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Memory appraisals by older people; associated factors and spousal relationship quality

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by

Christine Dawn Hanson, BSc (Hons), PGCert

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Overview

This portfolio thesis has three parts:

Part one is a systematic review of the factors associated with awareness of memory function in older people without dementia. Recent research suggests that subjective memory complaints may precede objective cognitive decline in older people, but whilst several factors have been associated with increased complaints, the pattern of factors associated with actual awareness of memory functioning is less clear. This review focused on the factors associated with memory awareness in people who do not have a diagnosis of dementia. The evidence from 19 papers was critically appraised to consider how several demographic, physiological, psychological and cognitive factors may influence memory appraisal. The independent influence of different factors upon subjective and objective measures of memory was considered, in addition to the overall effect upon memory awareness. The quality of the studies was also evaluated and the strengths and the weaknesses of these papers discussed. The implications of these results are discussed with relevance to clinicians working at the point of assessment and diagnosis of memory conditions.

Part two is an empirical research study which aimed to consider how expressed emotion (a measure of relationship quality) is related to estimates of ability made by couples affected by cognitive impairments. Participants included 46 people with a diagnosis of mild cognitive impairment, Alzheimer's or vascular dementia, and their cognitively healthy spouse. It was found that couples with high expressed emotion

(that is a poorer relationship quality) were more likely to disagree about how capable the person with the cognitive impairment is. This result is discussed with relevance to helping couples maintain their relationship quality and with helping them to adjust when one of them develops cognitive difficulties.

Part three comprises the appendixes relating to the research, including a reflective statement on the process of carrying out the research.

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Part One: Systematic Literature Review

A systematic review of the factors associated with awareness of memory function in older people without dementia

This paper is written in the format ready for submission to Psychology and Aging.

Please see Appendix 1 for author guidelines.

Word count: 5,756

A systematic review of the factors associated with awareness of memory function in older people without dementia

Christine Hanson and Christopher Clarke

Department of Clinical Psychology, University of Hull, Hull. HU6 7RX. UK.

Abstract

Subjective memory complaints are frequent in older people, and it has been suggested that these may precede objective cognitive decline. However, previous research has tended to focus on the factors associated with memory awareness in people with dementia, rather than on the factors associated with awareness of memory function in people without dementia. Similarly, most meta-memory studies have been limited to the effects of aging upon memory appraisal and have not considered the full range of factors which may accompany overall awareness of memory functioning in older people. A systematic review of the literature in this area was conducted. This identified 19 articles studying the association between subjective and objective memory in people aged 60 or over, with either normal cognition or mild cognitive impairment. The results highlighted a range of demographic, physiological, psychological and cognitive factors thought to influence memory appraisal. The most consistent evidence was found for affective factors such as depression and anxiety which appear to negatively distort appraisal of memory functioning in the absence of objective impairment. The implications of these findings for clinicians working at the point of assessment and diagnosis of memory impairments and associated conditions are discussed, and the strengths and weakness of the existing methodological approaches to assessing awareness of memory functioning are considered.

Keywords: appraisal, self-report, meta-memory

Introduction

As the aging population continues to grow, greater emphasis is now being placed on the early detection of cognitive changes that may indicate the possible onset of a progressive disorder such as dementia (National Dementia Strategy, 2009). An important issue in the detection of such decline is the extent to which individuals themselves are aware of cognitive changes. In the dementia literature this knowledge of a deficit is referred to as awareness, which encapsulates the 'fact, degree and implications of one's own illness' (see Clare, 2004), although definitions vary. Previous research indicates that people with dementia commonly over estimate their abilities (Clare, Marková, Verhey, & Kenny, 2005), although awareness is a complex concept, with different theoretical models having been developed (Marková, Clare, Wang, Romero, & Kenny, 2005). Several factors including concurrent anxiety and depression may influence a person's degree of awareness (Aalten, Van Valen, Clare, Kenny, & Verhey, 2005).

The concept of awareness has also been studied in mild cognitive impairment (MCI), where an individual shows decline in a specific cognitive domain in excess of normal aging, but retains overall functional ability (Petersen et al., 2001). A recent review of the literature demonstrated that there are also varying levels of awareness in MCI (Roberts, Clare & Woods, 2009). In the healthy population, awareness of functioning comes under the umbrella of meta-cognition, which pertains to knowledge about one's own cognitive processes, beliefs, attitudes and being able to monitor and evaluate changes in one's cognitive functioning (Flavell, 1979).

Common to both deficit-focused models of awareness and meta-cognition is the need for an explicit object of awareness. An object of awareness may be a specific cognitive domain or an aspect of everyday functioning. Although dementia involves global cognitive decline, deficits in memory are a necessary diagnostic criterion, and the most common form of MCI is the amnestic type, in which memory performance is affected. Some MCI diagnostic criteria clearly state that individuals should present with complaints about their memory (Petersen, 2001), although this is incongruent with studies which have observed variations in levels of awareness. A limitation of previous awareness research is that it has been based on people with known objective impairments or those with subjective complaints. Subsequently people who do not complain, but may have an undiagnosed memory difficulty have been missed by awareness research (Roberts et al., 2009). Specific awareness of memory functioning in the cognitively healthy population can be conceptualised as a facet of meta-memory, which includes the monitoring and evaluation of memory performance (Hertzog, 1992). The need to target research in this area is demonstrated by a recent longitudinal study which found over 14 years that cognitively healthy adults with subjective cognitive complaints at baseline were more likely to decline into MCI and dementia than cognitively healthy adults without subjective cognitive complaints (Reisberg, Shulman, Torossian, Leng, & Zhu, 2010).

To date, little research has examined the factors associated with awareness of memory functioning in older people who do not have dementia or MCI. Some studies of memory disorder have included healthy participants as controls (e.g. Oyebode,

Telling, Hardy & Austin, 2007) but often this is for the purpose of controlling for the influence of normal age associated cognitive decline. In studies of healthy older people, comparisons are typically made with younger adults, which again illuminates the role of normal aging on meta-memory, without identifying any of the other factors which may influence the extent to which older people are aware of their memory functioning.

The aim of the current review was to consider factors associated with awareness of memory function, specifically in older people who do not have dementia. No previous review has attempted to identify a broad range of factors potentially associated with awareness of memory functioning in older people with normal cognitive function or mild impairments. In elucidating some of the factors associated with greater or poorer awareness of memory functioning at higher levels of cognitive functioning, it is hoped to contribute to the knowledge already gained from previous reviews that have focused upon people with observable deficits, such as in dementia. It is also hoped that this information will be useful to clinicians working at the point of assessment and diagnosis, to help identify those at risk of cognitive decline and those older people who are more likely to experience and report memory difficulties despite intact cognitive function.

Method

On 14th February 2010 the following databases were searched for relevant papers; ISI web of Knowledge (incorporating Web of Science, Medline, and BIOSIS),

PsychInfo, CINAHL, Embase (via OVID) and Scopus. The terms 'older adult* OR older people OR elder*' were combined with 'healthy OR normal OR unimpaired', 'memory performance' and 'meta-memory OR metamemory OR self-report OR self-assessment OR appraisal OR insight OR awareness OR complaint'. No date limit was applied, although, where possible, searches were restricted to peer-reviewed research. This initially returned 226 results, which was reduced to 162 after duplicates had been removed. Forty-nine potentially relevant papers were identified on the basis of their abstract and title. These papers were then retrieved and compared to the list of inclusion and exclusion criteria below. The references of the included papers were then manually searched and a further 22 articles were retrieved after checking the abstracts against the inclusion criteria.

