Concordance in psychological distress between people with dementia and caregivers

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

An individual’s distress has an impact on those around them. The focus of the thesis is on psychosocial factors associated with concordance in psychological distress between people with dementia and caregivers. This volume consists of three parts.

Part one presents a literature review on the current evidence for concordance in depression and anxiety symptoms between people with dementia and family caregivers. Despite symptoms being highly prevalent in both dyad members, no previous review has examined evidence for concordance in symptoms. Three longitudinal and 14 cross-sectional studies were examined. A consistent finding of concordance was observed across the longitudinal studies, whereas the cross-sectional studies produced inconsistent findings. Evidence of variables that may account for whether concordance exists is considered.

Part two presents an empirical paper on concordance in psychological distress between 132 people with dementia and their family caregivers, and the influence of psychosocial factors on this, over a one year period. Results showed a weak concordance in psychological distress was evident at one year but not at baseline. Psychosocial factors including caregivers’ perception of relationship quality and use of dysfunctional coping strategies, and not sociodemographic variables or cognitive or functional capacity in the person with dementia, were associated with concordance both cross-sectionally and longitudinally.

Part three presents a critical appraisal containing reflections on the issues that arose during the conceptualisation and implementation of the research. It considers the theoretical, ethical, practical and methodological issues of including people with dementia in research and taking a dyadic perspective to dementia research.

Acknowledgements

First of all I would like to thank Dr Georgina Charlesworth for her invaluable guidance, feedback and support throughout this research project. I would also like to thank Professor Nancy Pistrang for her helpful feedback at various stages of the project. Thanks also to Professor Martin Orrell and the members of the research teams at the various trial sites for warmly welcoming me into their teams and for their helpful advice. Finally, I would like to thank those who participated in the study. I admired their enthusiasm to take part in research to help build upon our understanding of dementia.

Part 1: Literature Review

Is there a concordance in psychological symptoms between people with dementia and caregivers?

Abstract

Objectives: Psychological symptoms are highly prevalent, and negatively impact upon wellbeing in both people with dementia and caregivers. Despite this, little is known about whether there is a concordance in psychological symptoms between members of this dyad. This review examined the current evidence for a concordance in depression and anxiety symptoms between people with dementia and their family caregivers.

Method: Studies were included if they examined the association in either depression or anxiety symptoms between the Person with Dementia (PwD) and family caregiver, using quantitative measures or diagnostic clinical interview.

Results: Three longitudinal studies and 14 cross-sectional studies were identified that met criteria. All three longitudinal studies found a positive association in symptoms of depression between the PwD and caregiver compared to five out of 14 cross-sectional studies. The one study in the review that examined symptoms of anxiety found no association. Variables that influenced whether a concordance in symptoms was observed included informant source for measures of depression in the PwD, cohabitation, symptom severity and sample size. However, conclusions were limited as only three studies in the review had an explicit aim of examining the association in psychological symptoms between dyad members.

Conclusions: Further research is needed which explicitly focuses on whether there is a concordance in psychological symptoms between people with dementia and their caregivers, including identifying which variables influence whether concordance occurs. This can enable interpersonal factors that contribute to and maintain psychological symptoms in dyad members to be identified and guide interventions.

Introduction

Despite the wealth of evidence reporting the negative impact of dementia on psychological symptoms in both the Person with Dementia (PwD) and caregiver, little is known about whether there is a concordance in psychological symptoms between both members of this dyad. Dementia is a syndrome leading to a progressive decline in higher cortical functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement (World Health Organisation, International Classification of Diseases-10, 2010). Alongside cognitive decline, behavioural and psychological symptoms are highly prevalent in people with dementia, in particular depression and anxiety (Aalten et al., 2007). Symptoms of depression and anxiety are not only experienced by the PwD, they are also highly prevalent in family caregivers (Cuijpers, 2005; Schulz, O'Brien, Bookwala & Fleissner, 1995; Sorensen, Duberstein, Gill & Pinquart, 2006). Taking a dyadic perspective and examining concordance in psychological symptoms amongst the care recipient/caregiver dyad can provide useful insights into interpersonal factors contributing to these symptoms, as well as identify potential targets for interventions.

Prevalence and impact of symptoms of depression and anxiety in people with dementia

Prevalence of depression in people with dementia is estimated to range from 15-20% for major depression and 30% for symptoms of depression (Alexopoulos & Abrams, 1991). The presence of depression in people with dementia negatively impacts upon quality of life (Hoe, Hancock, Livingston & Orrell, 2006) and is associated with functional impairment in activities of daily living (Pearson, Teri, Reifler & Raskind, 1989), increased mortality rates (Rovner et al., 1991) and increased risk of admission to nursing care placements (Haupt & Kurz, 1993).

Prevalence of anxiety in people with dementia is estimated to range from five to 21% for anxiety disorders and eight to 71% for anxiety symptoms (Seignourel, Kunik, Snow, Wilson & Stanley, 2008). As with depression, the presence of anxiety is associated with decreased quality of life (Hoe et al., 2006), functional impairment in activities of daily living (Porter et al., 2003; Teri et al., 1999), increased behavioural problems (Teri et al., 1999) and increased risk of admission to nursing care placements (Gibbons et al., 2002).

Prevalence and impact of symptoms of depression and anxiety on caregivers

The symptoms of depression and anxiety that can accompany dementia are not only experienced by the PwD, but have also been found to be highly prevalent in caregivers. Family caregivers provide the majority of care for people with dementia (Baumgarten, Battista, Infante-Rivard, Hanley, Becker, & Gauthier, 1992), with an estimated 670,000 family primary caregivers for people with dementia in the UK (Department of Health, 2009). Prevalence rates of depression in family caregivers range from 15-32% for major depression (Cuijpers, 2005) and 28-55% for symptoms of depression (Schulz et al., 1995). Prevalence rates of anxiety range from three to 16% for anxiety disorders and 15-77% for symptoms of anxiety (Cooper, Balamurali & Livingston, 2007). As with the PwD, the presence of psychological symptoms impacts upon wellbeing in the caregiver including being associated with physical morbidity (Schulz et al., 1995).

Interpersonal theories of depression and anxiety

Providing emotional support to a person in distress is a psychologically demanding task that impacts on the mood of the person offering support and influences their ability to continue to provide care (Barrowclough & Parle, 1997). Interpersonal theories of depression and anxiety emphasise that symptoms are best understood in terms of how they exist within the context of our interactions with other people in our environment, and the interpersonal functions they serve (Parkinson, 1996).

Coyne's (1976) interpersonal theory of depression contends that individuals with depression present with excessive social behaviours, such as self-criticism, designed to elicit reassurance from others in order to validate their worth and importance to others. However, the response of others does little to reassure the individual with depression in the long term and further reassurance is sought. At the same time as producing a sense of responsibility in others for reducing their distress, these behaviours also elicit negative responses such as impatience and rejection. These negative responses in turn exacerbate the depressed person's negative cognitions. Thus depression is maintained through social interaction with others.

There is empirical support for the premises of Coyne's theory (Gotlib & Hammen, 2008), particularly in regards to the role of reassurance seeking. Excessive reassurance seeking has been theorised to be the predominant behavioural means by which individuals with depression elicit a response of rejection from others (Joiner, Alfano & Metalsky, 1992). It has been found to be associated with symptoms and diagnosis, as well as predicting the onset, of depression (Davila. 2001; Joiner & Metalsky 2001; Starr & Davila 2008). Furthermore, individuals who present with excessive reassurance seeking have also been found to experience higher levels of interpersonal rejection from others (Starr & Davila 2008) and be in family environments displaying high levels of expressed emotion (Benezon, 2000), i.e. criticism and emotional over-involvement directed towards the individual (Vaughn & Leff, 1976).

Symptoms of anxiety have also been theorised to serve a function within a context of our interactions with other people in our environment, for example seeking comfort by gaining social support (Parkinson & Simons, 2012). A person may present with anxiety to provide social information to another that makes them aware that they perceive themselves as vulnerable. This expression of vulnerability may motivate others to support the individual to reduce their distress for example by providing reassurance. However, any reduction in distress by the provision of reassurance often results in a paradoxical effect of a long-term increase in anxiety. Reassurance provides only a temporary reduction in anxiety and prevents habituation to the experience of anxiety; therefore over time the frequency of reassurance seeking increases (Abramowitz, Schwartz, & Whiteside, 2002; Salkovskis & Warwick, 1986). Thus anxiety can be maintained through our interaction with others.

Concordance in psychological distress

In viewing emotions in a social context, psychological distress in dementia can be understood not just in terms of the distress experienced by each member independently but also in terms how distress in one member impacts on the distress experienced by the other. In the short-term distress in one member may impact on the emotional state of the other, in the long term it may result in similar psychological symptoms being experienced in both dyad members. Concordance in levels of psychological distress, as well as quality of life and well-being, between care recipients and caregivers is evident across a number of conditions (Meyler, Stimpson & Peek, 2007; Monin & Schulz, 2009).

The predominant theoretical explanation for concordance in psychological distress in chronic health conditions is emotion contagion theory (Meyler et al., 2007). Emotion contagion theory proposes that individuals converge emotionally, or ‘catch’, the intense emotional states of those with whom they are interacting (Hatfield, Cacioppo & Rapson, 1994). According to Hatfield et al.’s (1994) concept of ‘primitive emotion contagion’, during interpersonal interaction individuals have a natural tendency to synchronise with and mimic the expressions and postural changes of others. The individual’s perception of these mimicked non-verbal behaviours results in feedback that generates convergent emotional states and over time results in concordance in psychological symptoms.

In support of this theory, research has found that interaction with a depressed, genetically unrelated, individual induces depression (Joiner & Katz, 1999) and even subliminal exposure to facial expression stimuli elicits convergent emotional experiences (Dimberg, Thunberg & Elmehed, 2000; Doherty, 1997; Hatfield, Cacioppo, & Rapson, 1993). Emotion contagion has been proposed to be more likely to occur with others we feel similar to (Heider, 1958) and when facing the same situation (Gump & Kulik, 1997), factors particularly applicable to care recipient and family caregiver dyads.

Concordance in psychological distress has typically been examined in two primary ways: by examining correlation of health status between dyad members or examining whether the health status in one member impacts upon the same health status in the other (Meyler et al., 2007). Reviews examining concordance in psychological symptoms in chronic conditions (Meyler et al., 2007; Monin & Schulz, 2009) have provided little insight into whether a concordance is evident between people with dementia and caregivers. Only one study in the narrative review by Monin and Schulz (2009) addressed this question: Drinka, Smith and Drinka (1987) found a positive association in symptoms of depression between care recipients and caregivers in their sample, of which 73% of care recipients met diagnostic criteria for dementia. The present review aims to systematically identify research examining associations in symptoms of depression and/or anxiety between the PwD and their caregiver to establish the current evidence base for concordance in symptoms in this population.

Examining concordance in psychological symptoms can ascertain interpersonal factors that contribute to and maintain symptoms of depression and anxiety in dementia, and identify whether a dyad member is at risk of experiencing a decrease in psychological health when their partner experiences a decline in psychological health. This is particularly pertinent in a population which in the UK is estimated at over 800,000 and predicted to increase with the aging population (Luengo-Fernandez, Leal & Gray, 2010), and where experience of psychological distress is well documented. The need to support both the PwD and their caregiver is evident and has been identified in the guidelines for dementia by the National Institute for Clinical Excellence (NICE/SCIE, 2006).

Aims of the present literature review

The primary aim of the present literature review was to examine whether there is empirical support for a concordance in symptoms of depression and anxiety between people with dementia and their family caregivers. A secondary aim of the review was to examine evidence of variables that may impact upon findings of concordance.

Method

Search strategy

The literature was systematically searched to identify papers that included the study of the association between symptoms of depression and/or anxiety between people with dementia and their informal caregivers. The electronic databases PsycINFO and Medline were utilised to conduct the searches for papers published up to July 2013. The searches were limited to include only papers that were published in peer reviewed journals and in English. Additionally, a citation and reference lists search of relevant papers was conducted.

Search terms

Relevant thesaurus terms were identified in both PsycINFO and Medline to reflect three central domains relevant to the literature review question: the presence of dementia, the presence of depression and/or anxiety symptoms and a dyad involving an informal caregiver. The thesaurus terms used for both PsycInfo and Medline are displayed in Table 1.

Each term was exploded (indicated by “exp”) to include descriptors and narrower subject headings. Each term within each domain was combined by the function “or”. The three domains were then combined with the function “and” to produce the final search results.

Table 1: Thesaurus terms used in the literature search for PsycInfo and Medline databases

Domain	PsycINFO	Medline
Dementia	exp Dementia Or exp Cognitive impairment	exp Delirium, Dementia, Amnestic, Cognitive Disorders Or exp Dementia
Depression and/or anxiety symptoms	exp Emotional States Or exp Anxiety Disorders Or exp Major Depression Or exp Atypical Depression Or exp Caregiver Burden Or exp Health Or exp Well Being Or exp Quality of Life	exp Anxiety Or exp Anxiety Disorders Or exp Depression Or exp Affect Or exp Mental Health Or exp Health
Dyad	exp Dyads Or exp Couples Or exp Interpersonal Interaction Or exp Interpersonal Relationships Or exp Significant Others Or exp Family Or exp Family Members Or exp Caregivers Or exp Elder Care Or exp Filial Responsibility Or exp Home Care Or exp Home Care Personnel Or exp Respite Care Or exp Homebound Or exp Contagion Or exp Family Therapy Or exp Family Systems Theory Or exp Couples Therapy	exp Interpersonal Relations Or exp Family Or exp Caregivers Or exp Family Therapy Or exp Systems Theory Or exp Adaptation, Psychological

Inclusion and exclusion criteria

Papers were included in the review if they met the following criteria: (i) The care recipient had a diagnosis of dementia. This could be any type of dementia diagnosis including Alzheimer’s disease, vascular dementia and frontal temporal dementia. (ii) The caregiver was an adult (aged 18 or over) family caregiver including relatives, partners, or close kin to the individual they provided care for. This could include spouses, adult children, parents, siblings, extended family members or close friends. Studies that only reported findings for paid caregivers were excluded.

(iii) The presence of depression and/or anxiety was diagnosed via a clinical interview or measured using a quantitative, standardised and validated measure. These measures could be either self-report or proxy measures.

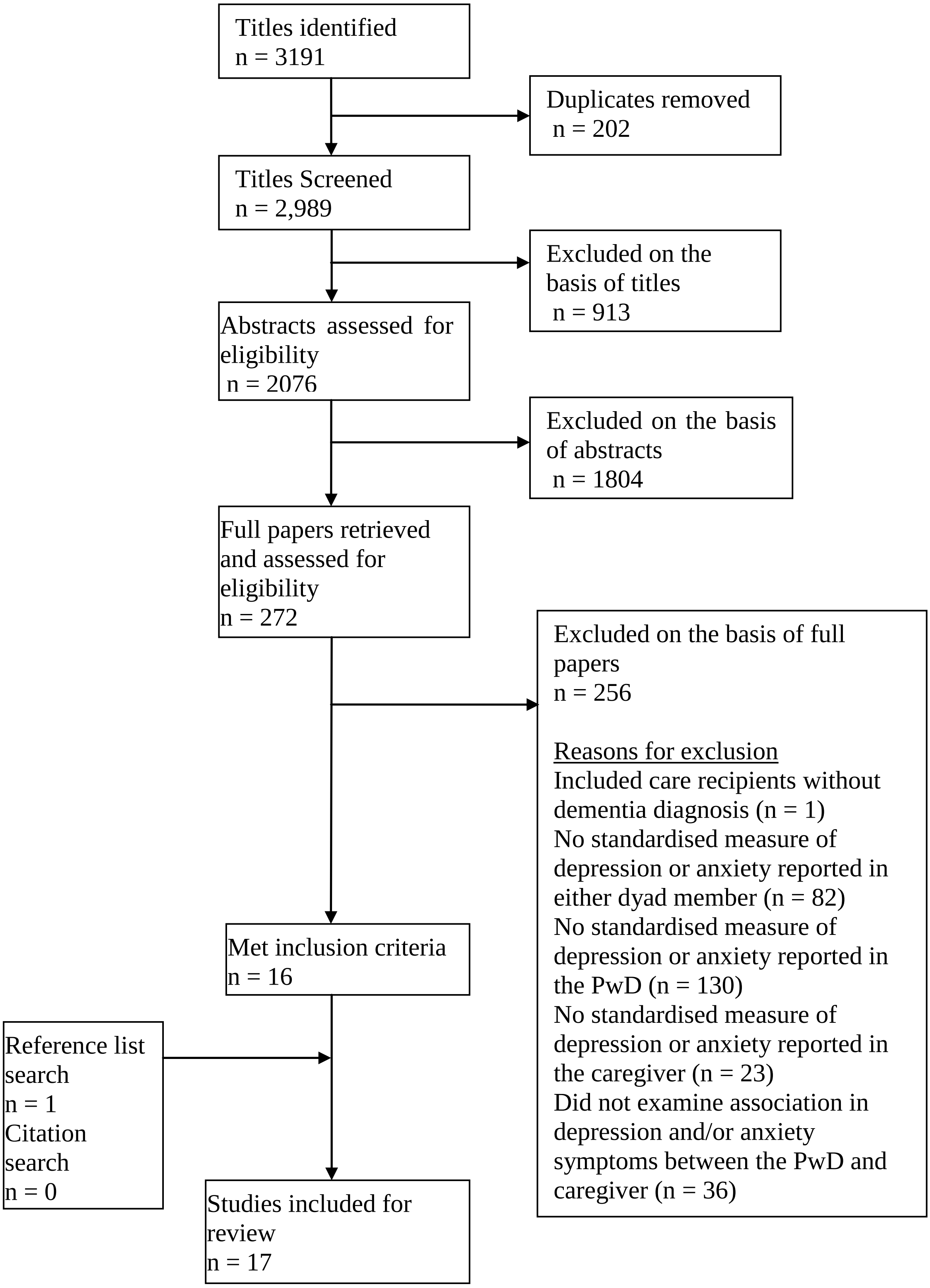
(iv) The study examined the association in symptoms of depression and/or anxiety between the PwD and caregiver. Studies were excluded if they only reported measures of depression and/or anxiety in one member of the dyad, or if they reported measures in both members of the dyad but did not examine whether these measures were associated.

Study selection

Figure 1 presents the process of study selection. Titles were screened and abstracts retrieved for those titles that appeared relevant. Abstracts were examined against the inclusion and exclusion criteria and full papers retrieved for studies that potentially met criteria. Full papers were then read to examine whether they met the inclusion criteria. Reasons for exclusion at this stage were samples including care recipients without a dementia diagnosis, no standardised measure of depression or anxiety reported in the PwD, caregiver or both, and no examination of association in depression and/or anxiety symptoms between the PwD and caregiver.

Studies in which there was uncertainty over whether inclusion criteria were met were discussed with a second researcher. For example, Braekhus, Oksengard, Engedal and Laake (1999) used the Caregiver Stress Scale (CSS; Greene, Smith, Gardiner & Timbury, 1982) as an outcome measure in caregivers and found that factor analysis of the CSS produced a two factor solution, one of which they labelled “depressive stress”. It was decided that as this was not a validated measure of depression; therefore this study was excluded. Ott and Fogel

Figure 1: Study selection flowchart



(1992) in their study examining the measurement of depression in people with dementia, included individuals who were classified as having amnesic disorder secondary to depression. It was decided to exclude this study on the basis that not all care recipients had a diagnosis of dementia.

Appraisal of studies

Critical appraisal tools provide an analytical framework for the evaluation of the quality and utility of research (National Health and Medical Research Council, 2000). There is no 'gold standard' critical appraisal tool (Katrak, Bialocerkowski, Massy-Westropp, Kumar, & Grimmer, 2004) and selection is based on the methodology utilised by studies. Kmet, Lee and Cook (2004) developed standard quality assessment criteria which can be utilised to simultaneously evaluate the quality of research using diverse study designs. They defined quality as the extent to which studies demonstrate internal validity.

Given the diversity of methodologies utilised in the studies in the review which includes randomised control studies, cross-sectional studies, longitudinal studies and studies examining the effects of an intervention, the framework developed by Kmet et al. (2004) appeared to be the most applicable critical appraisal tool. Quantitative studies are assessed as meeting (assigned a score of two), partially meeting (assigned a score of one) or not meeting (assigned a score of zero) 14 checklist items (see Appendix I). The 14 checklist items predominantly focus on study design and analytic factors that contribute to the internal validity. An overall score is calculated by dividing the obtained scores by the total possible score across the 14 items, yielding an overall score that can range from zero to one. The criteria include assessing whether sample size was appropriate for the type of analysis used. Guidance from Cohen (1992) was used to determine whether sample sizes were appropriate. The criteria has been found to demonstrate good inter-rater reliability with by-item agreement ranging from 73% to 100% (Kmet et al., 2004).

Results

Overview

To address the aims of the review, the results section firstly describes the key characteristics of the studies included in the review. It then examines the association between symptoms of depression in the PwD and their caregiver, firstly across cross-sectional studies followed by longitudinal studies. Potential variables influencing findings are then explored including informant source used to measure symptoms in the PwD, whether dyads cohabit, severity of symptoms of depression, sample size of studies and quality of studies. The results section ends with a description of the one study that examined the association in anxiety symptoms between the PwD and their caregiver.

Of the 17 studies included in the review, 15 were independent studies and two reported findings from the same sample (Roth et al., 2003; Schulz et al., 2008). The studies are summarised in Table 2. All 17 studies examined the association in depression symptoms between the PwD and the caregiver. Only one study (Mahoney, Regan, Katona & Livingston, 2005) examined the association in anxiety symptoms.

