

UNIVERSITY OF SOUTHAMPTON

**Investigating the Ways that Older People Cope With
Dementia: A Qualitative Study**

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**This thesis is submitted in partial fulfilment of the degree of
Doctor of Clinical Psychology**

**School of Psychology
Faculty of Medicine, Health and Life Sciences**

July, 2003

**Word count: 19,967 (excluding tables, diagrams, footnotes,
references and appendices)**

(Volume 1/1)

GENERAL ABSTRACT

In recent years, there has been a growing trend in dementia research towards understanding subjective experiences, which has led to the direct involvement of people with dementia in research. Understanding how older people cope with the range of difficulties posed by dementia has important implications for enhancing psychological well-being and quality of life.

This first part of this thesis contains a review of the theoretical literature and empirical studies pertaining to coping in dementia. Relevant understandings of coping taken from the broader literature are considered. The few qualitative studies specifically investigating aspects of coping with dementia are outlined. Taken together, these provide complementary information about a number of coping processes, but it is unlikely that the full range of coping types are comprehensively represented. Existing coping models appear to be insufficient in explaining coping with dementia, suggesting the need for further exploratory research.

Taking more of a critical realist approach, the second part of this thesis contains a qualitative research study, which aimed to provide a comprehensive overview of the range of coping methods and processes used by people with dementia. Details of personal coping experiences were elicited in semi-structured interviews with 12 older people with early-stage dementia. Interview data was analysed using interpretative phenomenological analysis. Three major themes emerged in relation to coping: “making sense of dementia” “managing identity in relation to dementia”, and “coping strategies and mechanisms”. Findings are

discussed in relation to: previous research; the relevance of existing models to coping with dementia; and, implications for further research and provision of services for people with dementia.

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ACKNOWLEDGEMENTS

Firstly, I would like to thank the twelve people who agreed to take part in this study, whose personal contributions made this research possible. Secondly, I have greatly appreciated the ongoing enthusiasm and support from my research supervisors, Romola Bucks and Ann Marshall, who braved the drafts of this thesis.

LITERATURE REVIEW PAPER*

Understanding Older People's Experiences of Coping with Dementia: a Review of the Literature

Running head: Coping with Dementia

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* American Psychological Association publication guidelines have been applied, as if
for submission to *Age and Ageing* (see Appendix A for Guide for Authors).

Abstract

This paper provides an overview of the research pertaining to coping in dementia, in order to consider what is currently known, and to clearly identify directions for future research. It draws from both the theoretical literature, and evidence from a range of qualitative, quantitative, single-case and/or observational studies.

Firstly, the range and nature of coping tasks, or challenges, associated with dementia are outlined. As there is little research specifically investigating coping with dementia, an overview is given of the general coping frameworks and evidence derived from the broader literature that may be relevant to dementia. A comprehensive review of the small number of studies exploring the coping processes of people with dementia is then presented. Finally, the implications for further research are considered, and some possible clinical implications highlighted.

Introduction

In recent years, there has been a growing trend away from the traditional, and often inaccurate, assumptions that have been made about older people's experiences of dementia, towards developing richer, more holistic understandings of these (see Bender & Cheston, 1997; Kitwood, 1993). Involving people with dementia in research has helped to highlight the individuality of experiences and the social and emotional needs of this group of people, identifying possibilities for enhancing psychological well-being.

The way in which older people cope with dementia is a key area of interest. In wider studies of the management of life events and physical illness, for example, coping has been found to be an important moderator of the impact of stressful events on the individual (e.g. Arbuckle, Pushkar, Chaikelson & Andres, 1999). Equally, coping is an important mediator between the objective challenges dementia poses and the subjective experiences of individuals facing these. This is an area that is only just beginning to receive research attention in its own right, but is important in developing our understanding of how to facilitate more positive well-being in this group of people. A summary of research and theory pertinent to our current understandings of coping with dementia therefore appears timely, in order to consider the clinical implications of what is currently known and to clearly identify directions for future research.

In the following, a definition of dementia is provided, and what is known about the challenges presented by these disorders is reviewed. Secondly, a definition

of coping is outlined and a brief overview provided of the main frameworks of coping from the general literature. The review then moves on to consider the ways in which models from the literature on chronic health problems and coping in later life can be applied to people with dementia. Finally, the few studies that provide direct insights into how people with dementia cope with the challenges they face are critically reviewed. Conclusions are then drawn, in which the potential for further research and clinical implications are considered.

The Challenges of Dementia

Defining Dementia

Dementia is defined as a progressive and irreversible condition that causes global impairment of higher cortical functions, including memory, the capacity to solve problems of daily living, performance of learned perceptuo-motor skills and correct use of social skills (World Health Organisation, 1993). There is great variation in the way dementia manifests itself between different people. However, memory and communication are the two predominant functions affected (McGregor & Bell, 1993). Secondary to these, other cognitive and behavioural functions, including social and occupational functioning, are significantly affected (e.g. Hubbard, Downs & Tester, 2003).

Social, Emotional and Personal Challenges

In their model of subjective experiences, Bender and Cheston (1997) proposed that anxiety, fear, depression and despair are commonly engendered by the process of dementia. A wider range of emotions including frustration, anger, despondency and embarrassment, have been identified in further studies (e.g. Cohen, Kennedy &

Eisdorfer, 1984; Keady & Gilliard, 1997; Harris & Sterin, 1999). Psychiatric, mood-related problems are highly prevalent among people with dementia (e.g. Reifler & Larson, 1990). Such emotions can cause the person to resort to behaviours that are considered either challenging (see Cheston & Bender, 1999) or regressed (such as attachment behaviours; see Miesen, 1993), leading to further social problems.

Kitwood (1993; 1997) highlighted the importance of factors related to personality and biography in the experience of dementia. In undermining a person's sense of stability and security, dementia can exacerbate personal vulnerabilities. Miesen and Jones (1997), for example, discussed the resurfacing of traumas from earlier life in the context of dementia. Additional challenges may arise that are more specific to the individual or their environment, such as financial problems or pre-morbid psychiatric difficulties.

Social interactions and relationships have been highlighted as sources of difficulty for many people with dementia (e.g. Golander & Raz, 1996; Bond, Corner, Lilly & Ellwood, 2002). Distress can be caused by loss of closeness and reciprocity, a reversal of roles (Blieszner & Shifflett, 1990; Chesla, Martinson & Muwaswes, 1994), and the person with dementia perceiving themselves to be a burden (Cheston, Jones & Gilliard, 2003). Such changes are likely to lead to a reduced sense of independence, dignity, and self-esteem (McGregor & Bell, 1993; Woolhead, Calnan, Dieppe & Tadd, 2004). The ways in which the social self is affected are discussed below.

Existential Challenges

Later life is an important context within which dementia occurs. Older people commonly experience loss associated with mental and physical health, work and other roles, and bereavements of close family and friends (e.g. Chiriboga & Cutler, 1980). The main tasks associated with ageing are to maintain a positive and continuous sense of self (Ruth & Coleman, 1994), achieve integrity (e.g. Erikson, Erikson & Kivnick, 1986) and make meaning of the life that has been lived (McAdams, 1990). These tasks appear equally important for people with dementia.

Charmaz (1987) suggested that people learn how contingent their identities are on wellness-related factors when they experience illness. Threats to the self derive from trauma, disruption of life goals, dramatic or persistent disconfirmation of self concept, disruption of relationships between self and social structure, changes in cognitive capacity, and experiences of failure (see Clare, 2003), all of which are often experienced by people with dementia. Indeed, managing selfhood appears to be a central challenge. For example, the social self is eroded when many roles diminish with the changes in lifestyle and living situation that occur. The preferred social self is often ignored, undermined, invalidated or denied (e.g. Sabat & Harré, 1992; Golander & Raz 1996; Mills & Coleman, 1994). Narrative identity is also weaker in people with dementia due to impairments in autobiographical memory (Mills, 1997; Phinney, 2002; Addis & Tippett, 2004). People with dementia report attempting to strike a balance between maintaining a sense of continuity with their previous life, whilst coping with and integrating changes (e.g. Menne, Kinney & Mordhardt, 2002; Pearce, Clare & Pistrang, 2002; Clare, 2002a). For some, however, this does not appear to be possible: although some elements of identity appear to be maintained even in the later

stages of dementia, many personal and social identities are lost or forgotten (Harris & Sterin 1999; Cohen-Mansfield, Golander & Arnheim, 2000).

Maintaining a meaningful existence is also made more difficult when conventional roles and tasks cannot be sustained (Clare, 2003; 2004). People with early stage dementia actively strive to explain, find meaning in and cope with challenges (Menne et al., 2002; Clare 2002a). This can sometimes involve developing positive new ways of being, such as new skills, greater openness and creativity (see Kitwood, 1995). Related challenges include gaining control in life (Taylor, 1983), maintaining dignity, and avoiding dependency (Cohen et al., 1984).

Overall, the challenges of dementia appear to arise from three levels: as a direct result of neurological impairment; in the form of the individual's own reaction to these problems (such as affective states of anxiety and depression); and, from the individual's response to social reactions (e.g. self-esteem decreasing as a result of being ignored). Maintaining a sense of self and a meaningful existence are suggested to be central to the challenges faced. It is acknowledged that the onset of dementia is likely to pose a range of challenges in addition to those outlined above, which vary between individuals. Whilst dementia often occurs in the context of the losses of later life and the adaptations that have been made to these, it also presents losses beyond those of normal ageing, imposing a more immediate and extreme demand upon coping resources and abilities.

General Coping Literature

The following section reviews what can be drawn from the wider literature on coping (coping in general adult populations, coping with chronic health problems, and coping in later life) to provide a framework for understanding how people manage the challenges of dementia.

Conceptual Frameworks

For this review, coping is defined as: “an individual’s cognitive and/or behavioural efforts to manage specific external or internal demands (and conflicts between them) that are appraised as taxing or exceeding the resources of the person.” (Lazarus, 1991, p.112). It functions to increase a sense of well-being in the individual, enabling them to avoid being harmed by aversive situations (see Turnbull & Turnbull, 1993). Coping refers to both the dynamic process of responding to adversity and the specific strategies or mechanisms that are used in this process (Cramer, 1998).

Moos and Schaefer (1993) provided a general framework for conceptualising coping. This suggested that environmental and personal resources influence life crises (such as the challenges of dementia), which are filtered through the individual’s cognitive appraisals and subsequently determine coping responses. Coping is regarded both as a pivotal process and as an outcome, depending on when it occurs in relation to life stresses, influencing health and well-being. Any new coping skills, developed as a result of the coping experience, can later serve as personal resources when future crises occur (see also Hobfoll, 1989; Pearlin, Lieberman, Menaghan & Mullan, 1981, for example). The framework shares much in common with Lazarus and Folkman’s

(1984) transactional theory of stress and coping. Each of these models has received empirical support (see Moos & Schaefer, 1986, 1993; Maes, Leventhal & DeRiddler, 1996; Nolan, Grant & Keady, 1996).

Both models focus on coping as a dynamic process that changes over time. This is particularly pertinent when considering coping in dementia, which is likely to change as a result of corrective readjustment, changing contextual factors, and the progressive nature of the disorder. The models also usefully distinguish between coping resources and coping strategies.

Research indicates that the impact of identified factors on coping is by no means straightforward, varying according to the nature of the stressor and situational factors (Hewitt & Flett, 1996). This is reflected in the above models. However, in providing such general theoretical models, paradoxically the frameworks fail to offer any specific, testable hypotheses for individual coping situations (such as the onset of dementia). They also fail to offer differential weightings of specific factors affecting the coping process, or types of coping strategies used.

Coping is often classified according to its focus (i.e. a person's style or orientation in response to a stressor) or function (i.e. the purpose of coping efforts, which covers a range of behaviours). The types of coping most consistently referred to in the literature according to focus are: emotion-focussed, problem-focussed, and appraisal-focussed coping (e.g. Lazarus & Folkman, 1984; Moos & Schaefer, 1986). Approach coping, avoidance coping, emotional regulation, and reappraisal are the most common coping function distinctions (e.g. Ferguson & Cox, 1997; Roth &

Cohen, 1986; Miller, 1990). All of these may be cognitive and/or behavioural in orientation (see Moos & Schaefer, 1986, for a detailed review).

Any assessment of the adaptiveness of a coping strategy requires an analysis of coping responses in the context of specific stressor characteristics (Holahan & Moos, 1996). No particular type of coping has emerged as consistently more successful than others across different situations. A number of authors suggest that all strategies are potentially useful, but must be matched to both the individual and the stressor (e.g. Krohne, 1990; Lazarus, 1993). Zeidner and Saklofske (1996) note that coping varies both between and within individuals; adaptive coping involves a flexible repertoire and combined use of strategies, and the efficacy of responses may vary across phases of a stressful encounter, such as dementia.

Coping with Chronic Health Problems

Whilst there is a vast literature examining the effects of coping on health outcome (e.g. see Penley, Tomaka & Wieble, 2002), fewer studies have contributed to knowledge about the relationship between mental health or chronic illness and coping. However, Radley and Green (1987) suggested a conceptual framework based on two basic dimensions of adjustments to chronic illness that may have relevance to dementia. Dimensions of loss/retention of social participation and relationship of self to illness merge to define four different modes of adjusting to illness. These describe attempts to resolve demands of both the symptoms and society. The four modes are: active-denial, aimed at resisting the illness through maximising participation in other areas of life as far as possible; resignation, signalling the individual facing the effects of loss of valued and self-defining roles; accommodation to the condition, which

involves accepting the illness and then finding ways round it; and, secondary gain, referring to the positive qualities that can be gained from the illness.

As in the more general literature, reviews of the health literature conclude that a wide range of variables influence choice of coping strategies and health outcomes (Zeidler & Saklofske, 1996; Aldwin & Brustrom, 1997). There is some empirical evidence identifying the coping strategies that are most adaptive to specific health-related areas (e.g. see Zeidler & Saklofske, 1996) but, overall, generalisations cannot be made (e.g. Maes et al., 1996). Use of a wider range of strategies in managing health problems is related to higher self-esteem and better psychological adjustment (e.g. Wikblad & Montin, 1992).

Coping in Later Life

There appear to be key differences in the way that older people cope with losses (see Ruth & Coleman, 1994). Older people generally show more active responses in handling health stress, and superior adjustment in certain situations (Auer, 1987; Rott & Thomae, 1991). However, the major changes in life circumstances that accompany physical frailty appear to affect the availability of coping resources (e.g. Atchley, 1991), and more serious challenges are posed to the self (Coleman, 1996), as occurs in dementia. The very stability and continuity of the self that have been achieved through the processes of ageing make coping more difficult when more extreme change is required (Coleman, 1996). The following two models provide complimentary frameworks that incorporate much of the literature concerning coping in later life: these may be particularly relevant in considering maintenance of identity in dementia.

Brandstädter & Greve (1994) presented a model of assimilation, accommodation and immunisation (AAI). The model assumes that older people's experiences of loss generally involve discrepancies between desired and actual self-states. Self-discrepancies may be reduced and eliminated firstly through assimilation: intentionally transforming the situation so that it fits more closely with personal goals and/or aspects of identity. Perceived discrepancies may also be resolved by adjusting personal goals and preferences in line with the perceived contextual constraints: accommodative coping. Here, the evaluation of the problem rather than the actual situation itself is changed. This mode is hypothesised to regulate situations that are not perceived to be open to actual change. Immunising mechanisms manage self-referent evidence in protective ways, using processes such as cognitive dissonance, self-serving attributions and subtle shifts in semantic structure (see Brandstädter & Greve, 1994, for further information). Immunising processes protect the most central aspects of the self or identity, and are not intentionally chosen strategies. The three modes of this model are postulated to be antagonistic, or mutually exclusive. However, in an episode of acute loss, such as dementia, there may be a synergy between the modes, as such crises often require a range of coping responses.

The AAI model predicts that, as the loss situations older people face are often irreversible and uncontrollable, accommodative processes enable them to maintain a sense of control and accommodate meaning perspectives (see Hess, 1999; Heckhausen & Schultz, 1996). Older people show a more realistic ideal self, lowered expectations (Dittmann-Kohli, 1990), increased self-acceptance (Ryff, 1989) and greater use of religious beliefs (Koenig, Weiner, Peterson, Meador & Keefe, 1997), all of which

suggest the presence of accommodative processes. Brandstädter & Wentura (1995) found that accommodative flexibility (that is, having a wide range of potential goals) lessens the emotional impact of problems associated with later life. However, Coleman, Ivani-Chalian & Robinson (1999) found that accommodative processes of coping emerged only towards the very end of life. This may indicate that it is not until older people reach advanced old age, or are faced by serious challenges such as dementia, that assimilative processes can no longer be relied upon.

A complimentary model is Baltes & Baltes (1990) model of selection, optimisation and compensation (SOC), which has also received empirical support (see Freund & Baltes, 1998, 2002). This is a framework for understanding developmental change and successful ageing across the lifespan. Selective optimisation with compensation can be considered as one unified, integrated process of adaptive mastery, or the facets of SOC can be seen as individual processes that each contribute to successful development.

The primary focus of selection (S) is on setting goals. There are two types of selection: elective selection (ES), which involves developing, choosing and committing oneself to goals; and loss-based selection (LBS), that is reconstructing the goal system in response to a loss that threatens the attainment of ES goals. Optimisation (O) is defined as the allocation and refinement of resources as a means of achieving higher levels of functioning in selected domains. Compensation (C) is the use of alternative means to maintain a specific level of functioning when original goal-relevant means are no longer available.

The use of SOC itself requires effort and is resource-dependent. Although the theories are distinct, the authors note that the concept of assimilation from the AAI model captures aspects of each of S, O and C, whilst accommodation is linked to ES and LBS (see Freund & Baltes, 2002). Empirical findings have indicated that there is a decline in self-reported frequency of use of SOC in older people compared to middle-aged adults (Freund & Baltes, 1998, 2002), suggesting that resources available in later life may not be sufficient for engagement in SOC processes. However, despite this decline, older people continue to use SOC, and display better states of functioning when they do so (Baltes & Lang, 1997; Li, Lindenberger, Freund & Baltes, 2001). Therefore, both models may be relevant to understanding aspects of coping in dementia.

Aldwin and Brustrom (1997) identified a number of specific coping strategies that older people use to cope with physical health problems, most of which demonstrated a combination of AAI and SOC processes. These were: compensation through the development or use of alternative strategies and manipulation of the physical environment; development of routines that allow functioning despite disabilities; revision of expectations; manipulation of meaning (including using downward social comparisons); acceptance of problems, and development of caregiving dyads in which each person compensates for the other's incapacities.

Heckhausen and Schultz (1996) hypothesised that, due to the increasing proportion of stressors faced by older people that cannot be resolved or controlled, behavioural action has reduced effectiveness. They also found an enhanced effectiveness of cognitive strategies that reframe the problem to reduce emotional

distress, many of which represent accommodative processes (see also Diehl, Coyle & Labouvie-Vief, 1996; Essex & Klein, 1989). In support of this, Folkman, Lazarus, Pimley and Novacek (1987) found that older people used more passive, intrapersonal emotion-focussed forms of coping, and less active, interpersonal, problem-focussed forms of coping than younger people. Similarly, some studies suggest that older people focus more on emotional coping and less on problem-solving (e.g. Quayhagen & Quayhagen, 1988). Moreover, it appears that these types of coping are more adaptive for older people (Arbuckle et al., 1999).

Overall, the literature on coping is diverse, with models and studies indicating the importance of individual factors affecting coping types. The wider coping literature provides potentially useful initial frameworks and distinctions for conceptualising coping in dementia, indicating that coping incorporates a variety of forms and functions. Research on chronic health problems outlines some key coping modes, whilst the models of AAI and SOC appear to account for much of the literature pertaining to coping in later life. If applied to dementia, these models may suggest that it is more realistic for older people with dementia to cope using accommodative rather than assimilative processes, whilst the use of SOC will be resource-dependent. However, caution must be taken in generalising from the wider literature to coping with dementia, which presents a distinct coping challenge. General coping frameworks may be too simplistic to sufficiently encompass the complexities of coping with dementia.