Studies were included in the review if:

a. The study elicited self-appraisal of memory function from older adult participants.
b. The study measured memory through an additional method (which can be used as an indication of awareness).
c. The study considered additional factors that may be associated with awareness.
d. The study was empirical, quantitative and peer-reviewed.

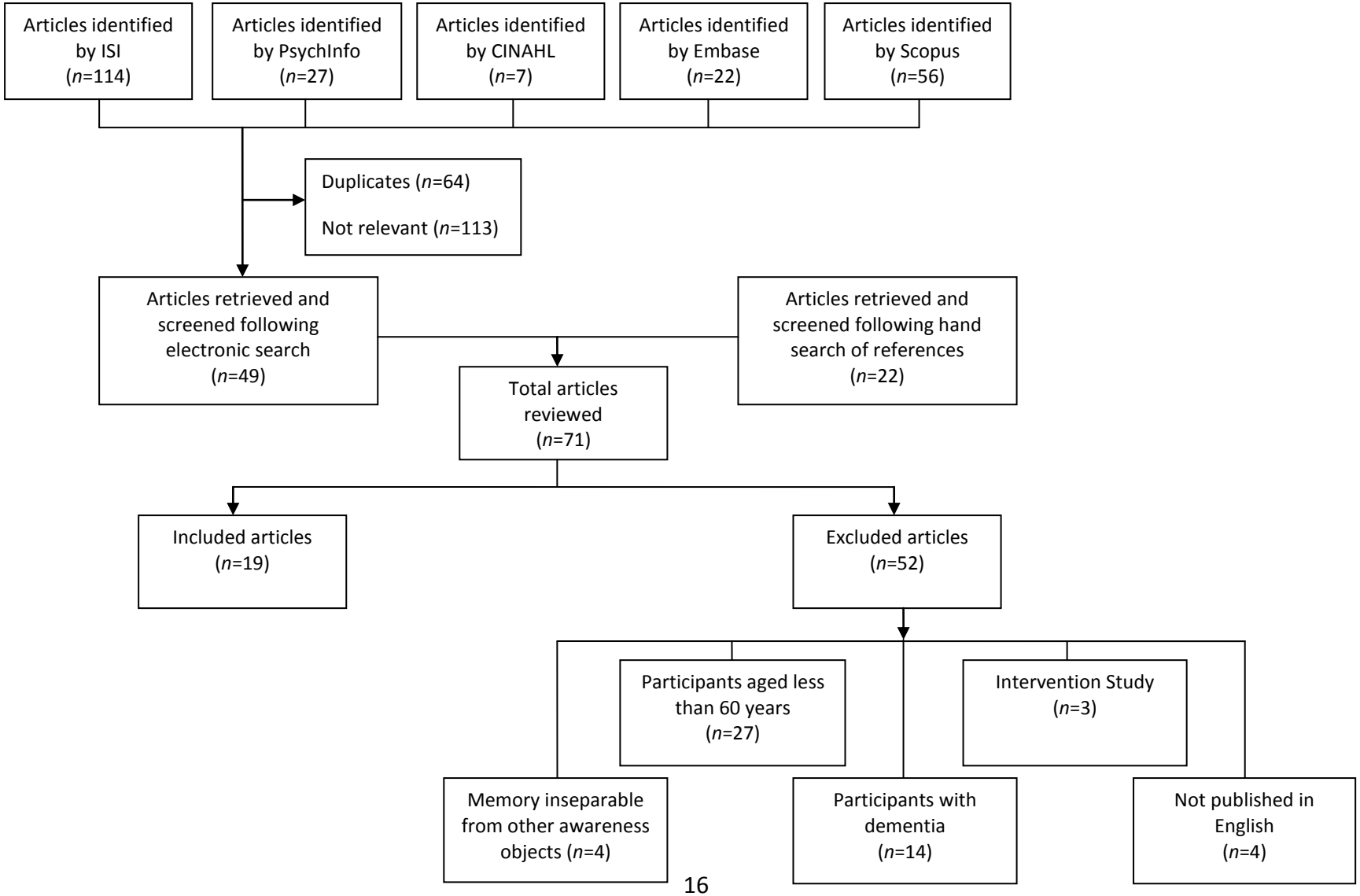
Studies were excluded from the review if:

a. The study included participants aged below 60 years.

b. The study included participants with dementia (only applicable at baseline in longitudinal studies).
c. It was not possible to differentiate memory from other objects of awareness.
d. The study was an evaluation of a memory intervention.
e. The study was not published in English.

In total, 71 full articles were reviewed for inclusion. Fifty-two articles were excluded. The remaining 19 articles were accepted and subsequently examined for methodological quality. Figure one demonstrates the selection procedure and reasons for exclusion.

Figure 1: Flow chart demonstrating the screening and selection process.



Results

Characteristics of included studies

The 19 studies included in the review are summarised in table one. Of the 19, 16 were cross-sectional and three longitudinal (Dik et al., 2001; Poitrenaud, Malbezin, & Guez, 1989; Wang et al., 2000). The studies were drawn from a variety of countries including Austria, Brazil, China, England, Finland, France, Germany, the Netherlands, Sweden, and the USA. Sample sizes ranged from 20 to 2,726, equalling 11,430 people in total, with five studies drawing participants from longitudinal cohort studies of aging (Gagnon et al., 1994; Jonker, Launer, Hooijer, & Lindeboom, 1996; Dik et al., 2001; Jungwrith et al., 2004; Jessen et al., 2007). All 19 studies either described the cognitive status of participants as 'normal' or outlined their method for excluding potential participants with dementia. Only three studies also excluded people with mild impairments (Dik et al., 2001; Dux et al., 2008; Jessen et al., 2007), although the definition of mild impairment varied between studies. Dik et al. excluded people with a Mini Mental State Examination score of below 27 (MMSE; Folstein, Folstein & McHugh, 1975), Dux et al. excluded people with an objective impairment on the Dementia Rating Scale (Mattis, 1988) or the Rey Auditory and Verbal Learning Test (Rey, 1964; Schmidt, 1996), and Jessen et al. excluded people meeting diagnostic criteria for MCI (Winbald et al., 2004).