Key characteristics of studies

Aims of included studies

Only three studies in the present review explicitly included the aim to examine the association in symptoms of depression between the PwD and caregiver (Cummings, Ross, Absher, Gornbein & Hadjiaghai, 1995; Neundorfer et al., 2001; Schulz et al., 2008). None of the studies had an explicit aim of examining the association in symptoms of anxiety. The aim of the majority of studies, 15 studies, was to examine variables influencing care recipient or caregiver outcomes; these included depression, anxiety, burden and quality of life. Of the two remaining studies, one study aimed to compare different caregiver measures in predicting

Table 2: Studies included in the review

Authors	**Study design and number of dyads**	**PwD characteristics**	**PwD depression measure**	**Caregiver characteristics**	**Caregiver depression measure**	**Association in depression between dyad members**
Berger et al. (2005)	Cross-sectional, 45 dyads	AD 72%, VD 9%, FTD 9%, other dementia 10%. Cohabiting 76%	BEHAVE-AD Affective disturbances scale	Spouse 69%, child 27%, other family caregiver 4%	GDS-15, BDI	No significant association
Cummings et al. (1995)	Cross-sectional, 33 dyads	AD. Cohabiting not reported	HDRS	Full-time family caregivers.	BDI	No significant association
Fuh et al. (1999)	Cross-sectional, 74 dyads	AD. Cohabiting 89%	RMBPC	Spouse 46%, child 43%, other family caregivers 11%	GDS-S	No significant association
Harwood et al. (1998).	Cross-sectional, 653 dyads	AD. Cohabiting not reported	Diagnostic clinical interview	Spouse 55%, child 46%	CES-D	No significant association
Mahoney et al. (2005)	Cross-sectional, 153 dyads	AD, Cohabiting 49%	CSDD, NPI	Spouses 44%, child 51%, other 11%	HADS	No significant association
Mohamed et al. (2010)	Longitudinal, 421 dyads	AD with psychosis or agitated aggressive behaviour. Cohabiting not reported	CSDD	Spouses 39%, child 26%, other family caregiver 35%	BDI	Significant positive association. Small effect size
Neundorfer et al. (2001)	Longitudinal study, 353 dyads	AD 94%, Other dementia 6%. Cohabiting 87%	BRSD Depressive subscale	Spouse 71%, Child 23%, other relatives 6%	CES-D .	Significant positive association , small effect size

Papastavrou et al. (2007)	Cross-sectional, 172 dyads	AD. Cohabiting not reported	MBPC	Spouse 41%, child 54%, other family caregiver 4%	CES-D	Significant positive association, small effect size
Rankin et al. (2001)	Cross-sectional, 96 dyads	AD 73%, VD 16%, other dementia 11%. Cohabiting not reported	GDS-S	Family caregivers, spouses 85%	CES-D	No significant association
Rosenberg et al. (2005)	Cross-sectional, 44 dyads	AD and major depressive disorder. Cohabiting not reported	CSDD, HDRS.	Spouses 32%, child 48%.	BDI	No significant association
Roth et al. (2003)	Cross-sectional, 1229 dyads	AD or related dementia. Cohabiting not reported	RMBPC	Spouses 48%, child 44%, other family caregiver 8%.	CES-D	Significant positive association, small effect size
Schulz et al. (2008)	Longitudinal, 1222 dyads	AD or related dementia. Cohabiting 100%	RMBPC	Spouse 48%, other family caregiver 52%	CES-D	Significant positive association
Shua-Haim et al. (2001)	Cross-sectional study, 77 dyads	AD. Cohabiting not reported	GDS-S	Spouse 49%, child 43%, other family caregiver 8%	GDS-S	Significant positive association
Teri & Truax (1994)	Cross-sectional, 41 dyads	Primary degenerative dementias. Cohabiting not reported	HDRS, CESD	Spouses 92%, child 7%	HDRS, CESD	Significant positive association, medium effect size
Thomas et al. (2006)	Cross-sectional, 100 dyads	AD 84%, other dementia 16%. Cohabiting 100%	CSDD	Spouse 50%, child 36%, other relative 13%	Mini-GDS	Significant positive association
Victoroff et al. (1997)	Cross-sectional, 35 dyads	AD 89%, other dementia 11%. Cohabiting 100%	CSDD	Not reported	Zung	No significant association

Waite et al. (2004)	Cross-sectional, 72 dyads	Dementia. Cohabiting 64%.	CSDD	Spouse 46%, Child 32%, other family caregiver 3%	GDS-15	Overall, no significant association

Diagnosis: AD (Alzheimer’s Disease), FTD (Frontal Temporal Dementia), VD (Vascular Dementia).

Measures: BDI (Beck Depression Inventory; Beck, Ward, Mendelson, Mock & Erbaugh, 1961), BEHAVE-AD (Behavioural Abnormalities in Alzheimer’s Disease; Reisberg, Auer & Monteiro, 1996), BRSD (Behaviour Rating Scale for Dementia; Mack & Patterson, 1996), CES-D (Centre for Epidemiological Studies- Depression Scale; Radloff, 1977), CSDD (Cornell Scale of Depression in Dementia; Alexopoulos, Abrams, Young & Shamoian, 1988), GDS-15 (Geriatric Depression Scale-15 item; Yesavage et al., 1983), GDS-S (Geriatric Depression Scale-Short Form; Yesavage & Sheikh, 1986), HADS (Hospital Anxiety and Depression Scale; Zigmond & Snaith, 1983), HDRS (Hamilton Depression Rating Scale, Hamilton, 1960), MBPC (Memory and Behaviour Problem Checklist; Zarit, Anthony, & Boutselis, 1990), Mini-GDS (Mini-Geriatric Depression Scale; Clement, Peugnet, Preux & Leger, 2000), NPI (NeuroPsychiatric Inventory; Cummings, Mega, Gray, Rosenberg-Thompson, Carusi & Gornbein, 1994), RMBPC (Revised Memory Behaviour Problem Checklist; Teri, Truax, Logsdon, Uamoto, Zarit & Vitaliano, 1992), Zung self-rated depression scale (Zung; Zung, 1965).

depression in the PwD (Rosenberg, Mielke & Lyketsos, 2005) and one study aimed to conduct a psychometric evaluation of Revised Memory Behaviour Problem Checklist (Roth et al., 2003).

Settings and design

Studies were published between 1992 and 2008, and the majority were conducted in the USA. Only six were conducted outside the USA, with two in the UK (Mahoney et al., 2005; Waite, Bebbington, Skelton-Robinson & Orrell, 2004), one in Germany (Berger, Bernhardt, Weimer, Peters, Kratzsch & Frolich, 2005), one in Taiwan (Fuh, Wang, Liu, Liu & Wang, 1999), one in Cyprus (Papastavrou, Kalokerinou, Papacostas, Tsangari & Sourtzi, 2007) and one in France (Thomas et al., 2006). Studies were mainly cross-sectional in nature with 12 utilising this design. Five studies used a longitudinal design (Berger et al., 2005; Mohamed, Rosenbeck, Lyketsos & Schneider, 2010; Neundorfer et al., 2001; Rosenberg et al., 2005; Schulz et al., 2008), but the analysis of the association in depression symptoms between the PwD and caregiver used in two of these studies (Berger et al., 2005, Rosenberg et al., 2005) were cross-sectional. Therefore for the purposes of this review both these studies will be categorised as cross-sectional studies.

Samples

Sample sizes ranged from 33 to 1229 dyads. Alzheimer’s disease was the most prevalent diagnosis of dementia in all studies. In addition to a diagnosis of dementia, Mohamed et al. (2010) included care recipients who also presented with psychosis or agitated aggressive behaviour, and Rosenberg et al. (2005) included care recipients who also had a diagnosis of major depressive disorder. Means for age for the PwD ranged from 70 to 81, and for caregivers ranged from 54 to 66.

Measures

Eight different measures were used across studies to assess symptoms of depression in the PwD. These included standardised measures of depression, broadband measures of behavioural and psychological symptoms in dementia, and clinical interviews. Different measures relied on different informants, including the PwD, the caregiver and clinicians. More consistency was observed in measures of caregiver depression; all studies utilised at least one self-rated measure of depression, of which the Centre for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977) appeared most frequently. Only one study, Teri and Truax (1994), used the same measure of depression for both the PwD and the caregiver.

Quality appraisal of included studies

Ratings of the studies using the Kmet et al. (2004) appraisal tool ranged from 0.75 to 0.95 (see Table 3). Areas of strength across the studies included the use of operationally defined measures of outcome variables, detailed discussion of analytical methods and results, and conclusions that had clear links to the study results (criteria 8, 10, 13, 14). Areas where studies received lower scores included using a sampling technique that had potential to result in a biased sample, participant characteristics not sufficiently described, inappropriate sample sizes and no estimates of variance provided (criteria 3, 4, 9, 11).

Association in symptoms of depression between the PwD and caregiver

To explore the association in symptoms of depression between the PwD and caregiver, the prevalence and severity of depression symptoms in people with dementia and caregivers will firstly be examined separately. This is followed by a discussion of findings of the association in depression symptoms across cross-sectional studies, followed by longitudinal studies.

Table 3: Quality appraisal scores of studies included in the review

	Berger et al. (2005)	Cummings et al. (1995)	Fuh et al. (1999)	Harwood et al. (1998)	Mahoney et al. (2005)	Mohammed et al. (2010)	Neundorfer et al. (2001)	Papastavrou et al. (2007)	Rankin et al. (2001)	Rosenberg et al. (2005)	Roth et al. (2003)	Schulz et al. (2008)	Schua-Haim et al. (2001)	Teri & Truax (2004)	Thomas et al. (2006)	Victoroff et al. (1997)	Waite et al. (2004)
1. Question/objective sufficiently described?	2	2	1	2	2	2	2	2	2	2	2	2	1	2	2	1	2
2. Study design evident and appropriate?	2	1	1	1	2	2	2	2	2	2	2	2	2	2	2	1	2
3. Method of subject/comparison group selection or source of information/input variables described and appropriate?	2	2	1	1	2	2	1	1	1	1	2	2	1	1	2	2	1
4. Subject (and comparison group if applicable) charachteristics sufficiently described?	2	1	2	1	1	1	2	1	1	1	1	1	1	1	1	1	1
5. If interventional and random allocation was possible, was it described?	n/a	n/a	n/a	n/a	n/a	1	n/a	n/a	n/a	1	2	2	n/a	n/a	n/a	n/a	n/a
6. If interventional and blinding of investigators was possible, was it reported?	n/a	n/a	n/a	n/a	n/a	2	n/a	n/a	n/a	0	2	2	n/a	n/a	n/a	n/a	n/a
7. If interventional and blinding of subjects was possible, was it reported?	n/a	n/a	n/a	n/a	n/a	2	n/a	n/a	n/a	2	n/a	n/a	n/a	n/a	n/a	n/a	n/a
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias? Means of assessment reported?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
9. Sample size appropriate?	1	1	1	2	2	2	2	2	1	0	2	2	1	1	1	1	1
10. Analytic methods described/justified and appropriate?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	1	2	2
11. Some estimate of variance is reported for the main results?	1	1	1	2	2	2	2	0	2	2	1	2	2	2	2	2	0
12. Controlled for confounding?	n/a	n/a	n/a	n/a	n/a	2	n/a	n/a	n/a	2	2	2	n/a	n/a	n/a	n/a	n/a
13. Results reported in sufficient detail?	2	2	2	2	2	2	2	2	2	2	2	1	1	2	2	2	2
14. Conclusions supported by the results?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
Total	0.90	0.80	0.75	0.85	0.95	0.93	0.95	0.80	0.85	0.75	0.93	0.93	0.70	0.85	0.85	0.80	0.75

Prevalence and severity of symptoms of depression in people with dementia and caregivers

Prevalence of depression symptoms in people with dementia were reported in six studies (Berger et al., 2005; Cummings et al., 1995; Shua-Haim, Haim, Shi, Kuo & Smith, 2001; Teri & Truax, 1994; Thomas et al., 2006, Waite et al., 2004) and ranged from 15-68%. Prevalence of major depression disorder was reported in two studies and ranged from six to 21% (Cummings et al., 1995; Harwood, Barker, Cantillon, Loewenstein, Ownby & Duara, 1998). Five studies reported means on measures with an established cut-off score for symptoms depression (Cummings et al., 1995; Mohamed et al., 2010; Rankin, Haut & Keefover, 2001; Rosenberg et al., 2005; Teri & Truax, 1994). Three out of the five found a mean score above the established cut-off score (Mohamed et al., 2010; Rosenberg et al., 2005; Teri & Truax, 1994). However one of these studies (Rosenberg et al., 2005) used a sample of individuals with Alzheimer's disease and major depressive disorder, therefore a mean score for depression above cut-off would be expected.

Prevalence of depression symptoms in caregivers were reported in 10 studies (Berger et al., 2005; Cummings et al., 1995; Fuh et al., 1999; Harwood et al., 1998; Mahoney et al., 2005; Neundorfer et al., 2001; Papastavrou et al., 2007; Rankin et al., 2001; Shua-Haim et al., 2001; Waite et al., 2004) and ranged from 10-51%. Only one study, Papastavrou et al. (2007), from 10 which reported means (Cummings et al., 1995; Fuh et al., 1999; Mahoney et al., 2005; Mohamed et al., 2010; Neundorfer et al., 2001; Papastavrou et al., 2007; Rosenberg et al., 2005; Schulz et al., 2008; Teri & Truax, 1994; Waite et al., 2004) found a mean score above the established cut-off for depression.

Association in depression symptoms across cross-sectional studies

The 14 cross-sectional studies used different statistical procedures to explore the association between symptoms of depression in the PwD and caregiver including bivariate correlations, regression analysis and chi-square statistics. These will be discussed in turn.

Seven cross-sectional studies examined bivariate correlations between measures of depression in the PwD and caregiver. Three of these reported significant positive correlations (Papastavrou et al., 2007; Roth et al., 2003; Teri & Truax, 1994), with r values ranging from 0.19 to 0.62, a small to medium effect size. The four remaining studies found no significant correlation (Berger et al., 2005; Cummings et al., 1995; Fuh et al., 1999; Rankin et al., 2001).

Of the five cross-sectional studies using regression analysis (Harwood, Barker, Cantillon, Loewenstein, Ownby, & Duara, 1998; Mahoney et al., 2005; Rosenberg et al., 2005; Shua-Haim et al., 2001; Victoroff, Mack & Nielson, 1997), only one found that depression scores in the PwD were a significant predictor of depression in the caregiver (Shua-Haim et al., 2001). Shua-Haim and colleagues (2001) found that for caregivers of people with dementia with symptoms of depression, the odds of them experiencing symptoms of depression themselves was nearly three times higher compared to caregivers who supported a PwD who did not experience symptoms of depression. This analysis included adjusting for functional level and hallucination status of the PwD.

Two cross-sectional studies examined whether depression in the PwD was associated with depression in the caregiver using a chi-square analysis (Thomas et al., 2006; Waite et al., 2004). One study found an association in depression symptoms between the PwD and caregiver (Thomas et al., 2006), whilst the remaining study found no association (Waite et al., 2004).

Longitudinal Studies

All three studies that explored the association in depression symptoms longitudinally (Mohamed et al., 2010; Neundorfer et al., 2001; Schulz et al., 2008) found a positive association in depression symptoms between dyad members at baseline. All three also found that increases in depression symptoms experienced by the person with dementia over time were associated with increases in depression symptoms experienced by the caregiver.

Mohamed et al. (2010) found a significant correlation in PwD scores on the Cornell Scale of Depression in Dementia (CSDD, Alexopoulos, Abrams, Young & Shamoian, 1988) and caregiver scores on the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock & Erbaugh, 1961) at baseline (r= 0.26, p= <.001) and in change in scores when comparing baseline scores to six month follow-up scores (r =0.18, p = <.001).

Neundorfer et al. (2001) gathered data at a variable number of data collection points with variable time intervals. The mean time interval from first observation to last observation was one year for the caregiver and two years for the PwD. A significant positive correlation was found at baseline for depression symptoms between dyad members (r= 0.16, p= <.01). Multilevel analysis also found a significant positive association for the rate of increase in symptoms, but not for acceleration of symptoms.

Schulz et al. (2008) conducted a factor analysis of the depression subscale of the Revised Memory Behaviour Problem Checklist (RMBPC; Teri, Truax, Logsdon, Uamoto, Zarit & Vitaliano, 1992) and found a two factor solution: emotional distress and existential distress. Higher scores on both factors for the PwD were found to significantly predict higher caregiver scores on the CES-D at baseline, after controlling for sociodemographic characteristics, physical and cognitive disability in the PwD, and time spent caregiving (emotional distress: β= 1.24, p= <.001; existential distress: β= 0.66, p= .008). Increases in both emotional distress and existential distress experienced by the PwD from baseline to six month follow-up assessment were associated with increases in caregiver depression (emotional distress: β= 1.02, p= <.01; existential distress: β= 0.64, p= <.01).

Summary

There is a consistent finding across the three longitudinal studies that increases in depression symptoms experienced by the PwD over time are associated with increases in caregiver depression, indicating a concordance in depression symptoms. However, less consistency was found across the 14 cross-sectional studies with five finding a positive association and nine finding no association, giving a less clear picture about whether a concordance in depression symptoms is present.

To help try and understand the inconsistent findings, factors that may impact upon the findings of the association in depression symptoms between people with dementia and caregivers will be examined. These factors include the type of informant used for the measure of depression for the PwD, whether dyads cohabit, severity of depression symptoms, sample size and study quality.

Types of informant

Clinician rated measures

Across both cross-sectional and longitudinal studies, 10 (Berger et al., 2005; Cummings et al., 1995; Harwood et al., 1998; Mahoney et al., 2005; Mohamed et al., 2010; Rosenberg et al., 2005; Teri & Truax, 1994, Thomas et al., 2006; Victoroff et al., 1997; Waite et al., 2004) used a measure of depression for the PwD that incorporated a clinician rating. Measures included the CSDD, the Hamilton Depression Rating Scale (HDRS; Hamilton, 1960), the Behavioural Abnormalities in Alzheimer's disease (BEHAVE-AD; Reisberg et al., 1999) and clinical interviews assessing for a diagnosis of depression according to DSM criteria. The most frequently used measure was the CSDD, utilised in six studies.

A significant association in symptoms of depression between the PwD and caregiver was found in three of the 10 studies (Mohamed et al., 2010; Teri & Truax, 1994; Thomas et al., 2006). Mohamed et al. (2010) and Thomas et al. (2006) both found a significant association using the CSDD and self-report measures of depression in caregivers. Mohamed and colleagues (2010) found a significant positive correlation in depression symptoms between the PwD and caregiver, with caregiver depression being measured by the BDI ($r= 0.26$, $p= <.001$). Thomas et al. (2006) found that depression symptoms experienced by caregivers, as measured by the mini-GDS, was associated with providing care to a PwD with depression symptoms: 36 out of 51 caregivers with depression symptoms provided care to a PwD with depression symptoms. Teri and Truax (1994) measured symptoms of depression experienced by the PwD and caregiver with the HDRS, and found a significant positive correlation between the two measures ($r = 0.34$, $p < 0.05$).

Caregiver proxy-rated measures

Across both cross-sectional and longitudinal studies, six used a measure of depression in the PwD that were based on caregiver ratings (Fuh et al., 1999; Neundorfer et al., 2001; Papastavrou et al., 2007; Roth et al., 2003; Schulz et al., 2008; Teri & Truax 1994). These measures included versions of the MBPC, the BRSD and the CES-D. The most frequently used was the MBPC (in various versions), utilised in four studies. All six studies utilised caregiver self-report measures to assess depression symptoms in caregivers.

A significant positive association in symptoms of depression between the PwD and caregiver was found in five of the six studies. Four of these studies (Neundorfer et al., 2001; Papastavrou et al., 2007; Roth et al., 2003; Teri & Truax, 1994) used correlation analysis finding r values ranging from 0.16 to 0.62, a small to medium effect size. The remaining study (Schulz et al, 2008) found both emotional and existential distress (derived from the depression scale of the RMBPC) were significant predictors of symptoms of depression in caregivers using a regression analysis.

Self-rated measures of depression

Across both cross-sectional and longitudinal studies, only two studies used a self-rated measure of depression in the PwD. Both used versions of the Geriatric Depression Scale (GDS; Yesavage et al., 1983) to measure depression symptoms in the PwD and self-report measures in caregivers. Shua-Haim et al. (2001) found a significant association between depression symptoms in the dyad. Caregivers of a PwD with depression symptoms were nearly three times more likely to experience symptoms themselves compared to those who took care of a PwD without depression symptoms. In comparison, Rankin et al. (2001) found no significant correlation between self-rated scores in the PwD and caregiver self-reported CES-D scores.

Summary

It appears that studies that use caregiver proxy ratings of PwD depression symptoms are more likely to find a significant association in depression symptoms. Five out six studies using caregivers as informants found a significant association compared to three out of 10 studies that used measures involving clinician ratings and one out of two studies which used self-report measures. Therefore informant source may explain some of the inconsistency in findings of the association in symptoms observed across cross-sectional studies. In regards to the consistency in the finding of a positive association in depression symptoms across longitudinal studies, two of the three longitudinal studies used a carer rated proxy measure of depression in the PwD (Neundorfer et al., 2001; Schulz et al., 2008). This may have contributed to the finding of a significant association in these two longitudinal studies. The remaining longitudinal study (Mohamed et al., 2010) used a clinician rating.

Cohabitation

Waite and colleagues (2004) found that cohabiting dyads were more likely to both have depression than in the overall sample. Across both cross-sectional and longitudinal studies, seven other studies reported the number of dyads who cohabited, two of which included samples containing only cohabitees. Of the two samples of cohabitees, Thomas et al. (2006) found a significant positive association between depression in the PwD and caregiver, in contrast Victoroff et al. (1997) found no such association.

Summary

There appears to be limited evidence to suggest that a significant association is more likely in dyads that cohabit. This variable may therefore explain some of the inconsistencies observed in the findings of association in symptoms across cross-sectional studies. Two out of the three longitudinal studies, reported the number of dyads cohabiting. Both Neundorfer et al. (2001) and Schulz et al. (2008) used samples that consisted of a high percentage of dyads cohabiting, 87% and 100% respectively. This therefore may be a potential factor why both these studies found positive associations in symptoms. However, the conclusions that can be drawn about the impact of cohabitation are limited as only eight studies included in the review reported the number of dyads who cohabited.

Severity of depression symptoms

Across both cross-sectional and longitudinal studies, five reported mean scores for measures of depression in the PwD which have established cut-off scores for depression. Three of the five studies found that the mean scores were above cut-off criteria (Mohamed et al., 2010; Rosenberg et al., 2005; Teri & Truax, 1994). Whilst both Mohamed et al. (2010) and Teri and Truax (1994) found a significant association in depression symptoms, Rosenberg et al. (2005) found no significant association. The remaining two studies reported means that were below cut-off criteria for depression in the PwD (Cummings et al., 1995; Rankin et al., 2001); both found no significant correlation in depression scores between dyad members.

Summary

There appears to be limited evidence to suggest that concordance is more likely when symptoms of depression are more severe in the PwD. This variable may therefore explain some of the inconsistencies observed in findings of association in symptoms across cross-sectional studies. Only one out of the three longitudinal studies used a measure of depression in the PwD with an established cut-off; Mohamed et al. (2010) reported a mean for depression, as measured by the CSDD, above cut-off. The severity of symptoms in this sample may be one contributing factor to the positive association in symptoms observed.

Sample size

Across both cross-sectional and longitudinal studies, five had sample sizes of less than 50 dyads (Berger et al., 2005; Cummings et al., 1995; Rosenberg et al., 2005; Teri & Truax, 1994; Victoroff et al., 1997), only one of which (Teri & Truax, 1994) found a positive association in symptoms of depression. Eight studies had sample sizes of 100 or more dyads, six of which found positive associations in symptoms of depression (Mohamed et al., 2010; Neundorfer et al., 2001; Papastavrou et al., 2007; Roth et al., 2003; Schulz et al., 2008; Thomas et al., 2006). Studies with small sample sizes may be underpowered to detect a significant finding and may represent a type II error. However, although six of eight studies with sample sizes over 100 found significant associations, it is noteworthy for those that reported r values that only small effects were observed.

Summary

It appears that studies with smaller samples are less likely to find an association in symptoms of depression between the PwD and caregiver, with five out of six studies with sample sizes of less than 50 dyads finding no association. Differences in sample size may therefore explain some of the inconsistencies observed across cross-sectional studies. It may also explain why there was more consistency in the finding of a positive association across the three longitudinal studies as all three had large sample sizes, ranging from 353 to 1222 dyads.