Having reviewed the wider literature on coping, the following section discusses in detail the main studies that provide more specific insights into the coping processes of people with dementia.

Research Investigating Coping with Dementia

Many studies have examined the coping of supporters of people with dementia (e.g. see Kramer & Vitaliano, 1995), but it is only in recent years that research has focussed on how people with dementia cope. Evidence has suggested that people with dementia actively seek to make sense of and cope with what is happening to them (Friel-McGowin, 1993), and different coping styles may be adaptive as dementia progresses (e.g. Kitwood, Buckland & Petrie, 1995; Cheston et al. 2003).

Table 1 summarises the main studies, to date, that provide insights into aspects of coping with dementia, many through the exploration of related or broader areas. The studies are all qualitative and exploratory in nature, and most used semi-structured interviews with older people with mild or moderate dementia. Some of the studies triangulated this interview data with information from carers and/or observational data. Most participants were community-dwelling, and of white, European origin, with varying educational and vocational backgrounds (where this information is reported). Although this allows for the comparison of findings, it also has implications for generalisability.

Table 1

Summary of the Main Studies Relevant to Coping with Dementia

| Author(s) | Participants ^a | Aims ^b | Method | Main findings ^c | Coping strategies identified |
|----------------------------|--|--|--|---|---|
| Keady and Gilliard (1997). | 15 people with "very mild" Alzheimer's disease (AD); 67-86 yrs; living in the community. | To explore: experience of dementia/coping behaviour; how/when professional help is sought; stresses and coping behaviours of family members; views of resources. | - Joint interviews with participants and family supporters (prompting questions not reported). - Data analysed using a Grounded Theory approach. | Two strategies explained coping behaviours: "taking stock" (including "closing down", "regrouping", and "covering your tracks") and "sharing the load". | "Closing down" included: keeping feelings secret, withdrawing, staying in familiar places, using repetition, doing puzzles, crying, keeping active, avoiding new situations, and self-reliance. "Regrouping" included acceptance, self-belief, taking comfort in familiarity, and social support. "Covering your tracks" included: using lists, fighting memory loss, confabulation, keeping calm, and taking one day at a time. "Sharing the load" also involved keeping calm, as well as being thankful for/relying on family support, and talking about memory loss. |
| Harris and Sterin (1999). | 17 people with "early stage" AD; 54-84 yrs; living in the community; varied | To explore: how dementia affects a person's life/sense of self; core values most important in defining self; social interactions | - Interviews with participants and supporters, prompting: impact of living with memory loss, concept of self, family relationships, coping strategies to preserve sense of self worth. | Core values related to identity were meaningful productivity, primacy of autonomy, and importance of comfort/security. Five typologies of reaction patterns were identified. Authors concluded that participants' identity was in a | Five typical reaction patterns/ profiles in maintaining sense of self were identified: "I'll live until I die", "I accept what I have", "There is nothing wrong with me", "I'm just struggling to get through the day", and "I'm giving up". Most effective and frequently used coping |

| Author(s) | Participants ^a | Aims ^b | Method | Main findings ^c | Coping strategies identified |
|--------------------|--|---|---|--|--|
| | occupations/ education. | affecting defined sense of self. | - Data analysed using Grounded Theory . | state of flux. | strategies reported were: maintaining a daily routine, written prompts, support from others, sense of humour, and turning to faith. |
| Gillies (2000). | 20 people with diagnosis of dementia; 64-89 yrs, living in the community. | Exploring the perspectives/experi ences of people with dementia. | -Interviews, prompting: experiences of ageing, impact of memory loss, view on daily activities, future hopes and ambitions. - Data analysed with a “thematic coding scheme”. | Memory loss led to low self- esteem, feelings of incompetence and letting others down; coping strategies used to manage these were reported. | Comparisons with previous self and others; practical coping (note keeping, diaries, labels and notices); dependence on carers (for reassurance, guidance, clarification, “proxy memory”); avoidance; acceptance, resignation and pragmatic attitude to problems; normalising memory problems. |
| Clare (2002a). | 12 people with early stage AD (MMSE ^e 19- 29); 57-83 yrs, living at home with spouse; white European; varied vocational background. | Explore the phase in which people adjust to dementia (see Clare, 2000), and consider the range of ways that people cope with changes they experience. | - Separate, repeated interviews (3 months apart) with participants and partners, prompting: background/life experience, self-concept; preferred coping; changes noticed (esp. in memory); explanation and impact of changes, and nature of attempts to adjust and cope. - Data analysed using IPA ^d . | Conflict was experienced between wanting to deny/minimise changes (self-protective tendencies) and simultaneously acknowledge, accept and integrate changes with identity (integrative tendencies). Responses were characterised by reactions, explanations and emotional responses. | Most participants described self-protecting responses: “holding on” (trying, sticking to routine, hoping, using medication) and “compensating” (relying on their partner, using devices, using strategies). Integrative responses were: “developing a fighting spirit” (fighting impact of difficulties, finding out more, talking about it, being useful, focussing on the good things) and “coming to terms” (aiming for a level of acceptance that balanced hope and despair, accepting limitations and losses). |

| Author(s) | Participants ^a | Aims ^b | Method | Main findings ^c | Coping strategies identified |
|--------------------------|--|--|--|--|---|
| Pearce et al. (2002). | 20 men with mild AD (MMSE 18+); 60-85yrs; living with partner in the community; white European; varied past occupations. | To explore the appraisals and coping processes of men with AD. | - Separate interviews with men and wives, prompting: men's background, past/present social roles, capabilities and interests (i.e. self-concept); man's view of dementia and effects on social roles; coping attempts. - Data analysed using IPA. | Sense of self was managed by an ongoing process that combined maintaining an ongoing sense of self and re-appraising/reconstructing a new sense of self. | Strategies linked to maintaining sense of self were: viewing memory problems as having limited impact on functioning, normalising memory loss in terms of ageing, putting more effort into performing to previous standards, making the most of things, relying on wife, and relying on medication and/or services. Strategies linked to re-appraising and reconstructing sense of self were: acknowledging loss and change over time, and downgrading expectations/setting lower limits. |
| Nygard and Öhman (2002). | 7 people diagnosed with dementia (MMSE=24-29); 62-77 yrs; living alone in the community, varied social and marital status and vocational | To investigate how people with dementia respond to problems and changes experienced in everyday occupations. | - Repeated structured interviews and observations of participants performing everyday occupations. Interview prompted: former/present occupations; perceptions of consequences of dementia, how challenges were met and concrete examples of these. - Data analysed using an empirical, | Strategies functioned to (a) manage altered conditions, or (b) manage occupational problems. The latter divide into three strategies, based on environment, habituation and cognition. | (a) Acceptance; normalising, balancing taking on/avoiding challenges; training and activating; avoiding and relinquishing; adjusting habits.(b) Environment-based: strategically placing objects; support from others; perceptual compensation; verbalising aloud; written information; memory aids; body and space/spatial automatic pilot; body language. Habituation-based: habits and routines, comparing with the familiar. Cognition-based: controlling/checking; extra time; planning; immediately doing; caution; |

| Author(s) | Participants ^a | Aims ^b | Method | Main findings ^c | Coping strategies identified |
|--------------------------------|---|--|---|---|---|
| | background. | | phenomenological psychological method. | | rigour and attention; one at a time; corrective acts; stopping and reversing; trying, repeating and starting again; taking chances/letting go. |
| Nygard and Starkhammar (2003). | 10 people diagnosed with dementia (MMSE 11-27), 65+ yrs, living alone in community. | To describe participants' difficulties and responses in telephone use. | <ul style="list-style-type: none"> - Structured interviews and observation of telephone use, prompting: telephone location and habits, and changes experienced with these; difficulties experienced when using the telephone, and possible management strategies. - Data analysed using a Grounded Theory approach. | <ul style="list-style-type: none"> - Types of difficulties were described as knowing what, knowing where and knowing how - Participants tackled perceptual, verbal and environmental problems by either accepting the problems or responding to them using environmental or cognitive techniques. | <p>Environmental strategies were: visual (e.g. written prompts), sensory, verbalising aloud, seeking help, modifying the environment, using habits and habitual places.</p> <p>Cognitive strategies were: repeating (e.g. checking), and stopping and reflecting.</p> |
| Kemp (2003). | 4 people with AD (MMSE=15-23); 68-80 yrs; living at home with family member | To elicit the experiences of people with dementia (with no predetermined line of enquiry). | <ul style="list-style-type: none"> - Interview with participant (no details given of the prompts used). - Data analysed using Grounded Theory approach. | Two of the main themes were making sense of memory changes and coping strategies. There was an overarching theme of maintaining connections and managing disruptions. | Making sense of memory changes involved: keeping going (in a way that was continuous with the past, whilst acknowledging changes), remembering past identities, and maintaining relationships. Strategies to manage ongoing memory change were: maintaining relatedness (by maintaining interactional exchange removing self from source of distress, |

| Author(s) | Participants ^a | Aims ^b | Method | Main findings ^c | Coping strategies identified |
|-----------|---------------------------|-------------------|--------|----------------------------|---|
| | | | | | accepting wider limitations of memory changes); containing emotional responses and balancing independence and reliance. |

^a Number of participants, age range, stage of dementia and MMSE, living circumstances and occupational/educational background is given as reported by authors, where information is available. Only Clare (2002a) and Pearce et al. (2002) report number of participants using anticholinesterase medication (n=5; n=10, respectively).

^b Aims given are as stated by authors.

^c In some cases, only the information related to coping has been reported, which is derived from wider findings. Coping strategies are cited using authors' descriptions (in full or abbreviated form).

^d Interpretative Phenomenological Analysis

^e Mini Mental State Examination (Folstein, Folstein & McHugh, 1975)

Overview of Studies

Stated aims, specific areas of interest, and theoretical orientations vary across the studies. This is reflected in the focus of questions used in interviews and influenced the way that data have been analysed and reported. Harris and Sterin, (1999), Pearce et al. (2002), and Clare (2002a) for example, appeared to focus on understandings of coping with dementia in relation to an individual's sense of self¹. A wide range of strategies were reported, providing detailed insights into coping in relation to identity maintenance. Both Pearce et al. (2002) and Clare (2002a) carried out separate interviews with people with dementia and their spouses, giving extra depth and validity to their studies. However, interviewees may have been guided to reflect more on issues of identity and self-concept, reducing emphasis on other areas.

Harris and Sterin (1999) acknowledged that particular biases may have resulted from the fact that one of the interviewers in their study had recently been diagnosed with AD; interviewees may also have been influenced by the presence of a family member during most of the interview. The value of this study lies in its identification of some general coping styles and philosophies, although these are not described in great detail due to the wider focus of the study.

In contrast, Nygard and Starkhammar (2003) and Nygard and Öhman (2002) focussed on how specific, pre-defined tasks, namely telephone use and "everyday occupations" (e.g. ironing, preparing a meal, food shopping) are managed. The strength of these studies lies in triangulation of data collection sources and methods, although the effect of observing participants performing tasks they found difficult and

¹ Clare's (2002a) findings are derived from a wider study examining selfhood and awareness in dementia (see Clare, 2000).

subsequent rapport with the interviewer must be considered. In focussing on one or a small number of concrete difficulties, the authors were able to investigate a range of responses in detail. However, results are not necessarily generalisable to other coping challenges of dementia (particularly less concrete tasks), nor do they necessarily represent the full range of strategies used. Despite only focussing on concrete problems with daily occupations, a range of cognitive and behavioural, emotion-focussed and problem-focussed strategies emerged from the studies: this may be due to the structured interview employed.

Gillies' (2000) research appeared to place a particular emphasis on memory problems in dementia, studying them within the context of general experiences of ageing. Experiences of coping represent only one subsection of findings, therefore they are not reported in great detail.

Keady and Gilliard (1997; see also Keady & Nolan, 1995a, 1995b) elicited a wide and detailed range of coping strategies, their studies focussing on a broad range of experiences related to dementia. Their findings were the product of joint interviews eliciting the views of both the person with dementia and their supporter. Kemp (2003) also adopted a broad approach: the explicit aims of the research were generally to explore subjective experiences of dementia.

Comparison of Findings

In the initial section of this review, it was concluded that people with dementia face a wide range of challenges. Different studies appear to focus on different types of challenges or aspects of coping. However, despite the variation in areas explored and

research aims, there appear to be a number of commonalities in findings regarding coping.

Nearly all studies reviewed commented on the wide range of coping strategies used by individuals, and the importance of contextual and individual factors in coping (as is suggested by Kitwood, 1993). Importantly, this research also indicates that people with dementia are able to participate in such collaborative research, contrary to traditional assumptions (e.g. Cotrell & Lein, 1993).

A number of studies summarised findings with reference to a continuum of coping strategies, running from those aiming to maintain continuity to those focussing on managing and integrating change. Clare (2002a) and Pearce et al. (2002) identified similar continua related to coping with threats to selfhood, that ran from tendencies to minimise and normalise difficulties to responses that involved confronting problems and revising the self-concept (i.e. self-adjusting/self integrative). This was reflected in Kemp's overarching theme of "maintaining connection-managing disruption" (p.35, Kemp, 2003). Nygard and Öhman (2003) suggested a slightly different continuum, running from managing problems with activities of daily living, to responding to the problems. All the studies suggested that, although there may have been a tension between ends of continua, individuals tended to use strategies from both ends. There was also evidence that both accommodative and assimilative processes occurred in many of the studies (e.g. Pearce et al., 2002; Keady & Gilliard, 1997; Kemp, 2003).

In terms of overall coping patterns or philosophies, development of an acceptant attitude towards problems arose consistently across all studies. An attitude of wanting

to fight dementia also emerged repeatedly as a theme, commonly linked to a need to firstly, or simultaneously, accept the problem (e.g. Clare, 2002a; Pearce et al., 2002; Harris & Sterin, 1999). The wider literature on dementia supports this; for example, Cheston et al. (2003) observed that some people's decision to be open about having AD was accompanied by a determination that they should be listened to by the world. Focussing on the positive things in life (e.g. Pearce et al., 2002; Clare, 2002a), and evidence of denial and/or avoidance (e.g. Harris & Sterin, 1999; Kemp, 2003; Nygard & Öhman, 2002) were also themes (or aspects of themes) common to a number of the studies. The latter included mechanisms such as not thinking about problems, and using distraction.

Harris and Sterin (1999) provided the only study to comment on the range of coping patterns, or profiles, demonstrated by participants (see Table 1). Aspects of these coping patterns can also be found in the observational data from Kitwood et al. (1995).

As in the wider coping literature, authors of these studies on coping with dementia have used a variety of coping definitions in reporting findings, as would be expected in research that inductively identifies themes. Overall, findings do not appear to favour any particular conceptualisation of coping. However, both Pearce et al. (2002) and Clare (2002a) noted that the coping strategies they identified could be divided into emotion-focussed and problem-focussed strategies, in line with Lazarus and Folkman (1984). There also appear to be examples of appraisal-focussed coping (e.g. Kemp, 2003). Strategies could also be organised according to function (see Ferguson & Cox, 1997). Examples of strategies reported by three or more studies are:

seeing the humorous side of difficult situations (e.g. Harris & Sterin, 1999; Nygard & Starkhammar, 2003); using social support (e.g. Kemp, 2003; Gillies, 2000); setting lower limits/reducing expectations (e.g. Gillies, 2000; Pearce et al., 2002); using written or visual prompts (e.g. Keady & Gilliard, 1997; Nygard & Öhman, 2002); preventing problems by relying on routines or developing habits (e.g. Nygard & Öhman, 2002; Nygard & Starkhammar, 2003); seeking professional help and information (e.g. Pearce et al., 2002; Keady & Gilliard, 1997), and normalising and/or minimising problems (e.g. Clare, 2002a; Gillies, 2000). A number of authors distinguished between managing the primary cognitive problems of dementia and the secondary difficulties resulting from these. Refer to Table 1 for a full list of the coping strategies that have emerged from studies.

In addition to the common strategies reported above, Harris and Sterin (1999) found that some participants spoke of “giving up”. The lack of evidence of this in other studies may be due to biases in participant samples towards people who are coping more successfully, or have greater confidence, for example. Also, participants’ self-reports are likely to be subject to social desirability. In an observational report, Cheston et al. (2003) noted that a number of dementia psychotherapy group members wished to be forgotten about, in order to reduce their sense of burden on others. The authors commented that feeling a burden was highly distressing for these people, and allowing themselves to be forgotten represented one of the few ways in which they could demonstrate acts of caring towards their supporters. Harris and Sterin (1999) also appear to be the only authors who reported that participants turned to their spiritual or religious faith as a means of coping.

Finally, Nygard and Öhman (2002) found that participants reflected more on the inadequacy of the strategies they reported than their actual efficacy. There was also an explicit emphasis on cognitive apprehension and awareness of possible shortcomings running across many of the strategies. It is difficult to compare this with other studies, as efficacy of coping is generally not explored or commented upon, and it may be that participants were biased towards reporting the more successful strategies from their coping repertoires.

Defences and Coping with Dementia

Due to the self-report nature of these studies, the role played by unconscious defences in coping with dementia is not acknowledged. It has been suggested that denial can be adaptive for people with dementia, serving as a protective cognitive bias which is used when the environment is not sufficiently safe for the individual to explore their experiences (e.g. Bender & Cheston, 1997; Clare, 2002b). Other biases demonstrated by people with dementia have been found to include: attributing difficulties to age-related decline or situational factors, making selective comparisons with those who are perceived to be worse off, seeking positive evidence to counterbalance negative information, and ignoring or discounting negative information (Clare, 2002b; Taylor & Brown, 1988). Aspects of these are evident in the studies related to coping in dementia. Controlling internal meanings in this way may be the only way in which individuals can exert control over their lives.

Based on their clinical experience and interviews, Bahro, Silber and Sunderland (1995) concluded that, in the early stages of dementia, people used a variety of coping defences, finding denial, avoidance, dissociation of affect,

minimisation, externalisation, somatisation, displacement and self-blame to be evident. They commented that the cognitive deficits that increase as dementia progresses promote the increased need for these psychological defences. Bender and Cheston (1997) also suggested that living in the past is another adaptive means of coping. They suggested that this allows people to establish an identity other than the often negative one associated with their present self, and to explore their current experiences on an emotional level by drawing comparisons and taking metaphors from the past (see Bender & Cheston, 1997). However, further research would be required to justify the conclusions drawn. It may be that people with dementia rely on an identity based on the long-term past due to the increasing unavailability of autobiographical memory for the more recent past (see Kopelman, 1989; Eustache et al., 2004). A number of studies have reported that people with dementia present confabulated or imaginary roles (e.g. Cohen-Mansfield et al. 2000; Golander & Raz, 1996). Biggs (1997) considered the social mask as a tool to manage or mediate the gap between the restrictive social environment and expanded inner self.

In summary, research investigating coping in dementia is still in its very early stages. However, those qualitative studies that exist indicate that older people with dementia cope with their difficulties using a wide range of strategies and styles. Studies reporting coping profiles have suggested that individual differences in coping would be expected (e.g. Kitwood, 1997). In many cases, coping strategies emerging from studies can be fitted with popular coping paradigms and distinctions from the general literature (e.g. emotion-focussed vs. problem-focussed coping, Lazarus & Folkman, 1984), understandings about coping in later life, and models of coping with chronic health problems. However, it appears that pre-existing models may not

comprehensively cover or fairly represent the complexities of coping with dementia. They may be insufficient in explaining the more complex levels of coping (such as overall coping styles or philosophies), or the ways in which these interact and presumably change as dementia progresses. No single study appears to have attempted to provide a comprehensive overview of coping in dementia in general: studies either focus on one aspect of dementia, or investigate coping in the context of wider experiences of dementia. Taken together, the limited number of studies appear to provide complementary information about a range of coping methods, but it is unlikely that the full range of coping types are comprehensively covered. Also, caution must be taken in further interpreting how coping strategies identified in different studies fit together, overlap and/or generalise across situations, and some of the assumptions and biases in these studies have been highlighted.

Conclusions

It can be concluded that the challenges of dementia are diverse and perhaps unique, in that dementia leads to loss of functioning in a number of domains, including the very capacities and resources individuals rely upon to cope with adversity. Research on subjective experiences in dementia suggests that challenges range from managing tasks of everyday living to the more abstract tasks of maintaining a sense of self and finding meaning in what is happening.