Ten studies used a questionnaire based measure to assess subjective appraisal of memory functioning. The specific questionnaires used varied greatly between studies (see table one) but generally required participants to rate several aspects of

their memory function on a Likert scale. One study used the questionnaire results to create two groups, with or without memory complaint (Hänninen et al., 1994), and the remaining studies used the questionnaire score in further analyses (Chung & Man, 2009; Cook & Marsiske, 2006; Dux et al., 2008; Harwood, Barker, Ownby, Mullan, & Duara, 2004; Larrabee & Levin, 1986; McDougall, 2004; McDougall, Becker & Arheart, 2006; Minett, Dean, Firbank, English, & O'Brien, 2005; Potter & Hartman, 2006). Four studies classified people into groups on the basis of their answer to either a single memory question or a series of short questions (Dik et al., 2001; Gagnon et al., 1994; Jungwrith et al., 2004; Wang et al., 2000), and two studies used combinations of methods to generate groups (Mattos et al., 2003; Poitrenaud et al., 1989). One study used a cluster analysis to generate three groups, characterised by their level of subjective memory appraisal and objective difficulty (Jessen et al., 2007). The remaining two studies used formal semi-structured interviews and categorised participants into complaining and non-complaining groups depending upon their responses (Jonker et al., 1996; Pálsson, Johansson, Berg, & Skoog, 2000). All 19 studies assessed objective memory using neuropsychological tests, and one study also asked participants and their main carer to fill in a separate memory questionnaire (Chung & Man, 2009). Awareness of memory functioning was assessed in one of two ways. For studies using groups defined by the presence or absence of subjective complaint, the score for each group on objective tests of memory was compared. For studies using continuous questionnaire scores, awareness was assessed by correlating the subjective and objective measures. Seven studies showed a relationship between poorer subjective memory appraisal and reduced performance on objective tests of memory, before taking into account other factors (Dux et al., 2008; Gagnon et al., 1994; Jessen

et al., 2007; Jonker et al., 1996; Larrabee & Levin, 1986; Potter & Hartman, 2006; Wang et al., 2000). A further eight studies showed no association (Dik et al., 2001; Hänninen et al., 1994; Harwood et al., 2004; Jungwrith et al., 2004; McDougall, 2004; Minett et al., 2005; Pálsson et al., 2000; Poitrenaud et al., 1989), and the remaining four studies had mixed results (Chung & Man, 2009; Cook & Marsiske, 2006; Mattos et al., 2003; McDougall et al., 2006).

Table 1. Summary of studies investigating factors associated with awareness of memory functioning.

Study	**Participants** *n*, gender, mean age years (sd)	**Cognitive Status** MMSE Mean (sd)	**Memory Self-report Measures**	**Main Associates Measured**	**Findings**	**Average Quality** (0-18)
Chung & Man (2009)	MCI (*n*=69) 19 male, 50 female Age: 79.0 (5.29) No MCI (*n*=86) 17 male, 69 female Age: 76.8 (5.33)	MCI: 20.42 (3.96) No MCI: 26.54 (3.21)	Chinese Multifactorial Memory Questionnaire (MMQ; Troyer et al., 2002)	Age Depression Education	For MCI significant correlation with MMQ strategy and memory tests, for no MCI all MMQ scales significantly correlated with memory tests, even after controlling for depression. No difference between groups for self-appraised ability and contentment when age and education were controlled for.	15
Dux et al. (2008)	*n*=130 37 male, 93 female Age: 76.7 (8.5)	Used alternative: Dementia Rating Scale	General frequency of forgetting Subscale from the Memory Function Questionnaire (MFQ; Gilewski et al., 1990)	Anxiety sensitivity Depression Positive and negative affect Worry	After controlling for higher order negative affectivity, increases on anxiety sensitivity were associated with SMC in the absence of objective memory impairment.	14.5
Jessen et al. (2007)	*n*=2389 860 male, 1529 female Age: 80.1 (3.52)	Used alternative	Single direct question 'Do you feel like your memory is becoming worse? Four possible answers. Questions from Subjective Memory Decline Scale (Jorm et al., 2001) Used to generate three clusters; 1. SMC- 2. General SMC+ but no reported specific problems 3. SMC+ and reported frequent impairment on specific questions	Age APOE-ε4 Depression Education Gender	Memory performance in SMC+ inferior to SMC- after controlling for depression. Gender, age, education, APOE-ε4 did not distinguish between clusters, but one measure of memory distinguished between APOE-ε4 carriers and non-carriers in cluster 2.	14

Potter & Hartman (2006)	*n*=99 All female Age: 72.9 (7.4)	29.14 (1.03)	General frequency of Forgetting Subscale from the Memory Function Questionnaire (MFQ; Gilewski et al., 1990)	Anxiety Depression Executive function	Response inhibition associated with greater subjective memory complaints after accounting for depression, anxiety, and objective memory performance.	15
McDougall et al. (2006)	*n*=265 60 male, 205 female Age: 74.67 (6.00)	28.34 (1.69)	Revised Meta-memory in Adulthood Scale (MIA; Dixon et al., 1988)	Depression State-trait anxiety	Individuals in moderately impaired memory group had greater memory complaints than normal and poor groups. As memory performance decreased, anxiety and depression increased.	13
Cook & Marsiske (2006)	MCI (*n*=16) 11 male, 5 female Age: 76.94 (7.62) No MCI (*n*=57) 21 male, 36 female Age: 74.77 (5.03)	MCI: 26.63 (1.82) No MCI: 28.7 (1.18)	Memory Functioning Questionnaire (MFQ; Gilewski et al., 1990) Meta-memory in Adulthood Scale (MIA; Dixon et al, 1988)	Depression	For MCI group, significant relationship between objective memory performance and capacity scale of MIA. In no MCI group, no significant relationship between scales and objective memory performance. These relationships not affected by depression.	15.5
Minett et al. (2005)	*n*=60 23 male, 37 female Age: 72.6 (4.7)	27.1 (2.1)	Memory Complaint questionnaire (MAC-Q; Crook et al., 1992)	Depression Proportion of white matter lesions in brain (pWML)	Memory and other cognitive performance not associated with subjective memory complaint after controlling for pWML and depression. Depression was the best correlate of subjective memory complaint.	15
Jungwrith et al. (2004)	*n*=302 113 male, 189 female Age: Reported by degree of impairment	Reported by degree of complaint but ≥24	Series of specific questions to yield two overall groups, SMC+ and SMC-	Age Depression State-trait anxiety	No significant difference between SMC+ and SMC- on age and objective memory tests. SMC+ significantly correlated with depression and trait anxiety, but not state anxiety.	11.5

Harwood et al. (2004)	*n*=232 82 male, 150 female Age: 74.1 (7.0)	Age adjusted: 28.1 (1.8)	Memory Questionnaire (MQ; Harwood, 1998)	Age APOE-ε4 Depression Education Gender	Subjective memory complaint associated with depressive symptoms, but not with age, education, gender, APOE-4, or objective memory score. Subjective memory complaint not related to presence of APOE-ε4 when objective memory is controlled for.	15.5
McDougall (2004)	*n*=172 Gender not reported Age: 76.52 (5.15) 89 black, 83 white	≥23	Meta-memory in Adulthood Questionnaire (MIQ; Dixon et al, 1988) Memory self-efficacy Questionnaire (Berry et al. 1989)	Depression Education Race	MIQ not predictive of objective memory performance. Black participants had poorer subjective perception of memory, poorer memory performance and were significantly more depressed. Age, education, and memory self-efficacy accounted for 9-13% of variance in objective memory performance.	13.5
Mattos et al. (2003)	*n*=71 8 male, 63 female Age: 70.0 (not reported)	≥18 for 4-7 years education, ≥26 for 8+ years education, in accordance with Brazilian norms	Single direct question 'Have you been having memory difficulties that upset your everyday life?' Answers 'yes' or 'no'. Memory Complaint Questionnaire (MAC-Q; Crook et al, 1992) Combined to create two groups SMC+ and SMC-	Age Education Gender	33 complainers, 38 non-complainers in total. SMC+ related to worse objective memory performance, but not to MAC-Q score. Complaints not related to age, gender or education.	15
Dik et al. (2001)	SMC+ (*n*= 298) 160 male, 138 female Age: 72.8 (6.7) SMC- (*n*=870) 438 male, 432 female Age: 71.8 (6.4)	SMC+ 28.3 (1.1) SMC- 28.4 (1.0)	Single direct question 'Do you have problems with your memory?' Answers 'yes' or 'no' to produce two groups, SMC+ and SMC-	Age APOE-ε4 Depression Education Gender	SMC+ 25.5% at baseline. No association between subjective memory complaints and objective memory tests or information processing speed. SMC+ group significantly older and more depressed, also a non-significant trend for SMC+ to carry APOE-ε4. No association with education.	14