Quality of studies

Longitudinal studies were generally appraised to be of a higher quality compared to cross-sectional studies, with quality ratings ranging from 0.93-0.95 compared to 0.75-0.95 for cross-sectional studies. Therefore longitudinal studies included in the review generally had higher levels of internal validity, increasing the power of these studies.

Summary

Longitudinal studies were appraised to be of a higher quality compared to cross-sectional studies. Therefore the consistency in the finding of a positive association across longitudinal studies may be contributable to these studies having greater power due to both larger sample sizes and higher internal validity.

Summary of findings for the association of depression symptoms

A consistent finding of a positive association in symptoms of depression between the PwD and caregiver was found across the three longitudinal studies included in the review. Less consistency was found across the 14 cross-sectional studies included in the review with five finding a positive association and nine finding no overall association. A number of variables were examined to try to understand the inconsistency in results observed in the cross-sectional studies and the consistent result in longitudinal studies. Key findings relating to these variables are summarised in Table 4.

Association in anxiety symptoms between people with dementia and caregivers

Only one study examined the association between anxiety symptoms in the PwD and caregiver (Mahoney et al., 2005). Mahoney et al. (2005) measured anxiety in the PwD using the NeuroPsychiatric Inventory (NPI; Cummings, Mega, Gray, Rosenberg-Thompson, Carusi & Gornbein, 1994) and in caregivers using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) cross-sectionally, in a sample consisting of 49 percent of dyads who were cohabiting. The NPI is a caregiver rated measure and the HADS is a self-report measure. Using regression analysis they found that anxiety in the PwD was not a significant predictor of anxiety in the caregiver. Other variables included in the regression

Table 4: Variables impacting the findings of an association in symptoms of depression

Variable	Key Finding
Informant source for measure of depression in the PwD	Studies using caregivers as informants are more likely to find a significant association. Five out six studies using caregivers as informants found a significant association compared to three out of 10 studies using clinician ratings, and one out of two studies who used self-report measures.
Cohabitation	There is limited evidence to suggest that a significant association is more likely in dyads that cohabit.
Severity of depression symptoms	There is limited evidence to suggest that an association is more likely when symptoms of depression are more severe in the PwD.
Sample size	Studies with a large (>100) sample size are more likely to find a significant association. Six out of eight studies with sample sizes over 100 found significant associations.
Quality of study	Longitudinal studies were rated to be of a higher quality and all found an association in symptoms.

were cohabitation, care recipient gender, cognition, neuropsychiatric symptoms, functioning in activities of daily living, depression, use of psychotropic medication and caregiver demographic variables.

Discussion

Overview

Despite the wealth of evidence reporting the negative impact of dementia on psychological outcomes in both the PwD and caregiver, little is known about whether there is a concordance in psychological outcomes between both dyad members. The aim of the present review was to establish the current evidence base for a concordance in symptoms of depression and anxiety between people with dementia and caregivers.

The discussion begins with a summary of the main findings which are examined in relation to the aims of the literature review. Potential factors influencing findings and an evaluation of the studies included in the review are then discussed. Consideration is then given to the theoretical and clinical implications of the review followed by the limitations of the current review, implications for future research and conclusions.

Summary of findings

Systematic search of the literature identified 17 studies which met inclusion criteria. All studies examined association in depression symptoms but only one examined anxiety symptoms. Therefore the following discussion predominantly focuses on the concordance of depression symptoms.

The main aim of the literature review was to examine whether there is a concordance in symptoms of depression and anxiety between people with dementia and caregivers. Across studies, high prevalence rates were found for depression symptoms in the PwD and caregiver which is consistent with previous research (Alexopoulos & Abrams, 1991; Cuijpers, 2005; Schulz et al., 1995). All three longitudinal studies found a positive association in symptoms of depression between the PwD and caregiver, however less consistency was found across the 14 cross-sectional studies, with only five finding a positive association. Across both longitudinal and cross-sectional studies, five of the eight studies that found a positive association reported information to determine effect sizes. Effect sizes were small, with the exception of Teri and Truax (1994) who found a medium effect size. Cohen (1992) recommends that to detect a medium effect using bivariate correlations, a sample of 85 participants is required. These five studies had sample sizes ranging from 41 to 1,229 dyads. Studies that used a large sample size and found a small effect may therefore represent a type I error.

The inconsistent findings of the review therefore neither support nor refute psychological theory and prior research that would predict a concordance in depression symptoms between the PwD and the caregiver. Based on the theory of emotional contagion

(Hatfield et al., 1994) it would be hypothesised that individuals would ‘catch’ the intense emotional states of those they are interacting with and therefore a concordance in symptoms would be predicted. Previous reviews have found support for a concordance in psychological distress between care recipients and caregivers across a range of illnesses (Meyler et al., 2007; Monin & Schulz, 2009). The findings of the present review suggests that the presence of depression in one dyad member will not necessarily be associated with depression in the other in this population, and other variables may influence this relationship.

What is the explanation of the findings?

The review examined a number of variables that may influence whether symptoms of depression in one member of the dyad is associated with symptoms of depression in the other dyad member.

Informant source

A challenge of examining concordance between the PwD and caregiver is obtaining reliable and valid measures of depression and anxiety for the PwD. Measures used in the review relied on different informants including the PwD, caregivers and clinicians (e.g. Alexopoulos, 1988; Cummings et al., 1994; Reisberg et al., 1996; Sheikh & Yesavage, 1986; Zigmond & Snaith, 1983).

The present review indicates that the type of informant used influences whether a concordance in symptoms is found. Studies that used caregivers as informants were more likely to find a significant association in symptoms of depression between the PwD and caregiver. Caregivers’ ratings of depression have been found to demonstrate greater consistency with clinician diagnosis compared with care recipient self-report (Teri & Wagner, 1991). However, the use of caregivers as a proxy measure of depression brings its own challenges and potential sources of bias. Rating depression and anxiety in others involves inference of an internal state and may be biased by an individual’s own internal state. Cognitive models propose that depressed and anxious individuals present with negative biases in information processing (Beck, 1979; 1985) which may impact their ability to accurately assess the emotional states of others. Therefore the finding that concordance is more likely to be found in studies that used caregiver proxy measures of depression may reflect a bias in caregivers perception, influenced by their own emotional state, rather than the actual presence of a concordance in symptoms.

However, there is evidence to suggest that caregivers can rate depression symptoms in the PwD without being influenced by their own experience of depression symptoms. In the study by Teri and Truax (1994), in addition to rating depression in the PwD, caregivers were asked to rate depression in two videotaped care-recipients with dementia. In the videos the care recipient was portrayed as either depressed or non-depressed. Caregivers were found to be able to correctly identify the presence of depression in the videos and there was no association between caregiver ratings of the video and their own self-reported depression.

Proxy measures are frequently used in research with people with dementia as the cognitive deficits and reduced awareness associated with dementia may prevent accurate self-report (Burke, Roccaforte, Wengel, McArthur-Miller, Folks & Potter, 1998; Ott & Fogel, 1992; Snow et al., 2005). Deficits in memory, language, attention and insight may result in difficulties in recalling and reporting relevant information for a valid assessment. Caregivers have been found to report higher rates of depression in the PwD compared to self-report measures and this discrepancy has been found to be predicted by PwD awareness (Snow et al., 2005; Burke et al., 1998). Therefore awareness might be beneficial to assess in studies using self-report in the PwD to assess concordance in symptoms with caregivers. Two studies in the current review utilised self-report measures in the PwD, only one of which found a significant positive association in depression symptoms. Neither study used a measure of awareness for the PwD which may have provided one explanation of the contradictory findings.

With the potential biases that can arise in the use of both self-report and proxy-rated measures of depression and anxiety in people with dementia, the use of multiple assessments may be beneficial. This can aid in directly examining whether informant source impacts upon whether a concordance in symptoms is found or not.

Cohabitation

Consistent with previous research (Anderson, Keltner & John, 2003), Waite et al. (2004) found a significant association in depression symptoms between the PwD and caregivers in dyads who cohabited but not in dyads who did not cohabit. From the perspective of emotion contagion theory, cohabitation is likely to increase exposure to the intense emotions of the other person. However, the review found that this factor alone does not suffice in explaining which studies found a concordance in symptoms. Two other studies in the review included samples containing only dyads living together, whilst Thomas et al. (2006) found a significant positive association, Victoroff et al. (1997) did not. Therefore there appears to be limited evidence to suggest that a significant association is more likely in dyads that cohabit.

Sample size

Studies with small sample sizes may be underpowered to detect a significant finding. Sample size did appear to impact on whether an association in depression symptoms were found between the PwD and caregiver, with studies with a larger sample size more likely to find an association. Six studies in the review had sample sizes of less than 50 dyads and therefore are likely to be underpowered to find even a medium effect (Cohen, 1992).

Quality of studies

The Kmet et al. (2004) quality appraisal tool used to assess study quality in the review defined quality as the extent to which studies demonstrate internal validity. Therefore studies that rated highly on the appraisal tool would have greater power to detect a significant association. Quality of studies did appear to impact on whether an association in depression symptoms were found between the PwD and caregiver: Longitudinal studies in the review were appraised to be of a higher quality and all three longitudinal studies found a positive association in depression symptoms.

Summary

Overall, it appears that studies are more likely to find a positive association in symptoms of depression between the PwD and caregiver if caregivers are used as informants for measures of depression for the PwD, dyads cohabit, they have a large sample size and have high internal validity. These variables may explain the inconsistency in findings across cross-sectional studies. They may also explain why there was more consistency across longitudinal studies of a positive association in depression symptoms. Longitudinal studies had large sample sizes, were rated to be of a higher quality, two of three longitudinal studies used caregiver proxy measures of depression for the PwD, and the two longitudinal studies that provided information on the number dyads cohabiting reported a high percentage of cohabitation.

Evaluation of studies included in the review

Study quality was evaluated using the Kmet et al. (2004) appraisal tool and scores ranged from 0.75 to 0.95 indicating that they were generally of a high quality. A key limitation of a number of studies included in the review was the use of small sample sizes. For example, six studies used samples of less than 50. These studies may have been underpowered to find an effect.

Studies were predominantly cross-sectional in design, which are limited in providing information on temporal relationships between variables. Analysis also predominantly used correlations, therefore inference about causal effects are limited. Furthermore, all studies used samples where caregivers were providing care from the beginning. Therefore it is hard to gage at what stage in the care-recipient/caregiver relationship symptoms of depression and anxiety are experienced and potential concordance occurs. In addition, using samples where caregivers are providing care from the beginning may result in a non-response bias. For example, caregivers experiencing higher distress may be less willing to participate in research than those who experience less distress.

To meet inclusion criteria of the present review, all studies utilised validated measures of depression or anxiety. This is advantageous as they have been examined in regards to their reliability and validity. They also provide a clear operationalised definition of how depression and anxiety is assessed. However, with the exception of Mahoney at al. (2005) and Teri and Truax (1994), studies measured depression in the PwD from one perspective, i.e. either self-report, proxy report or clinician rated. As previously discussed, the use of multiple measures of depression in the PwD from different perspectives may be beneficial.

Theoretical and clinical implications of review

Theoretical implications

The review's results indicate that the presence of depression or anxiety in one dyad does not necessarily equate to these symptoms being experienced in the other dyad member, as would be predicted by the theory of emotion contagion. The inconsistency in findings of the present review would suggest that other factors may influence whether a concordance in symptoms is found. The review has examined the potential impact of informant source, cohabitation, severity of symptoms, sample size and study quality. The studies in the review were limited in that they did not examine potential psychosocial factors impacting upon concordance. This is also a limitation of the wider health concordance literature (Meyler et al., 2007).

A number of psychosocial factors may potentially impact upon concordance in psychological symptoms. Relationship quality is intrinsically dyadic, pertaining to the experience of the interaction between one person and another. Relationship quality has interpersonal, as well as intrapersonal, effects on psychological distress between individuals with chronic health conditions and their partners (Segrin, Badger, Dorros, Meek & Lopez, 2006). Relationship quality declines over time in dementia (De Vught et al., 2003; Horowitz & Shindelman, 1983; Morris, Morris & Britton 1988; Wright, 1991) and as well as the intrapersonal effects on psychological distress (Quinn, Clare & Woods, 2009), it may also exhibit interpersonal effects contributing to concordance in psychological distress.

Concordance in psychological symptoms may also depend on the strategies dyad members employ to regulate their emotions when faced with psychological distress in the other (Monin & Schulz, 2010). Coping strategies are psychological and behavioural approaches employed by an individual in order to reduce or tolerate distress elicited by stressful events (Cooper, Katona, Orrell & Livingston, 2008). The type of coping strategies employed by caregivers has been found to moderate the relationship between behavioural stressors displayed by the PwD and caregiver depression (Morano, 2003). Therefore concordance in psychological distress may be moderated by the strategies individuals employ when faced with psychological distress in the other.

Social support may also buffer the potential detrimental psychological impact of being faced with psychological distress in another. Caregivers of a PwD with higher levels of perceived social support are less reactive to stressors than those with lower levels of perceived support (Atienza, Collins & King, 2001). Therefore concordance in psychological distress may be more likely in dyads that have low social support, as the support of others may not buffer the psychological impact of being faced with psychological distress in the other.

Clinical implications

The review highlights a number of issues relevant for clinical practice. Consistent with previous research high prevalence rates of depression in both the PwD and caregiver were found. Therefore, there is a clear need to assess these symptoms in both members of the dyad as these symptoms have been found to be associated with having a detrimental effect on wellbeing. The findings of the review indicate that the presence of psychological symptoms in one member of the dyad does not necessarily equate to these symptoms being experienced by the other member. Therefore, for example, caregivers should be assessed for depression regardless of whether these symptoms are or are not present in the PwD. There is limited evidence from the current review, to suggest that concordance in symptoms is more likely in dyads that cohabit. Therefore psychological assessment and support may be particularly prudent in dyads that cohabit where one dyad member presents with depression symptoms.

Although, the results of the review indicate that depression in one dyad member does not necessarily mean these symptoms are experienced in the other dyad member, the positive association between symptoms found by eight of the studies is suggestive that it may be a risk factor. This would suggest that in order to provide effective interventions for those facing dementia, both dyad members may need to be included in treatment plans with aim of reducing distress in dyads simultaneously. If interventions aim to reduce distress in one member, this attempt may be limited if they are continued to be exposed to distress in the other.

Limitations of present review

There are a number of limitations of the current review. Firstly, with the exception of three studies, the remaining studies were not designed with the explicit aim of examining the association between symptoms of depression between the PwD and caregiver. Therefore very few studies in the current review went beyond an initial correlation analysis between symptoms to explore potential factors influencing the association in symptoms. A lack of examination of psychosocial variables that impact upon concordance was particularly evident.

In addition studies did not report a number of demographic and baseline characteristics relevant to the question of whether there was a concordance in symptoms, as reflected by 14 out of 17 studies only receiving a score of 1 for this criteria (criteria 4) on the Kmet et al. (2004) quality appraisal tool. For example, nine studies in the review did not report how many dyads cohabited. As a result this made it hard to make sense of a set of inconsistent findings across studies.

The heterogeneity of measures used to assess depression in the PwD and caregiver also made comparison difficult. Despite different measure of depression having been found to positively correlate with each other (e.g. Cummings, 1997; Korner et al., 2006), different rates of depression symptoms can be observed in the same sample depending on the measure of depression used (Ott & Fogel, 1992). Furthermore, studies using the same measure used different cut-off criteria for depression. This makes comparison across studies difficult and limits conclusions that can be drawn.

A further limitation of the review is the lack of studies using dyad level models to examine concordance. Dyad level models such as the Actor–Partner Interdependence Model (APIM; Kenny, Kashy & Cook, 2006) allow the exploration of both intrapersonal and interpersonal effects contributing to interdependence between dyad members. Intrapersonal effects examine the association between a person's own independent variable with their own dependent variable, whilst interpersonal effects are explored by examining the association between a person's own independent variable with their partner's dependent variable. Using this framework a concordance, or interdependence, in psychological distress may arise as a result of psychosocial factors impacting upon an individual’s levels of psychological distress and their partner’s psychological distress.

Another limitation of the review is that, with the exception of one study, studies were carried out in North America or Europe. Therefore the review reflects a western perspective on concordance between the PwD and caregiver. One study (Harwood et al., 1998) did examine ethnicity and the association in depression symptoms amongst dyads. No association between depression symptoms was found for either white Hispanic or white non-Hispanic caregivers.

The current review is also limited in its discussion on the concordance of anxiety symptoms between the PwD and caregiver due to only one study in the review providing information addressing this question. This is an area that warrants further investigation as symptoms of anxiety have been found to be highly prevalent, and have a detrimental impact, in both the PwD and caregiver. However, given that ‘pure’ anxiety or depression is relatively rare in older adults compared to mixed anxiety and depression (Beekman, de Beurs, van Balkom, Deeg, van Dyck & Tilburg, 2000; Kvaal, McDougall, Brayne, Matthews & Dewey, 2008), examining concordance in psychological distress which encapsulates both symptoms of anxiety and depression may be beneficial.

The quality appraisal tool used to evaluate studies also has its limitations. The Kmet at al. (2004) standard quality assessment criteria was chosen to appraise studies as it can be utilised to simultaneously evaluate the quality of research which use diverse study designs. Although the tool allows comparison between studies of which studies are of a higher quality, it provides no general guidelines as to what score is considered to indicate a good or acceptable level of internal validity. Furthermore, the tool does not provide any extra weight for studies which are a randomised controlled study. Randomised controlled designs often involve measures to increase internal validity such as random allocation of participants to conditions and blinding of researchers and participants. Therefore the findings of these studies provide stronger evidence but this is not adjusted for in the criteria set out by Kmet et al. (2004).

Implications for future research

This review highlights a number of areas that warrant future research in order to address the current limitations in the evidence. There is a gap in the current evidence base in examining what factors, particularly psychosocial factors, impact on whether a concordance in psychological symptoms is found between the PwD and caregiver. Future research addressing this question directly would be beneficial to gain insights into how interpersonal factors may contribute to depression symptoms and identify potential targets for interventions. Three potentially fruitful areas have been discussed above; exploring the influence of relationship quality, coping strategies and social support. These are potentially modifiable variables which could be targeted in intervention if indicated as having an influence.

Conclusion

Symptoms of depression and anxiety are highly prevalent in both people with dementia and caregivers and negatively impact upon functioning, quality of life and physical morbidity. Understanding interpersonal factors that contribute to symptoms of depression and anxiety may guide potential interventions. Emotions are theorised to have an interpersonal function and have found to be concordant in care-recipient/caregiver dyads across a number of chronic conditions. The findings of the current review suggest that in dementia the presence of depression in one dyad member does not necessarily mean that there will be symptoms of depression in the other member, as would be predicted on the basis of previous research and the theory of emotion contagion. The review highlights the need for further research to examine what factors influence whether a concordance in symptoms occurs, particularly psychosocial variables. This would provide insight into interpersonal factors contributing to symptoms of depression and anxiety amongst people with dementia and caregivers, and guide interventions.

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Part 2: Empirical Paper

Concordance in psychological distress between people with dementia and caregivers

Abstract

Aims: The experience of dementia is interpersonal; it significantly impacts upon the psychological health and well being of both people with dementia and family caregivers. Despite this, there is a lack of research that takes a dyadic perspective of dementia. The present study aimed to examine concordance in psychological distress between people with dementia and caregivers, and the influence of psychosocial factors including relationship quality and coping strategies on this.

Method: A one year longitudinal design was used to examine concordance in self-rated psychological distress between people with dementia and caregivers in 132 community dwelling dyads. Dyadic regression and moderation analyses were used to study the impact of relationship quality and caregiver use of coping strategies on concordance respectively.

Results: Low levels of psychological distress were found for both people with dementia and caregivers. Self-rated psychological distress between dyad members correlated significantly at one year, but not at baseline. Caregiver relationship quality and use of dysfunctional coping strategies were positively and negatively associated with concordance respectively, both cross-sectionally and over time. Relationship quality was associated with an individual's own psychological distress but not with psychological distress in the other member of the dyad. Caregiver use of problem focused coping strategies moderated the relationship between distress in the caregiver and person with dementia at baseline only.

Conclusion: Concordance in psychological distress can develop over time and is influenced by both caregiver relationship quality and coping strategies. Interventions aiming to build upon relationship quality and reducing use of dysfunctional and problem-focused coping strategies could lead to concordant low distress in dyad members. A dyadic perspective is essential in research, theory and policy that endeavour to support those who experience dementia.

Introduction

There are over six million care-recipient/family caregiver dyads in the UK (Office for National Statistics, 2011) and this number is predicted to rapidly increase with the aging population. The economic value of care provided by family caregivers is £119 billion per year (Carers UK, 2011). In light of this, and financial strain on government expenditure, supporting the resilience of dyads is paramount. This involves recognising the physical, psychological and social needs of dyad members.

Psychological distress in dyads can be understood not just in terms of the distress experienced by each member independently but also how distress in one member impacts on distress experienced by the other. Cognitive behavioural models assert that an individual's beliefs about an activating event results in emotional and behavioural consequences (Ellis, 1991). The emotional and behavioural consequences of one dyad member can act as an activating event and can impact upon the beliefs of the other member (Ellis, Sichel, Yeager, DiMattia & DiGiuseppe, 1989; Parkinson & Simons, 2012). As a result, vicious cycles can emerge which have important implications for care recipient/caregiver dyads. For example a care recipients mental health challenges may act as an activating event for a caregiver, which may elicit beliefs such as being unable to cope and consequences such as burden and displaying high levels of expressed emotion (i.e. displays of hostility and over involvement; Vaughn & Leff, 1976). High levels of expressed emotion are associated with increased risk of mental health relapse in care recipients and thus a vicious cycle emerges (Barrowclough & Parle, 1997).

One person's emotions can also impact on another person's emotions via more automatic and predominantly unconscious processes. Emotion contagion theory proposes that individuals converge emotionally, or 'catch', the intense emotional states of those with whom they are interacting (Hatfield, Cacioppo & Rapson, 1994). According to Hatfield et al.'s

(1994) concept of ‘primitive emotion contagion’, during interpersonal interaction individuals have a natural tendency to synchronise with and mimic the expressions and postural changes of others. The individual’s perception of these mimicked non-verbal behaviours results in feedback that generates convergent emotional experiences.

A dyadic approach to research is needed in understanding the psychological distress experienced by care-recipient/family caregiver dyads. This allows interpersonal factors that may contribute and maintain each dyad member’s distress to be explored, and identify potential targets for intervention.

Dyadic perspectives in dementia care

The emphasis of welfare policy in the United Kingdom since the 1980s on providing community care for people with dementia for as long as possible (Department of Health, 1981) has placed the relationship between the Person with Dementia (PwD) and family caregiver centre stage (Johnson, 1998). The majority of people with dementia are supported by family caregivers in the community (Callahan et al., 2012). This provision is associated with a decrease in hospitalisation (Mittleman, Haley, Clay & Roth, 2006) and a better quality of life (Hoe, Katona, Orrell & Livingston, 2007). The magnitude and benefits of this relationship highlights the challenge to clinicians, researchers and policy makers to take a dyadic perspective of dementia (Kahana & Young, 1990).

