the interviews, where it was evident that their husbands were experiencing quite significant difficulties.

Normally he will sit here and he'll talk to you and you'll think 'there's nothing wrong with him, he's quite a normal man', it's strange isn't it? (Mrs B)

Although some of these difficulties may have appeared clearer in retrospect, at the time participants had tended to place them in the context of their husbands' retained abilities, such as an excellent long-term memory, the ability to manage social interactions with outsiders, and what they would expect with age.

Obviously as you get older, he's 86 you see, things, you know, I mean I sometimes go into the shed for something and I forget what I'd gone in there for (laughs). (Mrs A)

It's hard to assess because when you're living with someone everything becomes habitual. (Mrs C)

4.2.2 Seeking professional opinion

The decision to seek the opinion of health professionals was made in the context of an ongoing process of accommodating subtle changes in their husband into their day-to-day lives. With the exception of Mrs C, for whom contact with specialist mental health services was inadvertently instigated by her husband mentioning *'I'm getting so forgetful these days'* (which she regarded as a consequence of old age) during a routine consultation with his *'well meaning'* GP, the remaining participants referred to specific incidents that had forced them to look more closely and re-evaluate these changes.

For Mrs A, it was her husband voicing *his* concerns to the GP that led to a snowball effect in that she began a process of re-evaluating experiences that she had previously normalised.

We did go to the GP, and we'd left it about two months, and he said, 'if you really think it's, you know, getting a bit worse' and it was really I think ... and then you tend to look for it, don't you? Everything. (Mrs A)

Similarly, Mrs B found herself radically re-evaluating her husband's difficulties after a dramatic incident in which he had become lost driving home late at night, leading her to the GP, who shared her concerns.

He was late getting home and I mean I thought 'that's funny, it's', you know, anyway, it appears that when he did get home a couple of hours afterwards, he said, 'I didn't know where, I lost my way'. Now he'd done this journey for the last, ooh, five years I suppose, 'I lost my way', he said 'and I couldn't find where we' and he got out the car several times to ask somebody the way, which I felt was dangerous, at night, so after that I noticed things, he was a little bit forgetful and he kept repeating things to me, and so we went to see [GP], and um, she referred us to [Consultant Psychiatrist] ... and it, all of a sudden things come to light, and you realise why and what for, don't you, why does he keep saying the same thing over and over again, why does he do this, why does he do that, and then it dawned on me that his memory

was going, so we went to see [Consultant Psychiatrist] that sort of made me realise that there was something wrong, but before that he had been a bit hesitant. We were in the car, and he kept saying, 'now, what way do we go now, do we turn left?', now [husband] has always been a good driver and had a wonderful memory, he could always remember where he'd been in a car, and I didn't really pick up on that right away, it's only this, the incident when he got lost that I realised it had been coming on slowly for quite a while. (Mrs B)

For Mrs D, seeing her husband engage in an out-of-character behaviour triggered memories of her father-in-law's Alzheimer's and a very similar behaviour. This helped to convince her of the need to approach specialist services.

Although there was clearly a fear of 'opening up of a can of worms', Mrs A, Mrs B, and Mrs D were in no doubt that talking to the GP would be the next step.

People say if you can try and go early, you know, there is this tablet, whatever it is (...) for what it's worth, and so on that basis I thought we ought to ... we did go to the GP. (Mrs A)

'Oh that's good, we're going to see a doctor, and she's going to help [husband]', that's all I thought about, I didn't think about what would happen if he didn't see anybody, because once they realised that he had this problem, everybody sort of, wanted to help. (Mrs B)

4.2.3 Experiences of diagnostic disclosure

Three of the participants commented that by the time they had met with specialists and undergone a number of assessments, disclosure of the diagnosis (AD) had merely been a *confirmation* of their fears (in contrast, Mrs C rejected the diagnosis at the time and continued to do so, but deemed it inappropriate to outwardly disagree with the psychiatrist).

Mrs A: Well she didn't explain anything really but she did say at the end that she um, that it is the early stages, it isn't dementia but it is Alzheimer's, that's really what she said, which is what I think we both realised really.

Researcher: And what was it like to hear her say it?

Mrs A: Well, I think, you know, because we half expected it, we just went along with it.

Nevertheless, disclosure provoked a range of strong emotional reactions. These included feeling overwhelmed ('*wanted to stick my head in the sand*'), tearful, defeated, daunted ('*how will I cope?*'), and anger that a judgment had been made without professionals really knowing

the patient. For Mrs D, the diagnosis represented the next in a series of health related blows for loved ones that spanned a lifetime.

Well it's there isn't it, you don't want to come forward with it, um, I was very unwell afterwards, I think I had a sort of bug of some sorts, but I went down, and I was really, really low, um, 'I can't cope with this, I can't...' , that type of thing (...) well, I got through it obviously (laughs), you just have to. There's no use feeling sorry for yourself because, there's more to it, isn't there? He's got to be looked after, as it were.

Researcher: right, but it sounds like it hit you quite hard.

YES, you know, although you've got it in your mind what it is, when it actually is there in black and white. As I say, I think I was unwell anyway at the time, and just went down (Mrs D)

Although the diagnosis had been disclosed to all four husbands (by three different psychiatrists), and all had had a brief talk with their wives following the consultation, only one had mentioned it again after the initial disclosure interview, and none of the wives saw any point in raising the matter again with their husband.

I think he's basically forgotten. I mean he was in the room when he told me, told us, (...) but no, I don't think he thinks about it. [Researcher: it didn't seem to have an impact at the time?] I think that in the office it did at the time, and when we came out to the car I sort of talked to him about it, and that was it. We didn't prolong the issue. There's no point in it. (Mrs C)

All of the participants made positive comments relating to their contact with GP's and specialist services, in particular relating to the 'caring' and 'helpful' attitudes, and the 'no end of trouble' taken by staff, although views about the helpfulness of the diagnosis varied widely, from seeing it as a route into a supportive network of statutory and voluntary agencies, to feeling that although the diagnosis had been made, it was an unnecessary and unhelpful 'title' imposed by professionals. For all four participants, access to cholinesterase inhibitor medication was the key consequence of the diagnosis. Again, a range of views were expressed, from feeling that it can do no harm ('my husband's got a strong constitution'), to feeling that it offered hope in terms of offering some stability. Although there was a feeling of being helped, there was also a sense of uncertainty about the future and a feeling that there is not much anyone can really do to help their partner.

4.3 MAKING SENSE OF THE DIAGNOSIS

Following disclosure of the diagnosis, and given the sense of uncertainty that they were left with, participants described a range of strategies to make sense of the diagnosis and the implications it held for them and their partner. Strategies included interpreting direct and indirect communication by professionals, interpreting socio-cultural discourses through the social attitudes that they experienced or projected onto others, making social comparisons and comparisons with previous caring roles they had held, and attempting to understand and empathise with their partner's experiences, generally through indirect inferences in relation to their previous personality and life story. Generally, participants made efforts to position themselves as better off than others in a similar situation, to develop complex explanations of their husband's difficulties that took into account factors such as their personality, life history, and approach to coping with adversity (rather than a simple biomedical explanation of their difficulties). The diagnosis meant that participants were all sensitive to situations which might leave their husband feeling invalidated, and aware that the future was uncertain with a fragile hope that somehow their husband's situation could remain relatively stable.

4.3.1 Interpreting professional and socio-cultural discourses on Alzheimer's disease

The participants all drew on professional and wider socio-cultural discourses about the nature of Alzheimer's disease in order to construct accounts of how the diagnosis applied to their own situations. In particular, they made inferences from the ways in which services and health professionals related to them, as well as how friends and family had responded to the diagnosis, or how they predicted friends and family would respond.

4.3.1.1 Making sense of communication from services

Participants all referred to both explicit and implicit messages from health professionals, voluntary agencies, and the wider culture (e.g. through the media), and how these assisted in the process of constructing meaning.

All referred to their husband's condition as the '*early stages*', or a '*very mild form of Alzheimer's*', although there were differences in how they interpreted this terminology. For example, defining it for themselves as '*not dementia*', '*Alzheimer's with a small 'a'*', or representing something more specific than '*dementia*'.

I mean obviously with her questions she was trying to get to the severity of it I suppose really, and then of course she made her diagnosis ... um, but she realised I suppose that it wasn't just dementia, which sometimes you know is very similar. (Mrs A)

Several participants were struggling to untangle which aspects of their husband's experience could be related to 'Alzheimer's', and which could be attributed to old age, other medical problems, personality, or normal reactions to their difficulties. This seemed to mirror the way in which medical services are divided into different specialties, with a number of consultants involved in their husband's health care. For example, Mrs D's husband had also been diagnosed with heart disease, bowel cancer, and diabetes within the past 10 years.

When he's unwell I don't quite know which one of the things it is. That's why I'm saying that things that you might think were Alz', they might not be Alzheimer's, they might be one of the other bits, as it were ... I think to myself, oh, it's, no, no it can't be Alzheimer's, it's (laughs), it's one of the other things, but I don't, I really don't know, and I don't think the doctors do either. (Mrs D)

There was a sense of frustration from some participants that medical consultations did not help them to make sense of why their husband had developed cognitive difficulties. The participants made use of the media to fill some of the gaps. Participants referred to ideas about Alzheimer's disease being caused by complications associated with medical procedures, genetics, past trauma, and unresolved grief. For example, Mrs B had begun to question whether previous medical procedures had caused the Alzheimer's.

I've heard it said a few times, people who've had a heart bypass are prone to Alzheimer's. I don't know if you know anything about that, but I've read it a few times in articles. (Mrs B)

For many there had been the hope that problems in later life could be prevented through leading a healthy lifestyle, and the diagnosis had therefore reinforced feelings of helplessness.

I think one thinks its either going to be the big 'c' or, you know, heart, isn't it, and there are these other things ... um, I suppose, and all the time you're trying to prevent it ... you know, you try to eat healthily, do things healthily, you know. (Mrs A)

It's how it grabs you as a disease. (Mrs C)

Inherent in the assessment procedures used by specialist services was the opportunity for participants to make their own evaluation of their husband's performance, placing them in a position where they could be construed as allied to health professionals as well as eliciting protective feelings towards their husband.

I went in there and then the two of us, yes ... no, well it was just questions, questions, questions really, and I, you know, obviously had to be asked, but um, relating to him rather like an IQ test.

Researcher: and how did you find that?

Mrs A: he wasn't too bad I thought, he got his date of birth I think and he got um, um, I think he got the month and the year, the only thing he didn't do was the 'world' backwards, he got to the middle, you know, so I, you know, but he copied the triangles, not triangles but you know the things that you copy out, perfectly well, he counted all the parts of it and then drew it perfectly well. (Mrs A)

Several participants made interpretations of how their husband was through aspects of their care such as the frequency of appointments, or the fact that they were prescribed expensive medication, implying that others saw hope in their situation as otherwise this would not have been done in a financially stretched NHS.

And the last time we saw [consultant psychiatrist] she was very pleased with his progress. And he's going back to see her again in six months, I think, um, so that's not too bad is it? (Mrs B)

Researcher: so it sounds like you're quite sceptical about whether these tablets will work.

Mrs A: well, you know, if there's anything else that's better, but obviously [consultant psychiatrist] has given us the best that she can prescribe. I mean it's an expensive tablet, I know that ... of course we should go along with it. (Mrs A)

Mrs C narrated a story where she placed a strong emphasis on how she did not believe that her husband had Alzheimer's disease and that to her and her children his difficulties represented age-related decline. Nevertheless, she attended appointments with her husband who 'looks forward to going' and 'went along' with the diagnosis as 'they know better than I'. Privately she canvassed support from friends and family in dismissing the diagnosis, and she ensured

that she was not involved with medication, which she felt would implicate her in colluding with health professionals.

Well, I have told people, yes, because at first I couldn't quite believe they'd put a name to it, er [Psychiatrist] told us in [outpatients], and he said he's got a very mild starting form of Alzheimer's...and at first I was a bit upset because um, I still don't think so. But I'm not a doctor or a psychologist, you see, um, because when you get to nearly 90, something's got to go, something's got to go! And on the whole he's pretty good, because I compare him with lots of people who are no good whatsoever with Alzheimer's or dementia. What's the difference between Alzheimer's and dementia? (...) whoever I've said it to have said that they haven't got it right (...) they just said 'no, you know, a load of rubbish' (...) Of course, I could be kidding myself, if I was honest ... er, I don't think so, because it's a ripe old age. (Mrs C)

Nevertheless, she appeared to defer subconsciously to the diagnosis in the interview when talking about difficulties that did not seem to fit with her age-related formulation,

He's got very short term memory at this stage, which is part and parcel of Alzheimer's isn't it? or used old age and Alzheimer's interchangeably,

You have to change your way of doing things completely, as all people with age, older people or people with Alzheimer's or dementia.

and on occasion spoke in a way that depersonalized her husband

Sometimes I tell him to get up and make it (the tea) (laughs), because I think you've got to keep them busy.

Whereas another time he'd have half the amount and shout at me! (...) you see, this is the thing, you don't know with mental differences, how they're going to react. (Mrs C)

This reflects the need for an explanation, as well as highlighting the limitations of any one explanatory model.

Participants' discourses reflected a view that there is little anyone can do for their husband, with the possible exception of medication, which might help stabilise an expected decline.

It's just his brain that loses some things, there's not a lot they can do about is there really? (Mrs B)

All we had was another appointment and some tablets really, really that was the future (...)

Researcher: do you think it makes a difference having a diagnosis?

Mrs A: well, only because hopefully you can stall it, I mean that's my hope. (Mrs A)

4.3.1.2 Taking on social attitudes

Participants all emphasised the impact of social attitudes on their situation, drawing attention to the social stigma associated with Alzheimer's, experiences of friends distancing themselves, or anticipating such reactions. All were particularly vigilant of how their partners behaved in social situations, looking for signs that they might be struggling.

For Mrs A, the fear of experiencing social stigma acted as a barrier to disclosing the diagnosis to friends, as she anticipated people relating to her husband differently, or not relating to him at all. For her, there was the hope that people would not notice her husband's difficulties as she and he were skilled at covering these up, and for them to continue to relate to her husband as before.

I want everybody to accept him as he is. I mean I don't want to sort of draw away or anything like that ... that's not the idea ... sometimes I think he repeated things and um, I would jump and say, 'yes, well, you've said that', you know, and they probably wouldn't go along, or they probably wouldn't realise. I don't think that anybody that came here would realise that there's anything wrong, quite honestly ... because he tends to, er, listen, you know, and um, not that he ... obviously he does join in the conversation ... so I think that's really why.

Researcher: and you were saying that you don't want people to relate to him differently?

Mrs A: no [pause].

Researcher: is that, do you think that other people knowing would make them relate to him differently?

Mrs A: maybe, well maybe, yes.

Researcher: in what ways?

Mrs A: well, I don't know if they would direct things to me, you know, it's rather like 'does he take sugar?' and that's what I don't want. (Mrs A)

Mrs B had not anticipated these reactions and she had openly disclosed the diagnosis to friends who had enquired about his wellbeing. However, Mrs B's experience was that friends very quickly distanced themselves.

I'm a bit disappointed, I think that people have got a thing about Alzheimer's, perhaps they're afraid to get in contact. I'm amazed that some of the people - I suppose we'd call them friends - ...haven't made a point of getting in touch or bothering to come and see us, um ... and I thought, perhaps it's because [husband] the way he is, perhaps they're feeling a little bit

afraid of...talking to him or trying to talk to him .Because it's a brain thing isn't it, really, it's not just a broken arm or a leg or anything like that, it's, it involves the brain. It seems as though they don't really want to know (laughs), which is a bit, you know, upsetting. But I've got over that, I don't really care – we've got a family. (Mrs B)

Mrs C and Mrs D had both told friends about the diagnosis, and had both found that they continued to relate to their husband as before. However, in both cases, friends had questioned the diagnosis, which may explain the lack of impact socially.

He's well liked, [husband], although nowadays he doesn't say very much but er, as a person I think, VERY WELL LIKED.' (Mrs C)

In contrast, family relationships and less close relationships, such as acquaintances within the local community, were felt to be less under threat, and none of the participants had questioned informing family or neighbours about the diagnosis.

4.3.2 Making comparisons

Participants tended to make a large number of comparisons in order to make sense of the diagnosis and what it meant for them. They made social comparisons, usually positioning themselves and their partner as better off than others with whom they made comparisons. They also made comparisons with previous social and professional care-giving roles in order to define their current role as the partner of someone with a diagnosis of Alzheimer's disease.

4.3.2.1 Making social comparisons

The process of making social comparisons was evident, to varying degrees, throughout participants' accounts. As argued by Festinger (1954), the process of making social comparisons was understood to be an important means of making sense for participants in the absence of certainty regarding the implications of the diagnosis.

Making comparisons with *other people of a similar age* enabled some of the participants with older husbands to comment that the diagnosis had come at a time of their life where they felt more prepared for it.

Mrs A: well we're older now, I mean one expects ... we've got friends that, you know, lots of things have happened to them as well, we've lost friends and er, I suppose you just, one goes along with it a little bit.

Researcher: so is that different from how things might have been in the past?

Mrs A: well I think so, yes ... I mean perhaps we've been lucky ... touch wood, you know I suppose we've just had the um, usual sort of ailments really. (...) every individual I suppose is different, of course it depends on age doesn't it, as well, I mean, thank goodness it didn't come earlier in our lives, because they do, don't they?(...) and that must be awful, really. (Mrs A)

Mrs A also used social comparison to make the point that her husband should not be treated differently just because of the diagnosis, as others worse off may not choose to make services aware of their difficulties.

We had a friend to lunch on Sunday and er, I thought he's much worse than [husband] and he hasn't got any of it diagnosed. (Mrs A)

Mrs C frequently drew on her experiences of working within a service for people with dementia as evidence for the view that her husband was merely displaying signs of old age.

I think, I suppose I'm lucky, you know, I know I am. That, when I make comparisons, there is a big difference. There is no comparison really, to him, in the condition he's in to others. And I have got a good comparative, er, er, a good way of comparing it, having been there, done it all, you know, with the others. (Mrs C)

She also used social comparison to define what 'Alzheimer's' meant to her.

We've got a friend and his wife um is Alzheimer's, she's gone downhill in the last 12 months, I mean, once or twice I've found her wandering around, around the corner. And someone else in this block (of flats), for 12 months she wasn't that good, and now, they've operated twice to try and relieve the pressure. And ... you know, they're younger, the first one I mentioned is much younger than [husband], she's only, probably she's in her early 70's, but she's, I think if you've got Alzheimer's with a big 'A' then you go downhill quickly, you know. (Mrs C)

Mrs B made a large number of social comparisons to emphasise that she considered herself lucky in comparison with others. For example, making comparisons with the situations of the

large number of widows living on her street who were less fortunate because they were on their own now, with other people of a similar age, who she considered would have significant physical disabilities and health concerns, people with dementia who rely on paid carers and were thus completely isolated, and other men with dementia who were 'in their own world'.

Along with the other participants she made a point of emphasising the importance of her husband's independence with self-care.

But he's very, the doctor says to me, is he all right, does he look after himself, I said 'he looks after himself', he's very clean, washes himself, does everything himself. When we go to the little Monday Alzheimer's club, we go to a church up the top, there's a man there with his wife, brings his wife, but she, poor lady, was telling me he has to do these things for her, which is a very sad situation, isn't it? For that lady she can't look after herself in that way, whereas [husband] can, he's very particular, so that's another thing that we've got to be grateful for, you know. Not that I wouldn't, I mean, come to it I'd do it wouldn't I, I'd have to do it.'

(Mrs B)

In contrast with other participants who largely used social comparison to position themselves in a less bad position than others may expect, Mrs D, whose husband was much younger than the others, used social comparison to emphasise the tragic element of receiving a diagnosis so young.

I try not to think forward now, yeah. But that could be general at the age, I don't know. I don't consider it should be at our age, but in your 70, in the mid 70's you must be thinking, well, I'm on borrowed time, you've had your three score and ten haven't you (laughs) (R: mm). And I know that the lifespan is longer now.

Researcher: so you'd expected to feel this way at some point maybe later on in life.

Mrs D: later on, mm, I think we've been hit early. (Mrs D)

Mrs D drew on experiences of caring for her husband's father who was diagnosed with Alzheimer's in his late 70's, in order to construct a parallel narrative for her husband's future. Referring to her father-in-law, she said:

He disappeared a couple of times, and of course they found him on the M25 in [town] (laughs), he'd walked [10 miles away]. He was a very military type of man, so he was up all night, we

were out in the forest looking for him and things like that (...) I just couldn't cope any longer. And we'd have to lock the door when he went to bed, and then he finally got out the back door, and he was climbing over the side gate to get out, and then it becomes, you're not getting any sleep with him up all night. I felt awful when he had to go in, but I just couldn't, couldn't take any more. (Mrs D)

And to her husband,

I've just got this awful fear that he's going to get into the car one day and he'll go off. But I can't do much about it, if I'm not there, can I? (Mrs D)

4.3.2.2 Making role comparisons

With the exception of Mrs A, who '*hadn't experienced anything like this before*', participants made comparisons with previous care-giving experiences, in particular nursing, family care-giving, and parenting, although all rejected the title '*caregiver*' to describe their current role within the relationship.

Mrs B related her current experience to caring for her children when they were young, and described a sense of loss in terms of the transition to a non-sexual and more '*parent-child*' relationship, as well as the loss of a husband to take care of her needs.

I get tired very quickly these days, I've got arthritis, and a little heart problem as well, which can be a bit tiring, you know, when you're looking after somebody else. I thought to myself, 'oh dear, it's just like having a child again', you know, looking after him like a little, a, a child. And I feel a bit sorry for myself sometimes, I feel as if I want somebody to look after me, you know (laughs) ... you do, you can't help feeling like that, but, on the hand I've still got him, and I'm happy to still have him aren't I really? (Mrs B)

She also emphasised her strength of character within previous caring roles, from which she appeared to draw a sense of self-esteem as a '*tough old bird*' who can cope with anything.

Well, once you've had babies as well, after you do, you know, you have babies to look after and things like that. And if you've worked in a hospital, anybody who's worked in a hospital and nursed people, well, you've got to know, you've got to know what you're doing and understand about things, about life. (Mrs B)

Similarly, Mrs C drew similarities between her current role and caring for others, which allowed her to gain esteem as a provider and nurturer to others.

In contrast, Mrs D highlighted her childhood experiences of living with a mother with chronic illness, and then caring for her own son with a terminal illness, and her reluctance to identify with care-giving roles, for instance breaking with family and peer expectations and choosing a career in business rather than nursing. She made comparisons with her previous caring roles, particularly caring for her father-in-law until she could take no more.

I felt awful when he had to go in, but I just couldn't, couldn't take any more (...) I felt, you know, I've got to go through all of this again with [husband]. (pause) But it might be different, mightn't it? Although as I said, this getting their clothes all out seems strange to me, that they both done that the same. (Mrs D)

These comparisons left her with a great sense of apprehension that she would not be able to cope, and in contrast with previous experiences, there was no aspect of hope.

I think, with your mother it's different because dad was around ... and with [son] I had [husband] around, and there was always hope there. Now I feel a bit, age is on, isn't on our side any more, and um, you know, you know, it's the beginning of the end almost isn't it.

Researcher: that's how it feels?

Yes this phase. it's a bit morbid isn't it. But it is truth though isn't it? It's the truth (Mrs D)

4.3.3 Making sense of their partner's experience

None of the couples entered into discussion about 'Alzheimer's', largely because the husbands were seen to be in a state of denial or had forgotten. There was generally felt to be no point talking about it, particularly in the case of Mrs D who was not prepared to challenge a strong transgenerational history of denial.

He hasn't taken it in, [consultant psychiatrist] explained to him that he's got Alzheimer's, 'oh', he said, 'my dad had that, I never thought I'd ...'. And he's never mentioned it since, doesn't want to know. But he was exactly the same when he had the bowel cancer diagnosed. I thought they hadn't told him, because he never mentioned it, he came out of hospital and never said anything ... and um, the doctors assured me that they'd told him, the staff nurse said that

she'd talked to him and said about it, but he switched off, and he's done exactly the same with this.

Researcher: so is that generally how he copes with things?

I think so, when I try to sort of think back then, his parents were both like that, both of them.

We had um, our son died when he was [adolescent]with [cancer], his parents, um, I mean they were lovely, but they couldn't cope, so they switched off from it, wouldn't discuss it, it was all going to get better. (Mrs D)

Nevertheless, participants all made inferences on their husbands' experiences on the basis of their reactions in day-to-day life. Amongst these were an intense sense of frustration at their situation, insecurity, rejection, and a realisation that they were becoming or had become dependent.

He said he's going looney in the head, you know. Well of course he has to see the GP now because of the tablets ... um, but, well, yes he realises, yes, and its terribly frustrating for him as an intelligent man. (Mrs A)

I am very conscious he's, he's 'where have you been, and where are you and?' I think he's realised that he's reliant (...) he won't like that at all (Mrs D)

I think he's happier if I'm there - he always says to me 'are you going to come?' So, if I say, 'no I won't be able to', 'oh well I won't go' (...) I'll stay here with you'. (Mrs B)

All of the participants commented that one day might be quite different from another, and there were moments of surprise, for example when Mrs D's husband made an insightful and empathic comment on how difficult her life had been, leading her to question whether his empathic abilities had been lost or were being repressed.

