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Relationships between people with dementia and their carers

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Doctorate in Clinical Psychology

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Department of Clinical Psychology**

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Declaration

The material presented in this thesis has not been submitted for a degree at any other University.

The thesis is entirely the candidates own work and does not contain work carried out in the context of collaborative research projects .The author developed the research ideas and design, led the data collection and conducted the analysis. The thesis was carried out under the supervision of Gregory Jones, University of Warwick; and Jane Muers, Coventry and Warwickshire Partnership Trust. Coordinating supervision and additional support with drafting was provided by Sarah Kent, Department of Clinical Psychology, Universities of Coventry and Warwick. The data collection was supported by Fiona Palmer, Rugby MIND; Charlotte Carthy, Coventry and Warwickshire Partnership Trust; and Jane Tooby, Coventry and Warwickshire Hospital Trust.

A proportion of the data presented in the empirical paper submitted here was presented as a poster at the British Psychological Society Division of Clinical Psychology Conference in December 2007, (see Appendix 11).

Thesis Synopsis

This thesis consists of three papers, a literature review, an empirical paper and a reflective paper. The literature review covers two distinct but interlinked areas of research: the impact of dementia on the quality of relationships, and the impact of relationship quality on the experience of living with dementia. The literature review clarifies the interactions between these factors by using a model to demonstrate the influence of relationship factors on the experience of living with dementia. Methodological issues and suggestions for future research are discussed, and the findings are summarized with particular reference to clinical implications.

The empirical paper reports on a study of the awareness of carer distress in people with dementia. Ratings of carer psychological health were elicited from people with dementia and from the carers themselves as a pair. Comparison of the ratings showed that people with dementia are aware of their carers' psychological health. A control group of people with arthritis also participated in the study. The level of awareness shown by the participants with dementia was comparable to the level of awareness of carer psychological health shown by the control group. The level of awareness of carer psychological health in the participants with dementia was not related to their level of awareness of their own memory difficulties.

The thesis concludes with a reflective paper which focuses on observations made whilst conducting research interviews and recruiting participants through support groups. Reflections and learning drawn from these observations are discussed.

**Living with Dementia: the influence of
relationship factors**

Literature Review drafted for submission to Aging and Mental Health

Word count: 7,981.

1.1. Abstract

Many people with dementia are supported to live at home by a close family member who takes on the role of a carer. A great deal of research has investigated the impact of caring for a person who has dementia. However in the early stages of dementia research there was a tendency to overlook the experiences of the person with dementia and, in particular, to overlook the relationship between the two people. There is now a growing body of research on the relationship between people with dementia and the family members who care for them.

This paper reviews this literature in two distinct but interlinked sections: the impact of dementia on the quality of relationships, and the impact of relationship quality on the experience of living with dementia. The paper then clarifies the interactions between these factors. First, the possible forms that relationships can take in the context of dementia are set out as four distinct categories. These categories give insights into the mechanisms that determine relationship quality and the experiences of the carer and the person with dementia. Second, a model is proposed which draws together the previous sections and demonstrates the influence of relationship factors on the experience of living with dementia taking into consideration potential reciprocal interactions and causal links.

Two methodological issues are discussed, retrospective reporting of prior relationship quality and the focus on caring reporting. The review concludes with suggestions for future research and with clinical implications drawn from the material relevant to supporting the carer, the person with dementia, and their relationship.

1.2. Introduction

Over the last twenty-five years dementia has moved from a position in the shadows where it was rarely acknowledged, to take a more central position in the awareness of health and social care professionals, researchers, policy makers and society as a whole. The need to improve the level of services and the quality of care for people with dementia and their carers has been formally stated (National Audit Office, 2007; National Institute for Health and Clinical Excellence, 2006) and a National Dementia Strategy is in preparation in the UK.

Interconnected with this increasing awareness is the rising prevalence of dementia caused by greater longevity. Current estimates of the incidence of dementia suggest that in the UK 5% of people over 65 years of age and 20% of people over 80 years of age have dementia (Alzheimer's Society, 2007). Similar incidence levels have been identified in the US (Alzheimer's Association, 2008). It is anticipated that the number of people with dementia will rise dramatically over the coming years. In the UK estimates suggest that prevalence will increase by 40% over the next 15 years (Alzheimer's Society, 2007) whilst international estimates suggest that global levels will double every twenty years with highest increases occurring in developing countries (Ferri et al., 2005).

These changes in awareness and prevalence have prompted a series of shifts in dementia research over the last thirty years (Harris, 2002; Whitlatch, 2001). Medical research continues to seek mechanisms to slow or even reverse deterioration in cognitive function, but alongside this there is a growing field of research on the experience of living with dementia.

An initial focus was on the experience of the unpaid 'carer', usually a close family member or friend who cares for and supports the person with dementia to live in their own home. It was found that they often experience considerable psychological, practical and economic strain as a consequence of their caring role (Ferri et al., 2005) and may experience clinically significant levels of psychological illness (Cuijpers, 2005). It became clear that the level of burden and distress experienced by carers varies and that some carers are more vulnerable to a greater emotional impact than others (Morris, Morris, & Britton, 1988b). Research on factors contributing to this variation explored illness factors in the person with dementia such as the level of cognitive and functional impairment and behavioural aspects of the dementia presentation, and then expanded to investigate wider factors such as demographics, coping styles and level of support received by the carer (for review articles see: Donaldson, Tarriner, & Burns, 1997; Dunkin & Anderson-Hanley, 1998; Kneebone & Martin, 2003; Sorensen, Duberstein, Gill, & Pinquart, 2006).

During the 1990s a second focus emerged which centred on the experiences of the person with dementia themselves. Tom Kitwood played a central role in challenging researchers and professionals across disciplines to recognise the 'person' within the dementia sufferer (Harris, 2002) and (Woods, 2001). This led to research exploring the experiences and perspectives of the person with dementia, and the development of clinical approaches which acknowledge their individual history and social context (Kitwood, 1997; Wilkinson, 2002; Woods, 2001).

A third focus brought together thinking about the experience of the carer and the experience of the person with dementia to consider the relationship between the two

An initial focus was on the experience of the unpaid 'carer', usually a close family member or friend who cares for and supports the person with dementia to live in their own home. It was found that they often experience considerable psychological, practical and economic strain as a consequence of their caring role (Ferri et al., 2005) and may experience clinically significant levels of psychological illness (Cuijpers, 2005). It became clear that the level of burden and distress experienced by carers varies and that some carers are more vulnerable to a greater emotional impact than others (Morris, Morris, & Britton, 1988b). Research on factors contributing to this variation explored illness factors in the person with dementia such as the level of cognitive and functional impairment and behavioural aspects of the dementia presentation, and then expanded to investigate wider factors such as demographics, coping styles and level of support received by the carer (for review articles see: Donaldson, Tarrier, & Burns, 1997; Dunkin & Anderson-Hanley, 1998; Kneebone & Martin, 2003; Sorensen, Duberstein, Gill, & Pinqart, 2006).

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A third focus brought together thinking about the experience of the carer and the experience of the person with dementia to consider the relationship between the two

people. The carer is often a close family member and the experience of giving and receiving care occurs in the context of a long-standing relationship which predates the onset of dementia and continues to evolve as the illness progresses. Aspects of the prior relationship impact on the way the caring relationship functions and how the care giver and care recipient roles are experienced (Daire, 2002; Steadman, Tremont, & Davis, 2007; Williamson & Schulz, 1990). At the same time the experience of living with dementia impacts on the relationship causing change or loss which is difficult to accept or adjust to (Blieszner & Shifflett, 1990; Hellstrom, Nolan, & Lundh, 2007). The aim of this article is to review this third area of research on the relationships between people with dementia and the family members who care for them.

1.2.1. Search Strategy

Searches were carried out through Web of Science, PsychInfo, Embase and MedLine using combinations of the following search terms: dementia and Alzheimer's disease, carer or caregiv*, reciproc*, family relations*, martial relations* and parent child relations*. A number of additional studies were identified using the reference lists and citation lists of the initial set of papers. No timeframe restrictions were applied. Inclusion criteria were set requiring papers to be to peer-reviewed publications written in English. Papers that used a quantitative approach or used qualitative methodology to generate or assess specific models were included. Qualitative papers that took an open exploratory approach and did not generate a specific model were excluded. The scope of this paper is limited to carers who were family members, relationships between a person

with dementia and their main carer, and psychological or emotional aspects of the relationship.

1.2.2. Description of Literature Identified

Thirty-one papers were identified that fulfilled the criteria. The family relationships studied included specific groups of spouses or child-parent caring dyads and mixed groups of main family carers. Relatively little information was given about the diagnosis or severity of the dementia, and the duration of the illness. A wide range of measures relating to relationship factors were used and there was considerable variation in the design of research questions and the approaches and methodologies adopted.

1.2.3. Overview of Literature Review

The literature identified by this review is diverse in nature. Different aspects of relationship quality are studied and many different measurement tools are used to assess them (Table 1). The majority of the studies do not separate out and systematically evaluate factors such as the nature of the relationship (i.e. distinguishing spouses from parent-child relationships) or the severity, form or duration of the dementia.

The quantitative studies can be separated into two groups. In the first group the studies consider how dementia changes the quality of the relationship and could be characterised as having dementia as the independent variable and relationship quality as the dependent variable. In the second group the studies investigate how the quality of the relationship, past and present, affects how carers and people with dementia cope with the experience of living with dementia. This latter group could be characterised as

Table 1. Overview of papers reviewed.

Authors	Sample	Relationship	Relationship measures used	Results
Hirschfeld, 1983	30 dementia - carer dyads	Spouses and children	Grounded theory interviews and observation	The level of mutuality perceived by the caregiver was the most significant factor in predicting institutionalisation.
Gilhooly, 1984	37 dementia carers	Not specified	Semi-structured interviews	The quality of the prior relationship was not found to be related to carer well-being.
Gilleard et al., 1984	227 carers, of which 198 were dementia carers	Not specified	Own set of questions on quality of prior relationship	Carer depression was related to negative reports of the prior relationship.
Morris et al., 1988	20 dementia carers	Spouses	Own Intimacy Scale (covering past and present intimacy).	Past and present intimacy were inversely related to levels of strain and depression in carer. The decrease in intimacy was related to depression but not to strain.
Blieszner et al., 1990	11 dementia carers	Spouses and children	Miller Social Intimacy Scale	Intimacy declined in the period when symptoms first emerged and in the months after diagnosis. No evidence of further decline was found at 16 and 22 months post diagnosis. Four stages of relationship transition identified.
Robinson, 1990	78 dementia carers	Wives	Marital Adjustment Test	Past marital adjustment was related to subjective burden in the carer.
Williamson et al., 1990	151 dementia carers	Spouses, children, siblings, grandchildren	Part of Family Assessment Scale Communal Orientation Scale	Closeness of the past relationship was inversely related to carer burden. Past communal orientation (of carer) was inversely related to carer depression.
Wright, 1991	30 dementia-carer dyads. 17 well couples.	Spouses	Semi-structured interviews with couples Dyadic Marital Adjustment Rating Scale Own questions about coping	Dementia couples had lower congruence in their perceptions of the quality of the relationship. Gender differences in areas of incongruence were identified. Dementia couples had lower cohesion and overall perceived relationship quality than well couples. Differences were not found for affection, tension or perception of instrumental tasks.

Kramer, 1993	72 dementia carers	Wives	Quality of Prior Relationship Scale	The quality of the prior relationship was associated with depression and quality of life for the carer, and caregiver satisfaction. Having one or more prior marriages was associated with increased depression and decreased quality of life for the carer but not with caregiver satisfaction.
Chesla et al., 1994	30 dementia carers	Spouses and children	Semi-structured interviews	Three different forms of relationships identified: continuous, continuous but transformed, and radically discontinuous.
Uchino et al., 1994	31 dementia carers	Spouses, children and in-laws.	Own/adapted questions on past affection and cohesion	Where past affection was high carers showed lower resting blood pressure and reactive heart rate. Where past cohesion was high carers showed higher resting blood pressure.
Wuest et al., 1994	15 carers 11 people with dementia	Spouses, children and siblings.	Grounded-theory interviewing	Three stages of relationship change: dawning, holding on and letting go.
Townsend et al., 1995	90 carers	Children	Own closeness and conflict scales	Closeness and conflict explained the impact of cognitive impairment on carer well-being. They did not explain impact of functional impairment on carer well-being.
Neufeld et al., 1995	20 female dementia carers	Partners, daughters, daughters-in-law, granddaughters. Parent-child	Semi-structured interviews	Four forms of reciprocity identified: waived, constructed, generalised, and obligation.
Carruth, 1996.	110 dementia carers 195 non-dementia carers		Caregiver reciprocity scale Motivating factors index Exchanged pattern index	Dementia carers gave more direct care, received more negative and fewer positive exchanges, and had lower levels of warmth, regard and intrinsic reward from caregiving. Diagnosis of dementia did not relate to level of reciprocity in the relationship.
Quayhagen et al., 1996	10 dementia-carer dyads.	Spouses	Observation, interviews and participant log books.	Four phases of relationship change: discordance, equilibrium, regeneration and emergence.

Townsend et al., 1997	75 carers	Spouses	Own scales for closeness, conflict and subjective caring effectiveness (SCE)	Cognitive impairment predicted low SCE, functional impairment did not. Cognitive impairment was inversely related to closeness. Closeness explained the impact of cognitive impairment on SCE. Conflict did not but had strong direct impact on SCE.
Knop et al., 1998	63 dementia carers	Spouses	Own questions about perceptions of past and present relationship quality	Past relationship quality was higher than present relationship quality. Past level of relationship quality was related to present level of relationship quality. Past and present relationship quality was related to confrontative coping (a positive strategy) and inversely related to emotive coping (a negative strategy) and caregiver depression.
Neufeld et al., 1998	22 male dementia carers	Partners, sons, sons-in-law, grandsons and brothers.	Semi-structured interviews and a focus group	Carer experiences and motivations considered in terms of four forms of reciprocity: waived, constructed, generalised, and obligation. Some men move from one form to another over time.
Murray et al., 1999	280 dementia carers	Spouses	Semi-structured interviews	Difficulties for carers: loss of companionship due reduced communication quality, and loss of reciprocity due to increased dependence. Positives for carer: continued mutual affection and reciprocity (delayed/generalised and constructed).
Gallagher-Thompson et al., 2001	27 dementia-carer dyads, 27 non-care dyads.	Spouse (husband with dementia)	Video recording of couple at a meal time and whilst planning an outing	Interactions between the two groups showed different patterns. Differences were not linked to carer stress. Mutuality scale showed dementia dyads had lower reciprocity and fewer shared positive activities.
Rankin et al., 2001	96 dementia carers	Spouses	Family Adaptability and Cohesion Scale – Couples Version Family Satisfaction Scale	Current low marital cohesion was related to carer depression.

Author	Sample	Spouses	Mutual Communal Behaviours Scale	Findings
Williamson et al., 2001	71 dementia carers 71 non-dementia carers	Spouses	Own set of four relationship reward questions	Communality in the past relationship was related to present and past relationship rewards and lower carer depression. Dementia carers were more depressed and had fewer present relationship rewards than non-dementia carers but had the same levels of past rewards and communality.
Burgener et al., 2002	96 dementia-carer dyads	Spouses, children, siblings and other	Elder-Caregiver-Family Relationship subscale of the Caregiving Burden Scale	The quality of the relationship was related to care recipient well-being and problem solving. Caregiver role stress was related to care recipient social behaviours.
Eloniemi-Sulkava et al., 2002	42 dementia carers	Spouse	Own questionnaire on atmosphere in marriage, happiness in marriage, and relations before and after onset.	Happiness, equality of relationships, and fulfilment of role expectations decreased. Tenderness increased in a third of the cases studied.
Daire, 2002	40 dementia carers	Parent-son	Parental Bonding Inventory	Level of reported care received in early/childhood relationship was inversely related to the amount of distress attributed to the caring role.
de Vugt et al., 2003.	55 dementia carers	Spouse	Southern California Scale, Visual Analogue Scale + interview. Relationship change: Likert scale	Negative changes in relationship quality were associated with patient apathy but not with cognitive deterioration or hyperactivity / psychosis.
Woods et al., 2003	104 dementia carers	Not specified	Quality of Relationship Scale	Closeness in the relationship did not decline. Previous poor communication and current good communication were linked to higher distress in carer.
Savundranayagam et al., 2005	89 dementia carers	Spouses, children, children-in-law	Montgomery Burden Measure	Hypothesised model (supported): dementia causes semantic and pragmatic communication problems triggering problem behaviour and aggression and then increased burden.
Hellstrom et al., 2007	20 dementia-carer dyads	Couples	Grounded theory interviews	Three main relationship phases identified: sustaining couplehood, maintaining involvement, and moving on.
Steadman et al., 2007	72 dementia carers	Spouses and children	Burns Relationship Satisfaction Scale (prior relationship) Family Assessment Device	Pre-morbid relationship satisfaction was inversely related to carer burden. High PRS related to lower burden, less reactivity to problems, better problem solving and more effective communication.

having relationship quality as the independent variable and the experience of living with dementia as the dependent variable. Whilst these two sets of literature are separate and could be framed as opposites they are inherently linked and could more helpfully be seen as two halves of the same circle. The qualitative studies tend to describe stages of relationship change around the time of diagnosis and in the early stages, or the different forms that relationships take in the middle and late stages of the dementia.