Early research in dementia was predominantly unidirectional, viewing the PwD as a source of burden for caregivers and focused on understanding the challenges faced by caregivers (Woods, 2001). Research on stress in caregivers has been based on Lazarus and Folkman’s (1984) transactional model of stress. Distress is theorized as being influenced by how caregivers perceive and appraise demands being placed on them. Stress coping models in dementia theorise that psychological distress is predominantly linked to primary stressors such as cognitive status, problematic behaviour, dependencies with activities of daily living of the PwD, as well as the secondary stressors associated with them including roles strains and intrapsychic strains (Pearlin, Semple, Mullin & Skaffs 1990). This approach fails to reflect the potential positive and negative impact of care for both dyad members and neglects the experiences of the PwD (Coltrell & Schulz, 1993).

Holistic approaches to dementia care emphasise the importance of viewing the PwD as a social being whose presentation is influenced by a number of factors including social environment and not solely reflective of neurological impairment (Kitwood, 1997; Woods, 2001). Kitwood (1997) described how a PwD can find them self in an environment which is disempowering and devaluing. The wider caregiving literature indicates that support provided by caregivers may not always be perceived positively by care recipients, and negative responses to support provided by caregivers is fairly common (Clark & Stephens, 1996; Newsom & Schulz, 1998). Therefore, to understand the experience of dementia, an appreciation of the inter-relationship between the PwD and caregiver is needed (Kahana & Young, 1990; Kitwood, 1997; Woods 2001). Although more recent research has explored the views of people with dementia, most studies have typically been restricted to examining the experiences of the PwD without exploring the experience of the caregiver (Nolan, Ryan, Enderby & Reid, 2002; Forbat, 2003). This focus diverges from the holistic view of dementia care and the importance of the inter-relationship between the PwD and the caregiver.

To understand the experience of distress in dementia, both the PwD and the caregiver need to be seen as part of a dyad rather than independent members (Hellstrom, Nolan & Lundh, 2005). A similarity, or concordance, in psychological distress, quality of life and well-being between care-recipient/caregiver dyads is evident across a number of conditions (Meyler, Stimpson & Peek, 2007). Concordance has been examined in two primary ways: by examining correlation of health status between dyad members or examining whether the health status in one member impacts upon the same health status in the other (Meyler et al, 2007).

Studies including an analysis of the association in psychological distress between the PwD and caregiver cross-sectionally have produced inconsistent findings. Whilst some have found a positive association (Papastavrou, Kalokerinou, Papacostas, Tsangari & Sourtzi, 2007; Roth et al., 2003; Shua-Haim, Haim, Shi, Kuo & Smith, 2001; Teri & Truax, 1994; Thomas et al., 2006), others have found no association (Berger, Bernhardt, Weimer, Peters, Kratzsch & Frolich, 2005; Cummings, Ross, Absher, Gornbein & Hadjiaghai, 1995; Fuh, Wang, Liu, Liu &Wang, 1999; Harwood, Barker, Cantillon, Loewenstein, Ownby & Duara, 1998; Mahoney, Regan, Katona & Livingston, 2005; Rosenberg, Mielke & Lyketsos, 2005; Victoroff, Mack & Nielson, 1997). More consistent findings of a positive association in depression symptoms between the PwD and caregiver has been found across longitudinal studies (Mohamed, Rosenbeck, Lyketsos & Schneider, 2010; Neundorfer et al., 2001; Schulz et al., 2008). Whether concordance in psychological distress between the PwD and caregiver exists therefore remains unclear.

Theoretical explanations of concordance

Emotion contagion is a predominant theoretical explanation for concordance in psychological distress in chronic health conditions (Meyler et al., 2007). From this perspective, concordance in psychological distress arises due to individuals synchronising with and mimicking the expressions and postural changes of others. The individual's perception of these synchronised non-verbal behaviours elicits feedback generating concordant emotional experiences.

Previous research has tested whether there is a concordance of psychological symptoms attributable to the process of emotion contagion by examining whether depression in one member predicts depression in their partner, above the contribution of known predictors of depression. Using this methodology a number of studies have demonstrated depression symptoms in care recipients predict depression symptoms in caregivers, above the contributions of demographic variables, activities of daily living and shared life events, and attributed the finding to emotion contagion of depression symptoms (Bookwala & Schulz, 1996; Goodman & Shippy, 2002; Tower & Kasl, 1995; 1996).

The current evidence base in dementia discussed previously suggests that the presence of psychological distress in one dyad member does not necessarily equate to these symptoms being experienced in the other dyad member, as would be predicted by the theory of emotion contagion. The inconsistency in findings indicates that other factors may influence whether a concordance in psychological distress occurs. Despite concordance in psychological distress being psychosocial in nature, there is a lack of research examining psychosocial factors influencing concordance in dementia and the wider healthcare literature (Meyler, 2007).

Psychosocial factors influencing concordance

Dyad level models of analysis such as the Actor–Partner Interdependence Model (APIM; Kenny, Kashy & Cook, 2006) have been increasingly used in dyadic research where one member is diagnosed with a chronic health condition. It has been used to examine how each dyad members' characteristics impacts upon their own and their partners' psychological health (Chung, Moser, Lennie & Rayens, 2009; Karademas, & Giannousi, 2013; Kershaw et al., 2008; Segrin, Badger, Dorros, Meek & Lopez, 2007; Taylor et al., 2008; Thomson, Molloy & Chung, 2012). The framework enables exploration of both intrapersonal and interpersonal effects that may account for concordance in psychological distress to be explored. Intrapersonal effects are explored by examining the association between an independent and dependent variable for an individual, termed the 'actor effect'. Interpersonal effects are explored by examining the association between an independent variable for one individual with a dependent variable for the other member of the dyad, termed the ‘partner effect’.

Figure 1 depicts a basic APIM. The APIM proposes that concordance, or interdependence, can arise from four circumstances: Each dyad member may display both an actor effect and a partner effect (Figure 2a and 2b), both dyad members may demonstrate partner effects (Figure 2c) or both dyad members display actor effects and the independent variable across partners is correlated (2d).

Relationship quality is inherently dyadic as it pertains to the experience of interaction between the PwD and the caregiver. It has interpersonal, as well as intrapersonal, effects on psychological distress between individuals with chronic health conditions and their partners (Segrin et al., 2007). Quality of relationship declines over time in dementia (De Vught et al., 2003; Horowitz & Shindelman, 1983; Morris, Morris & Britton, 1988; Wright, 1991) and as well as the intrapersonal effects of relationship quality on psychological distress (Quinn, Clare & Woods, 2009), it is possible that it may also exhibit interpersonal effects contributing to concordance in psychological distress.

Whether dyad members are concordant in their levels of psychological distress may also be dependent on the strategies they employ to regulate their emotions when faced with psychological distress in the other (Monin & Schulz, 2010). Coping strategies are psychological and behavioural approaches employed by an individual in order to reduce or tolerate distress elicited by stressful events (Cooper, Katona, Orrell & Livingston, 2008). Coping strategies can be divided into three subtypes: emotion focused, problem focused and dysfunctional (Carver, Scheier, & Weintraub, 1989; Cooper et al., 2006).

Emotion-focused coping aims to regulate the emotional consequences of a situation. Examples include acceptance, involving learning to live with the reality of what has

Figure 1: Basic Actor Partner Interdependence Model (APIM; Kenny, 2014)

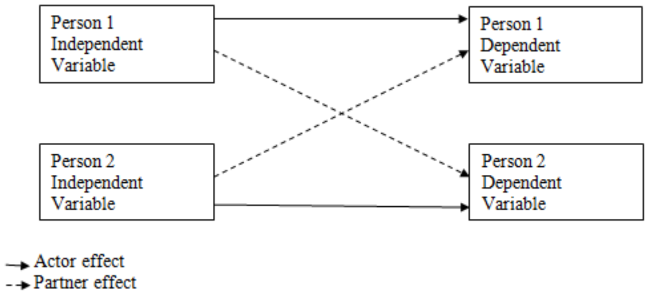
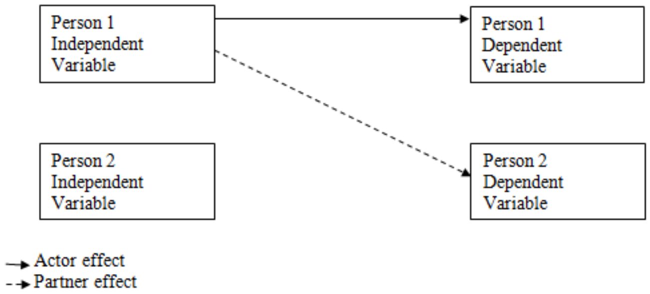
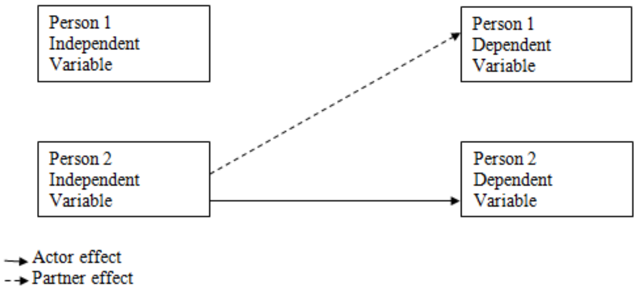


Figure 2: APIM explanations of interdependence (Kenny, 2014)

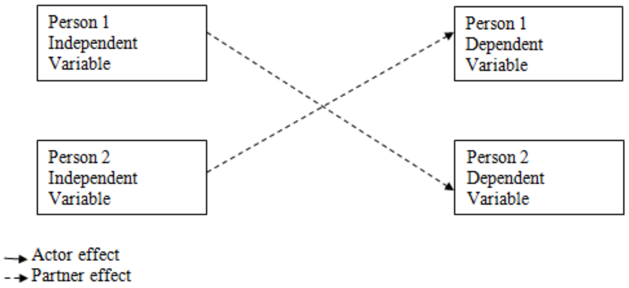
2a



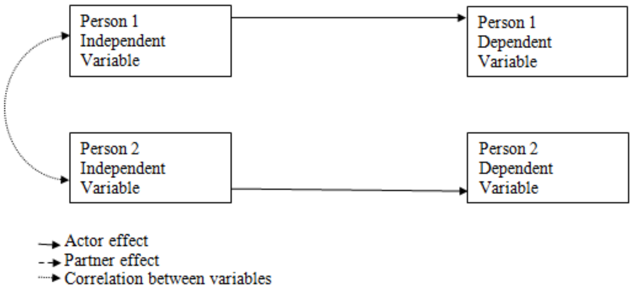
2b



2c



2d



happened, and positive reframing, involving positively connoting the situation which you are in. Problem-focused coping aims to confront the source of distress and deal with the tangible consequences. Examples include strategies such as active coping, involving taking action to improve the situation and instrumental support, involving seeking advice from others. Dysfunctional strategies involve disengagement from the problem and include strategies such as behavioural disengagement, which involves giving up trying to cope with the problem, and venting, involving saying things to express negative feelings.

Research on the impact of coping strategies on outcomes in caregivers of people with dementia has largely held the view that coping strategies are mediators of the relationship between stressors and outcomes (Morano, 2003). Morano (2003) examined whether coping strategies mediated or moderated the relationship between behavioural stressors displayed by the PwD and depression in the caregiver. Coping strategies were found to moderate this relationship. As well as moderating the relationship between behavioural stressors displayed by the PwD and psychological distress in the caregiver, it is possible that the relationship between psychological distress in the PwD and caregiver may also be moderated by coping strategies.

Summary

Psychological distress is common in both people with dementia and caregivers, and negatively impacts upon functioning, quality of life and physical morbidity. Despite this, few studies have taken a dyadic perspective and examined whether distress in one member impacts upon the distress experienced by the other. Concordance in psychological distress has been observed in a number of chronic health conditions; however previous research into concordance in dementia has a number of limitations. One key limitation is a lack of research examining psychosocial factors influencing concordance.

Examining concordance in psychological distress is important in understanding whether the PwD and caregiver experience similar emotional states. From a theoretical perspective, if shared emotional states are observed this provides support for theories of emotional convergence such as emotional and behavioural consequences of one dyad member eliciting congruent beliefs of the other member (Ellis et al., 1989; Parkinson & Simons, 2012) and emotion contagion (Hatfield et al., 1994). From a clinical perspective, if concordance in distress is observed it suggests that interpersonal factors may contribute to and maintain symptoms of distress in dementia, and that a dyadic approach to interventions aiming to reduce distress is necessary.

Aims

The aim of the present study was to explore psychological distress in dementia from a dyadic perspective. The primary aim was to examine concordance in psychological distress between people with dementia and caregivers, and the variables associated with concordance. Specifically it aimed to explore the influence of psychosocial variables of relationship quality and coping strategies on concordance.

Hypotheses

Given the theories and research discussed above, this study aimed to test the following three hypotheses:

i) There will be a concordance in psychological distress between the PwD and caregiver.

ii) Ratings of relationship quality by the PwD and caregiver will predict their own psychological distress and distress in the other member of the dyad.

iii) Coping strategies will moderate the relationship in distress between dyad members.

Method

Participants

Recruitment

The recruitment process for the trial included direct recruitment within the community via leaflets, flyers, posters and invitations in local papers and newsletters. Indirect recruitment was also used and involved the use of gatekeepers, such as the Alzheimer's Society and Admiral Nurses already in contact with the target population. These gatekeepers informed potential participants about the study and distributed recruitment literature. The trial ran in community settings in North East London, Norfolk, Northamptonshire and Berkshire.

Inclusion and exclusion criteria

Caregiver: Inclusion criteria for the trial were being over 18 years of age, English speaking, and providing care for a relative or close friend living at home in the community with a primary progressive dementia as defined by DSM-IV (American Psychiatric Association, 2000). Caregivers were excluded from the trial if they had a congenital learning disability, non-progressive brain injury, or terminal illness. Caregivers were also excluded if they were currently involved in any other current psychosocial intervention.

PwD: Inclusion criteria for the trial were having a primary progressive dementia as defined by DSM-IV (American Psychiatric Association, 2000) and living in the community. An additional inclusion criterion for the present study was being able to self-complete the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) at both baseline and after one year. The PwD was excluded from the study if they had a congenital learning disability or non-progressive brain injury.

Ethics

Ethical approval for the peer support trial was obtained by the Outer North East London Research Ethics Committee (09/H0701/54; see Appendix 2), which included approval for analysis of associations between variables. Local governance procedures at the North East London NHS Foundation Trust, Norfolk and Suffolk NHS Foundation Trust and Berkshire Healthcare NHS Foundation Trust were followed for this study and a Letter of Access to be part of the research teams was obtained (see Appendix 3a, 3b, 3c).

Design

Research context

The data used for this study was collected as part of the Support at Home - Interventions to Enhance Life in Dementia, Carer Supporter Programme (SHIELD CSP) trial. This is a single-blind randomised controlled trial, investigating the effectiveness and cost-effectiveness of one-to-one peer support (Carer Supporter Programme, CSP) and a group reminiscence programme (Remembering Yesterday Caring Today, RYCT; Schweitzer & Bruce, 2008), both separately and together, on health related quality of life in caregivers (Charlesworth et al., 2011). The trial had four arms: CSP alone, RYCT alone, CSP and RYCT combined, and treatment as usual. Data was collected at baseline, and five months and one year post-randomisation.

Design of present study

The study used a longitudinal design, examining data from the trial at baseline and one year. Data was combined across the four trial arms for both the PwD and caregiver. At a group level, a 2x2 mixed groups factorial design was used to measure the effects of time, which had two levels (baseline and one year), and role which also had two levels (person with dementia and caregiver), on psychological distress. At a dyad level, correlation and regression analyses were undertaken to examine concordance in psychological distress and predictors of concordance. Dyadic regression and moderation analyses were used to study the impact of relationship quality and caregiver use of coping strategies on concordance respectively.

Sample Size

A power analysis calculation was carried out using G*Power 3 (Faul, Erdfelder, Lang & Buchner, 2007). The analysis which included the largest number of potential variables is the planned multiple regression examining predictors of psychological distress concordance between the PwD and caregiver, with a potential of 14 predictors. With a multiple regression model (Fixed Model, R^2 deviation from zero) specifying a medium effect size of 0.25, with an alpha of 0.05, a power of 0.8 and with fourteen predictors a sample size of 135 was calculated. Given the lack of research into factors predicting concordance in psychological distress to guide effect size, a medium effect size was chosen as a compromise between strength of effect identified and feasibility of participant recruitment.

Measures

Demographics

Demographic data collected included gender, age, ethnicity and education level for both dyad members. Number of months of caregiving, kinship of caregivers to the PwD and whether dyads cohabited were also recorded.

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)

The HADS was used as a measure of psychological distress in both the PwD and the caregiver, and used to calculate a measure of distress concordance. The HADS is a self-report measure with individuals rating how they have been feeling in the previous week. It comprises two subscales, an anxiety subscale (HADS-A) and a depression subscale (HADS-D), both consisting of seven items. Items are scored on a scale of zero to three, where a higher score indicates greater anxiety or depression. For each subscale, total scores between eight and 10 indicate mild symptoms, between 11 and 14 indicate moderate symptoms and scores of 15 and above indicate severe symptoms. It has been validated across a range of settings in screening for clinical levels of symptoms of anxiety and depression (Bjelland, Dahl, Haug & Neckelmann, 2002), however, it has seldom been used in individuals with neurodegenerative illnesses and its validity in these circumstances has not been examined (Schrag, Barone, Brown, Leentiens, McDonals & Starkstein, 2007).

In the research trial (Charlesworth et al., 2011), the HADS was observed to have a four factor solution for people with dementia (see appendix 4), with overlap in items of the depression and anxiety scale. Therefore a single distress scale was used in this paper with possible scores ranging from zero to 42. Good internal reliability was demonstrated for a one factor solution to HADS scores for both people with dementia and caregivers (Cronbach's α = .77, .91 respectively) and no improvement to the internal reliability was indicated by the removal of any of the items. However, given that that this one factor had 14 items, the Cronbach's α value needs to be interpreted with caution. The value of Cronbach's α increases as the number of items on a scale increases. Therefore it is possible to get a high value for Cronbach's α because there are a high number of items on a scale rather than the scale being reliable (Field, 2005).

Distress concordance was derived by calculating the absolute difference between distress scores for the PwD and caregiver. The distress concordance score could therefore range from zero to 42, with higher scores indicating lower concordance.

The Neuropsychiatric Inventory (NPI; Cummings, Mega, Gray, Rosenberg-Thompson, Carusi & Gornbein, 1994)

The NPI assesses 12 types of behavioural disturbances that commonly occur in people with dementia, including depression and anxiety. It is completed by the caregiver and starts with a screening question to identify the presence of the behavioural disturbance in question. If a positive response is provided to the screening question, further questions about the presentation of the behavioural disturbance follow. Frequency of the behavioural disturbance is then rated on a four point scale, where a higher score indicates a higher frequency of behaviour. Severity of the behavioural disturbance is rated on a three point scale, where a higher score indicates a higher severity. A total score for each behavioural disturbance is calculated by multiplying the frequency score by the severity score. The NPI has been found to demonstrate acceptable levels of content validity, concurrent validity, inter-rater reliability, and test-retest reliability (Cummings, 1997). For the purposes of this paper, only scores from the combined depression and anxiety subscales are reported, providing a rating of the caregivers' perception of the frequency and severity of distress in the PwD. Possible scores range from zero to 24 with higher scores indicating greater distress.

Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975)

The MMSE was used as a measure of cognitive function. It was administered to the PwD by the researcher. It measures six aspects of cognitive functioning: orientation for time and place, repetition, concentration, short term memory, language and praxis. It has a maximum score of 30 points, with higher scores indicating greater cognitive functioning. The MMSE is a reliable and extensively used measure in the assessment of cognitive functioning (Folstein et al., 1975; Spencer & Folstein, 1985)

Alzheimer's Disease Co-operative Study – Activities of Daily Living Inventory (ADCS-ADL; Galasko et al., 1997)

The ADCS-ADL was used to measure functional capacity in the PwD. It was completed by the caregiver. Each item consists of a series of hierarchical questions to determine the ability of the PwD to perform activities of daily living (e.g. eating, toileting, using the telephone and going shopping). The overall score ranges between zero (worst performance) and 78 (best performance). It has demonstrated good test-retest reliability and concurrent validity with measures of cognitive functioning (Galasko et al., 1997).

Quality of Care-giver Patient Relationship (QCPR; Spruytte, van Audenhove, Lammertyn, & Storms, 2002)

The QCPR was used to measure perceptions of relationship quality in both the PwD and the caregiver. The QCPR is a 14 item scale which measures relationship quality in terms of expressed emotion, which covers two dimensions: the level of (lack of) criticism and warmth. Responses are scored on a five point scale which range from totally disagree to totally agree. Scores range from 14-70. Previous studies have shown that the QCPR has good internal consistency and concurrent validity for both the PwD and caregiver (Spruytte et al. 2002; Woods et al., 2012).

Brief COPE (*Carver, 1997*)

The Brief COPE was used to measure the use of coping strategies by caregivers. It is a self-report measure completed by caregivers and is a shortened version of the original COPE scale (Carver et al., 1989). The present study used the three scale structure (Coolidge, Segal, Hook & Stewart, 2000; Cooper et al., 2008): emotion focused coping (consisting of 10 items), problem focused coping (consisting of 6 items) and dysfunctional coping (consisting of 12 items). Each item is rated on a four point scale with scores ranging from one to four, higher scores indicating a higher frequency of use of the coping strategy. The Brief COPE has been demonstrated to have good internal consistency, adequate test-retest reliability and good construct validity in caregivers of people with dementia (Cooper et al., 2008).

Table 1 summarises the measures completed by participants in the study at baseline and one year.

Procedure

Following caregivers expressing an interest in the peer support trial, a member of the research team provided further information either by post or by telephone. An information

Table 1: Study measures completed at baseline and one year

Type of measure	Measure
PwD self-report	HADS, QCPR
Caregiver self-report	HADS, QCPR, Brief COPE
Caregiver assessment of PwD	NPI, ADCS-ADL
Researcher administered to PwD	MMSE

booklet was then sent to both the family caregiver and PwD, accompanied by a covering letter. If the caregiver continued to express interest in taking part, a member of the research team completed a telephone screening checklist to assess eligibility and answer any queries the caregiver may have. An appointment was then made for informed consent to be requested.

In the research interview, both the PwD and caregiver were interviewed by the research team. The present study examined data collected at baseline and at one year follow-up. At the baseline interview participants were asked to provide their demographic details such as age, ethnicity and education. At both baseline and one year, the PwD self-completed the HADS, QCPR and was administered the MMSE by the researcher. Caregivers completed self-report measures including the HADS, QCPR and Brief-COPE. They also completed measures assessing the PwD which included the NPI and ADCS-ADL. These measures were administered alongside other measures included in the peer support trial. The author of the present paper completed 27 assessments at one year as part of the larger research team

Analytic Strategy

Data preparation was first conducted, followed by examining baseline characteristics. Analysis to test each of the study's hypotheses was then carried out in turn.

Preliminary analysis

Missing data: If the participant had managed to complete 80% of a scale of a measure, pro-rating of 20% was applied to the missing item to allow a total score to be computed. If less than 80% of a scale was completed then the total score was considered missing.