It's funny, he said something to me, was it yesterday, um, can't think how it came about, something about somebody's getting married again (pause) for the second time to the same person, and he turned around to me and said 'would you do it again?' (pause), 'I said, you must be joking!', you know, laughing about it, and he said, 'no, I'm serious', I said 'why, would you?', and he said 'oh yes', he said 'but you've had the rough end, haven't you?', something like that ... and I thought, 'oh, you do realise'. (Mrs D)

4.4 STAYING ON AN EVEN KEEL: MAKING INTRA-PERSONAL AND INTER-PERSONAL ADJUSTMENTS

Given the uncertainty associated with the diagnosis, and the sense that there is not much that services can do to help their husband (with the exception of medication), all of the participants expressed hope that their situation would remain stable, and that they could somehow keep things 'on an even keel'. Participants all described some of the intra-personal and inter-personal changes that they had made or were in the process of making in order to achieve this sense of stability, and to protect what they perceived as their husband's frail sense of competence. Re-construing oneself and/ or one's partner as 'old', re-defining social relationships to avoid stigma, and subtly taking on a position of increased power within the relationship in ways that their partner would remain unaware of were seen to facilitate these goals. Finally, although the diagnosis was seen as having an emotional impact, participants tended to minimise the emotional consequences of their experience and adopt a 'just get on with it, what else can one do' attitude, which may have served the purpose of protecting them from overwhelming feelings of loss.

4.4.1 Intra-personal adjustments

Following disclosure of the diagnosis, participants had entered a process of reflecting on their past, present and future, and re-defining their identity in order to adjust to a future life with a partner with Alzheimer's disease. In particular, participants had begun to re-define themselves or their partners as 'old', to emphasise a need to maintain a sense of independence both for themselves and their partners, and to re-define their anticipated future and priorities in life.

4.4.1.1 Becoming 'old'

A key issue for all participants, particularly for Mrs B and Mrs D, was the impact that the onset of dementia and in particular the disclosure of the diagnosis had on their identity, acting as catalysts to a process of re-construing themselves as 'old'. Prior to the diagnosis, none of the participants had regarded themselves as 'old', and indeed emphasized how others saw themselves and their husband as younger than their chronological age. All of the participants described ways in which they had attempted to 'keep young' during their retirement, for instance by socialising, exercising and being physically active, caring for grandchildren, going on trips and taking regular holidays. In their accounts, all of the participants emphasised continued activity in order to resist feeling old, although all felt curtailed to an extent by their husband's disability.

All of the participants spoke in terms of life '*coming full circle*', voicing an increased awareness of the end of their lives being closer. For Mrs C, the current experience was a way for her children to learn more about '*what life throws at you*', thereby creating an added incentive to be seen to be coping with her husband's difficulties.

Mrs B, for whom regular socializing at a club had been an important aspect of her and her husband's lives, had experienced the pain of friends distancing themselves from her husband. She dealt with what appeared to be a significant loss by '*suddenly*' withdrawing socially, and re-defining herself as an '*old woman*', by which she meant being more family oriented, enjoying the '*quieter things in life*', and letting go of the sense of urgency to carry out some of the daily chores that had previously driven her. This process was facilitated by her husband saying that he preferred to be at home, appearing more at ease when in her company. So when asked in what ways her life had changed since the diagnosis, she responded,

It hasn't really changed. Apart from our social life which, I don't mind, it was getting all a bit too much, all this dancing and, I'll be honest with you, the noise of the music, when we went to the dances was a little bit too much, playing these records rather loud, bang bang bang (...) I read a book and listen to some nice music, I'm happy as a sandboy. I'd rather do that now than go out to a dance and drinking. I can still drink here if I want. (Mrs B)

4.4.1.2 Maintaining a sense of independence

All of the participants commented on their husband's increasing dependency, which they felt they were also aware of although it was left unsaid. Nevertheless, Mrs A and Mrs D in particular felt that their husbands would resent this, and experienced some unease in taking away from their husbands' sense of independence.

I still let him drive, maybe once a week, if I'm not using the car, um, because I don't want to take away his independence (), although he's not supposed to, really (laughs), but you know, that's life. (Mrs C)

It was also important to Mrs C and Mrs D that they themselves retained a degree of independence, for example by maintaining friendships independent of their husband, or going shopping, although there was a sense of grief for this independence, much of which had been curtailed.

I've started to go out in the evenings, only for a couple of hours or something, to a friend, um, he's safe to leave, shall we say, but um, you know, when I first, I thought I couldn't leave him at all, first of all. But then I thought, 'no, this could go on for a few years' (Mrs D)

I'll sit him down, well I'm going to have a look around and get something I went for, and then I'll go back and see if he's all right, knowing he is but, and it's a hindrance at times like that, so you have to change your way of doing things completely. (Mrs C)

In common with several participants, Mrs A articulated the fear of becoming dependent on others and being construed as a burden.

We've got stacks of very good friends, I'm sure if we wanted them, and family as well, but I don't want to if I can help it, I don't want us to be a burden on them like that. (Mrs A)

Similarly, the other participants all welcomed and appreciated increased support from their children, but placed a high value on remaining independent from them.

I'm very fortunate with my daughter, and two lovely grandchildren, so there's a reason for it all. But we must try not to live in their world though too, I don't want to be ... I can't do as much as I would like to do for them, because I'm limited with [husband], [daughter] understands how things are (...) (pause) It's the next generation coming around, a full circle isn't it (...) We've got a bit deep haven't we (laughs)' (Mrs D)

Thankfulness was expressed that at least they remained in good health and were therefore able to maintain their sense of independence, whilst acknowledging that this position felt at times like being on a tightrope.

Well I'm thankful that I am OK and that I'm well enough to cope with it. As I say, if both of us were unwell ... we were up a couple of weeks ago, and there were two, a bit older than us obviously, um, but they both got sticks, zimmer, one a zimmer frame and one with sticks, you know, going along and helping each other (laughs) and I thought, 'oh my goodness, we could be like that' (laughs) you know, but fortunately I seem to be able stand up without him.
(Mrs D)

4.4.1.3 Revising future chapters of one's life story

'*Staying on an even keel*' was a term used by three of the four participants, and was a guiding principle for all four.

You know, as long as you keep on that even keel it's OK. (Mrs C)

With the exception of Mrs C, who did not accept the validity of the diagnosis, participants all felt that their husband's difficulties had probably stabilised since the diagnosis was made and they started on medication. All expressed hope that the medication would facilitate stability, although varying degrees of scepticism about the effectiveness of medication were expressed.

Differences emerged in terms of how the diagnosis had impacted on their views of the future, although all talked of living day by day and not thinking too far ahead.

I'm a great believer in taking each day as it comes. Um, not at your age, but (laughs) as you get older (Mrs C)

For Mrs A, who reported having '*no experience of anything like this*', the future was something she did not wish to think about, and perhaps was unable to imagine.

I suppose I'm a bit of an ostrich and I just, I don't want to really know. I just live from day to day I think, and that's really ... we're doing things that you know, haven't stopped doing anything really (...) well, I mean, I do think, of course I do (think about the future), yes, of course I do, but I think, lets go on as we can normally, you know, at the moment anyway ... well I'm determined (...) just take it as it comes, I have to. (Mrs A)

Mrs C, who did not accept the diagnosis, saw the future in terms of a gradual and hopefully painless deterioration for her husband, with her in a supporting role.

I don't think it will kill him as it does some, but then it's not the Alzheimer's that kills you it's maybe a heart attack or whatever. And I don't think so, and um, I think it'll be just general fading away I think probably, as he gets older. Hopefully without suffering, because I'm a great believer in euthanasia, so. Not that I'd do it! But I don't know of course, I had somebody that was um, younger, a young man or a friend whose mother was with tubes in and tubes out

and in and out of every orifice, and doesn't know what day it is or whether it's night or day, and I think we've had dogs put down for less, and that's how I think it should be.

(Mrs C)

In a similar vein, Mrs B and Mrs D both articulated fears about the future, how the diagnosis represented the *'beginning of the end'*, and how they might manage their husband's difficulties. At the same time, they both emphasised the need to stay on an even keel, and take each day as it comes. Both referred to medication as offering hope that things would remain relatively stable. Although they both questioned their ability to cope, both had undertaken caring roles in the past in very challenging circumstances, and saw themselves as *'strong'*.

4.4.2 Inter-personal adjustments

Although none of the participants referred to themselves as *'carers'* and some actively challenged the term, all spoke of taking on a position of increased power and responsibility within the relationship, with them being increasingly responsible for their husband's welfare, through guiding, protecting and supporting him, usually at the expense of their own needs or sense of *'choice'*. This was generally seen as an unconscious process, although for Mrs B it was more explicit, given that services had attempted to position her as a *'carer'*.

I thought 'well, this is it, I've got to look after him. The doctor said 'now you must, you're a carer, you must write and tell them this and tell them that because you look after him', and I said 'well he's my husband, I've got to look after him, I will look after him', 'yeah but it doesn't matter, you're a carer, you will be paid as a carer', which is tr, you know ... I, I look after him because he's my husband, he'd look after me wouldn't he (...) it's the language, so then they say 'a carer would be paid, you're the carer so you'll be paid', so I'm not, I don't argue, the money goes in the bank every week so that's it. (Mrs B)

4.4.2.1 Taking 'control'

In their accounts, all of the participants referred to taking control within the relationship, adopting roles and responsibilities that had previously been their husband's, such as driving, or managing the household accounts and correspondence. There was a sense of responsibility for overriding their husband's wishes if it were in his best interests, for example *'I decided he needed medical assessment'* or *'it's up to me to give him quality of life'*, and thinking aloud about euthanasia. Issues such as deciding whether to disclose the diagnosis to others, making important decision such as whether to keep his car, or whether to move closer to family were

also taken unilaterally rather than being negotiated, as their husband's were not seen as competent to enter into a process of negotiation, jumping instead to *'losing their temper'*.

Although there was the recognition that the balance of power had shifted, participants generally expressed some discomfort with this, for example, not wanting to take away their husband's independence.

So to suddenly take it away, he won't take it. I mean, he's always been a good driver, I've always felt very comfortable with him (...) he's let me drive the last few times we've been up there (...) He hasn't sort of said 'let me have a go', that's what I'm dreading. (Mrs D)

Mrs B managed this discomfort by giving her husband the impression that he was still in control, although she continued to make the decisions.

I've had to learn to, sort of, what shall I say, agree with him on certain things, I don't always agree but that, I say 'ooh yes, that's right', you know, just so he won't get worked up and in a temper, which he can get into a temper ... it's very unusual, he never used to, but he gets into a little bit of a temper, if I don't agree with him all the time, so, but there you are. (Mrs B)

Her discomfort was also evident in that she was unhappy that people, even services, often did not relate to her husband directly. For example,

'Would [husband] be interested in, now he's not going to [day hospital], er, would he like to come to our [day service]?', so I said 'why don't you ask him!' (Mrs B)

In all of the cases there was the sense that it was they themselves who had to do most of the adapting as generally their husbands were seen to be *'quite happy going along on his own sweet way'* (Mrs D, 336). For Mrs C, she felt more competent as a woman in terms of being able to adapt, and felt that her husband had always been resistant to change but always learnt to cope.

Men are very definitely () not change, no change. (...) men don't like change. And they have to be talked into it. Obviously it's not all one sided, there's always a very good reason for it obviously (...) women can adjust, yeah (Mrs C)

In all cases, their husband's poor short-term memory and declining initiative were seen to facilitate the adjustment process by him relinquishing roles without too much long-term 'fuss'.

The shifting balance of power and unilateral nature of adjustment was experienced as restricting as well, as it was born out of necessity rather than choice.

I feel that I do everything now (...) just feel as though I do everything now, (said more slowly, sadly) it's just ... but you know, that's normal. At least you're in charge (laughs) – that's the way I try to look at it anyway (laughs), whatever I say goes! (Mrs D)

Taking control was described as a learning process by several participants, made more challenging because of the unpredictable nature of their husband's responses from day to day.

Researcher: what has been the most challenging aspect of the last few years, and learning about the diagnosis?

Mrs C: getting it right I think, which isn't always easy (...) you see, this is the thing, you don't know with a mental differences, how they're going to react. And, he would shout, which he's never done (...) he's normally um, pretty cool if you like, so it's only at times like that when I get angered. Not to him, or at him, but I think to myself 'why don't I do as he says?' but then I'm a great believer in food (...) offered him a cake, after he'd been telling me he didn't want much, and he shouted at me, and I'm telling myself, 'well, why the hell didn't I take any notice of him and not offer him a piece of cake?'. Whereas today he had double the amount of sandwiches, and a cake, and this is Alzheimer's isn't it, basically? (Mrs C)

4.4.2.2 Becoming more protective

There was a feeling that their husbands were increasingly vulnerable, which elicited an increased sense of protectiveness, both on a practical level (e.g. ensuring that he was no longer involved in lighting the gas fire, or did not go alone on errands to unfamiliar shops) and an emotional level (e.g. protecting him from situations in which he may feel incompetent or rejected socially). For Mrs D, the motivation to protect him from invalidating experiences stemmed from the belief that her husband not expressing grief and other 'negative emotions' had been partially responsible for him developing Alzheimer's.

It's good to talk, isn't it? I've always found, um, as I say my friends are good, they listen to me and I talk (laughs), and I do feel you get, you do get rid of emotions and things talking.

[husband] never did, he never talked when we lost [son], my daughter was the same, just switched off (...) but I used to talk about him all the time (...) and I feel they were wrong, and I often wonder now if some of [husband]'s things the wrong thing. Researcher: the grief? Mrs D: the deepness of, yeah. Not getting into grief. My daughter had to see a psychiatrist, um, 10 years afterwards, because she was so low, and it was back to that (...) but of course [husband], it's his father again, we thought the Alzheimer's with him, he was in the war, he was um, Desert Rats, as they were called then, with Monty, and he came back he'd obviously seen a lot of distressing things, and he never spoke about it (Mrs D)

In common with other participants, Mrs A appeared to be protecting her husband's sense of competence by implying that change was due to external factors rather than her husband's difficulties. Although she placed high value on regular exercise, she also voiced anxieties about her husband's social competence and feared that people would treat him differently if she were not there to protect him from 'making slips'.

We used to do a lot of walking, but at the moment the dog is lame, and he used to go for a walk for about an hour every morning with the dog, and he meets people, and met people, but he can't do that because we're waiting for an orthopedic appointment, um, and I think he misses that because he had, he's got friends that he used to go around the lake with, which was so, um ... I think that was good as well, but there's no reason he can't go on if the dog's alright ... we've had two months of anti-inflammatory tablets and he's really () so something's got to be done ... so that's um, hopefully we can solve that, then we shall be back to, you know, to him walking again, which is good really. (Mrs A)

A particular dilemma that emerged from all of the interviews was making the decision to prevent their husbands from driving, as had been recommended by health professionals. Only one of the participants had made the decision that she 'had to get rid of the car'. For the others, there was the dilemma between protecting their husband from getting into a dangerous situation on the road and protecting his sense of self, which in all cases was very much tied in with being a driver. Mrs C dealt with the dilemma by allowing him to drive once a week in order to retain his independence, whereas Mrs A ensured that she was present with her husband in the car and taking on the role of co-pilot.

When we're travelling in the car he can drive perfectly well but, some places he says, you know, sort of, 'which way?' and I do (gestures turn with left hand) like that, and you know, he's

always done starboard and whatever you call it, to do with aircraft (laughs) you see, but I have to do the hands (laughs) because I don't know that (Mrs A)

Mrs D's husband had 'allowed' her to temporarily take on the driving under the guise that he was waiting for an operation to improve his eyesight, but she emphasised her dread for her husband wanting to drive and her having to prevent him from doing so. In order to manage this, she had allowed the battery to run down, had facilitated him to lose the keys, and ensured that she always parked her car in front of the garage so that he couldn't get out. Nevertheless, her anxiety levels were particularly high around this issue.

My big worry with him is, they've said he shouldn't drive, and I don't want him to drive quite frankly, and er, we've still got his car, he won't get rid of it, 'I might need to drive it', how can you, how can I turn around and say 'no you won't, you mustn't'? I've just got this awful fear that he's going to get into the car one day and he'll go off. But I can't do much about it, if I'm not there, can I? (Mrs D)

The issue of getting it right also emerged from the interviews. For example, for Mrs D, the diagnosis had an immediate impact in that she began to 'watch her husband like a hawk', anxious that he would begin to deteriorate rapidly.

Researcher: so has the way that you're kind of managing things, has that changed since the diagnosis? Mrs D: um, I was watching him like a hawk to start with obviously, but I've learnt now to let him get on with it, let him do it (...) he'll say, 'I'm going to walk up the town, up to the high street, I need a new watch strap', and I thought, well I could say 'I'll come', but I thought 'no', I feel he's got to perhaps do these things, do you think that's right? That he does it himself? (...) he came back with a new watch strap so he must (laughs) be doing OK, he must have coped with it all all right. Researcher: so was the idea that you might be being maybe too protective? Mrs D: I'm wondering if I have been, and I'm trying not to be now. You know I'm conscious of what's up ahead (...) and he turns around to me 'you're watching me all the time', and yes, I am, I've got to stop it (Mrs D)

4.4.2.3 Directing / 'keeping his brain ticking over'

As their husband's confusion and lack of initiative became more evident, participants reported taking on the role of directing their husbands to do everyday tasks, as well as finding other

ways of occupying his time, and 'keeping his brain ticking over', particularly after the diagnosis.

I try to stimulate and we try to be as active as we can (...) I think stimulation is a good thing, we try and do, try and do a crossword every evening, not always but you know, I think that might help (Mrs A)

I make and get and do all the food, so, he won't make a drink, he can be dying for a drink and say in the afternoon for a cup of tea, and unless I say to him 'would you like a cup of tea?', and sometimes I tell him to get up and make it (laughs), because I think you've got to keep them busy. (Mrs C)

All morning he's been sticking stamps on for my lad's firm, to send out all these notices about whatever, and so he sat there for about two hours sticking stamps on. Luckily they're self-adhesive ones, but er, I make sure that he, if I'm out or busy with a grandchild or other and he doesn't want to go or there's no need, I say 'well I'd like you to Hoover' or er, polish. (Mrs C)

I don't like him to go too far on his own, but the way, he goes to the [high street] shops every morning for me to get milk and bread and the paper. You see, that is a familiar thing, he does that because it's a, he does it every single day, and all the girls in Sainsburys say hello to him and talk to him, and he comes home and says 'ooh, I've seen this one and I've seen that one', and he tells me all about it. (Mrs B)

4.4.3 Minimising the emotional impact

In all the accounts that participants gave of their experiences was an inherent minimising of the impact of the diagnosis and their own emotional reactions, as well as a need not to be seen to be blaming towards their husband.

He'll want to go in the garden and that's OK, I cut that, and I say 'don't cut it down' (as if telling off child), he cut something down a few months ago and I'd trained it nicely in the garden, and he went out and he cut it all down again and I, I was furious and I thought 'well there's no use getting furious because he thinks he's doing the right thing. (Mrs B)

Fatalistic discourses were commonly adopted, whereby there was little that could be done to help, and that they just had to cope. For example, 'don't talk about it - put a good face on it even though I feel lousy inside, as it will pass' (Mrs C), 'you've got to get on with it don't you,

you can't turn around and weep, you've just got to crack on' (Mrs D), 'lets go on as we can normally, you know, at the moment anyway (...) I'm determined (...) just take it as it comes, I have to' (Mrs A), 'we've got our memories so mustn't grumble' (Mrs B).

Although curtailed, there was still the sense in participants' accounts that life was there to be appreciated still.

I believe and still do, um, believe in enjoying life to the full. I mean, neither of us go to bed, I mean I know people who go to bed at 9, 10 o'clock! What for?! You're lucky if you die in bed (laughs) so, and er, no, it's kind of 'make hay while the sun shines' (hmm), that's what it boils down to. (Mrs C)

Although all admitted to times when they felt low, daunted, resentful, alone, guilty, grief-ridden, or helpless, all of the participants reverted to the position whereby they just had to 'get on with it'.

I feel a bit sorry for myself now and again, I have a little weep, but I think everybody does, but (...) I think I am a tough old bird, I can deal with almost anything, you know. (Mrs B)

This was often in the context that there were still many positives in their lives for which they should feel grateful.

Once or twice I thought to myself, 'oh blow, look, you're retired, you won't be flitting off on holidays anymore, we should be now, er, doing things we want to do, going where we want to go and not worrying, we should still be driving the car I suppose, something like that', and then I think to myself 'what are you groaning about you silly old moo', (laughs), you know, 'you've got a good life, you, you've got each other, you've got a nice house, you've got a nice family, we don't want for anything at all, nothing, anything we want we can have', so, there you go. (Mrs B)

Humour, patience, and 'laid back' attitude were qualities that were felt to be particularly important from themselves and from friends and family. Talking to others, as well as venting emotions through housework were commonly-used strategies to 'get rid of' unwanted emotions that may be damaging towards husbands.

It's good to talk, isn't it? I've always found my friends are good, they listen to me and I talk (laughs), and I do feel you get, you do get rid of emotions and things talking. (Mrs D)

As outlined previously, participants were often focussed on maintaining a sense that life continued as usual, albeit with a few adjustments on their own part. Problems that may have appeared related to Alzheimer's were often displaced. Although social and practical support were valued and there was a sense that 'everyone says they want to help', there was also a sense of reluctance to ask for help for fear of being seen as a burden.

Despite narratives which implied that deterioration was to be expected, all of the participants talked of being focused on maintaining an even keel, and living from day to day wherever possible. All expressed hope that their husband's condition would remain stable, and felt that this had been the case since they started on medication. For Mrs D, the need to believe was important in helping her cope. The final interview extract illustrates the importance of denial in assisting participants to manage day-to-day life.

Mrs D: ...I've always believed, but I now question myself on that (...) after we lost [son] I always thought, 'well we'll meet again', but I've got a little bit more sceptical about that sort of thing. I don't want to think about it. Do you understand?

Researcher: You don't want to think about meeting again?

Mrs D: that we wouldn't. And if I start questioning myself, which I can easily do, I switch off now. I want to believe in it, I want to believe that.

Researcher: and those doubts come from the things that are happening to you?

Mrs D: well just the world in general, it's just. I always remember my grandfather saying to me, 'you have to have the rough with the, to enjoy the good things', and I think he possibly was right, but um its all made me cold. I always hear him saying that, I was only small (laughs).

Researcher: so does that help you now, it sounds like there's a lot of kind of, a lot of things that aren't good things at the moment.

Mrs D: mm, as I say I don't want to question myself. I feel, let's just keep going.

(Mrs D)

This concludes the chapter. The results of the study will be discussed in the context of existing theory and research literature in the following chapter.

5 Discussion

Very few published studies have focused on partners' experiences in the early stages of Alzheimer's disease. In particular, this study has focused on attempting to understand some of the idiosyncratic and personal ways in which partners make sense of the diagnosis, and how these personally constructed meanings influence ways in which they cope and manage their situation. These issues were addressed using Interpretative Phenomenological Analysis to identify themes from in-depth interviews with four participants whose husbands had recently (within the past six months) been diagnosed with Alzheimer's disease.

The Discussion section focuses predominantly on a discussion of the results in the context of existing theory and research literature (5.1). Possible clinical implications (5.2), methodological issues (5.3), and suggestions for further research are considered in depth in the *Critical Review* (briefly summarized in the *Discussion*), which is focused on issues of relevance to clinical practice and to others undertaking research in this field.

5.4 Key findings

Three key themes *emerged* from the analytic process, and are illustrated in the Analysis: '*Receiving confirmation of a diagnosis of Alzheimer's disease*'; '*Making sense of the diagnosis*'; and '*Staying on an even keel*'. Two areas of the research literature were felt to resonate particularly with participants' accounts of their experiences. First, the narrative constructivist framework proposed by Neimeyer (e.g. Neimeyer, 2001; 2004) to conceptualise a process of *meaning reconstruction* by people dealing with bereavement and loss. Second, research literature on *identity management in later life* (reviewed by Coleman, 1999). This helped to situate participants' accounts within the context of contemporary theoretical understandings of 'normal' ageing.

Neimeyer (e.g. Neimeyer, 2001; 2004), draws on narrative, constructivist, existential and social constructionist paradigms (see Introduction, Section 1.3.2) to critique traditional grief theory and to present an alternative framework whereby grieving is viewed as an act of affirming or reconstructing a personal world of meaning that has been challenged by loss. Individuals are understood to actively construct meaning in relation to loss, with successful adaptation involving restoration of coherence to the narrative of one's life. He also emphasises how context-dependent this process is, in that we construct and re-construct our identities in

relation to others, rather than as discrete individuals. Similarly, Kitwood (e.g. Kitwood, 1996), whose work has been particularly influential within the dementia care field, viewed the bereavement metaphor for caregiving as too passive, instead proposing an active reworking of roles and relationships by caregivers. This approach is reflected in contemporary gerontology research, which tends to conceptualise individuals as active agents who seek ways of maintaining and developing their self-image, even in disadvantageous circumstances (Coleman, 1999).

In common with other qualitative studies on the onset and diagnosis of dementia and chronic illness (e.g. Charmaz, 1987; Orona, 1990), in the present study the onset of difficulties and 'receiving confirmation of a diagnosis of Alzheimer's disease' was seen to represent a significant biographical disruption, forcing partners into a process whereby they were seen to reconstruct their ideas about the past, present, and future in light of the diagnosis.

All of the participants emphasised positive aspects of their husband's personality and achievements within their narratives, and interpreted current behaviours within the context of their life story (for example viewing current denial of their condition as a means by which they had *always* dealt with illness and loss). This reflects Perry and O'Connor's (2002) observation that the wives they interviewed tended to present narratives about positive aspects of their husband's past personality and achievements before entering into dialogue with the researchers about the difficulties that they were experiencing in relation to their husband with dementia. Perry and O'Connor argue that this contextualising by wives served the function of emphasising the need to preserve their husband's personhood as a directive for their own role within the relationship.