The way in which individuals cope with these difficulties is an important topic that needs to be explored and understood in its own right. It has implications for improving the focus of psychological interventions and, more generally, promoting well-being in this important group of people. The general population may have much to learn from how these people manage such adversity.

Models and research from the general coping and health literature provide us with a potential theoretical basis from which we can begin to develop understandings of coping in dementia. However, these may need elaborating and adapting to incorporate emerging research evidence. Contextual factors, such as the developmental stage of later life, are repeatedly highlighted as important in influencing modes of coping. Research from the field of ageing suggests that older people strive to maintain a sense of continuity and personal integrity, and make meaning of their lives (Coleman, 1996). Older people with dementia appear to work towards similar goals. However, the nature of challenges, and therefore the routes to achieving these goals, are perhaps very different. In order to work towards an

improved quality of life for people with dementia, it needs to be acknowledged that these disorders present challenges to coping resources beyond those generally experienced in later life, or those posed by other chronic health problems.

There is a lack of shared understanding or definition of coping in the general literature, and theoretical distinctions have been made between many different types of coping. There is a need to be open-minded about what constitutes coping and consider it in the broadest sense, so as to identify what is adaptive for individuals at different stages of their experience of dementia.

Importantly, studies indicate that it is both viable and highly informative to involve people with dementia in such research; which can be argued to be the most valid way of achieving a comprehensive understanding of their experiences. Research in this area clearly requires a sensitive approach that is likely to involve the researcher on personal and emotional levels: this may help to explain why this area has been neglected in the past. Overall, research on coping with dementia is still at an early, exploratory stage, and there is insufficient evidence to begin to make assumptions about the similarities and differences with coping in other situations, or develop models. The few studies that exist provide some detailed insights into specific aspects of coping. However, many have made held intentional biases towards exploring specific aspects of coping, or made particular assumptions regarding the main challenges of dementia. Whilst this is useful and appropriate, it limits our current understanding of the full range of ways in which people with dementia approach coping and use strategies. In order to lay the foundations for future research, further qualitative studies are needed which aim generally to explore the full range of coping

strategies used, by eliciting the thoughts and experiences of people with dementia regarding coping. In doing this, it will be important to report the methodology used in sufficient detail (regarding interview schedules and participant characteristics, for example) to allow for the comparison of results and to make explicit the level of generalisability of findings. Initially, it will be more appropriate to study coping comprehensively in more homogenous samples (see also Pearce et al., 2002) than to explore coping in diverse groups, where individual differences may detract from the overall picture. Following this, the diversity of methods of coping across people with different characteristics and across different contexts, for example, can be explored. Taken together, existing studies suggest a wide range of coping mechanisms, from coping style to coping strategy levels, but it is difficult to understand how these fit together in the absence of a study that comprehensively explores and reports these.

Once this foundational research has been achieved, further work will be possible to improve our understanding of particular key areas. For example, little is known about how the person with dementia perceives the coping challenges that they face (which are most important, and which are more demanding than others, for example), how the role of coping is perceived, or the types of coping associated with a more positive quality of life. Individual differences in coping and the relationship between coping mechanisms and other psychological, neurological and social variables, including pre-morbid styles of coping and relationship with carer stress, is also a key area that has not been explored in any detail. Longitudinal studies are also needed as a means of understanding changes in the coping process as dementia progresses. The development of a psychometric scale of coping with dementia would aid clinical assessment, and could be used in research studies. Overall, the potential

for further studies is immense, with a broad range of implications for service provision and clinical practice.

The difficulties associated with dementia are highly amenable to psychological interventions (see also Woods, 2001). Broadly, it appears that interventions targeting identity issues and providing opportunities to explore the meaning of experiences may be useful for many people. The potential importance of working systemically to address social, emotional and environmental challenges has also been suggested from the findings of the current review. However, it may be inappropriate to draw further clinical implications at this early stage.

In summary, research aiding understanding of how people cope with the challenges of dementia is only in its early stages. An increased interest in this field will have important implications for developing better services, and generally facilitating a more positive quality of life for this group of people.

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EMPIRICAL PAPER*

**Investigating the Ways that Older People Cope With
Dementia: A Qualitative Study**

Running head: Coping with Dementia

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* American Psychological Association publication guidelines have been applied, as if for submission to *Age and Ageing* (refer to Appendix A for Guide for Authors).

ABSTRACT

This qualitative study explored how older people cope with dementia, by engaging 12 people with early-stage dementia in semi-structured interviews. Interpretative phenomenological analysis (IPA) was used to identify the shared themes in participants' accounts.

Three major themes emerged in relation to coping: "managing identity in relation to dementia", "making sense of dementia", and "coping strategies and mechanisms". The latter theme divided into "everyday, individual strategies", "coping in relation to others", and "personal attitude/approach". Issues of conflict and control were evident across all themes; individuality and the importance of contextual factors in coping with dementia were also evident. Findings are discussed in relation to previous research in this field, and some implications for further research and clinical practice are outlined.

INTRODUCTION

Understanding the way that older people cope with dementia has important implications for the enhancement of psychological well-being and quality of life of this group of people. Recent advances in dementia research have begun to elucidate some of the experiences of people with dementia from a psychological perspective. However, there are few studies providing information about the ways in which people manage the many challenges posed by dementia.

Moos and Schaefer (1986) identified seven major adaptive tasks that individuals face in coping with illness, which relate to the tasks of dementia. These include, maintaining an emotional equilibrium and sense of self (including sense of mastery and feelings of competence); maintaining relationships with friends and family; and, preparing for future possibilities, such as disability and death. For older people, such tasks superimpose on the challenges associated with later life, which involve achieving integrity (Erikson, Erikson & Kivnick, 1986); maintaining a persistent and positive perception of the self (e.g. Ruth & Coleman, 1994); and, making meaning of life (e.g. McAdams, 1990) in the context of a number of losses. Dementia poses further demands on coping resources, through its primary effects on cognition and behaviour; secondary effects on personal, social and occupational functioning, and the subsequent impact of others' reactions to both of these (see also Kitwood, 1993). In addition, the 'coping tasks' faced on a daily basis are far more serious and wide-ranging than those commonly associated with later life. Dementia can be understood as a unique coping challenge. Not only does it impact on most aspects of daily living, but it also undermines the individual's coping resources. Nevertheless, it appears that maintaining a sense of self and finding meaning and

purpose in life continue to be the central existential challenges faced (e.g. Sabat & Har  , 1992; McGregor & Bell, 1993; Menne, Kinney & Mordhardt, 2002; Clare, 2003).

Broad models of coping (e.g. Moos & Schaefer, 1993; Lazarus & Folkman, 1984) provide basic frameworks for distinguishing between different types of coping. Coping has traditionally been classified according to focus (i.e. emotion-focussed, problem-focussed or appraisal-focussed coping, Folkman & Lazarus, 1984) or function (i.e. approach coping, avoidance coping, emotional regulation, and reappraisal, Ferguson and Cox, 1997). The literature consistently identifies the importance of the complex interaction between individual and contextual factors in determining coping strategies used and how adaptive these are (e.g. Holahan, & Moos, 1996). Radley and Green (1987) identified four modes of coping with chronic illness: active denial; resignation; accommodation to the condition; and, secondary gain. Literature on coping in later life suggests that the ageing self is remarkably adaptive and resourceful in maintaining a positive sense of self and self-esteem, despite the increased number of losses faced at this stage in life. Models of assimilation, accommodation and immunisation (see Brands  der & Greve, 1994) and selection, optimisation and compensation (see Baltes & Baltes, 1990) may be helpful in understanding this. The general literature on coping is helpful in considering the mechanisms in coping with dementia. However, it cannot be assumed that it can be directly applied without prior investigative research.

Research investigating the individuals' perspectives of coping with dementia is still in its very early stages: there are few studies directly investigating this area, in contrast to the relatively large body of research pertaining to the coping of supporters

of people with dementia. This may be due to the ethical complexities and personal involvement required on the part of the researcher to engage individuals with dementia in such research (also see Wilkinson, 2000). The few studies that do exist are qualitative in nature, reflecting the early, investigative stage of research. Some provide information on coping in the context of broader investigations of personal experiences of dementia (e.g. Keady & Nolan, 1995; Keady & Gilliard, 1997; Kemp, 2003). Others' findings relate to how individuals with dementia cope with a range of specific, concrete activities of daily living (Nygard & Öhman, 2002; Nygard & Starkhammar, 2003); the impact of on sense of self, or identity (Clare, 2002a; Pearce, Clare & Pistrang, 2002; Harris & Sterin, 1999); and, the specific aspect of memory loss (Gillies, 2000). Nearly all studies commented on the wide range of coping strategies used by individuals, and the importance of individual and contextual factors in coping. General coping patterns or philosophies that repeatedly emerged across studies included both attitudes of wanting to fight dementia and simultaneously needing to accept its impact; focussing on the positive aspects of life; and, denial or avoidance of problems. The strategies most commonly reported in the studies include: seeing the humorous side of difficult situations; using social support; setting lower limits or reducing expectations of abilities; use of written prompts; preventing problems by relying on routines or developing habits; seeking professional help and information; and, normalising and/or minimising problems.

Importantly, these studies inform us that people with dementia are able to participate meaningfully in qualitative, interview-based research. It has been shown that their contributions are not only reliable, valid and accurate when compared with information from other sources (e.g. see Pearce et al., 2002), but also provide rich and powerful insights into the complexities of their experiences.

However, further studies are needed to complement and extend these findings. Existing studies have either prompted participants to reflect on specific aspects of coping and dementia, or explored coping within wider research aims: whilst these provide detailed insights into these aspects of coping and dementia in general, it is difficult to develop a full overview of the range and nature of coping strategies and processes.

Due to the unique aspects of dementia, it cannot be assumed that people with these disorders continue to use the types of coping processes described in existing models. Although findings regarding some specific coping strategies can be placed within popular coping paradigms, there is inadequate information to assume that existing models are sufficient to explain or account for all aspects of coping experiences in dementia, or the ways in which coping methods interact and, presumably, change as dementia progresses. It would, therefore, be inappropriate to directly apply existing coping paradigms in carrying out further research in this field.

The purpose of the present study was to extend previous findings by broadly exploring coping with dementia. It was intended to elicit the views of people with mild dementia about the range of ways in which they coped with various difficulties faced, without imposing preconceptions about coping challenges, or the nature of coping. In doing this, the study aimed to provide a more comprehensive understanding of the range of coping methods and strategies used by people with dementia.

METHOD

Methodological Approach

Due to the lack of empirical evidence regarding coping in dementia and the intended focus on subjective experiences, an open-ended, investigative, qualitative approach with a clear focus on coping was deemed most appropriate. Both study aims and participants' cognitive (particularly expressive) impairments were taken into account in considering the choice of qualitative method. Interpretative Phenomenological Analysis (IPA) was considered the most appropriate approach as its epistemological underpinnings best matched the research aims, i.e. to explore participants' personal experiences of coping with dementia (see Appendix B).

IPA provides a method of analysing interview data to develop a rigorous and comprehensive structure of emergent themes, drawing an epistemological perspective of critical realism. It is phenomenological, in that it attempting to explore and report what participants believe and think about the topic in question, also drawing on hermeneutics. It is also interpretative; acknowledging that the participant's views are elicited through an interactive process involving the researcher's own subjectivity (see Smith, 1996, 2004). In the present study, it was assumed that people with dementia would have a range of ways of managing challenges faced and that they would be able to identify and reflect on these, with facilitation, to provide valid accounts of their experiences. As a trainee clinical psychologist, the author had an orientation towards cognitive and behavioural understandings of coping processes, and a particular interest in identity in dementia.

Participants

Inclusion and Exclusion Criteria

Criteria for participation were that the person had been referred to a Community Mental Health Team (CMHT); was diagnosed with mild dementia; had a Mini Mental State Examination (MMSE, Folstein, Folstein & McHugh, 1975) within the past two years; was proficient in English; and, capable of giving informed consent to participation. People were not approached if they had unstable mood or other current major physical or psychiatric disorder, or were experiencing life events thought to impact significantly on their ability to engage or increase the likelihood of distress in the interviews.

Sample Size and Characteristics

Twelve people with dementia were recruited for the study¹. Participants' ages ranged from 58-81 (mean 71.08, SD 7.44) years; 5 were female and 7 male. Participants scored between 19 and 28 (mean 25.25, SD 2.86) points on the MMSE, as initially assessed within 20 months prior to participation. Continuous monitoring indicated that scores had not fallen below 19 at the time of participation. Eleven participants were taking acetylcholinesterase-inhibiting medication. All participants were of white ethnic origin; 11 were British, and one man was European (but had lived in England for 20 years). All had been told of their diagnosis of dementia, which occurred between 2 and 20 months prior to participation: 9 had been diagnosed with Alzheimer's disease (AD), 3 with vascular dementia. Eleven

¹ Sample size was in keeping with the IPA approach see Smith & Osborn, 2003.

participants lived in their own homes: 9 with their spouse and 2 alone. One participant lived in supported accommodation for people with dementia. During the interviews, 8 participants mentioned a chronic physical complaint, including back pain, hearing, arthritis and heart problems. Of the 9 participants who spoke of their occupational background, 4 (all men) had managerial or professional occupations, 2 described themselves as housewives and the remainder had technical, clerical or manual jobs. Interviewees were estimated to be of average to above-average socio-economic status. See Appendix C for brief descriptions of participants.

Recruitment

In total, 23 people were approached; 11 refused and 12 agreed to participate². Of those who declined, 2 indicated believing they would find it too anxiety provoking to take part, and 2 had other priorities at the time of contact; the others did not give a reason.

Of the 12 participants, 9 were recruited via a memory skills group, which they had attended for a length of 6 weeks to 2 years. Eight had completed this group and 1 had just commenced attendance. Five of these people were also attending a weekly support group for people with dementia at the time of the interviews. One participant was recruited following a psychology assessment. These participants were approached, in person, by a Clinical Psychologist during routine contact and given an information sheet (see Appendix D). The remaining 2 participants were recruited via an outpatient memory clinic, where a psychiatrist provided them with

²Eight declined to participate when initially approached; 3 stated an interest in participating but then declined when contacted by interviewers.

the information sheet during a routine appointment. As recommended by Dewing (2002), those who expressed an interest in participating were contacted by telephone.

Eleven participants chose to be interviewed in their own homes, and 1 elected to be interviewed at the local CMHT base. Prior to beginning the interviews, researchers spent some time introducing themselves to the participant and engaging them in casual conversation. The information sheet was verbally summarised, checking participants' comprehension of each section and answering questions, before gaining written consent (see Appendix E). Tape-recording began following the signing of the consent form. A short de-briefing was given after the interview³.

Procedure

In designing the procedure, careful consideration was paid to the optimal inclusion of people with dementia in research (see Hubbard, Downs, & Tester, 2003; Wilkinson, 2000).

Construction and Application of Semi-structured Interview

The interview schedule was developed by drafting items in supervision, and piloting these on peers. Questions were designed to be open-ended, and no presuppositions were made as to what constituted coping or managing difficulties.

³A full written debriefing, including the findings of the study and an invitation to attend a verbal presentation, will be sent to participants following the completion of the written account of the study. All participants indicated that they found it acceptable to wait this period of time before receiving a full debriefing.

The first two interviews were initially considered as pilots, but later included in the study due to the minimal changes made to the procedure following piloting.⁴

Details of the Interview

Interviews lasted between 40 minutes and 3 hours (length was determined by the interviewee), and were tape-recorded. As IPA is committed to the detailed exploration of personal experience, efforts were made to interview participants alone. However, 5 participants chose to have their spouse present during the interview. To minimise influence on participants' response, the spouse was encouraged to make any contributions at the end of the interview, although their contributions were later omitted from the analysis.

The semi-structured interview (see Appendix F) prompted a comprehensive exploration of the range of challenges participants faced as a result of dementia (e.g. has there been anything difficult that you have had to manage/deal with/cope with? Could you tell me a bit more about this? What separates a good day from a bad day?), and the ways in which they coped with these (e.g. So how do you think you coped with this?/What helped you to manage this?/How did you react?). The interview schedule consisted of a variety of different questions to prompt these areas. Towards the end of the interview, participants were invited to consider what advice they would give to someone who had recently been diagnosed with dementia (or similar difficulties to themselves). The schedule was designed to be flexible,

⁴ The only change made at this stage was to place more emphasis on describing the interview as a casual conversation when making initial telephone contact with participants. The interview schedule was not revised any further following piloting.

allowing unanticipated topics or themes related to coping to be discussed (see Smith, 2004). Interviewers also drew upon clinical interviewing skills to provide more specific prompts. Ambiguous statements were explored in an open way, particularly avoiding the use of leading questions. Reflection and open-ended prompts were used to facilitate discussion.

Interviews were arranged as an informal conversation. Any difficulties in comprehension or communication were considered to be the shared responsibility of the interviewer and participant, and interviewees were put at ease as much as possible prior to the interview. Participants were reminded that they were experts in speaking about their experiences with dementia, and that the interviewer was keen to learn about these (see Wilkinson, 2000; Kvale, 1996). Difficulties were referred to as memory or thinking problems until an opportunity could be taken at the beginning of the interview to ask participants how they referred to their difficulties (see Appendix G). Participants were subsequently encouraged to speak about the full range of difficulties they encountered.

One of two interviewers conducted each of the interviews: the author interviewed 8 participants, and an assistant psychologist interviewed the remaining 4 participants (see Appendix H for an overview of training provided to the second interviewer). The second interviewer was recruited with the hope of increasing the diversity of responses, which could be influenced by the interviewer (Smith, 2004), and to make interviewer effects more transparent when conducting the analysis. The author and second interviewer kept reflexive accounts throughout involvement in the research process, in which they reflected upon issues such as their motivations to

carry out the research, responses to different aspects of the research process, and personal biases and assumptions that may have affected it (see Appendix I).

Ethical Considerations

Ethical issues were particularly pertinent to the present study, with respect to the focus of the study and characteristics of the participant group (see Wilkinson, 2000). Issues such as informed consent, the possibility of participant distress, safety issues, and confidentiality/anonymity were considered at each stage of the research process, from designing through to reporting stages (see Appendix G). Local NHS Research Ethics Committee approval was obtained (see Appendix J).

Data Management and Analysis

Analysis Procedure

The tape-recorded interviews were transcribed by the interviewers according to clearly established guidelines (Silverman, 2001), and any additional observations made during the interview (e.g. body language, vocal intonation) were noted. A brief transcription check was carried out (i.e. two interviewers transcribed the same 8-minute portion of tape-recorded material).

Analysis of interviews was based on the IPA procedure outlined by Smith, Jarman and Osborn (1999), which aims to provide a comprehensive account of shared themes that are representative of the original texts. The analysis process involved describing and interpreting the meaning of all relevant information from each transcript, and grouping these meanings into thematic clusters, through an

iterative process of reading and re-reading. Once this had been completed for each transcript, a shared theme analysis was conducted, initially on 4 accounts (chosen to represent the range of themes arising from all 12 accounts). The tentative themes were re-examined across all 4 transcripts, to provide a full list of themes. Similar or related themes were then grouped, to produce shared theme clusters. This resulted in a hierarchical structure of themes that represented the 4 accounts. The remaining 8 transcripts were coded similarly, with reference to this tentative structure. Analysing themes from these 8 accounts led to a revision of the initial hierarchical theme structure.

The analysis for the present study was considered complete was when it resulted in a coherent, comprehensive account of coping in dementia, as understood and conveyed by participants, which included interpretations on a number of levels (Smith, 2004).

Representation of Results

The excerpts contributing to each theme were studied again to devise a full verbatim account of the content of each theme. Where there was diversity within sub-themes, this was described in full (ensuring that the complexity and detail of original data was preserved in the process of developing a shared account). Self-explanatory quotes that were felt to summarise the essence of the sub-theme were chosen to exemplify each sub-theme. As far as possible, participants' own words were used to label themes.