These groupings are used to form the basis of a framework for evaluating the literature. The first section sets out the evidence on how dementia impacts on relationships covering changes in relationships following the onset of dementia and comparison between relationships with dementia and relationships without dementia. The second section reviews the other half of the circle and sets out the evidence on how the quality of the relationship, past and present, impacts on the experience of living with dementia.

The review then takes steps to unpick the interactions between relationship qualities and the experience of living with dementia. Firstly an outline is given of the way in which prior relationship quality determines the form that the relationship takes following the onset of dementia, and consequently determines the quality of the relationship in the context of dementia. Secondly a model is presented to illustrate the interactions between these factors.

The methodological issues section picks up on two themes that run through the research. The first is retrospective reporting, an issue that arises both when considering the quality of past relationships and change following the onset of dementia. The second is the tendency to focus on the perspective of the carer and the obstacles to involving

people with dementia. This issue significantly influences the whole review as only seven of the thirty-one studies identified include people with dementia as participants.

In the final section the findings of the review are summarised and implications for new directions in research and for clinical practice are discussed.

1.3. Literature Review

1.3.1. The Impact of Dementia on Relationships

The opening section of this review sets out the evidence about the way in which relationships change as a result of dementia. It considers reports of changes in the relationship with the family member who has become the carer following the onset of dementia, and at comparisons between relationships where one person has dementia and relationships where neither person has cognitive impairment.

1.3.1.1. Relationship Change Following the Onset of Dementia. The majority of studies identified investigate changes in the quality of the relationship following the onset of dementia focus on carers' reports and use quantitative research methods. Carers' reports consistently indicate a decline in the quality of the relationship. Specific areas in which a decrease has been shown include: intimacy (Blieszner & Shifflett, 1990; Morris, Morris, & Britton, 1988a), reciprocity (Eloniemi-Sulkava et al., 2002; Murray, Schneider, Banerjee, & Mann, 1999), communication (de Vugt et al., 2003; Murray et al., 1999; Savundranayagam, Hummert, & Montgomery, 2005),

happiness in the marriage (Eloniemi-Sulkava et al., 2002), and overall perceived quality of the relationship (Knop, Bergman-Evans, & McCabe, 1998).

However not all aspects of the relationship are affected in the same way. Closeness (de Vugt et al., 2003), warmth (Eloniemi-Sulkava et al., 2002) and mutual affection (Murray et al., 1999) have been shown to increase following the onset of dementia. Changes may also occur at different stages in the progression of the illness. Relationship intimacy has been studied over a period of 18 months by Blieszner and Shifflett (1990) who found significant drops in intimacy in the period in which symptoms were emerging and in the four months immediately after diagnosis but no further reduction in intimacy over the subsequent 12 months.

Five studies that used qualitative methods to investigate perceived changes in the relationship were identified and four of these include the person with dementia, either through a joint interview with the carer or through separate interviews. Several focus on the time around the diagnosis. The participants describe frustration and the need to cover up mistakes before diagnosis, a wide range of emotions in response to the diagnosis including relief, shock, grief and wishing to withdraw from each other, and a period of time post diagnosis in which there is greater willingness to work together and to sustain the relationship (Blieszner & Shifflett, 1990; Hellstrom et al., 2007; Quayhaven & Quayhaven, 1996; Wuest, Ericson, & Stern, 1994). After the initial post-diagnosis phase the focus of the relationship shifts to attempts to 'hold on' (Wuest et al., 1994) and 'maintain involvement' (Hellstrom et al., 2007). The carer increasingly takes over roles previously owned by the person with dementia; in some cases the person with dementia deliberately hands over these roles passing on their knowledge. Hirschfeld (1983)

analysed factors that predicted whether a person would continue to be cared for at home during the later stages of dementia or whether the family would consider institutionalization. The ability to maintain a sense of mutuality in the relationship was found to be the most significant factor.

1.3.1.2. Comparison of Relationships with and without Dementia. The relationship between a person with dementia and the family member who acts as their main carer has been compared with relationships where care is needed for health reasons other than dementia (Carruth, 1996; Townsend & Franks, 1995, 1997), and with close family relationships where there is no caring role (Gallagher-Thompson, Dal Canto, Jacob, & Thompson, 2001; Wright, 1991). In questionnaire-based studies eliciting responses from the carer or from the equivalent family member in the non-caring groups, relationships where one person has dementia showed lower relationship quality in the following areas: reciprocation of care and concern, and of gratification and satisfaction in the relationship (Carruth, 1996), shared pleasurable activities (Gallagher-Thompson et al., 2001; Wright, 1991), reciprocity (Gallagher-Thompson et al., 2001), and overall marital quality (Wright, 1991). Sons and daughters caring for a parent with dementia have reported receiving more negative exchanges and less positive exchanges from their parent than those caring for parents with other health needs (Carruth, 1996).

In contrast some aspects of the relationship did not differ across groups. Carruth (1996) found that carers of people with dementia reported a similar level of love and affection in their relationship as did those who cared for family members with other health needs. Gallagher-Thompson et al. (2001) found that dementia carers reported a

comparable sense of shared values and emotional closeness in their relationships as healthy couples did.

Gallagher-Thompson et al. (2001) used video recordings to observe couples where the husband had Alzheimer's disease carrying out everyday tasks in their own homes. These were compared with video recordings of couples who did not have any significant mental or physical health problems. Where the husband had Alzheimer's disease there were less interactions overall and fewer ideas exchanged than in the interactions between spouses who were both well (Gallagher-Thompson et al., 2001). Wives of husbands with Alzheimer's disease were less supportive of their husbands' ideas and focused their energy on problem solving and clarifying communication. Husbands with Alzheimer's disease were less supportive and facilitative, but showed more rapport building behaviours like smiling, laughing and attending closely. This latter difference was more evident in a planning task than during a meal, suggesting that the husbands with Alzheimer's disease had retained the ability to use humour to diffuse discomfort in challenging situations.

Wright (1991) interviewed couples together to explore the level of congruence in spouses' perceptions of the quality of their marriage. Couples with no significant health problems showed a high level of congruence in perception of overall relationship quality and the specific dimensions considered. In couples where the wife had Alzheimer's disease there were differences in perceptions of distribution of instrumental tasks, whilst in couples where the husband had Alzheimer's disease there were differences in perceptions of the level of tension and sexual activity. This finding suggests that there may be gender differences in the specific areas of the relationship which come under

pressure as a result of dementia. In both groups the person with Alzheimer's disease had a more positive perception of the overall quality of the marriage than their spouse.

1.3.1.3. Summary It is clear that dementia has a distinct impact on relationships causing decline in reciprocity, communication, opportunities for shared activities and happiness in the relationship. However both areas of research show that some positive aspects of the relationship may remain intact, specifically love, emotional warmth and closeness, and affection.

In the earliest stages of the illness the person with dementia and the family member who has become their main carer may work together to support each other and maintain positive qualities in their relationship despite the losses. As the illness progresses the carer takes over roles and responsibilities but the ability to maintain a sense of mutuality continues to be important to the experience of both the carer and the person with dementia.

1.3.2. Impact of Relationship on Living with Dementia

This section considers the way in which the quality of the relationship between the person with dementia and their carer impacts on their experience of their caring and care-recipient roles. The first section reviews the impact of the quality of the current relationship and the second section reviews the impact of the quality of the relationship prior to the onset of the dementia.

1.3.2.1. Current Relationship Factors. The majority of research described in this section has been carried out through the carer and consequently focuses on the carers' experience and on their reports of the quality of the relationship. There is considerable variation in how relationship factors are operationalised in the literature and in the measures used. All the authors reviewed in this sub-section used different terms, e.g. intimacy, marital functioning, and relationship quality. However their findings consistently show that lower current relationship quality is associated with higher levels of depression in the carer (Knop et al., 1998; Morris et al., 1988a; Rankin, Haut, & Keefover, 2001; Townsend & Franks, 1995). Lower relationship quality was also related to greater levels of carer strain (Morris et al., 1988a) and the carer reporting a lower perception of his or her effectiveness as a carer (Townsend & Franks, 1997).

The only exception to this pattern was the finding of Woods, Wills, Higginson, Hobbins and Whitby (2003) that higher levels of communication quality in the current relationship were related to higher distress in the carer. Woods et al. (2003) suggest that the carers with lower communication quality may have distanced themselves from the person with dementia as a coping strategy.

Burgener and Twigg (2002) focused on the experience of the person with dementia and looked at the impact of carer factors and relationship factors. They used interviews with the person with dementia and the carer to facilitate the completion of questionnaire measures over an 18-month period. They found evidence that the quality of the current relationship (reported by the carer) predicted psychological well-being in the person with dementia and their problem solving ability. Three carer factors were studied; personal distress, disruption to social functioning and routine, and negative

feelings towards the person with dementia. All three were related to the psychological well-being of the person with dementia and to various aspects of their functional ability.

1.3.2.2. Prior Relationship Factors. The literature on the impact of the prior relationship factors on the experience of dementia has similar features to the research on current relationship factors. Again a wide range of terms and measures are used, and again there is a high degree of consistency in the findings. All the studies identified that consider the impact of prior relationships draw solely on carers' reports. Reports of prior relationship quality and current relationship quality made by carers have been found to be related (Knop et al., 1998).

Carers who report lower relationship quality prior to the onset of dementia report more depression and distress (Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984; Knop et al., 1998; Kramer, 1993; Morris et al., 1988a; Williamson & Schulz, 1990), burden (Robinson, 1990; Steadman et al., 2007; Williamson & Schulz, 1990), strain (Morris et al., 1988a), and emotional reactivity to the challenges of caring (Daire, 2002; Steadman et al., 2007). Conversely carers who report higher prior relationship quality report more sense of reward and satisfaction (Kramer, 1993; Williamson & Shaffer, 2001), better problem solving and communication (Steadman et al., 2007), and higher quality of life (Kramer, 1993). Only one study found no association between the carer's report of the prior relationship quality and the carers' morale or mental health (Gilhooly, 1984). Morris et al. (1988b) have since suggested that this finding may be a consequence of the relatively low mental health of the sample.

Uchino, Kiecoltglaser, and Cacioppo (1994) discriminated prior affection from prior cohesion in an investigation of the physiological impact of the caring role. They found that carers who reported higher levels of affection in their prior relationship showed lower resting blood pressure and lower heart rate response to stressful tasks than those with lower levels of prior affection. In contrast they found that carers who reported higher levels of cohesion in the prior relationship showed higher resting blood pressure than those reporting lower prior cohesion. Uchino et al. (1994) suggest that cohesion – close sharing of tasks and experiences – is more likely to be lost than affection and that the loss of that closeness in itself, may be a particular stress for carers.

Several authors speculated on the factors that mediate the relationship between prior relationship quality and adverse experiences in the carer. For example Morris et al. (1988) and Williamson and Schulz (1990) suggested that those carers who experienced less intimacy and closeness in their prior relationship are more likely to resent their carer role. Williamson and Schulz (1990) noted that prior closeness does not affect the amount of caring done but suggest that the sense of resentment may cause a greater sense of burden.

1.3.2.3. Summary The studies reviewed in this section indicate that lower current relationship quality relates to increased depression in carers and people with dementia, and to increased strain in carers. It also relates to reduced perceived self-efficacy in carers and reduced functional ability in people with dementia. The significance of the quality of the prior relationship has only been investigated in carers. Lower prior

relationship quality has been shown to relate to depression, burden and emotional reactivity in carers.

Whilst higher relationship quality appears to be a protective factor there is some evidence that high levels of closeness can increase distress in carers. High levels of cohesion in the prior relationship may lead to the loss of a particularly close companion, and high levels of communication quality in the current relationship may reflect continuing close involvement leading the carer to share the difficult and distressing experiences of the person with dementia.

1.4. Interactions between Relationship Factors and the Experience of Living with Dementia

In this section the different forms that relationships can take in the context of dementia are used as a framework to clarify the interactions between relationship quality and the experience of dementia. Prior relationship quality is one of the main determinates of the form that the caring relationship will take in the context of dementia (Neufeld & Harrison, 1995 1998). The relationship form impacts on the current relationship quality and on the way in which the carer and the person with dementia experience living with dementia. A model which explains the interactions between relationship quality and the experience of living with dementia is then presented.

1.4.1. Relationship Forms

A number of studies have identified different forms of relationship between a person with dementia and their carer (Blieszner & Shifflett, 1990; Chesla, Martinson, &

Muwaswes, 1994; Hellstrom et al., 2007; Hirschfeld, 1983; Murray et al., 1999; Neufeld & Harrison, 1995 1998; Orona, 1990). In this review these distinctions have been mapped together to give four categories: Continuity, Reciprocity, Detachment and Duty.

The distinctions between the categories reflect differences in the way the carer perceives the change in the person with dementia, their motivations to care and the quality of the prior relationship. These relationship categories generally apply to the middle stages of dementia when the two people are no longer able to work together as a team and a new relationship form is needed. The studies reviewed in this section include studies that focus solely on the carer and studies that involve both the carer and the person with dementia. The categories draw predominantly on the perspectives and motivations of the carer but their impact is considered from the perspective of both the carer and the person with dementia.

1.4.1.1. Continuity. The carer works to maintain the past identity of the person with dementia and actively seeks out small positive responses from the person. Both the carer and the person with dementia continue to experience companionship in their relationship.

Carers in the Continuity group feel positive about their role (Neufeld & Harrison, 1998) and both they and the person with dementia experience a high level of mutuality (Hirschfeld, 1983). In some cases this form may be maintained for a long period of time; however Chesla, Martinson, and Muwaswes (1994) note that the carers in this group may have difficulty recognizing the person's limitations, consequently

their beliefs and behaviour may become incongruent with the experience of the person with dementia. It may be difficult to maintain a focus on continuity in the face of decline and some carers may experience a sudden and delayed realization of the actual level of severity of the dementia. Evidence from longitudinal studies suggests that a subsequent shift from a Continuity position to a position akin to Detachment or Duty may occur (Blieszner & Shifflett, 1990; Neufeld & Harrison, 1998).

1.4.1.2. Reciprocation. The carer perceives the person as changed but is motivated to care because they have received care from this person in the past or believe that 's/he would have done the same for me'. Mutual affection continues to be experienced.

As with the Continuity group, carers tend to feel positive about their role (Neufeld & Harrison, 1998) and mutuality is likely to be maintained in the relationship (Hirschfeld, 1983). Carers in the Reciprocity group are likely to be more congruent with the experience of the person with dementia and experience the process of change more fully themselves (Chesla et al., 1994). They make ongoing adaptations and changes and, whilst this may protect them from a sudden and delayed realization of loss, it may be a very emotionally demanding experience.

1.4.1.3. Detachment. The carer perceives the person as radically different from their former self. They are motivated to care by their personal connection with the person but they no longer expect to receive anything from the person. The carer may be

factual or clinical in their approach and there is little personal or emotional interaction between the two people.

Within the Detachment group, carers may view caring as positive or negative or experience mixed views (Neufeld & Harrison, 1998). Their distanced role may serve to protect them from the intensity of emotional experience required in sharing the journey of the person with dementia. However responses and strengths may be overlooked and care may not be well tailored to the person's needs. In some cases it may be possible to support these carers to see that the person's identity has not been entirely lost but for some an increased closeness would be too emotionally demanding (Chesla et al., 1994).

1.4.1.4. Duty. The carer feels a sense of duty or a moral obligation to care driven by generalized beliefs about a moral code. The prior relationship and personal connection with the person may not be strong. There is minimal or no mutuality in the relationship.

Carers in the Duty group may have mixed or negative views of their role as a carer (Neufeld & Harrison, 1998). They may find considerable value in their beliefs about a moral code and sense of duty (Murray et al., 1999), but this group may also be particularly vulnerable to high levels of stress and becoming overwhelmed (Hirschfeld, 1983; Neufeld & Harrison, 1998).

1.4.2. Relationship Model of Well-being in Dementia

The model presented here draws together all three sections of the literature reviewed in this paper to demonstrate the influence of relationship factors on the experience of living with dementia.