Outliers: Following the guidance of Field (2005), scores on each of the measures were firstly screened for outliers by converting scores into standard scores. Given the medium sample size of the present study, standard scores with an absolute value of above 3.29 were identified as outliers. Outliers were firstly checked for errors in data entry and then remained in analysis to examine their impact on the distribution of measures. Where distribution of measures deviated from normality, transformations were applied subsequently reducing the impact of outliers on the data.

Normal distribution: Whether variables were normally distributed was examined by visual inspection of histograms and calculating standard scores for skew and kurtosis. Given the medium sample size of the present study, absolute z-scores of above 3.29 were used to indicate a distribution that significantly deviated from normality. Transformations were applied to variables where the distribution deviated from normality.

Baseline Characteristics

Means and standard deviations of demographic variables and measures were calculated for both the PwD and caregiver at baseline.

Hypothesis i: There will be a concordance in psychological distress between the PwD and caregiver.

Group level: Concordance in mean distress between the PwD and caregiver at both baseline and one year was analysed by using a t-test to examine whether there was a significant difference in mean distress score between the two groups. The analysis included a

Levene’s test to check for homogeneity of variance in distress scores between the two groups. Concordance in mean distress was analysed longitudinally using an ANOVA to examine whether time had a similar effect on the two groups. A two by two mixed groups factorial design was used to measure the effects of time, which had two levels (baseline and one year), and role which also had two levels (person with dementia and caregiver), on psychological distress.

Dyad Level: Pearson’s correlations were used to examine whether there was a significant association in psychological distress in PwD-caregiver dyads, with separate calculations for self-rated and caregiver (proxy) rated measures of distress in the PwD. The same analytic procedure was carried out for both baseline data and one year data. The percentage of caregivers with higher, equal and lower distress scores relative to the PwD was then calculated. This was followed by deriving the distress concordance score for dyads by calculating the absolute difference between distress scores on the HADS. Whether the interventions associated with four arms of the trial had an impact on distress concordance was analysed using ANOVAs. A one-way between groups ANOVA was used to measure the effects of intervention group, which had four levels (CSP alone, RYCT alone, CSP and RYCT combined, treatment as usual), on distress concordance at both baseline and one year.

Pearson’s correlations were then conducted between distress concordance, baseline demographic variables (age of PwD, age of caregiver, gender of PwD, gender of caregiver, length of caregiving, cohabitation, kinship of caregiver to PwD), baseline functioning in the PwD (cognitive functioning, activities of daily living), baseline relationship quality (rated by the PwD, rated by the caregiver) and baseline caregiver use of coping strategies (emotion focused, problem focused, dysfunctional) and examined for significant relationships, as well as any potential problems with multicolinearity. As gender, cohabitation and relationship were categorical variables, point-biserial correlations were used. All three variables were treated as comprising of a discrete dichotomy: male or female, cohabiting or non-cohabiting and spouse or non-spouse respectively.

Variables with significant correlations were then entered into a multiple regression to examine what proportion of the variance in distress concordance was explained by the different variables. Standardised predicted values were plotted against standardised residuals from the model to check for linearity and homoscedasticity. Standardised residuals were also checked as to whether they were normally distributed and Cook's differences calculated to identify any cases which had a large influence on the regression model.

Hypothesis ii) Ratings of relationship quality by the PwD and caregiver will predict their own psychological distress and distress in the other member of the dyad.

To determine the impact of relationship quality on a dyad member's own, as well as their partner's psychological distress, the Actor–Partner Interdependence Model (APIM; Kenny et al., 2006) was used to accommodate for the concept of dyadic interdependence within analysis of data produced by dyads. There are a number of different statistical procedures that can be used within the APIM framework, and the present study used a distinguishable dyad multi-level modelling APIM and follows the procedure outlined in Kenny et al. (2006). The distinguishable dyad multi-level modelling APIM differentiates between dyad members based on some defining characteristic, which in this case was whether the individual was a PwD or caregiver. Multilevel modelling is a statistical model for data which contains a hierarchy of units where one set of units is nested within another. Basic multilevel models contain two levels of units: lower level and upper level. In the present study the lower level unit was the person and the upper level was the dyad. Variance associated with each level was estimated. The application of multilevel modelling has to be adapted when used with dyadic data as dyads do not have enough lower level units (i.e. dyad members) for the slopes to be allowed to vary from dyad to dyad. Therefore for dyadic data, the slopes have to be constrained so that they are equal across dyads.

Data was entered as a pairwise data set where each individual’s outcome score is associated with both their own predictor score and that of the other member of the dyad. This results in each person’s predictor score being entered twice, once as an ‘actor’ predictor score and once as a ‘partner’ predictor score. Predictor scores were grand mean centred to aid the interpretation of results. Standardised predicted values were plotted against standardised residuals from the model to check for linearity and homoscedasticity. Standardised residuals were also checked as to whether they were normally distributed.

Hypotheses iii) Coping strategies will moderate the relationship in distress between dyad members.

To conduct the moderation analysis a process tool was downloaded (Hayes, 2013). In a moderation analysis the predictor (independent) variable, moderator variable and the interaction between the predictor variable and the moderator are regressed on to the outcome variable. The same analytic procedure was conducted for both baseline and follow-up data.

The analysis examined whether the relationship between psychological distress in the PwD and caregiver varied according to the extent to which caregivers used three different coping strategies at baseline: emotion focused, problem solving and dysfunctional coping. Baseline distress in the PwD was entered as the independent variable, distress in the caregiver was entered as the outcome variable, and use of each of the three coping strategies at baseline were entered separately as moderator variables.

Results

The results section begins by describing the outcome of the preliminary analysis. Baseline characteristics are then presented followed by the analysis conducted to test each of the study’s hypotheses.

Preliminary Analysis

Missing Values

Missing values were identified in the following measures: education level of the PwD, caregiver months of caring and baseline activities of daily living of the PwD.

Outliers and distribution of measures

At baseline, outliers were identified in the following measures: self-rated psychological distress in the PwD, proxy rated psychological distress for the PwD, self-rated psychological distress in the caregiver, distress concordance (absolute difference between caregiver and PwD self-rated scores on the HADS), caregiver emotion focused coping strategies, caregiver age and caregiver months of caring. At one-year outliers were identified in distress concordance.

At baseline psychological distress in caregivers, caregiver proxy ratings of distress for the PwD and distress concordance were positively skewed and leptokurtic. Self-rated psychological distress in the PwD and caregiver months of caring were positively skewed. All five measures were transformed using the square root of values to result in scores being normally distributed. At one year, self-rated psychological distress in the PwD, caregiver proxy rated psychological distress for the PwD and distress concordance were positively skewed and leptokurtic. Psychological distress in caregivers was also positively skewed. Therefore all four measures were transformed using the square root of values to result in scores being normally distributed.

Baseline Characteristics

A total of 291 dyads were recruited to the trial at baseline, of which 221 dyads included a measure of self-rated psychological distress in the PwD. At one-year, 241 dyads remained in the trial, of which 132 dyads included a measure of self-rated psychological distress in the PwD. Therefore the analysis was conducted on the 132 dyads that included a measure of self-rated psychological distress in the PwD at both baseline and one year. Of these 132 dyads, 25 dyads were in the CSP only intervention group, 46 dyads were in the RYCT only intervention group, 41 dyads were in the CSP and RYCT combined intervention group, and 20 dyads were in the treatment as usual group. The baseline demographic characteristics of both dyad members are presented in Table 2. People with dementia had a mean age of 79.11 (*SD* = 6.77) and the predominant diagnosis of dementia was Alzheimer's disease (52%). The mean MMSE for the PwD was 20.36 (*SD*=4.47) indicating a moderate severity of dementia. *S*everity of dementia ranged from mild to severe (MMSE range = 9-30). Caregivers had a mean age of 66.89 (*SD* = 12.05) and had provided care for an average of 47.91 months (*SD* = 36.20). The majority of caregivers were spouses or partners (61%) and most dyads cohabited (78%).

Hypothesis i: There will be a concordance in psychological distress between the PwD and caregiver.

Group level: Means and standard deviations for baseline and follow-up measures are presented in Table 3. Levels of psychological distress were low for both dyad members. Baseline self-rated distress was higher in caregivers (*M* = 11.27, *SD* = 7.80) compared to the PwD (*M* = 8.21, *SD* = 5.51): *t*(262)= 3.36, p=.001. Similarly, at follow-up higher levels of distress were reported by caregivers (*M* = 13.30, *SD* = 8.17) compared to the PwD (*M* = 7.13, *SD*= 5.70): *t*(262)= 7.08, p= <.001. There was no significant main effect of time on self-rated distress, *F*(1, 262)= .09, p= .765. There was a significant effect of role on self-rated distress with caregivers experiencing higher levels of distress compared to the PwD: *F*(1, 262)= 33.33, p= < .001. However, these factors interacted, *F*(1, 262)= 23.30, p= <.001 (see Figure 3). Whilst caregivers reported an increase in distress over time, people with dementia reported less distress at one year than at baseline.

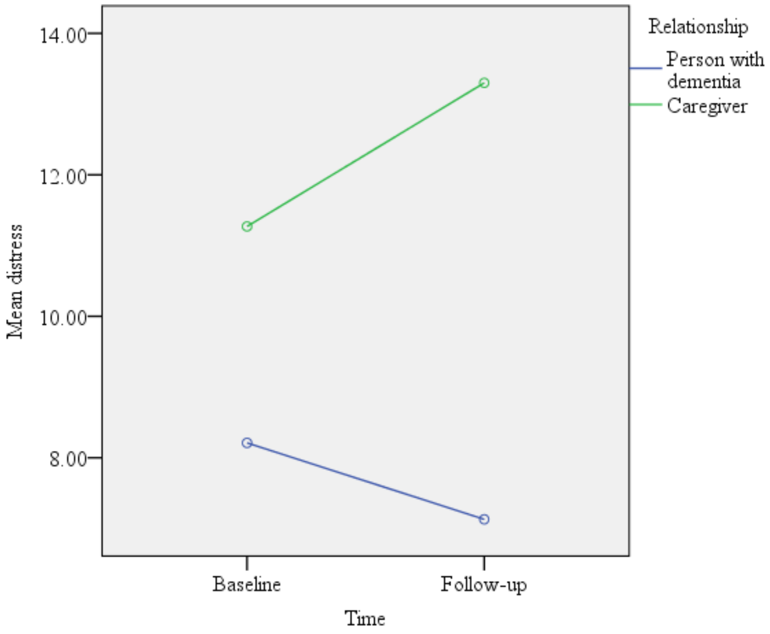
Table 2: Baseline demographics

Demographic variables	**PwD (N = 132)**	**Caregivers (N = 132)**
Age mean (*SD*)	79.11 (6.77)	66.89 (12.05)
Gender (%)		
Male	52	27
Female	48	74
Ethnicity (%)		
White British	93	93
White non-British	2	2
African	1	1
Caribbean	2	2
Asian	2	1
Other	1	1
Level of education (%)		
Completed higher education	10	14
Diagnosis (%)		-
Alzheimer’s disease	52	
Vascular dementia	14	
Lewy body dementia	2	
Frontotemporal dementia	2	
Other dementia or unknown	29	
Mean months since diagnosis (*SD*)	29 (28)	-
Cohabiting with caregiver (%)	78	-
Caregiver kinship (%)	-	61
Spouse/partner		38
Child (adult)/ other family		2
Other relationship		
Mean months caregiving (*SD*)	-	47.91 (36.20)

Table 3: Means and standard deviations for baseline and one-year measures

Measure	**PwD**		**Caregiver**	
	Baseline Mean (*SD*)	1 year Mean (*SD*)	Baseline Mean (*SD*)	1 year Mean (*SD*)
Distress (HADS total score)	8.21 (5.51)	7.13 (5.70)	11.27 (7.80)	13.30 (8.17)
NPI (Depression and Anxiety subscales combined)	3.02 (4.06)	2.86 (3.55)	-	-
MMSE	20.36 (4.47)	18.11 (5.44)	-	-
ADCS-ADL	50.84 (13.86)	45.71 (16.00)	-	-
Relationship quality	59.41 (6.28)	59.80 (6.98)	53.39 (9.51)	52.96 (9.60)
Brief COPE-	-	-		
Emotion focused coping			22.39 (4.85)	22.07 (4.44)
Problem focused coping			14.19 (4.29)	13.86 (3.79)
Dysfunctional coping			18.40 (4.20)	18.92 (4.53)

Figure 3: Mean distress scores for the PwD and caregiver at baseline and one year.



In contrast with self-rated distress in the PwD, carergivers’ proxy ratings of distress in the PwD on the NPI demonstrated no significant change from baseline to follow-up: *t*(131)= .652, p= .515. Change in self-rated distress in the PwD was negatively associated with baseline cognitive functioning: r(132)= -.25, p= .004, that is, the greatest changes in self-rated distress over one year occurred in those with the lowest cognitive functioning at baseline. No such association was observed between change in carer proxy rated distress in the PwD and baseline cognitive functioning $r_s(132) = -.06$, p= .466.

Dyad level: At baseline no association was found between self-rated distress in the PwD and caregiver: *r*(132) = .13, p= .135. Of the 132 dyads, in 73 (55%) self-rated distress was higher in caregivers, in 53 (40%) dyads self-rated distress was higher in PwD and in six (5%) dyads equal levels of self-rated distress were reported. Despite self-rated and carer rated measures of distress in the PwD being significantly correlated *r*(132)= .22, p= .011, a different relationship was observed between distress in the PwD and caregiver when caregiver proxy ratings of distress in the PwD were used; a positive association was observed, *r*(132) = .18, p= .037.

Distress concordance demonstrated a strong positive association with distress in caregivers, *r*(132) = .57, p= <.001, but no association with distress in the PwD, *r*(132) = -.06, p =.485. No difference in distress concordance was observed across the four intervention groups of the trial: *F*(3, 128)= 1.79, p= .152. Results for baseline correlations for distress concordance between the PwD and caregiver are presented in Table 4. No demographic or functioning variables were found to correlate with distress concordance. Caregiver rating of relationship quality demonstrated a weak negative association with distress concordance, indicating that the greater the caregiver's rating relationship quality, the greater the concordance (i.e. the smaller the difference in distress): r(132) = -.21, p= .015. Caregiver use of dysfunctional coping demonstrated a moderate positive association with distress concordance, indicating that the greater the caregiver's use of dysfunctional coping strategies, the lower the concordance (i.e. the greater the difference in distress): r(132) = .42, p = <.001.

Caregiver relationship quality and use of dysfunctional coping strategies were therefore entered into the multiple regression model. The multiple regression model was a significant model and explained 18% of the variance in distress concordance: F(2, 129)= 13.87, p= < .001, f^2 =22. Caregiver use of dysfunctional coping strategies was the only significant predictor of distress concordance (see Table 5): standardised β = .39, *t* = 4.56, *p* = <.001. An increase in the use of dysfunctional coping strategies by one standard deviation would therefore be predicted to lead to an increase in the transformed distress concordance (i.e. a lower concordance in distress) by 0.39 (untransformed =0.15). As caregiver relationship quality and use of dysfunctional coping strategies were observed to correlate (see Table 4), the multiple regression model was checked for problems with multicollinearity by

Table 4: Correlations between baseline demographics, measures of functioning in the PwD, relationship quality, and coping with distress concordance at baseline.

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1.Distress concordance		-.05	.08	-.01	-.01	.07	.03	.00	-.03	-.14	-.21*	.03	.00	.15	..42**
Demographic variables															
2. CG age			-.24**	.00	-.29**	-.06	-.53**	-.75**	.05	-.11	-.11	-.09	-.11	-.09	-.11
3. CG gender				.11	-.42**	.11	.07	.11	.12	-.15	-.11	.02	.10	-.06	.14
4. PwD age					.22*	.04	.35**	.45**	-.26**	-.29**	-.01	-.13	-.05	-.04	-.04
5. PwD gender						-.08	.35**	.53**	-.27**	-.02	.20*	.25**	.00	.13	-.06
6. Care months							-.02	.10	-.08	-.27**	-.11	.02	.20*	-.02	.11
7. Cohabiting								.67**	-.19*	.07	.09	.27**	-.01	.16	.05
8. Kinship									-.17	-.02	.13	.13	.03	.08	.08
PwD functioning															
9. PwD MMSE										.41**	-.06	.04	-.06	-.05	.06
10. PwD ADCS-ADL											.05	.06	.02	.04	-.08
Relationship quality															
11. CG relationship quality												.34**	.10	.03	-.39**
12. PwD relationship quality													.03	.05	.04
CG coping strategies															
13. Emotion focused														.46**	.17
14. Problem focused															.34**
15. Dysfunctional															

*Correlation is significant at the .05 level, ** Correlation is significant at the .01 level. CG= caregivers, PwD= person with dementia.

Table 5: Variables entered into baseline multiple regression predicting distress concordance

	Standardised B	**T**	**P**
Caregiver QoR	-.06	-.69	.494
Caregiver dysfunctional coping strategies	.39	4.56	<.001

examining the variance inflation factor (VIF). No VIF was observed to be greater than 10, which has been proposed as criteria of when to be concerned about multicollinearity (Myers, 1990).

At one year, in contrast to baseline, both self-rated and caregiver proxy rated distress in the PwD demonstrated a weak positive association with caregiver distress: *r*(132) = .19, p = .029, r(132)= .21, p= .016 respectively. Of the 132 dyads, in 96 (73%) dyads self-rated distress was higher in the caregiver, in 36 (27%) dyads self-rated distress was higher in the PwD. Distress concordance at one year was associated with distress concordance at baseline: r(132) = .44, p= <.001. No difference in distress concordance was observed across the four intervention groups of the trial: *F*(3, 128)= 1.32, p= .270. Results for one year correlations for distress concordance between the PwD and caregiver are presented in Table 6. Similarly to baseline, no demographic variable or functioning variable were found to correlate with distress concordance. As at baseline, caregiver rating of relationship quality demonstrated a weak negative association and caregiver use of dysfunctional coping demonstrated a moderate positive association: r(132) = -.21, p= .018, r(132) = .43, p= <.001 respectively.

Caregiver rating of relationship quality and use of dysfunctional coping strategies were therefore entered into the multiple regression model. The multiple regression model was a significant model and explained 19% of the variance in distress concordance: F(2, 129)= 14.83, p= < .001, f^2= 23. Similarly to baseline, caregiver use of dysfunctional coping

Table 6: Correlations between baseline demographics, measures of functioning in the PwD, relationship quality, and coping with distress concordance at one year.

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Distress Concordance		-.02	-.01	.00	-.02	-.04	-.06	-.02	.09	-.07	-.21*	.11	-.10	.12	.43**
Demographic variables															
2. CG age			-.24**	.00	-.29**	-.08	-.53**	-.75**	.05	-.11	-.11	-.09	-.11	-.09	-.11
3. CG gender				.11	-.42**	.11	.07	.11	.12	-.15	-.11	.02	.10	-.06	.14
4. PwD age					.22*	.04	.35**	.45**	-.26**	-.29**	-.01	.13	-.05	-.04	-.04
5. PwD gender						-.08	.35**	.53**	-.27**	-.02	.20*	.25**	.00	.13	-.06
6. Care months							-.02	.10	-.08	-.27**	-.11	.02	.20*	-.02	.11
7. Cohabiting								.67**	-.19*	.07	.09	.27**	-.01	.16	.05
8. Kinship									-.17	-.02	.13	.13	.03	.08	.08
PwD functioning															
9. PwD MMSE										.41**	-.06	.04	-.06	-.05	.06
10. PwD ADCS-ADL											.05	.06	.02	.04	-.08
Relationship quality															
11. CG QoR												.34**	.10	.03	-.39**
12. PwD QoR													.03	.05	-.04
CG coping strategies															
13. Emotion focused														.46**	.17
14, Problem focused															.34**
15. Dysfunctional															

*Correlation is significant at the .05 level, ** Correlation is significant at the .01 level. CG= caregivers, PwD = person with dementia.

Table 7: Variables entered into one year multiple regression predicting distress concordance

	Standardised B	***T***	***P***
Caregiver QoR	-.05	-.54	.590
Caregiver dysfunctional coping strategies	.41	4.79	<.001

strategies was the only significant predictor of distress concordance in the model (see Table 7): standardised β= .41, t= 4.79, p= <.001. An increase in the use of dysfunctional coping strategies by one standard deviation would therefore be predicted to lead to an increase in the transformed distress concordance (i.e. a lower concordance in distress) by 0.41 (untransformed =0.17). As caregiver relationship quality and use of dysfunctional coping strategies were observed to correlate (see Table 6), the multiple regression model was checked for problems with multicollinearity by examining the variance inflation factor (VIF). No VIF was observed to be greater than 10.

Hypothesis ii) Ratings of relationship quality by the PwD and caregiver will predict their own psychological distress and distress in the other member of the dyad

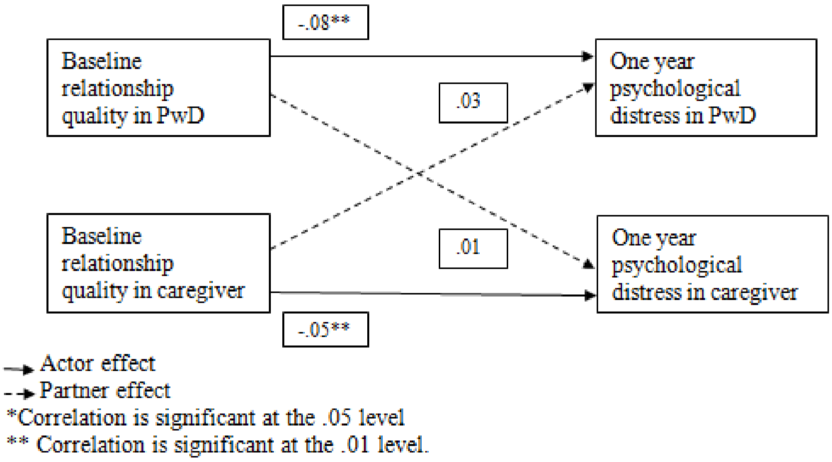
The positive correlation in self-rated distress between the PwD and caregiver at follow-up suggested potential interdependence, which is necessary for an analysis using the Actor Partner Interdependence Model. Characteristics of variables included in the actor-partner interdependence multi-level model are presented in Table 8 and Figure 2. A longitudinal model was used with baseline relationship quality used to predict distress at one year. Baseline relationship quality between the PwD and caregiver demonstrated a medium positive association: r(132)= .34, p= <.001. Ratings of relationship quality by PwD at baseline exhibited an actor effect on their own ratings of psychological distress at one year: People with dementia with higher ratings of relationship quality at baseline had lower levels of psychological distress over time (β= -.08, p= < .001). Similarly, there was an actor effect of ratings of relationship quality by caregivers on their own ratings of psychological distress.

As with people with dementia, caregivers with higher ratings of relationship quality at baseline had lower levels of psychological distress over time (β= -.05, p= < .001). The actor effect for people with dementia was greater than the actor effect for caregivers: t(230.934) = -6.45, p= <.001. There was no partner effect of ratings of relationship quality by the caregiver at baseline on psychological distress in the PwD at one year (β= .03, p= .143), indicating that caregivers perception of relationship quality does not impact upon psychological distress in the PwD over time. Similarly, there was no partner effect of ratings of relationship quality by the PwD at baseline on psychological distress in caregivers at one year (β= .01, p= .488), indicating that perception of relationship quality by the PwD does not impact upon psychological distress in caregivers over time.