As suggested by Bender (2003), in his (anecdotal) constructivist model which postulates that partners enter into an explanation cycle whereby they tend to construct the least threatening explanation for their partner's difficulties, participants in this study had been aware of changes but had tended to minimise these (e.g. by construing them as normal ageing) until confronted with a situation which forced them to consider the possibility of Alzheimer's disease. This probably reflects observations that some of the earliest 'symptoms' of dementia, such as personality change and mild forgetfulness are relatively non-specific to dementia (Evans, 2004). It may also reflect the observation that individuals tend to adapt to adversity even to the point of distorting and denying reality (Coleman, 1999). Mrs C reflected this issue by

commenting '*of course, I could be kidding myself, if I was honest ...*' in relation to believing that her husband's difficulties were age related rather than the early stages of Alzheimer's disease. Despite comments by other participants that they were prepared for the diagnosis, all described experiencing it as a considerable blow.

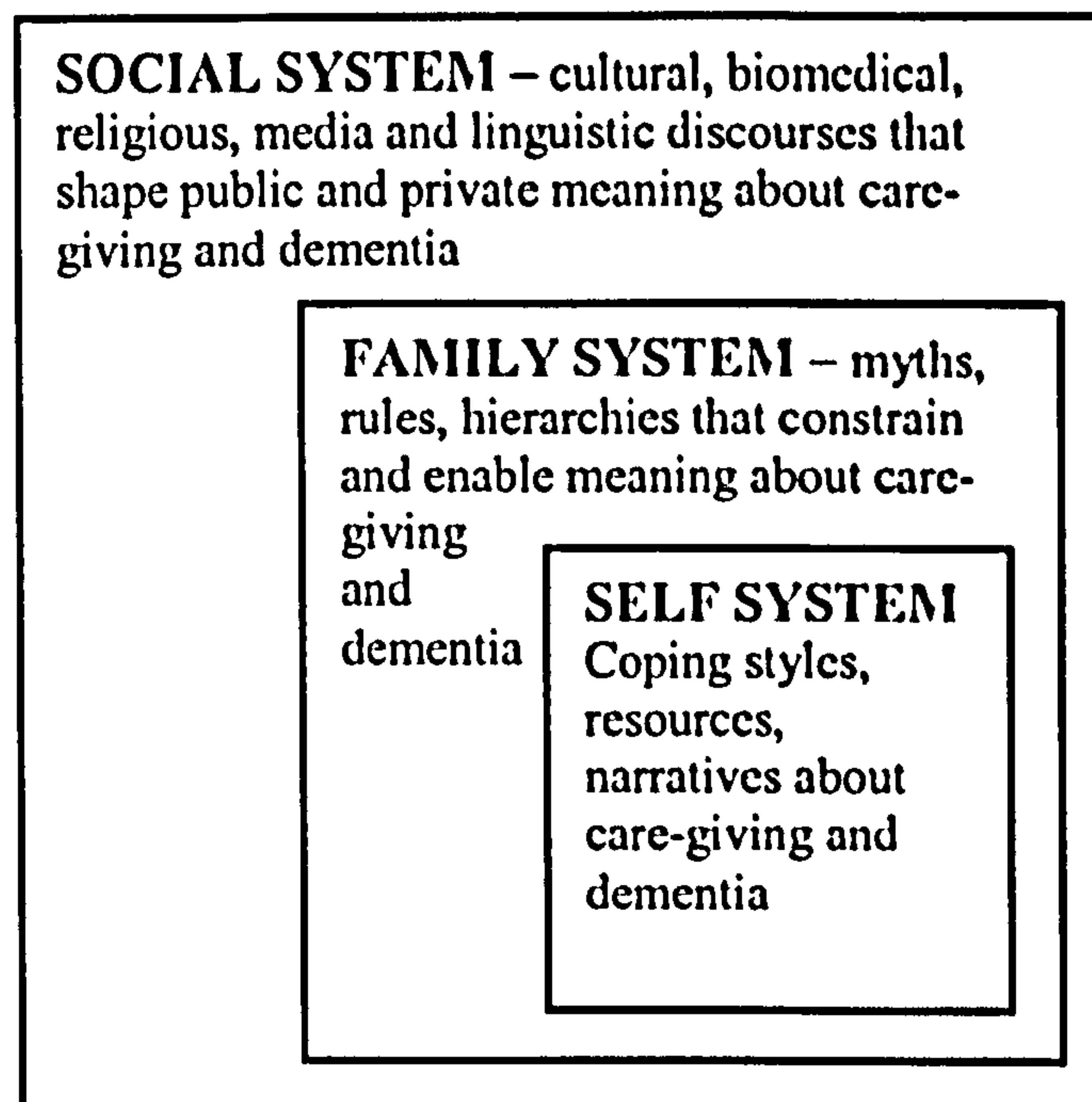
Following assessment by specialist services and receiving the diagnosis, participants were understood to be making sense of, or '*making sense of the diagnosis*', in a range of ways. For some participants this meant challenging the diagnosis, for others it meant minimising, and for others integrating the diagnosis into their way of viewing their situation. As Clare (2002) found, integrating the diagnosis was uncommon, with only Mrs B seeming to refer openly to her husband as someone with Alzheimer's disease.

Strategies for making sense of the diagnosis included interpreting direct and indirect communication by health professionals, interpreting socio-cultural discourses through the social attitudes that they experienced or projected onto others, making social comparisons, and reflecting on difficulties within the context of their own lived experiences, and attempting to understand their partner's experiences, generally through indirect inferences in relation to their previous personality and life story.

Making sense of Alzheimer's disease and care-giving was thereby achieved through a multi-systemic approach, as outlined by Neimeyer (2004) and illustrated in Figure 5. The results were that participants tended to hold multiple concurrent illness representations. For example, Mrs D spoke at different times of Alzheimer's as having been caused by family genes, unresolved grief from an earlier phase of her husband's life, and as a disease in the same way as her husband's diabetes or cancer. As well as having an impact on how she managed the difficulties, these multiple illness representations reflect the uncertainty associated with Alzheimer's disease, as well as the fact that personal illness attributions are not by necessity exclusive (Larkin, 2004; Levy *et al*, 2000).

Participants' discourses did appear to reflect dominant professional (biomedical) discourses about dementia, in terms of reflecting a narrative of 'tragic decline' (Gergen & Gergen, 1984) on the one hand, and offering the hope of the condition remaining stable through the use of cholinesterase inhibitor medication on the other. In an audit of the memory clinic in the region in which this study was conducted, Sweetman and Davies (2002) found that clients and their

Figure 5: Systemic context of meaning-making in relation to caregiving and dementia (adapted from Neimeyer, 2004)



families were often disappointed with the advice and explanations that they received relating to their memory difficulties, and whereas only 4% had expected to be prescribed medication, this was in fact the only intervention offered in the vast majority of cases. This may have reinforced clients' views that there is little else one can do.

The lack of diversity of discourses may reflect the fact that there are not really any widely shared socio-cultural representations of dementia that is diagnosed in the early stages, as it falls somewhere between representations of normal ageing and the dependency associated with advanced dementia (Clare & Shakespeare, 2004). Alzheimer's tended to be used where other explanations, such as normal ageing, were insufficient, for example relating to one's husband becoming aggressive, which was seen by all participants as completely out of character. Although all of the participants at times talked in a way that reflected negative discourses on ageing, such as associating ageing with burden, biological illness and incapacitation, these discourses in fact seemed to help participants normalise their difficulties.

Social comparison (Festinger, 1954) was a strategy that participants frequently used to make sense of their situation, as were reflections on past identity. Both strategies tended to be used to minimise the impact of Alzheimer's as well as bolster a sense of self-efficacy as able

partners. Research (e.g. Baltes & Baltes, 1990) has indicated that such strategies are of considerable importance in the maintenance of selfhood in older age.

The third and final theme, 'staying on an even keel; making intra-personal and inter-personal adjustments', encapsulated both intra-personal and inter-personal adjustments focussed on living from day-to-day and maintaining a sense of continuity. In particular, accepting that one is 'growing old', and accepting a position of increased power within the relationship were seen to facilitate this goal. Dittman-Kohli (1990) presents convincing evidence that continuing life in the same way is a sufficient and satisfying goal for many older people, as their identity is largely based on their past self and past life.

Prior to the diagnosis, none of the participants considered themselves or their husbands to be 'old', and indeed had 'bought into' cultural discourses relating to the possibility of leading healthy and independent lives well into later life. All had engaged in efforts to 'stay young' (i.e. not a burden, not incapacitated, not ill) through activities such as socialising, exercising, doing voluntary work, taking dreamed-of holidays, and helping look after grandchildren. However, Mrs B and Mrs D both referred to re-construing themselves as 'old', and Mrs A and Mrs C to their husbands becoming 'old' following the diagnosis.

These findings fit with gerontological research that has suggested that most people refuse to label themselves as 'old' as they reject its negative connotations, and its association with closeness to death (e.g. Thompson, Itzin & Abendstern, 1990). In this case, however, accepting 'old age' appeared to facilitate the process of coping with Alzheimer's disease. For Mrs B it meant disengaging from socialising that had become stressful due to her husband's difficulties, and allowed her to deal with the loss by becoming focussed on 'enjoying the moment' and the simple pleasures in life, as well as becoming more family-oriented. She was also able to reflect positively on her past and accept that she would no longer be able to experience former dreams. For Mrs C, it meant that she 'allowed' her husband to live a more detached life whilst she continued with her socialising as before without experiencing guilt. Mrs A and Mrs D both appeared to be struggling more with the idea of 'old age', as they both associated it with a loss of dreams and opportunities, being incapacitated, and being ostracised by friends.

An awareness of social stigma associated with Alzheimer's was apparent in all of the participants' accounts. For Mrs B this meant revising social boundaries in a way in which she accepted the loss of previously important friendships. Others were holding onto friendships, although in these cases, either they or their friends construed their husband's difficulties as normal ageing rather than Alzheimer's. This may be a means of maintaining self-esteem, which is one of the best indicators of adjustment to difficult circumstances (e.g. Lund, 1989), as well as protecting others from some of the harsher facts of later life, such as decline, dependency and death (Coleman, 1999). Pratt and Wilkinson (2003) argue that social context is crucial for determining levels of distress or maximising coping in response to a diagnosis, and the above findings indicate that partners can be skilled at developing narratives and conditions that minimise the potential for the distress caused by social stigma.

In terms of interpersonal adjustments, all four participants described efforts to stay on an even keel that had involved taking on a position of greater power within the relationship. As other qualitative researchers (e.g. Candey, 2001; Perry & O'Connor, 2002) have found, many of these actions were taken in an effort to protect their husbands' sense of competency and independence, and thus prevent suffering. These adjustments in the balance of power were seen as necessary in that husbands were seen to have lost much of their capacity to function independently and make decisions, and a good outcome for them was seen as them being able to *'carry on happily in their own sweet way'*.

Of note was a reluctance to use the term 'caregiver', which appeared to be related to a discomfort at taking away many of their husband's roles, particularly as this was often done using deception, relying on their husband's poor memory to facilitate the process. This desire to be seen as a partner rather than caregiver has been noted by other qualitative researchers, such as Clare and Shakespeare (2004), O'Connor (1999), and Perry and O'Connor (2002). These researchers found that caring was seen as a natural extension of the marital relationship. Indeed, in the pilot interview to this study, the partner who was interviewed commented that he had not viewed himself as a 'carer' until it was necessary to become involved in assisting his wife with self-care tasks.

In terms of coping with the emotional impact of their experiences, participants tended to minimise any such impact and adopt a 'just get on with it' attitude. It may be that this reluctance to acknowledge the emotional impact served a self-protecting purpose. Loos' work

on chronic sorrow in caregiving suggests that the meanings that individuals develop in relation to the condition can act as a defence against the existential confrontation with the reality of human vulnerability, aloneness, and death (e.g. Loos & Bowd, 1997).

One might intuitively anticipate that, given the negative socio-cultural discourses on dementia, a diagnosis of Alzheimer's disease could signal the collapse of hope. Golsworthy and Coyle (1999) argue that the construct of 'hope' and what sustains coping has been little explored within the bereavement research. In this study, hope was strongly associated with medication, perhaps indicating that with the exception of religion, there are few publicly available discourses on coping positively with Alzheimer's disease (e.g. Farran, 1997). However, it was clear in this study that participants were making creative and often effective psychological manoeuvres to cope with the change and loss that they were experiencing. It was my impression that they were doing this with a sense of determination, resilience, patience, strength of character and sense of humour that I had not necessarily expected.

5.5 Clinical Implications

A number of authors (e.g. Bamford *et al*, 2004; Bender, 2003; Coleman, 1999; Nolan *et al*, 2004) have highlighted the lack of in-depth research into the experiences of family caregivers in the early stages of dementia, and in particular ways in which they cope following a diagnosis. Such a rich, nuanced and dynamic understanding is essential if services are to develop in a way that responds effectively to the needs of family caregivers (Clare, 2002; Nolan *et al*, 2004), a need that has been highlighted in recent policy initiatives which place care in the community and family carers 'centre-stage' (e.g. Department of Health, 2001).

Implications of the current study for clinical practice are discussed in the Critical Review section. In particular, given that learning of the diagnosis tends to be an incremental process, a case is made for pre- and post-diagnostic counselling, alongside a discussion of issues relating to considering partners as individuals and developing interventions that offer the hope of 'remaining on an even keel'. Ways in which services can better engage with individuals is considered in relation to validating partners' competencies as well as their need to protect the person with dementia's fragile sense of competency and selfhood. The need to consider the social context of dementia is also considered, in relation to the lack of socio-cultural discourses on care-giving in the early stages of dementia and the sense of social isolation and stigma that may arise. Finally, the sense that there is nothing much that can be done for

caregivers is discussed in relation to the research literature on the effectiveness of psychosocial interventions.

5.6 Methodological considerations

5.6.2 Strengths and Limitations of the study

This study represents one of very few attempts within the research literature to understand the idiosyncratic and personal psychological manoeuvres made by partners in order to cope with and manage a diagnosis of Alzheimer's disease.

Smith and Osborn (2003) argue that a successful IPA study involves theoretical rather than empirical generalisability, with success being defined in terms of readers being able to make links between the findings of the study, their own personal and professional experience, and the claims of the existing literature. Readers will have to make up their own minds on these issues. Feedback received in supervision, from an external auditor, and from informal discussions with 'experts' in the field has been positive to date. The researcher's attempts to be meticulous, rigorous and transparent in the analytic process are also considered to be strengths of the study.

The study is modest in its claims, in that the results are based on the experiences of a small, relatively homogenous group of people, which may or may not resonate with the wider population of family caregivers. Given the high rate of people declining to take part in the study, it is suggested that those recruited may have been those who were coping better with the onset and diagnosis of dementia. The fact that the findings resonate with, and at times add depth to the understanding gained from other in-depth studies of the experiences of family caregivers adds to the credibility of the study.

A fundamental limitation relates to the cross-sectional nature of the research design. Ideally, a (prospective) longitudinal approach would have been adopted in order to better understand the dynamic and complex processes described within the analysis.

These methodological issues are considered in depth in the *Critical Review*.

5.6.3 Reflexive Considerations

Willig (2001) points out that IPA does not theorise reflexivity, with IPA terminology emphasising the 'identification' and 'emergence', rather than 'construction' of themes. However, a more constructionist approach has been taken by engaging in a process of reflecting on factors that influenced the development of this analysis.

Clearly the research did not take place within a vacuum, and it is acknowledged that the narratives produced were interpersonally constructed (e.g. Miller, 2000). Several factors were seen to have a potential impact on the accounts presented by participants. First, the researcher's professional and personal world view and interest in constructivist, narrative and constructionist thinking which would have influenced the issues pursued within the interviews and the analysis, although supervision and the use of an external auditor were used to review the process for discrepancies, overstatements and errors (Elliott *et al*, 1999). Second, despite attempts to clarify the distinction of roles, the researcher may have been construed as a representative of the clinic. This could have led to participants presenting what they considered to be socially acceptable narratives rather than reflecting concerns that may be at odds with what they considered acceptable (e.g. Miller, 2000). Third, in relation to the participants, the researcher was young and male. This difference may have been helpful in some ways, for example, in terms of promoting a dialogue about what it means to feel 'old', or views about gender differences, such as the view that women can adapt whereas men cannot. Some issues I was surprised to encounter, such as those relating to sexuality in later life, and it may be that generational differences acted as a barrier to the researcher exploring these when they may have held particular significance for participants. Finally, it was acknowledged that the interview may have been a context in which participants used the opportunity to create new and preferred narratives (Neimeyer, 2002), rather than focussing on more personal and possibly more negative or ambivalent aspects of their experience (Edwards & Ribbens, 1998).

5.7 Suggestions for further research

Suggestions for further research are discussed in the Critical Review. These include further in-depth qualitative studies in this area with other groups of family caregivers, in order to establish the credibility of the current analysis. Participants in the study reported on in this thesis were all white-British, female and living within a particular region of the country. It may be that the analysis does not fit with the experiences of male caregivers, those from other ethnic groups or social classes, or adult children. It may also be that there are significant in the

experiences of those interviewed compared with those who declined to take part in the study, and efforts would need to be made to assess this further by examining the recruitment strategy and method of data collection.

Various authors have highlighted the lack of a theoretical basis behind many psychosocial interventions evaluated in the research literature (e.g. Brodaty *et al*, 2003; Pusey & Edwards, 2001), and further in-depth qualitative research in this area could ultimately lead to the development of theoretical frameworks that can better inform clinical practice. Nolan *et al* (2004) argue that a paradigm shift is required by researchers evaluating psychosocial interventions, as to date there is a striking lack of empirical evidence to support such interventions. They argue that this is due in part to the use of outcomes that are not personally relevant to many family caregivers, as qualitative data suggests that such interventions have been viewed as personally valuable. Thus a case is made in the Critical Review for a greater use of mixed qualitative / quantitative research in this area, rather than being limited by the paradigm into solely focussing on 'gold standard' randomised control trials.

Lastly, a case is made for more qualitative research focussed on the diagnostic assessment and disclosure process, and it is suggested that a Discourse Analytic approach may be particularly valuable for gaining a better understanding of how 'reality' is negotiated in clinical encounters, and thereby provide insight into why many caregivers may end up disillusioned with services that have been set up to support them.

5.8 Conclusion

'Staying on an even keel' was a key guiding principle for participants in this study, for whom receiving confirmation of a diagnosis of Alzheimer's disease represented a significant biographical disruption. Various means of making sense of the diagnosis were talked about. These included making social comparisons, interpreting professional and social discourses about Alzheimer's disease, making comparisons with previous phases of their life, and trying to imagine their partner's experience on the basis of their reactions and their previous self.

The partners who were interviewed engaged in a range of idiosyncratic intra-personal and inter-personal psychological manoeuvres to stay on an even keel and protect their partner's fragile sense of competence and identity. These included re-evaluating their life story and re-defining themselves or their partners as 'old', re-defining social boundaries to avoid social stigma, and subtly taking on an increasingly powerful position within the relationship in a way in which their partners would not be aware.

The results were considered in the context of current research evidence and found to resonate with, as well as provide further insight into the findings of previous studies on the experiences of family caregivers. The results were also considered in relation to clinical practice, where a need has been identified to support family caregivers more effectively (e.g. Department of Health, 2001), and where there is a lack of in-depth research to support such service developments.

To conclude, this study represents one of very few efforts to understand the experiences of partners coping with a diagnosis of Alzheimer's disease in the early stages of dementia. The capacity to attach meaning to disruptive life events has seldom been studied within the social sciences (Coleman, 1999), and this study offers insight into some of the idiosyncratic and personal meaning-making strategies by which partners make sense of a diagnosis of Alzheimer's disease, and ways in which these are used to actively and creatively manage their often difficult situations. It has been argued that such an understanding is necessary in order to develop more personally relevant and acceptable services that respond to the needs of family caregivers in the early stages of dementia.

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References

- Adams,K. & Sanders,S. (2004). Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease: a mixed-method analysis. *Dementia*, 3 (2), 195-210.
- Aneshensel,C.S., Pearlin,L.I. & Schuler,R.H. (1993). Stress, role captivity, and the cessation of caregiving. *Journal of Health and Social Behaviour*, 34, 54-70.
- Ashworth,P. (2003). The origins of qualitative psychology. In J.A.Smith (ed.), *Qualitative Psychology: a Practical Guide to Research Methods*, pp. 4-24. London: Sage.
- Askham, J. (1995). Making sense of dementia: carer's perspectives. *Ageing and Society*, 15, 103-114.
- Baltes,P.B. & Baltes,M.M. (1990). Psychological perspectives on successful ageing: the model of selective optimisation with compensation. In P.B.Baltes & M.M.Baltes (eds.), *Successful Aging: Perspectives from the Behavioural Sciences*, pp. 1-34. Cambridge: Cambridge University Press.
- Bamford,C., Lamont,S., Eccles,M., Robinson,L., May,C. & Bond,J. (2004). Disclosing a diagnosis of dementia: a systematic review. *International Journal of Geriatric Psychiatry*, 19, 151-169.
- Barnett,E. (2000). *Including the person with dementia in designing and delivering care*. London: Jessica Kingsley.
- Bender,M. (2003). *Explorations in dementia – theoretical and research studies into the experience of remediable and enduring cognitive losses*. London: Jessica Kingsley.
- Bodily,C.L. (1994). Ageism and the deployment of 'age' – a constructionist view. In T.R.Sarbin & J.I.Kituse, *Constructing the Social: Inquiries in Social Construction*. London: Sage.
- Bonnano,G.A., Wortman,C.B. & Nesse,R.M. (2004). Prospective patterns of resilience and maladjustment during widowhood. *Psychology and Aging*, 19 (2), 260-271.
- Bosanquet, N. (2001). The socioeconomic impact of Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 16, 249-253.
- Botella,L. (2004). Constructivism and narrative psychology.
<http://www.informed.es/constructivism/documswcb/andreas.html>
- Brody,H., Green,A. & Koschera,A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51, 657-664.
- Bruner,J. (1990). *Acts of meaning*. London: Harvard University Press.
- Burr,V. (1995). *An introduction to social constructionism*. London: Routledge.

References

- Adams,K. & Sanders,S. (2004). Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease: a mixed-method analysis. *Dementia*, 3 (2), 195-210.
- Aneshensel,C.S., Pearlin,L.I. & Schuler,R.H. (1993). Stress, role captivity, and the cessation of caregiving. *Journal of Health and Social Behaviour*, 34, 54-70.
- Ashworth,P. (2003). The origins of qualitative psychology. In J.A.Smith (ed.), *Qualitative Psychology: a Practical Guide to Research Methods*, pp. 4-24. London: Sage.
- Askham, J. (1995). Making sense of dementia: carer's perspectives. *Ageing and Society*, 15, 103-114.
- Baltes,P.B. & Baltes,M.M. (1990). Psychological perspectives on successful ageing: the model of selective optimisation with compensation. In P.B.Baltes & M.M.Baltes (eds.), *Successful Aging: Perspectives from the Behavioural Sciences*, pp. 1-34. Cambridge: Cambridge University Press.
- Bamford,C., Lamont,S., Eccles,M., Robinson,L., May,C. & Bond,J. (2004). Disclosing a diagnosis of dementia: a systematic review. *International Journal of Geriatric Psychiatry*, 19, 151-169.
- Barnett,E. (2000). *Including the person with dementia in designing and delivering care*. London: Jessica Kingsley.
- Bender,M. (2003). *Explorations in dementia – theoretical and research studies into the experience of remediable and enduring cognitive losses*. London: Jessica Kingsley.
- Bodily,C.L. (1994). Ageism and the deployment of 'age' – a constructionist view. In T.R.Sarbin & J.I.Kituse, *Constructing the Social: Inquiries in Social Construction*. London: Sage.
- Bonnano,G.A., Wortman,C.B. & Nesse,R.M. (2004). Prospective patterns of resilience and maladjustment during widowhood. *Psychology and Aging*, 19 (2), 260-271.
- Bosanquet, N. (2001). The socioeconomic impact of Alzheimer's disease. *International Journal of Geriatric Psychiatry*, 16, 249-253.
- Botella,L. (2004). Constructivism and narrative psychology.
<http://www.informed.es/constructivism/documsweb/andreas.html>
- Brody,H., Green,A. & Koschera,A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51, 657-664.
- Bruner,J. (1990). *Acts of meaning*. London: Harvard University Press.
- Burr,V. (1995). *An introduction to social constructionism*. London: Routledge.

Buzan,T. (1995). *The mind map book: radiant thinking –the major evolution in human thought*. London: BBC.

Candey,L. (2001). *Women's understandings of their relationship with their husband in the early stages of his gradual onset dementia*. University of East Anglia: unpublished DClinPsy thesis.

Caron,C.D. & Bowers,B.J. (2003). Deciding whether to continue, share, or relinquish caregiving: caregiver views. *Qualitative Health Research*, 13 (9), 1252-1271.

Charmaz,K. (1987). Struggling for a self: identity levels of the chronically ill. *Research in Sociology of Health Care*, 6, 283-321.

Cheston,R. & Bender,M. (1999). *Understanding dementia – the man with worried eyes*. London: Jessica Kingsley.

Chung,J.C.C. (2000). Lay interpretation of dementia. *International Psychogeriatrics*, 12 (3), 369-377.

Clare,L. (2002). We'll fight it as long as we can: coping with the onset of Alzheimer's disease. *Aging & Mental Health*, 6 (2), 139-148.

Clare,L. (2003). Managing threats to self: awareness in early stage Alzheimer's disease. *Social Science and Medicine*, 57, 1017-1029.

Clare,L. & Shakespeare,P. (2004). Negotiating the impact of forgetting: dimensions of resistance in task-oriented conversations between people with early-stage dementia and their partners. *Dementia*, 3 (2), 211-232.

Clare,L. & Woods,B. (2001). Editorial: a role for cognitive rehabilitation in dementia care. *Neuropsychological Rehabilitation*, 11 (3/4), 193-196.

Coleman,P.G. (1999). Identity management in later life. In R.T.Woods (ed.), *Psychological Problems of Ageing: Assessment, Treatment and Care*, pp. 49-72. Chichester: Wiley.

Cooke,D.D., McNally,L., Mulligan,K.T., Harrison,M.J.G. & Newman,S.P. (2001). Psychosocial interventions for caregivers of people with dementia: a systematic review. *Aging & Mental Health*, 5 (2), 120-135.