Validity Checks

Supervision and peer review were used extensively throughout the analysis process to provide validity checks and ensure the comprehensiveness of interpretations, resulting in minor revisions throughout the process. In particular, supervision was used to reflect upon and limit the effects of the author's personal biases. The principal researcher and two supervisors simultaneously analysed a portion of one transcript, to compare resulting descriptions and interpretations. Experts in IPA who had not been involved in the development of the study, were also consulted at various stages of the process.

A formal check of the validity of the analysis and interpretation of participants' accounts was carried out by the second interviewer (who had not had any input into the analysis process beyond transcription) and a second independent person with knowledge of IPA. All original excerpts contributing to 5 of the sub-themes (chosen randomly) were closely scrutinised, and the 'paper trail' through the stages of analysis followed for verification.

Overall, the analysis aimed to achieve a detailed and comprehensive description of themes related to coping with dementia, taking measures to ensure quality of results (following guidelines from Elliott, Fischer, & Rennie, 1999; and, Yardley, 2000). Appendices K and L describe the analysis procedure in detail, and contain an example of the analysis of an excerpt of original transcript.

RESULTS

Three major themes were identified in relation to coping with dementia⁵: ‘Managing identity in relation to dementia’, ‘Making sense of dementia’ and ‘Coping strategies and mechanisms’. These emerged as being reflexively connected, as depicted in Figure 1.

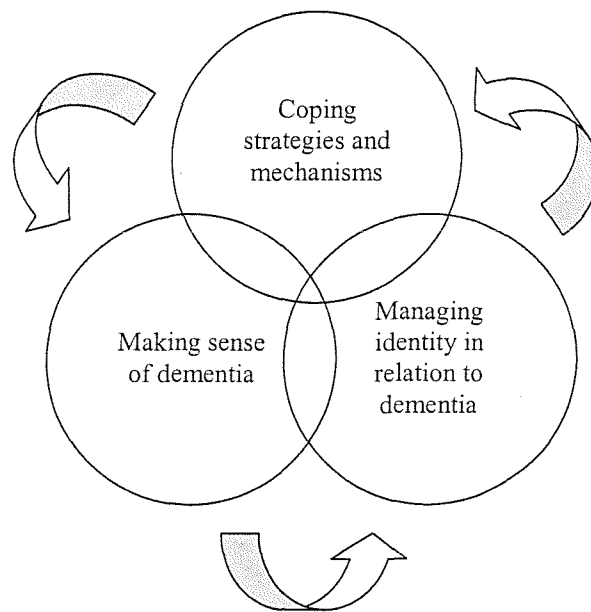


Figure 1: Diagrammatical representation of the major themes

The major themes divide into sub-themes; “Coping strategies and mechanisms also has a number of sub-theme components⁶. Table 1 provides an overview of this hierarchical structure.

⁵ Descriptions of the individual challenges posed by dementia also emerged (see Appendix M); however, it was beyond the scope of the present study to explore and report these.

⁶ Between 4 and 12 participants contributed to each category

Table 1

Emergent themes

| Major theme: | Sub-theme: | Sub-theme component: |
|---|---|---|
| Managing identity in relation to dementia | Continuity between the past and present self | |
| | Discontinuity between the past and present self | |
| | Integration of dementia | |
| | Lack of integration of dementia | |
| | Self as able/valued | |
| | Self as substandard | |
| Making sense of dementia | Making sense of dementia as a whole | |
| | Making sense of individual experiences | |
| | Lack of understanding | |
| Coping strategies and mechanisms | Everyday, individual strategies | Use of visual prompts and formal memory techniques |
| | | Information |
| | | Being logical |
| | | Cathartic expression |
| | | Say it whilst it's there |
| | | Medication |
| | Coping in relation to others | Talking and sharing |
| | | Being with similar people |
| | | Getting help |
| | | Social comparisons |
| | Personal attitude/approach | Being positive |
| | | Looking after myself/taking it easy |
| | | Putting problems into perspective and knowing when to let it go |
| | | Patience and having faith |
| | | Accepting it vs. fighting it |
| | | Avoidance and covering up vs. being open and not hiding |

Description of Themes⁷

Please refer to Appendix O for a table indicating which themes individual participants contributed to.

Managing Identity in Relation to Dementia

Managing identity was repeatedly referred to as not only a challenge of dementia, but also a way of managing dementia. The sense of identity, or self (“who I am/me”), was referred to in terms of continuity, integration and perception of self. These appeared to be perceptions that enabled participants to protect a sense of identity.

Continuity between the Past and Present Self

Participants referred to an ongoing use of skills, enjoyment in the same activities, and/or continuity of personal characteristics (characterised by, “I still”/“I never was”).

(Participant had previously spoken about difficulty with handwriting)

“When I come to write a birthday card for the family, [*name of husband*] does a lot of the kind of writing. But when it’s for the family I really like to write it. I love choosing cards that I, you know...It’s always been part of my life is choosing the card for the person.” (P211, 10-16)

There was evidence of both a natural sense of continuity, and an ongoing effort to maintain a sense of continuity in some areas. Participants spoke of pre-existing skills (e.g. organisation, having a routine) becoming more valuable. Some

⁷ Refer to Appendix N for further exemplary quotes for each of the themes

talked about or demonstrated focussing on characteristics and roles that were unaffected by dementia. Continuity was achieved by both integrating dementia with the self and/or viewing dementia as detached from the self (see “Integration of dementia” and “Lack of integration of dementia”).

Discontinuity between the Past and Present Self

Interviewees referred to perceiving changes resulting from their experience of dementia as discontinuous with their prior sense of self. This involved acknowledgement of a decrease in valued abilities and characteristics.

(Participant talking about his ability to think logically)

“...but it's not as good as it should be. It's not as good as it used to be therefore it irritates from that point of view....not quick enough.” (P207, 873-878)

However, some participants' also recognised positive new skills and/or characteristics, developed as a result of their experience with dementia (see “Being positive”).

Integration of Dementia

Some participants demonstrated having integrated experiences of dementia with their pre-existing sense of identity. This was evident from participants relating current difficulties to pre-existing characteristics or perceived areas of weakness; making direct references to dementia being “my problem” or “part of me”; and/or acknowledging dementia as one of the different aspects of the self.

“...and when I go there, I go to be a woman. It's the women's group. It's not like when I go to the memory club to be, um, well to be with other people with Alzheimer's. Which is good for me as well. I go there as someone who has Alzheimer's if you, um (*pause*). It's the different bits of me at these places, um [*pause*]. It's all me, but I'm being most conscious of the woman bit with the women and the Alzheimer's bit at the club.” (P211, 591-604)

Lack of Integration of Dementia

Others indicated that they did not relate dementia to their identity. There were descriptions of dementia as a series of highly unfamiliar, and sometimes traumatic, episodes. There was also evidence of denial of having dementia; and of dissociation and/or minimisation of frightening or serious episodes, whilst less serious episodes had been accepted and integrated.

(Participant talking about becoming disorientated)

“But I knew exactly where I was at and it hasn't happened since...I was petrified...it made me think of how people that really lose their memory, because that's just what I call a blip wasn't it. It must be terrible.” (P202, 449-457)

Some participants spoke of difficulties accepting and integrating their own acknowledgement of difficulties.

“Yes, I think I start opening cupboards, and then I stop and think. And I think it's partly because my, my [*pause*]. My brain understands the um, oh, [*pause*]. My brain refuses to accept the idea that my thinking processes have slowed down [*pause*].
....And it, it's as if, if I give it a bit more thought I'd get it right the first time, but I

don't like the idea of accepting the fact that my thought process is no longer as efficient as it used to be." (P203, 61-69)

Self as Able/Valued

Many people repeatedly referred to positive aspects of the self through reference to skills, achievements, characteristics and others' perceptions of them. There were many examples of this directly proceeded talk about "inabilities" or difficulties. One participant explicitly commented on the importance of positive sources of esteem in the context of what she was unable to do.

(Participant referring to newly acquired skills in alternative therapies)

"...is another big lift when you think there are so many things that I just can't do."
(P211, 157-159)

Participants spoke of positive aspects of both the past and present self. Many asserted identities as "helpers", and were eager to aid others by taking part in the research. A number of participants commented that their abilities were masked by the challenges of dementia. In the following example, the participant described how he was able to answer the question, but could not access the words from his memory long enough to communicate them.

"It was something [*pause*]. It was something that you asked me, something you asked me. Instantly the answer is formulated in the brain, and. Before I could even answer, put it into words that you could hear, I then knew I'd lost the first word of what I wanted to say." (P201, 44-49)

The only positive sense of self that emerged from the accounts of a few participants took the form of assertions against the negative positioning of others, or the acknowledgement of an absence of negatives.

“So I haven’t wasted your time, then.” (P212, 444)

Self as Substandard

A majority of participants (half of whom also asserted the self as positive) gave frequent indications of feeling that they were “substandard”, or not good enough, in comparison with other people and/or the past self. Participants indicated perceiving themselves as silly, stupid, daft or weak as a result of dementia. There was also evidence of self-criticism and self-blame. Some people spoke of the negative identities ascribed to them as a result of dementia, such as being disabled, a child, stupid, or frightening. There were also indications of participants feeling insane or “round the twist”.

“And she treated me like I was a little girl.” (P212, 108)

Making Sense of Dementia

Many participants expressed or demonstrated motivation to comprehend experiences related to dementia, in a way that was meaningful to them. Some used the research interview as an opportunity to explore their understanding. In doing so, at least one participant indicated having enhanced his comprehension of dementia.

Making Sense of Dementia as a Whole

Trying to make sense of dementia as a whole appeared to be an ongoing process for many participants, who voiced a sense of frustration and sadness at not being able to reach an understanding that seemed reasonable to them. Some related dementia to biological and/or medical understandings, describing an abnormal brain, brain dysfunction, brain decay, or viruses, for example.

“Because it’s like having a – to me, is like, is a disease or is a thing you have, a cold, you have a cold. A virus.” (P208, 362-365)

Broader metaphors and familiar frameworks were also used to understand dementia. For example, Participant 201 referred to his understanding of physics, something that was abstract but familiar and comprehensible to him, unlike dementia.

“Ever so faint, I knew it had just decayed [*pause*]. Like a sine wave...It was like it just decayed away, like that [*shows flattening sine wave*].” (P201, 67-72)

Other participants referred to the brain as a computer, engine or machine that was dysfunctional in some way. Less overt parallels were also drawn with weakening physical strength and increased frailty.

Making Sense of Individual Experiences

Participants also demonstrated trying to make sense of individual difficulties. For example, some compared individual experiences of dementia with past traumatic

events, whereas others focussed on understanding the factors that contributed to specific problems, such as trying to explain the onset of dementia.

“Because this paperwork was the biggest strain I’d ever come across. [*Pause*]. I was trying to cope...I think, um, it’s what turned my brain.” (P201, 604-610)

Lack of Understanding

A majority of the participants repeatedly indicated difficulties associated with making sense of dementia. Dementia, or related experiences, were described as strange, puzzling and/or unbelievable.

“That’s what puzzles me sometimes, I think I said this earlier on. I can go back to when I was about seven years old....But something that happened, like. Like when you’ve gone, if somebody rang me and said what have you been doing today, I might say I don’t know. I could have forgotten.” (P202, 1240-1247)

There was evidence of acceptance of this lack of understanding in some cases, whilst a struggle was evident in the accounts of others. In some cases, difficulties understanding were related to a lack of available information. Also, some participants reflected on the uncertain future progression of dementia.

“Whilst it’s fading and then it’s gone. I, I find that is um, I don’t find it frightening or upsetting, although I sometimes wonder, I wonder you know how this ends, you know, how does it round up. Well eventually, of course, I die.” (P203, 159-162)

Coping Strategies and Mechanisms

A wide range of ways of coping emerged. Participants spoke of coping in terms of individual, everyday strategies, coping in relation to other people, and coping attitudes and approaches.

Everyday, Individual Strategies

This involved cognitive and behavioural strategies that the participant performed (or could perform) alone.

Use of visual prompts and formal memory techniques. Many participants mentioned using written prompts to aid memory and minimise cognitive confusion. This included keeping diaries and making notes or lists. Some participants indicated that these were not always effective, as the existence of the prompt was forgotten, or it was insufficient to cue memory. Participants also described making visual cues as reminders, and seeking visual cues when experiencing memory loss or confusion, which were usually more effective than imagining visual images or thinking alone.

(Participant referring to seeing something on a computer screen as a prompt to know what to do next)

“Yes, to think. And I had to see practically and then it ahh, then, and then I would say right.” (P208, 694-695)

Participants also described using word association, and going through the alphabet to prompt memory, although this was not always successful.

Information. Interviewees described seeking or receiving information and advice from the media, professionals, and other people with dementia, both directly and indirectly. Three participants had knowledge from previous contact with others who had dementia.

“I think the more info you have on it, the better.” (P207, 465)

It appeared that the usefulness of information provided partly depended on timing: for example, some spoke of ‘too much’ information being unhelpful at the time of diagnosis. In some instances, there were indications that medical information available was perceived to be too far removed from participants’ subjective experiences, or inadequate in fully explained symptoms.

Being logical. Some participants described stopping and thinking when they encountered a difficulty, planning before acting to prevent difficulties/mistakes, and learning from past experiences.

(Participant speaking about remembering to put the car in gear)

“And I think I’m far less likely to repeat that particular type of error. Because the first thing I shall think of now if I do switch the thing on and it doesn’t go, I’ll think, oh, I know what that is. I had this the other day, I forgot to do so-and-so.” (P203, 1412-1417)

A few people described practical systems or routines for managing or preventing difficulties. This included “rewinding” (retracing steps) or starting again when things went wrong or memory failed; following steps to rectify situations physically; and, using spatial cues to aid memory.

(Participant talking about having a system of keeping her tablets in different places to aid her memory)

“I know I have to take one, er, two in the evening. I got one up there [*points to bathroom upstairs*] and one out there [*points to kitchen, laughs*]...I’ve got one upstairs, for the same ones, and I take one in the morning...So there’s one up there and one down here...Otherwise I think, oh, which one did I take?” (P209, 1254-1278)

Many participants appealed to logic when experiencing memory loss or confusion. This included developing a series of steps to resolve difficulties, or doing one thing at a time to prevent feeling overloaded.

Cathartic expression. Some participants described swearing, shouting, slamming doors, crying and engaging in forms of physical exercise, such as cleaning and walking, to make themselves feel better. Participants described limitations to the extent to which they were able to use this strategy, due to interpretations others made of this behaviour.

“Sometimes I curse and blind and shout it out [*laughs*]. Anyone would think I’m barmy.” (P212, 259-260)

Say it whilst it’s there. Participants described and demonstrated politely interrupting the person they were speaking to, in order that they could communicate their thoughts before the memory trace was lost.

(Participant interrupts interviewer)

“Oh yes. Yes, because I can think – sorry I came straight back in.” (P201, 43-45)

Medication. A few participants described that taking medication had helped their memory. Many questioned how the medication worked, and indicated that the effect of medication contradicted their understanding of dementia.

(Participant talking about his memory having improved)

“Yes. I can’t understand it. The cells have been destroyed, and they’re not there any more.” (P208, 596-597)

Coping in Relation to Others

These methods of coping involved the contributions of other people.

Talking and sharing. A majority of participants indicated the usefulness of talking to family, friends, health professionals and strangers. Participants described feeling understood and more positive as a result of simply having someone to listen to them. Telling other people things also functioned to share the responsibility and reduce the burden of difficulties, and to increase their sense of safety at difficult times. For some, feelings of support appeared to compensate for feelings of loss in other areas.

“I think those are the main things. And those were things that were in between that filled the gap, somehow. I must say we got wonderful neighbours here who really helped.” (P208, 838-842)

Some participants who were living with a spouse referred to a shared identity and shared ownership of difficulties, whilst others indicated perceiving dementia as their problem.

(Participant describing his admission to hospital)

“He got us into hospital.” (P210, 239)

Being with similar people. Many participants explicitly spoke of the benefits derived from being with other people who had dementia, as this helped to normalise their own difficulties, prevent feeling alone, and model ways of coping.

“Well if there is a group yes, that would help, because it would help you to understand your problem...But seeing other people and listening very carefully to what they say, er, you realise that they got exactly the same problem as you have, and perhaps worse...And some people might even say the way they cope, or the way they don’t cope, and that is definitely not what to do...Listen to people. Not just, er, but really listen to what they say.” (P208, 995-2010)

Just knowing that others existed with similar difficulties was comforting for some. Some participants also indicated gains from being with people who had something in common with themselves other than dementia.

Getting help. All participants described seeking different levels of emotional and practical support from their spouse, family members, friends, professional carers and strangers. This included: remembering appointments; advocacy; and, guidance in practical tasks such as following directions and taking medication.

(Participant talking about being helped by his wife)

“She’s very supportive, yes, er, I won’t say dependent, but essential.” (P207, 117-120)

Social comparisons. Half the participants compared themselves with other people with dementia and other people more generally. Some indicated that comparing themselves to those perceived to be better off functioned to provide a sense of comfort. Comparing themselves to those worse off functioned to put their situation into perspective, or reinforce their own coping strategies.

(Participant talking about what is helpful about meeting other people with dementia)

“I think, um, knowing that people who are obviously worse off. And, er, they get a certain amount of comfort I think from seeing that there are people around who haven’t been as badly affected...And hearing other people’s stories and how they’ve coped.” (P203, 602-611)

Participants also commented how such comparisons could be unhelpful:

(Participant speaking about attendance to a memory group)

“It was difficult for me, you know, when the other members of the group are doing much better.” (P206, 119-121)

Personal Attitude/Approach

These were overall coping approaches, or ways of perceiving difficulties.

Being positive. Having a sense of humour evoked positive feelings in participants and others. In some cases, it created a point of contact or a shared experience. Humour also functioned to give perspective to problems, and diffuse difficult feelings.

“I suppose I try to take the um, the sort of the unpleasantness out of the situation...Um, I mean the, in the memory group, er, you know we sometimes roll about with laughter because something’s happened. Someone will come in and tell us you know, a funny thing that happened on his way to the meeting or something and all sort of daft things...And, er, I tend to sort of encourage that sort of thing because I feel that laughter is the best tonic, you know. And um, you have to be careful obviously because I wouldn’t want to hurt anyone. You know, er. Um. You never laugh at people, only at situations you know.” (P203, 287-302)

Many participants indicated relying on positive thinking, a positive outlook on life and an awareness of their ability to be positive and cope with problems.

“Yes, always stay positive and say we are going to be ok.” (P206, 462-463)

These participants also indicated: finding intrigue, stimulation and challenge in situations rather than feeling depressed by them; focussing on positive aspects of

situations and self-praise, rationalising negative thoughts; being willing to try anything that may help; holding onto a sense of hope; making the most of opportunities; and, reframing potentially difficult circumstances/situations.

(Participant talking about AD)

“I can't be sure that you can never correct it...I think yes, what's dead, you cannot correct that, but the brain is such a wonderful thing that I don't believe that you can't use a different part of the brain to take over.” (P207, 480-483)

Some participants spoke about focussing on positive emotion, particularly satisfaction, comfort and pleasure, often derived from everyday things.

“This is a thing that [*name of wife*] bought [*indicates a book*]. This thing its lovely sh, her, her, her father gave it to us when I got when we got married about, err, twenty years ago and, err, that was left on the table for us to have...And, err, that that sort of thing I, I still umm, I get a great comfort out of...for instance this my, my father is, is err, he's over there [*indicates photographs*], and in the corner is my mother and they gave me this [*indicates another book*] for instance. It's only a little book...Yes, and these sort of things, and I use it occasionally [*pause*]. It all, err, it all helps.” (P204, 583-601)

Furthermore, a few participants also described positive changes they had achieved as a result of their experiences of dementia. These were: meeting new people; developing a greater sensitivity towards others; developing new interests and sources of meaning; being more open; no longer worrying about less significant things; and, having greater determination.