Table 8: Variables included in the Actor Partner Interdependence Model

Variable	***B***	***T***	***P***
PwD actor effect	-.08	-4.80	<.001
PwD partner effect	.01	-.70	.488
Caregiver actor effect	-.05	-4.18	<.001
Caregiver partner effect	.03	1.47	.143

Figure 4: APIM results



Hypotheses iii) Coping strategies will moderate the relationship in distress between dyad members

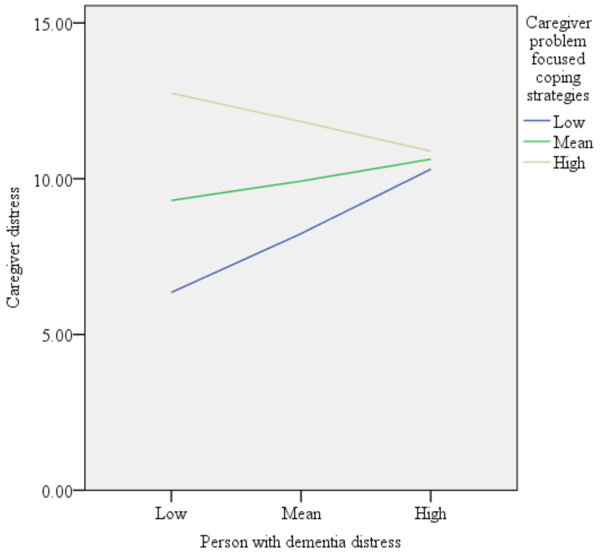
Results of a cross-sectional moderation analysis using baseline data are presented in Table 9. Only problem-focused coping was found to moderate the relationship between distress in the PwD and distress in the caregiver, with no significant findings for either emotion-focussed coping or dysfunctional coping. Simple slopes analysis (See Figure 3) revealed that when problem focused coping is low, there was a significant positive relationship in distress between the PwD and caregiver: β= .33, 95% CI (.016, .642), *t* = 2.08, *p* = .040. The relationship in distress between the PwD and caregivers was not significant at either the mean [β= .10, 95% CI (-.094, .293), *t*= 1.02, *p*= .311] nor high [β = -.13, 95% CI (-.411, .150), *t*= -.92, *p*= .360] levels of problem-focussed coping

Table 9: Interaction effects predicting caregiver distress at baseline

	B	**SE β**	***T***	***P***
Emotion focused coping x PwD distress	-.04	.03	-1.56	.121
Problem focused coping x PwD distress	-.05	.03	-2.01	.046
Dysfunctional focused coping x PwD distress	-.02	.03	-.87	.387

Longitudinal moderation analysis was carried out in which the outcome was caregiver distress at one year, the predictor was distress in the person with dementia at baseline and the moderator was coping at baseline. In contrast to cross-sectional analysis at baseline, none of the longitudinal moderation analyses were significant at the 5% level, although the analyses for both problem-focused coping and dysfunctional coping approached significance: Emotion focused coping strategies β= -.01, 95% CI (-.06, .04), *t*= -.57, *p*= .570, problem focused coping strategies β= -.05, 95% CI (-.11, .00), *t*= -1.85, *p*= .066, dysfunctional coping strategies β= -.06, 95% CI (-.12, .00), *t*= -1.93, *p*= .056.

Figure 5: The relationship between PwD distress and caregiver distress at baseline for different levels of caregiver problem focused coping.



Summary

Correlation, regression, dyadic regression and moderation analyses were undertaken to look at different aspects of distress concordance.

*Hypothesis i: There will be a concordance in psychological distress between the PwD and caregiver***.**

This hypothesis was supported at both baseline and one year when distress in the PwD was rated by carers, and at one year only when distress was self-rated by the person with dementia. At a group level, concordance was not observed between people with dementia and caregivers.

Psychosocial factors including caregiver quality of relationship and use of dysfunctional coping strategies, and not socio-demographic variables. cognitive functioning or functional capacity in the PwD, predicted concordance both cross-sectionally and longitudinally.

Hypothesis ii) Ratings of relationship quality by the PwD and caregiver will predict their own psychological distress and distress in the other member of the dyad.

This hypothesis was partially supported. Actor effects were observed for both the PwD and caregiver. No partner effects, however, were observed for either the PwD or caregiver. The APIM analysis suggests that the concordance in psychological distress observed at one-year can be explained by the fact that actor effects of relationship quality on psychological distress are observed in both dyad members, and that there is a positive association in relationship quality between the PwD and caregiver.

Hypothesis iii) Coping strategies will moderate the relationship in distress between dyad members.

This hypothesis was partially supported. At baseline problem focused coping was found to moderate the relationship between distress in the PwD and caregiver, whereas no coping strategy was a significant moderator in the longitudinal analysis.

Discussion

Key findings

The present study aimed to explore psychological distress in dementia from a dyadic perspective. The primary aim was to examine concordance in psychological distress between people with dementia and caregivers, and the variables associated with concordance. The key findings were that, on a dyad level, self-rated distress concordance increased over time. Overall levels of distress were low for both people with dementia and caregivers; therefore dyads were concordant in experiencing relatively low levels of distress at one year. The strength of concordance was weak and therefore instead of examining whether dyads are concordant in psychological distress, a more helpful question may be which dyads are more likely to demonstrate concordance. The present study found that caregiver perceived relationship quality and coping strategies both influenced concordance.

One possible explanation of why self-rated concordance was observed at one year and not at baseline is that there is a time lag between changes in one person's psychological distress and changes in their partner's distress. Emotion contagion theory (Hatfield et al., 1994) would suggest that repeated exposure to symptoms results in repeated mimicry and feedback over time resulting in concordance in psychological distress. Therefore the greater exposure may explain why a concordance in psychological distress was observed at one year compared to baseline.

The findings of the present study, however, do not support this explanation. No association was found between distress concordance and months of caregiving. Furthermore, dyad members had experienced the caregiving relationship for an average of four years at baseline which would suggest that they would have been exposed to the emotional states of the other for a considerable length of time at baseline. In addition, cohabitation was not associated with concordance. This suggests that duration and intensity of exposure to symptoms are not sufficient to explain why concordance was observed at one year and not baseline; other factors appear important in understanding concordance. The present study extended the literature on health concordance by examining possible psychosocial variables that predict concordance in psychological distress, including relationship quality and coping strategies. Both relationship quality and coping were associated with distress concordance. In line with previous research, socio-demographic variables or cognitive or functional capacity of the PwD did not predict distress concordance (Bookwala & Schulz, 1996; Goodman & Shippy, 2002; Tower & Kasl, 1995; 1996).

As relationship quality increased, concordance in psychological distress was found to be greater in the present study. Interestingly, kinship, i.e whether the caregiver was a spouse or non-spouse, did not predict distress concordance. It appears the relationship quality, not the nature of the relationship, is important. One potential explanation of relationship quality being associated with distress concordance is that as well as exerting intrapersonal effects on distress in the individual, relationship quality may demonstrate interpersonal effects and impact upon distress in the other dyad member. This hypothesis was tested using the APIM. In accordance with previous research (Quinn, Clare & Woods, 2009), on an intrapersonal level greater relationship quality was associated with lower distress. However, in contrast to previous research (Segrin et al., 2007), on an interpersonal level relationship quality in one dyad member was not associated with distress in the other dyad member. Therefore the hypothesis that concordance would be attributable to interpersonal effects of relationship quality was not supported. Higher relationship quality in one dyad member was associated with higher relationship quality in the other. Therefore the APIM model suggests that concordance in psychological distress can be attributed to the association in relationship quality between the PwD and caregiver, and that for both dyad members greater relationship quality is associated with lower distress. This would suggest that increasing relationship quality would be beneficial in reducing distress for both dyad members.

An alternative explanation is that greater relationship quality may provide a platform for emotion contagion to take place. Emotion contagion has been hypothesised to be a generally healthy trait which enhances empathy (Hatfield et al., 1994). Empathic concern for another person has been found to be greater in individuals with whom we have a closer relationship (Block, 1981; Cialdini, Brown, Lewis, Luce & Neuberg, 1997); therefore emotional contagion, and thus concordance, may be greater with those with whom we have a better quality of relationship. This highlights the question of how much empathy is beneficial when in a dyad faced with a long-term condition. If distress is low, empathy may be beneficial in experiencing concordant low levels of distress. However, if distress in the other is high, a balance is needed between enough empathy to allow appropriate care for the individual, but not so much empathy that an individual’s own health deteriorates which then impacts upon the care they can provide for the other (Morse, Mitcham & van der Steen, 1998).

Coping strategies employed by caregivers were also found to impact upon concordance in the present study. As use of dysfunctional coping strategies increased, concordance in psychological distress was found to be lower. In addition, at baseline when use of problem focused coping by the caregiver was low, there was a concordance in distress between dyad members. Dysfunctional coping strategies have been shown to be associated with higher levels of distress (Cooper et al., 2006; Mausbach et al., 2006). The use of dysfunctional coping strategies may therefore increase the level of distress experienced in the caregiver to greater than that of the person with dementia. This may be particularly apparent if the PwD is using relatively less dysfunctional coping strategies. The use of problem-focused coping strategies has also been shown to be associated with higher levels of distress (Cooper et al., 2008). Therefore, in the short-term, low use of problem-focused coping strategies may maintain concordant low levels of distress. This may be particularly evident if the person with dementia is equally using low levels of problem-focused strategies. Taken together, the findings suggest that the coping strategies caregivers employ when faced with psychological distress in the other appears to influence the emotional consequences for the caregiver and whether concordant emotions are experienced (Monin & Schulz, 2010).

This study adds to the existing longitudinal research (Mohamed et al., 2010; Neundorfer et al., 2001; Schulz et al., 2008) by gathering self-ratings of distress from the person with dementia rather than relying on proxy-ratings. In common with previous longitudinal studies, a positive association in psychological distress was found between the PwD and caregivers when distress in the PwD was proxy-rated. The correlation remained significant when distress in the person with dementia was self-rated, although only at the one year time point.

One potential explanation for the variance between ratings is that caregivers' ratings may be biased by their own internal state. Cognitive models propose that depressed and anxious individuals present with negative biases in information processing (Beck, 1979; 1985) impacting on their ability to accurately assess the emotional states of others. However the results of the present study do not provide support for this hypothesis. Caregivers rated themselves as more distressed at one year whilst no change in proxy-rating distress for the PwD was observed from baseline to follow-up, suggesting that caregiver proxy ratings were not influenced by their own emotional state. An alternative explanation is that the PwD may be unable to accurately self-report symptoms due to difficulties with cognition. This explanation was also not supported by the findings of the present study: Caregiver proxy ratings of distress in the PwD and self-rated distress in the PwD were found to be positively correlated at both baseline and one year, despite cognitive functioning in the PwD being observed to decline from baseline to one year.

Clare's (2004) biopsychosocial framework for understanding awareness in early-stage dementia may add to our understanding of factors contributing to difference in self and proxy ratings of distress. At a biological level, impairment in awareness may be a result of cognitive decline in areas such as memory and executive function. At a psychological level the response of the individual at the onset of dementia can be viewed as a potential source of threat to self. An individual registers that changes are occurring and their attempts to make sense, and to adjust to, changes fall along a continuum of self-maintaining to self-adjusting approaches. Self-maintaining responses aim to preserve the pre-existing self-concept whilst self-adjusting responses aim to incorporate new experiences into a changing self-concept. Self-adjusting responses are associated with higher levels of awareness (Clare, Wilson, Carter, Roth, & Hodges, 2002). On a social level, the awareness a person with dementia presents may be dependent on the social context. For example, they may adapt the level of awareness they express depending on how they believe it will be perceived by others including family members, clinicians and researchers. Therefore difference in ratings of distress between the PwD and caregiver is likely to be influenced by a complex interaction between biological, psychological and social factors.

Limitations of the present study

The reliance on self-report measures for distress, relationship quality and coping strategies is problematic as it raises the possibility of shared method variance, i.e. that two variables may covary due to common measurement method. This may therefore inflate the association between the independent variable and dependent variable (Billings & Wroten, 1978).

Using a different measure to assess self-rated distress and caregiver proxy rated distress in the PwD also had limitations. Asking caregivers to complete proxy-ratings on the HADS may have been more beneficial. This would have allowed direct comparison of the difference in ratings of distress in the PwD and identification of any specific items where ratings particularly diverge.

A further limitation of the study was the absence of a measure of coping strategies used by the PwD, which meant coping impacting on concordance could not be examined from a dyadic perspective. The importance of examining coping in both members of a dyad facing a shared threat has been asserted by researchers (Bodenmann, 2005). For example, dyads where both members use ineffective coping styles have been found to show higher levels of distress (Badr, 2004; Giunta & Compas, 1993). Concordance in distress may therefore depend on whether dyad members use concordant coping strategies.

Characteristics of the sample also need to be taken into account when considering the generalisability of the findings. Overall levels of psychological distress were low in both people with dementia and caregivers. This is likely to be a result of participants being recruited to the trial based on their dementia and caregiving status as opposed to their clinical status. Individuals who experience high levels of distress may be less likely to participate in research. The generalisability to dyads that experience higher levels of distress may therefore be limited. In addition, only participants who did not drop-out of the study from baseline to one year were included. This is advantageous in examining factors impacting concordance longitudinally as it ensures the demographic variables of the sample remain consistent. However those who dropped out of the study may systematically differ from those who remain in the study, and thus limit the generalisability of the findings. Furthermore, the majority of dyads were of a white British ethnicity which may limit the generalisability of the findings to dyads from other ethnic backgrounds.

Future Research

A number of avenues for future research have emerged from the present study. It highlights the importance of examining the interrelationship between dyad members in a field of literature which predominantly examines the experiences of dyad members independently (Nolan et al. 2002; Forbat, 2003). The use of statistical models that are able to use the dyad as the unit of analysis is recommended. This allows exploration of how each dyad member's characteristics impacts on their wellbeing and their partners' wellbeing. The present study used the APIM to examine how one dyads member's perception of relationship quality impacts on their own psychological distress and their partner's psychological distress. Further research could use this framework to examine other variables that may have both intrapersonal and interpersonal effects on distress. For example the APIM analysis could be used to explore one person's distress at baseline on their own and partner's distress at follow-up. The APIM framework could also be used to examine coping from a dyadic perspective. The impact of each dyad members use of coping strategies on their own, as well as their partner's levels of psychological distress could be explored.

Future research could also explore whether psychosocial factors are independent in their impact of health concordance or whether they provide a context for the process of emotion contagion to take place. One possibility would be to incorporate a measure of emotion contagion such as The Emotional Contagion Scale (Doherty, 1997) which assesses susceptibility to others emotions as a result of afferent feedback generated via mimicry. Whether people with dementia and caregivers who rate themselves as having a high relationship quality also rate themselves as being more susceptible to the emotions of the other could be examined. In addition, whether the association between susceptibility to the emotions of others and distress is moderated by the use of coping strategies could be explored. Another possibility is to examine whether distress in one dyad member predicts distress in the other independently of psychosocial variables. This could be achieved by controlling for psychosocial variables using hierarchical regression models.

Other avenues for future research would to be to examine self-rated and caregiver proxy rated distress in the PwD using the same measure of distress. This would allow direct comparison of the difference in ratings of distress in the PwD and identification of any specific items where ratings particularly diverge. Future research could also examine the generalisability of the present study’s findings by replicating the research with dyad members who experience higher levels of distress and dyad members from different ethnic backgrounds.

Implications for practice

The findings of the present study highlight interpersonal risk factors for psychological distress in people with dementia and caregivers experiencing dementia. In order to provide effective interventions for those facing dementia, both dyad members should be included in treatment plans with the aim of reducing distress in dyads simultaneously. If interventions aim to reduce distress in one member, the effects may be limited if the individual continues to be exposed to distress in the other. Relationship quality and coping strategies, which were highlighted as important in the present study, may be beneficial to target in interventions. The findings of the present study suggest that interventions aiming to build upon relationship quality could lead to concordant low distress. Caregivers may also benefit from help in reducing dysfunctional coping strategies to regulate their emotions when faced with psychological distress in their partner. Government policy emphasises providing support for both the PwD and caregiver (Department of Health, 2009). The present study suggests that a dyadic perspective may be beneficial in providing this support. This may involve joint assessment of both dyad members on presentation to services and follow-up, and the provision of treatments that aim to reduce psychological distress in both dyad members concurrently.

Conclusion

In conclusion, the study investigated whether there was a concordance in psychological distress between people with dementia and caregivers, and the psychosocial variables that influence this. The findings of the study indicate that concordance in psychological distress increases over time and that relationship quality and coping strategies impact upon concordance. A question remains to whether these variables influence concordance independent of processes such as emotion contagion or whether they provide a platform for such processes to take place. The findings represent an avenue for further research rather than an endpoint in themselves. Despite the limitations of the study, it has highlighted the importance of taking a dyadic perspective in research, theory and policy that endeavours to support those who experience dementia.

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Part 3: Critical Appraisal

Introduction

This critical appraisal contains my reflections on the issues that arose during the conceptualisation and implementation of the research presented in part 2 of this thesis. It begins by focusing on the theoretical, ethical and practical issues that arise when including people with dementia in research. Reflections on the limitations of the use of quantitative measures in examining distress from a dyadic perspective are then presented. The appraisal concludes with a discussion of hopes for what the research will contribute to the dementia literature.

Including people with dementia in research

Personhood in dementia

The value of including people with dementia in research and policy was often overlooked until the 1990s (Cotrell & Schulz, 1993; Hubbard, Downs & Tester, 2003; Lyman, 1989). Research tended to be conducted about people with dementia, rather than with them. People with dementia also face a double stigma of being both old and having a neurodegenerative illness (Benbow & Reynolds, 2000; Graham et al., 2003; Lyman, 1989; Sartorius, 2003; Vernooij-Dassen et al., 2005), emasculating the individual's moral status (Goffman, 1963; Liu, Hinton, Tran, Hinton & Barker, 2008). With the increasing public awareness of the burden of the ageing population and dementia, and with older adults and individuals with dementia transgressing key Anglo European-American cultural values of independence, mastery and productivity (Herskovits & Mitteness, 1994), the stigma of old age and dementia remains ever present.

Moving away from a position where the experience of people with dementia was understood as a disease process with a focus on cognitive and functional decline (Lyman, 1989) to a biopsychosocial perspective has had important implications for research. Biopsychosocial models of dementia (e.g. Spector & Orrell, 2010) challenge researchers to consider the extent to which psychological and contextual factors contribute to the experiences of people with dementia and caregivers. Kitwood’s (1997) conceptualisation of personhood asserts the need to recognise that people with dementia are individuals with a sense of self, who live in a world of relationships, and who have, and are capable of expressing, thoughts and feelings. This challenges cultural beliefs that a lack of cognitive capacity equates to a lack of personhood (Dewing, 2008). Including people with dementia in research and acknowledging the value of their lived experience, is one way to sustain the personhood of people with dementia and challenge the cultural image of people with dementia as individuals lost to illness.

My experience of interviewing people with dementia in the current research study, suggests that individuals with dementia often value taking part in research. Many individuals expressed a keenness to contribute to research to help understanding of dementia, with a common theme emerging in wanting to help others who may face dementia like themselves. It struck me that participants had wisdom about dementia beyond what research could inform me about. I valued how open individuals were to share this wisdom with me. Wisdom is commonly attributed as a potential positive aspect of aging (Baltes & Smith, 2008; Erikson, 1963; Ranzijn, 2002; Knight & Poon 2008). Wisdom reflects the rich depth of procedural and factual knowledge developed over the course of a lifespan, a relativism of values and life priorities, and a recognition and tolerance of uncertainty (Baltes & Staudinger, 2000). Personhood is constructed and maintained in the context of our interactions with others (Kitwood, 1997). Therefore as researchers if we relate to people with dementia as individuals with wisdom about their lived experience, focusing on what they can contribute as opposed to what they cannot contribute, the emphasis is on maintenance of personhood.

Ethical considerations

Dementia research faces the ethical challenge of including people with dementia in research, whilst safeguarding the rights and interests of individuals who may be vulnerable due to lacking the capacity to provide informed consent (Karlawish, Kim, Knopman, Van Dyck, James & Marson, 2008; Warner, McCarnery, Griffin, Hill & Fisher, 2006; Black et al., 2008). Where informed consent is unable to be given by the person with dementia, the common procedure is to obtain informed consent from a proxy as well as obtaining assent from the person with dementia and respecting dissent. Assent refers to the individual's affirmative agreement to partake in research (Cahill & Wichman, 2000) and dissent to the refusal to partake in research even when informed consent has been obtained from a proxy (Cohen-Mansfield, 2003). If a person with dementia who lacks capacity assents but the proxy does not provide consent, the convention is that the decision of the proxy prevails. If the proxy provides consent but the person with dementia dissents then the decision of the person with dementia prevails (Black et al., 2011).

My experience of conducting the interviews was that as well as assenting, the vast majority of participants appeared keen and enjoyed participating in research. I observed this enthusiasm to participate across the sample, including participants who scored poorly on tests of cognitive functioning and who therefore might have been considered at higher risk of not being able to provide informed consent. This highlights the importance of competence not being viewed as a global capacity; instead, it is important to consider whether a person can do a specific task in a specific context (Mental Capacity Act, 2005). My experience was that a number of participants who scored poorly on tests of cognitive functioning and measures of activities of daily living appeared capable, with some support, of providing considered responses on the measures administered, e.g. questions about psychological distress and the quality of relationships. The kind of additional support that appeared beneficial is discussed below in the section of research challenges.

Interestingly, there were occasions where my perceptions of competence in the person with dementia appeared to differ from the caregiver's perception. For example, when I went to conduct the interview with one person with dementia, the caregiver commented that they were "not sure if she will be able to tell me anything useful". However my experience was that the person with dementia was willing and capable of providing considered responses. I was curious about what factors might be influencing these different perceptions of competence. Clare's (2004) biopsychosocial framework for understanding awareness in early-stage dementia may help to understand how perceptions of competence in people with dementia may differ. This model proposes that awareness in dementia is not just a reflection of cognitive decline in areas such as memory and executive function, but is also influenced by psychological adjustment and social context. On a social level, people with dementia may adapt the level of awareness they present with based on how it will be perceived by others. A research study which includes gathering self-report information may create an opportunity where people with dementia feel they have licence to discuss their experiences of dementia. This opportunity may not be as readily available or have different connotations when discussed with caregivers.

The difference in perceptions of competence has implications for people with dementia who participate in research. All participants in the current research, who were unable to provide informed consent, had informed consent from a proxy and provided assent to take part in the research. There may be a group of people with dementia in the population who may not be able to provide informed consent but would provide assent to take part in research, however they are restricted to take part because informed consent is not given by a proxy. There is no straightforward resolution to this dilemma (Hellstrom, Nolan, Nordenfelt

& Lundh, 2007). While obtaining proxy consent provides important safeguards, it is important to bear in mind that this may exclude a sub-sample of participants where there is discrepancy in the views of competence in the person with dementia. This is a particularly important point for dyadic research, as the interrelationships between dyads where there is discrepancy in perceptions of competence in people with dementia may differ in nature from dyads where there is greater consensus.