Cooper,B. & Feam,R. (1998). Dementia care needs in an area population: case register data and morbidity survey estimates. *International Journal of Geriatric Psychiatry*, 13, 550-555.

Department of Health (2001). *National Service Framework for Older People*. Government Policy Document, DoH March 2001.

Department of Health (2002). *Shifting the balance of power: the next steps*. London: NHS Executive.

DesRosiers,G. (1992). Primary or depressive dementia: clinical features. *International Journal of Geriatric Psychiatry*, 7, 629-638.

- Dittman-Kohli, F. (1990). The construction of meaning in old age: possibilities and constraints. *Ageing and Society*, 10, 279-294.
- DuPlock, S. (1994). What is Existential Psychotherapy? *British Journal of Psychiatry*, 165, 699-701.
- Edwards, R. & Ribbens, J. (1998). Living on the edges: public knowledge, private lives, personal experience. In J. Ribbens & R. Edwards (eds.), *Feminist Dilemmas in Qualitative Research: Public Knowledge and Private Lives*. London: Sage.
- Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Evans, M. (2004). Alzheimer's disease. *GM Care of the Elderly Mind*, 34 (10), 12-16.
- Farran, C.J. (1997). Theoretical perspectives concerning positive aspects of caring for elderly persons with dementia: stress / adaptation and existentialism. *The Gerontologist*, 37 (2), 250-256.
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, 7, 117-140.
- Flowers, P., Smith, J.A., Sheeran, P. & Beail, N. (1997). Health and romance: understanding unprotected sex in relationships between gay men. *British Journal of Health Psychology*, 2, 73-86.
- Folstein, M.F., Folstein, S.E. & McHugh, P.R. (1975). Mini-mental state: a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.
- Forbat, L. (2004). Relationship difficulties in dementia care: a discursive analysis of two women's accounts. *Dementia*, 2 (1), 67-84.
- Forette, F. & Rockwood, K. (1999). Therapeutic intervention in dementia. In G.K. Wilcock (ed), *Diagnosis and Management of Dementia*, pp. 294-310. Oxford: Oxford University Press.
- Fratiglioni, L. (1998). Epidemiology. In A. Wimo, B. Jönsson, G. Karlsson & B. Wimblad (eds.), *Health Economics of Dementia*, pp. 13-31. Chichester: Wiley.
- Gergen, M.M. & Gergen, K.J. (1984). The social construction of narrative accounts. In K.J. Gergen & M.M. Gergen (eds.), *Historical Social Psychology*, pp. 173-188. Hillsdale, NJ: Lawrence Erlbaum.
- Gilliard, J. & Gwilliam, C. (1996). Sharing the diagnosis: a survey of memory disorders clinics, their policies on informing people with dementia and their families, and the support they offer. *International Journal of Geriatric Psychiatry*, 11, 1001-1003.
- Golsworthy, R. & Coyle, A. (1999). Spiritual beliefs and the search for meaning among older adults following partner loss. *Mortality*, 4 (1), 21-40.

- Good, M.D. (1995). Cultural studies of biomedicine: an agenda for research. *Social Science and Medicine*, 41 (4), 461-473.
- Gottlieb, B.H. & Wolfe, J. (2002). Coping with family caregiving to persons with dementia: a critical review. *Aging & Mental Health*, 6 (4), 325-342.
- Haley, W.E. (1997). The family caregiver's role in Alzheimer's disease. *Neurology*, 48, S25-S29.
- Harding, N. & Palfrey, C. (1997). *The social construction of dementia*. London: Jessica Kingsley.
- Heal, H.C. & Husband, H.J. (1998). Disclosing a diagnosis of dementia: is age a factor? *Aging & Mental Health*, 2 (2), 144-150.
- Hinton, W.L. & Levkoff, S. (1999). Constructing Alzheimer's: narratives of lost identities, confusion and loneliness in old age. *Culture, Medicine & Psychiatry*, 23, 453-75.
- Holroyd, S., Turnbull, Q. & Wolf, A.M. (2002). What are patients and their families told about the diagnosis of dementia? Results of a family survey. *International Journal of Geriatric Psychiatry*, 17, 218-221.
- Karlsson, B., Jönsson, B., Wimo, A. & Winblad, B. (1998). Methodological issues in health economic studies of dementia. In A. Wimo, B. Jönsson, G. Karlsson & B. Winblad (eds.), *Health Economics of Dementia*, pp. 13-31. Chichester: Wiley.
- Kelly, G. (1955). *The psychology of personal constructs*. New York: Norton.
- Kirsi, T., Hervonen, A. & Jylhä (2000). A man's gotta do what a man's gotta do: husbands as caregivers to their demented wives: a discourse analytic approach. *Journal of Aging Studies*, 14 (2), 153-169.
- Kitwood, T. (1996). A dialectical framework for dementia. In R.T. Woods (ed.), *Handbook of the Clinical Psychology of Ageing*, (pp.267-282). Chichester: Wiley.
- Kitwood, T. (1997). *Dementia reconsidered – the person comes first*. Buckingham: Open University Press.
- Kvale, S. (1996). *Interviews: an introduction to qualitative research interviewing*. London: Sage.
- Larkin, M. (2004). IPA as a method for exploring culture in psychology. University of Birmingham. Paper presented at annual IPA conference, Nottingham, 2004.
- Levy, B., Hillygus, J., Lui, B. & Levkoff, S. (2000). The relationship between illness attributions and caregiver burden: a cross-cultural analysis. *Journal of Mental Health and Ageing*, 6 (3), 213-225.
- Lincoln, Y. & Guba, E. (1985). *Naturalistic Inquiry*. Beverly Hills: Sage.

- Lindesay, J., Marudkar, M., vanDiepen, E. & Wilcock, G. (2002). The second Leicester survey of memory clinics in the British Isles. *International Journal of Geriatric Psychiatry*, 17, 41-47.
- Lishman, W.A. (1987). *Organic psychiatry*. Oxford: Blackwell.
- Lobban, F., Barrowclough, C. & Jones, S. (2003). A review of the role of illness models in severe mental illness. *Clinical Psychology Review*, 23, 171-196.
- Loos, C. & Bowd, A. (1997). Caregivers of persons with Alzheimer's disease: some neglected implications of the experience of personal loss and grief. *Death Studies*, 21, 501-515.
- Lund, D.A. (1989). *Older bereaved spouses: research with practical applications*. New York: Hemisphere.
- McLeod, J. (1997). *Narrative and psychotherapy*. London: Sage.
- Macran, S., Stiles, W.B. & Smith, J.A. (1999). How does personal therapy affect therapists' practice? *Journal of Counselling Psychology*, 46 (4), 419-431.
- Marzanski, M. (2000). On telling the truth to patients with dementia. *Journal of Medical Ethics*, 26, 108-113.
- Mathieson, C.M. & Stam, H.J. (1995). Renegotiating identity: cancer narratives. *Sociology of Health and Illness*, 17, 283-306.
- Melzer, D. (1998). New drug treatment for Alzheimer's disease: lessons for healthcare policy. *British Medical Journal*, 316, 762-4.
- Meuser, T.M. & Marwit, S.J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. *The Gerontologist*, 41 (5), 658-670.
- Miesen, B. (2002). Presentation on Alzheimer's café's in the Netherlands. British Psychological Society, Psychologists' Special Interest Group for working with Older People Conference. Winchester, UK.
- Miller, T. (2000). Losing the plot: narrative construction and longitudinal childbirth research. *Qualitative Health Research*, 10 (3), 309-323.
- Mishler, E.G. (1997). The interactional construction of narratives in medical and life-history interviews. In B.L.Gunnarsson, P.Linell, B.Nordberg (eds), *The Construction of Professional Discourse*. Harlow: Addison Wesley Longman.
- Moniz-Cook, E., Agar, S., Gibson, G., Win, T. & Wang, M. (1998). A preliminary study of the effects of early intervention with people with dementia and their families in a memory clinic. *Aging & Mental Health*, 2 (3), 199-211.
- Morgan, D.G. & Laing, G.P. (1991). The diagnosis of Alzheimer's disease: spouse's perspectives. *Qualitative Health Research*, 1 (3), 370-387.

- Morris,R.G. (1999). The neuropsychology of Alzheimer's disease and related dementias. In R.T.Woods (ed.), *Psychological Problems of Ageing: Assessment, Treatment and Care*, pp. 111-136. Chichester: Wiley.
- Neimeyer,R.A. (2001). Meaning reconstruction and loss. In R.A.Neimeyer (ed.), *Meaning Reconstruction and the Experience of Loss*, pp. 1-12. Washington: American Psychological Association.
- Neimeyer,R.A. (2002). The relational co-construction of selves: a postmodern perspective. *Journal of Contemporary Psychotherapy*, 32 (1), 51-59.
- Neimeyer,R.A. (2004). *Trauma, loss and the quest for meaning*. Workshop presented for the British Psychological Society Psychotherapy Section. London: Tavistock Clinic.
- Nolan,M., Ingram,P. & Watson,R. (2004). Working with family carers of people with dementia: 'negotiated' coping as an essential outcome. *Dementia*, 1 (1), 75-93.
- Norman,I., Redfern,S., Briggs,K. & Askham,J. (2004). Perceptions and management of change by people with dementia and their carers living at home. *Dementia*, 3 (1), 19-44.
- O'Connor,D. (1999). Living with a memory-impaired spouse: (re)cognizing the experience. *Canadian Journal on Aging*, 18 (2), 211-235.
- Orona,C.J. (1990). Temporality and identity loss due to Alzheimer's disease. *Social Science and Medicine*, 10, 1247-1256. Reprinted in: A.Strauss. & J.Corbin (eds) (1990) *Basics of qualitative research: grounded theory procedures and techniques*. London: Sage.
- Pearce,A., Clare,L. & Pistrang,N. (2002). Managing sense of self: coping in the early stages of Alzheimer's disease. *Dementia*, 1 (2), 173-192.
- Pearlin,L.I., Mullan,J.T., Semple,S.J. & Skaff,M.M. (1990). Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*, 30, 583-594.
- Perry,J. & O'Connor,D. (2002). Preserving personhood: (re)membering the spouse with dementia. *Family Relations*, 51 (1), 55-62.
- Phipps,A.J. & O'Brien,J.T.O. (2002). Memory clinics and clinical governance – a UK perspective. *International Journal of Geriatric Psychiatry*, 17, 1128-1132.
- Pratt,R. & Wilkinson,H. (2003). A psychosocial model of understanding the experience of receiving a diagnosis of dementia. *Dementia*, 2 (2), 181-199.
- Pusey,H. & Richards,D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging & Mental Health*, 5 (2), 107-119.
- Riessman,C.K. (1993). *Narrative analysis*. London: Sage.
- Riessman,C.K. (1990). Strategic use of narrative in the presentation of self and illness: a research note. *Social Science and Medicine*, 30 (11), 1195-1200.

Roberts,G. (2000). Narrative and severe mental illness: what place do stories have in an evidence-based world? *Advances in Psychiatric Treatment*, 6, 432-441.

Rosen,H. (1996). Meaning-making narratives: foundations for constructivist and social constructionist psychotherapies. In H.Rosen & K.T.Kuehlwein (eds.), *Constructing Realities: Meaning Making Perspectives for Psychotherapists*, pp. 3-54. San Francisco: Jossey-Bass.

Rubin,H.J. & Rubin.I.S. (1995). *Qualitative interviewing: the art of hearing data*. London: Sage.

Sabat, S.R. (2001). *The experience of Alzheimer's disease: life through a tangled veil*. Oxford: Blackwell.

Schulz,R., O'Brien,A.T., Bookwala,J. & Fleissner,K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates and causes. *The Gerontologist*, 35, 771-791.

Shaw,R. (2004). Interpretative Phenomenological Analysis Conference workshop on validity and reliability in qualitative research. Nottingham Trent University.

Smith,J.A. (1995). Semi-structured interviewing and qualitative analysis. In J.A.Smith, R.Harré & L.Van Langenhove (eds.), *Rethinking Methods in Psychology*, pp. 9-26. London: Sage.

Smith,J.A. (1996). Evolving issues for qualitative psychology. In Richardson,J.T.E. (ed.), *Handbook of Qualitative Research Methods*. Leicester: British Psychological Society.

Smith,J.A., Flowers,P., & Osborn,M. (1997). Interpretative Phenomenological Analysis and the psychology of health and illness. In L.Yardley (ed.), *Material Discourses of Health and Illness*, pp.68-91. London: Routledge

Smith,J.A. & Osborn,M. (2003). Interpretative Phenomenological Analysis. In J.A.Smith (ed.), *Qualitative Psychology: a Practical Guide to Research Methods*, pp. 51-80. London: Sage.

Smith,J.A., Osborn,M. & Jarman,M. (1999). Doing Interpretative Phenomenological Analysis. In M.Murray & K.Chamberlain (eds.), *Qualitative Health Psychology*. London: Sage.

Spencer,L., Ritchie,J., Lewis,J. & Dillon,L. (2003). *Quality in qualitative evaluation: a framework for assessing research evidence*. Cabinet office: HMSO.

Spinelli,E. (1989). *The Interpreted World*. London: Sage.

Spinelli,E. (1996). The existential-phenomenological paradigm. In R.Woolfe & W.Dryden (eds.), *Handbook of Counselling Psychology*. London: Sage.

Stoller,E.P. & Cutler,S. (1992). The impact of gender on configurations of care among married elderly couples. *Research on Aging*, 14, 313-330.

Strauss,A. & Corbin,J.(1990). *Basics of qualitative research: grounded theory procedures and techniques*. London: Sage.

Sweetman,C. & Davies,S. (2002). *An audit of the Derwent Centre Memory Clinic: client feedback*. Harlow: unpublished audit.

Tarrier,N., Barrowclough,C., Ward,J., Donaldson,C., Burns,A. & Gregg,L. (2002). Expressed emotion and attributions of carers of patients with Alzheimer's disease: the effect on carer burden. *Journal of Abnormal Psychology*, 111 (2), 340-349.

Thompson,P., Itzin,C. & Abendstern,M. (1990). *I don't feel old: the experiences of later life*. Oxford: Oxford University Press.

Thompson,C. & Spilsbury,K. (2003). Support for carers of people with Alzheimer's type dementia (Cochrane Review), *The Cochrane Library*, Issue 2, 2003.

Van Hout,H.P.J., Vernooij,M.J.F.J., Hoefnagels,W.H.L. & Grol,R.P.T.M. (2001). Measuring the opinions of memory clinic users: patients, relatives and general practitioners. *International Journal of Geriatric Psychiatry*, 16, 846-851.

Viney,L.L. (1993). *Life stories – personal construct therapy with the elderly*. Chichester: Wiley.

Wadley,V.G. & Haley,W.E. (2001). Diagnostic attributions versus labeling: impact of Alzheimer's disease and Major Depression diagnoses on emotions, beliefs, and helping intentions of family members. *Journal of Gerontology*, 56B (4), 244-252.

Wald,C., Fahy,M., Walker,Z. & Livingston,G. (2003). What to tell dementia caregivers – the rule of threes. *International Journal of Geriatric Psychiatry*, 18, 313-317.

Walker,R.J., Pomeroy,E.C., McNeil,J,S. & Franklin,C. (1994). Anticipatory grief and Alzheimer's disease: strategies for interventions. *Journal of Gerontological Social Work*, 22, 21-39.

Werner,P. (2001). Correlates of family caregivers' knowledge about Alzheimers disease. *International Journal of Geriatric Psychiatry*, 16, 32-38.

Whitlatch,C.J. (1998). Distress and burden for family caregivers. In A.Wimo, B.Jönsson, G.Karlsson & B.Wimblad (eds.), *Health Economics of Dementia*, pp. 123-137. Chichester: Wiley.

Willig,C. (2001). *Introducing qualitative research in psychology: adventures in theory and method*. Buckingham: Open University Press.

Wilson,H.S. (1989). Family caregivers: the experience of Alzheimer's disease. *Applied Nursing Research*, 2 (1), 40-45.

Woods,R.T. (2001). Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects. *Aging & Mental Health*, 5 (supplement 1), S7-S16.

Yardley,L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.

Yin,R.K. (2003). *Case study research: design and methods* (Third Edition). London: Sage.

Zarit,S.H. & Edwards,A.B. (1999). Family caregiving: research and clinical intervention. In R.T.Woods (ed.), *Psychological Problems of Ageing*. Chichester: Wiley.

Appendices

Appendix A: Local Research Ethics Committee Approval

**Appendix B: Participant Information Sheet
Consent Form
Letter to GP**

**Appendix C: Interview Schedule
Interview Feedback Sheet**

Appendix D: Extract from coded interview transcript

Appendix E: Examples of memos (code note, theoretical note, process note) relating to coded interview transcript extract (Appendix D)

**Appendix F: List of themes for all four participants
Example of mind map to develop connections between themes
Example of a theme with identifiers for each participant**

Appendix G: Examples from transcript of the pilot interview

Appendix H: Notation used within verbatim interview extracts

APPENDIX A

West Essex Local Research Ethics Committee
c/o The Princess Alexandra Hospital NHS Trust
Terminus House The High Harlow Essex CM20 1XA

Tel/Fax: 01279 694860
Email: liz.wrighton@essexsha.nhs.uk

6th January 2004

Mr R Casson
76 Maynard Road
London
E17 9JF

**1587-1103
PARTNERS' EXPERIENCES OF A DIAGNOSIS OF ALZHEIMER'S
DISEASE**

Dear Mr Casson

The Research Ethics Committee considered your project at its meeting on 13th November 2003, and requested certain additional information and amendments to your submission and protocol.

The revised documentation and information submitted has been considered by the Chairman under delegated powers. He has given ethical approval for your project to proceed.

The following documents were considered by the Committee and/or Chairman:

- LREC Application Form version 1 dated 17/10/03
- Research Proposal version 1 dated 24/10/03
- Participant Information Sheet version 1 dated 24/10/03
- Reply Form version 1 dated 24/10/03
- Participant Consent Form version 1 dated 24/10/03
- Researcher's CV (undated)
- Student Form dated 23/10/03
- CV for Stephen Paul Davies (undated)
- CV for Pieter W Nel (undated)
- CV for David Anthony Winter (undated)
- Letter from Researcher dated 20th December 2003
- Letter from Clinician version 1 dated 12/12/03
- Participant Information Sheet version 2 dated 12/12/03 (please note spelling error on pg 2 – anonymised)
- Reply Form version 2 dated 12/12/03
- Consent Form version 2 (undated)
- GP Letter version 1 dated 12/12/03

Whilst this letter gives approval to the ethical aspects of your application, it is the researcher's responsibility to ensure that all other approvals necessary or required are received prior to commencing work on the research.

It is the researcher's responsibility to ensure that the research is carried out in strict accordance with the protocol submitted and that no changes to the protocol are undertaken without the prior approval of this Committee (other than matters of urgency for the safety of the participants).

Should any serious unexpected events occur in connection with your research, these should be reported immediately to the Committee, together with your recommendations as to any changes to the protocol or other action that might be necessary. These reports should be received within 7 days of the incident concerned.

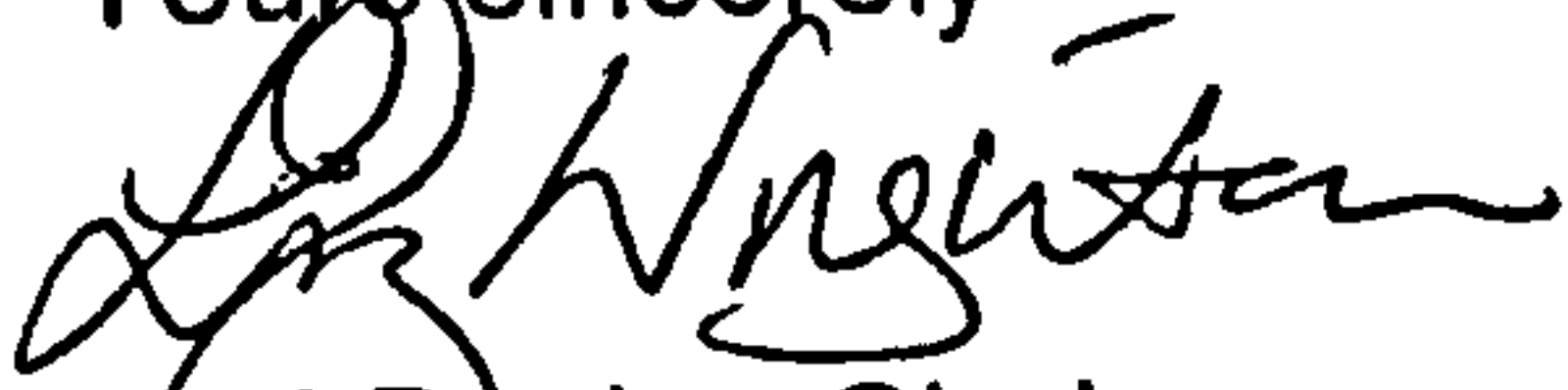
The Committee retains the right to inspect or review your project at any time during the currency of the research.

You should submit a progress report not less than annually (where appropriate). A brief report or Abstract on the final results of the research should be submitted within 3 months of its completion.

It is confirmed that this Committee operates under ICH-GCP guidelines and in accordance with the Declaration of Helsinki 2000. A list of members in attendance at the meeting when your project was considered is attached.

May I wish you every success with your research.

Yours sincerely



Dr J Davis - Chairman
West Essex Local Research Ethics Committee
cc: R&D Administrator

Members at the meeting in November were:

Dr J Davis	Chairman
Dr Q Abbas	Hospice Physician – Palliative Medicine (left 4.20pm)
Dr G Bhusari	Community Paediatrics
Mr H Bliss	Lay Member (Vice-Chairman)
Mrs P Boutell	Lay Member
Mr G Hay	Lay Member
Mrs S Humphreys-Moore	Nurse Member
Dr T Sikdar	Consultant Radiologist
Dr Z Walker	Consultant Psychiatrist (left 4.20pm)
Mrs V Wright	Lay Member (left 3.30pm)
Mrs J Yeo	Nurse Member



West Essex Local Research Ethics Committee
c/o The Princess Alexandra Hospital NHS Trust
Terminus House The High Harlow Essex CM20 1XA

Tel/Fax: 01279 694860
Email: liz.wrighton@essexsha.nhs.uk

17th May 2004

Mr R Casson
76 Maynard Road
London
E17 9JF

1587-1103

PARTNERS' EXPERIENCES OF A DIAGNOSIS OF ALZHEIMER'S DISEASE

Amendment number: 01
Amendment date: 26/4/04

The above amendment was reviewed by the Sub-Committee of the West Essex Local Research Ethics Committee at the meeting held on 30th April 2004.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Your email dated 27th April 2004
Amendment Form dated 26th April 2004
Participant Information Sheet version 3 dated 26/4/04
Reply Form version 3 dated 26/4/04
Invitation Letter version 2 dated 26/4/04
Letter from Dr Pieter W Nel (supervisor) dated 6th May 2004

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Management approval

Before implementing the amendment, you should check with the host organisation whether it affects their approval of the research.

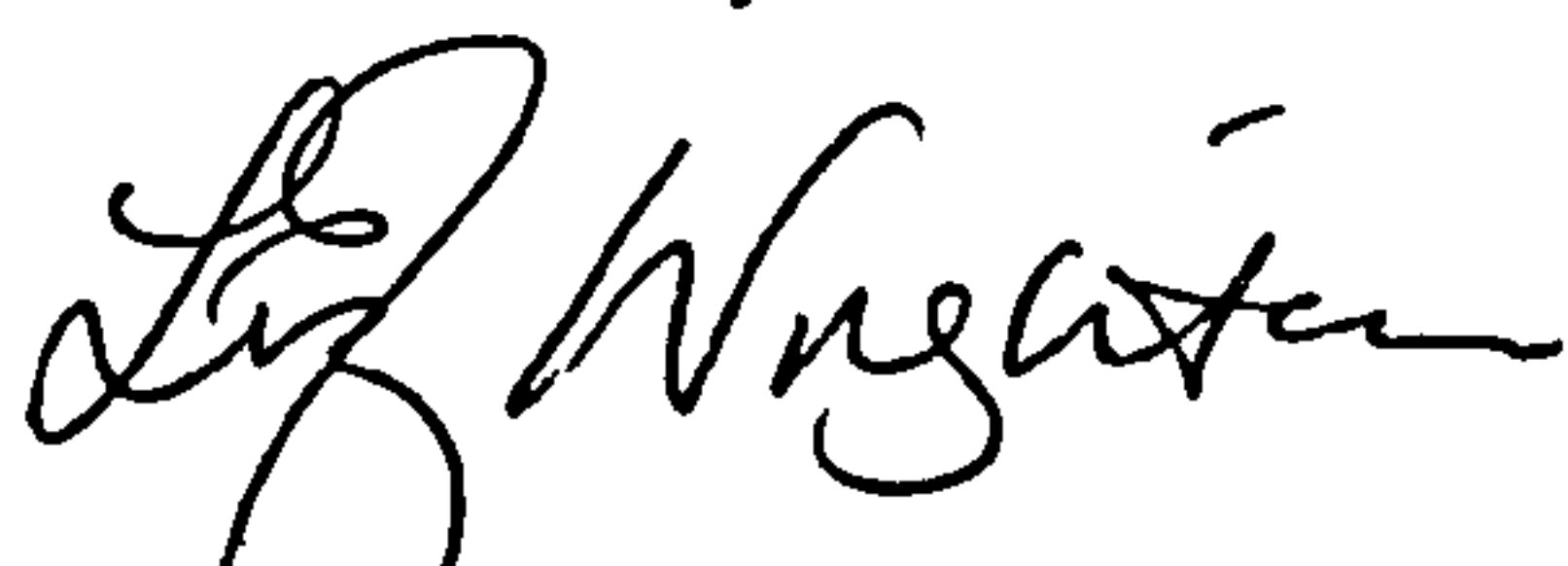
Statement of compliance

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.