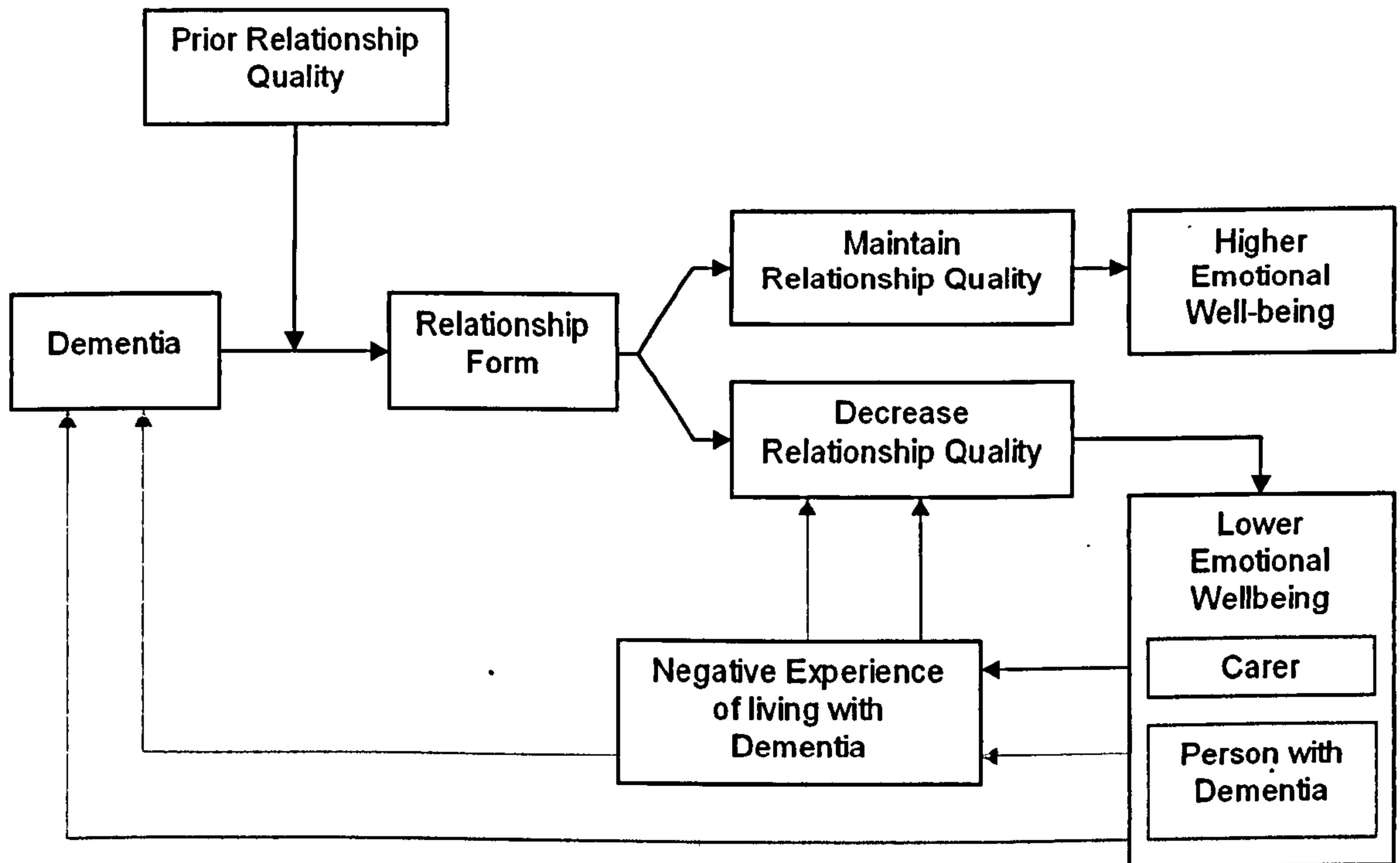


Figure 1. Relationship Model of Well-being in Dementia.

The model in Figure 1. starts at the point when a person develops dementia and a family member takes on the role of carer. The quality of the prior relationship will then determine the form that their relationship takes in the context of the dementia, and the extent to which relationship quality is maintained or decreases. Where relationship quality is maintained both the carer and the person with dementia experience continued

mutuality. People in this group will face challenges, losses and negative experiences but the impact of them may be lessened by continuing positives within the relationship.

Where relationship quality decreases, lower emotional well-being is likely in both the carer and the person with dementia. Lower emotional well-being in the carer will increase their negative experience of their caring role and is likely lead to responses like frustration or withdrawal which further decrease the quality of the relationship. Lower emotional well-being in the person with dementia will follow the same pattern as described for the carer but may also lead to further loss of functional ability and exacerbate the presentation of the dementia itself.

This model is a first step in clarifying our current understanding of the interactions between relationship quality and the experience of living with dementia. If the scope of the model were to be extended other predisposing factors such as the coping styles in the carer and the person with dementia, and support networks should be considered. More detailed exploration of factors such as type of relationship and severity, form and duration of dementia would be valuable. At present the scope for pulling together the literature at this more detailed level is limited. The operationalisation of concepts associated with relationship quality is too diverse to allow systematic detailed comparison across studies. There is also a tendency for studies to identify relationships between factors but not to provide evidence about causal relationships. Only a small number of studies have given insights into causation through the use of longitudinal research or designs involving comparison groups. For instance a causal role for communication deficits in determining caregiver burden has been identified (Savundranayagam et al., 2005). However models that test a hypothesis about

a causal role for a single factor do not tell us how significant this factor is in relation to all the other factors that could potentially have a causal influence.

1.5. Methodological issues

1.5.1. Retrospective Reporting

The use of retrospective reports, generally given by the carer, to evaluate the quality of past relationships and change following the onset of dementia raises some methodological questions. Steadman et al., (2007) suggest that, in addition to poor prior relationships leading to greater carer burden, the high levels of burden associated with caring for a person with dementia may make the carer more likely to report the prior relationship in a negative light. This concern can be tested through a comparison between dementia carers and a control group of carers who care for a family member with less extensive needs. There are relatively few studies of this type however Williamson and Shaffer (2001) found no difference in reports of past relationship quality when carers for people with dementia were compared with a general caring population. This finding suggests that the burdens associated with caring for a person with dementia do not necessarily lead to negative retrospective reports of the prior relationship.

Daire (2002) suggested that those carers who received positive care from that parent as a child may be less likely to attribute their stress to the caring role than those who received poorer care in the past. This highlights a tendency in the literature to measure distress or burden in the carer and to make the assumption that it is a

consequence of the caring role. It is likely that carers experience some other stressors in addition to those associated with caring, and questions about how much stress is attributed to which cause and why are relatively unexplored.

1.5.2. Obstacles to Involvement of People with Dementia

Throughout this review the tendency to involve carers in research more frequently than people with dementia has been noted. Of the thirty-one studies, seven involved people with dementia, four used joint interviews or observations with the carer, two used individual interviews with the person with dementia, and one used a mixture of joint and individual interviews. The paucity of research involving people with dementia limits the strength of the models and conclusions presented in this review. Four factors can be identified that act as obstacles to the involvement of the person with dementia in research: ethical concerns, practical limitations, beliefs about potential for change, and personal challenges for the researcher. These four obstacles and possible responses to them are discussed below.

1.5.2.1. Ethical Concerns. Research conducted in healthcare settings must conform to recognised ethical standards and potential participants are required to give their consent to participate (Department of Health, 2005). Formal informed consent requires the person to receive full information, to have the capacity to understand it and to make a voluntary decision. In people with severe dementia this is unlikely to be possible and even in mild-to-moderate dementia it may be difficult to ascertain whether the person is genuinely able to fulfill these criteria.

The challenges associated with obtaining informed consent and meeting standard research ethics requirements are likely to deter researchers from working with people who have cognitive impairment. The subsequent constraint of research may limit the development of theoretical understanding, and consequently limit the development of the support and services for these groups (Medical Research Council, 2007). Guidelines have been published encouraging researchers and ethics committees to develop practical solutions that allow research to continue in fields where informed consent is not easily obtained (Department for Constitutional Affairs, 2005; Medical Research Council, 2007).

1.5.2.2. Practical Limitations. There are many practical difficulties in conducting research with people with dementia. Expressive and receptive language impairments are a common feature of some types of dementia and may impact on the person's ability to communicate their experience or to understand the researcher. Impairments that occur independently of the dementia such as hearing loss or visual impairment may also impact on the scope for carrying out interviews or eliciting responses to written material. Memory difficulties present considerable problems, for instance causing the person to forget who the researcher is and why they are there and either to question this repeatedly or misconstrue the situation and respond to the researcher according to this misperception (Hubbard, Downs, & Tester, 2002; Pratt, 2002). Misunderstandings about the situation may lead to questions about the reliability and validity of the reports given by the person with dementia.

Joint interviews with the person with dementia and their carer can be used to ensure that the person with dementia is supported and reassured. However the presence of the carer may limit what the person with dementia is willing to say. Possible alternative approaches include combining joint interviews and individual interviews or involving a different person who is familiar to the person with dementia to facilitate the interview. There is also a valuable role for observational methods although ethical issues may arise in situation where the person forgets that they are being observed.

1.5.2.3. Beliefs about Potential for Change. Historically there has been a tendency to believe that people with dementia are unable to express feelings or opinions (Wilkinson, 2002) and little can be done to improve their situation leading to a gap in research and services for people with dementia (Yale & Snyder, 2002).

Over the last fifteen years there has been an increasing move to investigate and measure quality of life in people with dementia (Ettema, Droes, de Lange, Mellenbergh, & Ribbe, 2005), and to work to improve their quality of life. Individualised approaches that consider the person's needs in the context of what is known about their character and previous roles and experiences have been advocated (Kitwood, 1997). Cognitive rehabilitation interventions for people with dementia have shown positive outcomes although evidence is limited by small sample sizes and lack of appropriately sensitive measures (Clare & Woods, 2005; Yale & Snyder, 2002). Marshall (2005) reflects on the development of the concept of rehabilitation for dementia and proposes a distinction between rehabilitation as a time-limited intervention and rehabilitation as an approach underlying the provision of dementia care. All of these advances illustrate the

meaningful benefits people with dementia can gain from improvements in services and to challenge researchers to expand their involvement in research.

1.5.2.4. Personal Challenges for the Researcher. Another factor may be a tendency for researchers to protect themselves from circumstances that are personally and emotionally challenging. When meeting a person with moderate or severe dementia a researcher may be faced by someone who seems unable to communicate, to make sense of the world, and at worst, seems no longer to be reachable as a person. In these situations researchers may also be faced by their worst fears about their own futures and distance themselves from the person in order to protect themselves from the possibility that they might, one day, share that experience (Kitwood, 1997). These factors can lead researchers to avoid direct involvement with the person with dementia.

In order to develop research with people with dementia it is critical that we recognise the specific demands of this type of work. It is necessary for the researcher to be responsive to the person with dementia and validate their experiences in order to ensure that the person feels respected and genuinely listened to (Clarke & Keady, 2002). A conventional detached style of interviewing may not be possible or appropriate in this situation (Clarke & Keady, 2002; Pratt, 2002).

Researchers need to plan an approach that is genuinely responsive to the person, maintains the integrity of the research and can be managed by those carrying out the research. It is helpful to prepare for possible personal and emotional responses when interacting with people with dementia, for instance by ensuring that peer support and supervision are available (Pratt, 2002). It is also important that the potential impact of

participating for the person with dementia is considered. It may be appropriate to make time for debriefing with the person following participation or to ensure that support from carers will be available (Pratt, 2002).

This brief overview sets out some of the challenges faced by researchers wishing to involve people with dementia in their work. It also reflects the recent shifts in the field that offer potential for overcoming these obstacles. There is increasing recognition that improved understanding of the experiences and perspectives of people with dementia can allow us to improve the care which they receive (Woods, 2001). There is also an increasing move to balance our responsibility to protect vulnerable people with our responsibility to listen to their voices and to strive to find ways to include them in research in a meaningful way (Wilkinson, 2002).

1.6. Implications for Research and Practice

1.6.1. Future Directions for Research

In order to progress beyond the basic model presented here and unpick the interactions and causal relationships between detailed factors it is necessary to move beyond studies that identify that relationships exist between factors. Greater insights into interactions between factors and causal relationships could be gained through more longitudinal studies, studies using comparison groups, and, most importantly, larger scale systemic studies allowing comparison of the predictive power of different potential causal factors.

This literature review has also highlighted a tendency to involve carers as research participants and not people with dementia, even when studying aspects of the relationship between them. This continues to be an issue in this field, despite the increasing interest in researching the experiences and perspectives of people with dementia mentioned in the introduction. Some of the obstacles to involving people with dementia in research are discussed in the methodological issues section of this paper and in each case potential for overcoming the obstacles are identified. Further work is needed to find ways to involve people with dementia in research in order to gain a more balanced and complete view of the interaction between the quality of relationships between people with dementia and the family members who care for them and the experience of living with dementia. This should include using interviews to facilitate the collection of responses to questionnaires to give quantitative information, and the development of approaches other than joint interviews with the carer to facilitate interview-based research.

1.6.2. Clinical Implications

1.6.2.1. Supporting the Carer. The findings discussed here consistently show that the quality of relationship between the carer and the person with dementia before the onset of the illness has a significant impact on the level of depression and stress experienced by the carer. Carers who had a good prior relationship with the person who they now care for tend to have less severe experiences of distress and burden. They may be more able to solve problems and find ways to continue to communicate meaningfully with the person. Those with less positive prior relationships are likely to experience

higher levels of distress and burden and may feel some resentment about their caring role. However there may be factors that cause variation in the relationship between prior relationship history and carer well-being, for instance where there were particularly high levels of closeness and task sharing in the prior relationship carers may experience stress due to the loss of this close companionship.

There is a substantial evidence basis relating to support for carers which is beyond the scope of this review. However the findings presented here show that, for those working to support carers, an understanding of the relationship history may provide a valuable insight into the experiences of the carer, the level of distress and burden, and their feelings about their caring role. Information about the prior relationship can also set a context which allows recognition of strengths in the relationship.

Carers' previous experience of the relationship may also influence the approach they take to their caring role and the form that the relationship takes. Thinking about caring relationships in this way allows recognition of possible strengths and vulnerabilities. Those carers who strive to maintain mutuality and seek continuity in the person with dementia may struggle when this is no longer possible. Those who recognise the changes and respond to them may experience the loss more gradually but find the process of caring emotionally exhausting. Those who step back and no longer expect to share things with the person with dementia may be acting consistently with their prior relationship or protecting themselves from the emotional impact of their loss. Some of these carers may benefit from support to recognise continuing aspects of their family members' personality whereas others may struggle to do this. Those who care

due to a sense of duty may be particularly vulnerable to stress and becoming overwhelmed by their caring role. The framework of relationship forms set out in this paper provides an initial outline of possible patterns of caring. This framework can act as a useful tool allowing professionals to tailor the support they offer to different caring styles and to adjust the amount, type and timing of support according to individual needs.

1.6.2.2. Supporting the Person with Dementia. The evidence about the impact of relationship factors on people with dementia is much more limited than the evidence relating to carers. However the information we have indicates that the quality of the current caring relationship impacts on the level of depression and stress they experience and may also impact on their functional abilities. It seems likely that the quality of the prior relationship would affect the way the person experiences being in a care-recipient role and the way that they respond to their family member in the carer role.

There is some evidence that the well-being of the carer impacts on the well-being of the person with dementia. This finding indicates that improved support for carers may improve the well-being of the person with dementia. It certainly seems probable that a carer who is well supported and is able to manage the impact of the caring role relatively well would be likely to be able to provide a better quality of care with greater responsiveness to the person with dementia.

If we move away from the focus on the carer's perspective to think about both people as contributors to the relationship, we can consider the impact of the well-being of the person with dementia on the well-being of the carer. It is plausible that

interventions that support the person with dementia and reduce their distress would alleviate some of the stress experienced by the carer.

1.6.2.3. Supporting the Relationship. The quality of the current relationship between the person with dementia and the carer impacts on the psychological well-being of both parties. Whilst the overall quality of the relationship tends to deteriorate as a consequence of dementia, some positive aspects such as affection and closeness may remain or even increase. This finding indicates continuing strength in the relationship and raises the possibility that intervention to support the maintenance or development of the relationship may be of value.

Smits et al. (2007) reviewed the effectiveness of combined interventions for the person with dementia and the carer and found that more than half showed positive outcomes in terms of mental health of both the person with dementia and the carer. The majority of these studies involved interventions for the carer and the person with dementia which were carried out separately not together. Two examples which do use joint intervention programmes including communication and problem solving aspects have shown significant positive outcomes in terms of cognitive rehabilitation and some evidence of improvement in marital interactions (Quayhagen & Quayhagen, 2001; Whitlatch, Judge, Zarit, & Femia, 2006).

Joint interventions could play a valuable role in complementing separate interventions which may otherwise overlook or even undermine relationship factors, and in acknowledging and supporting the need for the carer and the person with dementia to work together as a team (Yale & Snyder, 2002). The aims would be to facilitate

communication, joint problem solving and recognition of enduring qualities in the relationship. An awareness of the quality of the prior relationship would be critical to the success of such interventions as a positive relationship history can not be assumed. The impact of the prior relationship on the current caring relationship will determine what approach and goals would be most constructive and attainable for a given pair of people.

1.7. Conclusion

There is clear evidence for interaction between the quality of the relationship between the person with dementia and their carer, and their experience of living with dementia. This review proposes a model in which the quality of the prior relationships determines the form that the relationship takes in the context of the dementia. The form of the relationship influences current relationship quality and the experience of living with dementia for both the carer and the person with dementia.

Clinicians supporting people with dementia and their carers need to be aware of the interactions between the two people and the impact of these interactions on each person. Consideration of the relationship history and the form of the current relationship allows clinicians to recognise strengths and vulnerabilities within different relationships. Furthermore it provides a basis to tailor interventions to meet the needs of individual people in terms of the amount and timing of support, and in terms of the specific aims of the intervention.

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Awareness of caregiver distress in people with dementia

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2.1. Abstract

People who care for family members who have dementia often experience considerable levels of stress, anxiety and depression. Relatively little is known about the extent to which carer distress impacts on the person with dementia.

This study investigated whether or not people with dementia are aware of the level of distress experienced by their carers by focusing on two aspects of psychological health; anxiety and depression. Two groups of participants were studied, a dementia group and a control group of people with arthritis. Each group consisted of pairs of people, the person with dementia or arthritis and the family member who acted as their main carer. For both groups, the carer's psychological health was rated by the carer themselves and by the person being cared for, using the Hospital Anxiety and Depression Scale and a Visual Analogue Scale. For the dementia group, memory functioning in the person with dementia was rated by the people with dementia themselves and by the carers, using the Memory Function Scale. The ratings given by the carers and those given by the participants who received care were compared to give an indication of the level of awareness.