Wang et al. (2000)	*n*=543 258 male, 285 female Age: 75.4 (6.0)	Used alternative: Chinese Cognitive Abilities Screening Instrument	Single direct question 'Do you have trouble with your memory?' Answers 'yes' or 'no' to produce two groups, SMC+ and SMC-	Age Depression Education Gender	SMC+ 49% at baseline. SMC+ associated with poorer objective memory performance but not other cognitive tests after controlling for age, gender, education and depression.	13.5
Pálsson et al. (2000)	*n*=224-275 (task dependent) Gender not reported Age: 75.0 (0.0)	Reported by task	Rated following a semi-structured interview according to the Comprehensive Psychopathological Rating Scale as 'none', 'mild' or 'moderate-severe'	Depression	SMC not related to objective memory test performance or other cognitive tests in depressed or non-depressed groups. Females in depressed groups reported significantly more memory complaints than men or non-depressed females.	15.5
Jonker et al. (1996)	*n*=2537 1115 male, 1422 female Age: <75= 1325, ≥75 = 1212	Median 28	Based on CAMDEX protocol (Roth et al., 1993); general question followed by specific examples; used to generate four groups; 1. No complaints, no problems 2. Complaints, no problems 3. No complaints, no problems 4. Complaints, problems	Age Premorbid intelligence Gender	Participants with subjective complaints and problems performed worse on objective tests of memory and other cognition, after adjusting for age, gender and premorbid intelligence.	13
Hänninen et al. (1994)	SMC+ (*n*=10), Gender not reported, Age: 71.7 SMC- (*n*=10), Gender not reported, Age: 71.5	26.0 (2.81)	Memory Complaint Questionnaire (MCQ; Crook & Larrabee, 1990); cut off at highest quartile to create two equal groups, SMC+ and SMC-	Depression Hypochondriasis Psychasthenia	Subjective memory difficulties more closely related to personality traits of hypochondriasis and psychasthenia than objective memory performance.	10.5

Gagnon et al. (1994)	*n*=2,715 1094 male, 1632 female Age: 74.83 (6.87)	Used alternative	Direct question: Participants asked to respond 'yes' or 'no' if they perceive problems in memorising new simple information.	Age Depression scale Education Gender	All factors correlated with objective and subjective memory measures, however females and those with depressive symptoms reported more subjective difficulties, whereas older age and low education displayed more objective memory difficulties.	13.5
Poitrenaud, Malbezin & Guez (1989)	*n*=125 All male Age: ≥63	Used alternative	Visual analogue scale for rating memory from 'very bad' to 'very good' Single multiple choice question 'With respect to your examination seven years ago, do you think that your memory has declined, improved, or remained stable?'	Neuroticism Extraversion	No relationship between scores on memory self-rating scale and change on objective memory performance. Memory complaints linked to neuroticism.	8.5
Larrabee & Levin (1986)	*n*=88 20 male, 68 female Age: 73.2 (6.9)	Not reported	18 item self-rating scale based on scale of Squire et al. (1979)	Depression	Memory self-rating primarily related to affective state, however subjective memory complaints may also accurately reflect objective impairment.	9

Abbreviations: SMC+ Participants reporting subjective memory complaints; SMC - Participants not reporting subjective memory complaints; APOE- ε4 Apolipoprotein-E gene (allele subtype epsilon 4)

Assessing Methodological Quality

The majority of articles in this review were cross-sectional in design and, as Sanderson, Tatt & Higgins (2007) have identified, there are few tools for assessing methodological quality in such studies. In order to assess the methodological quality of the articles included in this review a new methodological checklist was devised. The new checklist was adapted from the well validated Downs and Black checklist (1998). In order to guide this process the Strengthening the Reporting of Observational Studies in Epidemiology checklist of items that should be included in reports of cross-sectional studies was used (STROBE, retrieved April 21, 2010). Although this tool is not a quality checklist itself, it was developed with the aim of improving the reporting of observational research in medical literature. The emergent checklist contained 18 items, scored from 0-18 depending on the number of items met. To ensure the reliability of this scoring system, all included studies were further assessed by an independent rater (RA). The single measure intra-class correlation coefficient was 0.68 (p<.001), indicating substantial inter-rater consistency. Most studies had comparable methodological quality; however some studies were rated particularly poorly, for example Poitrenaud et al. (1989) scored less than half. Whilst no studies were excluded on the basis of methodology quality, conclusions drawn from studies with a lower rating are indicated in the relevant sections below.

Factors associated with memory functioning

The factors that were associated with awareness of memory functioning have been organised under the headings of demographic, physiological, psychological, and cognitive. Due to varying methodologies and analyses it is not always possible to

directly consider the influence of these additional factors on the association between subjective and objective memory. For this reason, some factors are discussed with reference to their association which each of these individually, and more detailed evidence for overall awareness is presented where available.

Demographic Factors

Age

Nine of the studies explicitly considered the influence of age upon subjective memory appraisal, and of these five concluded that there was no association (Harwood et al., 2004; Jessen et al., 2007; Jungwrith et al., 2004; Mattos et al., 2003; Wang et al., 2000). However, three found a significant increase in negative memory appraisals with increasing age (Dik et al., 2001; Gagnon et al., 1994; Jonker et al., 1996). Chung and Man (2009) reported similar results for their no-MCI group. Of the studies that found an association between subjective and objective memory, three reported that participants with subjective difficulties were more likely to be older (Chung & Man, 2009; Gagnon et al., 1994; Jonker et al., 1996), and three did not (Jessen et al., 2007, Mattos et al., 2003; Wang et al., 2000). In studies that controlled for the influence of age upon awareness, the association between subjective and objective memory remained significant (Jonker et al., 1996; Wang et al., 2000). In the absence of cognitive impairment, age was not found to be associated with more negative appraisals by Harwood et al. or Jungwrith et al., although Dik et al. did find older participants made more negative memory appraisals. This suggests that increasing age may increase the likelihood of older people making negative memory appraisals, however as the evidence from the available literature is inconsistent, this

may genuinely be accompanied by cognitive decline, and not indicate that increasing age is a confounding variable when measuring awareness in this population.