REC reference number: 1587-1103

Please quote this number on all correspondence

Yours sincerely



Liz Wrighton
Committee Administrator

Copy to: *R&D Dept, NEMHPT*

Members at the Meeting on 30th April 2004:

Mr H Bliss (Vice-Chairman)
Ms V Wright (Lay Member)



West Essex Local Research Ethics Committee
c/o The Princess Alexandra Hospital NHS Trust
Terminus House The High Harlow Essex CM20 1XA

Tel/Fax: 01279 694917
Email: liz.wrighton@ntlworld.com

23rd August 2004

Mr R Casson
76 Maynard Road
London
E17 9JF

1587-1103

PARTNERS' EXPERIENCES OF A DIAGNOSIS OF ALZHEIMER'S DISEASE

Amendment number: 02

Amendment date: 6/8/04

Dear Mr Casson

The above amendment was reviewed by West Essex Local Research Ethics Committee at the meeting held on 19th August 2004.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Notice of substantial amendment form (Amendment No 2)

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Management approval

Before implementing the amendment, you should check with the host organisation whether it affects their approval of the research.

Statement of compliance (from 1 May 2004)

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.

Yours sincerely



Liz Wrighton
Committee Administrator

Copy to: *Sponsor*

Enclosures *List of names and professions of members who were present at the meeting
and those who submitted written comments*

APPENDIX B

Participant information sheet

Project title: Partners' experiences of a diagnosis of Alzheimer's disease

**Researcher: Roland Casson, Clinical Psychologist In Training,
University of Hertfordshire**

You are being invited to take part in a research study. Before you make a decision it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. You should consider discussing your participation with your partner / consider informing them if you decide to take part. If anything is unclear or you would like more information, please feel free to contact me. Take your time to decide whether or not you wish to take part. I would be grateful if you could use the attached reply slip and stamped addressed envelope to let me know if you wish/ do not wish to take part. If I have not heard from you in the next month, then I will assume you do not wish to take part in the study and will not contact you again.

Thank you for taking the time to read this.

What is the study about?

In order to improve services for people with memory problems in later life, it is important to understand people's needs and what they find helpful. Little is known about people's experiences of a diagnosis of Alzheimer's disease. The aim of the study is to learn about how a diagnosis of Alzheimer's disease changes the way people see their situation, how they manage it, and whether they feel adequately informed and supported by services.

Why have you been approached?

I am approaching people whose partner has recently been diagnosed with Alzheimer's disease. I am looking for 5-6 partners to take part in the study. My aim is to gain a good understanding of the experiences of these people, rather than asking them to complete simple questionnaires which might not reflect the issues that are important to people.

What does taking part in the study involve?

If you decide to take part in the study, Roland Casson (main researcher) will contact you and arrange to meet with you to talk with you about the issues outlined above.

It would be up to you to decide whether the interview takes place in your home or at the Princess Alexandra Hospital, wherever you felt most at ease (we could try to arrange another venue if you prefer). The interview could be done over one or two meetings, lasting up to 1 hour each. We could pay travelling expenses to get to the meetings if necessary.

You will be asked to sign a consent form to take part in the study (you will be given a signed copy to keep). However, during the meetings, you would not have to talk about anything you don't want to talk about, and you can decide to withdraw from the study at any point without feeling that you have to give an explanation. Deciding not to take part, or withdrawing from the study will not affect the services that you or your partner receive.

I want to involve people as much as possible in the study and would share the results with you to make sure that they fit with your experiences before presenting the results to the service.

I would like to tape record the conversations so that I don't forget anything that is said. The information from the tapes will be written down and the tapes returned to you or destroyed, depending on what you prefer. Anything that is written down will be anonymised (i.e. names, places, and any other information that might allow people to identify you or your partner will be removed) so that no one can recognise that it is you.

What are the potential benefits or problems

I understand that this is a difficult time for people and that taking part in the study might not be possible for whatever reason. As outlined above, you can withdraw from the study at any stage, or refuse to answer questions if you wish. I will ask you if you wish your GP to be informed that you are taking part in the study, and if so will send a copy of this information sheet. If you find that you end up talking about distressing issues or find that there are things that you need to understand better, I will help you to identify ways of getting further information and/or support.

Although it is time consuming, many people who have taken part in similar studies have said that they found that taking part was helpful as they were able to

talk about issues more openly than they might with family and friends, and they managed to clarify things in their own mind.

What will happen to the information

Your name or the names of anyone that you talk about will not be written down so that no one could identify you. The tapes will be returned to you or destroyed at the end of the study. All the information from the people who take part in the study will be put together in a report which will be fed back to the service and may be published for academic use. The report will include quotations from the interviews but these will be anonymous. The researcher is not part of the service and your participation in the study, and any conversations with the researcher will be kept confidential.

What do I do if I decide to take part or if I need more information before making a decision?

If you would like to take part, or would like more information, please return the reply form (next page) in the stamped addressed envelope (enclosed), or phone Roland Casson on 01707 286322

Remember that participation in the study is entirely voluntary

Thank you for your consideration

REPLY FORM

Please return this form in the stamped addressed envelope enclosed.

(to Roland Casson, Clinical Psychologist in Training, Department of Clinical Psychology,
University of Hertfordshire, College Lane, Hatfield AL10 9AB)

	Please tick relevant
box	
I wish to take part in the study and agree for the researcher (Roland Casson) to contact me to arrange a meeting with me	
I do not wish to take part in the study	

Name:

Signature:

Address:

Telephone number:

For those who wish to take part,

		Please tick relevant box
I prefer to be contacted	by letter	[]
	by telephone	[]

CONSENT FORM

Project title: Partners' experiences of a diagnosis of Alzheimer's disease

Researcher: Roland Casson, Clinical Psychologist in Training, University of Hertfordshire

- Please tick box
- I confirm that I have read and understood the information sheet dated 12/12/03 (version 2) for the above study and have had the opportunity to consider it, and discuss it with people independent of the research. []
- I confirm that I have had the opportunity to ask questions and that these have been answered to my satisfaction []
- I understand that my participation is entirely voluntary and that I can withdraw from the study at any time, without giving any reason, and without my own/ my partner's care being affected in any way. []
- I agree for the interviews to be recorded on audio tape. I understand that the tapes will be returned to me or destroyed on completion of the study. I understand that information from the tapes will be written down with any identifying information anonymised. []
- I agree to take part in the above study []
- I understand that the content of the interview will be kept confidential []
- I would like my GP to be informed that I am taking part in the study and for them to be sent a copy of the information sheet []
Name and address of GP (if applicable).....
.....
.....

Name of participant Date Signature

I have established that the participant understands the nature of the study, the purpose, and the risks involved, and that they agree to participate voluntarily

Name of researcher Date Signature

Copy 1: for participant Copy 2: for researcher

COVERING LETTER TO GP

(NHS Trust headed paper)

(University department address)

*(GP
GP's address)*

(date)

Dear Dr X,

(Participant's name)

Participation in research study: 'Partners' experiences of a diagnosis of Alzheimer's Disease'

I am writing regarding *(participant)*, a patient of yours, who agreed to participate in a research project that I am conducting. In line with the research protocol, *(participant)* agreed for me to inform you of her participation in the study. I am therefore enclosing an information sheet about the study.

I met with *(participant)* on *(date)* to talk about her experiences of her partner being diagnosed with Alzheimer's disease, and how the diagnosis has affected the way she sees her situation. Although people tend to value the opportunity to participate in such research, talking about such personal issues may also cause distress. Although no concerns arose during our meeting, participants are being advised that, should distressing issues arise that they require further support with, one of their options would be to approach their GP.

If you have any questions, or if there are any issues that you wish to discuss, please do not hesitate to contact me.

Yours sincerely,

Roland Casson
Clinical Psychologist in Training

APPENDIX C

Interview Schedule

N.B. Questions that are underlined / italic represent questions added during later interviews. Questions in (brackets) are those where less emphasis was placed in later interviews.

Checklist: TAPE RECORDER / 2 TAPES/ SPARE BATTERIES / MICROPHONE / ALZHEIMER'S SOCIETY INFORMATION SHEETS/ CONSENT FORM / NOTE-PAPER

Aim to gain: DEPTH / NUANCE / EXAMPLES

Keep the interview open and be prepared to prompt on the issues below if necessary

Introductions

- How prefer to be called?
- 'Thank you for agreeing to take part in the research. Before we start the interview, there are a few things that I need to tell you about, and obviously I will answer any questions that you might have'
- Trainee CP / final year / part of training
- Expect the interview last up to an hour with possibility of second interview
- Consent form x2 signing
- Confidentiality – will not affect care – recording – data protection
- Don't have to answer questions / take a break if need one

Getting the diagnosis

1. Can you tell me a brief history of the difficulties from when you first became aware of them to the present?
 - a. first concerns / difficulties
 - b. making sense of those difficulties
 - c. managing the difficulties
 - d. decision to seek help from services
 - i. How was decision made?
 - ii. Expectations / hopes?
 - e. Experiences of the assessment
 - i. Description
 - ii. What was it like for you
 - f. Experiences of disclosure
 - i. When were you told?
 - ii. How were you told?
 - iii. What were you told?
 - iv. What was it like for diagnosis to be disclosed? What feelings did the diagnosis bring up for you?
 - g. What has life been like since the diagnosis was disclosed
 - i. Behavioural responses
 - ii. Emotional responses

Identity

Interested in how diagnosis affects how people see themselves and their situation

1. how would you describe yourself as a person? (prompt for 3 characteristics)
 - a. in what ways has the diagnosis affected how you see yourself?
2. how would you describe partner (3)
 - a. in what ways has the diagnosis affected how you see your partner

Relationships

1. have you told anyone else about the diagnosis
 - a. how did you come to that decision?
 - b. what was it like for you?
 - c. How have other people responded? How has it affected them?
 - d. in what ways has the diagnosis affected how others see you and your partner?
2. in what ways has the diagnosis affected your relationships with other people?
OR in what ways do you anticipate it will affect your relationships
 - a. Friends
 - b. Family
 - c. Wider community
3. is your partner aware of the diagnosis?
 - a. In what ways has it affected the way you relate to each other?

Coping / Impact on world view

1. What has been the most challenging aspect of the experience for you?
2. how do you cope on a day to day basis?
3. what has helped you manage during this time?
4. what life experiences have helped you to manage your current situation?
5. what philosophical or spiritual beliefs have contributed to your experience? / How have they been affected by your experience?
6. how has the diagnosis affected your views about life?
7. how has the diagnosis affected your sense of priorities?
8. how would life be different if you had not visited the doctor?
9. plans for the coming weeks / months?

Reflections

- if you were to reflect on your life as a series of chapters, what would you call the current chapter? Previous chapter? Next chapter?
- What image or metaphor would you use to characterise Alzheimer's disease?
- In what ways is having the diagnosis helpful / unhelpful to you?

Demographics

Prompt if necessary for Ages / length marriage / children / other important family

Ending

- Feedback key issues that I have heard in interview
- Any important aspects of your experience that we have not talked about? (i.e. anything that I should have asked you about?)
- Are there any questions that you would like to ask me?
- What was it like doing the interview? (similarities and differences from expectations)
- What advice would you offer to other people thinking about participating?
- NEGOTIATE SECOND INTERVIEW IF APPROPRIATE
- DISCUSS NEXT STEPS / MEMBER VALIDATION
- INFORMATION PACK FROM ALZHEIMERS SOCIETY IF WANTED

INTERVIEW FEEDBACK SHEET

Interview feedback sheet used to guide process of reflecting on the interview immediately afterwards. Its use was based on the premise that interviewing is an iterative process, with the aim of building rich descriptions and data.

Reflections on interview

- Content - key themes / issues / conflicts / dilemmas
- Process
- Unexpected themes / issues
- Links to theoretical concepts / models
- Directions that I could / should have followed
- Issues / probes / prompts for inclusion / exclusion in future interviews
- Formulation / reformulation of research questions
- Observation on the interview e.g. tense, relaxed, comments on non-verbal, process
- How did I feel about interviewee / interactions

Evaluation of interviewer performance

(after interview and then after listening to audiotape)

- Managed to build relationship with interviewee?
- Managed to reinforce interviewees sense of competence?
- subtle shifts from topic to topic
- relaxed interview style
- appropriate pace of interview e.g. introducing difficult topics
- focussed on what interviewee saying
- curiosity
- allow interviewee to speak their mind – not imposing own values – supportive when interviewee contradicts interviewer
- discouraged talk about certain issues?
- repair conversation subtly e.g. if question is misunderstood, allow it to be answered and then re-phrase rather than saying ‘what I meant to ask was’
- beginning / middle / ending
- content – depth – examples (not accepting generalisations)
- enough open questions
- questions intelligible and straightforward and unambiguous
- follow up on themes appropriately
- use of notes during interview
- listening for indirect communication especially from female interviewees

APPENDIX D

EXTRACT FROM CODED INTERVIEW TRANSCRIPT

Participant 4: pages 4-9 (lines 122-359)

Participant 4 interview 1

121
122 P4: err, he hasn't taken it in, [consultant psychiatrist] explained to him
123 that he's got Alzheimer's, 'oh', he said, 'my dad had that, I never
124 thought I'd ...'. And he's never mentioned it since (R: right), doesn't
125 want to know. But he was exactly the same when he had the bowel
126 cancer diagnosed. I thought they hadn't told him, because he never
127 mentioned it, he came out of hospital and never said anything ... and
128 um, the doctors assured me that they'd told him, the staff nurse said
129 that she'd talked to him and said about it, but he switched off, and he's
130 done exactly the same with this.

131
132 R: so is that generally how he copes with things?
133

134 P4: I think so, when I try to sort of think back then, his parents were
135 both like that, both of them. We had um, our son died when he was 16
136 with Leukaemia, his parents, um, I mean they were lovely, but they
137 couldn't cope, so they switched off from it, wouldn't discuss it, it was
138 all going to get better, understand?
139

140 R: yeah, mmm, and so he's kind of learnt to do things that way.
141

142 P4: I think so, I think this is it, yeah.
143

144 R: mmm, and how is that for you then?
145

146 P4: err, I think I've got a lot on my plate (laughs)! But you can't,
147 you've got to get on with it don't you, you can't turn around and weep,
148 you've just got to crack on.
149

150 R: yeah, I mean, I'm just wondering what kind of feelings it brought up
151 for you hearing the doctors say that they thought it was Alzheimer's?
152

153 P4: well there's a resentment in that 'it's not fair' type of thing, isn't it
154 But I think basically I ... was ready, I knew ... because of having gone
155 through it with [father in law], dad.
156

157 R: so how does, how does kind of knowing, how does that change
158 things?
159

160 P4: in what way do you mean?

contrast: responses to diagnosis
qualitative of diagnosis
P4: err = reaction - period
of hearing diagnosis -
all his reactions to hearing diagnosis -
comparison - reaction to cancer
general avoidance

switched off - coping strategy
rejection - emotion, the same

avoidance
history - make sense
loss - context - comparison
'well' - not coping 'why?'
switching off when can't cope
coping - history - all going to get better -
hope

comparison of coping strategies -
in relation to get on with it
emotional expression in his life
'other says it's a way of
coping with grief
'swimming' - special means
'challenges' not to identify feelings
resentment - 'it's not fair' (avoidance)
preparation
comparison with previous experiences - prepared

122-30
making sense through pattern's reaction
avoiding invalidation 122-30
learning from previous experiences

narrative repetition (129/130)

reflecting on his story - making sense
avoiding invalidation (134-8)
- notes generalised coping styles
- protective for father

134-8
coping style (146-8)
- minimise, source of loss =
- just got to crack on
(can't turn around and weep)
avoiding emotion

avoiding emotion
minimising grief longer resentment
confirmation (153-5)
learning from experience - narrative repetition

Participant 4 interview 1

201 R: I know a little but I'm not an expert

202

203 P4: no, I don't think the memory's got any worse, it's bad enough but
204 it hasn't got any worse.

205

206 R: mm, so things are kind of quite stable at they moment?

207

208 P4: mm, mm, yeah. He has what I call 'wobbles', but he was having
209 those, I don't know, as I say whether they're to do with any (laughs),
210 which of the things it's to do with, he had a bad one this morning ...

211

211 just because ... he was feeling giddy I think, sickish, and he needs to
212 sit down, I mean really no good all day. But he's just been out with the
213 dog, and I waited until he got back to make sure he's OK, and then I
214 came up here obviously. I wouldn't go out and just take things for
215 granted. We're very fortunate, we live right next to the forest, so he

216

216 goes into the forest, so if the dog came back, which she would on her
217 own, um, I would know that there was something wrong, so really he
218 can walk. He'll go out every morning, except this morning, and he'll
219 walk a long way in the mornings, which I feel is good for him. But he
220 can't um, retain anything for long, he starts doing something and then

221

221 loses it. Like with the gardening, and then he goes off and does
222 something else, you know, he never seems to be able to stay at it, is
223 that part of it, isn't it?

224

225 R: mm, I suppose.

226

227 P4: his dad was the same.

228

229 R: so has the way that you're kind of managing things, has that
230 changed since the diagnosis?

231

232 P4: umm, I was watching him like a hawk to start with obviously, but
233 I've learnt now to let him get on with it, let him do it (R: mm). he'll
234 say, 'I'm going to walk up the town', up to the high street, I need a
235 new watch strap', and I thought, well I could say 'I'll come', but I
236 thought 'no', I feel he's got to perhaps do these things, do you think
237 that's right? That he does it himself?

238

239 R: Ok, yeah, so what, so what ...

240

memory - if poor of indicator
import of indication (198-204)
memory - stability emphasis

even well (206-8)
search for expansion 211 (208-12)

role - monitor well (211-7)
- being used for
em - very source of dependence (215-9)

symptoms - car monitor activities
make sense of symptoms (220-23)

social comparison (219-224)
social comparison with father - how difficulties

watching him like a hawk
learned to let him do it - dilemma
natural impulse is to help
resolution dilemma
uncertainty in how to help

becoming 'stronger' (229-33)
reaction to diagnosis from like a hawk
adjustment - resolution dilemma (229-237)
maintaining identity - learning to step
managing uncertainty (238-7)

Participant 4 interview 1

241 P4: he came back with a new watch strap so he must (laughs) be doing
242 OK, he must have coped with it all all right

243
244 R: so was the idea that you might be being maybe too protective?
245

246 P4: I'm wondering if I have been, and I'm trying not to be now. You
247 know I'm conscious of what's up ahead and how, and various things he
248 wants to do, and he turns around to me 'you're watching me all the
249 time', and yes, I am, I've got to stop it.

250
251 R: right, and are there situations, I mean I'm just wondering if there are
252 situations where, where you're more conscious or less conscious of
253 doing that?

254 P4: no, I think it's there absolutely, you're wondering all the time what
255 he's doing, is he all right.

256
257 R: are there things he can do that you're not so worried about?
258

259 P4: pottering about in the garden and that is no problem is it, sort of
260 thing. Um, he doesn't really do much at all now, as regards jobs or
261 anything like that, he'd never think to.

262
263 R: right, and how does that affect you?
264

265 P4: well I do ??? (laughs), like putting the dustbin out and that type of
266 thing. I mean last night it was pouring with rain, and he said 'why
267 don't you put my coat on?' and I said 'why don't you do it!' (laughs).
268 But that doesn't seem, it seems to have, that's gone, you know.

269
270 R: and what stopped you saying that?
271

272 P4: well I just didn't feel it warranted a, it might have gone into a full
273 blown row mightn't it (laughs).
274
275

276 R: right, OK, so, yeah. So, it must be putting more pressure on you to
277 be doing some of the things that he would have done?
278

279 P4: yes, well I feel that I do everything now, because um, I've always
280 done household management, the accounts and all that sort of thing,

relief? / doing his share / independent / evaluation / [protected] / [protected] / [protected]

counterbalance / protective / [protected] / [protected] / [protected] / [protected] / [protected] / [protected]

constant worry / [protected] / [protected] / [protected]

doesn't do much at all now / lack of initiative

re-define role / take on his tasks / being positioned in cognitive order / [protected] / [protected] / [protected] / [protected] / [protected]

predicting arguments - take on more / avoid row conflict

feeling that I do everything now / continuing role

role adjustment - monitoring (251-2)

role adjustment - balance of [protected] / [protected] / [protected]

adjustments / constructive / [protected] / [protected] / [protected]

role adjustment - constant worry (251-6)

symptoms - loss of initiative (260-69)

role adjustments - taking on more (266-74)

avoiding conflict / [protected] / [protected] / [protected]

avoiding conflict

taking on more - do everything now

Participant 4 interview 1

281 I've always done letter writing. He's never ever done anything along
282 that line. And um, just feel as though I do everything now, (said more
283 slowly, sadly) it's just ... but you know, that's normal.

role conflict
feeling anxious
normal coping behavior
social comparison

284 R: so how does that feel for you?

285 P4: at least you're in charge (laughs) - that's the way I try to look at it
286 anyway (laughs), whatever I say goes.

power/control
copy the - trying to look at it differently

287 R: so there's some good aspects to it as well.

288 P4: in some respects, yes, in some respects you do know what's going
289 on. But he couldn't cope now with ... dealing with anything like that,
290 with the household accounts and things.

acknowledging positive
he couldn't cope
loss

291 R: and is that different from how things were?

292 P4: well as I say I've always done them anyway (R: yeah), I mean it's
293 my job so (laughs).

role definition (it's my job)

294 R: but before the diagnosis was made I'm just wondering if you, you
295 were saying that things have been quite stable, but I'm just wondering
296 what other things might have changed as a result.

control of life before diagnosis
from different perspective

297 P4: he's slowed up, very slow ... he's never been a speed merchant, he
298 was always a methodical sort of person, if he did something it was
299 methodical (R: mmm). But he's so slow, just getting ready to go out.

loss in speed of thinking
methodical person
daily things, e.g. slowness

300 You know, the other day going out with the dog in the morning, and
301 um, I got my coat and everything on, and he was still upstairs pottering
302 around, I got, I hovered all downstairs while I was still waiting just to
303 get his coat. Very, very slow, and he's got um, when he's trying to put
304 his coat on now, he's sort of turning it around and around, trying to
305 find the way in, is that, that would be a normal thing would it, with the
306 Alzheimer's?

learning to do things at his own pace
emphasis on slowness / appearance
get a coat
social comparison
trying to normalize
Alzheimer's - slowness / confusion

307 R: yeah, quite common.

308 P4: I wasn't aware of it quite so with dad, but he is, it is very pointed
309 now, um, with a jumper he's often got it on back to front.

comparison with previous performance
awareness of differences

role adjustment - done it all myself
social comparison - relaxation (282-3)

power/control (282-284)
control - looked from perspective
control - narrow horizon (287-288)
reference

role adjustment - no choice we adjust
(287-288)

adjustments - slowness (305-7)
make sense - personality (305-14)

adjustments - got the pace (307-11)

social comparison - make sense
normalization (311-4)

social comparison - difference (318-9)
father's behavior

Participant 4 interview 1

R: so is that something that you're kind of getting more involved in or.

P4: well I just leave it.

R: so it doesn't bother you too much.

P4: well, I'm getting, it did do, but I think it would just make more hassle for both of us, if you start, um, kind of going on about things, doesn't it really? (pause) anyway I don't want to make, he must, deep down I think he must know he's not right ... and if you're going to go on about it, it's not going to help is it?

R: mmm, no, I'm just kind of wondering what it might be like for him if you did. It sounds like it would make it worse.

P4: I don't think he wants to, I think it's going to make it worse, I don't think he wants to know. He's quite happy going along on his own sweet way. My big worry with him is, they've said he shouldn't drive, and I don't want him to drive quite frankly, and er, we've still got his car, he won't get rid of it, 'I might need to drive it', how can you, how can I turn around and say 'no you won't, you mustn't'? I've just got this awful fear that he's going to get into the car one day and he'll go off. But I can't do much about it, if I'm not there, can I?

R: hmm, so what's stopping him driving at the moment then?

P4: I don't, I think he must know that he's not up to it. I think his eye sight has gone down, well I know it's gone down terribly, um, to do with the diabetes, in fact we're going on Tuesday to have some more laser treatment, and I wonder if in his mind he's thinking 'I can't see properly'. But it's um, I don't think he's got access to the key now, I managed to find it in his pocket one day (laughs), but if he says to me 'I want the car, can we get it going?'

R: have you thought how you might deal with that?

P4: I don't know. I think wait until it comes, it might not happen. Well actually the battery's so flat it won't go (R: right)(laughs). But he, he's got one of those jump things to get it going, but while it's in the garage

just leave it

is it expected to be bad, just wait
is it possible
protective partner sense of competence
deep down he must know he's not right
access is not going to help

don't think he wants to know - denial
protective partner sense of competence
avoidance
worry about challenges to partner
advice from peers
avoidance
worry about challenges
same narrative as other in-law escape
and disapproval into fear (25)

belief that husband is aware inside
impact of other illnesses
fear of wild - consider what he is
other barriers in his place
fear of confrontation

avoidance, denial (318-331)
adjustment - accept as he is

adjustment
protective partner - sense of competence
322-331, 387

protective partner sense of self
adjustment - agree down with him (316-8)
challenges to adherence to medication (328-40)
avoidance, denial - powerless (328-43)
narrative of rejection (341-43)

awareness - make sense (347)
make sense - aggressive, his experiences
power - directive, indirectly (351-3)
fear of confrontation (352-7)

wait until it comes, might not happen
determination (similar to father-in-law
being determined to escape the
house)

forget a time - might not happen (352-7)
power - directive, indirectly (352-8)
narrative - parallels (357-9)

APPENDIX E

EXAMPLES OF MEMOS

From Participant 4: pages 4-9 (lines 122-359)

5.8.2 Code note: take each day as it comes

08/11/2004 16:51

Line 193-99

Participant 1, Participant 2, Participant 3 also emphasise how they are now taking each day as it comes. This seems to be more that a generational issue, in that participants talk in terms of putting many of their plans and dreams on hold. This theme links in with denial, talk of being on an even keel where taking things a day at a time may give the impression of being on an even keel, and may blind people to change to a certain degree. This may also relate to what Participants 2 and 3 said when they introduced me to their husbands about people wouldn't notice that their husbands were struggling, whereas when I met their husbands it was clear that they were (of course it is likely that their husbands would relate more freely to people that they know and therefore their difficulties may well be more hidden) – the point being that taking things a day at a time may help in that 'reality' can become quite distorted and therefore minimise a sense of loss. In terms of literature, would be helpful to consider gerontology literature on the way in which older people view day to day life.