The results showed that people with dementia do have a significant level of awareness of their carers' psychological health and, furthermore, that their level of awareness is comparable to the level of awareness shown by a control group of people with arthritis. The level of awareness of carer psychological health shown by the dementia group was not related to their level of awareness of their own memory difficulties.

2.2. Introduction

Many people with dementia are supported to live at home by a close family member who has taken on the role of a carer. The person with dementia and the carer share the experiences of managing the early signs such as memory slips and misunderstandings, of receiving a diagnosis, and of living through a succession of stages of change, adaptation and loss. People who have a caring role tend to have higher levels of psychological morbidity than people who do not (Pinquart & Sörensen, 2003), and the difference is particularly pronounced in people who care for family members with dementia (Baumgarten et al., 1992). A substantial body of research has been conducted on the level of distress and burden experienced by carers and on the factors that influence the extent of the negative impact of the caring role. These factors include the level of cognitive and functional impairment in the person with dementia, behavioural aspects of the dementia presentation, and wider factors such as demographics, coping styles, and level of support received by the carer (for review articles see: Donaldson, Tarrier, & Burns, 1997; Dunkin & Anderson-Hanley, 1998; Kneebone & Martin, 2003; Sorensen, Duberstein, Gill, & Pinquart, 2006).

This extensive literature on carer distress and burden reflects a tendency to focus on the carer and to overlook the experiences of the person with dementia and, in particular, to overlook the interactions between the two people (Whitlatch, 2001). Consequently relatively little is known about the extent to which carer distress impacts on people who have dementia. Woods (2001) has described possible dynamic patterns of interaction in which carer strain causes the carer to be more critical and less

responsive, causing the person with dementia to be more anxious and agitated, which in turn would increase carer strain. In one of the few experimental studies on these interactions, Burgener and Twigg (2002) found that aspects of carer psychological well-being and relationship quality predicted well-being in the person with dementia and their level of functional ability.

These reciprocal interactions between the psychological health of the carer and the psychological health of the person with dementia often occur in the context of a long-standing relationship. Research on the quality of relationships where one family member cares for another family member emphasizes the importance of continuing reciprocal emotional support (Carruth, Tate, Moffett, & Hill, 1997; Horowitz & Shindelman, 1983). However where a person has dementia, established roles and patterns of interaction within the relationship are changed or lost and cognitive impairment may limit the person's awareness of their carer's psychological health and level of distress, therefore limiting their ability to give emotional support.

Little is known about the extent to which people with dementia are aware of the level of distress experienced by their carers. Awareness in people with dementia has been studied in relation to their awareness of their own cognitive deficits. It has proved to be a complex phenomenon without a clear set of causal factors. Typology and severity of the dementia do not explain variation in awareness on their own and it is likely that personality style and pre-existing coping patterns also play a role in determining an individual's level of awareness (Derouesnea et al., 1999; Seiffer, Clare, & Harvey, 2005).

The likelihood that a person with dementia is aware of the level of distress experienced by their carer can be considered as follows. Memory deficits may prevent people with dementia from remembering conversations or incidents where their carers express distress, and consequently people with dementia may be unaware of their carers' current level of distress. Alternatively people with dementia may retain awareness of their carers' level of distress because memory for emotionally significant material can be retained more effectively by people with dementia (Hamann, Cahill, McGaugh, & Squire, 1997; Kazui et al., 2000; Satler et al., 2007) and by the general population (Cahill & McGaugh, 1995; Mikels, Larkin, Reuter-Lorenz, & Carstensen, 2005).

This study takes initial steps to explore this area. It focuses on the psychological health of the carer, specifically on anxiety and depression. The three main research questions are:

1. Are people with dementia aware of the psychological health of the family member who cares for them?
2. Is the level of awareness of the psychological health of the family carer in people with dementia comparable to the level of awareness in a control group of people who receive care from family members for physical health needs?
3. Is awareness of the psychological health of the carer related to the person's awareness of their own memory difficulties?

Alongside the main quantitative study, qualitative records were made of the main explanatory narratives of the participants in the dementia group to give an indication of the different perspectives underlying the main findings.

2.3. Method

2.3.1. Participants

Two groups of pairs of participants were involved in the study, eighty-four participants in total. The main group consisted of people with dementia and their carers. The control group consisted of people with arthritis and their carers.

2.3.1.1. Dementia Group. Twenty-two pairs of people with mild to moderate dementia and their family carers were recruited. Thirteen pairs were recruited through a day care service, six through courses for people with dementia and carers, and three through psychiatric follow-up clinic appointments. (See Appendices 1, 2, 3, and 4 for letters of invitation, participant information sheets, consent forms, and questionnaires used to elicit demographic information.)

The people with dementia had all been diagnosed by a psychiatrist more than six months prior to the study. Diagnoses included: eleven participants with Alzheimer's disease, three with vascular dementia, four with mixed type dementia, one with fronto-temporal dementia, and two with mild cognitive impairment. Thirteen were female and nine were male. They were all over 60 years of age (mean 79 years).

The dementia carer sample was made up of sixteen women and six men. Eleven were spouses of the person with dementia and eleven were children (although note that the average age of the 'child' carers was 57). Fourteen carers lived in the same house as the person with dementia. The remaining eight visited at least once a week and also spoke on the telephone at least once a week. In most cases levels of contact were well above these minimum levels set for inclusion in the study. Carers were included if they

did not have cognitive impairment themselves, had not been under the care of a consultant psychiatrist in the last ten years, and did not have health problems requiring a greater level of care than their family member with dementia. All the participants with dementia and their carers were white.

2.3.1.2. Control group. Eleven pairs of people with arthritis and their family members were recruited through a hospital Rheumatology Department, the remaining nine pairs were recruited through support groups. (See Appendices 1, 2, 3, and 4 for letters of invitation, participant information sheets, consent forms, and questionnaires used to elicit demographic information.) The participants with arthritis were all over 60 years old (mean 74 years) and had acquired arthritis at an age above 40 years (mean 60 years). Thirteen were female and seven were male.

The arthritis carer sample was made up of twelve women and eight men. Twelve were spouses of the person with arthritis, three were siblings, and five were children (again note that the average age of the 'child' carers was 44). Twelve carers lived in the same house as the person with arthritis. The remaining eight visited at least once a week and also spoke on the telephone at least once a week.

Participants with arthritis and their carers were included if they did not have cognitive impairment, had not been under the care of a consultant psychiatrist in the last ten years, and if the carer did not have health problems requiring a greater level of care than their family member with arthritis. All the participants with arthritis and their carers were white.

2.3.2. Measures

2.3.2.1. Psychological Health. The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used to give measures of anxiety and depression. The combined HADS score gave an overall measure of psychological health. Carers completed the standardized HADS form as a self-rating measure. An amended version of the HADS was used by the participants with dementia and with arthritis to make observer ratings of the carer's psychological health. (See Appendix 6). A clinical cut-off score of 11 was used for the Anxiety scale and the Depression scale (Crawford, Henry, Crombie, & Taylor, 2001).

A Visual Analogue Scale (VAS) was administered as an additional measure of carer psychological health. This was done because it was possible that the language demands of the HADS would be too great for some of the participants and a visual alternative might be preferable. The Visual Analogue Scale measured Anxiety, Sadness, and Frustration. The term 'Sadness' was used in place of 'Depression' because depression is a clinical term and is not commonly used as a term for mood, especially amongst older adults. Frustration was added to give an indication of emotion associated with stress and burden. The scale consisted of three 10cm horizontal lines with labels at either end given in words, "Extremely Anxious" and "Not Anxious", "Extremely Sad" and "Not Sad" and "Extremely Frustrated" and "Not Frustrated". Measurements were taken from the "Not" end of the scale meaning that higher VAS scores reflect responses closer to the "extremely anxious/sad/frustrated" end of the scale. Carers completed a self-rating version of the VAS and the participants with dementia and arthritis used an

observer-rating version to rate the carer's psychological health. (See Appendix 7). There are no generally accepted clinical cut-off scores for the VAS.

Visual analogue scales have shown high levels of correlation with the HADS when used with cognitively impaired older adult populations (Bennett, Thomas, Austen, Morris, & Lincoln, 2006) although the level of agreement may be lower than in cognitively intact participants (Kertzman et al., 2004).

2.3.2.2. Memory Functioning. The Memory Functioning Subscale (MFS) of the Memory Awareness Rating Scale (MARS) (Clare, Wilson, Carter, Roth, & Hodges, 2002) was used to assess perceptions of memory functioning in everyday memory situations. This measure is designed to elicit self-ratings from the person with dementia and observer-ratings from their carer. Comparison of the level of agreement between the two sets of ratings is used as an indicator of awareness. (See Appendix 8).

2.3.3. Procedure

The procedure and recruitment process were approved by the relevant ethics bodies. See Appendix 10 for documentation of ethical approval and appendix 5 for the research protocol.

2.3.3.1. Dementia Group. Carers were invited to complete a set of questionnaires and return them by post. The carers completed self-rating versions of the HADS and the VAS, and used the observer-rating component of the MFS to rate the memory functioning of the person with dementia. If the carers returned their questionnaires the person with dementia was approached and invited to participate. The participants with dementia were interviewed individually in the day centre or in their own homes and

were introduced to the researcher by a familiar person. The researcher talked them through each question and recorded their responses. The carer was not present for the interview. The participants with dementia responded to questions from the self-rating component of the MFS and from the observer-rating versions of the HADS and VAS for rating the psychological health of their carers. The researcher also made written records of the person's comments and explanations to generate a small amount of qualitative data.

2.3.3.2. Control Group. Sets of questionnaires for patients and their carers were given to arthritis patients during routine appointments in the clinic or at support group meetings. The questionnaire packs for the patient and carer were packaged separately with separate postal return envelopes and clear instructions were given that responses should not be discussed. The carers completed self-rating versions of the HADS and VAS. The participants with arthritis completed observer-rating versions of the HADS and VAS rating the psychological health of their carers.

2.4. Results

2.4.1. Sample Characteristics

Table 1 presents the mean scores for the measures of carer psychological health given by the dementia group and the arthritis group; self-ratings by the carer and observer-ratings by the person with dementia or arthritis are included. The HADS scores and the VAS scores were investigated separately because they are not numerically comparable. Two three-way analyses of variance were conducted with one within-

subjects variable, HADS scores or VAS scores, and two between-subjects variables, dementia group vs. arthritis group, and carers vs. participants who received care. Overall HADS scores for Anxiety ($M=7.13$, $SD=4.25$) were higher than for Depression ($M=3.59$, $SD=3.19$), main effect of HADS scores $F(1,76)=89.96$, $p<0.000$. A significant main effect was also found for VAS scores, $F(2,150)=14.295$, $p=0.000$: Anxiety ($M=41.83$, $SD=26.71$), Depression ($M=29.48$, $SD=25.30$) and Frustration ($M=42.29$, $SD=27.67$). The following effects were also significant: main effect for dementia group vs. arthritis group, $F(1,75)=5.697$, $p=0.020$, and the interaction between VAS scores and dementia group vs. arthritis group ($F(2,150)=3.902$, $p=0.022$).

A multivariate analysis of variance was performed to investigate differences in ratings of carer psychological health between carers and participants who received care, and between the arthritis group and the dementia group. A statistically significant difference was found between the dementia group and arthritis group ($F(3,65)=2.88$, $p=0.011$). There was a significant difference between the dementia group and arthritis group for VAS Frustration ($F(1,71)=13.89$, $p=0.000$). Inspection of the mean scores indicates that the dementia group reported higher levels of frustration than the arthritis group. The effects for individual measures also showed a difference between the carers and the participants with health needs for HADS Depression ($F(1,71)=6.89$, $p=0.011$). The mean scores indicate that carers reported higher levels of depression than care-recipients.

All the participants were able to complete the HADS. Two participants were unable to understand the VAS and consequently their data is missing.

Table 1. Characteristics of the sample as measured by the HADS and VAS.

	Dementia carer (self-rating)		Person with dementia (observer-rating)		Arthritis carer (self-rating)		Person with arthritis (observer-rating)	
	Mean (SD)	Proportion above clinical cut-off	Mean (SD)	Proportion above clinical cut-off	Mean (SD)	Proportion above clinical cut-off	Mean (SD)	Proportion above clinical cut-off
HADS								
Anxiety	8.52(4.95)	31%	6.89(3.54)	13%	6.44(4.50)	9%	6.44(3.87)	9%
Depression	5.41(3.75)	4%	2.52(4.70)	0	3.39(3.07)	4%	2.89(2.89)	0
Total	13.93(8.24)		9.41(4.70)		9.83(7.20)		9.33(5.71)	
VAS								
Anxiety	46.45(28.77)	-	43.29(26.53)	-	37.59(27.24)	-	37.45(25.03)	-
Depression	35.00(29.55)	-	31.20(23.58)	-	28.94(29.66)	-	22.15(16.44)	-
Frustration	56.59(28.64)	-	44.67(26.05)	-	28.53(24.83)	-	33.80(24.39)	-
Total	138.05(79.09)	-	123.15(52.48)	-	95.06(75.50)	-	93.40(56.20)	-

The level of agreement between the HADS ratings and VAS ratings given by each individual was assessed using correlations (Table 2). Statistically significant correlations were found for all comparisons except for the ratings of carer anxiety given by the participants with dementia. The lack of a relationship between the ratings on the HADS and the VAS in the dementia group, and the difficulties that some participants had understanding the VAS measure, raised questions about the validity of the VAS results from the dementia group. On the basis of these concerns only the findings from the HADS are reported.

Table 2. Level of agreement between HADS scores and VAS scores.

	<i>Dementia carer correlation coefficient_a</i>	<i>Dementia patient correlation coefficient_a</i>	<i>Arthritis carer correlation coefficient_a</i>	<i>Arthritis patient correlation coefficient_a</i>
Anxiety	0.811**	0.356	0.662**	0.668**
Depression	0.697**	0.602**	0.484*	0.425*

a. One-tailed correlations. ** p<0.01 * p<0.05

2.4.2. Self and Observer Ratings of Psychological Health

Correlations of the HADS self-ratings made by the carer and the HADS observer-ratings made by the participants with dementia and arthritis are set out in Table 3. Correlations in the dementia group were significant for the anxiety score ($r(20)=0.384$, $p=0.048$) and overall score ($r(20)=0.457$, $p=0.016$). In the arthritis group the same pattern of significant correlations was found, anxiety ($r(15)=0.512$, $p=0.018$) and overall score ($r(15)=0.516$, $p=0.017$).

The self-rating and observer-rating score for each pair of participants was used to calculate a discrepancy score by subtracting the observer rating from the self rating. A multivariate analysis of variance was performed to investigate differences

in discrepancy scores between the arthritis group and the dementia group. No statistically significant differences were found ($F(3,36)=1.837, p=0.174$).

Table 3. Relationships between self-ratings and observer-ratings of carer psychological health.

	Dementia group correlation coefficient _a	Arthritis group correlation coefficient _a
HADS		
Anxiety	0.384*	0.512*
Depression	0.331	0.203
Total	0.457*	0.516*

a. One-tailed correlations. * $p < 0.05$

2.4.3. Psychological Health and Memory Function

The self-observer discrepancy scores from the HADS ratings of the psychological health of the carer were firstly compared with carers ratings of the memory function of the person with dementia (i.e. MFS raw scores), and secondly compared with the self-observer discrepancy in MFS ratings of the memory ability of the person with dementia. No significant correlations were found: total HADS with MFS raw scores ($r(20)=-0.257, p=0.124$), and total HADS with MFS discrepancy ($r(19)=0.111, p=0.316$) (Table 4).

Table 4. Level of agreement between discrepancies in self/observer ratings of carer psychological health and memory functioning data.

	MFS carer rating raw scores correlation coefficient _a	MFS self-observer discrepancy scores correlation coefficient _a
HADS		
Anxiety	-0.237	0.014
Depression	-0.199	0.213
Total	-0.257	0.111

a. One-tailed correlation.

2.4.4. Narrative Information

Records were made of the main explanatory narratives of the participants in the dementia group during the interviews. Participants generally made one or two key points and often repeated these several times through the course of the interview. Their comments were categorised as: 1). the carer does not have any significant problems, 2). the carer is affected emotionally by the difficulties experienced by the person with dementia or 3). the carer is affected emotionally by a different factor with no indication given of awareness of the impact of their caring role. Four participants were not included because they said very little or made a wide range of contrasting comments. Examples of the narratives and numbers of participants in each category are given in Table 5. (See Appendix 9 for full record of narratives given).

Table 5. Explanatory narratives given by participants with dementia during their interviews.

<i>category</i>	<i>n</i>	<i>example narrative</i>
Carer is fine	6	"She's a strong girl, she's in control of her mind, I think she's ok." "She's happy, she has a wonderful husband"
Carer impacted by caring role	9	"He worries about me. He tries to protect me." "I'm quite a worry to her; she feels she has to do things for me."
Carer impacted by other factor	3	"He's stressed with his work." "She gets worried and frustrated with Richard ^a ."

a. Alternative name used.