“I actually met these people through just going, they weren’t friends but they’ve become friends, you know, and it’s just through um, Alzheimer’s. And that’s what I say, have Alzheimer’s has been, I think it’s made me a different person. I think I’m more, more, um, aware of other people’s problems.” (P211, 382-388)

Some of those interviewed described remaining positive by cognitively and practically compensating for their difficulties. Cognitive compensation involved focussing on alternative sources of meaning, such as activities, relationships, possessions and aspects of their identity, often functioning to overcome negative feelings. Practical compensation involved using different equipment, and making physical repairs, for example.

Looking after myself/taking it easy. Many participants referred to removing pressure from themselves at times; being aware of their own limits and focussing on what they were able to do; taking time away from stressful situations; protecting/guarding themselves in certain situations; and, consciously taking care of themselves.

(Participant talking about what happens if she is having a bad day)

“Or, if you don’t feel like anything you say, well what we gonna have for dinner and I know what he’ll say, he’ll take the easiest thing you can do, because he knows...Oh let’s have um, fish and chips or something. Put it in the oven and it’s done [laughs]...Makes it easy, yep. No good fretting, no good.” (P209, 1652-1669)

A few participants spoke about lowering others' expectations as a way of reducing the pressure on themselves.

(Participant referring to signing the consent form)

"I did say that I couldn't do it, didn't I. I said, I won't be able to do that...But I thought I might be able to. Said it so no-one expects too much like." (P212, 180-187)

Putting problems into perspective and knowing when to let it go. There were many examples of participants putting their difficulties into perspective, in relation to what they were able to do, other people, their previous characteristics, present and future hopes and needs, their stage in life or a life course perspective, life in general, and more important things.

"If you understand what I mean, umm, no, I know where I am. I...remember my family and I know if I went out here and turned left I'd be into Southampton. I think?...I am not too bad I don't think at the moment anyway. I don't think so no, no not too bad." (P205, 15-20)

Some participants described the importance of not "getting stuck" on problems that could not be solved/resolved or were not important, and being able to "let it go".

(Participant having lost track of what he was saying)

"No, no leave that one." (P203, 1079)

Equally, the same people indicated the need to persevere with problems that were important. A few participants appeared to perceive such “letting go” as negative and frustrating, whilst most accepted this.

(Same participant having lost track of what he was saying)

“I do want to tell you this story though, because it’s quite important.” (P203, 669-670)

Patience and having faith. Most participants referred to taking time to combat difficulties associated with slow processing speed or anxiety, having patience with their difficulties (for example, waiting for a memory to come back in its own time), and having faith in their ability to overcome problems.

“And I look round and in my red, head. And it comes back to me. Sometimes it’s just being patient.” (P212, 303-305)

Accepting it vs. fighting it. A majority of participants highlighted the importance of initially accepting aspects of dementia, both emotionally and cognitively, and then developing a fighting attitude towards it.

Acceptance was described as a gradual, effortful process that occurred over time. Some participants demonstrated having achieved overall acceptance, whilst it was an ongoing process for others, involving some conflict. There was evidence of participants accepting both individual difficulties and the progressive and serious nature of dementia as a whole. Furthermore, gaining acceptance from others appeared to be a challenge.

“I think first of all I’d say you’ve got to take it on board that you have got a problem...And then you’d sort of, if possible, go about your things as you normally have done.” (P202, 757-763)

Nearly all participants also described the need to “fight” dementia, or not let it get the better of them: this attitude was repeatedly referred to as central to coping efforts for many. Fighting involved motivating oneself to use cognitive and behavioural strategies to “beat” dementia. This was done either by preventing, managing and/or “getting round” problems.

e.g. Participant 212, lines 310-314

“You mustn’t give up...You gotta fight it.” (P212, 312-314)

Avoidance and covering up vs. being open and not hiding. A majority of participants described acknowledging some problems existed, but avoiding thinking or talking about them, cognitively minimising them, normalising them, distracting themselves from them, covering up evidence of problems, or avoiding activities affected by the difficulties (e.g. driving). Some participants spoke directly about this, whilst such coping strategies became indirectly evident from others’ accounts.

(Participant speaking about how “bluffing” gave him time to recover memory)

“I just couldn’t. So I had to bluff a lot...Basically what I used to do, if it was a few weeks into the courses...I used to say to the students, if I didn’t remember anything I would say, shouldn’t you know how to do it.” (P208, 681-688)

Some of these participants also spoke about the importance of telling people about their difficulties. Some spoke of the positive aspects of sharing problems with others, such as finding humour, unexpected empathy or a point of contact. One lady spoke about feeling the need to tell people she had AD, to help educate people about dementia and address negative stereotypes. The extent of disclosure appeared to vary between participants, and according to the audience.

(Participant speaking about disclosing her diagnosis of dementia)

“I mean the only person I’ve told here is [*name of neighbour*] and his wife around the corner, and [*name of neighbour*] next door. And that’s all...But if I was speaking to anyone else and I got stuck, I’d just say I’ve got a bit of a problem with my memory.” (P202, 348-357)

Some participants indicated feeling that they could no longer hide due to their problems having become increasingly evident to others.

“Now that I have literally, this memory problem is literally obvious to other people.” (P201, 162-164)

Additional Results

Overarching Themes

One overarching theme (a theme that spanned across the major and sub-themes) was that of conflict. For example, “self as substandard” and “self as able/valued”, and “being open vs. avoiding and covering up” indicate opposing strategies, and conflict existed for individuals as they oscillated from one strategy to

the other. There was evidence of contradiction and lack of resolution in some accounts. However, as indicated in theme descriptions, some people also used apparently opposing strategies in different circumstances or in an otherwise complimentary way. For example, one participant described being open about dementia with his close family, but needing to cover it up in professional contexts.

Another overarching theme was that of control. There was evidence of participants feeling in control of some aspects of dementia, in making difficult decisions for themselves and continuing to use skills. However, nearly all participants acknowledged having little or no control over their difficulties and coping techniques failing, despite their efforts. Many participants reflected on an increasing lack of control as dementia progressed. There were also many examples of others taking control of situations.

(Participant talking about how he cannot prevent short-term memory loss)

“Now, that I find irritating, obviously, because I think well now, hang on a minute. I almost feel myself trying to reach out and grab the thought and bring it back.” (P203, 153-158)

Motivations and Anxieties Relating to Participation

All participants engaged well in the interviews, providing relevant, coherent and detailed accounts related to coping in dementia. However, the risk that some participants took in volunteering to engage in the research was clear in some cases, through anxieties voiced about not being able to articulate sufficiently well, or of contributions not being useful or good enough. These were balanced by motivations

to take part. All participants commented that they had enjoyed and/or benefited from the process of the interview. They particularly commented on having had the opportunity to reflect on experiences and speak openly, and to be useful in contributing to the research. One participant contrasted this to his experiences of dementia, which he perceived as useless and destructive. There was evidence in at least three interviews of people further developing their understandings and viewpoints as the interview progressed (see Kvale, 1996).

Additional Findings

The importance of context in relation to coping was also highlighted by the accounts. Many participants acknowledged their individuality in coping with dementia, reflecting on how their own coping methods may not be useful or viable for other people:

“People are all individual. And we all cope with it in a different way.” (P208, 920-921)

It was also apparent that participants used a variety of strategies to cope with the same difficulty, both across time and in parallel.

Many problems occurred as “vicious circles”, with management strategies sometimes becoming problems themselves. For example, one participant spoke of how she managed her frustration by energetically cleaning the oven. However, others perceived her repetitive cleaning to be a result of short-term memory loss, or as signs

of “madness”. This led to the individual experiencing further frustration and feelings of low self-esteem.

Differences in Interviewing Styles

Although this was not subject to formal analysis, a difference between the two interviewers in interviewing styles was evident. This impacted on the interviews and, therefore, the resulting themes. The second interviewer relied more heavily on prompts from the interview schedule, whilst the author tended to use more specific, open-ended prompts in addition to these. This and other interviewer differences resulted in a wider range of coping, particularly more attitudinal coping being elicited, in interviews conducted by the latter, whilst the second interviewer tended to produce more detailed information contributing to sub-themes of practical/behavioural coping and coping in relation to others.

Effects of the Presence of a Spouse

Three of the 5 spouses who were present made a significant number of contributions during the interviews. Overall, there were more instances in which the interviewer did not follow up ambiguous statements, due to difficulties in being able to do this. Equally, sensitive and unobtrusive prompts from the spouse enhanced the breadth of participants’ contributions in some instances. The level of disclosure of people interviewed with their spouse did not appear to differ significantly to those interviewed alone.

Validity Checks

The transcribing check indicated only very minor, non-significant differences in transcription. No changes were made as a result of the formal validation check. The resultant analysis was validated as being free of logical contradictions, with a sensible theme structure that had a coherent unity (Smith, 2004). Furthermore, a number of clinical psychologists working with older people (with whom the results were shared for further comment) indicated that the descriptions of themes shared much in common with their clinical observations of older people with dementia (i.e. the results ‘resonated’, Elliott et al., 1999).

DISCUSSION

This study aimed to provide a comprehensive account of themes related to coping with dementia, as evident from the accounts of 12 people with mild dementia. Three major themes emerged: “managing identity in relation to dementia”; “making sense of dementia”; and, “coping strategies and techniques”. Whilst all are distinct, there is some overlap, and coping involves an interaction between themes. Despite the current focus on commonalities in experience, the importance of individual differences and contextual factors has also become clear from the diversity of methods and functions described within themes.

Description of Findings

“Managing identity in relation to dementia” has sub-themes relating to both continuity and discontinuity between the past and present self; integration and lack of

integration of dementia with the self; and, positive and negative perceptions of the self (i.e. “self as able/valued”, and “self as substandard”). It is interesting to note how participants who contributed to “self as substandard” also contributed to “self as able/valued”, the latter directly after the former, in many examples. It is possible that identity management involves actively compensating for or counteracting a negative sense of self resulting from experiences of dementia, by acknowledging more positive aspects of identity. Charmaz (1987) proposed that individuals with chronic illness attempt to salvage a sense of self by maintaining some positive past images in the face of present adverse circumstances, as is evident here. Previous studies have also highlighted the role of both the past and present self in dementia (e.g. Kemp, 2003; Harris and Sterin, 1999).

Overall, managing identity can be viewed as a coping task of dementia. However, accounts of coping suggest that focussing on identity in these ways also provides means of actively managing dementia. For example, whilst a perception of “dementing” aspects not being integrated with identity (or discontinuous with their sense of self prior to dementia) may be a source of difficulty for some people, some participants indicated that perceiving dementia to be unrelated to their identity (i.e. compartmentalising it) was a means of protecting their prior, more positive sense of self. Equally, some appeared to cope with dementia by viewing it as integrated or continuous with their present self. For some, “discontinuity between past and present self” involved the development of new skills and ways of being. This can also be considered as coping, in terms of creating compensatory sources of meaning and positive self-esteem.

The second major theme is “making sense of dementia”. This has three sub-themes: “making sense as a whole”; “making sense of individual experiences”; and, “lack of understanding”. Making sense can also be considered as both a task of dementia and a coping method. In the process of making sense, participants were actively managing their difficulties, by making them cognitively less threatening. Accepting a lack of understanding can be viewed as a passive means of coping with dementia.

Generally, participants either tried to understand dementia by fitting it to their own pre-existing frameworks (understandings of physics or mechanics, for example), or in terms of less familiar medical or biological understandings, which reflect the traditional paradigms often used by medical professionals. Difficulties making sense perhaps indicate the inadequacies of these frameworks. A major theme of making sense also emerged from Kemp’s (2003) study investigating experiences of dementia. The observation that many participants used the interview process as an opportunity to explore and develop their understanding of dementia has been made in previous studies (e.g. Clare, 2003), and supports Gubrium’s (1995) notion of the interview as a meaning-making occasion.

Finally, “coping strategies and mechanisms” is the third major theme to emerge from accounts. Components of the sub-theme, “everyday, individual strategies” are: “being logical”; “visual prompts and formal memory techniques”; “information”; “medication”; “cathartic expression”; and, “say it whilst it’s there”. All aspects of this sub-theme are conscious, active, cognitive and/or behavioural methods, whilst “coping in relation to others” also includes more passive methods. This divides into: “talking and sharing”; “getting help”; “being with similar people”;

and, “social comparisons”. This provides support for previous authors’ emphases on the importance of social aspects of coping (e.g. Kitwood, 1997). Whilst there is evidence here of the negative effects of the social environment, the ways in which others positively support the coping of people with dementia have also been highlighted (see also Kitwood, 1997). The use of social support and social comparisons have also been reported previously (e.g. Keady & Nolan, 1997; Harris & Sterin, 1999; Charmaz, 1987).

The third sub-theme, “personal attitude/approach”, includes components of: “accepting vs. fighting it”; “being positive”; “avoidance vs. being open”; “looking after myself/taking it easy”; “putting things into perspective/knowing when to let it go”; and, “patience and having faith”. There is evidence in themes of the role of appraisal in the coping process (see Moos & Schaefer, 1993; Lazarus & Folkman, 1984). Many theme components suggest the existence of continua, and the need to balance extremities both within and across themes (see also Clare, 2002a; Pearce et al., 2003). There are descriptions of balancing between persevering with a problem and knowing when to “let it go”, and between covering up and being open about difficulties, for example. Conflict also surrounds this, suggesting that the act of balancing was not always successful, and that this represents an ongoing process (also see Pearce et al., 2003). “Being positive” includes a particularly wide range of cognitive strategies. It is interesting to note that positive biases in interpreting events were often overtly recognised. Positive growth as a result of dementia is supported by Kitwood’s (1995) observations of positive long-term changes, and is acknowledged by extensions of Schaefer and Moos’ (1993) and Lazarus and Folkman’s (1984) coping frameworks.

Participants were aware of their difficulties and the way in which they coped with them: some were also aware of using minimisation and cognitive biases, for example. This supports Clare (2002b, 2004), who suggested that people with AD have greater awareness of their difficulties and coping than has traditionally been assumed.

Links with Previous Studies of Coping in Dementia

Many aspects of the current themes gain support from findings of previous studies that have investigated coping with dementia. Examples of these include: using visual and written prompts (e.g. Keady & Nolan, 1995; Nygard & Öhman, 2002); use of humour (e.g. Harris & Sterin, 1999; Nygard & Starkhammar, 2003); using social support (e.g. Kemp, 2003; Gillies, 2000); making social comparisons (e.g. Gillies, 2000; Pearce et al., 2002); aspects of “being logical” relating to relying on routines and developing habits (e.g. Nygard & Öhman, 2002; Nygard & Starkhammar, 2003); aspects of “information” and “getting help” relating to seeking professional help and information (e.g. Pearce et al., 2002; Keady & Nolan, 1995); and aspect of “avoidance” relating to normalising and/or minimising problems (e.g. Clare, 2002a; Gillies, 2000). Previous research has also identified some similar coping attitudes to those found in the present study. Themes of fighting and accepting dementia are the most consistently supported (e.g. Clare, 2002a; Pearce et al., 2002; Cheston, Jones & Gilliard, 2003). Other attitudes found in previous studies are: focussing on positives (e.g. Pearce et al., 2003; Clare, 2002a; Taylor & Brown, 1988), and avoiding thinking about difficulties (e.g. Harris & Sterin, 1999; Kemp, 2003; Nygard & Öhman, 2002).

Links with the Wider Literature

Findings from this study suggest a possible need to revise popular stage models of dementia (e.g. Bender & Cheston, 1997; Keady & Nolan, 1995; Cohen, Kennedy & Eisdorfer, 1984). Such models have suggested sequential reactions to dementia, whilst this study indicates that a number of emotional and coping responses simultaneously occur in the early stages of dementia. For example, in the second stage of their model, Bender and Cheston (1997) identified a behavioural response of living in the past. Current findings indicate a role for the past self for participants in the early stages of dementia which is balanced with acknowledgement of the present self. This suggests a more balanced use of the past self, possibly in an earlier stage of dementia, than is indicated by the stage model.

Findings can be linked to aspects of the broader literature on coping. For example, themes regarding continuity/discontinuity and the integration of dementia with the self are supported by Charmaz's (1987) conceptions of people faced by chronic illness re-evaluating their previous identities. Literature from Leventhal and Nerenz (1980) also offers parallels to integration and lack of integration of dementia with the self, with reference to fusion with or compartmentalisation of chronic illness. Radley and Green's (1987) four types of coping (active denial, resignation, accommodation to the condition, and secondary gain) are also represented in these themes.

The centrality of issues of identity and making sense/findings meaning to people with dementia has been highlighted here. These themes have spontaneously emerged from participants' accounts in relation to coping, whilst previous studies

reporting similar themes tend to have prompted direct exploration of these areas (e.g. Pearce et al., 2002; Clare, 2002a; Kemp, 2003). With reference to the literature on coping in later life, these themes indicate that managing the self and making meaning of aspects of life (e.g. Erikson et al., 1986; McAdams, 1990) continue to have relevance to older people when they are faced with dementia, although the qualitative nature of these appears to differ. Tornstam's (1997) notion of gerotranscendence, a shift towards taking a more philosophical perspective of life, is also evident in many of the sub-themes of "coping attitude/approach". There is also evidence of a form of selection, related to reconstructing values and goals in response to loss, and compensation (i.e. loss-based selection and compensation, see Baltes & Baltes, 1990). Aldwin and Brustrom (1997) identified strategies of developing new routines, revision of expectations, manipulation of meaning (including use of downward comparisons) and acceptance of problems, in relation to coping with health problems in later life, all of which are also evident here. This suggests that there may be similarities between coping with chronic health problems and coping with dementia in later life. However, findings from this study may not indicate the predominance of accommodative processes common to later life that have been suggested by Heckhausen and Schultz (1996) and Brandstädter and Greve (1994), in that both accommodative and assimilative processes were evident (see also Clare, 2002a; Pearce et al., 2002; Coleman, Ivani-Chalian & Robinson, 1999). Also, current findings of active, interpersonal methods of coping (see also Harris & Sterin, 1999; Pearce et al., 2003) suggest that there may also be qualitative differences between coping in dementia and coping more generally in later life, which has generally been found to involve more passive, intrapersonal coping methods (Folkman, Lazarus, Pimley & Novacek, 1987).

Overall, there are similarities between current findings and aspects of the broader literature regarding coping with health difficulties and coping in later life. However, there are also important differences, and this study suggests that coping with dementia may require an extension of this literature, perhaps due to the additional coping challenges it poses, and its simultaneous effects on coping resources.

This study's broad focus on coping has led to wider range of more detailed descriptions of coping than appear to have been provided previously. In particular, some aspects of "looking after myself and taking it easy", "patience and having faith", "being positive", and "knowing when to give up" have not previously been reported, to the author's knowledge. Whilst the social element of coping has been acknowledged by previous research, the range of social coping behaviours and functions do not appear to have been explored as widely.

It has been confirmed that people with dementia can provide rich accounts of their experiences in engaging in collaborative research. The research process can be reciprocal: participants reported gaining from and enjoying the interview process (see also Clare, 2002a). Ethical issues need not pose a barrier to engaging people with dementia in research; furthermore, it could be considered unethical to exclude them. It is also evident that employing a second interviewer may be valuable in increasing the range of information derived from interviews and highlighting interviewer effects in future studies. The author learned much from the research process (see Appendix P), and reflected on personal reactions to engaging in interviews and analysis of transcripts (see Appendix I).

Organisation of Themes

Findings have been presented as a hierarchical structure of themes, which are reciprocally related. The structure presented is an initial framework, intended for modification following future research. It is possible, for example, that the way in which individuals make sense of dementia determines or influences the relationship between identity and dementia, and the coping strategies used. “Making sense of dementia” and “managing identity in relation to dementia” may mediate coping challenges and some coping strategies. Equally, aspects of people’s attitude to dementia may organise and/or determine the particular coping strategies they use (see also Krohne, 1993): further research is needed to elucidate these links.