5.8.3 Theoretical note: shifts in power

13/11/2004 18:07

Line 336-343

Participant talks about investing considerable energy in avoiding bringing her partner's awareness to his difficulties. Her task is to enable him to go along in his own sweet way. The thought of challenging him terrifies her, for example in relation to driving, but at the same time she is clearly having to adjust to a position where she is in control of both of their lives. She has to put aside her own needs, in the way that P2 talked about, to allow him to do things his way, in contrast with P3 who took much more charge of the situation and allowed husband to fit in with her. Taking on powerful position is clearly an issue that all of the participants struggle with to a certain extent, particularly in this case where previously husband made all the decisions despite P4 coming across as someone with a great deal of strength of character. Power seems to be accrued sometimes in a 'deceptive' manner in order to protect husband. At the same time she is feeling quite powerless in the face of dementia which she has had previous experience of, and in terms of having to revolve her life around her husband. So, have a look at references on power in relationships and to what extent this fits with theoretical issues.

5.8.4 Operational note: uncertainty / use of rhetorical questions

07/11/2004 11:32

Line 236 – 237

Throughout the interview participant is asking me what I think, whether I am in agreement with her approach / her understanding of things. It felt difficult within the interview situation to deal with these questions, which on reading the transcript often seem to be rhetorical as she frequently does not wait for me to respond or talks over my response. This could reflect her lack of opportunities to sound out her 'story' with others, and in the process of constructing a narrative that makes sense to her (re-look at Neimeyer references on research subjects presenting preferred narratives in the interview context). She may be asking for permission to talk in a way that would not normally be socially sanctioned (→ Tina Miller references on dominant narratives and getting under these to participants lived experiences). I need to find a way of dealing with these rhetorical questions and sense of uncertainty in the follow-up interview, and provide a context whereby she can talk freely rather than being constrained by what she thinks is a socially acceptable way of talking about her experiences → supervision.

APPENDIX F

INITIAL CODE LIST (codes are not exclusively put into one category)

PROCESS NOTES:

Reflexivity (11-13) depends what you want to know

Defines what will be of interest to me (45)

Got a bit deep (706), is it of any help (711), yacking on about me (764)

Narrative structure - metaphors (398-405)(593-99) = old house

History repeating itself (476-86) = escape

NARRATIVE DISRUPTION

Existential coordinate - one of a series of health related blows (18-23)

Diagnosis means its there in black and white / no going back (165)(173-7)

Becoming aware - subtle changes (52-54)

Confirmation (70-72)

Emotional impact (165-77) low and daunted

Life stage transition - loss of retirement (583-88)

Narrative disruption - usually happens later on (660-3)

MAKING SENSE / SEARCH FOR MEANING / MEANING MAKING / PROCESSES

AD in the context of health problems (18-23)(515-7)

Need to make sense (cannot wait on NHS waiting list)(95-99)

Disclosure (106-9) = confirmation

Not adhering to medical advice (338-40) = driving → presence of doctorhood

Symptoms

Loss of initiative - does nothing (260-9)

Slowness (305-7)

Memory (449, 454)

Aggression (464-66)

Making sense / interpreting symptoms (27-30) (38-40) (45-51) (58-65) (220-3) (311-14)

Interpreting behaviours as won't speak concerns (417-23)

Uncertainty (27-30) (38-40)

Disintegration / fragmentation (27-30) symptoms may be due to one of a number of bits, as reflected by the health care system (208-12) = wobbles

Confirmation (153-5) I knew because I went through it before (70-72)

(In context of partner's personality (305-14) (411-5) and shared history (411-2)

(AD springs from unresolved grief (718-53))

Making sense through partner's reactions - in fact on how she manages loads

Denial / switching off (122-30)

Transgenerational patterns of coping (134-38) parents coped exactly as he does

Awareness? (347) insight (540)(544-52) empathy / insight (552)

Making sense of own ability to cope (564-71) = thankful able to cope → social comparison with older people who were frail and interdependent

Making sense in context of life stage transition (583-6) = retirement

Making sense in context of a life history ruled by illness and from which she has not been able to escape (619-31)

social comparison

making sense of own ability to cope

social comparison

making sense in context of a life history ruled by illness and from which she has not been able to escape (619-31)

social comparison

making sense of own ability to cope

social comparison

making sense in context of a life history ruled by illness and from which she has not been able to escape (619-31)

social comparison

making sense of own ability to cope

social comparison

making sense in context of a life history ruled by illness and from which she has not been able to escape (619-31)

social comparison

PRELIMINARY THEMES FOR PARTICIPANT FOUR

MAKING COMPARISONS

Social comparison - emphasising difference (3-9) - setting interview agenda

Acknowledging the limitations of social comparison as dependent on context (496-508) → social construction of AD??

Noticing the signs (45-51)

Comparing historical context with father-in-law (49-52)

Comparing his with father's behaviour (58-65) (219-27) (318-9) (470-1)

Medical messages (114-7) = early stages

Comparison with older people - usually happens later (564-79)(654-58) = questioning how one should feel at this age

Comparison with previous caring experiences (475-494) = father in law (491-3) = might be different this time (512-7) (519-24) = at least there were people around me before (637-44) = in comparison now alone and without hope

Interpreting omens from the past (491-4)

Illness model - physical / psychological (166-9) [compare with medical segmentation discourse]

Social construction of AD (430-440) = recovers under right circumstances

Loss - uncertainty (425-440)

Having to live in own world (701-2) that is not of her choosing

Existential questioning (665-96) want to believe but difficult - try to avoid confronting nothingness

Existential questioning (544-52)(54-9)(586-88) = questioning life choices (Also under narrative reconstruction)

Reasons to live (700-6)

KEEPING ON AN EVEN KEEL = Adjustments

Importance of even keel → hoping that its not getting worse (197-99) 'wobbles' (206-8)

Hoping to keep on an even keel (389-393)

Lets not rock the boat (454-6)

Hope - role of medication in sustaining hope (197-99) (198-204)(431-445)

Day at a time - it might not happen (352-7)(651-5) = try not to think forwards

Messages from the past - rough with the smooth (686-90)

Lets just keep going (695-6)

Minimising impact of the AD in comparison with other health problems (19-20) [control?]

Problem-focussed coping - acting quickly (45-54) (167-71)

Constraints of the system - waiting lists (95-99)

Just got to crack on / avoid emotions (146-8) get rid of emotions (716-8)

Minimising grief / resentment (153-5)

Re-framing (282-8)

Revitalising self (603-7)

Needing social support (182-85)(526-36)(716-8)

Becoming a caregiver - no use feeling sorry for yourself (169-71)

Role identity - have to cope (182-5)(193-6) there's only me isn't there?

MAKING COMPARISONS

Social comparison - emphasising difference (3-9) - setting interview agenda ✓
 Acknowledging the limitations of social comparison as dependent on context (496-508) → social construction of AD? ✓
 Noticing the signs (45-51) ✓
 Comparing historical context with father-in-law (49-52) ✓
 Comparing his with father's behaviour (58-65) (219-27) (318-9) (470-1) ✓
 Similar narratives (341-3) - father disappearing fear of him doing the same ✓
 Medical messages (114-7) - early stages ✓
 Comparison with older people - usually happens later (564-79) (654-58) -
 questioning how one should feel at this age ✓
 Comparison with previous caring experiences (475-494) - father in law (491-3) - might be different this time (512-7) (519-24) - at least there were people around me before (637-44) - in comparison now alone and without hope. ✓
 Interpreting omens from the past (491-4) ✓
 Illness model - physical / psychological (166-9) [compare with medical segmentation discourse] ✓
 Social construction of AD (430-440) = recovers under right circumstances ✓
 Loss - uncertainty (425-440) ✓
 Having to live in own world (701-2) that is not of her choosing ✓
 Existential questioning (665-96) want to believe but difficult - try to avoid confronting nothingness ✓
 Existential questioning (544-52) (554-9) (586-88) - questioning life choices (Also under narrative reconstruction) ✓
 Reasons to live (700-6) ✓

KEEPING ON AN EVEN KEEL

[Importance of even keel] → hoping that its not getting worse (197-99) 'wobbles' (206-8) ✓
 Hoping to keep on an even keel (389-393) ✓
 Lets not rock the boat (454-6) ✓
 Hope - role of medication in sustaining hope (197-99) (198-204) (431-445) ✓
 Day at a time - it might not happen (352-7) (651-5) - try not to think forwards ✓
 Messages from the past - rough with the smooth (686-90) ✓
 Lets just keep going (695-6) ✓
 Minimising impact of the AD in comparison with other health problems (19-20) [control?] ✓
 Problem-focussed coping - acting quickly (45-54) (167-71) ✓
 Constraints of the system - waiting lists (95-99) ✓
 Just got to crack on / avoid emotions (146-8) get rid of emotions (716-8) ✓
 Minimising grief / resentment (153-5) ✓
 Re-framing (282-8) ✓
 Revitalising self (603-7) ✓
 Needing social support (182-85) (526-36) (716-8) ✓
 Becoming a caregiver - no use feeling sorry for yourself (169-71) ✓
 Role identity - have to cope (182-5) (193-6) there's only me isn't there? ✓

PARTICIPANT FOUR

No choice - he couldn't cope (287-94) ✓
 Entering role alone as guilt about involving daughter (193-4) ✓
 Role adjustment - fears (195-7) ✓
 Defining role - watch like hawk vs step back (229-33) (241-2) (244-9) safety (535) giving him his own space / QoL (538) ✓
 Managing uncertainty about how to support him (232-7) ✓
 Questioning ability to cope (482-6) guilt at not coping with father (485-6) (512-5) - 'they' took him off our hands to claybury ✓
 Aloneness / lack of everyday support (522-4) - LOSEN ✓
 Taking on new role (398-405) - loft ✓
 Monitoring wellbeing / vigilance (211-7) constantly worrying about him (251-6) ✓
 Independence / dependency ✓
 Facilitating a sense of independence (215-9) - dog walking (229-237) - watch strap (534-40) - leave at home alone ✓
 Dependency fears (540-44) - from husband's perspective ✓
 Taking control (95-99) 'I' decided that he needed medical assessment ✓
 Power / control (282-94) = at least I'm in charge (351-3) and (357-8) - directing ✓
 indirectly (370-5) - not taking things away from him (375-80) and (382-7) - him relinquishing role (482-4) = discomfort at locking father in room ✓
 Having to go at his pace (307-11) going along with him (336-38) - powerlessness? ✓
 Avoiding invalidating partner (122-30) (134-8) transgenerational coping styles ✓
 Protecting partner's sense of competence (327-87) - car narrative (530-4) - leaving him alone in house 338-40 → not okay to medical control ✓
 Avoiding conflict (266-74) i.e. not being assertive (318-31) (338-43) - powerless (352-7) - fear of confrontation (377-80) = dreading conflict ✓
 Avoiding thinking about the future (195-7) take each day as it comes ✓

NARRATIVE RECONSTRUCTION

Re-constructing the future in light of diagnosis (70-72) this is where we are heading ✓
 Parallel narratives with father in law (341-3) - disappearing one day (357-9) = determination to do what they want and her being powerless to stop it (476-86) - MD5 story ✓
 Conscious of what is up ahead → impacts on her behaviour (244-9) ← 'early stages' (114-7) ✓
 Narrative repetition - history repeating itself (122-30) (153-5) (488-94) - this is what I've got to go through all over again ✓
 My life has been ruled by illness (619-26) have not managed to escape mindng someone ✓
 Except it will be worse this time around (519-24) ✓
 Social comparison - Feel I do everything now, that's normal (282-3) ✓
 Tragedy narrative (282-8) what's next sort of thing (633-5) (648-9) ✓
 Existential questioning (544-57) (554-9) (586-88) - questioning life choices ✓
 Life stage transition (536-9) ✓
 This is the beginning of the end (637-49) ✓
OTHER (LESS OF INTEREST)
 Medical intervention - tests / medication (81-93) (103-9)

PRELIMINARY LIST OF THEMES FOR PARTICIPANT TWO

1. NARRATIVE DISRUPTION

EXISTENTIAL COORDINATES

Becoming aware / denial

MAKING SENSE OF THE DIAGNOSIS

Social reactions to diagnosis / stigma

Partner's reactions to diagnosis

Interpreting professional discourse

Illness models

Life story review - patterns

Making social comparisons

Making comparisons (child/ physical/ past and future self/ STM LTM)

Acknowledging loss

2. NARRATIVE RECONSTRUCTION (COUNTERING DISRUPTION TO SENSE OF CONTINUITY / STABILISING)

UNCERTAINTY / STABILITY / HOPE

MINIMISING SENSE OF LOSS

Denial / avoidance / self-pity / normalising / displacement / avoiding situations where loss apparent

Sense of rejection / stigmatisation

Making social comparisons

Focussing on good life lived

Hope – medication

MAINTAINING PARTNER'S IDENTITY – AVOIDING INVALIDATION

Protective shield

Focussing on competencies

Avoiding situations where he will become a different person (frustration)

Redefining social boundaries – family lifecycle – avoiding stigma

MAINTAINING OWN SENSE OF IDENTITY

Feeling valued / competency

Coper

EXISTENTIAL REVISION

Accepting growing old – in context of life story – physical limits / shifting priorities

Re-defining 'supporting cast'

Sacrificing own needs / revising perceived needs

Maintaining a sense of self / competency

Revising priorities - Relaxing attitude to life

Sense of purpose

ROLE ADJUSTMENTS

Preserving relationship / Emphasising interdependency / partner not carer

Being placed in role by others

Learning / comparison with previous roles

Directing / shifting power balance within relationship / interpreting

Accepting responsibility / resentment

DEPENDENCY / INDEPENDENCE

DEPENDENCY FEARS

INTERDEPENDENCE

ACCEPTING SUPPORT FROM OUTSIDE

ISOLATION

SENSE OF CONTROL

PRELIMINARY LIST OF THEMES FOR PARTICIPANT THREE

5.9 A. NARRATIVE DISRUPTION

5.10 *ONSET*

5.10.2 REINTERPRETING EXPERIENCES IN LIGHT OF DIAGNOSIS

PUTTING A NAME TO IT

VALIDATING / INVALIDATING

Making social comparisons

Drawing on lay expertise

Going along with professional expertise

Adopting professional discourse

B. RESTORING NARRATIVE COHERENCE

5.10.3 MAINTAINING A SENSE OF STABILITY

Accepting fluctuations

Looking to the future

5.10.4 PLACING EXPERIENCES IN CONTEXT OF LIFECYCLE

Family lifecycle / Old age / Acceptance

5.10.5 COMPETENCY

5.10.6 INDEPENDENCE / DEPENDENCY

5.10.7 IDENTITY MAINTENANCE

Maintaining own identity

Maintaining partner's identity – focus on physical not mental, social validation

Resilience

5.10.8 MINIMISING SENSE OF LOSS

C. ADJUSTMENTS

UNILATERAL ADJUSTMENTS

Gender differences

POWER BALANCE

Aided by memory loss

Gender issues

Keeping them going – distancing / Directing

Taking on responsibility – mobility / social network

LEARNING FROM EXPERIENCE

Making mistakes

Past roles

INTRAPERSONAL ADJUSTMENT

Compromising – own needs – avoiding conflict

Independence / dependency – being curtailed

Public / private – maintaining social identity

REDEFINING SOCIAL BOUNDARIES

Taking part in research (Linda Clare)

Being validated socially

REWARDS / DEMANDS

Validation

Exhaustion

PRELIMINARY LIST OF THEMES FOR PARTICIPANT ONE

DESCRIPTION OF PROBLEMS

Forgetting - Short-term vs long-term
Forgetting in everyday situations
Emotional impact on partner

(Husband's insight / frustration / fears about memory difficulties)

CONTEXTUALISING PROBLEMS

Forgetting comes with ageing
 comparison with own everyday memory 'slips'
Joint life story
 Expecting her older husband to be the one to develop problems first
Expecting illness in later life despite preventative measures
At least it didn't happen sooner (minimising impact)
 Reflecting on life story (we have been lucky really)
Changes in social attitudes towards older people (e.g. loss privileges)

IMPACT OF DIAGNOSIS

Expectations of consultation
expecting a diagnosis of AD
surprise at being taken seriously / given expensive medication (age)

'Going looney' vs 'it doesn't really matter' (Denial)

Construal of the future

Avoid thinking about the future – day at a time
Future as continuation of past (will go back to walking the dog once the dog has recovered)

Relationship / Shifting roles

Taking on responsibilities (e.g. making sure bills are paid)
Taking on responsibility for anticipating husband's difficulties and preventing them from happening
Emphasising that they remain on the same wavelength
Husband loss of personhood / autonomy / privacy – going public (husband going for consultation with GP alone, but not seen alone by psychiatrist)

Social network

Fear of being pitied
Fear of becoming a burden to others
Fear of other people perceiving / relating to husband differently
Safe vs dangerous disclosure of diagnosis to others
 Testing the water with far away people and neighbours
Withdrawing socially

Support

Medical – consultant / GP (at least we have them)
People will not care - will avoid asking for support
Not much others can do to help (practical help only)

Emotional impact

LOSS / DENIAL (including not wanting to take part in research)
 Avoid articulating fears
Avoidance – prefer to keep my head in the sand
 Hope vs hopelessness
 Ambivalence about medication
 Efforts always thwarted (e.g. Ginko story)
Relief from guilt (at least we are doing all we can about it / at least we acted quickly) - responsibility
 Power / Powerlessness
 Fear of pity

Protecting selves against people not caring – expectations
Preventing husband embarrassment / frustration / despair

Coping

Psychological importance of medication (hope / relief / focus)
Determination – deal with what life throws at me
Day at a time
 Avoid thinking about the future
At least it didn't happen sooner
Reflecting on life story (we have been lucky really)
Personal qualities
 Humour / patience

Comparisons

With 'Dementia' – at least it is not dementia
With 'Heart disease' / 'c word' – expected one of these
Social comparisons with friend without a diagnosis but with 'dementia'

MAINTAINING PARTNER'S COMPETENCE / IDENTITY

'intelligent man'

Evaluating his performance during consultation – emphasising the intelligence test aspect of assessment

 Continue reading newspaper from cover to cover

 Preventing situations in which he might forget

Rescuing partner in social situations

 Avoiding social embarrassing situations (dog as excuse)

 Protecting partner from being seen differently by friends

 Dilemmas of disclosure to friends and family

 Social competence / popularity / sociable

Making excuses for social withdrawal (walking the dog / going on holiday)

NARRATIVES

Narrative Structure - stability narrative

Life is continuing as always – changes (e.g. not going on holiday, no longer going on walks by self blamed on other circumstances)

Maintaining narrative of life where illness will occur and be dealt with in later life

Illness stories / public narratives

Done all we can to protect ourselves from illness in later life

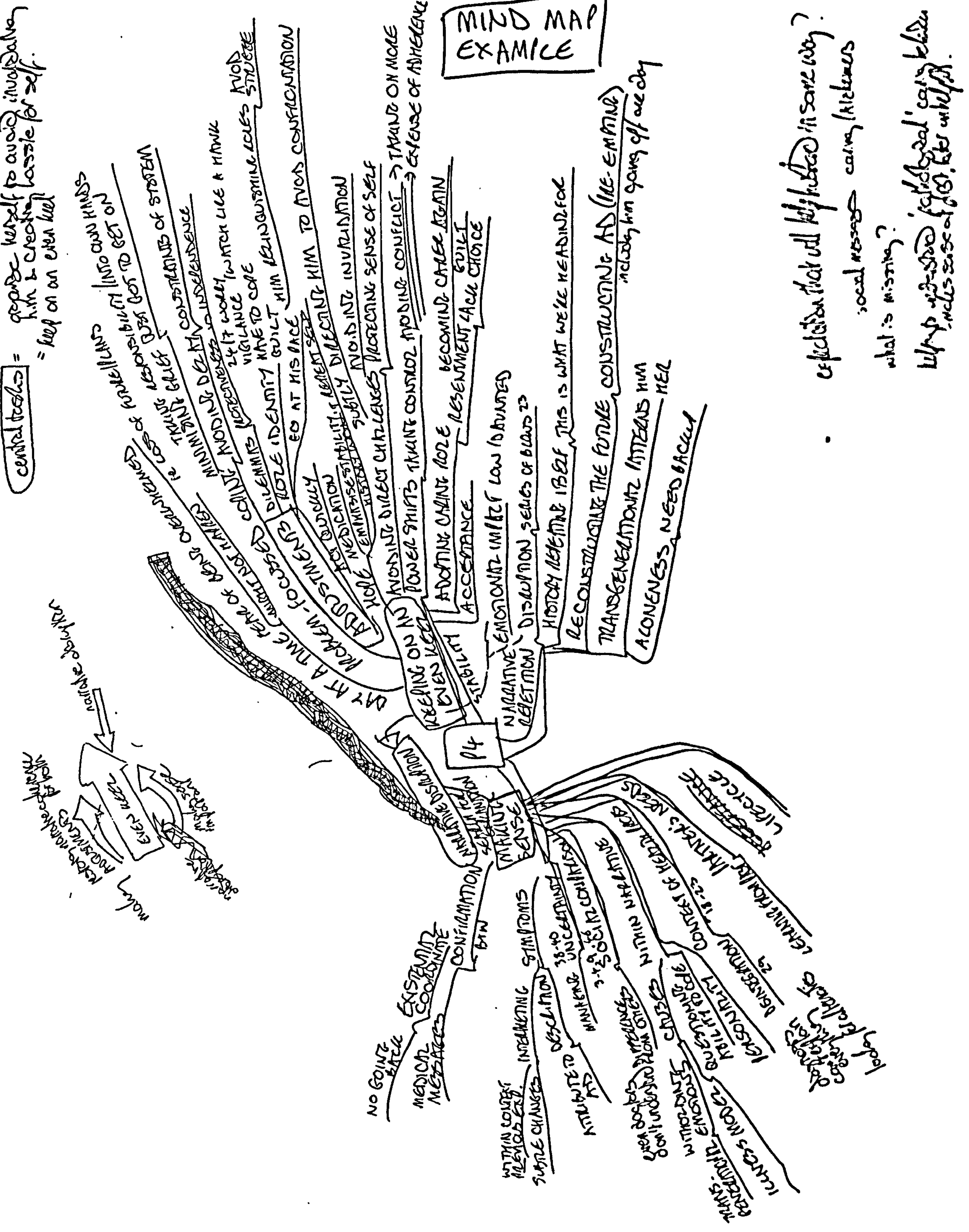
People won't care

Pity

 Hope vs Hopelessness

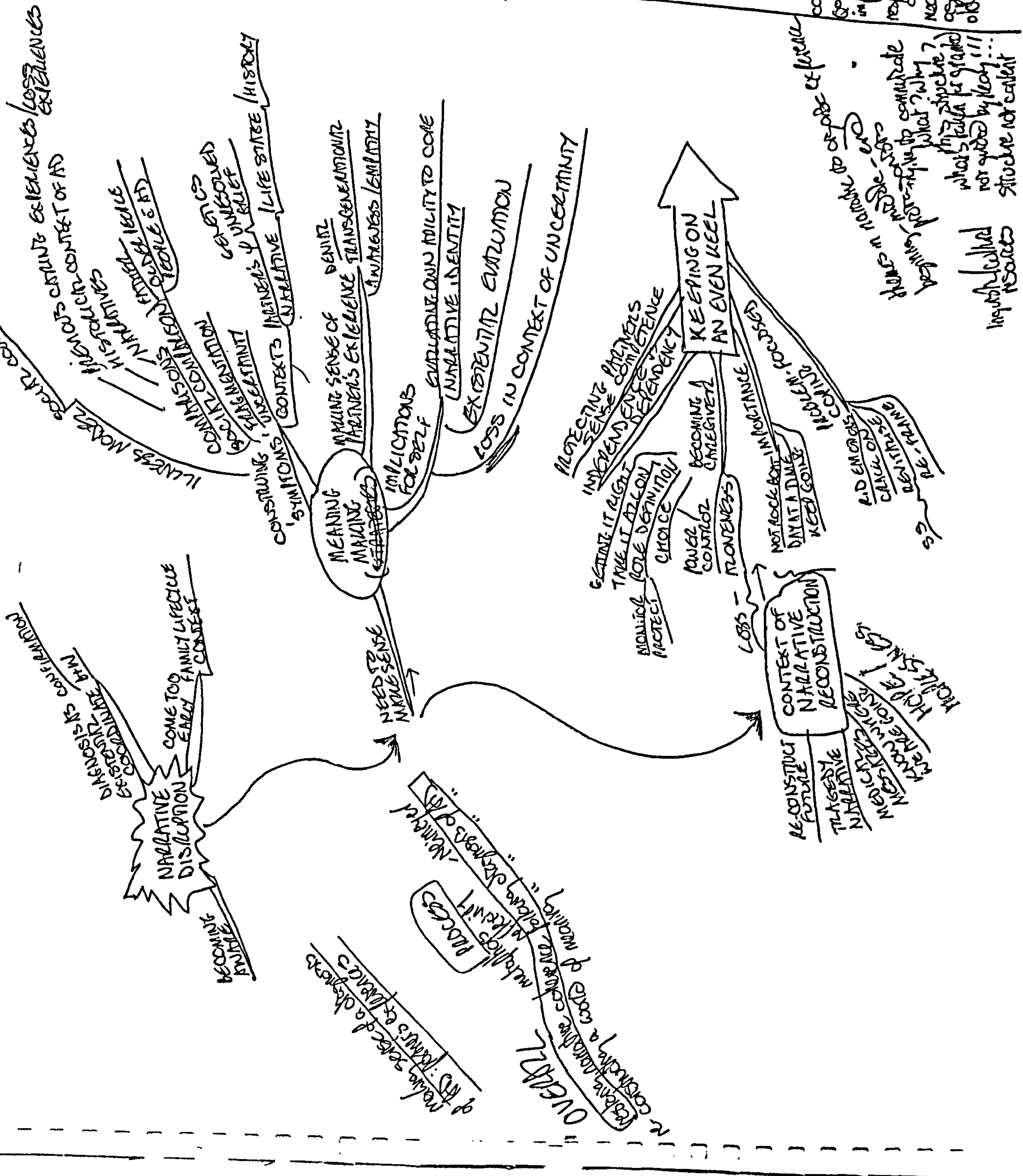
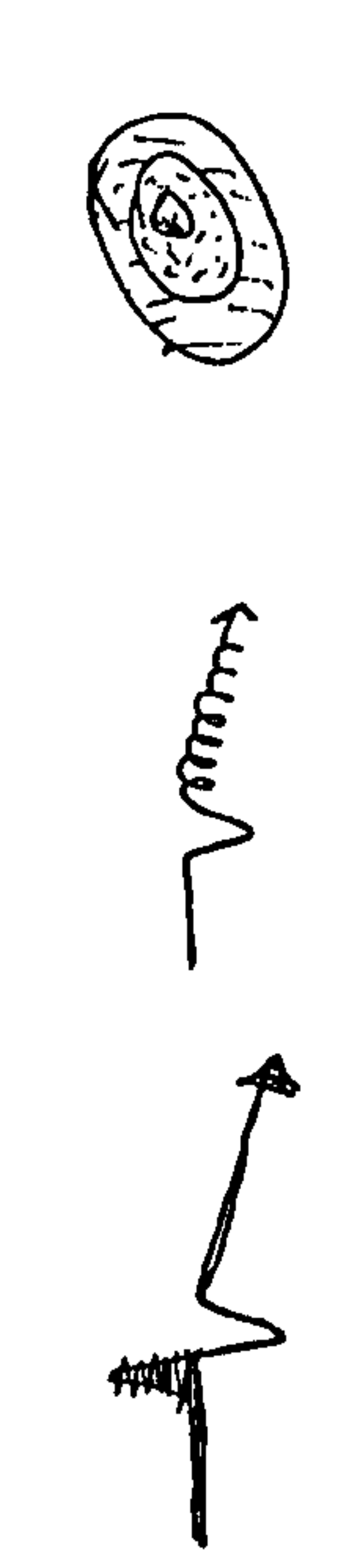
central thesis = regard herself to avoid involving him & creating hassle for self. = keep on an even keel

MIND MAP EXAMPLE



expectation that will help husband in some way?
social messages carrying messages
what is missing?
help up with school 'physical' carry blame
includes sense of self, later with self.