2.5. Discussion

The findings of this study show that people with mild to moderate dementia are aware of the psychological health of the family member who cares for them. Specifically, they show that their perceptions of their carer's level of anxiety and overall psychological health are consistent with the carer's own perceptions. No evidence for awareness of the carer's level of depression was found. This may be partly due to the relatively low ratings for carer depression given by both the carer and the person with dementia which reduced the likelihood of generating a clear correlation between the two data sets. The level of awareness of carer anxiety and overall psychological health in the dementia group was found to be comparable to the level of awareness in a control group of people with arthritis who did not have cognitive impairment.

Two possible hypotheses about awareness of carer psychological health in people with dementia were set out in the introduction to this paper. Firstly that people with dementia would be unaware of the psychological health of the carer because memory impairment prevents them from recalling recent episodes in which anxiety or distress were expressed. Secondly that enhanced memory for emotional significant memory would allow people with dementia to be aware of the carer's level of psychological health. This awareness would not necessarily be related to their level of awareness of their own memory difficulties. This study found no relationship between the level of awareness that people with dementia have of their carer's psychological health and either their level of awareness of their own memory difficulties, or their functional memory abilities as rated by the carer. These findings support the second hypothesis that memory for emotionally significant material, such

as distress in the family member who acts as the main carer, may remain relatively intact in people with dementia. This finding is compatible with the work of Hamann et al. (1997), Kazui et al. (2000), and Satler et al. (2007) who showed that the emotional arousal caused by emotionally significant material enhances memory in people with cognitive impairment.

This study takes initial steps to explore a new aspect of awareness in people with dementia, awareness of carer psychological health. A number of approaches to the measurement of awareness have been developed to evaluate the awareness of memory difficulties in people with dementia and each has strengths and weaknesses (see Clare, 2004; Howth & Saper, 2003 for a review). This study used measures which compare self-ratings of memory functioning made by the person with dementia to observer-ratings made by their carer. Awareness measures which use carer observer-ratings make the assumption that the carer is able to give an accurate objective rating. However factors such as emotional state, personality and relationship issues are likely to influence observer-ratings (Clare, 2004). Similar factors are likely to influence observer responding on the HADS which was also used to give self- and observer-ratings. This limitation was addressed by comparing the discrepancy scores from the dementia group with discrepancy scores from a control group. The observer-ratings made by the carers in the control group would contain variation caused by a similar range of factors. The control group was matched to the dementia group in that it was made up of older adults who received care from a family member for a health problem, arthritis, which they had acquired relatively late in life. However the strength of this match is limited because the demands associated with caring for a person with dementia tend to be considerably higher than the demands of caring for a person with arthritis. This difference is

likely to underlie the statistically significant difference in frustration between the dementia group and the arthritis group noted in the description of the characteristics of the sample.

This study makes a novel use of the HADS by generating both self-ratings made by the carer and observer-ratings made by the person with dementia. The HADS is not standardized for use as an observer measure. Questions can be raised about the validity of this approach both at a general level and in particular whether participants with dementia can act as valid observer-raters. The comparability of results from the dementia group and in the arthritis group suggests that the participants with dementia were no less able to act as observer-raters than the participants with arthritis. Further evidence of the validity of the ratings made by the participants with dementia came from the records of their explanatory narratives which showed that they were able to think about the questions in relation to their carer and form a view about the carer's psychological health. However further work on the use of discrepancy measures would be beneficial and investigation of this area using different approaches would paint a fuller picture of different aspects of awareness (Howth & Saper, 2003).

Two measures were selected for this study, the HADS as the main measure and the VAS as a secondary measure in case the HADS was too demanding for the participants with dementia. Paradoxically none of the participants had difficulties understanding the HADS but two participants were unable to understand the VAS and did not complete it. There was a high level of agreement between individuals' scores on the HADS and VAS in both the arthritis groups and the dementia carers. For participants with dementia there was no evidence of a relationship between scores on the HADS and scores on the VAS for the anxiety scale. Elsewhere in the

literature Dennis, Boddington and Funnell (2007) found that a VAS scale specific to anxiety was a weak assessment tool for use with older adults. The specific problem with the anxiety VAS scale could be a consequence of the term used. Older people may speak about feeling anxious but they also make use of the term 'worry' and the phrase 'my nerves are bad'. This group of participants may find a question about overall level of anxiety quite abstract and it may be too demanding for participants with dementia. In this study the term 'sadness' was used in place of the more clinical term 'depression' because depression is not used as a generalized descriptor of mood by older adults. It is possible that using 'worry' in place of 'anxiety' would have improved the accessibility of this scale for older adults and, in particular, participants with dementia. The difficulties some participants experienced understanding the VAS and the lack of agreement with the HADS shown by the anxiety scale raised questions about the validity of the VAS responses in this study. For these reasons the paper focuses on the findings from the main measure, the HADS. These issues illustrate the importance of careful evaluation of measures for use with participants with dementia and of the process that underlie their responses. It would be beneficial to assess the construct validity of the different possible terms for emotional states specifically for use in research with this population.

Professionals working in clinical settings with families with dementia are likely to observe the level of awareness of memory deficits in the person with dementia and use this information to inform the support they offer the family. However it may be important for professionals not to assume that a person with low awareness of their own memory difficulties is unaware of the psychological health of their carer.

The qualitative findings from the narrative accounts of the participants with dementia give an indication of the range of perspectives that underlie the overall finding of a significant level of awareness of the psychological health of the carer. The narratives fall into three distinct groups. Those people in the first group are aware of the psychological health of the carer and that their psychological difficulties are a consequence of their caring role. Members of the second group perceive their carer to have no significant psychological difficulties. This group may be made up of two subgroups, people who have no awareness of the psychological difficulties experienced by their carers, and people who accurately report that their carer is coping well and is experiencing relatively little psychological difficulty. Those in the third group are aware of the psychological health of the carer but attribute the cause of the psychological difficulties to another separate factor. Again, this group may be made up of two subgroups, people who are aware of the carer's psychological difficulties but do not recognise that they are a consequence of the caring role, and people who accurately report that their carer's psychological difficulties are related to another stressor.

The group of people with dementia who are aware of the psychological health of their carer are more likely to express concern about their carer's well-being and to be supportive of them. The impairments associated with dementia limit the ability of the person to carry out their previous roles within the relationship and change the level of reciprocity and mutual support. Acknowledgement of the carer's difficulties and expression of concern by the person with dementia may have a positive effect in maintaining some sense of reciprocity and continued mutuality in the relationship. However awareness that the carer is experiencing psychological difficulties as a consequence of the caring role could also cause considerable distress for the person

with dementia who may feel responsible and unable to change the situation. People with dementia who are aware that their carer is experiencing psychological difficulties but are not aware of the reason may attempt to be supportive but not succeed, or feel frustrated and confused by the situation.

It appears that, despite the overall picture of awareness, some people with dementia are not aware of the psychological health of their carer. Whilst this group may have a cheerful positive view of the situation, they are unable to offer acknowledgement or emotional support to the carer. This is likely to result in a higher level of loss of reciprocity within the relationship and to increase the carers' sense of isolation and burden.

2.6. Conclusion

This study highlights the shared impact of dementia and caring within relationships. Carers may experience considerable distress as a consequence of their caring role and it is likely that a significant proportion of people with dementia are aware of this situation. Those people who are aware may be able to provide acknowledgement and emotional support to their carers and, in doing so, to maintain some of the mutuality and reciprocity in the relationship. However these people may also be distressed themselves by the psychological difficulties experienced by the carer. It could be hypothesized that a carer intervention that is successful in reducing psychological difficulties in the carer would also reduce distress in the person with dementia giving a double benefit, but also that an intervention which involved both people and recognized their shared experiences could be even more valuable.

Research including the perspectives of people with dementia has a valuable contribution to make in developing our understanding of the interactions between people with dementia and their carers, and in informing clinical interventions which take a holistic view of the situation of people with dementia and their carers.

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On Learning from my Participants

Reflective Paper

Word Count: 3,449.

This paper makes references to individual participants. Names and minor details have been changed to ensure that they remain anonymous.

3.1. Introduction

This reflective paper focuses on my experiences during the data collection phase of the research. The reflective material has been developed from observations that I recorded in a diary after carrying out interviews with people with dementia and after attending support groups to recruit people with arthritis and their carers. The insights that I gained from these experiences have been broad. They have increased my awareness of research and service-level issues and have informed my clinical practice.

This paper begins with a section which sets the reflections in context by describing my developing interest in this research area and my approach to the research design. It concludes with a section bringing together the different areas of learning that have arisen from my reflections. My title for this paper is a reference to Patrick Casement's "On Learning from the Patient" (Casement, 1985) a book on internal supervision in psychodynamic practice which reminds us that we must listen attentively and with curiosity to the people with whom we work.

3.2. Research Context

My interest in older adult psychology developed during my first placement as a trainee clinical psychologist. I particularly enjoyed the breadth of work that falls within the role of the psychologist working with older adults and the requirement to be able to draw on many different aspects of psychological theory. One of the experiences I remember from the early stages of my

placement was a meeting with a woman with dementia who had no awareness of her memory deficits. She knew that her daughter was stressed and very unhappy but had no idea why. She was worried about her daughter but felt powerless to help.

This meeting influenced me to develop research ideas about awareness of carer distress in people with dementia. I was concerned about working in an area which was not closely related to my supervisors' research interests and about developing a research project based on an observation made by myself as a new trainee. However I struggled to find another topic that caught my interest and enthusiasm to the same extent. During this process I heard several anecdotal accounts about situations similar to that of the woman who had made such an impression on me at the start of my placement. This affirmed my curiosity about these research ideas. My supervisors supported me to focus my ideas and to form the clear question "do people with dementia show awareness of their carers' well-being?" and a manageable and useful research project began to emerge.

I have previous research experience using quantitative methods and am more comfortable with this approach than with qualitative methods. However I have a growing interest in the experiential aspects of the phenomenon which I am researching. I chose to carry out my study for this thesis using a quantitative method but I have used this reflective paper as an opportunity to develop further my thinking about the experiential aspects of carrying out the research. This focus on learning from individual participants links the thesis back to its origins in my reflections about the experiences of the woman who knew her daughter was unhappy.

3.3. Interviewing with People with Dementia

In the first week of my data collection phase I carried out fifteen interviews. I quickly realised that the experience of each interview was very different and intriguing in its own right. Some of these early observations led to fascinating conversations with my clinical research supervisor and so I began to make notes about each interview.

3.3.1. Emotional Disconnection

As the week drew to a close I found myself very tired. I think this was partly due to the level of attention required during the interviews, but I also realised that carrying out the interviews had been emotionally tiring. I was able to identify two interviews where this had especially been the case.

These two interviews were with the people who showed the greatest level of insight into their difficulties and the impact it had on the person who cared for them. Alistair was a smartly turned out, polite man. He said that his illness had changed everything and he was aware that, at times, he was difficult, unpleasant and violent towards his wife. He was aware of the impact on her and felt responsible for it. Margaret was a confident, open woman. She spoke in a matter of fact manner saying that she now needed her son's support to manage even the simplest of everyday tasks and that he had to give up a great deal to look after her.

One of the most striking things about these two interviews was that there was considerable incongruence between the potential emotional weight of what was being said and the level of emotion expressed by the person. Alistair spoke

seriously but with little emotion, whilst I found what he described to be shocking and deeply saddening. Margaret clearly enjoyed being interviewed, she smiled and laughed through out despite describing complete dependence in herself and considerable distress in her son. Again my emotional response was far stronger than hers.

In both cases I struggled during the interview. I couldn't express my responses either for myself or as empathy for them because it was so inconsistent with what they were expressing. Consequently I simply had to hold what I felt. This was a challenging experience for me and I was grateful for good clinical supervision which allowed me to process the experience. However it is also a fascinating phenomenon.

These two people showed a far higher awareness of the true impact of the dementia on themselves and on other people than any of the others interviewed. The factors determining the level of awareness in people with dementia are unclear, the illness itself may play a part but it seems that personality and pre-existing coping styles may also contribute (Seiffer, Clare, & Harvey, 2005). In the cases of Alistair and Margaret awareness was not limited by the illness or by psychological factors but they were not experiencing the emotions that belong with the concepts that they were articulating. It is possible that the changes in brain function due to the dementia caused the incongruence. Perhaps the processing of information and emotion had become separated to such an extent that a person could relay negative and potentially distressing information whilst laughing and smiling in response to the positive experience of being invited to participate in something novel. A second possibility is that a psychological defence mechanism was causing the emotional detachment, because to actually

experience the feelings that went with the situation that was being described would be unbearably painful. A third possibility is that Alistair and Margaret had a long-standing tendency not to express emotion that pre-dated the onset of the dementia. Perhaps the most likely explanation is that these three processes all played a part with cognitive impairment accentuating pre-existing personality traits or coping mechanisms.

3.2.2. Ambiguities in Identity

Another phenomenon which I noticed in several of the interviews was uncertainty about whether the person was talking about themselves or the person who cared for them. This was particularly striking in the case of Richard, an articulate former head teacher. During the interview with him I got a clear picture of his character and his sense of identity and values. As we went on to speak about his daughter I noticed that he was portraying her character as very similar to his own. His description of her as happy and strong was not consistent with the anxiety and low mood she reported experiencing in her caring role which had led to her being signed off work for several months. I wondered if Richard and his daughter really were this alike in character and he was simply describing her as he remembered her prior to his illness. However I felt that other things could have been happening too; I wondered if he was slipping into talking about himself rather than her, or alternatively was speaking about an idealised daughter.

A subsequent interview with Michael, a gentleman with some mild expressive language difficulties showed a related phenomenon. At times it was clear that he answered a question about his wife by talking about himself and I

needed to prompt him to think about her. At other times he used the pronoun "I" when he clearly meant "she" or vice versa. It seemed that Michael's language difficulties were causing confusion between his wife and himself.

In both these cases memory deficits may have caused the person to forget the question and to answer with the information that was then most salient to them – their own experience. However on further reflection this phenomenon may not be associated with dementia. Do we not all have a tendency to move from thinking about someone else's experience to thinking about our own? And is it not the case that many of us create an idealised sense of people we care about, especially when something distances us from them? Perhaps in my vigilance to attentional and cognitive processes that might invalidate the research I had noticed processes that occur in all of us and are a consequence of our human nature and were simply magnified by the cognitive impairment.

3.3.3. New Insights about Familiar People.

The majority of the interviews with participants who had dementia were carried out in a day centre environment. Participants were accompanied during the interviews by Fiona a member of staff who knew each participant well, and was recognised by them. She invited each person to speak to me and was able to help me to judge how well they were managing the interviews.

As we reached the end of the interview phase we took some time to reflect on the experience. Fiona was fascinated by the interviews because she had found that she had sometimes been surprised by how people responded. Despite knowing all of them well, she found that her anticipation of who would agree to participate or decline, and who would be nervous or relaxed, was not always

correct. Some people were generally quite withdrawn or abrupt when in the small group settings of the day centre but relished the experience of individual conversation and attention. Other people were confident in the group settings but were uncomfortable about the interview.

We could have attempted to predict which people would be uncomfortable with the interview and would decline to participate. This would have allowed us to exclude them at the outset and limit their discomfort by not asking them to participate at all. This may appear to be a way to develop ethical practice further, but our experience showed that it would have had negative consequences. From a research point of view we would have limited the participant numbers unnecessarily, and from an ethical point of view we would have deprived several people of an experience which they enjoyed.

3.4. Recruiting People with Arthritis and their Carers

When I embarked on this research project I expected the data collection for the dementia group to be very challenging, but anticipated that the data collection for the control group would be relatively straightforward. In fact I found collecting data for the control group to be just as challenging

My initial approach to data collection was to work with a senior physiotherapist in a Rheumatology Department and to invite patients attending clinics there to participate. A number of unanticipated practical obstacles arose such as changes in the structure of the Rheumatology Department, and staff shortages in the team which limited the time that could be given to the research. However as I broadened my approach and began to recruit through local support

groups, I became aware of other processes that were contributing to difficulties recruiting to the control group.

3.4.1. Participants' Perceptions of 'carers'

It has become common parlance among health professionals and researcher to use term "carer" to describe a person who provides support and care to a family member or close friend who has a long-term health condition (Department of Health, 1999). My previous involvement in Carers' Courses for people supporting family members with dementia showed that most people in that group had come to see themselves as 'carers' and were comfortable in having their role labelled in that way.

People who support family members with other health conditions may not share this comfort with the descriptor 'carer'. Some of the people in the control group made notes in the margins of the questionnaires. One person wrote "my sister also has health problems but to a lesser extent, we care for each other". Another person wrote "my husband is not a carer, he is simply a caring person".

The first of these responses points to the fact that the distinction between caregiver and care-recipient is less clear where both people experience a range of needs. The second comment challenges the idea that someone who is caring can be termed a carer. Perhaps there is some confusion with professional carers who work for social services or voluntary sector agencies. These people are often referred to as paid carers or formal carers by professionals and researchers but are usually called carers by the general public. Another possible explanation is that the comment expresses discomfort at the way in which the term 'carer' defines a person by their role. The term carer and its implication of a distinct role

within the relationship may be more acceptable where the relationship has been radically changed by an illness, for instance by dementia, but might not feel right where the impact of the illness on the relationship is less fundamental.

These reflections raise questions about the use of the phrase 'carer' in communications from health services aimed at people who support family members who have health problems. I wondered if this has been explored systematically and whether other terms could be more appropriate. A brief initial literature search did not bring up any research on this although I think other clinicians may be interested in the issue. It is something that I now bear in mind in clinical practice and would consider as a possible area for future research.