It is acknowledged that it would be equally valid to organise themes in an alternative way. For example, they could be divided into coping resources and strategies; or cognitive and behavioural techniques (as in Lazarus & Folkman, 1984). Indeed, this is already reflected somewhat in “everyday, individual strategies” and “personal attitude/approach”. Equally, divisions could be made according to the focus of coping: themes include examples of emotion-focussed, problem-focussed and appraisal-focussed coping, in accordance with Moos and Schaefer (1986). In terms of coping function (Ferguson & Cox, 1997), approach coping, avoidance coping, emotional regulation and reappraisal were all represented in the accounts. These conceptualisations are useful for distinguishing between the different ways that people cope with dementia. In using these, however, there is a danger of oversimplifying and masking some of the content of themes. The centrality of roles of identity and making meaning that emerged would not be represented if themes were reorganised according to established coping conceptualisations, suggesting a need for

these to be extended. For example, maintaining identity may be an appropriate additional coping function to add to Ferguson and Cox's (1997) categorisation of coping in terms of function (as findings suggest this is qualitatively distinct from reappraisal). Overall, present findings indicate the need to continue to explore coping in dementia without the preconceptions that accompany established frameworks.

Limitations of Findings

Findings of the present study need to be considered in relation to the methodology used. IPA acknowledges that the account of themes is, in part, a reflection of the researcher's biases and assumptions, and the wider contexts and characteristics of participants (Smith, 1996). Reliance on first-hand interview information provides information that the individual is able to access consciously, excluding sub-conscious coping defences, and may be biased in terms of social acceptability. This study represents a cross-sectional view of coping in the early stages of dementia. As coping is likely to change over time as dementia progresses, findings cannot necessarily be generalised to people in the later stages of dementia.

Although appropriate to this study, the size and relative homogeneity of the present sample, in terms of social and demographic factors, also has implications for the generalisability of results. Personal and contextual factors have been found to be important in determining coping in younger adults (e.g. Lazarus & Folkman, 1984), therefore further research will be needed to determine the validity of the present findings in application to people with dementia who are younger, institutionalised, and/or come from different social or cultural backgrounds, for example. The sample is likely to be biased by a number of factors: the restriction of invitations to people

who were accessing NHS services⁸; the high level of recruitment from a support and memory skills groups; and, most participants' use of anti-cholinesterase medication. Further biases, common to all studies of this type, result from the characteristics of people who chose to participate, as compared to those who declined. Higher motivation to engage in research is likely to be found in people who cope more effectively, or are more confident in speaking about their experiences. Cheston et al. (2003) reported that many older people in a psychotherapy group for people with dementia expressed a desire to hide: this may be common to many people with dementia, but such a desire is less likely to be found in people volunteering for research

Triangulation of data collected with information from interviews with relatives and/or supporters of the participants may have enhanced the study. This may have resulted in additional details that were difficult for the person with dementia to access as a result of their cognitive impairment; information regarding sub-conscious coping processes, and/or details of coping methods that the individual did not wish to speak about, for example. The study may also have benefited from additional information from mood inventories and observations of coping. A formal measurement of inter-rater agreement between the principal researcher and supervisors, for portions of transcripts independently analysed (see "Validity Checks") may have been useful.

⁸ It has been found that only a small proportion of people with mild cognitive impairments are in contact with health services (Cooper & Fearn, 1998).

Although further research is indicated, the present findings are nevertheless valid in providing foundational work in the area of coping in dementia, and have implications for both the direction of future research and clinical practice.

Implications for Future Research

The present study represents exploratory research, elucidating a range of coping processes used by people with dementia. It is intended to provide a basis from which further research (including validation of these findings) can be developed, to establish a framework for understanding coping processes in dementia.

It is apparent that data gathered for this study have the potential for further analysis. The present study focussed on the shared aspects of coping across participants: alternatively, transcripts could be used to study individuals' coping profiles. The series of single cases could then be compared to explore individual differences in coping. The role of appraisals in the coping process, which has been outlined as key to coping processes in younger adults (e.g. Lazarus & Folkman, 1984), could also be analysed. Interviewer effects could also be explored: there are many further possibilities.

It would be useful to extend findings by exploring each of the major themes in greater detail. Research is needed to elucidate which strategies are considered by people with dementia to be most central to their coping experiences, the frequency with which these are used, and the perceived efficacy of these, for example. Longitudinal case studies (e.g. see Mills, 1997) are indicated to explore how coping changes as dementia progresses. Once a better understanding of the range of coping

methods used by people with dementia has been explored and validated, service provision for this group of people could be enhanced by exploring the personal, social and cultural factors affecting coping, such as links with pre-morbid coping. The development of a psychometric scale assessing methods of coping with dementia would be useful for clinical assessment and evaluation, and for conducting research⁹. Ultimately, we may learn a great deal about coping at a general level by studying this group of people, who are coping with some of the most difficult challenges of life.

Many people with dementia may not be given the opportunity to participate in this type of research, or choose to do so. It is important to attempt to address this by recruiting from a wider population, and making participation more attractive and less threatening to a wider range of people with dementia. However, it is perhaps inevitable that biases in the characteristics of people who choose to participate in such research will continue to exist. It is suggested, therefore, that consideration also needs to be given to the use of alternative methodologies to represent these people, such as analyses of observational information from individual or group therapy (e.g. see Cheston et al., 2003). Gaining more information about the personal and demographic details of people who decline to take part in this research may be an important starting point in considering these issues.

As described in the methodology section, a second researcher was recruited for this study to conduct four of the interviews, with the hope of increasing the diversity of participant responses. Much additional time was allocated to the necessary training and supervision of this interviewer, and whilst their input helped

⁹ The Index for Managing Memory Loss (IMMEL, Keady & Nolan, 1995) has previously been developed, but is only designed to measure coping with one aspect of dementia (i.e. memory loss).

the principle researcher to reflect further on interviewer effects, the diversity of responses was not increased. It may be useful to consider these findings when planning similar future research.

Clinical Implications

Although further research is required to validate findings, the present study has wide-ranging potential implications when considering the enhancement of psychological well-being and quality of life of individuals, some of which are outlined below.

Importantly, the types of difficulties people with dementia face appear to be amenable to psychological intervention. A number of therapies are effective when adapted for people with dementia (see Bryden, 2002; Woods, 2001), yet many services do not currently provide more than assessment. Findings from this study suggest that such intervention could include cognitive approaches focussing on coping attitudes or styles, such as promoting a balanced and accepting view of difficulties; and, identity issues, such as helping individuals to integrate dementia with their sense of identity, reflect on issues of continuity, and promote more positive self-esteem. Intervention could equally involve teaching behavioural strategies, such as “say it whilst it’s there” and the use of individualised practical systems or routines to aid memory. The provision of a therapeutic forum in which individuals can develop their understanding of and relationship with dementia is also important. Some participants appeared to achieve a greater understanding as a result of the single interview in the present study, indicating the potential effectiveness of short-term therapies for some individuals. Another important role for health professionals

may be to flexibly provide ongoing education to people with dementia, sensitive to their changing needs over time. Current findings suggest the primacy of medical and biological understandings of dementia, which participants often indicated to be insufficient in some way: sharing more psychological, holistic understandings of dementia is likely to be helpful to people in making personal sense of their experiences. In respecting individual differences, it is also important to acknowledge that some people with dementia may not wish to engage with psychology services (which may represent an aspect of their chosen coping methods).

The emergence of the importance of social aspects of coping indicates a continued need to facilitate support groups focussing on the opportunity to share and normalise experiences, and learn from others (also see Clare, 2002a). This also highlights the need to work systemically with the informal and professional supporters of people with dementia (e.g. see Pusey & Richards, 2001). The development of genuine and meaningful roles, based on the valuable knowledge and abilities of people with these disorders, is likely to have a positive impact on self-esteem and sense of meaning. Dissemination of findings from this and related studies, particularly to supporters and health care professionals, is likely to enhance understanding and aid in the ongoing identification and reinforcement of coping. We are not currently in a position to make assumptions about what constitutes adaptive coping for different individuals in different contexts: those providing input to need to be aware that all types of coping are potentially helpful at some stage.

The abilities and strengths of people with dementia have been highlighted, contrary to the assumptions often made about this group of people. It is important that these findings are also communicated at a wider, societal level, to help develop

more accurate understandings of dementia. Beginning to address these attitudes could make a significant difference as it has been indicated, both here and in previous research, that the attitudes and actions of others in response to dementia have a major impact on self-esteem and well-being (see Kitwood, 1993; McGregor & Bell, 1993).

On a related note, it is vital to make a final acknowledgement of the important contributions that individual participants made to make this research possible. These people indicated that engaging in the present study enabled them to be heard, validated and feel that they were doing something worthwhile; sadly in contrast to many of their other experiences. The findings stand as testament to their “usefulness”, their ability to provide rich and meaningful accounts, and openness in sharing some very personal and difficult experiences. It is hoped that the present paper has communicated the meanings of these individuals justly. It is also hoped that individuals’ expressed desires to be helpful to others in some way, and to create something constructive from their negative and often destructive experiences, are realised.

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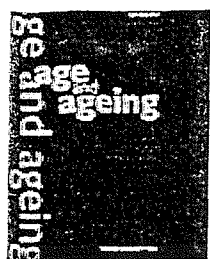
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Information for Authors

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- **Numbered on each page**
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authors' names do not appear anywhere else on the manuscript (including figures).

Manuscripts should include:

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- Details of **sources of research funding**
- Details of any possible **conflicts of interest** (see details below)
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Additional guidelines:

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Further Information:

References

References should be numbered in order of citation and cited in the text by numbers in square brackets. They should be listed in the reference list in the form prescribed in the Uniform Requirements (giving the names and initials of all authors, unless there are more than six, when the first three should be given, followed by *et al.*). Provenance of laboratory and biochemical equipment specifically mentioned in the text of your paper must also be provided, including full contact details of manufacturers.

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For longer reference lists: please select the 30 most important references and put the reference numbers for these in bold type throughout the text. Example: "Several previous publications have addressed the management of asymptomatic PHPT in the general population [**4,5,6,7,8,9,10**]." In the reference list at the end of the paper, list only these 30 references. Send a separate full list of references clearly marked as Supplementary Data.

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Declaration of Sources of Funding All sources of funding must be disclosed at the end of the Methods section or, if there is no Methods section, as an acknowledgement at the end of the text, under the heading 'Declaration of Sources of Funding'. Authors must also describe what role their financial sponsors played in the design, execution, analysis and interpretation of data, or writing of the study. If they played no role the authors should state this.

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2. **Figures and graphs:** Please **save electronic versions of figures or graphs in TIFF (.tif) format or another commonly used file format (jpg, gif, Powerpoint, etc.) and embed them** at the end of the text of the manuscript.

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3. If you click on 'View comments/respond' you will see the editor's letter to you together with the referees' comments.

4. Rather than using the comments boxes please submit along with your paper a completed Revision Sheet that you will have previously downloaded from our website as per the instructions in the decision letter sent to you.

5. Please ensure that your paper has been revised using Track Changes which show the changes made in the text.

Appendix B – Rationale for Use of Methodology

Choice of Qualitative Methodology

Qualitative methods were considered to be most appropriate with regards to the investigative nature of the present study. Use of a quantitative approach would have necessitated making the unsubstantiated assumption that existing coping paradigms were sufficient in explaining coping with the challenges of dementia in later life. Quantitative approaches would also have failed to reveal the personal dimensions of experience that are of interest in relation to coping (see Chamberlain, Camic & Yardley, 2003).

Consideration of Alternative Qualitative Approaches

A number of alternative qualitative approaches were considered, including discourse analysis (Yardley & Murray, 2003) content/thematic analysis (e.g. Joffé & Yardley, 2003), and grounded theory (e.g. Glaser, 1999; Strauss & Corbin, 1994). Discourse analysis was considered inappropriate due to its primary focus on the process of talk and verbal expression (which may be affected by dementia), rather than subjective experience and personal meaning. Content and thematic analysis rely heavily on frequency outcomes, and can be criticised for removing meaning from its context (e.g. Joffé & Yardley, 2003), and were, therefore, also less suitable for this study. Whilst a grounded theory or grounded analyses approach is also concerned with the lived experiences of participants (see Chamberlain, Camic & Yardley, 2003), it lacks the specific psychological focus of interpretative phenomenological analysis (IPA). The assumption of objectivity that appears to accompany grounded theory (an idealist approach) is not in keeping with what is known about the

importance of contextual and personal factors in coping, or the potential influences of the researcher on interview data (e.g. Willig, 2001). Although it is acknowledged that a grounded theory approach could have been used, IPA was considered to be more appropriate, due to its explicit and specific focus on people's lived experiences and views of the world. Also, it has been described as particularly relevant for understanding subjective responses to illness (e.g. Smith, 1996).

Further Details of IPA

The key features of IPA are that it is idiographic (i.e. starting with the detailed examination of single cases before conducting a cross-case analysis); inductive (not having any specific hypotheses and employing techniques flexible enough to allow unanticipated themes to emerge from the data); and interrogative (i.e. it illuminates existing research by allowing discussion of results in relation to psychological literature). It is potentially compatible with a wide range of psychological models, including socio-cognitive and biopsychosocial models, which have more recently been used to understand dementia. However, theory links are not made until the completion of the analysis, and are therefore guided by the emerging analysis. A series of single interviews is the exemplary mode of data collection in IPA. The approach assumes a link between self-report and both lived experience and cognition. Refer to Smith (1996, 2004) for further details.

IPA draws on a critical realist perspective. Although there is no belief in the existence of a single objective reality, there is an assumption that participants' accounts of their experiences are a reflection of their internal realities (i.e. realism). The critical element of the perspective refers to the assumption that the construction

of these accounts is influenced by interviewer effects and the process of interpretation.

Appendix C: Brief Descriptions of Participants

Following are brief descriptions of the individuals who participated in the study. Much information has been excluded or disguised in order to protect their anonymity, and initials used do not relate to participants' real names. As personal information was not specifically prompted during the interviews, the summaries below vary according to information divulged.

Participant 201 – Mr A

Mr A lived alone in his own home at the time of the research interview, and appeared to be a highly independent man. He reported to enjoy keeping busy and active, and had a number of hobbies and pastimes that appeared to provide a major source of positive self-esteem for him. He spoke of having worked in a technical/manual job since leaving school aged fifteen, and had a strong interest in woodwork . Mr A was particularly keen to participate in the research, in the hope that he could be of help to other people with dementia. He referred to a number of charitable activities he engaged in throughout the interviews, and discussed his wish to volunteer to help older people who were less able than himself. Mr A was open in speaking about his diagnosis, but was particularly puzzled and intrigued by it. He spoke of having been diagnosed following a family member noticing changes in his cognitive functioning and independently going to his G.P. to discuss this.

Participant 202 – Ms B

Ms B also lived alone in the community. She reported having a number of friends and family in her local area, and appeared to be a highly sociable lady. Ms B

had previously worked in an office, and reflected on her organisational abilities and the high level of independence she continued to have. Ms B referred to having chronic health problems, but these did not appear to affect her daily functioning. She felt she had few memory difficulties since commencing anticholinesterase medication, and did not refer to a diagnosis of dementia during the interview. Although she appeared mildly anxious at times, Mrs B appeared to enjoy the social aspect of the interview, and spoke at length without need for much prompting.

Participant 203 – Mr C

Mr C was one of the oldest gentlemen in the sample, who lived in his own home with his wife. He appeared to enjoy a range of pastimes, some of which had been restricted as a result of his declining physical health. He appeared to be a particularly humorous person, and spoke of enjoying socialising with a number of different groups of people. Mr C had previously worked in skilled/professional occupations, having had a private education. He was open in speaking about his diagnosis of dementia. Mr C was particularly thoughtful in his contributions during the interview, and used the time to reflect on his experiences from a philosophical perspective.

Participant 204 – Mr D

Mr D also lived in the community with his wife and family, whom he spoke of relying on heavily for support. He had spent most of his working career in the national services. Mr D was very aware of the restrictions his physical health problems imposed on his level of independence and ability to engage in hobbies. He spoke of how this impacted negatively on his self-esteem, and appeared quite critical

of himself at times. Mr D spoke openly of his diagnosis of dementia during the interview, but reflected on the lack of opportunity to do this at other times.

Participant 205 – Ms E

Ms E lived alone in her own flat within supported residential accommodation, having recently moved from her nearby house, where she lived independently. Ms E had lived locally all her life, where she had raised a family. She avoided speaking of her diagnosis of dementia, preferring to focus on present abilities and sources of meaning. Ms E appeared to be keen to participate in order to help the researcher with the study.

Participant 206 – Mr F

Mr F lived in the community with his wife, who was also present at the interview. Mr F reported spending all of his time with his wife, and relying on her heavily for practical and emotional support. Prior to his early retirement he had worked in a skilled manual profession. Mr F demonstrated a good sense of humour, and enjoyed speaking about events from his life as a young adult. He was particularly open in speaking about the range of difficulties he encountered, although he never explicitly referred to having dementia. Like many of the other participants, he enjoyed the social aspect of participating in the interview, and commented on the potential opportunity to be helpful to future generations of people with cognitive problems.

Participant 207 – Mr G

Mr G also lived with his family, in a neighbourhood where he had a number of close friends. He was a particularly active man, who worked part-time in a professional job. Mr G had one particular hobby that he spent most of his time pursuing, and also reported spending a lot of time with his family. He spoke openly of his diagnosis from the outset of the interview, but reported experiencing only mild difficulties which impacted minimally on his daily functioning. Mr G was particularly keen that his experiences of dementia were heard and passed onto others via the study, expressing a wish to be able to help in the way that he had been helped by other people with dementia in the past.

Participant 208 – Mr H

Mr H had lived in his current home in the community with his wife since retirement, prior to which the couple had lived in various locations in the United Kingdom, following his professional career. His wife was present during the interview. Mr H spoke of a few pastimes, but appeared particularly aware of the impact dementia had on his functioning. Mr H appeared to enjoy the mental stimulation provided by the interview, and took particular care in articulating himself. He frequently expressed anxiety regarding the value of his contributions, and talked frankly about some of the negative feelings his experiences of dementia evoked.

Participant 209 – Ms I

Ms I lived in the community with her husband, who was also present during the interview. The couple spoke of their heavy interdependence regarding her

cognitive difficulties and his physical health problem. From the age of 20 years, Ms I had worked with her husband, initially running their own small business and subsequently working in a shop; she had fully retired in recent years. Ms I appeared to be anxious about the worth of her contributions to the research, but was keen to be helpful, enjoying the social aspect of the interview.

Participant 210 – Mr J

Mr J had lived in the local area with his wife for over fifty years. He spoke at length of his past work as a civil servant. Mr J did not refer to his difficulties as dementia, but was open in speaking about a range of cognitive difficulties and the effects of these. He relied heavily on his wife, who was present during the interview, for prompts and to co-construct the stories that he told. Mr J said that he had been glad to help out the interviewer by participating in the research, and seemed very pleased that his contribution could be “put to some good”.

Participant 211 – Ms K

Ms K was one of the youngest participants, who lived with her husband. She expressed the importance of her family, many of whom lived close by. Ms K had a broad range of interests and hobbies, and was an active member of a number of groups and societies (some of which were for people with dementia). Ms K said that she felt very strongly about educating the wider society about dementia, and therefore had been pleased to have been invited to participate and share her views and experiences.

Participant 212 – Ms L

Ms L lived by herself in her own home, having been widowed for a number of years. She gained support from one particular family member and professional carers on a daily basis. She described her role as a mother and housewife in her earlier years, and enjoyed reflecting on these. Ms L was a member of a social group for older people, but otherwise enjoyed activities that she did alone, and spent a lot of time in her home. She appeared unsure of her ability to provide a meaningful contribution to the research, but reported enjoying taking part in something that was “doing some good”.

Appendix D: Information Sheet

(Copies given to potential participants were printed on NHS Trust headed paper)

**“INVESTIGATING THE WAYS THAT OLDER PEOPLE COPE
WITH MEMORY AND THINKING PROBLEMS”:
INFORMATION SHEET**

My name is Laura Preston, and I am a Trainee Clinical Psychologist. I am studying at the University of Southampton, and I also work for the NHS.

You are being invited to take part in a research project. Before you decide if you want to take part, 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 others if you wish. Ask me if anything is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of your study?

By talking to people with memory and other thinking difficulties, I hope to find out about all the different ways that people cope. The way that people cope is important as it is thought to be linked to wellbeing. The information will be written up and published. We hope it will eventually be used to put together a questionnaire about coping that psychologists can use to find out how useful their help is.

Why have I been chosen?