Gender

Six out of nine studies in this area found no association between gender and memory appraisal (Chung & Man, 2009; Dik et al., 2001; Harwood et al., 2004; Jessen et al., 2007; Jonker et al., 1996; Mattos et al., 2003). However the remaining three studies suggested females are more likely to make negative memory appraisals (Gagnon et al., 1994; Pálsson, et al., 2000; Wang et al., 2000). When controlling for gender, Wang et al. still observed a significant relationship between subjective and objective memory measures, as did Jessen et al., however in the absence of objective memory impairment, Pálsson et al. (2000) found increased complaints only for depressed females. Gagnon et al. observed a correlation of gender with both subjective and objective measures although this was more strongly correlated with the former. Other studies have not directly considered the relationship between gender and objective memory, or controlled for gender when investigating the relationship between objective and subjective memory. Two studies (Harwood et al., 2000; Dik et al., 2001) found no influence of gender upon appraisal in the absence of cognitive impairment. This was also supported by Chung and Man for their no-MCI group, and by Mattos et al., but only when measuring subjective memory complaint by direct question. These results suggest that females may be more inclined to make negative memory appraisals; but that this does not affect overall awareness as measured by the association between subjective and objective measures. However without clear evidence to address whether the subjective memory appraisals of females are accurate, it cannot be determined to what extent gender affects overall awareness.

Education

Gagnon et al. (1994) reported the comparative contribution of education to both memory appraisal and objective performance and found that although education was correlated with both measures, less education was more strongly correlated with greater subjective memory complaint. Other studies have replicated this finding (Chung & Man, 2009; Wang et al., 2000). However when controlling for education, the relationship between subjective memory appraisal and objective performance has been found to be unaffected (Wang et al., 2000). Three further studies report no association between years of education and memory appraisal (Dik et al., 2001, Harwood et al., 2004, Mattos et al., 2003), and subsequently did not control for this when investigating the relationship between subjective and objective memory measures. Jessen et al. (2007) found years of education did not distinguish between clusters of people with or without memory complaints regardless of performance. In summary there is some limited evidence to suggest that people with fewer years of education may have poorer memory appraisal, but no evidence to suggest that this moderates the relationship between subjective and objective memory performance.

Race

Although the studies in this review are drawn from a variety of countries, only McDougall (2004) has explicitly studied the contribution of race to memory changes. In a comparison of black and white elders, McDougall found higher memory self-efficacy was predictive of better performance in white elders, but not black elders. There were also racial differences on the measure of meta-memory used in this study, but for both groups meta-memory was not predictive of objective memory

performance. This suggests that there may be racial differences in how people appraise their memory, but that for white elders lower confidence in particular may predict poorer memory performance.

Physiological Factors

Apolipoprotein-E

Three studies investigated the contribution of a known genetic risk factor for Alzheimer's disease (Dik et al., 2001, Harwood et al., 2004, Jessen et al., 2007). This gene called apolipoprotein-E (APOE) has a specific subtype, allele ε4, which has been linked with a higher chance of developing Alzheimer's in later life. Although Dik et al. and Harwood et al. found no association between subjective and objective memory measures, Jessen et al. did find a relationship in their cluster analysis study. However all three studies found no consistent association of APOE-ε4 to memory appraisal, and Harwood et al. found this remained after controlling for objective memory performance. This may not be surprising given that participants are very unlikely to know their genotype. However, Jessen et al. found that participants carrying the APOE-ε4 allele and reporting general memory difficulty can be distinguished from non-carriers by tests of verbal delayed recall. This finding however was not replicated in the group of participants reporting specific memory difficulty, and APOE-ε4 carriers could not be distinguished in a third group of participants without subjective memory difficulty. Jessen et al. attribute this to potential differences in gene expression and depression between the clusters. Although the evidence is drawn from just three studies, Jessen et al. and Dik et al. recruited large community samples (gathering genotype data on 2,299 and 1,168 participants respectively) improving the power of their findings. It seems unlikely that APOE-ε4 affects subjective memory appraisal as

people are unlikely to know if they are carrying the allele, but their complaints could reflect actual cognitive changes, which indicate better awareness of memory functioning.

White Matter Lesions

Minett et al. (2005) measured the association between cerebral white matter lesions (WML), memory complaints and objective performance, also taking into account depression. Although participants with more severe lesions reported more cognitive complaints, subjective and objective memory measures were not significantly related, when controlling for WML and depression.

Psychological Factors

Anxiety

Although four studies in the review measured anxiety (Dux et al., 2008, Jungwrith et al., 2004; McDougall et al., 2006; Potter & Hartman, 2006) only two studies offer any clear indication as to whether anxiety moderates the relationship between subjective memory appraisal and objective performance. Potter and Hartman (2006) found anxiety accounted for a significant proportion of variance in memory complaints when objective measures were also included. In a more detailed study, Dux et al. (2008) have studied anxiety as a higher and lower order factor. In this study, exclusively of healthy non-impaired participants, overall negative affect was measured as a higher order factor. Specific anxiety measures included 'worry' as a 2nd order factor and 'anxiety sensitivity' (the fear of experiencing anxiety-related sensations) as a lower order affect. The results revealed that all these affective variables moderated the relationship between objective memory performance and

subjective appraisal, particularly anxiety sensitivity, suggesting that anxiety does influence awareness of memory functioning, such that memory complaints are elevated in the absence of cognitive difficulty.

Depression

All but two studies (Mattos et al., 2003; Poitrenaud et al., 1989) in this review measured depression, although not all studies have reported their findings in relation to awareness. Five studies found a positive relationship between subjective and objective memory measures remained after controlling for the effects of depression (Chung & Man, 2009; Cook & Marsiske, 2006; Jessen et al., 2007; McDougall, 2004; Wang et al., 2000) which initially suggests that awareness of memory functioning may not be distorted by depression status. However Dux et al. (2008) have argued that depression is a moderator of memory appraisal, such that people with depression have poorer awareness of memory functioning. In the absence of memory impairments Pálsson et al. (2000) found that women with depression were more likely to have poorer memory appraisal. Moreover, other studies have demonstrated through regression analyses that depression is a bigger predictor of variance in memory appraisal than objective measures (Larrabee & Levin, 1986; Minett et al., 2005).

In this review higher depression was found to be significantly associated with poorer memory appraisal in all studies except Hänninen et al. (1994), which may be explained by the study's small sample size. However depression is also found to be related to poorer objective memory performance, both in this review (e.g. Gagnon et al., 1994; McDougall et al., 2006; Pálsson et al., 2000) and in the general literature (Green, 2000). This latter finding suggests that in some cases poorer memory appraisal

by people with depression may reflect actual difficulties with cognitive performance. Cook and Marsiske (2006) have suggested that both depression and objective cognitive status are predictor variables of memory appraisal but that there is no interaction between the two. In this review it is unclear to what extent depression is associated with awareness; the evidence seems to suggest that depression may not alter overall awareness if an increase in memory complaints is accompanied by an increase in cognitive difficulties. However there is also some evidence that depression may distort awareness in the absence of actual memory difficulties.