3.4.2. Participants' Perceptions of 'care-recipients'

When I attended voluntary sector meetings for people with arthritis many people declined to participate because they said they were fine and got by ok. It is likely that some of these people had received effective treatment such that their arthritis did not impact on them significantly at that point, or that they had experienced their symptoms over a long period of time and had become accustomed to them. However I also wondered if some people declined because they did not want to identify themselves as someone in need of care and support from a family member.

This discomfort identifying with the care-recipient role also appeared to affect the approach taken by committee members within some of the support groups. At several of the groups the committee members expressed interest in my research but made it clear that they did not see themselves as potential

participants, whereas in other groups, members of the committee were willing to participate. I wondered if these two positions reflected the way in which they perceived their roles and their needs. Those in the groups where committee members did not see themselves as potential participants were very involved in their roles at the meeting and acted as helpers who organised things for the members of the group. These committee members acknowledged their own arthritis and other health problems but did not see themselves as in need of support or care. Those groups where committee members were willing to participate tended to have more of a feeling of shared ownership. Committee members were part of the group and were more comfortable identifying themselves as someone who needed care and support.

I saw that the volunteers who act as committee members within these support groups perform a vital role in running groups that bring pleasure to a great number of people. However I also wondered about the significance of care-recipient roles for those committee members who were very involved in supporting others and did not see themselves as potential participants. Drawing on constructs from Cognitive Analytical Therapy these people may have a reciprocal role of carer - care-recipient and see themselves as in one position or the other but not be able to integrate the two positions. From a more psychodynamic perspective their identification with the role of 'helper' may have been protective in emphasising their abilities and guarding them from the idea that they might in the future become one of those who needed to be helped. I was reminded as a clinician that sometimes the strong are strong because they need so desperately not to acknowledge that they are vulnerable.

3.5. Summary of Learning.

When I began to focus my reflective paper on my experiences interacting with participants during the collecting data phase I was concerned that this approach might generate a very narrow paper. However I have been really surprised by the breadth of learning I have taken from these reflections which included clinical professional learning, development of ideas about ethics in research and increased awareness of service-level issues. The key areas of personal learning from these three aspects are briefly summarised below.

From a clinical perspective I have made a number of observations in this paper that draw on psychodynamic ideas. For instance the possibility that defence against strong emotion caused some of the participants with dementia to speak cheerfully about distressing experiences, or that those who identify themselves as strong helpers may be protecting themselves from the possibility that they may need help themselves.

During the course of my training I have become increasingly interested in the use of psychodynamic ideas in therapeutic work. The experiences described here have led me to consider psychodynamic defences operating in non-therapy settings, in research interviews with people with cognitive impairment, and with volunteers running support groups. I feel that my developing ability to use concepts from a range of models in systemic and neuropsychological settings is a significant step in my development as a clinical psychologist and I am keen to build on this area of skill in the future.

As a researcher I have been challenged to think about ethical issues, particularly in relation to working with people with cognitive impairment. Firstly

do we notice behaviours in the participants that we study and attribute these to their condition when actually these behaviours are part of normal functioning? And secondly do we risk focusing too heavily on protecting vulnerable people and in doing so fail to offer them opportunities?

These questions are new to me and neither is easily answered but I think that clinicians are particularly well placed to raise questions such as these and that in doing so they make a distinct and valuable contribution to research. Through the experience of carrying out this research thesis I have gained a stronger interest in clinical research and the way in which clinicians and academic researchers interact. I hope to be able to be involved in future research work which draws on the strengths of clinical and academic disciplines.

At a service level this work has raised questions for me about the language we use as clinicians and the way in which it is received by members of the general public. My consideration of participants' responses to the term 'carer' made me wonder whether a better choice of term might connect more strongly with people's experiences and increase their engagement in services offered to support them. However I was aware that there wasn't an obvious alternative phrase and wondered if this in itself might be a valuable area for research.

3.6. Conclusion

During the process of carrying out my research and collecting material for this reflective paper I have been further persuaded of the value of making reflective records. I have been surprised by the breadth of learning that has arisen from one aspect of the research process, my experiences during data collection, and am reminded how rich the opportunities for learning are in a role as varied as clinical psychology. Perhaps it is not possible to capture all that is potentially there to be learnt, but proactive reflective strategies can help us not to let too much slip by. However the process has also reminded me that for reflective diary keeping to be good practice it must also involve revisiting reflections, drawing them together, and most importantly identifying specific learning or new questions (Cushway & Gatherer, 2003). These outcomes can be acted on to change clinical or research practice or can prompt further investigation be that in the form of research or professional development.

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DEMENTIA GROUP

Appendix 1.



THE UNIVERSITY OF
WARWICK

Coventry
University

Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

Dear carer,

The Bungalow Day Centre and local NHS services have worked together with the Universities of Coventry and Warwick to develop a research project which aims to find out about the impact of caring for a family member with dementia. This research takes a new approach to gaining understanding of this issue. The findings will help us to improve support for people with dementia and their carers in the future.

If you would like to participate, please complete the consent form and questionnaires and return them in the enclosed stamped addressed envelope.

We appreciate how busy you are in your role and that this looks like a lot of paperwork. However this pack contains information about the project and additional information about services that may be helpful for you in your caring role. The questionnaires will only take about 10 to 15 minutes to complete.

We hope that you feel able to take part,

Yours sincerely

Astri Ablitt
Trainee Clinical Psychologist
University of Coventry

Fiona Palmer
Manager
Bungalow Day Centre

Version 4. 27.04.07

Dean of Faculty of Health and Life Sciences

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IX

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ARTHRITIS PATIENTS AND CARERS

THE UNIVERSITY OF
WARWICK



Programme Director
 Doctorate Course in Clinical Psychology
 Professor Delia Cushway
 BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

Dear Carer,

We are writing to invite you to participate in a research project which aims to find out about the impact of long-term health conditions on family relationships. The study was developed by local NHS services working with the Universities of Coventry and Warwick and takes a new approach to gaining understanding of this issue. We hope that the findings will help us to improve support for people with long-term health conditions and their carers.

We appreciate that this looks like a lot of paperwork. However this pack contains information about the project and additional information about services that may be helpful for you. The questionnaires are in a tick-box style and will only take about 10 to 15 minutes to complete. All responses will be anonymous, names will not be used in the results.

You and the family member who you care for have both been invited to participate. In order for us to use the information we need both of you to complete the questionnaires.

Please feel free to discuss participating with your family member. However please complete the questionnaires separately and do not discuss the questions or your answers until after you completed the forms. Please do not alter your responses following discussion with your family member.

You can choose to complete the questionnaires whilst at the Department of Rheumatology or to take them home. Please return them in the enclosed stamped addressed envelope to the receptionist in the Department, or by post.

We hope that you feel able to take part,

Yours sincerely,

Astri Ablitt
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PARTICIPANTS WITH DEMENTIA

THE UNIVERSITY OF
WARWICK



Programme Director
 Doctorate Course in Clinical Psychology
 Professor Delia Cushway
 BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

Perceptions of emotional well-being in families with long-term illness.

Participant Information Sheet

What is the purpose of the study?

This research is about two issues which affect older people: changes in memory, and stress in families.

By improving our understanding of these issues we hope to be able to improve the support we can offer to older people.

Why have I been chosen?

The Bungalow Day Centre staff have agreed to help the researcher with this project.

What would taking part involve?

You would be asked how good or bad you think your memory is, and how emotionally well you feel your closest family member is.

Taking part will take around 20-30 minutes.

Do I have to take part?

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

Whether or not you participate will not influence the health services you receive.

What if I want to stop?

You can stop at any time. If you wish to stop please tell the researcher.

Will my taking part in this study be kept confidential?

Your responses will only be seen by the researcher and her supervisors.

What if I have a question, or am not happy about the project?

If you have any worries about this study please speak to the researcher or to a member of staff at the Bungalow.

Dean of Faculty of Health and Life Sciences
 Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology
 Professor Koen Lamberts BA BSc MSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

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 Priory Street, Coventry CV1 5FB
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DEMENTIA CARERS

THE UNIVERSITY OF
WARWICK



Programme Director
Doctorate Course in Clinical Psychology
 Professor Delia Cushway
 BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

Perceptions of emotional well-being in families with long-term illness.

Participant Information Sheet

You are being invited to take part in a research study. Please take time to read the following information carefully. Please contact the researcher on the telephone number given above if you would like more information.

What is the purpose of the study?

Acting as the principle carer for a family member who has dementia is challenging and can be very distressing at times. However we don't know how much people with dementia recognise and understand the emotional feelings of their carers. This study is a new approach to gaining understanding of this issue. A better understanding will help us to improve support for people with dementia and their carers in the future.

Why have I been chosen?

The research involves pairs of people, a person with dementia and the family member who acts as their main carer. The Bungalow Day Centre and the local Consultant Psychiatrist in Rugby have agreed to work with the researcher on this project. They have identified you and your family member as possible participants. No one from outside the Bungalow or Psychiatry Department has had access to your personal details.

As the carer, you are being approached first. If you decide to participate, your family member will be asked if they would like to participate. If you decide not to participate, your family member will not be approached.

Do I have to take part?

It is up to you whether or not you take part. Whether or not you participate will not influence the health services you and your family member receive.

What would taking part involve?

If you decide to take part you are being asked to complete two questionnaires on your own emotional well-being and one on your family member's memory abilities.

The questionnaires are short and are in a 'tick-box' style. They will take around 10-15 minutes to complete. Once you have done this you will not be asked to contribute further.

If your family member takes part they will be asked to complete similar questionnaires (on their own memory and your well-being). These will be completed at the Bungalow through an interview with the researcher, supported by staff from the Bungalow.

What happens if I want to withdraw from the study?

You can withdraw at any time. If you wish to withdraw after returning the questionnaires, please contact the researcher using the contact details below.

Are there any risks or benefits in taking part?

The questionnaires enclosed ask about your emotional well-being. If you feel that you are struggling emotionally and need help or advice please speak to your GP who can help you access appropriate support.

Enclosed is a leaflet about support which is available locally for people who care for family members who have memory difficulties.

Will my taking part in this study be kept confidential?

It is helpful for your GP to be aware that you have participated in this research so that he/she can provide you with support if needed. You will be asked to consent to your GP being contacted on the consent form attached.

The responses will be kept in a locked storage cabinet and will only be accessed by the researcher and her supervisors.

What if there is a problem?

If you are concerned about any aspect of this study please speak to the researcher or contact Dr Sarah Kent, Dept of Clinical Psychology, Coventry University, 024 7688 8328.

If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from Patient Advice and Liaison Service (PALS) on freephone 0800 028 420 or email PALS@uhcw.nhs.uk.

What will happen to the results of the study?

The findings of this research will be submitted for publication in a clinical research journal. The findings will also be shared with the staff at the Bungalow. If you would like to receive a copy of the findings please contact the researcher (see below).

Participants in this study will not receive feedback on their individual responses.

Who has organised and reviewed this study?

This study is being carried out as part of a doctoral thesis jointly organised by the Universities of Warwick and Coventry. This study has been reviewed by the Warwickshire NHS Research Ethics Committee.

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
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THE UNIVERSITY OF
WARWICK



Perceptions of emotional well-being in families with long-term illness.

Participant Information Sheet

You are being invited to take part in a research study. Please take time to read the following information carefully. Please contact the researcher using the contact details given below if you would like more information.

What is the purpose of the study?

Living with long-term health problems can be a stressful experience for the patient and for their families. However there is limited research on the impact on relationships within families. A better understanding will help us to improve support for people with long-term health problems and their carers in the future.

The study investigates perceptions of emotional well-being within families. Patients of the Rheumatology Department and their main carer will be asked to rate their own emotional well-being and each other's emotional well-being.

There are two groups of people involved in the study, one with rheumatology conditions and one with dementia. The data from the rheumatology group will be analysed and fed back to the Rheumatology Department. It will also be used as comparison data for the dementia group.

Why have I been chosen?

Your Rheumatologist has agreed to work with the researcher on this project. Possible participants were identified by members of staff of the Rheumatology Department. No one from outside the department has had access to your personal details.

Do I have to take part?

No. It is up to you whether or not you take part. Whether or not you participate will not influence the health services you and your family member receive.

What would taking part involve?

If you decide to take part you will be asked to complete some questionnaires.

The questionnaires are short and are in a 'tick-box' style. They will take around 10-15 minutes to complete. Once you have done this you will not be asked to contribute further.

1 of 2

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University · Priory Street Coventry CV1 5FB Tel 024 7679 5805

Chair of Department of Psychology
Professor Koen Lamberts BA BSc MSc PhD University of Warwick Coventry CV4 7AL Tel 024 7652 3096

XIII

Are there any risks or benefits in taking part?

There are no anticipated risks in taking part. However the questionnaires enclosed ask about your emotional well-being. If you feel that you are struggling emotionally and need help or advice please speak to your GP who can help you access appropriate support.

Enclosed is a leaflet about support which is available locally for people with rheumatology conditions and family members who care for them.

What happens if I want to withdraw from the study?

You can withdraw at any time. If you wish to withdraw after returning the questionnaires, please contact the researcher using the contact details above.

Will my taking part in this study be kept confidential?

The responses will be kept in a locked storage cabinet and will only be accessed by the researcher and her supervisors.

What if there is a problem?

If you are concerned about any aspect of this study please speak to the researcher or contact Dr Sarah Kent, Research Tutor, Dept of Clinical Psychology, University of Warwick, 024 7688 8328.

If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from Patient Advice and Liaison Service (PALS) on freephone 0800 028 420 or email PALS@uhcw.nhs.uk.

What will happen to the results of the study?

The findings of this research will be submitted for publication in a clinical research journal. The findings will also be presented to the staff at the Rheumatology Department.

If you would like a copy of the findings please contact the researcher (see below).

Who has organised and reviewed this study?

This study is being carried out as part of a doctoral thesis jointly organised by the Universities of Warwick and Coventry. This study has been reviewed by the Warwickshire NHS Research Ethics Committee.

Researcher contact details:

Dr Astri Ablitt, Department of Clinical Psychology, JSG24 James Starley Building
University of Coventry, Priory Street, Coventry, CV1 5FB. Tel: 024 7688 8328

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
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Programme Director
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Consent Form

Perceptions of emotional well-being in families with long-term illness.

Please initial box

1. I have understood the information about the study

2. I understand that my participation is voluntary

3. I understand that my care will not be affected

4. I agree to the researcher accessing my medical records for information about memory assessments

5. I agree to take part in this study

Name

Date

Signature

Name of researcher

Date

Signature

Dean of Faculty of Health and Life Sciences
Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

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DEMENTIA CARERS

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Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

Perceptions of emotional well-being in families with long-term illness.

Consent Form

Please initial box

1. I have read and understood the information sheet

2. I understand that my participation is voluntary

3. I understand that the care of my family member
receives will not be affected

4. I agree to my GP being informed of my participation
in the study.

Please give your GP's name and surgery. _____

5. I agree to take part in this study.

Name of Carer

Date

Signature

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

ARTHRITIS PATIENTS AND CARERS

THE UNIVERSITY OF
WARWICK



Programme Director
Doctorate Course in Clinical Psychology
Professor Delia Cushway
BA (Hons) MSc PhD AFBPS CPsychol (Clin Foren)

Consent Form

Perceptions of emotional well-being in families with long-term illness.

Please initial box

1. I have read and understood the information sheet

2. I understand that my participation is voluntary

3. I understand that the care I receive will not
be affected

4. I agree to take part in this study.

Name

Date

Signature

Name of researcher

Date

Signature

Perceptions of emotional well-being in families with long-term illness.

Demographic Information

1. Your name:

2. Your date of birth: 3. Your gender:

4. The follow questions concern carers themselves.

- a) Do you yourself have long-term health difficulties that require a greater level of care or support than the care required by your relative?
YES / NO (please circle the correct response)
- b) Do you have a diagnosis of dementia, brain damage, or developmental neurological impairment? YES / NO (please circle the correct response)
- c) Have you been under the care of a consultant psychiatrist in the last 10 years?
YES / NO (please circle the correct response)

If you answered 'YES' to any of the above questions you will not be asked to proceed with the study. Thank you for being willing to consider participating.

If you answered 'NO' to all three of the above questions please proceed.

5. Name of person who you care for:

6. What is your relationship to the person you care for? (please tick appropriate box)

- | | | | |
|------------------------------|--------------------------|-----------------|--------------------------|
| Wife / Husband / Partner | <input type="checkbox"/> | Mother / Father | <input type="checkbox"/> |
| Daughter / Son | <input type="checkbox"/> | Niece / Nephew | <input type="checkbox"/> |
| Daughter-in-law / Son-in-law | <input type="checkbox"/> | Friend | <input type="checkbox"/> |
| Other (please state) | <input type="checkbox"/> | | |

7. How much contact do you have with the person you care for?

Do you live in the same house? YES / NO (please circle the correct response)

If you do not live in the same house, how often on average do you visit?

- Several times a day Most days At least once a week Less than once a week

If you do not live in the same house, how often on average do you speak on the phone?

- Several times a day Most days At least once a week Less than once a week

8. What is your ethnic group? (please tick appropriate box)

- | | | | |
|------------------------|--------------------------|--------------------------------|--------------------------|
| White | <input type="checkbox"/> | Mixed | <input type="checkbox"/> |
| Indian | <input type="checkbox"/> | Pakistani and Bangladeshi | <input type="checkbox"/> |
| Black or Black British | <input type="checkbox"/> | Other Ethnic Group... | <input type="checkbox"/> |
| | | (inc. Chinese and Other Asian) | |

ARTHRITIS PATIENTS

Demographic information - patient.