Steebe + Shore + Seemeyer + 14 17/11/04



- 12**
- SIMILARITIES DIFFERENCES 1-12
- SOCIAL AFFINITIES → social context AC
 - MORE HIGHLIGHTS → narrative reconstruction
 - LOSS - MINIMISING → narrative reconstruction
 - POSITIVES - VALUABLE ASSE → avoid
 - RE-DEFINING SUPPORTING CARE → avoid
 - FINDING ALTERNATIVE ROUTINE
 - PRACTICES IN LIFE →
 - MAINTAINING INTERDEPENDENCY → own needs
- OTHERSIDE - SIMILAR THEMES!

- 13**
- VARIATING INVARIANTING DIAGNOSIS → medical messages
 - MAINTAINING SOCIAL IDENTITY
 - RE-DEFINING SOCIAL BOUNDARIES
 - OPTIMISE v. SIMILAR
- 11**
- PROTECTING FROM SOCIETY
 - MEDICIZ MODEZ - MAKING SENSE OF MEDICAL MESSAGES

MIND MAP EXAMPLE

- 14**
- NUMBERS - shown = especially idiosyncratically
Necessitates a basis of meaning & sense
coherence to the narratives of our lives.
- SIMILARITIES + DIFFERENCES IN COING
- distance
- P1
 - P2
 - P3
 - P4
- copying
impact of
diagnosis
refers to
senses
Medical model
other husband frame
age

EXAMPLE OF GROUP THEMES WITH IDENTIFIERS

<p>UNILATERAL ADJUSTMENTS Taking on more - loss of initiative</p>		<p>I've got to get used to him as he is, cannot expect him to be any different (207-9) Putting own health issues to one side (339-41) Impact of caring → exhaustion (4, 29) grr's wonderful - patience (90/11)</p>	<p>accepting own abilities will be curbed (20) boat trip everything handled (347) play to go and look re-think things.</p>	<p>Taking on everything now - that is normal (264-83) Taking on new roles e.g. loft (398-405) Monitoring wellbeing / vigilance (211-7) constantly worrying about him (251-6) Having to go at his pace (powerlessness) (307-11) Going along with his own sweet way (336-8)</p>
<p>POWER BALANCE Power / control Gender issues Avoiding conflict → power and powerless Driver = male role</p>	<p>allow him to keep driving taking on his role (305-310) avoid pity ie empowerment (421) in relation to avoid burden (421-3)</p>	<p>Friends speak to her, but not to him now (79-80) Don't always agree now - loss of negotiation within relationship (215-7) Decision to take action here (2) Becoming vulnerable - need to protect him (2, 102) Can be furious with him but not his fault - cannot express anger with him as he forgets → feeling powerless, subversive tactics (217-222) Don't like to trust him lighting fire - not safe - don't let him (50, 308) Making decisions by self - car</p>	<p>decision to get single leads to he has to be (226) adjustment with (237) he has to put up with (236-8) L (243-4) change in women can adapt (110-2) merge about with day Directly (19) find employment stamp (18) don't want to take away (10) independence (10) keep him going - intellectual stimulation (97-102)</p>	<p>Up to me to give him quality of life (338) Taking control - I decided he needed medical assessment (95-99) At least I'm in charge (351-3) Directing him indirectly (357-8) Not taking things away from him (375-80) ie power to do so He relinquishing power (382-7) Discomfort at locking dad in room at night (482-4) Having to go at his pace (powerlessness) (307-11) (336-8) Not feeling able to challenge him leads her into a sense of powerlessness</p>

7th Jan present CM2600

→ also disclosure

<p>ILLNESS MODELS / INTERPRETING PROFESSIONAL DISCOURSE</p> <p>experiences of disclosure</p> <p>experiences of disclosure</p> <p>experiences of disclosure</p>	<p>* evaluating his performance in medical consultation - he went to see help left only end of obses as performance (97 → 117-20) → becoming center of attention into power of professional suspect at being seen quickly & taken seriously (97-107) aware of stress (241) * nothing anyone can do except accept him (258-66) Didn't expect female consultant (351-3) likely have been taken seriously vs negative news of Mrs's diagnosis - we'll get lost in system - all we really got is pills - ie not much they can do (make her presentation to his response) (359-366) positive experience of NHS in light of - the expectations (377-81) alternatives Gino for admin against trust the doctors (439-58)</p>	<p>Interpreting medical discourse e.g. she's pleased with him (18), coming back in 6 months is a good sign (20) 29 (v. 1200) Their job is to keep his brain ticking over (139, 141) i.e. not her responsibility therefore avoids invalidating Social comparison - people worse off than him should be at the day centre (2) - a good sign when he was discharged Head scan reinforces its in the mind (300) X You're a carer now (194, 279) Heart bypass / diabetes caused the AD? (40-44) media message It's a brain thing, not like a broken leg (62) It's that his brain is losing things - nothing they can really do about it (290) i.e. adopting a medical discourse, more than other participants he's my husband Being told that she is now a carer - challenges in own mind but goes along with it (195) it's delirious by use Fear of opening up a can of worms by going to the doctor (113) → leads to avoidance</p>	<p>don't believe label AD (4-)(13) they way better than (8) at unsure how diagnosis made then maths tests (45-6) AD with big A vs small a (48-51) swapt into system as he said I'm getting forgetful - medicalise (51-56) (→ pre-expressive carer) MAD - told others so they can back her up (130) (140-2) ADs who don't keep it (194) as it takes away from what's not sure if pills help - they take put him on them (162-72) not going to clinic would have made no sense - 1st time today (318-20) how it gets to you as a carer (33) what's difference between AD & dementia? (134/5) X won't kill him (144)</p>	<p>Difficulty of attributing symptoms to different illnesses - fragmentation - trying to explain as medical system attempts to explain (27-30) → interpreting wobbles (208-12) Unresolved grief caused AD (718-53) Physical / psychological when explaining own experiences (166-9) Social construction of AD - recovers under the right conditions e.g. with friend (430-40)</p>
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↳ experience of disclosure

APPENDIX G

VERBATIM QUOTES FROM PILOT INTERVIEW RELATING TO THE ANALYSIS

Verbatim quotes from a pilot interview was with a husband whose wife was in the mid stages of dementia, and who had been diagnosed with Alzheimer's disease several years previously.

today she would have been a teacher or what have you

then she went to [...] and then she had a family of two, [names], and then she, we ... and then, um, she returned to work, doing part time work when the children started grammar school, and then she worked in, started off as a clerical officer, and then she finally worked up over the years ended up substituting as a high executive officer ... so she's quite a clever girl

after that we retired, we did a lot of rambling and walking ... and then, she did lots for charity, she did the day centre ... that's what I forgot to say she did voluntary work at the day centre, she helped at a school, did, er, did reading ... she did lots for charities, she did a lot else.

she was ... lively, always a smile, you know, a happy person, a very happy person

first concerns were when she, um, repeated questions, you know, she kept asking if the... if the... if the grandchildrens and um the childrens, our childrens and the grandchildrens, she kept saying, she kept repeating the question again, you know, and then, what really precipitated it was when she went in for um, a varicose vein operation, and you know of course you're not supposed to have anything to eat or drink, so I took her in at a quarter to eight in the morning, left her up there, went back at 12 and they said 'we asked her if she'd had anything to eat?', and of course she said 'oh yes', and then 'what day it is' and she didn't know ... and then they said we can't do anything they rung the doctor who spread from there, you know

R: do you remember how you kind of made sense of that at the time?

I: probably just thinking she's getting elderly, that's all

We went to the hospital, and after the brain scan they said it was Alzheimer's ... but it really didn't sink home, you know Alzheimers, it's sinking home now, because of the, you know, all the, you know, all the things occurring, you know (pause) she's actually on Aricept, which is prescribed

R: you were saying its only beginning to sink in now?

I: yeah, really, well, because of the work involved ... undressing, dressing, um ... sit there whilst she goes to the toilet, make sure she goes to the toilet, listen to her go to the toilet, things like that, so of course you go to bed at night, put a pad on her when you go to bed at night, wake up at 9 o'clock in the morning and she goes to the toilet again, and um ... feeding her, and then she has a cup of tea now, and I finish up, someone suggested give her a straw, which I do... and she finishes up at teatime when she come home today with a straw, I try to make sure she has 4 to 5 cups a day, you know

she's never accepted she's got Alzheimer's like that, I know people that know they have it, you know, a friend of mine, well she knows, she admits to it, you know, and talks about it, [wife] would never be like that

They just came out with it, they were saying 'I'm afraid it's Alzheimer's', it's the only way to do it really.

rather attractive, skirt up here, I remember she was a very attractive woman, you know, 'you've got Alzheimer's', you know, it meant nothing to her at all, you know, she's gone somewhere else, I never see her again

it really didn't sink in at all, you know ... it didn't really, it wasn't ... I've never seen the film 'Iris' or anything like that so it didn't sort of (short pause) I didn't really realise it was going to be this, well this terrible disease, its, you just see them going right in front of your eyes, they're not the same person obviously ... the doctor, you know, er ... he said and I think he said the Alzheimer's word and he said 'good luck to you', and he got hold of my arm, you know, he was probably well experienced at this and said 'there's going to be a lot of trouble to come'

I had no support, really no support from him at all, and that was the GP, you know, you read the books and they say you get support from your GP and all that, but no, I (emphasis) don't.

not really much changed because we, we kept walking, didn't go out with the Ramblers but we kept walking, doing our own walks, you know we ... we went on walks together, you know, obviously it'd be just her and I and we just kept on, you know, just doing walks, and once you keep walking and that's what's kept her going up until now, and its now deteriorating now and this stage, well it's past that stage but we did keep physical activity up And make light of things, you know, and we, er, we had, she had a good laugh sometimes, we always laugh on occasions at some silly little thing

as I say, she's quite happy, if you spoke to her now she, if you met her now and spoke to her you could get away without realising she's got Alzheimer's, but she's got serious Alzheimer's (laughs)

never has accepted it ... I've never said to her 'you've got Alzheimer's' obviously, but there's always literature around the place ... she still reads but it doesn't mean anything to her, you know, but she still does

when you go to the Alzheimer's meetings you can see people more advanced that are like this

friends are helpful, when they take her out to like to and play scrabble and things like that, you know, and are very friendly and er that's what's helpful

she loves it there but I don't think she reacts to other people at the other place, she doesn't It's, it's a different clientele you know.. it's er, it's old people you know, dotty old people

the district nurse was going to call one day and never did ... that was really upsetting

that's been pretty awful having to dry her dress out clean her off what have you and er, that's, that's ... that's about the worst because psychologically you're up here and then all of a sudden you fall and boom, like that, it really is, it's, um I'm realising now that I'm really (?) and thinking, go on, you look after her totally

but you can never say with Alzheimer's because ... er ... er .. um incontinence and messing her pants, you know when I said to my friend whose got experience of it, that's just what occurs, you know, you can never say whether it's going to be 3 o'clock on a Wednesday afternoon or something, or two hours after a meal or something, it's just, it's just occurs and that's the end of it

I mean, it's crazy, the cost of state help, if she was in a home it would cost 600 pounds a week, you know, a friend of mine up the road he got rid of his assets when she was first diagnosed and I didn't do that you know, and now I've been lumbered, but money's nothing now is it (laughs)

you pick up things as you go along you know, and er, I don't know, friends, I've we've lost friends you know, thought they'd come and see her but we, we're all getting elderly and that's took some different things out of people (laughs), I've got a friend, his wife got a stroke and some other friends haven't

come along and things like that (short pause) the telephone don't ring like it used to do, it's a bit like that (laughs) ... you're friends don't come so much because that's part of being elderly as well, you see, because that does, that does occur but I mean it's obviously going to occur isn't it

R: so do you see that as part of being elderly or ...

I: Alzheimers, well it's both ... people don't really want to know, do they? They're all very, they're all going to help you know, and , er, they would if you got pushed but (short pause) what are they going to do, I mean I'm all right at the moment

my brothers wife had alzheimers and er, she went into a home quite early and I can understand why they did, she was left to die there in there in the end, and of course they're not going to say you cant do it, but I think something like that will happen to [wife]

R: a lot of people would really struggle and I'm just wondering what is it that's kind of helped you?

I: well I think it's pre-planning, I mean I always have the plates and cups ready for the dinner, and (pause) the dishes filled up out there with muesli during the week for breakfast, and it's already in the dish, the porridge is already in the dish, I'm always in front all the time, it's the only way that you can get on really

she's getting really more distant with time, its not the wife that you knew obviously

it didn't, it didn't register you know, everyone was saying 'poor sod' and this sort of thing you know, but we didn't really have any contact with alzheimer's before, until now, you know

it didn't mean much, no, because I looked in the book and it didn't, they got (pause) one of these self, medical doctor things and it just said (?) but until you come into contact with it you don't know half of what happens really I mean and it, it's um (pause) you know, the obituary in the telegraph once it said 'rescued from the indignity of Alzheimer's' you know, and that's what it is, you know, indignified, undignified, you know and er they're not themselves are they?, I mean it's quite a reversal

she goes to the day centre now and I think she's going to help rather than be a patient

R: but it sounds like it's been, you know, you felt its been expected of you, you know, kind of services and stuff really they're not offering that much help unless you pay for it, and you're kind of expected to almost push yourself until you crack

I: that's right, til you drop, you know, until it knocks you out, and if you don't have any natural capability, then they'll say they'll take you into a home quite quickly, or something like that, you know

they don't address her, they address me when we're going down the road

R: so what's that like for you?

I: well it makes you think, well, you're on your own, you know, it's er, um Er, that's what it amounts to really, nothing else, you know, you've got to cope yourself, nobody else is going to do it for you so,

you read the books and they say the doctor comes up and sees you occasionally, but I think it's a question of perhaps who you're under, you know, simple as that, you know, I'm 75 and er, you're supposed to have your blood pressure checked, BY LAW, you know, and I never hear from him (laughs), it's just the quality you get with ... you know the practice nurse in [nearby town] they do it religiously for older people, it's where you are

this one on television was about 5 years, but she's been going 6 years, and I put down her long time, my OWN view is that it's because we kept walking, she's physically fit (...) its because we kept walking and its why things are going to go downhill from now

she's been a good wife, she's been an attractive wife, she's been a lovely wife and I always see her as though we're on honeymoon, you know, I've got a picture of us on honeymoon, she's (???) and she's slim and that's the way I see her

it's a slow death (pause) in my mind's eye all the time I'm thinking about her burial service and the hymns we're having and things like that which I've told her before, quite plainly this what's happening in my mind's eye, you know, I'm sitting like this and I'm 'do you like that hymn?' you know (laughs)

you're a carer now aren't you, a nurse, and that's all there is to it you know

Appendix H

Notation used within verbatim interview extracts

Symbol	Description
...	Brief pause
... (x seconds)	Longer pause of x seconds
(...)	Abridged sentence
Bold	Participant's emphasis
CAPITALS	Increased volume and emphasis by participant
()	Word/s on audiotape not audible / intelligible to researcher
(researcher's comment)	Researcher's comment to clarify a part of the unquoted interview to which the participant is referring
[job title, role, service]	Identifying name removed and replaced with descriptive information (e.g. role, job title, service) to protect confidentiality
(Mrs X, 13-19)	Identifying information so that quote can be located within the transcript (numbers refer to line number (Mrs A and Mrs D) or text unit number (i.e. sentence – Mrs B and Mrs C)

Critical Review:

Making sense of a diagnosis of Alzheimer's disease: partners' experiences

Overview

The present thesis reports on a qualitative (Interpretative Phenomenological Analysis) exploration of the experiences of partners whose husband had recently been diagnosed with Alzheimer's disease, reflecting a lack of in-depth research in this field as highlighted by a number of authors (e.g. Bamford *et al*, 2004; Bender, 2003; Nolan *et al*, 2004). In particular, the aims were to gain insight into how partners make sense of the diagnosis, and how the personal and idiosyncratic meanings that they develop relate to ways in which they cope with their situation. The results indicate that a key guiding principle for all participants was to '*remain on an even keel*' and protect their partners' sense of selfhood through the use of idiosyncratic intrapersonal and interpersonal psychological manoeuvres.

The aim of an IPA study is to gain insight into the experiences of a small and discretely defined group of participants, which can then be considered in relation to the wider population of family 'caregivers' in dementia. In this case, participants were all white, female, and living in a relatively affluent region of the country with relatively well developed services. It was hoped that the results could illuminate some of the evident shortcomings of the research literature, as well as inform current ethical and practical debates about diagnostic disclosure and how services can better understand and respond to the needs of family 'caregivers' in the early stages of dementia, a need which has been highlighted in recent policy initiatives (e.g. Department of Health, 2001).

The aim of the critical review is to critique the study with regards to methodological issues, to discuss possible clinical implications, and to consider issues that arose from the research process that may be of relevance to other researchers within the field.

Aims / research questions

The aim of the study was to gain insight into the experiences of participants whose partner had recently been diagnosed with Alzheimer's disease, reflecting a lack of in-depth research in this field, as identified by a number of authors (e.g. Bamford *et al*, 2004; Bender, 2003; Coleman, 1999; Levy *et al*, 2000; Nolan *et al*, 2004). More specifically, the aims were to gain insight into how partners make sense of the diagnosis, and how the personal and idiosyncratic meaning-making process informs ways in which they attempt to cope with their situation.

Given the lack of research within this field, the aims were fairly broad, guided by a framework which drew on constructivist, constructionist and narrative psychology paradigms. The emphasis was thus on the personal meanings that partners actively construct to make sense of, and creatively manage their situation, as well as how these are informed by socio-cultural discourses on dementia and care-giving.

Methodological issues

Design

The study employed a cross-sectional qualitative research design, using Interpretative Phenomenological Analysis (IPA) (e.g. Smith, 1995; Smith & Osborn, 2003) to analyse verbatim transcripts of in-depth semi-structured interviews.

The design evolved within the context of the time and resource restraints associated with undertaking a professional doctorate in clinical psychology. Under ideal circumstances, a longitudinal design would have been preferred, given the aims of the research. This could have facilitated a richer and more nuanced understanding of the process of adjustment and meaning-making in response to a diagnosis of Alzheimer's disease. A *prospective* longitudinal study would not have had the constraint of relying on retrospective self-report as a means by which to gain insight into how receiving a diagnosis affects people's perceptions of their situation. However, the use of such a design has clear resource and ethical implications, particularly in terms of recruiting people whose partners may not go on to be diagnosed with dementia.

A more general criticism could be levelled at research on family caregivers' experiences, in that the vast majority of research is based on cross-sectional data. Even where researchers have explicitly attempted to gain insight into the process of adjustment, for example Wilson's (1989) widely quoted stage model of the 'caregiving career', has relied on cross-sectional research design (Nolan, Grant & Keady, 1996). A number of authors writing from narrative and constructivist positions have argued that participants use interviews as a means of presenting a 'preferred narrative' (e.g. Miller, 2000; Neimeyer, 2002), which impacts on the validity of relying on retrospective accounts of people's experiences. One could of course argue that these preferred realities will have a strong influence on how individuals construct and actually cope with their difficulties.

A further potential advantage of using a longitudinal approach is that it would provide an opportunity for participants to reflect on their experiences between interviews, thus enabling them to communicate an increasingly rich, nuanced and self-reflective account of their experiences (e.g. Candey, 1999). This was found to be the researcher's experience where follow-up interviews were arranged.

Setting

Participants were recruited from a region in Essex with a population of 120,000 people living in urban and rural settings, ranging from deprived to very affluent. The vast majority of those living in the region are of a white-British ethnic status. The area is served by a multidisciplinary mental health team for older people, including two consultant psychiatrists (and their specialist registrars) and two clinical psychologists. A memory clinic operates for one day a week staffed partly by members of this department. As with most memory clinics, the primary function is as a diagnostic service, with medication being the intervention in the majority of cases, although with an increasing emphasis on psychosocial intervention (Sweetman & Davies, 2002). The area is also served by an active branch of the Alzheimer's Society, which provides outreach and day services as well as information and advice.

Participants

Due to Local Research Ethics Committee requirements, participants meeting the inclusion criteria (diagnosis of probable Alzheimer's disease disclosed within the past six months) were recruited indirectly through the psychiatrists responsible for their partner's care, or through an outreach worker from the local Alzheimer's Society. Recruitment was coordinated by a

clinical psychologist from the service as there were a number of concurrent psychology projects within the department. Ultimately, all of those who agreed to participate were recruited through the psychiatrists, who approached potential participants with recruitment packs which required them to opt-in to being contacted directly by the researcher. At least 17 people were approached, of whom four agreed to take part in the study. All were female, white-British, aged from their late-60's to their mid-80's, with three of the husbands being in their 80's and one in his late 60's.

The recruitment phase of the research was particularly challenging for a number of reasons, and led to bias in who was actually approached to take part. Attempts were made to recruit through another psychiatry department initially until it became evident how difficult it was to establish to whom a diagnosis had been disclosed, and if so, when, and by whom. This was less of an issue within the catchment area where the participants were ultimately recruited from as the psychiatry team was more established, there appeared to be a good understanding within the team of how others worked clinically, and patients tended to see the same psychiatrist from appointment to appointment. Another difficulty was that of clinicians' judgement on who was considered psychologically robust enough to participate. For instance, comments by a member of the local Alzheimer's Society branch indicated that he considered almost all of the partners to whom the diagnosis had recently been disclosed to be too emotionally fragile to be approached to participate. A further consideration, discussed under *'reflections on doing the research'*, is the difficulties often encountered in engaging professionals in medical settings in supporting qualitative psychological research. On reflection, this was a crucial issue that was not dealt with adequately when setting up the study.

In addition to these selection biases, there was also clearly a self-selecting element to who agreed to take part. Of the 17 people approached, only four agreed to take part, which was perhaps surprising given anecdotal and research evidence that older people are often more willing than other populations to take part in research, both because of a willingness to reflect on experiences and contribute to research (e.g. Clare, 2002). Comments from two people who initially agreed and subsequently declined to participate indicated that they felt unable to talk about the diagnosis and how it affected them due to the emotional pain and fear that talking would only make their difficulties more prominent. Barriers to participation such as the amount of distress associated with a diagnosis of Alzheimer's disease, and practical issues

such as how to talk about one's experiences without invalidating their partner were probably underestimated by the researcher, as well as by members of the psychiatry department involved in recruitment.

In order to gain insight into the experiences of a more diverse group of partners, these issues could perhaps be addressed in future studies by collecting data in less potentially threatening ways, such as by asking participants to write about their experiences, or dictate them into a tape recorder so that participants could be more in control of the issues talked about as well as offering flexibility into when they engage in the research.