Personality

Limited evidence from two studies in this review suggests that personality factors may also influence the awareness of memory functioning. Hänninen et al. (1994) found participants with higher scores on hypochondrasis and psychasthenia from the Multiphasic Personality Inventory (Dahlstrom, Welsh, & Dahlstrom, 1990) had significantly more complaints than non-complainers despite normal cognition. These scales represent greater tendency to somatic complaints, anxiety about physical health, feelings of incompetence and obsessive compulsive reactions. In a longitudinal study of aging, Poitrenaud et al. (1989) concluded that memory complaints reflected neurotic characteristics rather than actual age-related decline, although a similar pattern of results was not observed for extraversion. In both studies, the authors suggest that personality types prone to pessimism and anxiety are more likely to report memory complaints in the absence of cognitive impairment than their less anxious counterparts. However the results of these studies should be interpreted with caution as both were rated lowly for methodological quality. For example, the total sample size for Hänninen et al. was 20 participants, and for Poitrenaud et al. the

authors queried the reliability of one of the objective tests from which the study conclusions were drawn.

Cognitive Factors

Premorbid Intelligence

Jonker et al. (1996) found people with subjective complaints had significantly higher premorbid IQ. However after adjusting for age, gender and premorbid intelligence participants with complaints and problems were still found to perform more poorly on memory tests. Despite the majority of studies measuring awareness of memory functioning by comparing subjective memory appraisal to objective memory performance, it is surprising that only one study in this review reports on premorbid estimates of intelligence.

Response Inhibition

After controlling for objective memory performance, depression and anxiety, Potter and Hartman (2006) found that decreased response inhibition was associated with a greater frequency of memory complaints in females. The authors suggest that this may result from difficulty with inhibiting interference from information not relevant to the questions they asked about memory.

Discussion

This review highlights some of the complex issues surrounding the measurement and assessment of awareness of memory function in older people without dementia. Several factors which could be associated with awareness have

been identified although the conclusions which can be drawn are limited. It has been clearly demonstrated that older age, female gender, anxiety, depression, and some personality factors are associated with poorer memory appraisal. However, a relationship also exists with objective memory measures for some of these factors. What remains unclear is the extent to which these variables may affect overall awareness. The strongest evidence seems to exist for depression and anxiety, where it has been argued that greater negative affect distorts the perception of memory functioning, leading to greater memory complaints in the absence of any cognitive impairment.

However, depression in particular is known to affect cognitive functioning and Pálsson et al. (2000) have highlighted problems with concentration, memory retrieval and reduced processing speed as examples. Subsequently, lowered or negative appraisals of memory in some of the studies may have been due to genuine cognitive difficulties associated with depression. Alternatively it could be argued that depression and anxiety are known to be characterised by negative thinking styles which may reflect a cognitive bias towards poorer appraisal of memory (Potter & Hartman, 2006). When asked to evaluate memory, depressed older people may have a bias towards recalling memory failures which may lead to an artificially elevated number of memory complaints or difficulties. From an assessment perspective this makes it very difficult to tell if a depressed individual's awareness is poor or an accurate reflection of cognitive status.

Of interest in this review was that all studies used neuropsychological tests to assess objective memory functioning. However, it should be acknowledged that this

may reflect the use of the term 'memory performance' in the original search criteria. Despite this, only Jonker et al. (1996) reported any premorbid estimates of intellectual functioning. The data obtained from the neuropsychological tests can only inform researchers about current strengths and weaknesses and used in isolation give little indication of the degree to which cognitive abilities have declined. However, many of the memory appraisal measures used in this review asked participants to compare their current functioning to a previous level. Subsequently, some people who scored in the 'normal' cognitive range may have appraised their memory as poor if they previously enjoyed a higher level of cognitive functioning. The lack of premorbid assessment could be considered a methodological weakness of research in this area, as it is not clear what memory is being measured in relation to. For example, awareness could be relative to one's contemporaries, i.e. 'my memory is as good as the next person's', or relative to one's own previous level of functioning, i.e. 'it is not as good as it used to be'.

This is also demonstrated by the study of Chung and Man (2009). In addition to neuropsychological testing, they asked carers to fill in a separate memory assessment questionnaire, comparing the current functioning of their relative with that of ten years ago. Whilst the study did not compare carer appraisals to objective memory measures, they did compare between MCI and no-MCI groups. Their results found no correlation between self-appraised memory and carer appraised memory in their MCI group, but there was a significant correlation in their no-MCI group. The authors suggest this finding indicates poorer awareness of functioning in people with MCI. However, this may need to be interpreted more cautiously. Firstly, the individuals in the MCI group rated themselves as significantly more impaired than the individuals in

the no-MCI group, which suggests that they do have some awareness of their impairments. Secondly, the questionnaire for self-appraised memory was based on performance for the previous two weeks, unlike carers who rated decline over a much longer period of time. This is similar to the lack of premorbid assessment in neuropsychological testing, as without a clear focus different forms of memory assessment may not be directly comparable and may reach different conclusions.

Other methods of assessing awareness used by the studies in this review have also produced varying results. Mattos et al. (2003) found that when memory appraisal was measured using a self-rating questionnaire there was no association with objective memory performance. However, when the same participants were asked to respond 'yes' or 'no' to a question about whether they have memory difficulties that upset their everyday life there was a significant relationship with objective memory. Many of the studies in this review have questioned whether asking people about their memory directly alters their response as opposed to memory appraisals which are given spontaneously, although these would be difficult to elicit in a research setting. Awareness in all of the included studies was calculated by comparing different groups (e.g. complainers versus non-complainers, MCI versus no-MCI) on objective measures, or correlating subjective and objective measures. Whilst this latter method has been used in other studies of awareness (see Clare et al., 2005), it does limit the conclusions that can be drawn. For example, it is difficult to explore interactions between variables where awareness is based on a correlation, or more subtle relationships where awareness is based on overall groups. One alternative to this is to calculate a single discrepancy score between objective and subjective measures, as has been used in dementia studies.

A strength of this review is that it does not just focus upon people with a known memory deficit such as in dementia, or on conditions that require the presence of memory complaint such as in MCI. It includes both people who have memory complaints and those who do not, regardless of their cognitive functioning. This is important in the study of awareness of memory functioning for generating a profile of those people with 'normal' cognition who accurately complain of memory difficulty and those who do not. However, it was disappointing in the screening stage of this review that more studies of unimpaired older people could not be identified. Only three studies excluded MCI or other mild impairments which means that although none of the studies included people with dementia there is cognitive variation between participants in the studies retrieved and reviewed. This may in part be due to MCI being a more recent concept which some of the older studies in the review may not have been able to screen out. Alternatively, the detection of cognitive difficulties in a healthy older adult population would require a very large sample due to any differences in cognitive ability being so subtle. This may partially account for the lack of research in exclusively cognitively healthy people. It is also noteworthy that many studies were rejected from inclusion in the review on the basis of age range. Although several studies purported to focus on older people some of the inclusion ages started from 45 years (Schmidt, Berg, & Deelman, 2001). It could be argued that this represents a different generation who will face different challenges. For example, older people are likely to experience more physical heath problems, and to have very different social circumstances, for example having retired, in relation to people of middle age. In addition to this, the effect of normal aging may influence memory

appraisal and, taken together, all these factors may have implications for awareness of memory functioning as a whole.