1. Your name:

2. Your date of birth: 3. Your gender:

4. The follow questions relate to the research project inclusion criteria.

Do you have a diagnosis of dementia, brain damage, or developmental neurological impairment? YES / NO (please circle correct response)

Have you been under the care of a consultant psychiatrist in the last 10 years? YES / NO (please circle correct response))

If you answer 'YES' to either of the above questions you will not be asked to proceed with the study. Thank you for being willing to consider participating.

If you answered 'NO' to both of the above questions please proceed.

5. Name of your main carer:

.....

6. What is the medical condition for which you receive treatment from the Rheumatology Department?

.....

7. For approximately how many years have you had this condition?

8. What is your ethnic group? (please tick appropriate box)

White	<input type="checkbox"/>	Mixed	<input type="checkbox"/>
Indian	<input type="checkbox"/>	Pakistani and Bangladeshi	<input type="checkbox"/>
Black or Black British	<input type="checkbox"/>	Other Ethnic Group... (inc. Chinese and Other Asian)	<input type="checkbox"/>

ARTHRITIS CARERS

Demographic information - main carer.

1. Your name:

2. Your date of birth: 3. Your gender:

4. The follow questions concern carers themselves.

a) Do you yourself have long-term health difficulties that require a greater level of care or support than the care required by your relative?

YES / NO (please circle the correct response)

b) Do you have a diagnosis of dementia, brain damage, or developmental neurological impairment? YES / NO (please circle the correct response)

c) Have you been under the care of a consultant psychiatrist in the last 10 years?

YES / NO (please circle the correct response)

If you answered 'YES' to any of the above questions you will not be asked to proceed with the study. Thank you for being willing to consider participating.

If you answered 'NO' to all three of the above questions please proceed.

5. Name of the patient for whom you are the main carer:

.....

6. What is your relationship to the person you care for? (please tick appropriate box)

Wife / Husband / Partner	<input type="checkbox"/>	Mother / Father	<input type="checkbox"/>
Daughter / Son	<input type="checkbox"/>	Niece / Nephew	<input type="checkbox"/>
Daughter-in-law / Son-in-law	<input type="checkbox"/>	Friend	<input type="checkbox"/>
Other (please state)	<input type="checkbox"/>	

7. How much contact do you have with the person you care for?

Do you live in the same house? YES / NO (please circle the correct response)

If you do not live in the same house, how often on average do you visit?

Several times a day Most days At least once a week Less than once a week

If you do not live in the same house, how often on average do you speak on the phone?

Several times a day Most days At least once a week Less than once a week

8. What is your ethnic group? (please tick appropriate box)

White	<input type="checkbox"/>	Mixed	<input type="checkbox"/>
Indian	<input type="checkbox"/>	Pakistani and Bangladeshi	<input type="checkbox"/>
Black or Black British	<input type="checkbox"/>	Other Ethnic Group...	<input type="checkbox"/>
		(inc. Chinese and Other Asian)	

Group and setting	Dementia Carers Day Centre	Dementia Participants Day Centre	Dementia Carers Psychiatric follow-up clinics and carers groups	Dementia Participants Psychiatric follow-up clinics and carers groups
Initial contact	Mention of forthcoming research in the Day Centre newsletter	Known member of Day Centre staff asks person if they would be happy to speak to the researcher. Only people whose carers have participated are approached.	The researcher speaks briefly about research after follow-up appointment or at carers group meeting.	If carer returned questionnaires they were asked to discuss participation with the person with dementia.
Administration method	Questionnaire pack sent by post with SAE for return.	Questionnaire pack presented and administered in person by the researcher at the Day Centre with option of presence of known member of Day-Centre staff.	Questionnaire pack offered, with SAE for return.	Questionnaire pack presented and administered in person by the researcher in the person's own home. Carer present for introduction and debriefing but not during administration of measures.
Documents	<ul style="list-style-type: none"> • Covering letter • Information sheet • Consent form • Demographics sheet • HADS and VAS (self-rating version) • MARS (observer-rating version) • Stamped addressed envelope 	<ul style="list-style-type: none"> • Information sheet • Consent form • HADS and VAS (administered as informant version) • MARS (administered as self-report version) 	<ul style="list-style-type: none"> • Covering letter • Information sheet • Consent form • Demographics sheet • HADS and VAS (self-rating version) • MARS (observer-rating version) • Stamped addressed envelope 	<ul style="list-style-type: none"> • Information sheet • Consent form • HADS and VAS (administered as informant version) • MARS (administered as self-report version)
Additional enclosures	Carers pack about services and information available.	n/a	Carers pack about services and information available.	n/a

Group and setting	Control Group Participants Rheumatology Department	Control Group Carers Rheumatology Department	Control Group Participants Support Groups	Control Group Carers Support Groups
Initial contact	Known member of Rheumatology Dept clinical team asks person if they would consider participating.		The researcher speaks briefly about research at support group meeting.	
Administration method	Pairs of questionnaire packs offered, one for the patient and one for the carer. SEA enclosed for return.		Pairs of questionnaire packs offered, one for the patient and one for the carer. SEA enclosed for return.	
Documents	<ul style="list-style-type: none"> • Covering letter • Information sheet • Consent form • Demographics sheet • HADS and VAS (observer-rating version) • Stamped addressed envelope 	<ul style="list-style-type: none"> • Covering letter • Information sheet • Consent form • Demographics sheet • HADS and VAS (self-rating version) • Stamped addressed envelope 	<ul style="list-style-type: none"> • Covering letter • Information sheet • Consent form • Demographics sheet • HADS and VAS (observer-rating version) • Stamped addressed envelope 	<ul style="list-style-type: none"> • Covering letter • Information sheet • Consent form • Demographics sheet • HADS and VAS (self-rating version) • Stamped addressed envelope
Additional enclosures	Information sheet about services for people with arthritis or rheumatology conditions and for carers.			

Hospital Anxiety and

nferNelson
understanding potential

Depression Scale (HADS)

Name: _____ Date: _____

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

FOLD HERE

FOLD HERE

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

	A	D		A	D
	3		I feel tense or 'wound up'		
	2		Most of the time		3
	1		A lot of the time		2
	0		From time to time, occasionally		1
			Not at all		0
		0	I still enjoy the things I used to enjoy		
		1	Definitely as much		0
		2	Not quite so much		1
		3	Only a little		2
			Hardly at all		3
	3		I get a sort of frightened feeling as if something awful is about to happen		
	2		Very definitely and quite badly		3
	1		Yes, but not too badly		2
	0		A little, but it doesn't worry me		1
			Not at all		0
		0	I can laugh and see the funny side of things		
		1	As much as I always could		3
		2	Not quite so much now		2
		3	Definitely not so much now		1
			Not at all		0
	3		Worrying thoughts go through my mind		
	2		A great deal of the time		3
	1		A lot of the time		2
	0		Not too often		1
			Very little		0
		3	I feel cheerful		
		2	Never		3
		1	Not often		2
		0	Sometimes		1
			Most of the time		0
		0	I can sit at ease and feel relaxed		
		1	Definitely		3
		2	Usually		2
		3	Not often		1
			Not at all		0
			I feel as if I am slowed down		
			Nearly all the time		3
			Very often		2
			Sometimes		1
			Not at all		0
			I get a sort of frightened feeling like 'butterflies' in the stomach		
		0	Not at all		0
		1	Occasionally		1
		2	Quite often		2
		3	Very often		3
			I have lost interest in my appearance		
			Definitely		3
			I don't take as much care as I should		2
			I may not take quite as much care		1
			I take just as much care as ever		0
			I feel restless as if I have to be on the move		
			Very much indeed		3
			Quite a lot		2
			Not very much		1
			Not at all		0
			I look forward with enjoyment to things		
			As much as I ever did		0
			Rather less than I used to		1
			Definitely less than I used to		2
			Hardly at all		3
			I get sudden feelings of panic		
			Very often indeed		3
			Quite often		2
			Not very often		1
			Not at all		0
			I can enjoy a good book or radio or television programme		
			Often		0
			Sometimes		1
			Not often		2
			Very seldom		3

Now check that you have answered all the questions

This form is printed in green. Any other colour is an unauthorized photocopy.
 HADS copyright © R.P. Snath and A.S. Zigmond, 1983, 1992, 1994.
 Record form items originally published in *Acta Psychiatrica Scandinavica* 67, 361-70, copyright © Munksgaard International Publishers Ltd, Copenhagen, 1983.

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TOTAL

A	D

Version of the HADS for rating how you think someone else is feeling

Please think about your carer. Read each item below and underline the reply which comes closest to how you think they have been feeling in the past week.

She/He feels tense or 'wound up'

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

She/He still enjoys the things she/he used to enjoy

- Definitely as much
- Not quite as much
- Only a little
- Hardly at all

She/He gets a sort of frightened feeling as if something awful is going to happen

- Very definitely and quite badly
- Yes but not too badly
- A little, but it doesn't worry him/her
- Not at all

She/He can laugh and see the funny side of things

- As much as she/he always could
- Not quite so much now
- Definitely not so much now
- Not at all

Worrying thoughts go through his/her mind

- A great deal of the time
- A lot of the time
- Not too often
- Very little

She/He feels cheerful

- Never
- Not often
- Sometimes
- Most of the time

She/He can sit at ease and feel relaxed

- Definitely
- Usually
- Not often
- Not at all

Please turn over and complete questions on reverse

She/He feels as if she/he is slowed down

Nearly all the time
Very often
Sometimes
Not at all

She/He gets a sort of frightened feeling like butterflies in the stomach

Not at all
Occasionally
Quite often
Very often

She/He has lost interest in his/her appearance

Definitely
She/He don't take as much care as she/he should
She/He may not take quite as much care
She/He takes just as much care as ever

She/He feels restless as if she/he has to be on the move

Very much indeed
Quite a lot
Not very much
Not at all

She/He looks forward with enjoyment to things

As much as she/he ever does
Rather less than she/he used to
Definitely less than she/he used to
Hardly at all

She/He gets sudden feelings of panic

Very often indeed
Quite often
Not very often
Not at all

She/He can enjoy a good book or radio or television programme

Often
Sometimes
Not often
Very seldom

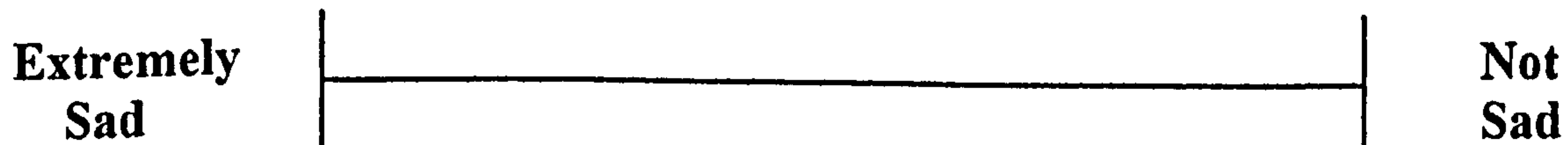
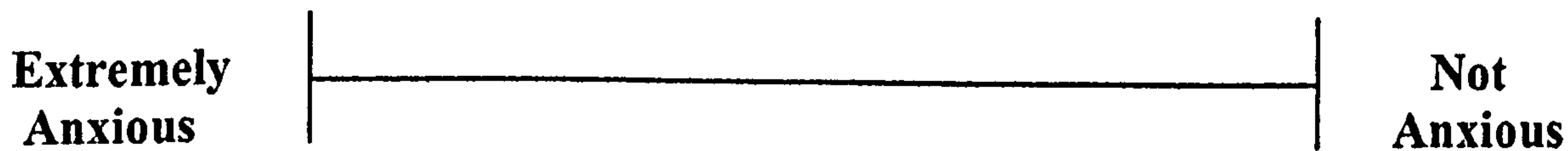
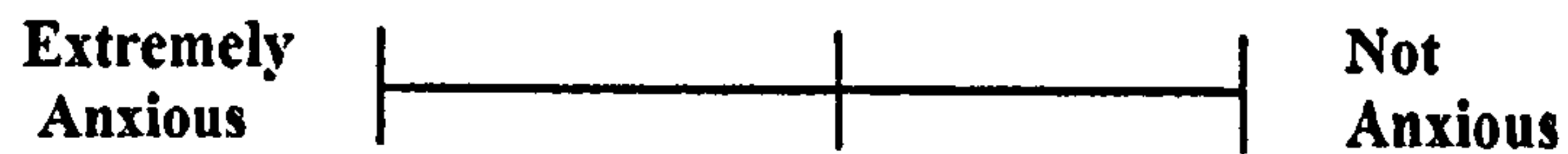
Responses will be transferred onto a standard HADS response sheet for scoring

Visual Analogue Scale

These scales allow you to rate your mood. Please look at each scale and decide where you feel you are on the line between the moods described at either end of the line, (e.g. between extremely sad and not sad).

Base your judgement on how you have been feeling on average over the past week.

Please make a vertical mark on the line to indicate where you think you are on the line, e.g.



Visual Analogue Scale

These scales allow you to rate the mood of the person who carers for you.

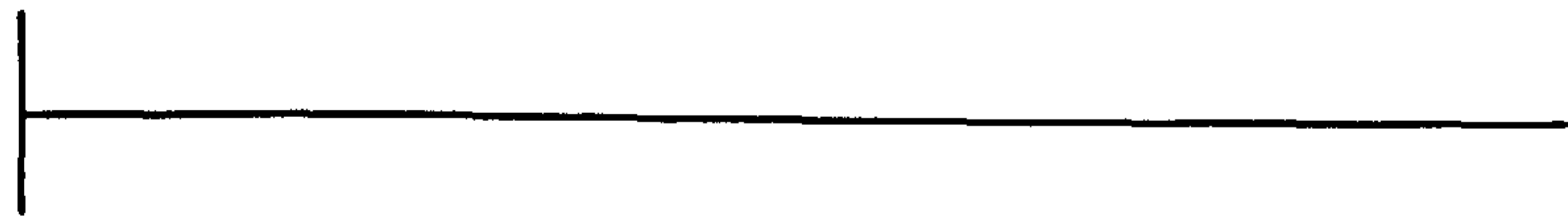
Please look at each scale and decide where you feel they are on the line between the moods described at either end of the line, (e.g. between extremely sad and not sad).

Base your judgement on how you think they have been feeling on average over the past week.

Please make a vertical mark on the line to indicate where you think they are on the line, e.g.

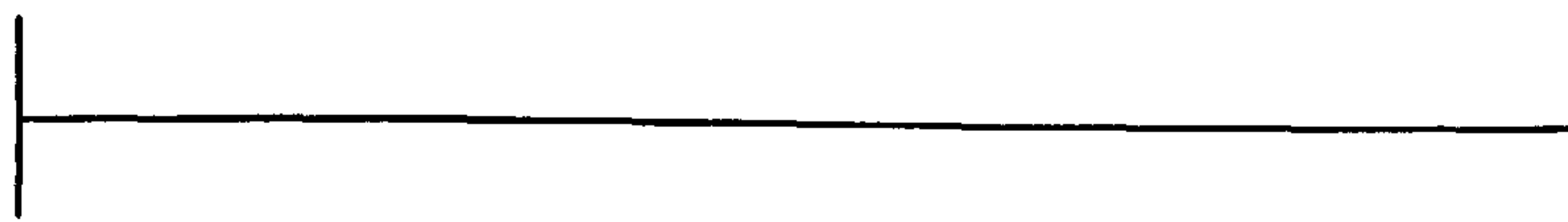
Extremely Anxious |-----| Not Anxious

Extremely Anxious



Not Anxious

Extremely Sad



Not Sad

Extremely Frustrated



Not Frustrated

Memory Situations

1. You meet someone and are told their name. Later on you meet them again, and you need to remember their name.
2. You have made an appointment. You need to remember to go along.
3. You have promised to do something later in the day. You need to remember to do it at the right time.
4. You have got a set of items to sort out, some of which you have seen before and some of which are new to you. You need to pick out the ones you have seen before.
5. You hear a news item on the radio.
 - (a) One of your family comes in at the end and asks you what was said.
 - (b) Later on - say half an hour later - someone else asks you what you heard.
6. You meet up with a group of people. Some of them you've met before, others you haven't. You need to recognise which ones you've met before.

7. You go to a new building and you are learning to find your way around. Someone shows you a short route which you will need to remember.
 - (a) You need to retrace the route immediately
 - (b) You need to retrace the route again later on - say half an hour later.

8. You have been given a message to deliver to someone. You need to remember to give that person the message when you see them.
 - (a) You see them right away.
 - (b) You see them later on.

9. You are being asked to give some information about yourself, such as your age, address, date of birth and so on, and to answer a few basic general knowledge questions.

10. Someone asks you for today's date.

MARS-MFS-S

I think I would be able to do this:



Always



Often



Sometimes



Rarely



Never

MEMORY AWARENESS RATING SCALE
Memory Functioning Scale - Informant Version (MARS-MFS-I)
SCORE SHEET

Below are some examples of everyday situations where a person might need to use his/her memory. Please think about your partner's/relative's memory, as it is now, and rate how you think he/she would manage in that situation.