You have been chosen as the study is about people with memory and thinking problems, such as yourself. I am hoping to interview about twelve people.

Do I have to take part?

It is up to you to decide whether or not to take part.

If you do decide to take part, you will be asked to sign a consent form. You would still be free to change your mind at any time. You don't need to give a reason if you decide not to take part in the project and your decision won't affect the care you receive.

What will happen to me if I take part?

I would ask to meet with you to talk about the ways you manage your life.

You can choose:

- Where you would like to meet
- When you would like to meet
- How long you want to see me for
- If you would like a friend or relative to be present

What do I have to do?

Taking part in the project would not affect your lifestyle at all. For example, you would not be asked to make any changes to your diet or medication.

We would meet and talk. I would also be asking your permission to tape record the discussion, so that I can remember all the important things you say.

What are the possible disadvantages or risks of taking part?

It is possible that people may become upset by talking about ways of coping with the difficulties in their lives. If this happens, we will stop our discussion and take a break. You will then be able to decide if you want to carry on or stop talking to me altogether.

You will never be expected to talk about things you do not want to talk about.

It is also possible that, after talking to you, I may have concerns about how you are feeling (for example, if you are depressed or very worried). If this happens, I will discuss my concerns with you.

What are the possible benefits of taking part?

Many people find talking about their experiences enjoyable. The information you give me may be useful to psychologists helping people like you in the future.

Will my taking part in this study be kept confidential?

Anything you tell me will be kept anonymous, unless you tell me that you intend to break the law, harm yourself, or someone else is at risk of being harmed. The notes I take will have your name and address removed from them so that you cannot be recognised from them. The tape recordings of the interviews will be kept locked away for fifteen years (in line with NHS guidelines), after which they will be destroyed. If, during the interview, I feel that it would be useful to pass on any information to your care co-ordinator, I would ask your permission to do so first, and not pass on any information unless you are happy for me to do so.

When I write a report of this study, I intend to use short quotes from the interviews as examples of what people talked about. Quotes will be anonymous: no information will be given that would allow anyone to link the quote to the person who said it, or identify anyone who participated in the study.

My work is supervised by two clinical psychologists. Both these supervisors will keep any information I need to discuss with them entirely confidential.

What will happen to the results of the research study?

I am hoping to publish the results of this study (which would include the short quotes from interviews). You would not be identified in anything that is published. If you would like to know results, I would be happy to send you some information or come and tell you about it in person, once I have finished.

Who is organising and funding the research?

The study is a collaboration between the University of Southampton and West Hampshire NHS Trust. If you choose to be interviewed at the clinic and need to use public transport or drive/be driven to get there, the cost of this will be reimbursed to you (at public transport rate). Regrettably, we cannot refund taxi fares.

Who has reviewed the study?

Both the University of Southampton and the North and Mid-Hampshire Local Ethics Committees have reviewed this study and given approval for it to go ahead.

Contact for further information

If you have any questions, I will be happy to discuss these with you. My contact details are below. If, for any reason, you are unable to get in touch with me, you can speak to Ann Marshall or Romola Bucks, whose details are also below.

Laura Preston (Trainee Clinical Psychologist)

Tel: 02380 595320

Address: Department of Clinical Psychology, University of Southampton, Building 44 (Shackleton), Highfield, Southampton, SO17 1BJ

Ann Marshall, Consultant Clinical Psychologist

Tel: 02380 620162

Address: Newtown House, Newtown Road, Eastleigh, SO50 9DB

Romola Bucks, Clinical Psychologist/Senior Lecturer

Tel: 023 8059 2633

Address: Department of Psychology, University of Southampton, Building 44 (Shackleton), Highfield, Southampton, SO17 1BJ

Thank you for taking the time to read this.

Laura Preston

Trainee Clinical Psychologist

Appendix E: Consent Form

(Copies given to potential participants were printed on NHS Trust headed paper)

Consent Form

Participant identification number:

Title of Project: Investigating the ways that older people cope with memory and thinking problems

Name of researcher: Laura Preston, Trainee Clinical Psychologist

Please initial box

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to ask questions. ☐
2. I understand that taking part is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree to take part in the above study ☐
4. I agree to our discussion being tape-recorded. ☐
5. I would like to receive information about the results of this study, once it is finished ☐

| | | |
|---------------------|-------|-----------|
| | | |
| Name of participant | Date | Signature |

| | | |
|---|-------|-----------|
| | | |
| Name of person taking consent (if different from researcher) | Date | Signature |

| | | |
|--------------------|-------|-----------|
| | | |
| Name of researcher | Date | Signature |

Appendix F: Semi-structured Interview Schedule

1. Could you tell me a little about you memory and thinking problems? (What do you call it/them?)

...any other problems similar to these?
 2. Has there been anything difficult that you have had to manage/deal with/cope with [since you first noticed these difficulties]?
 3. Could you tell me a bit more about [what has been difficult]?
 4. So how do you think you coped with [described difficulties]?/What helped you to deal with [described difficulties]/How did you manage that/how did you react?
 5. How did you manage/cope with those feelings [/other identified aspects of the experience]?
 6. And how else do you deal with this/other potential difficulties?
- [Repeat questions 4-10 until problems and ways of coping are exhausted]
7. How have things changed [since you have had memory, thinking and other problems/dementia]?
 8. What separates a good day from a bad day?
 9. Are there times when things are (relatively) easier?
 10. How would your life be different if you had not developed this [problem]?
 11. Given the knowledge and experience that you have, what would you advise someone like me if I found myself having similar problems [/if I was diagnosed with dementia]?

Appendix G: Summary of Ethical Considerations

In considering ethical issues as comprehensively as possible, a number of texts relating to the ethical issues arising from previous research and guidelines for engaging people with dementia were consulted (e.g. Wilkinson, 2000; Hubbard et al., 2003). Clinicians and researchers who had conducted similar studies engaging people with dementia were also consulted on an informal basis.

All participants had been made aware of their diagnosis of dementia. However, there was a potential ethical dilemma regarding use of terminology when speaking with participants about dementia. Whilst it was felt important that the interviewers were open in speaking about dementia (and therefore used the correct terminology), it was also acknowledged that this may cause discomfort for some individuals, and that the way that they wished to refer to problems related to dementia should be respected. The term, "memory and thinking problems" was therefore be used to discuss the difficulties until the initial interview, when the interviewer was able to determine and subsequently use each participant's personal terminology for their difficulties.

The issue of informed consent was also of importance. The position of process consent was assumed (i.e. the researcher continuously monitored whether the person agreed to participate, see Kvale, 1996; Hubbard et al., 2003), and there were instances when the tape-recorder was switched off during parts of the interview, when the participant imparted information that they wished to remain private. Consent to use tape-recordings for the research was again gained at the end of these

interviews. Participants who expressed any uncertainty about participating or had questions about the research were given appropriate information and subsequently encouraged to take time consider whether or not they wished to participate.

Due to the nature of the research, it was not possible to offer confidentiality. The nature of the anonymity offered and summary of what would be reported in the study was made clear to participants.

If the researcher had concerns about the well-being of participants, it was planned that this would be discussed with the individual concerned. If consent was gained, it was intended that the care co-ordinator would be informed of these concerns to allow the appropriate input to be provided. However, this was not necessary, as such a scenario did not arise during the research.

It was deemed unlikely that the interviews would cause any discomfort or distress to individuals. However, it was considered possible that some people may have experienced some discomfort or have become mildly upset if they chose to talk about experiences that were particularly difficult for them. It was felt that any such feelings were likely to have reflected the underlying level of distress and discomfort commonly experienced by people as they face the challenges imposed by dementia (which many people welcome the opportunity to discuss - Clare, 2002b), and would not be imposed directly by the interview process. It was planned that, if this did occur, a short break would be taken from the interview, and the interviewee asked whether or not they wished to continue. Interviewers were aware of the need to use clinical skills optimally to make decisions regarding the best course of action in such

scenarios and manage the situation. Whilst the obvious need to make the well-being of the participant the primary concern was recognised, it was also acknowledged that, if a participant did become upset, he or she may still wish to continue with the interview to complete their desired contribution to the research, and that this wish should be respected as far as possible. It was planned to assess the participant's mood prior to leaving them at the end of the interview, and make the necessary arrangements, with the participant's consent, if the researcher had any concerns about leaving them. Although this was not needed, a provision was made so that all participants had the option to meet with the researcher or a psychologist in the local Community Mental Health Team to discuss further any issues raised by the interviews.

The interview was led by the interviewee, and their wishes concerning what they did and did not wish to discuss respected at all times. Thought was given to the manner in which the relationship between interviewer and interviewee was established, to avoid promoting that of a therapeutic relationship, as far as possible.

It was also anticipated that engaging in the research may have been anxiety-provoking for some individuals. A number of measures were taken to minimise anxiety, such as emphasising the informal nature of the interviews in the initial telephone contact, reiterating the exploratory nature of the study (and therefore the open nature and participants' level of control over the interview), taking time to engage and develop a rapport with the participant prior to beginning the interview, and repeatedly giving participants reassurance of the validity and meaningfulness of their contributions.

The interviews were designed to be an enriching experience for the interviewee. Overall, it was anticipated that there would be some reciprocity in the research process (e.g. see Kvale, 1996; Wilkinson, 2000) in that many participants would value the opportunity to discuss their experiences (see Clare, 2002b; Cheston, et al., 2002) and benefit in the short-term from talking about difficult experiences on a single occasion (Wilkinson, 2000), as was found to be the case.

Provisions were also made regarding the supervision needs of the interviewers in terms of the emotional impact of engaging in the interviews.

Appendix H: Overview of Training of Second Interviewer

The second interviewer was selected on the grounds of having the necessary clinical skills, previous experience of interviewing people with cognitive and mental health difficulties, and high level of commitment to ethical and moral research issues. To supplement previous experience, the interviewer was given appropriate formal training, which covered the areas outlined below. The content of training was in line with the evidence base regarding interviewing skills and engaging people with dementia (e.g. Wilkinson, 2000). Each area was exemplified and discussed in detail, and role-plays used throughout, as appropriate.

- General interviewing skills – importance of introductions; emphasising to participants what is/is not expected of them; putting participants at ease; opening the interview; attending behaviour, observing the interviewee; use of open-ended questions; encouraging, prompting and summarising skills; awareness of participants' concentration, attention and other needs.
- Introduction to, and use of, the semi-structured interview schedule.
- Guidelines for explaining the contents of the information sheet; checking understanding and gaining consent.
- Procedure for initial contact with the participant and carrying out the interview (checklists were provided).
- Key differences between the research interview and a therapeutic relationship
- Particular considerations pertinent to interviewing older people with dementia (need to be sensitive to the ways that dementia impacts upon a person's memory, decision-making capacity and emotional disposition, for example).

- Safety issues regarding the researcher; procedure for situations in which the researcher feels unsafe.
- Risk issues: what constitutes concern about level of risk to self/others; procedure for managing concern about a participant's risk level.
- Management of a range of difficult interview scenarios.
- Ethical issues, ethical knowledge, and moral research behaviour (also see Appendix I).
- Confidentiality and anonymity.
- Overview of IPA approach.
- Guidelines for writing the reflexive account.
- Guidelines for transcribing.
- Use of supervision during the research process.

Appendix I: Summary of the Reflexive Account

A reflexive account was kept throughout the research process (Smith, 1996).

Content of the account was considered in supervision, particularly in relation to the content of the interviews and subsequent analysis. Some of the key areas covered by the account are outlined in the following.

- Consideration of personal motivations in initially choosing to research dementia (and comparison with supervisors' interests and motivations); acknowledgement of personally held hopes and fears associated with wishing to actively engage older people with dementia in research.
- Record of the formal and informal aspects of the process of establishing the aims and design of the study, and possible influences on these.
- Notes regarding conversations and progress made in gaining ethical approval to conduct the study, and reflections on this process.
- Notes of dates of events relevant to research, and thoughts regarding the content and outcome of these. These events included: telephone conversations and meetings with participants, research supervision meetings, meetings and conversations with people with particular expertise in the use of IPA, and emails to other researchers contacted, for example.
- Reflection on the personal effects of engaging in each of the interviews, particularly the emotions evoked during and following interviews, and the effects of process issues (including transference and counter-transference). These were based on both the author's initial awareness of reactions, and further insights stemming from study of the content of transcripts. For

example, the author reflected on feeling a strong sense of responsibility to accurately convey what participants had contributed during the interviews, and broadcast this to a wider audience. The author explored reasons underlying this, with reference to process and personal issues, and identified the potential effects this had on the data analysis (e.g. greater length of time spent performing micro-analyses of large portions of scripts; a tendency to want to use of more powerful language in conveying experiences in the written report). The author also reflected on the writings of other researchers engaging in similar work to help understand and normalise personal reactions.

- Consideration of the content of the interviews, and the ways in which the relationship developed between participants and researchers differed from therapeutic relationships (which were more familiar to the author).
- Reflection on the author's own ways of coping – both generally, and more specifically in coping with emotions aroused from engaging in the interviews.
- Ongoing reflections on the author's own beliefs, hopes and assumptions about coping and about dementia throughout the research process, and changes in these over the period of time. The author also considered the epistemological orientation of IPA that was assumed during the research, and explored how personal beliefs fitted this perspective.
- General thoughts about the IPA process (particularly following attendance to a conference on IPA, and subsequent discussions with other researchers).
- At the end phases of the analysis, the author considered the range of alternative ways that the content of the analysis could have been presented, and the possibilities for future research using the interview data.

- General reflections regarding writing up the study, and the effects that personal involvement in the interviews had at this stage (e.g. difficulty in having to choose between quotes to exemplify themes).
- Further reflection on the moral and ethical issues associated with engaging people with dementia in research, and potential barriers to this.
- Thoughts about the reciprocity of the interview/research process between researcher and participants. In particular, the author considered how the interview had provided participants with an opportunity to reflect on experiences, identity and meaning, and to know that these experiences, that so often represented uselessness and hopelessness, were genuinely being put to some positive use. It was also considered that the interviews provided the author with personal, privileged insights into the lives of individuals, in addition to the unusual opportunity to compare these “snapshots” of lives and experiences on a shared level.
- Acknowledgement of what had been learned from engaging in the research process (as outlined in Appendix O).

Appendix J: Copy of Local NHS Research Ethics Committee Approval Letter

Hampshire and Isle of Wight

Strategic Health Authority

North and Mid Hampshire Local Research Ethics Committees
 Harness House
 Aldermaston Road
 Basingstoke
 Hampshire
 RG24 9NB

Tel: 01256 332288
 Fax: 01256 818112
 Direct Dial: 01256 312248

Our ref: SKT/mk/03/B/041/L4867

Miss Laura Preston
 Flat 6, 41 Hawkwood Road
 Boscombe
 Bournemouth
 BH5 1DS

www.hiow.nhs.uk
www.rdsu.soton.ac.uk/rdsu/ethics.htm
sandra.lapping@nhpcd.nhs.uk

7th July 2003

Dear Miss Preston

03/B/041 – Coping in older adults with dementia : development of a coping responses scale

Following the conditional approval, I am pleased to confirm full approval having responded satisfactorily to the committee's concerns.

The following documents were re-considered:

- Letter dated 22.7.03
- Application Form
- Protocol version 4, 20.7.03
- Patient Information Sheet version 3, 24.7.03
- Consent Form version 2, 17.7.03

This approval was granted under Chair's action and will be recorded by the committee at their meeting in September.

I must emphasise that whilst the committee look at work on ethical grounds, it is up to the Trust to finally sanction the work, taking into account financial and other implications.

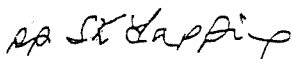
To comply with good practice a list of members at the 16 July 2003 meeting is enclosed.

The committee wish you every success with the study. The following conditions apply to all approvals:

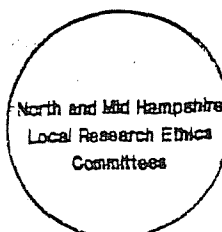
- (a) that you notify the LREC immediately of any information received or of which you become aware which would cast doubt upon, or alter, any information contained in the original application, or a later amendment application, submitted to the LREC and/or which would raise questions about the safety and/or continued conduct of the research.
- (b) you need to comply with the latest Data Protection Act and Caldicott Guardian issues.
- (c) you need to comply throughout the conduct of the study, with good clinical research practice standards, including obtaining informed consent.
- (d) you need to refer proposed amendments to the protocol to the LREC for further review and to obtain LREC approval thereto prior to implementation (except only in cases of emergency where the welfare of the subject is paramount).
- (e) you must supply an annual summary of the progress of the research project and of the conclusion and outcome of the research project and inform the LREC should the research be discontinued. Research terminated prematurely must be reported to the REC within 15 days with the reason for the termination. Final reports must be received within three months.
- (g) that satisfactory indemnity arrangements agreed with the Trust are in place before the study commences.

The committee is fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials involving the participation of human subjects as they relate to the responsibilities, composition, function, operations and records of an independent Ethics Committee/Independent Review Board. To this end it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997.

Yours sincerely



Rev'd Dr Rosemary Baker
 Chair – Qualitative and Non-invasive Committee



enc July meeting members

Appendix K: Further Details of the Analysis Procedure

Initial Reading

Prior to commencing the interviews and analysis, the principal researcher avoided reading related literature in depth, in an attempt to limit familiarity (and therefore potential biases) with previous findings and current theory.

Initially, all transcripts were read, and small sections of the interviews felt to be invalid were excluded from the analysis. These included all contributions from the spouse¹ (where present) and participants' responses deemed to be excessively influenced by the interviewer/spouse, such as responses to leading questions. It was not felt necessary to exclude any whole interviews from the analysis, as it appeared that, even with a partner present in some cases, participants were able to discuss their experiences in sufficient detail (Smith, 2004). Quality of interviews was also checked in accordance with guidelines from Kvale (1996).

Initial Analysis of a Sub-Group of Individual Scripts

A sub-group of 4 of the 12 interview transcripts were the focus of the initial analysis. Four contrasting transcripts that were, together, considered to be representative of the range of themes covered across the interviews were selected; it was ensured that an interview conducted by the second interviewer was among these.

Each transcript was analysed individually. Firstly, it was read and reread to familiarise the analyst with the content of the entire interview. Secondly, a

¹ Although the spouses provided valid potential contributions, the clear aims of the present study were to investigate the viewpoint of the people with dementia

description of the content of what the participant was saying, and initial interpretations of possible meanings were noted. The transcript was then read again, concentrating on possible meanings and interpretations of what was said by the participant, putting aside any portions of the transcript that were seemingly irrelevant in any way to the topic of interest (only a small amount of data was excluded at this point). On the final reading of this phase, emergent themes across the interview were identified in a final column. Any observations that had been noted during the interview were read in conjunction with the script, and used in the interpretation process. The analyst returned to portions of the original tape-recording where meanings were ambiguous, and vocal cues such as intonation and timing aided interpretation.

At each stage, there was a continuous back and forth process of verifying the content of the local text in the context of the interview as a whole. Some of the interpretations of meaning were initially based on intuitive understandings, and returned to at a later stage to be negated or supported in the context of the script as a whole, additional information, and/or peer review or supervision. Meanings were analysed on a number of levels, from the overt expressions of the individual to interpretation of metaphors, process issues and use of discourse. In this way, IPA is said to operate on a level that is clearly grounded within the text, but also moves beyond the text to a more interpretative and psychological level (Smith, 2004). However, any questionable interpretations were excluded and, where meanings were ambiguous, care was taken to note the range of different potential interpretations. Appendix L provides an example of the analysis.

Tentative themes were then examined and re-examined, and organised into initial theme clusters for each participant. These were later revised in accordance with the shared theme structure that was subsequently developed.

Analysis of Shared Themes across Transcripts

Once themes and potential clusters for individual transcripts had been identified, the themes across all 4 accounts were listed and compared. Similar or shared themes were grouped into theme clusters (some of which were the same, some reorganised versions of the theme clusters identified at the individual participant level). Each transcript was then coded so that all instances of each theme were identified. These clusters of shared themes were then considered in relation to each other, and organised into sets. The resultant structure was a hierarchically organised summary list of 3 levels of themes, named major themes, sub-themes and sub-theme components.