Given the suggestion that memory complaints may precede MCI and dementia by up to 15 years (Gauthier et al., 2006), it is important to be able to recognise the factors associated with memory appraisal, and also of overall awareness of memory functioning in older people. It has been argued by Dik et al. (2001) that memory complaints may accurately differentiate those who develop cognitive decline from those who do not, at a time when neuropsychological tests are unable to pick up any significant differences between the two groups. This review indicates that the factors associated with awareness of memory function in older people without dementia are complicated and vary depending upon the type of assessment method used. In particular it seems females with depression or anxiety are more likely to have complaints in the absence of any deficit, but there is conflicting evidence as to whether affective variables have a separate or moderating effect upon awareness. There is also some evidence that genetic signs may indicate changes in cognition which older people can accurately identify however this is still in its infancy. The findings that depression and anxiety are related to awareness in this review are consistent with the awareness literature in dementia which also documents a relationship with affective variables.

A suggestion for future research in this area is that studies focus more strictly on older adults, to minimise the influence of aging and different life stages. It may also be useful to investigate potential differences between the young-old and the old-old. Another suggestion is to clearly define whether awareness is being measured relative to an idiosyncratic level of functioning, or against the general population, which may

produce different results. In addition to this, future research might also consider taking previous cognitive functioning into consideration. This might be through the use of premorbid measures alongside neuropsychological testing, or by asking both people with impairments and their main carer to compare current and previous memory functioning. Given the variation in how awareness has been measured, it may be useful to minimise the number of comparisons made statistically by having a single index of awareness. Finally, it may be useful to have more longitudinal studies of aging and memory awareness to examine how different factors contribute to awareness of memory functioning over time.

References

Aalten, P., Van Valen, E., Clare, L., Kenny, G., & Verhey, F. (2005). Awareness in dementia: A review of clinical correlates. *Aging & Mental Health, 9*, 414-422.

Berry, J.M., West, R.L., & Dennehey, D.M. (1989). Reliability and validity of the memory self-efficacy questionnaire. *Developmental Psychology, 25,*701-713.

Chung, J.C.C., & Man, D.W.K. (2009). Self-appraised, informant-reported, and objective memory and cognitive function in mild cognitive impairment. *Dementia and Geriatric Cognitive Disorders, 27,* 187-193.

Clare, L. (2004). Awareness in early stage Alzheimer's disease: A review of methods and evidence. *British Journal of Clinical Psychology, 43,* 177-196.

Clare, L., Marková, I., Verhey, F., & Kenny, G. (2005). Awareness in dementia: A review of assessment methods and measures. *Aging & Mental Health, 9,* 394-413.

Cook, S., & Marsiske, M. (2006). Subjective memory beliefs and cognitive performance in normal and mildly impaired older adults. *Aging & Mental Health, 10,* 413-423.

Crook, T.H., Feher, E.P., & Larabee, G.J. (1992). Assessment of memory complaint in age-associated memory impairment: the MAC-Q. *International Psychogeriatrics, 4,* 165-175.

Crook, T.H., & Larrabee, G.J. (1990). A self-rating scale for evaluating memory in everyday life. *Psychology & Aging, 5,* 48-57.

Dahlstrom, W.G., Welsh, G.S., & Dahlstrom, L.E. (1990). *An MMPI handbook: Vol 1. Clinical interpretation.* Minneapolis: University of Minneapolis Press.

Department of Health (2009). *Living well with dementia: A national dementia strategy*. London: Department of Health.

Dik, M.G., Jonker, C., Comijs, H.C., Bouter, L.M., Twisk, J.W.R., van Kamp, G.J., et al. (2001). Memory complaints and APOE-ε4 accelerate cognitive decline in cognitively normal elderly. *Neurology, 57,* 2217-2222.

Dixon, R.A., Hultsch, D.F., & Hertzog, C. (1988). The metamemory in adulthood (MIA) questionnaire. *Psychopharmacology Bulletin, 24,* 671-688.

Downs, S., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health, 52,* 377-384.

Dux, M.C., Woodward, J.L., Calamari, J.E., Messina, M., Arora, S., Chick, H., et al. (2008). The moderating role of negative affect on objective verbal memory performance and subjective memory complaints in healthy older adults. *Journal of the International Neuropsychological Society, 14,* 327-336.

Flavell, J. H. (1979). Metacognition and cognitive monitoring: A new area of cognitive-developmental inquiry. *American Psychologist*, *34*, 906-911.

Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Psychiatry Research, 12,* 189-198.

Gagnon, M., Dartigues, J.F., Mazaux, J.M., Dequae, L., Letenneur, L., Giroire, J.M., et al. (1994). Self-reported memory complaints and memory performance in elderly French community residents: Results of the PAQUID research program. *Neuroepidemiology, 13,* 145-154.

Gauthier, S., Reisberg, B., Zaudig, M., Petersen, R.C., Ritchie, K., Broich, K., et al. (2006). International psychogeriatric association expert conference on mild cognitive impairment. *Lancet, 367,* 1262-1270.

Gilewski, M.J., Zelenski, E.M., & Schaie, K.W. (1990). The memory functioning questionnaire for assessment of memory complaints in adulthood and old age. *Psychology & Aging, 5,* 482-490.

Green, J. (2000). *Neuropsychological evaluation of the older adult: A clinician's guidebook.* London: Academic Press.

Hänninen, T., Reinikainen, K.J., Helkala, E., Koivisto, K., Mykkänen, L., Laakso, M., et al. (1994). Subjective memory complaints and personality traits in normal elderly subjects. *Journal of the American Geriatrics Society, 42,* 1-4.

Harwood, D.G., Barker, W.W., Ownby, R.L., Mullan, M., & Duara, R. (2004). No association between subjective memory complaints and apolipoprotein E genotype in cognitively intact elderly. *International Journal of Geriatric Psychiatry, 19*, 1131-1139.

Harwood, D., Barker, W., Ownby, R., & Duara, R. (1998). Memory complaints in the elderly: a comparative analysis of informant and subjects reports among Hispanics and white Non-Hispanics. *Clinical Gerontologist, 18,* 56-60.

Jessen, F., Wiese, B., Cvetanovska, G., Fuchs, A., Kaduszkiewicz, H., Kölsch, H., et al. (2007). Patterns of subjective memory impairment in the elderly: Association with memory performance. *Psychological Medicine, 37,* 1753-1762.

Jonker, C., Launer, L.J., Hooijer, C., & Lindeboom, J. (1996). Memory complaints and memory impairment in older individuals. *Journal of the American Geriatrics Society, 44,* 44-49.

Jungwrith, S., Fischer, P., Weissgram, S., Kirchmeyr, W., Bauer, P., & Tragl, K. (2004). Subjective memory complaints and objective memory impairment in the Vienna-Transdanule aging community. *Journal of the American Geriatrics Society, 52,* 263-268.

Jorm, A.F., Christensen, H., Korten, A.E., Jacomb, P.A., & Henderson, A.S. (2001). Memory complaints as a precursor of memory impairment in older people: a longitudinal analysis over 7-8 years. *Psychological Medicine, 31,* 441-449.

Larrabee, G.J., & Levin, H.S. (1986). Memory self-ratings and objective test performance in a normal elderly sample. *Journal of Clinical and Experimental Neuropsychology, 8,* 275-284.