I think my partner / relative would be able to do this:

0 = never
1 = rarely
2 = sometimes
3 = often
4 = always

SITUATION	FREQUENCY (please circle one number)
1. S/he meets someone and is told their name. Later on s/he meets them again, and needs to remember their name.	0 1 2 3 4
2. S/he has made an appointment and needs to remember to go along.	0 1 2 3 4
3. S/he has promised to do something later in the day, and needs to remember to do it at the right time.	0 1 2 3 4
4. S/he has got a set of items to sort out, some of which s/he has seen before and some of which are new to her/him. S/he needs to pick out the ones s/he has seen before.	0 1 2 3 4
5. S/he hears a news item on the radio. (a) One of the family comes in at the end and asks what was said. (b) Later on (half an hour later) someone else asks what was said.	0 1 2 3 4 0 1 2 3 4
6. S/he meets up with a group of people. Some of them s/he has met before, others are new. S/he needs to recognise which ones s/he has met before.	0 1 2 3 4
7. S/he goes to a new building and is learning to find the way around. Someone shows her/him a short route which s/he needs to remember. (a) S/he needs to retrace the route immediately (b) S/he needs to retrace the route again later on - half an hour later.	0 1 2 3 4 0 1 2 3 4
8. S/he has been given a message to deliver to someone and needs to remember to give that person the message when s/he sees them. (a) S/he sees them right away. (b) S/he sees them later on.	0 1 2 3 4 0 1 2 3 4
9. S/he is being asked to give some information about her/himself, such as age, address, date of birth and so on, and to answer a few basic general knowledge questions.	0 1 2 3 4
10. Someone asks her/him for today's date.	0 1 2 3 4

Complete set of Explanatory Narratives given by Participants with Dementia

Category	n	Narratives Given
Carer is fine	6	<p>"She's a good girl. She's happy with the boyfriend of hers."</p> <p>"She's a strong girl, she's in control of her mind, I think she's ok."</p> <p>"She's happy, she has a wonderful husband"</p> <p>"If she feel's sad or anxious she does something about it and she gets on fine. She's a coper"</p> <p>"I just forget about it and do the things I want to do. He's very good, he's very laid back"</p> <p>"She's fine, she has a wonderful husband".</p>
Carer impacted by caring role	9	<p>"She worries about me. She's very busy."</p> <p>"She's in control of herself. My illness changed everything. I'm sometimes a difficult person."</p> <p>"He worries about me. He tries to protect me, he's overprotective."</p> <p>"I'm quite a worry to her, she feels she has to do things for me."</p> <p>"Because of the things I can't do, it's all put on to her now".</p> <p>"She's frustrated with my condition. She's not anxious."</p> <p>"She's moving along the sliding scale (of anxiety and sadness)"</p> <p>"She's very worried and frustrated about my hearing and my memory".</p> <p>"I'm quite a worry to her, she feels she has to do things for me".</p> <p>"She worries about me".</p>
Carer impacted by other factor	3	<p>"He's stressed with his work."</p> <p>"She gets worried and frustrated with Richard^a."</p> <p>"She hide's her feelings, her husband is terminally ill"</p>

a. Alternative name used.

National Research Ethics Service



21 March 2007

Dr Astri J Ablitt
 Trainee Clinical Psychologist
 Universities of Coventry and Warwick
 Department of Clinical Psychology, JSG24, James Starley Building,
 University of Coventry, Priory Street,
 Coventry
 CV1 5FB

Warwickshire Research Ethics Committee
Accredited by UKECA to review Type 3 MREC Applications

Lewes House
 George Eliot Hospital
 College Street
 Nuneaton
 Warwickshire
 CV10 7DJ

Dear Dr Ablitt

Tel: 02476 865244
 Fax: 02476 865264
 pat.horwell@geh.nhs.uk

Full title of study: **The Impact of Dementia on Family Relationships:
 Awareness of the caregiver's emotions.**

REC reference number: **07/Q2803/22**

Thank you for your letter of 11 March 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Conditions of approval

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

Approved documents

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

Document	Version	Date
Application	1	24 January 2007
Investigator CV	Gregory Jones Supervisor	08 January 2007
Investigator CV		29 January 2007
Protocol	4	14 January 2007
Covering Letter		01 February 2007
Letter from Sponsor		31 January 2007
Questionnaire: Visual analogue scale	2	06 January 2007
Questionnaire: MARS		30 January 2000
GP/Consultant Information Sheets	1	11 March 2007
Participant Information Sheet: Dementia carers	5	11 March 2007
Participant Information Sheet: Physical Health	4	11 January 2007
Participant Information Sheet: Bungalow Carers	4	11 January 2007
Participant Information Sheet: Bungalow	4	11 January 2007

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority
 The National Research Ethics Service (NRES) represents the NRES Directorate within
 the National Patient Safety Agency and Research Ethics Committees in England

Participant Consent Form: Bungalow carers		11 January 2007
Participant Consent Form: Physical Health	4	11 January 2007
Participant Consent Form: Bungalow	4	11 January 2007
Participant Consent Form: Dementia carers	5	11 March 2007
Response to Request for Further Information		11 March 2007
Information leaflets		
Information on support for people with rheumatology conditions and their carers in Coventry		
Hospital anxiety Scale	HADS	
Checklist		

R&D approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final approval from the R&D office for the relevant NHS care organisation.

Statement of compliance

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

07/Q2803/22

Please quote this number on all correspondence

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

Yours sincerely


 Mr Paul Hamilton
 Chair

Enclosures: *Standard approval conditions*
 Site approval form

Copy to: University of Coventry
 R&D office for NHS care organisation at lead site



C/o Warwickshire PCT
 Westgate House, 21 Market Street
 Warwick, CV34 4DE
 DDI: 01926 493 491 ext 252
rd.office@swarkpct.nhs.uk

Astri Ablitt
 Trainee Clinical Psychologist
 Universities of Coventry and Warwick
 Department of Clinical Psychology
 James Starley Building
 Coventry University
 Priory Street
 Coventry, CV1 5FB

15 May 2007

ref: PAR160207

Dear Astri

I am pleased to confirm that **Coventry & Warwickshire Partnership Trust** have reviewed the research entitled "Impact of Dementia on Family Relationships: Awareness of the Caregiver's emotions" and give approval for this study to take place within the Trust on the condition that the Trust suffers no additional costs as a result of this study being undertaken. Your research has been entered into the Trust's Research database (if applicable this will be entered onto the National Research Register).

Please reply to this letter confirming the expected start date and duration of the study. As part of the Research Governance Framework it is important that the Trust is notified as to the outcome of your research and as such we will request feedback once the research has finished along with details of dissemination of your findings. We may also request brief updates of your progress from time to time, dependent on duration of the study. Similarly, if at anytime details relating to the research project or researcher change, the R&D department must be informed.

If you have any further questions regarding this or other research you may wish to undertake in the Trust please feel free to contact me again. The Trust wishes you success with your research.

Yours sincerely

A handwritten signature in cursive script, appearing to read "Clare O'Neill".

Clare O'Neill
 R&D Office – West Midlands South RM&G

cc Prof Scott Weich, R&D Clinical Lead - Coventry & Warwickshire Partnership Trust



University Hospitals Coventry and Warwickshire



NHS Trust

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Research & Development Department

Associate Medical Director (R&D): Professor Steve Thornton – Tel: 024 7696 6195

Personal Assistant: Karen MacKillop – Tel: 024 7696 6195

R&D Services Manager: Ceri Jones- Tel: 024 7696 6196

R&D Divisional Finance Manager: Chris Moore – Tel: 024 7696 6198

23rd April 2007

Our Ref: ST/KMK/JT04/0307

Dr Astri Ablitt
Trainee Clinical Psychologist
Department of Clinical Psychology
University of Coventry
Priory Street
Coventry
CV1 5FB

Dear Dr Ablitt,

Study Title: The Impact of Dementia on Family Relationships: Awareness of the Caregiver's Emotions.

Thank you for submitting the above study for registration and approval by the Research & Development Department. I am pleased to inform you that the study has been approved. For reference, the approval number is: JT04/0304. It would be appreciated if you could quote the reference in all future correspondence.

May I take this opportunity to remind you that, as a researcher, you must ensure that your research is conducted in a way that protects the dignity, rights, safety and well-being of participants. Trust R&D approval assumes that you have read and understood the Research Governance Framework and accept that your responsibilities as a researcher are to comply with it, the Data Protection and Health & Safety Acts.

Your project may be subject to ad hoc audit by our department to ensure these standards are being met.

The Trust wishes you every success with your project.

Yours sincerely,

Professor Steve Thornton
Associate Medical Director of R&D

Cc: Ceri Jones - R&D Services Manager, UHCW

COVENTRY UNIVERSITY ETHICS COMMITTEE (Form 1)

POSTGRADUATE STUDENT & STAFF APPLICATION FOR ETHICAL APPROVAL

Name	E-mail	
Astri Ablitt	[REDACTED]	
Designation / Subject & Faculty: Clinical Psychology, Faculty of Health and Life Sciences		
Title of Study: Relationships between People with Dementia and their Family: awareness of carers' emotions.		
1. Summary of proposal		
<p>Research on the quality of relationships between family members where one person cares for the other emphasises the importance of reciprocal emotional support. However where a person has dementia, cognitive impairment may limit their insight into their carer's emotional state, and therefore their ability to give emotional support. A greater understanding of this aspect of the impact of dementia on family caregivers will help those who provide support for carers.</p> <p>This study investigates whether there is evidence that people with dementia have insight into their carer's emotional state. It also considers whether or not there is a relationship between the person's insight into their own cognitive abilities and their insight into the carer's emotional state. A comparison group of older adults with rheumatism and/or arthritis who receive care from a family member will be used to give an indication of the level of insight in a familial caring relationship without dementia.</p>		
2. Sample of participants		
<p>The main participant group will be 25 people with a diagnosis of mild to moderate dementia and the family member who acts as their primary carer. The comparison group will be 25 people with a chronic physical disability and the family member who acts as their primary carer. There will therefore be 100 participants in total.</p>		
3. Site/s location		
<p>The dementia group will be recruited through the Bungalow Day Centre in Rugby, or the Psychiatric out-patient clinic at the Hospital of St Cross in Rugby. The comparison group will be recruited through the Rheumatism Department at the University Hospital in Coventry.</p>		
Tick / Cross. "Where answered 'NO', please give reasons on separate page.		
4. Scientific background, design, method and conduct of the study. (proposal)	Yes	No
a) Have you given a justification for the research? (COREC A-9)	✓	
b) Have you commented on the appropriateness of the design, the perceived benefits, risks and inconveniences to participants? (COREC)	✓	
5. Recruitment of participants.	Yes	No
Have you provided a comprehensive account of the characteristics of the population including the process for obtaining access as well as the inclusion and exclusion criteria? (proposal-participants section).	✓	
6. Care and protection of research participants and researcher.	Yes	No
Have you given an account of any interventions, situations and risks which have the potential to cause harm to the participants and researchers? (COREC)	✓	
7. Access, storage, security and protection of participants' confidentiality.	Yes	No
Have you identified who will have access to the data and what measures have been taken to ensure confidentiality and compliance with the Data Protection Act? (COREC)	✓	

8. Informed Consent. Have you given a full description of the process for requesting and obtaining informed consent? (COREC)		✓	
9. Community considerations. Have you considered how this study will benefit the participants or the community from which they have been drawn? (proposal - dissemination section).		✓	
10. Participant information Sheet and consent form. Are these attached?		✓	
11. Source of External Funding if any n/a			
Signature of student / staff <i>Aedin Abbott</i>	Address [REDACTED] [REDACTED] [REDACTED]	Date 10 th Dec 06.	
Signature of Supervisor <i>Sarah Kent</i>	Print Name <i>SARAH KENT</i> Internal Address <i>CLINICAL PSYCHOLOGY DOCTORATE</i>	Date 18/12/06.	
Signature of Chair <i>R.S. Crossman</i>	<input checked="" type="radio"/> Approved. <input type="radio"/> Approved with the conditions below:	Date 25/1/07	
Conditions / Comments:			

Please complete in full and return to: Research Manager, CU Ethics Committee, Richard Crossman RCG17, Coventry University.

This form should be accompanied by the full research study proposal, or the COREC form if applicable. Further help & information can be found on W / HLS / Student / Ethics or call Rhoda Morgan on 024 7679 5945, or e-mail

Awareness of Caregiver Distress in People with Dementia

Astri Ablitt^{1,2}, Gregory V. Jones² & Jane Muers³.

1. University of Coventry
2. University of Warwick
3. Coventry and Warwickshire Partnership Trust

Introduction

People who care for family members who have dementia often experience considerable levels of stress, anxiety and depression (Sorensen, Duberstein, Gill, & Pinquart, 2006). However relatively little is known about the extent to which carer distress impacts on the person with dementia.

Two possibilities may be distinguished. First, people with dementia may tend to be unaware that their carer is experiencing distress, because they do not remember conversations or incidents where their carers express their distress. Second, because there is evidence that emotionally significant material can be retained more effectively by people with dementia (Kazui, Mori, Hashimoto, Hirono, Imamura, et. al.2000), the alternative possibility is that such people may have a degree of awareness of their carers' levels of distress which is unrelated to their awareness of their own memory ability.

Research Questions

1. Are people with dementia aware of the emotional state of the family members who care for them?
2. Is awareness of the emotional state of the carer related to the person's awareness of their own memory difficulties?

Design

Participants were recruited in pairs made up of a person with dementia and the family member who cares for them.

The participants with dementia rated their own memory (self-assessment) and the emotional well-being of their carer (observer-assessment). The carers rated the memory of the person with dementia (observer-assessment) and their own emotional well-being (self-assessment).

Comparison of the ratings by the carers and by those cared for gave an indication of the level of awareness that the people with dementia had into their carers emotional well-being, and into their own memory difficulties.

Participants

Number of pairs	People with dementia		Carers		
	Age	Gender	Relationship	Gender	Living arrangements
18	66-89yrs	8 male 10 female	9 spouses 9 children	4 male 14 female	12 live together 6 visit & telephone multiple times a week

The participants with dementia had all been diagnosed more than six months previously. The diagnoses included: eight Alzheimer's disease, three vascular dementia, two mixed type dementia, and one fronto-temporal dementia.

All the participants were white. None had a history of brain damage or a recent psychiatric history.

Materials

The emotional well-being of the carers was measured using the Hospital Anxiety and Depression Scale (HADS) (Zigmond, & Snaith, 1983).

The memory ability of the people with dementia was measured using the Memory Function Scale (MFS) (Clare, Wilson, Carter, Roth, & Hodges, 2002).

Results

Awareness of emotional well-being.

The correlation between self-assessment HADS ratings given by the carer and observer-assessment HADS ratings given by the person with dementia approached significance.

Relationship between awareness of emotional state of the carer and awareness of memory difficulties.

In order to investigate this relationship discrepancy scores were calculated. The discrepancy score was the self-assessment rating minus the observer-assessment rating. The correlation between the HADS discrepancy scores and the MFS discrepancy scores was not significant.

	Participants	Pearson's correlation	Degrees of freedom	Significance
Dementia carers HADS – self ratings compared with observer ratings	n = 18	r = 0.396	df = 16	p = 0.052
Dementia MFS discrepancy scores compared with dementia carers HADS discrepancy scores	n = 17	r = 0.184	df = 15	p = 0.266

Summary of findings

Awareness of emotional well-being.

Correlations of the ratings of carer well-being given by the carer and those given by the person with dementia were non-significant. This suggests that people with dementia are not aware of the level of distress experienced by their carers. However a p value of 0.052 is approaching significance. This may reflect a weak effect caused by awareness in some of the participants. Additional data may clarify this point.

Relationship between awareness of emotional state of the carer and awareness of memory difficulties.

Comparison of the self /observer discrepancies in ratings of carer emotional well-being, and the self/observer discrepancies in ratings of the person's memory difficulties were not significant. This suggests that the level of awareness of carer distress is not necessarily related to level of awareness of memory difficulties.

Clinical Implications

The implications drawn at this stage must be tentative due to the incomplete data sets presented here. It appears that many people with dementia are not aware of the distress experienced by the family members who care for them. This would prevent the person with dementia from giving the carer emotional support. It is important for those working with carers to recognise that this loss of emotional acknowledgement and support in a long-standing close relationship is likely to increase the carers' sense of isolation and burden.

This research also raises the possibility that some people with dementia may have some awareness of distress in their carer. Furthermore, it appears that the level of awareness of distress is not necessarily related to the person's level of awareness of their own memory difficulties. In this case the carer's distress may also be causing distress for the person with dementia, especially as they may not understand why their family member is distressed.

References

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Acknowledgements

This research would not have been possible without the support of the people who have participated, and of Fiona Palmer of Rugby Mind. Thanks also to Dr Sarah Kent of the University of Warwick and Charlotte Carthy of Coventry and Warwickshire Partnership Trust for their input.

Astri.Robinson@warwick.ac

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Books for review should be sent to **Professor Murna Downs**, Bradford Dementia Group, School of Health Studies, University of Bradford, Bradford BD5 0BB, UK.

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

The first page should include the title of the paper, first name, middle initial(s) and last name of the author(s), and for each author a short institutional address, and an abbreviated title (for running headlines within the article). At the bottom of the page give the full name and address (including telephone and fax numbers and e-mail address if possible) of the author to whom all correspondence (including proofs) should be sent. The second page should repeat the title and contain **an abstract of not more than 250 words**. The third page should repeat the title as a heading to the main body of the text.

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

Key words: A list of 3-5 keywords should be provided. Words already used in the title should be avoided if possible

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

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

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