All of the participants had been assessed within the memory clinic and had the diagnosis disclosed by a psychiatrist specialising in working with older people, rather than by their GP. Only one had contact with the Alzheimer's Society, and only one (the same participant) had accessed non-medical interventions. The experiences of partners where the diagnosis was made by a GP, generally in the later stages of dementia, may therefore be quite different, and it would be of value to explore this in future studies. It would also be of value to explore how those who agreed to take part differed from those who did not. As mentioned, one potential factor was the degree of emotional distress, but as research by Bonnano *et al* (2004) indicates, many people may not approach services because they adjust to changing circumstances with little search for meaning, and taking part in research such as this could be construed as a threat to their sense of stability. These factors should be considered by researchers considering undertaking research in this field.

Procedure

In-depth, semi-structured interviews (lasting 50 – 120 minutes) were conducted either in participants' own homes or within the clinic, depending on their stated preferences. Only one participant elected for the interview to take place outside her home, although there appeared to be a tension expressed by all participants in terms of how to manage the interview with their husband at home. Such practical issues are likely to form a barrier to participation, or to giving an open account of one's difficulties and are an issue that would need to be addressed creatively in future studies.

An interview schedule was used flexibly to ensure that the research questions were addressed in a way that allowed participants to tell their story in their own way. The schedule also

facilitated the use of prompts that encouraged depth, nuance, detail and vividness to participants' responses (Rubin & Rubin, 1995). In accordance with the iterative IPA research process, revisions were made to the interview schedule between interviews in order that unexpected or interesting directions were followed up in subsequent interviews.

Interviews were recorded on audio-tape, from which verbatim transcripts were made. An interview feedback sheet was completed after each interview to increase reflexivity, focussing both on content and process issues. For example, how participants presented their narratives, unexpected issues and themes, and the interviewer's experience. This process was found to aid the data collection phase, in that it facilitated a greater sense of engagement, active listening and curiosity, resulting in a more relaxed and less structured interview style, particularly during later interviews.

Interpretative Phenomenological Analysis (e.g. Smith, 1995; Smith & Osborn, 2003) was used as a structured and systematic means by which to analyse the verbatim interview transcripts. Various steps were taken in an attempt to maintain *trustworthiness* (Lincoln & Guba, 1985). First, the researcher sought *member validation* by inviting participants to comment on a written summary of the analysis, as described by Macran *et al* (1999). This was also done within the context of the interviews and a second interview with one participant. *Triangulation* was gained through feedback on the analysis from local *experts* in the field. A further credibility check was provided in terms of appending an *audit trail*, as emphasised by Yin (1989), whereby readers can follow the process of the analysis from the interview transcript to the final analysis. A clinical psychologist independent of the study checked such documentation for one of the participants and was able to confirm that the final analysis provided a fair reflection of the issues described by that participant. *Supervision* by an experienced IPA researcher was a further means of establishing that the study was carried out with rigour. Smith & Osborn (2003) argue that the key goal for an IPA study should be to establish theoretical rather than empirical generalisability, with success being defined in terms of readers being able to make links between the findings of an IPA study, their own personal and professional experience, and the claims of the existing literature. It was anticipated that sufficient information was provided for the reader to make up their own mind.

Qualitative researchers such as Shaw (2004) argue that although member validation is currently in vogue in qualitative research, it is hampered by a number of concerns, particularly

in relation to power issues, as it is the researcher who holds the power to include or exclude interpretations. This ethical dilemma was resolved on a pragmatic level, in that time constraints meant that the thesis was submitted without feedback from all of those who participated. The researcher did attempt to clarify ambiguities and provide preliminary interpretations to participants within the context of the interviews, and generally received affirmative feedback. A written summary of the key findings was also provided inviting feedback. Smith (1996) argues that, even where such feedback is sought prior to submission, participants often feel reluctant to contradict a researcher's interpretations.

In hindsight, if I were to do this study again, I would consider the issue of gaining member validation more closely. One way of doing this could be to invite feedback by holding a focus group for participants. This may help to redress the power balance in that participants would be more likely to feel empowered to dispute interpretations. Gergen and Gergen (2000) comment from the perspective that the accounts given by participants are dialogically co-constructed, a further advantage of such an approach is that a discussion group can open up new form of consciousness that is less possible within individual interviews. For example, in this case, being in a group could provide the context for opening up a discussion on dominant discourses on the early stages of dementia that would add insight to issues raised in the individual interviews. Obviously this form of cooperative inquiry (Reason, 2003) may seem alien to potential participants who may not be from a particularly politicised cohort, at a time where many people appear to be focussing their energy on 'just being able to get on with it'.

Reflexivity in qualitative research is an important consideration, in terms of considering how the personal, cultural, and political values, interests, and influences on the researcher impact on the analysis, as well as how the context of the research and the need for the participant to present a particular story impact on the account (e.g. Miller, 2000; Smith, 1996). These issues were considered within the context of supervision and the use of a research diary and memos, and are reflected on in the thesis. One of the strengths of interviewing older women as a relatively young male researcher was that it may have encouraged more efforts to explain difference, for example what it is like to be an older woman or how priorities in later life may differ from those in earlier years. Of course there is also the danger that the difference may have been considered prohibitive, although my experience of the interviews did not suggest this.

In line with the broadly constructivist approach taken, the original intention was to triangulate interview data with repertory grids (e.g. Fransella *et al*, 2003; Jankowicz, 2003; Winter, 1994) in an attempt to gain insight into participants' implicit understandings of the early stages of dementia that participants may not have struggled to convey through finding the words to accurately express their thoughts, feelings and perceptions in words in an interview context. This aspect of the design was dropped for pragmatic rather than methodological reasons as considerable delays were experienced with recruitment.

Some studies (e.g. Clare, 2002; Pearce & Clare, 2002) have sought the views of both partners as another form of triangulation, albeit with an emphasis on understanding the experiences of the person with dementia. Conversely, it could have been beneficial to draw on the experiences of the husbands with the diagnosis to triangulate data from their partner by commenting on their experiences. This could provide insight into issues such as how power shifts within the relationship, for instance whether there is an element of insight and collusion by persons with dementia. In fact, a concurrent project was being undertaken by a trainee psychologist from another university in the same service at the same time with people recently diagnosed with Alzheimer's, and it is a sad reflection of the ongoing poor coordination of research in the NHS as well as individualised focus of training programs that these researchers were not made aware of each other's projects until they were in the process of collecting data.

Willig (2001) argues that as a methodology, IPA is reliant on the representational validity of language to accurately communicate, rather than construct, experiences, and that many research participants will struggle to find the words to accurately communicate their experiences. She also argues that IPA is limited in that in order to understand experiences well enough, one has to have a very good understanding of the context, such as the influence of past events, histories, or social and material structures within which people live. One could question whether one or two interviews are sufficient in order to meet these aims, and thus the use of triangulation is very pertinent, particularly methods that access different levels of consciousness, as described above.

To conclude, although various approaches could have been taken to address the research questions, the IPA approach adopted was found to be effective and enabled the researcher to gain valuable insight into the experiences of this group of women. Given the opportunity to redo the research without the same constraints, issues that would have been addressed would

have been to use a longitudinal and preferably prospective research design, identifying ways of involving participants more in the analytic process, and finding ways of triangulating participants accounts with multiple sources of data.

Main results

Three key themes emerged from the analytic process (*'Receiving confirmation of a diagnosis of Alzheimer's disease'*, *'Making sense of the diagnosis'*, and *'Staying on an even keel'*). In response to the diagnosis, which represented a form of *biographical disruption*, various means of making sense of, or *taking on the diagnosis*, were talked about. These included making social comparisons, interpreting professional and social discourses about Alzheimer's disease, making comparisons with previous phases of their life, and trying to imagine their partners experience on the basis of their reactions as well as their previous identity. The key issue that emerged from the analysis was participants' emphasis on *staying on an even keel* and protecting their partners' sense of self. They engaged in a range of idiosyncratic intra-personal and inter-personal psychological processes to manage this, including re-evaluating their life story and re-defining themselves or their partners as 'old', re-defining social boundaries to avoid social stigma, and taking on an increasingly powerful position within the relationship in a way that their partners would not be aware of. These findings are discussed within the context of existing theory in the Discussion section, where it is concluded that they provide a good 'fit' with existing literature as well as offering a more nuanced understanding with certain issues.

Future research

The study was undertaken in the context of a dearth of in-depth research into partners' experiences of care-giving in the early stages of dementia, and the impact of a diagnosis. The results provide some insight to inform the debate on diagnostic disclosure and how best to assist family 'caregivers' in the early stages of dementia, given the clear association between stress and burnout and care-giving in the later stages of dementia (Gottlieb & Wolfe, 2002; Schultz, O'Brien & Bookwala, 1995; Zarit & Edwards, 1999).

Further qualitative research in this area would help establish the credibility of the findings of this study, as well as help determine the degree to which the results can be generalised to other groups of family caregivers. In particular, participants in this study were all female and white, and it may be that the analysis does not fit with the experiences of male caregivers, those from

other ethnic group or social classes, or adult children. These experiences of these groups have been considered separately by several researchers (e.g. Ford *et al*, 1997; Harris, 1993; Kramer, 2000; Miller & Kaufman, 1996; Yamamoto-Mitani *et al*, 2000; Russell, 2001) although not relating to care-giving in the early stages of dementia.

A number of authors have highlighted the lack of a theoretical basis for psychosocial interventions with family caregivers, particularly in the early stages of dementia (e.g. Brodaty *et al*, 2003; Pusey & Richards, 2001). Further qualitative research in this area could ultimately lead to the development of theoretical frameworks that can better inform clinical intervention, which, where offered, often fail to meet the needs of caregivers (Nolan *et al*, 2004). Nolan *et al* (2004) argue that the lack of evidence of the effectiveness of psychosocial interventions with caregivers is in part due to the use of measures of success that do not reflect the priorities of caregivers. Further qualitative research could help establish ways in which outcome could be measured in a more personally relevant way. Although a typical conclusion that reviewers of the literature on psychosocial interventions with family caregivers has been that there is a need for more 'gold standard' quantitative research (e.g. Thompson & Spilsbury, 2003), an alternative conclusion might be to support greater use of mixed qualitative / quantitative methodologies, particularly as qualitative insights have highlighted elements of interventions which have failed to demonstrate change in quantitative measures but have been seen by caregivers as personally valuable (Brodaty *et al*, 2003).

Bamford *et al* (2004) highlight a need for more qualitative research to better understand partners' experiences of diagnostic assessment and disclosure, particularly given the existence of professional guidance on disclosure that has no empirical basis. An issue that arose in the context of this study is how 'reality' is negotiated in consultations with professionals. A discourse analytic approach, for example as used by Kirsi, Hervonen and Jylhä (2000) to investigate discourse on caregiving by husbands, may be particularly applicable to answer such issues. Such research could thereby help establish an empirical basis on which clinicians can base their practice, for example relating to their use of language and the implicit messages about dementia that they may be conveying (e.g. Mishler, 1997; Wodak, 1997).

Finally, as discussed in the 'Methodological Issues' section, a longitudinal study would help establish a more rich and nuanced understanding of the psychological manoeuvres used by individuals to remain on an even keel, and how these strategies modulate as time progresses.

Implications for clinical practice

The results are considered in relation to ethical and practical debates about diagnostic disclosure (see Literature Review) and the increasing emphasis on how services can better respond to the needs of family caregivers in the early stages of dementia care.

In relation to diagnostic assessment and disclosure, although participants talked of learning of the diagnosis in an incremental way, it was apparent that they did not always feel adequately prepared for the diagnosis when it was eventually received. In one case, the diagnosis was viewed as unnecessary and unhelpful, and in another, the participant did not feel she had sufficient time to consider the potential consequences of the assessment as the appointment came much sooner than expected. These cases reinforce a need for pre-diagnostic counselling through which such issues can be explored, as has been highlighted by authors such as Bender (2003) and Woods (1999). Bamford *et al* (2004) reviewed the research literature and found that only one third of carers reported having had the opportunity to discuss possible outcomes with professionals first.

In addition, all participants described strong emotional reactions to hearing the diagnosis which they had to keep hidden from their partner, despite the fact that many had expected it. A lack of opportunity to deal with the emotional consequences of diagnostic disclosure has been highlighted by relatives in several studies (Adams & Sanders, 2004). Moniz-Cook *et al* (1998) offered a comprehensive package of psychosocial support to persons with dementia and their partners following diagnosis, and reported that the aspect of the program that partners found most helpful was the sessions immediately following the diagnosis, through which many gained a sense of hope for the future.

The results of this study indicate that 'staying on an even keel' is a key goal for partners, and efforts to do so may be at the expense of other considerations such as addressing the issue of their husband wanting to continue to drive. It is likely that psychosocial interventions that help caregivers gain a sense of stability may be particularly valued. Clare (2002) and Pusey and Richards (2001) highlight a range of psychosocial interventions aimed at enhancing partners' well-being and self-esteem, including emotional support, improving social networks, stress management, problem-solving support, cognitive rehabilitation, self-maintenance therapy and advice and support. Despite their availability, none of the participants were accessing such

support from services, and it is suggested that this may have been due in part to a perception that their needs would not be met.

Pusey and Richards (2001) comment on the blanket, rather than targeted provision of services to support carers, which often results in interventions being rejected. In a prospective longitudinal study of 276 widows over 18 months, Bonnano, Wortman and Nesse (2004) found that the majority of participants adjusted well to the loss, with only a quarter of the sample characterised by 'chronic grief' or 'chronic depression' reactions. Bonnano *et al* argue that psychological interventions could be unhelpful or even damaging to the majority of those who had adjusted to the loss, in that their adjustment had been characterised by relatively little search for meaning, or an increasing but then decreasing depression with enduring positive memories. They suggest that those who would benefit most from intervention are those from the two groups mentioned above whose grief is characterised by an intense search for meaning and low self-esteem respectively. A case has been made here for carefully targeted interventions with partners following diagnosis in the early stages of dementia. Professional guidance tends to be prescriptive and treat caregivers as a discrete group, rather than acknowledging diversity in the experiences of family caregivers, which reflects the current lack of in-depth research into their experiences (Nolan *et al*, 2004).

Partners used the research interviews to establish narratives which emphasised their husbands' and their own positive attributes and competencies before appearing comfortable talking about their difficulties. Although research has demonstrated an association between problem-focussed coping and wellbeing (Norman *et al*, 2004), it may be that overly problem-focussed encounters with services that are based on professionals rigid perceptions of effective caregiving are experienced as invalidating by partners who are coping within the context of very individual circumstances and life histories (O'Connor, 1999). Such consultations may set up an ambivalent relationship with specialist services whereby partners do not feel adequately supported or listened to. Although there are clearly constraints on resources, allowing partners the space to establish the narrative context within which their husband's difficulties are occurring is likely to be helpful in terms of longer term relationships with services, whereby their individual needs can be better understood and responded to.

It is clearly a dilemma for professionals on how much information to provide to partners and when, particularly given the uncertainties associated with Alzheimer's disease. An issue raised

in this study was how partners may be reluctant to discuss issues and accept information in the presence of their partner as they may anticipate it being viewed by their partner as disloyal, distancing, and reinforcing a sense of incompetence and powerlessness. It appears that in many cases partners need to be considered in their own right in the early stages of dementia if they are to openly communicate their concerns.

Given the context within the NHS of early detection of dementia, the study highlights a lack of socio-cultural discourses on care-giving in the early stages of dementia. All participants expressed an interest in how their experiences were similar or different from those of others taking part in the study. There was a general 'just get on with it as there is nothing else we can do' attitude, and it may be particularly helpful for services to promote opportunities for contact with other partners in similar circumstances in order to help bolster their coping resources and self-esteem.

Pratt and Wilkinson (2003) emphasise a need for professionals to consider the social context of the early stages of dementia, as highlighted by all of the participants, and the fact that for many people, a diagnosis of Alzheimer's disease can quickly lead to a significant loss of social support, and ultimately self-esteem, which has been shown to be central to effective coping (Coleman, 1999).

Recent policy initiatives (e.g. Department of Health, 2001) have highlighted the fact that interventions to support family caregivers in the early stages of dementia are rarely offered within the NHS (see Introduction). In addition to resource issues, it could be that this is related to an assumption that care-giving is more about the practical demands than about the relationship, as reflected by the focus in the research literature on stress and coping in the later stages of dementia. Nolan *et al* (2004) comment that the lack of empirical evidence for the effectiveness of current psychosocial interventions may lead service providers to the fatalistic conclusion that there is little that can be done to support carers, rather than questioning the quality of the research. However, the results of this study indicate that partners are making often radical intrapersonal and interpersonal adjustments following a diagnosis, and it is postulated that these are issues that could lead to considerable stress. For example, several participants reported difficulty managing feelings of guilt associated with duplicity, even where this was seen as in the best interests of their partner. Such unresolved moral dilemmas

could contribute to later mental health difficulties such as anxiety and depression if not addressed early on.

References

Adams,K. & Sanders,S. (2004). Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease: a mixed-method analysis. *Dementia*, 3 (2), 195-210.

Bamford,C., Lamont,S., Eccles,M., Robinson,L., May,C. & Bond,J. (2004). Disclosing a diagnosis of dementia: a systematic review. *International Journal of Geriatric Psychiatry*, 19, 151-169.

Bender,M. (2003). *Explorations in dementia – theoretical and research studies into the experience of remediable and enduring cognitive losses*. London: Jessica Kingsley.

Bonnano,G.A., Wortman,C.B. & Nesse,R.M. (2004). Prospective patterns of resilience and maladjustment during widowhood. *Psychology and Aging*, 19 (2), 260-271.

Brodaty,H., Green,A. & Koschera,A. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society*, 51, 657-664.

Candey,L. (2001). *Women's understandings of their relationship with their husband in the early stages of his gradual onset dementia*. University of East Anglia: unpublished DCLinPsy thesis.

Clare,L. (2002). We'll fight it as long as we can: coping with the onset of Alzheimer's disease. *Aging & Mental Health*, 6 (2), 139-148.

Clare,L. (2003). Managing threats to self: awareness in early stage Alzheimer's disease. *Social*

Coleman,P.G. (1999). Identity management in later life. In R.T.Woods (ed.), *Psychological Problems of Ageing: Assessment, Treatment and Care*, pp. 49-72. Chichester: Wiley.

Department of Health (2001). *National Service Framework for Older People*. Government Policy Document, DoH March 2001.

Ford,G.R., Goode,K.T., Barrett,J.J., Harrell,L.E. & Haley,W.E. (1997). Gender roles and caregiving stress: an examination of subjective appraisals of specific primary stressors in Alzheimer's caregivers. *Aging & Mental Health*, 1 (2), 158-165.

Fransella,F., Bell,R. & Bannister,D. (2003). *A Manual for Repertory Grid Technique*. Chichester: Wiley.

Gergen,M.M. & Gergen,K.J. (2000). Qualitative inquiry – tensions and transformations. In N.K.Denzin & Y.S.Lincoln (eds.), *Handbook of Qualitative Research*, pp. 1025-1046. London: Sage.

- Gottlieb,B.H. & Wolfe,J. (2002). Coping with family caregiving to persons with dementia: a critical review. *Aging & Mental Health*, 6 (4), 325-342.
- Harris,P.B. (1993). The misunderstood caregiver? A qualitative study of the male caregiver of Alzheimer's disease victims. *The Gerontologist*, 33 (4), 551-6.
- Jankowicz,D. (2003). *The Easy Guide to Repertory Grids*. Chichester: Wiley.
- Kirsi,T., Hervonen,A. & Jylhä (2000). A man's gotta do what a man's gotta do: husbands as caregivers to their demented wives: a discourse analytic approach. *Journal of Aging Studies*, 14 (2), 153-169.
- Kramer,B.J.(2000). Husbands caring for wives with dementia: a longitudinal study of continuity and change. *Health and Social Work*, 25 (2), 97-106.
- Levy,B., Hillygus,J., Lui,B. & Levkoff,S. (2000). The relationship between illness attributions and caregiver burden: a cross-cultural analysis. *Journal of Mental Health and Ageing*, 6 (3), 213-225.
- Lincoln,Y. & Guba,E. (1985). *Naturalistic Inquiry*. Beverly Hills: Sage.
- Macran,S., Stiles,W.B. & Smith,J.A. (1999). How does personal therapy affect therapists' practice? *Journal of Counselling Psychology*, 46 (4), 419-431.
- Miller,T. (2000). Losing the plot: narrative construction and longitudinal childbirth research. *Qualitative Health Research*, 10 (3), 309-323.
- Miller,W.L. & Crabtree,B.F. (2000). Clinical Research. In N.K.Denzin & Y.S.Lincoln (eds.), *Handbook of Qualitative Research*, pp. 607-631. London: Sage.
- Miller,B. & Kaufman,J.E. (1996). Beyond gender stereotypes: spouse caregivers of persons with dementia. *Journal of Aging Studies*, 10 (3), 189-204.
- Mishler,E.G. (1997). The interactional construction of narratives in medical and life-history interviews. In B.L.Gunnarsson, P.Linell, B.Nordberg (eds), *The Construction of Professional Discourse*. Harlow: Addison Wesley Longman.
- Moniz-Cook,E., Agar,S., Gibson,G., Win,T. & Wang,M. (1998). A preliminary study of the effects of early intervention with people with dementia and their families in a memory clinic. *Aging & Mental Health*, 2 (3), 199-211.
- Neimeyer,R.A. (2001). Meaning reconstruction and loss. In R.A.Neimeyer (ed.), *Meaning Reconstruction and the Experience of Loss*, pp. 1-12. Washington: American Psychological Association.
- Nolan,M., Grant,G. & Keady,J. (1996). *Understanding family care*. Buckingham: Open University Press.
- Nolan,M., Ingram,P. & Watson,R. (2004). Working with family carers of people with dementia: 'negotiated' coping as an essential outcome. *Dementia*, 1 (1), 75-93.

- Norman, I., Redfern, S., Briggs, K. & Askham, J. (2004). Perceptions and management of change by people with dementia and their carers living at home. *Dementia*, 3 (1), 19-44.
- O'Connor, D. (1999). Living with a memory-impaired spouse: (re)cognizing the experience. *Canadian Journal on Aging*, 18 (2), 211-235.
- Pearce, A., Clare, L. & Pistrang, N. (2002). Managing sense of self: coping in the early stages of Alzheimer's disease. *Dementia*, 1 (2), 173-192.
- Pratt, R. & Wilkinson, H. (2003). A psychosocial model of understanding the experience of receiving a diagnosis of dementia. *Dementia*, 2 (2), 181-199.
- Pucci, E., Belardinelli, Borsetti, G. & Giuliani (2003). Relatives' attitudes towards informing patients about the diagnosis of Alzheimers disease. *Journal of Medical Ethics*, 29, 51-54.
- Pusey, H. & Richards, D. (2001). A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging & Mental Health*, 5 (2), 107-119.
- Reason, P. (2003). Cooperative Inquiry. In J.A. Smith (ed.), *Qualitative Psychology: a Practical Guide to Research Methods*, pp. 205-232. London: Sage.
- Rubin, H.J. & Rubin, I.S. (1995). *Qualitative interviewing: the art of hearing data*. London: Sage.
- Russell, R. (2001). In sickness and in health: a qualitative study of elderly men who care for wives with dementia. *Journal of Aging Studies*, 15, 351-367.
- Schulz, R., O'Brien, A.T., Bookwala, J. & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates and causes. *The Gerontologist*, 35, 771-791.
- Shaw, R. (2004). Interpretative Phenomenological Analysis Conference workshop on validity and reliability in qualitative research. Nottingham Trent University.
- Smith, J.A. (1995). Semi-structured interviewing and qualitative analysis. In J.A. Smith, R. Harré & L. Van Langenhove (eds.), *Rethinking Methods in Psychology*, pp. 9-26. London: Sage.
- Smith, J.A. (1996). Evolving issues for qualitative psychology. In Richardson, J.T.E. (ed.), *Handbook of Qualitative Research Methods*. Leicester: British Psychological Society.
- Smith, J.A. & Osborn, M. (2003). Interpretative Phenomenological Analysis. In J.A. Smith (ed.), *Qualitative Psychology: a Practical Guide to Research Methods*, pp. 51-80. London: Sage.
- Spencer, L., Ritchie, J., Lewis, J. & Dillon, L. (2003). *Quality in qualitative evaluation: a framework for assessing research evidence*. Cabinet office: HMSO.

- Sweetman,C. & Davies,S. (2002). *An audit of the Derwent Centre Memory Clinic: client feedback*. Harlow: unpublished audit.
- Thompson,P., Itzin,C. & Abendstern,M. (1990). *I don't feel old: the experiences of later life*. Oxford: Oxford University Press.
- Thompson,C. & Spilsbury,K. (2003). Support for carers of people with Alzheimer's type dementia (Cochrane Review), *The Cochrane Library*, Issue 2, 2003.
- Willig,C. (2001). *Introducing qualitative research in psychology: adventures in theory and method*. Buckingham: Open University Press.
- Wilson,H.S. (1989). Family caregivers: the experience of Alzheimer's disease. *Applied Nursing Research*, 2 (1), 40-45.
- Winter,D.A. (1994). *Personal Construct Psychology in Clinical Practice: Theory, Research and Applications*. London: Routledge.
- Wodak,R.(1997). Critical discourse analysis and the study of doctor-patient interaction. In B.L.Gunnarsson, P.Linell, B.Nordberg (eds), *The Construction of Professional Discourse*, pp173-200. Harlow: Addison Wesley Longman.
- Woods,R.T. (2001). Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects. *Ageing & Mental Health*, 5 (supplement 1), S7-S16.
- Yamamoto-Mitani,N., Tamura,M., Deguchi,Y., Ito,K. & Sugishita,C. (2000). The attitude of Japanese family caregivers toward the elderly with dementia. *International Journal of Nursing Studies*, 37, 415-422.
- Yin,R.K. (2003). *Case study research: design and methods* (Third Edition). London: Sage.
- Zarit,S.H. & Edwards,A.B. (1999). Family caregiving: research and clinical intervention. In R.T.Woods (ed.), *Psychological Problems of Ageing*. Chichester: Wiley.