The transcripts were then re-examined on an individual level to check that the themes were represented in the verbatim transcripts (note that not all themes could be found in every account), and that the developed shared theme structure fitted and was representative of each of the individual accounts.

The process of developing themes was a balance between representing diversity of coping and aspects related to coping, whilst being as parsimonious as possible. An aspect of coping was deemed to be shared if it had been expressed by 2 or more participants, although the themes of the resultant analysis had contributions from a minimum of 4 people.

Coding of the Remaining Transcripts

The product of the initial analysis of the sub-group of transcripts was a tentative structure of themes and sub-themes. The remaining 8 interviews were similarly analysed (using the same steps detailed above) with reference to this structure. Data from these 8 interviews were used to refine and reorganise the 3 levels of existing themes, creating new themes, where appropriate. A revised hierarchical structure of the 3 levels of themes resulted from this process.

Data that had initially been excluded following the descriptive stage of analysis was reconsidered in the context of the developed theme structure, and re-checked for relevance. The continual check between emerging themes and the original verbatim accounts at each stage ensured that the resultant structure and description of themes was grounded in the original data.

Two ‘overarching themes’ were also identified in relation to the emerging structure: these were recurring themes, evident in a majority of the transcripts, that spanned many of the major themes.

Appendix L: Analysis Extract

The following excerpt (the equivalent of one page, or thirty lines, of the original transcript) demonstrates the initial phases of the analysis process, up to the stage of generating initial themes (these initial themes were then grouped and renamed following comparison with other transcripts to generate the final themes). The extract has been chosen as a relatively uncomplicated example of original transcript to use for demonstration. However, it does not demonstrate the more complex interpretations of process issues and use of discourse (e.g. unusual use of tenses, use of the third person), which would, in many cases, require larger portions of the transcript. Behavioural observations from the interview have been noted in brackets in the transcript column. Generally, the first column describes what is being said by the participant, the second column places an interpretation of the meaning of this, and emergent themes are noted in the third column; however, there is overlap in places.

Some interpretations were made with reference to the content of the rest of the transcript. For example, in line 177, the use of the expression “kick start” is interpreted as referring to a metaphor of the brain as an engine or machine, due to similar comparisons in other parts of the transcript (the participant explicitly likens the brain to a machine at one point, and talks about the brain needing oiling at another point).

In line 192 the use of the word “specifically” is considered significant and interpreted as referring to an increased awareness of difficulties, with reference to the

participant's repetition of this and similar words ("literal", "obvious", "very apparent") throughout the interview.

The author initially noted alternative interpretations of meanings of the participant's words: only those that have been verified with reference to the whole transcript are shown here.

Participant 101, Lines 173-203

(Participant has been talking about how he goes upstairs to get something, but forgets what it was he wanted)

| Line no. | Original transcript: | Descriptive: | Interpretative: | Initial themes: |
|----------|--|---|---|--------------------------------------|
| 173 | P -But quite often I will still go back to | Frequently go back, I try to work it | Reminding | |
| 174 | where I was or where I think I was | don't always know where I was. | out, but my memory doesn't (ever) let me do that | retracing step |
| 175 | I -Right | | | |
| 176 | P -But, for some reason, that doesn't | Insufficient/don't help | Wondering why | |
| 177 | kick-start my brain again and I think, | Don't know why. | ↓ | Making sense, brain/engine |
| 178 | oh yeah I was gonna do x. It does | | Making sense using metaphor brain like an engine that's seized up/stopped running | -Making sense logic |
| 179 | sometimes. | Sometimes helps | | |
| 180 | I -Right, right | | | |
| 181 | P -But nowhere near as frequently as it | problem progressively worsening/coping strategy becoming less effective over time | awareness of change, deterioration | awareness of progression of dementia |
| 182 | used to | | | |
| 183 | I -Oh, right. Interesting | | Embarrassment? | social awareness, awareness |
| 184 | P -It seems a silly thing to do, to go | It looks/feels silly or stupid/feel unfamiliar? | Doing things differently to how used to. | Adapting/compensating? |
| 185 | back to where I was, what I was doing. | | | |
| 186 | I -Well, I think it makes sense | | | |

| | | | |
|-----|---|--|--|
| 187 | P - I've always said it's as if that | ...but it makes this | Always had |
| 188 | thought you walk into it and it goes back | and why it might work | understanding |
| 189 | into your head. | I've always believed | making sense |
| 190 | I - That does make a lot of sense! | the thought hangs in the air & goes back in my head. | using metaphor |
| 191 | Completely. | (I have a mental image) | |
| 192 | P - But now I've specifically got memory | Specific problem, diagnosed. | No pretending, Acceptance/ |
| 193 | problems... That doesn't work nearly as often. | Coming not as this problem; problem was not | recognition of need to accept problem (+ progression working of problem) |
| 194 | [pause]. [P gestures for help word-finding] | effective. Prompt me | |
| 195 | I - As it used to? | Help me | Getting help. (word finding) |
| 196 | P - Yes. Even if I'm going to get a | Can't remember simple, familiar, concrete, easy things. | Feeling stupid? Hard to believe (amazement). |
| 197 | screwdriver, a saw, or a tool that is easy | | Frustration. Negative emotional reaction |
| 198 | to remember, or a spanner, but that can | | It affects everything. Negative nature of dementia |
| 199 | drop out. That's so clear cut isn't it, to get out. | Memories drop out. | Metaphor - drop out |
| 200 | a spanner or a tool, but it's only when | That's concrete to remember, but drop out so quickly/easily. | Making sense with metaphor |
| 201 | I'm half way where I knew it was | | Progression of dementia, no escape |
| 202 | that's... [appears frustrated]. I don't know if | Do I make sense? | Frustration at not completing task/ reaching |
| 203 | you can follow. | | For memory. Social awareness. |

(Repetition)

Negative impact on self-esteem?
 confidence?
 and/or:
 - Desire to be understood
 or fear of being misunderstood,
 not making sense

Impact on self-esteem?
 Method of checking other's understanding.

Appendix M: Description of Challenges Posed by Dementia

Although it was not the aim of the present study to investigate this area, the challenges of dementia that emerged from participants' accounts are briefly outlined below.

Primary challenges (i.e. difficulties directly associated with the dementing process) were described as problems of attention, concentration and memory; articulation and expression; orientation in time and/or space; a sense of unfamiliarity or confusion; a general slowing of cognitive and behavioural abilities; and a "loss of the automatic" (including sequencing of tasks, etc, and tracking skills).

Secondary challenges (i.e. difficulties indirectly associated with the dementing process, arising as a result of/mediated by primary or other factors) involved a wide range of emotional reactions. These included frustration, resentment, regret, sadness, loneliness, fear and anxiety, shame, feeling generally "upset", and feeling overwhelmed, many of which appeared to be in response to multiple losses. Experiencing others' negative reactions comprised another major group of challenges for many participants. Reactions ranged from being negatively positioned to managing others' disbelief and minimisation of the problem, for example. Participants also spoke of problems arising from their social awareness of difficulties. Other secondary difficulties were: experiencing limitations in the range of activities they were able to participate in, such as driving; the effects of the summation of a number of problems (e.g. feeling overwhelmed/overloaded by the

frequency of difficulties and the pervasive and chronic nature of dementia); and, effort involved with having to do things differently.

Appendix N: Further Exemplary Quotes from Themes

The following provides one or more additional quotes to exemplify emergent themes: where appropriate, a number of additional excerpts have been provided to exemplify different elements of the same sub-theme/component. As in the main body of the report, quotes that have been selected that capture the essence of the theme, without requiring a large amount of contextual information from the rest of the interview.

Managing Identity in Relation to Dementia

Continuity Between the Past and Present Self

(Participant referring to how she had always been highly organised)

“...see you don’t forget it do you.” (P202, 1070-1076)

Discontinuity Between the Past and Present Self

“...worked for them in the Falkland Islands so that was really good...And fortunately I, you know, I had My full facility, the full, err, sort of, err, brain working still. But not now.” (P204, 251-254)

Integration of Dementia

(Participant previously spoken about experiences of disorientation)

“But before I ever heard of Alzheimer’s, when I was younger, I do remember things like, I’d always come out of the shop and turn the wrong way...So whether to a certain extent it’s not all Alzheimer’s, but how you’re sort of programmed at some time.” (P211, 187-195)

Lack of Integration of Dementia

Example of dissociating episodes of dementia in time:

(Participant referring to waking up feeling disorientated)

“And I thought well I’m not in a cabin, I didn’t quite know where I was, but it was just a split thing...and that was it.” (P202, 715-719)

Self as Able/Valued

Example of participant talking about positive aspects of the self based in past times:

“And I used to make all kinds of things. And they all thought it was, er, great. Liked it [pause]. Back then.” (P205, 893-898)

Example of participant talking about positive aspects of the self based in the present time:

“Oh, there’s still nothing that I can’t do....What’s within my envelope, if you like.” (P201, lines 1194-1197)

Self as Substandard

Example of participant expressing feeling that he was not good enough, in comparison with his previous self:

“Oh, maybe perhaps not as strong as I would like, I’m not as strong as I would be, I suppose, I’ve got the Alzheimer’s.” (P204, 847-850)

Example of self-criticism:

(Participant referring to mistake he had made)

“Now how silly can you get. Now that really annoyed me, because I thought well, how daft.” (P206, lines 1355-1356)

Example of participant feeling that he was insane:

“I have to do something over again, and I have to really, you know [*laughs*]. I feel such a nutcase.” (P203, line 1589)

Making Sense of Dementia

Making Sense of Dementia as a Whole

Example of biological/medical understandings:

(Participant talking about the experience of forgetting a sentence that he had been about to say)

“Because I’ve, the signal, well in the brains it’s chemical, chemically, I just felt it decaying, It was only a short sentence.” (P201, 93-95)

Example of broader parallels and comparisons:

(Participant likening the brain to an engine)

“My expression is, ‘my brain’s dropped out of gear’.” (P201, 1429-1430)

Making Sense of Individual Experiences

Example of participant comparing experiences of dementia with past traumatic events:

“I, think I, I lived in London during the war, and that was horrific, but that fear of up there of not knowing where I was, as worse than when all these bombs were falling round us.” (P202, 414-419)

Lack of Understanding

“Well, to start off with I was very forgetful, wasn’t I [*name of husband*]. Erm. But I can’t really explain any more than that.” (P209, 55-59)

“But how is the other person going to believe you. Because it is an unbelievable things, that you, ten minutes before you’ve forgotten. But I’ve forgotten it.” (P208. 466-469)

Coping Strategies and Mechanisms

Individual, Everyday Strategies

Use of visual prompts and formal memory techniques

“...whether it could when I’m driving, but I’m usually fine then because I have that visual picture.” (P201, 1451-1453)

“I can’t get any pleasure out of a phone call. Whereas when my sister came round, and we’re sitting like we are now...So I can see her, um, it’s lovely. And it takes me back to when I used to enjoy phone calls.” (P211, 519-524)

Information

(Participant speaking about having seen her mother’s symptoms of dementia)

“Well, what helped me was knowing the symptoms.” (P202, 807)

Example of participant finding that the information available was inadequate in providing the explanations or help that he was searching for:

“Because I think if I go along to the local library and say well something on this, I haven’t tried it, that’s a problem. But I don’t believe that without going along to the university library that I would be able to get the response I was looking for...And the response that I

would be looking for would be this: is the brain. And this is the way the various nerve cells connect with one another, and this is what happens when they don't connect with one another, fault-wise. And then what would be the route to reaching some understanding of what the problem was and how I can correct it.” (P208, 466-475)

Being logical

“To make sense of something I analyse things, the logical side of me, so I analyse to make sure I have understood. I think that's perfectly true. That I have to analyse to come to a decision...It works to a point.” (P207, 866-870)

“...feeling of, I'm going to make a mistake on here and then it's a, it's a nuisance because I have to get another form and start all over again.” (P211, 52-54)

Example of practically rectifying problems:

(Participant referring to fixing a machine)

“Yes. I might be working here at night at 2 or 4 o'clock in the morning, but I gotta finish it, I gotta do it.” (P207, 169-171)

Cathartic expression

“Well, I think it does help, to cry, it's better than bottling it up. It makes it easier, makes you feel more relaxed inside.” (P209, 1486-1492)

Medication

“It's definitely, um, I think those Arisept tablets have really helped me. I think without those possibly I would have been worse.” (P202, 684-686)

Coping in Relation to Others

Talking and sharing

(Participant referring to speaking to her sister)

“Well you see I’m on my own, and, well, I thought I’ve got to tell one of them, and she’s the nearest and so I thought I’ll just phone her and say...And I do keep, erm, them informed of anything that’s [*pause*]. Because the others live a bit further away, so they’re the nearest to me. But I don’t worry about it.” (P202, lines 493-502)

(Participant referring to how she and her husband approach coping with her memory difficulties)

“We say, we can do it. We can cope with it.” (P209, 1324)

Being with similar people

(Participant speaking about what is useful about being with other people with dementia)

“Well I think it shows that you’re not alone, for a start.” (P203, 548)

“There was a time when I didn’t, um, but again there was a time when I didn’t have this problem of losing track. But I tried the memory group. And I can’t say when the awareness that other people experienced this was as strong in me as it is now. It is very strong.”

(P208, 161-164)

Getting help

(Participant speaking about receiving help from his wife)

“But no, er, I think I could live a separate life if necessary. But er...it’s very helpful.”

(P207, 117-119)

Social comparisons

“I try not to worry about things. I don’t worry...’Cause one of the men at the, that goes to the memory group...we chat, and he worries about it...He worries about it, and I don’t. And he says, ‘Don’t you?’, and I say ‘No, it’s something that’s happened, and let’s get along with it.’” (P202, 18-30)

Personal Attitude/Approach

Being positive

(Participant talking about having a sense of humour)

“But I always had it, so. Without it I wouldn’t know how to cope, really.” (P208, 906-907)

Examples of positive thinking:

“And doing things, the main thing is keep your spirit up. If there’s nothing you can do about it in the sense of preventing it happening, I couldn’t stop with the stroke, there’s nothing I could do about it. So you can’t see it coming before, beforehand. So right, after it happened you will perhaps think, well perhaps if I could in those, changed my lifestyle or whatever, but it’s too late anyway.” (P207, 1062-69)

(Participant talking about managing difficult or frightening thoughts)

“I’d tell myself to buck myself up.” (P202, 995)

Example of concentrating on positive emotions:

(Participant speaking about spending time with her sister)

“I saw her a couple of days ago. And we had a really nice morning you know. Afternoon, my daughter came in the morning...And it was a thoroughly good day for me you know [*smiling*].” (P211, 408-413)

(Participant having previously spoken to about feeling frustrated that he cannot drive any more)

“And of course my wife has to drive the car. And she drives it all the way and umm... You know I just sit back and err, it’s a nice sort of thing to do...I like being driven like that.” (P204, 670-4)

Looking after myself/taking it easy

(Participant referring to how he does not admit not understanding in certain social situations)

“Now this might not help you at all, but it gives me a safe guard. I've got a guard which I put up, that's right I am.” (P207, 899-902)

(Participant referring to the help she receives in her supported accommodation)

“Well, that’s right there’s always somebody you know that will come in and but, err, up until now touch wood you know I get up in the mornings and get my shower and get dressed and make the bed such that it is doesn’t need much making. And, err, very easy life...Very easy, very lucky. (P205, 109-115)

Putting problems into perspective, and knowing when to let it go

Example of putting into perspective in relation to the life course perspective/their age:

“I must be I must be what shall I say hundreds of people like us getting older not being able to do the things that they used to do. Some are not so lucky to have people who you know like you trying to find out things.” (P110, 1112-1116)

“I mean it’s not a terrific age by present day standards, but it’s fairly good, I’m not complaining, and er, all I hope is that I keep well enough to be able to er, not exactly enjoy it but to er, to live with it as it were.” (P203, 779-782)

Example of “letting things go”:

“It’s always been the sort of thing hasn’t it you forget peoples names, err. With this life, dear, you don’t have to worry too much you know what I mean.” (P205, 23-26)

Example of putting it into perspective in relation to what is more important:

(Participant talking about having forgotten to take his medication)

“I didn’t know what to do. But they aren’t killers, so it’s not important...So I accept that I made a bit of a muddle.” (P201, 488-492)

Example of putting it into perspective in relation to life in general:

“Well, everything changes, I mean.” (P210, 1080)

Patience and having faith

“All I know is the best thing is to, to err, umm, you know time, and err there is always tomorrow, you know.” (P204, 635-636)

“But it don’t get me down. If I got to sit down and write the names I can’t do it, but if I’m there I associate the faces with the names, so yeah, it comes.” (P208, 575-577)

Accepting it vs. fighting it

Examples of acceptance:

“If it’s gone, then things just disappear out of my mind. Slowly I’m accepting.” (P201, 116-117)

“Yes, but I can’t now. I can only do one thing at a time. If I’m reading a book, I can only read that book, if someone talks to me I can’t.” (P211, 500-503)

“Yes, ah, yes. Accept it, and yet at the same time, fight it.” (P203, 1092)

Examples of “fighting it”:

“But you gotta push yourself. I’m determined not just to fold up and sit down.” (P202, 222-224)

Avoidance and covering up vs. being open and not hiding

Examples of avoidance:

(Participant talking about managing worrying thoughts by keeping busy)

“Well, it’s your mind [*pause*]. See this is why I get satisfaction: your mind is busy on what you’re doing, hardly ever does a thought enter your mind and like intrude.” (P201, 1058-1062)

Examples of being open/not hiding:

“When I go out to places, I do like to get the opportunity to tell people I have AD. I want them to know what it’s about...Because people don't know otherwise and have all kinds of

ridiculous ideas. And negative ideas. Er. When it's not all like that. So if I have the chance to tell them, I do." (P211, 654-659)

Appendix O: Summary of Participants' Contributions to Themes

Table A1: Summary of Participants' Contributions to "Managing Identity In Relation to Dementia" Sub-Themes

| | P201 | P202 | P203 | P204 | P205 | P206 | P207 | P208 | P209 | P210 | P211 | P212 |
|---|------|------|------|------|------|------|------|------|------|------|------|------|
| Continuity between the past and present self | X | X | X | | X | X | X | | | | X | |
| Discontinuity between the past and present self | X | | | X | X | | X | | | | X | |
| Integration of dementia | X | | X | | | | X | | | | X | |
| Lack of integration of dementia | X | X | X | | X | X | | | X | | X | |
| Self as able/valued | X | X | X | X | X | X | X | | | | X | X |
| Self as substandard | X | X | X | X | X | X | X | | X | X | X | X |

N.B.. Mark in column indicates participant contributed to sub-theme

Table A2: Summary of Participants' Contributions to "Making Sense of Dementia" Sub-themes

| | P201 | P202 | P203 | P204 | P205 | P206 | P207 | P208 | P209 | P210 | P211 | P212 |
|--|------|------|------|------|------|------|------|------|------|------|------|------|
| Making sense of dementia as a whole | X | X | X | | | | X | X | X | X | X | |
| Making sense of individual experiences | X | | | X | | X | | | X | X | | |
| Lack of understanding | X | X | X | | X | | | | X | | | X |

Appendix P: Personal Reflections on What was Learned from the Process of Conducting the Study

The author gained a great deal from engaging in different aspects of the research process, as acknowledged in the reflexive diary. This included learning about/gaining from:

- The differences between therapeutic and research relationships with people with dementia, and boundaries of these;
- The personal involvement required by researchers in engaging people with dementia in this studies of this nature;
- Management of challenging interview situations as a researcher;
- Moral and ethical responsibilities of the researcher;
- An enhanced appreciation of the use of qualitative techniques, and the rigour and power of IPA in representing subjective experiences;
- Appreciation of clinical skills and other prerequisites required to conduct IPA, and the potential use of IPA in NHS clinical settings;
- Greater awareness of personal biases and assumptions, as both a researcher and a clinician;
- Greater awareness of the strengths and weaknesses of personal clinical skills, through the close examination of interview transcripts;
- A greater personal insight into the lives and experiences of the individuals with dementia who engaged in the study.