Research challenges

Cognitive decline in areas such as memory, language and executive functioning may pose challenges for people with dementia to engage in research. Given the average age of caregivers in the research presented in part 2 of this thesis being 67, consideration of cognitive functioning in caregivers is also warranted. Cognitive aging is associated with a decline in mental processing speed, attention, language, memory and executive functioning (e.g. Finkel & Pederson, 2000; Hertzog & Bleckley, 2001, Zimproch, 2002). To reduce the cognitive load of the interviews, prompt cards were provided for both people with dementia and caregivers that displayed the response options for questionnaires. Other factors to facilitate effective communication with people with dementia were also considered, for example providing a calm and well paced presentation of questions, maintaining eye contact, being comfortable with pauses and expression of emotions (Goldsmith, 1996).

My experience of conducting the interviews was that caregivers used the prompt cards minimally whilst the person with dementia appeared more reliant on them. The majority of People with dementia I interviewed needed limited assistance using the prompt card after the initial presentation of the card and the range of responses being indicated verbally as well as pointed to. The structure of the interview appeared to assist with this with a repeated procedure of a question being asked and the participant given time to scan the prompt card and provide an answer. At times individuals did appear to find it difficult to hold the question in mind whilst scanning the response options and required the question to be repeated.

Limitations of quantitative measures

Presentation of anxiety and depression symptoms in different populations

Consideration is needed in the presentation of symptoms of distress when comparing adults and older adults. The current research aimed to compare experiences of distress between people with dementia and caregivers by combining scales measuring depression and anxiety. The benefit of this approach is that it facilitated comparisons to be made in distress in people with dementia and caregivers; however it fails to reflect how presentations of distress may differ between adults and older adults and between older adults with dementia and older adults without dementia.

In contrast to adults, ‘pure’ anxiety or depression is relatively rare in older adults; mixed anxiety and depression is a more common presentation (Beekman, de Beurs, van Balkom, Deeg, van Dyck & Tilburg, 2000; Kvaal, McDougall, Brayne, Matthews & Dewey, 2008). Beck (1976) proposed the cognitive content-specificity hypothesis, stating that different types of emotional problems have specific cognitive elements. Shapiro, Roberts and Beck (1999) examined the cognitive and affective symptoms of anxiety and depression in a sample of 283 older adults (age range 65-93). The authors concluded that the affective and cognitive presentation of anxiety and depression in older adults is different from that of younger adults. They report that they could find little evidence of distinctive cognitive and affective profiles to differentiate between anxiety and depression in older adults. However they postulate that physical health problems might represent a third variable that is interfering in this relationship.

Similarly to the general older adult population, anxiety and depression in dementia are highly comorbid (Seignourel, Kunik, Snow, Wilson & Stanley, 2008). However, results from factor analyses have produced contradictory findings as to whether anxiety and depression are distinct constructs (Seignourel et al., 2008). The Hospital Anxiety and Depression Scale (HADS) was used as a measure of psychological distress in the research presented in part 2. Its two factor structure of anxiety and depression has been supported across a number of samples (Bjelland, 2002). It has, however, been seldom used in individuals with neurodegenerative illnesses and its validity has not been examined (Schrag et al., 2007). In the research trial (Charlesworth et al., 2011), the HADS was observed to have a four factor solution for people with dementia (see appendix 4). There was some overlap in items of the depression and anxiety scale, with items from both scales loading on to factors 1 and 3. This is suggestive that anxiety and depression are not clear distinct constructs in dementia, as in the general older population. From my observations and reflections of the interviews conducted with people with dementia, mood appeared to be influenced by worries about being a burden to their caregivers. As discussed in further detail below, this was a common theme that arose in discussions during the interview and may be one factor influencing the overlap in symptoms of anxiety and depression.

The four factor solution observed also suggests that the presentation of anxiety and depression may differ in people with dementia compared to the general older population. The first factor appeared to reflect future focused anxieties. It contained the items ‘worrying thoughts go through my mind’, ‘I feel tense or wound up’, ‘I get a sort of frightened feeling as if something awful is about to happen’ and ‘I can enjoy a good book or radio or TV programme’. Whilst factor four appears to reflect a factor that other authors have described as momentary anxiety (Andersson, 1993). It contained the items ‘I get sudden feelings of panic’, ‘I feel restless as if I have to be on the move’ and ‘I get a sort of frightened feeling like butterflies in the stomach’. The second factor comprised of the items ‘I feel cheerful’, ‘I still enjoy the things I used to enjoy’, ‘I look forward with enjoyment to things’ and ‘I have lost interest in my appearance’. It is comparable to what other researcher have labelled as ‘wellbeing’ (Andersson, 1993), reflecting the enjoyment a person derives and hopes to derive in the future. The third factor appeared to relate to the pace of life and contained the items ‘I feel as if I have slowed down’ and ‘I can sit at ease and feel relaxed’. Further replication of factor analysis with the HADS in dementia is needed to establish the reliability of these findings.

The restrictive nature of quantitative measures

The most challenging aspect of using quantitative measures from my perspective was that people with dementia and caregivers were often keen to discuss their responses in further detail. Whilst wanting to respect and empathise with the experience of participants, I needed to balance this against the focus and time constraints of the study. This was particularly difficult when participants shared moving experiences of the challenges they were facing.

A common theme that emerged from people with dementia was that of becoming a burden to others, which is often a source of distress for people with dementia and individuals with other terminal illnesses (Cahill et al., 2004; McPherson, Wilson & Murray, 2007). Wider discussions with caregivers often appeared related to the theme of loss, specifically loss of personal identity in the person with dementia. Despite this experience of loss and grief being widely experienced by caregivers of people with dementia (Meuser & Marwit, 2001), it receives little social recognition (Doka, 2000). One potential reason why these themes may have emerged in discussion with the participants is that the measure of psychological distress used in the research (the HADS), does not address aspects of distress which are interpersonal and related to the experience of others.

I found the guidance of Moore and Hollett (2003) of listening to, empathising with, reflecting the key communication and asking the participant how this experience related to the question at hand particularly helpful. The response prompt card was also particularly helpful in this situation as it provided a concrete object to help redirect attention to the question being asked. However, I was left with a sense that the measures did not capture all aspects of distress which were important to people with dementia and caregivers.

On reflection of the measures used in the current research, another valuable area they did not appear to tap into was the nature of interactions between the person with dementia and caregiver. I observed a wide range of interaction styles between people with dementia and caregivers. For example, variations in communication interactions were evident between dyads such as the amount of directive and overprotective communications by caregivers. The style of communication used by caregivers and how it is perceived by people with dementia is influenced by gender and previous relationship, and impacts on psychological distress experienced by both dyad members (Baltes, 1995; Edwards & Noller, 1998). Variation was also observed in regards to the amount of emotional expression between dyad members. For example, some dyad members appeared to be using protective buffering strategies involving concealing difficult emotions and worries in an attempt to protect their partner (Coyne & Smith, 1991). Although intended to protect the partner, these strategies increase psychological distress in both dyad members (Coyne & Smith, 1991; SuIs, Green, Rose, Lounsbuiy & Gordon, 1997). The study presented in part two was limited by its lack of examination of the impact of communication interactions and protective buffering strategies on concordance in psychological distress and highlights an avenue for further research.

Building Rapport

Given the quantitative nature of the interviews and the fact that I would only be meeting with participants once, I was initially concerned about building rapport with participants in the current study. A good rapport reflects a basic sense of trust between the participant and the researcher and allows the participant to communicate openly. I was keen to build rapport as I hoped it would encourage participants take a considered approach when answering the questions on the questionnaire. From my clinical experience ways I have found helpful in building rapport have been to show a genuine interest in the perspectives of individuals, demonstrate empathy and using reflections of what the person is discussing picking up on key words. The quantitative nature of the research design limited the number of opportunities to do this. I therefore found it helpful to have an opportunity before going through the questionnaires to build rapport.

Social and political factors

Strengths of the research presented in part 2 of the thesis is that it examined the interpersonal nature of distress in dementia, however how wider social and political factors shape the experience of dementia for both dyad members was not explored within the quantitative measures used. Conducting research within a randomised controlled trial allowed me to have the opportunity to complete assessments in different geographical areas which included London, Hampshire and Norfolk. People living in rural communities have been underrepresented in the dementia literature (Blackstock, Innes, Cox, Smith & Mason, 2005) and I was surprised how apparent some of the differences in the challenges dyads faced were.

Dyads I interviewed in rural areas of Norfolk appeared to have less access to services such as Admiral Nurses. Disparity in service provision has been found when comparing individuals living in rural compared to urban areas (McCabe, Sand, Yeaworth & Nieveen, 1995; Shope et al., 1993). A related issue was that of access. Caregivers commented that they were aware of services available, but because they lived in rural areas where public transport was limited, accessing services was difficult. This appeared particularly challenging for dyads where the person with dementia was the previous driver in the relationship. Therefore social change may be needed to facilitate positive changes in intrapersonal and interpersonal experience of distress in dementia. A key objective of the Prime Minister's

Challenge on Dementia (Department of Health, 2012) is facilitating equal access to services for people with dementia and caregivers.

Conclusions and Implications for future research

Including people with dementia in research may help to sustain personhood in dementia and allow the mutual influence of dyad members to be examined. It is not without challenges; ethical, practical and methodological issues need to be considered. Research needs to aim to be inclusive whilst safeguarding the rights and interests of individuals who may be vulnerable due to lacking the capacity to provide informed consent. Consideration is needed regarding the support individuals with reduced cognitive capacity may need in order to give informed answers. The limitations of quantitative measures in capturing the complex interplay between intrapersonal, interpersonal and wider social and political factors that shape the experience of dementia also need to be held in mind. Despite these challenges and limitations, dyadic research provides valuable insights into the experience of dementia for both the person with dementia and caregiver. With the ambitions of the Prime Minister's Challenge on Dementia (Department of Health, 2012) to deliver improvements in health, care and research in dementia, it is crucial that future research, policy and services conceptualise dementia as an interpersonal experience.

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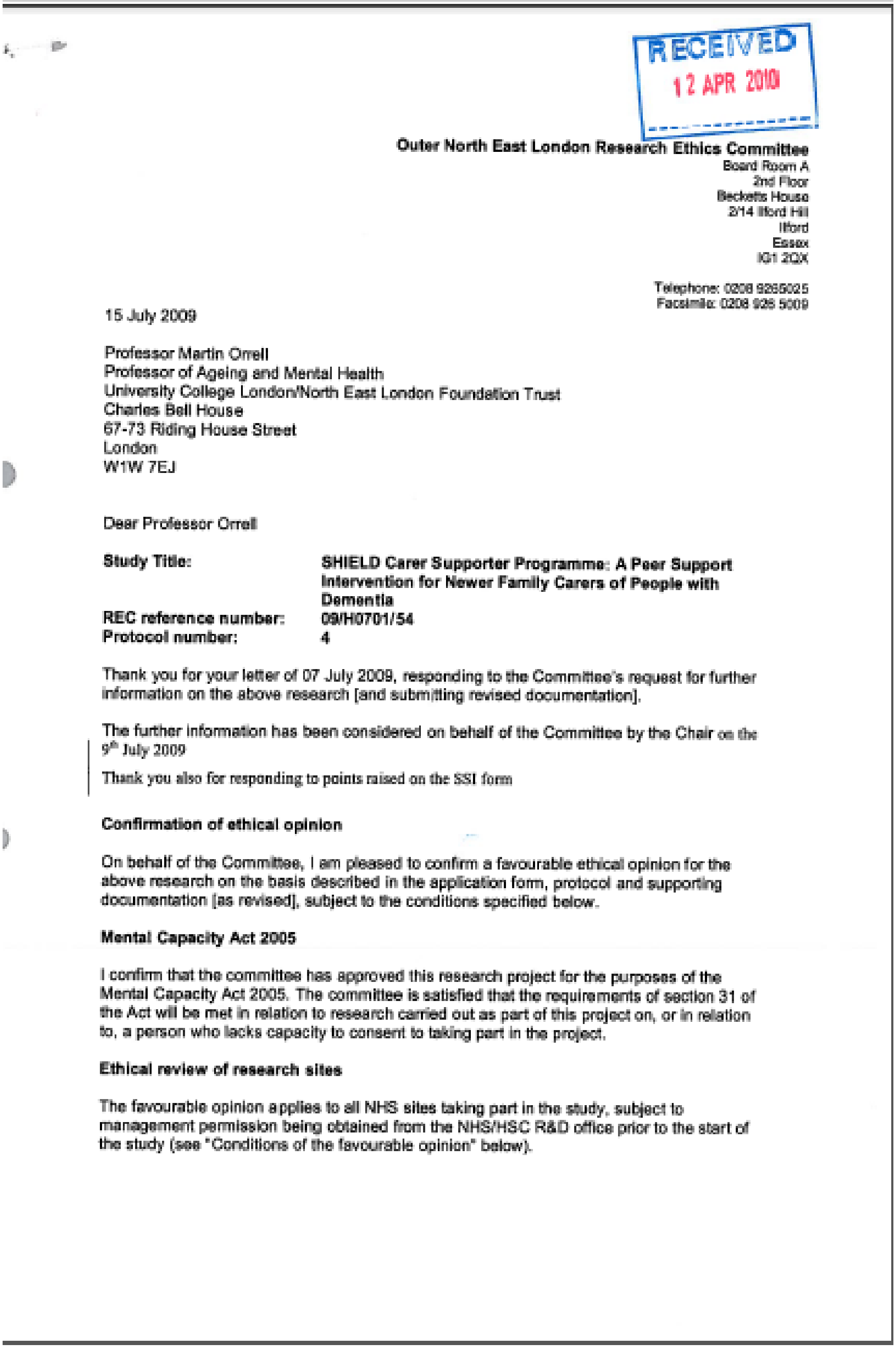
Appendices

Appendix I: Kmet et al. (2004) Standard Quality Assessment Criteria

Criteria
1. Question/objective sufficiently described?
2. Study design evident and appropriate?
3. Method of subject/comparison group selection or source of information/input variables described and appropriate?
4. Subject (and comparison group if applicable) characteristics sufficiently described?
5. If interventional and random allocation possible, was it described?
6. If interventional and blinding of investigators possible, was it reported?
7. If interventional and blinding of subjects possible, was it reported?
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement/misclassification bias?
9. Sample size appropriate?
10. Analytic methods described/justified and appropriate?
11. Some estimate of variance is reported for the main results?
12. Controlled for confounding?
13. Results reported in sufficient detail?
14. Conclusions supported by the results?

Appendix 2: Ethics approval letter for peer support trial



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12 APR 2010

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15 July 2009

Professor Martin Orrell
Professor of Ageing and Mental Health
University College London/North East London Foundation Trust
Charles Bell House
67-73 Riding House Street
London
W1W 7EJ

Dear Professor Orrell

Study Title:	**SHIELD Carer Supporter Programme: A Peer Support Intervention for Newer Family Carers of People with Dementia**
REC reference number:	**09/H0701/54**
Protocol number:	**4**

Thank you for your letter of 07 July 2009, 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 on the 9th July 2009

Thank you also for responding to points raised on the SSI form

Confirmation of ethical opinion

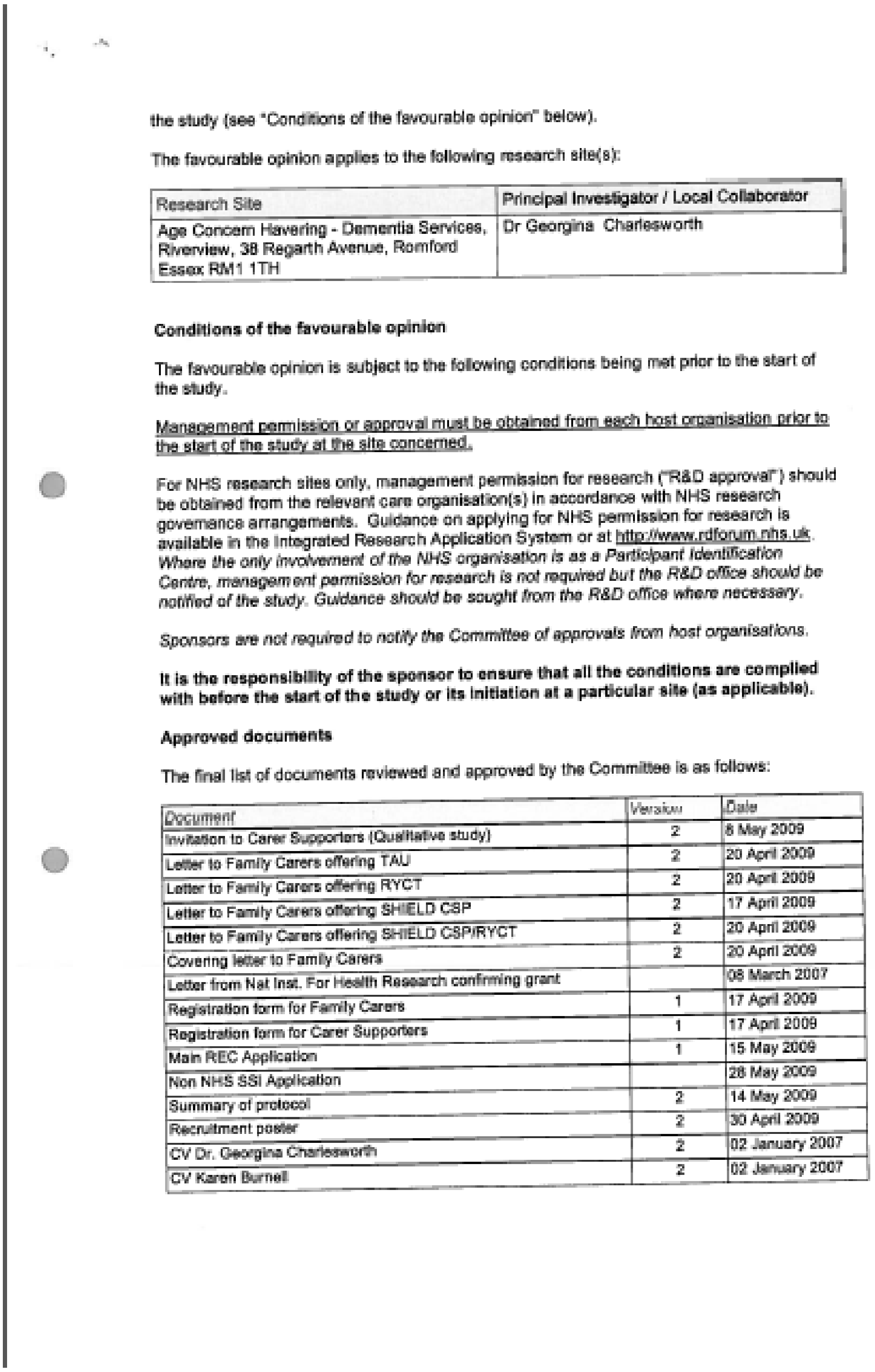
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

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



the study (see "Conditions of the favourable opinion" below).

The favourable opinion applies to the following research site(s):

Research Site	Principal Investigator / Local Collaborator
Age Concern Havering - Dementia Services, Riverview, 38 Regarth Avenue, Romford Essex RM1 1TH	Dr Georgina Charlesworth

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. *Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.*

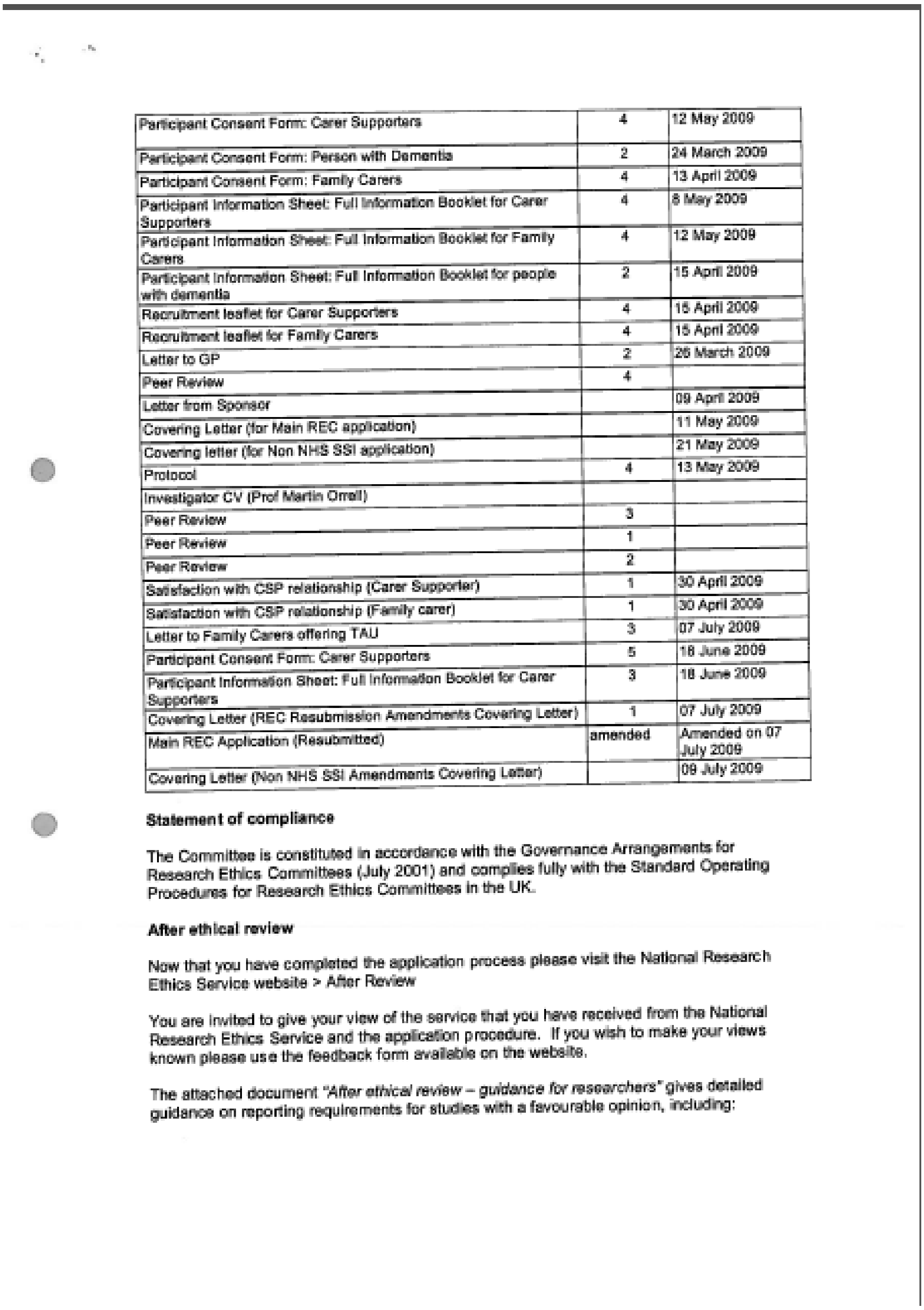
Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

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

Document	*Version*	*Date*
Invitation to Carer Supporters (Qualitative study)	2	8 May 2009
Letter to Family Carers offering TAU	2	20 April 2009
Letter to Family Carers offering RYCT	2	20 April 2009
Letter to Family Carers offering SHIELD CSP	2	17 April 2009
Letter to Family Carers offering SHIELD CSP/RYCT	2	20 April 2009
Covering letter to Family Carers	2	20 April 2009
Letter from Nat Inst. For Health Research confirming grant		08 March 2007
Registration form for Family Carers	1	17 April 2009
Registration form for Carer Supporters	1	17 April 2009
Main REC Application	1	15 May 2009
Non NHS SSI Application		28 May 2009
Summary of protocol	2	14 May 2009
Recruitment poster	2	30 April 2009
CV Dr. Georgina Charlesworth	2	02 January 2007
CV Karen Burnell	2	02 January 2007



Participant Consent Form: Carer Supporters	4	12 May 2009
Participant Consent Form: Person with Dementia	2	24 March 2009
Participant Consent Form: Family Carers	4	13 April 2009
Participant Information Sheet: Full Information Booklet for Carer Supporters	4	8 May 2009
Participant Information Sheet: Full Information Booklet for Family Carers	4	12 May 2009
Participant Information Sheet: Full Information Booklet for people with dementia	2	15 April 2009
Recruitment leaflet for Carer Supporters	4	15 April 2009
Recruitment leaflet for Family Carers	4	15 April 2009
Letter to GP	2	26 March 2009
Peer Review	4	
Letter from Sponsor		09 April 2009
Covering Letter (for Main REC application)		11 May 2009
Covering letter (for Non NHS SSI application)		21 May 2009
Protocol	4	13 May 2009
Investigator CV (Prof Martin Orrell)		
Peer Review	3	
Peer Review	1	
Peer Review	2	
Satisfaction with CSP relationship (Carer Supporter)	1	30 April 2009
Satisfaction with CSP relationship (Family carer)	1	30 April 2009
Letter to Family Carers offering TAU	3	07 July 2009
Participant Consent Form: Carer Supporters	5	18 June 2009
Participant Information Sheet: Full Information Booklet for Carer Supporters	3	18 June 2009
Covering Letter (REC Resubmission Amendments Covering Letter)	1	07 July 2009
Main REC Application (Resubmitted)	amended	Amended on 07 July 2009
Covering Letter (Non NHS SSI Amendments Covering Letter)		09 July 2009

Statement of compliance

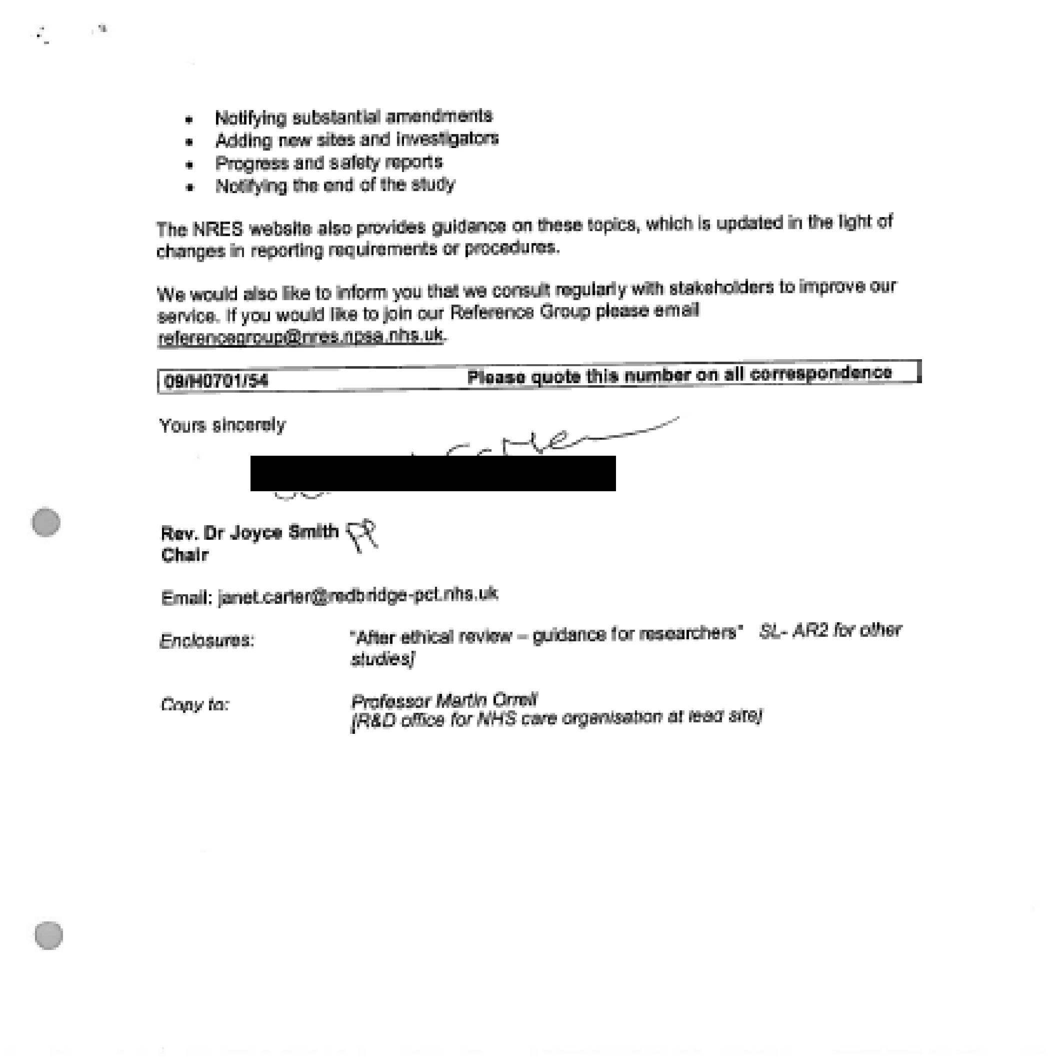
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

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

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



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

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

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

09/H0701/54	**Please quote this number on all correspondence**

Yours sincerely

[redacted]

Rev. Dr Joyce Smith
Chair

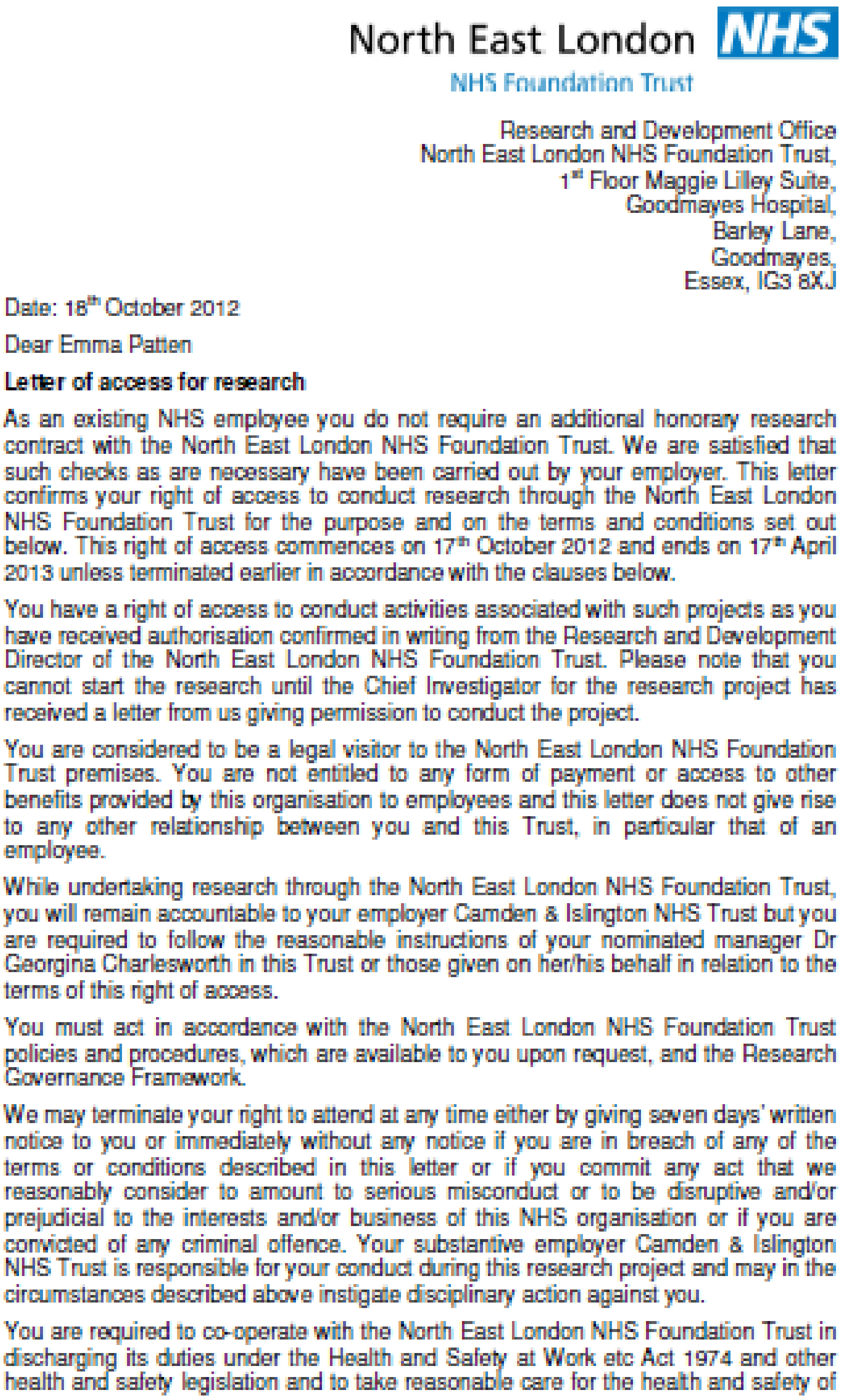
Email: janet.carter@redbridge-pct.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *SL- AR2 for other studies]*

Copy to: *Professor Martin Orrell*
[R&D office for NHS care organisation at lead site]

Appendix 3: Letters of access for research sites

A) North East London NHS Foundation Trust



North East London NHS
NHS Foundation Trust

Research and Development Office
North East London NHS Foundation Trust,
1st Floor Maggie Lilley Suite,
Goodmayes Hospital,
Barley Lane,
Goodmayes,
Essex, IG3 8XJ

Date: 18th October 2012

Dear Emma Patten

Letter of access for research

As an existing NHS employee you do not require an additional honorary research contract with the North East London NHS Foundation Trust. We are satisfied that such checks as are necessary have been carried out by your employer. This letter confirms your right of access to conduct research through the North East London NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on 17th October 2012 and ends on 17th April 2013 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct activities associated with such projects as you have received authorisation confirmed in writing from the Research and Development Director of the North East London NHS Foundation Trust. Please note that you cannot start the research until the Chief Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to the North East London NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this Trust, in particular that of an employee.

While undertaking research through the North East London NHS Foundation Trust, you will remain accountable to your employer Camden & Islington NHS Trust but you are required to follow the reasonable instructions of your nominated manager Dr Georgina Charlesworth in this Trust or those given on her/his behalf in relation to the terms of this right of access.

You must act in accordance with the North East London NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer Camden & Islington NHS Trust is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

You are required to co-operate with the North East London NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on North East London NHS Foundation Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998.

Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The North East London NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by the North East London NHS Foundation Trust in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Please also ensure that while on the premises you wear your NHS ID badge at all times, or are able to prove your identity if challenged. Please note that this Trust accepts no responsibility for damage to or loss of personal property.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform your employer through its normal procedures. You must also inform the Research and Development Department and your nominated manager in North East London NHS Foundation Trust.

Yours sincerely

[redacted]

Sandeep Toot

Research and Development Manager North East London NHS Foundation Trust

B) Norfolk and Suffolk NHS Foundation Trust

Norfolk and Suffolk NHS
NHS Foundation Trust

Research and Development Dept
The Knowledge Centre
Norfolk and Suffolk NHS Foundation Trust
Hellesdon Hospital
Drayton High Road
Norwich
NR65BE
Telephone : 01603 421255
E mail: RDofficemailbox@nsft.nhs.uk

Ms Emma Patten
Trainee Clinical Psychologist
University College London
Gower Street
London
WC1E 6BT

12th December 2012

Dear Ms Patten,

Re: NSFT Letter of Access for research

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that such checks as are necessary have been carried out by your employer and that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. This letter confirms your right of access to conduct research through Norfolk and Suffolk NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on 12th December 2012 and ends on 17th April 2013, unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

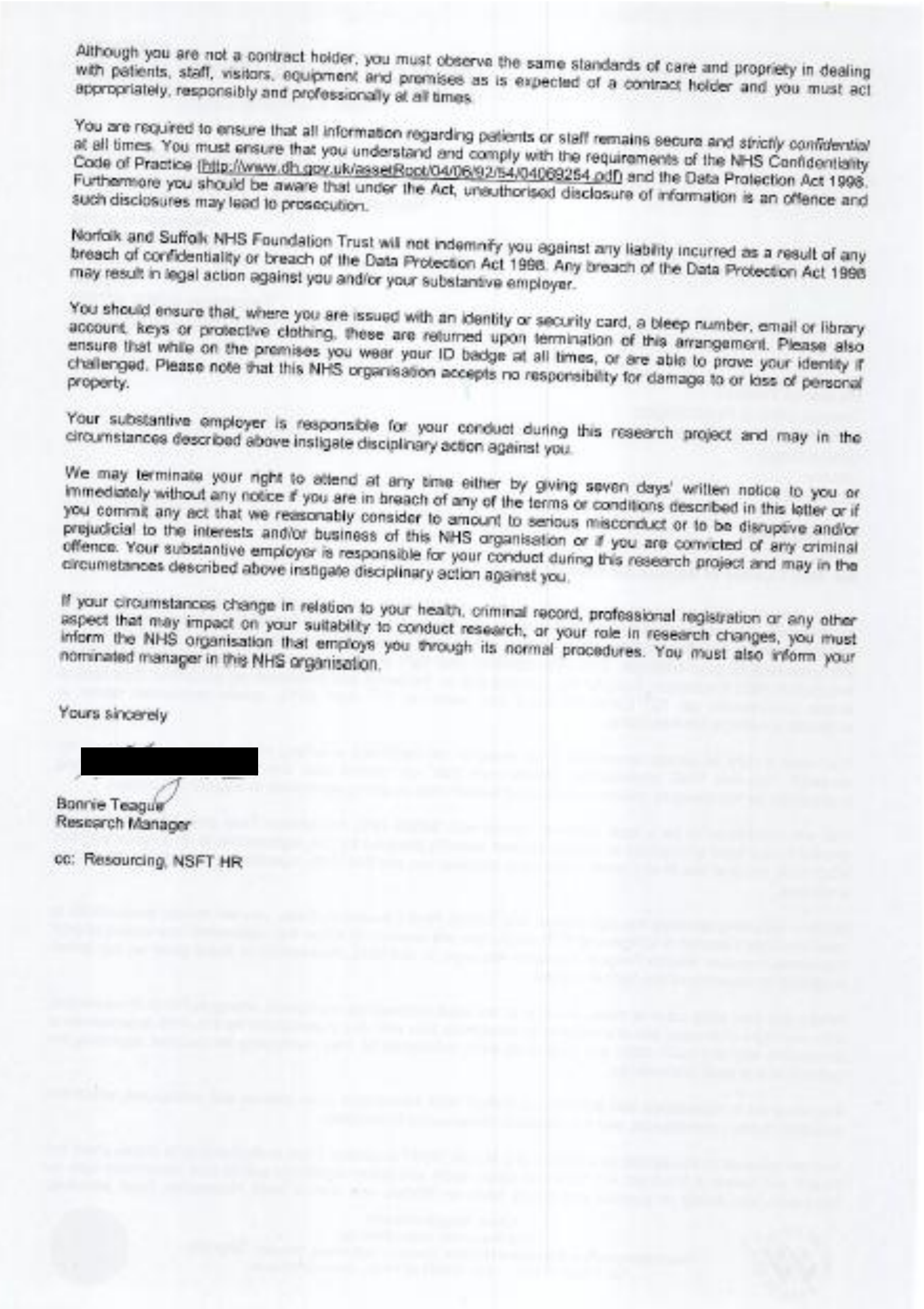
You are considered to be a legal visitor to Norfolk and Suffolk NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Norfolk and Suffolk NHS Foundation Trust, you will remain accountable to your employer Camden & Islington NHS Trust but you are required to follow the reasonable instructions of your nominated manager Bonnie Teague, Research Manager, in this NHS organisation or those -given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with Norfolk and Suffolk NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Norfolk and Suffolk NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Norfolk and Suffolk NHS Foundation Trust premises.



Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Norfolk and Suffolk NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

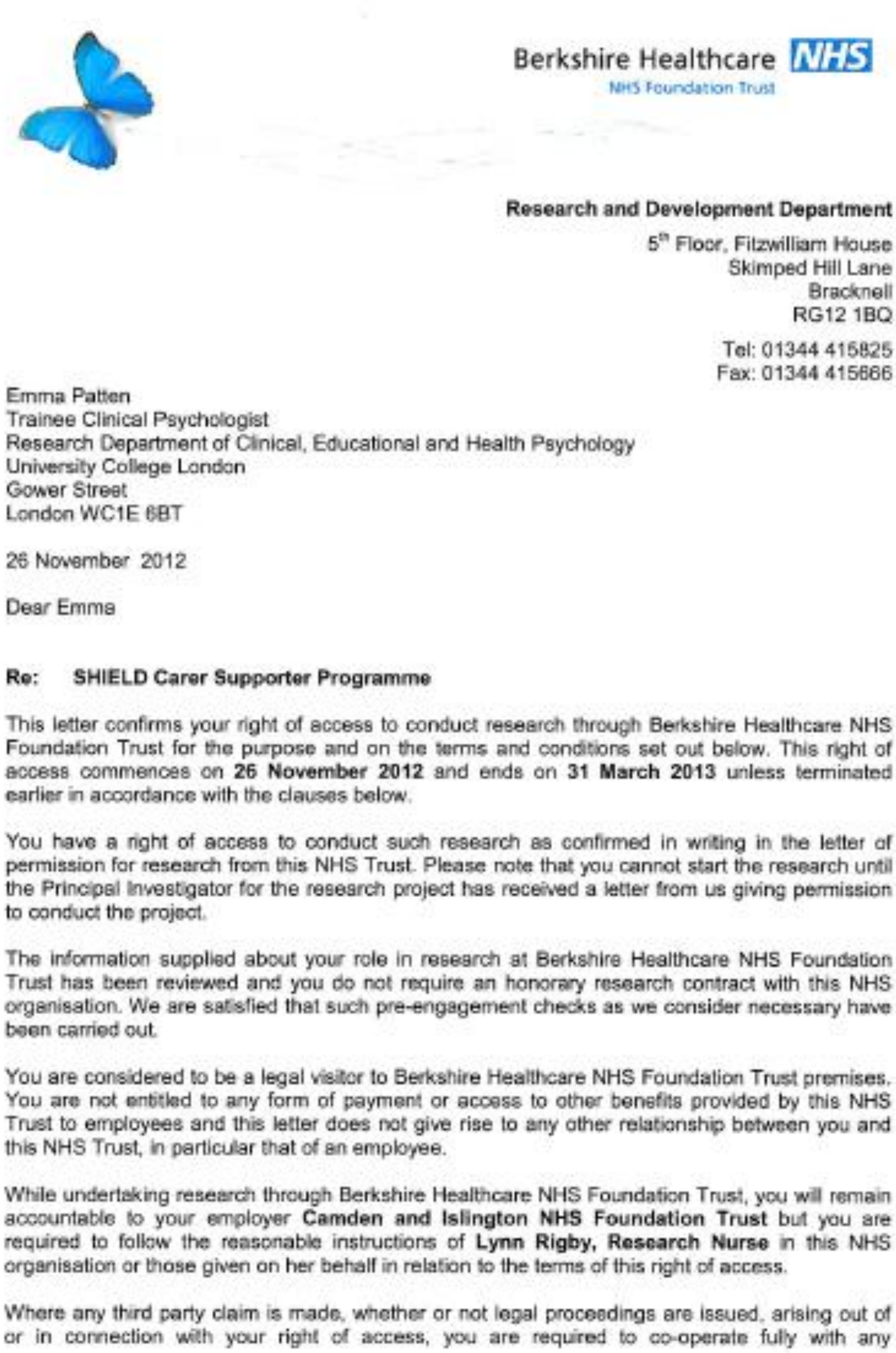
Yours sincerely

[redacted]

Bonnie Teague
Research Manager

cc: Resourcing, NSFT HR

C) Berkshire Healthcare NHS Foundation Trust



Berkshire Healthcare NHS
NHS Foundation Trust

Research and Development Department
5th Floor, Fitzwilliam House
Skimped Hill Lane
Bracknell
RG12 1BQ

Tel: 01344 415825
Fax: 01344 415666

Emma Patten
Trainee Clinical Psychologist
Research Department of Clinical, Educational and Health Psychology
University College London
Gower Street
London WC1E 6BT

26 November 2012

Dear Emma

Re: SHIELD Carer Supporter Programme

This letter confirms your right of access to conduct research through Berkshire Healthcare NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on **26 November 2012** and ends on **31 March 2013** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS Trust. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at Berkshire Healthcare NHS Foundation Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to Berkshire Healthcare NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this NHS Trust to employees and this letter does not give rise to any other relationship between you and this NHS Trust, in particular that of an employee.

While undertaking research through Berkshire Healthcare NHS Foundation Trust, you will remain accountable to your employer **Camden and Islington NHS Foundation Trust** but you are required to follow the reasonable instructions of **Lynn Rigby, Research Nurse** in this NHS organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS Trust in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with Berkshire Healthcare NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Berkshire Healthcare NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Berkshire Healthcare NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and **strictly confidential** at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS Trust or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Berkshire Healthcare NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS Trust.

Yours sincerely

[redacted]

Sylvia Warwick
Research & Development Manager
Berkshire Healthcare NHS Foundation Trust

cc: Luc Pierre, HR Administrator, St. Pancras Hospital, 4 St Pancras Way, London NW1 0PE

Appendix 4: Principal component analysis of HADS data from Charlesworth et al. (2011) trial

Table 1: Pattern matrix of principle components analysis of HADS for persons with dementia

Item	**Component**			
	1	2	3	4
Worrying thoughts go through my mind	.765	.166	-.040	-.012
I feel tense or wound up	.561	.011	.051	.444
I get a sort of frightened feeling as if something awful is about to happen	.556	.142	.075	.316
I can enjoy a good book or radio or programme	-.470	.455	-.158	.419
I can laugh and see the funny side of things	.031	.803	-.041	-.092
I feel cheerful	.037	.706	-.004	-.089
I still enjoy the things I used to enjoy	.279	.677	-.056	-.142
I look forward with enjoyment to things	-.200	.590	-.050	.294
I have lost interest in my appearance	.024	.557	.331	.093
I feel as if I have slowed down	.143	.129	.659	.331
I can sit at ease and feel relaxed	.061	.382	-.524	.203
I get sudden feelings of panic	.062	-.151	-.058	.834
I feel restless as if I have to be on the move	.080	.090	.234	.636
I get a sort of frightened feeling like butterflies in the stomach	.372	-.002	-.455	.489