Marková, I., Clare, L., Wang, M., Romero, B., & Kenny, G. (2005). Awareness in dementia: conceptual issues. *Aging & Mental Health, 9*, 386-393.

Mattis, S. (1988). *Dementia rating scale professional manual.* Odessa: Psychological Assessment Resources.

Mattos, P., Lino, V., Rizo, L., Alfano, Â., Araújo, C., & Raggio, R. (2003). Memory complaints and test performance in healthy persons. *Arquivos de Neuro-Psiquiatria, 61,* 920-924.

McDougall, G.J. (2004). Memory self-efficacy and memory performance among black and white elders. *Nursing Research, 53,* 323-331.

McDougall, G.J., Becker, H., & Arheart, K.L. (2006). Older adults in the seniorWISE study at risk for mild cognitive impairment. *Archives of Psychiatric Nursing, 20,* 126-134.

Minett, T.S.C., Dean, J.L., Firbank, M., English, P., & O'Brien, J.T. (2006). Subjective memory complaints, white-matter lesions, depressive symptoms, and cognition in elderly patients. *American Journal of Geriatric Psychiatry, 13,* 655-671.

Pálsson, S., Johansson, B., Berg, S., & Skoog, I. (2000). A population study on the influence of depression on neuropsychological functioning in 85-year-olds. *Acta Psychiatrica Scandinavica, 101,* 185-193.

Petersen, R.C., Stevens, J., Ganguli, M., Tangalos, E.G., Cummings, J.L., DeKosky, S.T. (2001). Practice parameter: Early detection of dementia: Mild cognitive impairment (an evidence-based review): Report of the quality standards subcommittee of the American Academy of Neurology. *Neurology, 56,* 1133–1142.

Poitrenaud, J., Malbezin, M., & Guez, D. (1989). Self-rating and psychometric assessment of age-related changes among young-elderly managers. *Developmental Neuropsychology, 5,* 285-294.

Oyebode, J.R., Telling, A.L., Hardy, R.M., & Austin, J. (2007). Awareness of memory functioning in early Alzheimer's disease: lessons from a comparison with healthy older people and young adults. *Aging & Mental Health, 11,* 761-767.

Potter, G.G., & Hartman, M. (2006). Response inhibition and everyday memory complaints in older adult women. *International Journal of Geriatric Psychiatry, 21,* 1115-1120.

Reisberg, B., Shulman, M.B., Torossian, C., Leng, L., & Zhu, W. (2010). Outcome over seven years of healthy adults with and without subjective cognitive impairment. *Alzheimer's and Dementia, 6,* 11-24.

Rey, A. (1964). *L'examen Clinique en psychologie.* [The clinical examination in psychology]. Paris: Universitaires de France.

Roberts, J.L., Clare, L., & Woods, R.T. (2009). Subjective memory complaints and awareness of memory functioning in mild cognitive impairment: A systematic review. *Dementia and Geriatric Cognitive Disorders, 28,* 95-109.

Sanderson, S., Tatt, I.D., & Higgins, J.P.T. (2007). Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: a systematic

review and annotated bibliography. *International Journal of Epidemiology, 36,* 666-676.

Schmidt, M. (1996). *Rey auditory and verbal learning test: A handbook.* Los Angeles: Western Psychological Service.

Schmidt, I.W., Berg, I.J., & Deelman, B.G. (2001). Relations between subjective evaluations of memory and objective memory performance. *Perceptual and Motor Skills, 93,* 761-776.

Squire, L.R., Wetzel, C.D., & Slater, P.C. (1979). Memory complaint after electroconvulsive therapy: Assessment with a new self-rating instrument. *Biological Psychiatry, 14,* 791-801.

Strengthening the Reporting of Observational Studies in Epidemiology (n.d.) *STROBE statement: Checklist of items that should be included in reports of cross-sectional studies.* Retrieved April 21, 2010, from http://www.strobe-statement.org/index.php?eID=tx_nawsecuredl&u=0&file=fileadmin/Strobe/uploads/checklists/STROBE_checklist_v4_cross-sectional.pdf&t=1275563707&hash=00ceb6f39611dda1934b41a225180d18

Troyer, A.K., & Rich, J.B. (2002). Psychometric properties of a new metamemory questionnaire for older adults. *Gerontology, 57,* 19-27.

Wang, P., Wang, S., Fuh, J., Teng, E., Liu, C., Lin, C., et al. (2000). Subjective memory complaint in relation to cognitive performance and depression: A longitudinal study of a rural Chinese population. *Journal of the American Geriatrics Society, 48,* 295-299.

Winbald, B., Palmer, K., Kivipelto, M., Jelic, V., Fratiglioni, L., Wahlund, L.O., et al. (2004). Mild cognitive impairment – beyond controversies, towards a

consensus: Report of the International Working Group on Mild Cognitive Impairment. *Journal of Internal Medicine, 256,* 240-246.

Part Two: Empirical Paper

Is expressed emotion related to perceptions of ability made by people with cognitive impairments and their partners?

This paper is written in the format ready for submission to Aging & Mental Health.

Please see Appendix 2 for author guidelines.

Word count: 5,177

Is expressed emotion related to perceptions of ability made by people with cognitive impairments and their partners?

Christine D. Hanson[1] *& Christopher Clarke*[1]

[1]Department of Clinical Psychology & Psychological Therapies, The University of Hull. Hull. HU6 7RX. UK.

Abbreviated Title: Expressed emotion and memory appraisal

Correspondence: Christine Hanson, Department of Clinical Psychology & Psychological Therapies, Hertford Building, The University of Hull, Hull. HU6 7RX, UK. Tel: +44 1482 464106. Email: c.d.hanson@2007.hull.ac.uk

Is expressed emotion related to ratings of ability made by people with cognitive impairments and their partners?

Aging & Mental Health

Abstract

Objectives: This study explored the relationship between expressed emotion and the amount of agreement between people with cognitive impairments and their partners on ratings of ability. Ratings were made of cognitive ability and instrumental activities of daily living (IADL) for the person with cognitive impairment. Discrepancies in ratings of ability have implications for assessing awareness and have previously been found to be associated with depression and carer distress.

Method: Forty-six people aged over 65 with mild cognitive impairment or early-stage dementia were recruited through NHS mental health services for older people. As part of a semi-structured interview, they and their partners gave separate ratings of cognitive abilities and IADL. Partners also completed a general measure of relationship quality and gave a five minute speech sample, used to assess level of expressed emotion. Depression and partner distress were also controlled for.

Results: Expressed emotion and general relationship quality scores were analysed separately. High expressed emotion was associated with larger discrepancies in ratings of ability on both cognitive and IADL measures. Additionally, people with cognitive impairment rated themselves as significantly less cognitively impaired if they had a

more critical partner. Expressed emotion was not associated with self-ratings or ratings made by partners.

Conclusion: The findings suggest that where disagreement is greater, the affective environment around a person with cognitive impairment is more likely to be characterised by criticism, emotional over-involvement or both. The implications of this for assessment, diagnosis, and helping couples to adjust to cognitive deterioration are discussed.

Keywords: relationships, spouses, awareness, discrepancy

Is expressed emotion related to ratings of ability made by people with cognitive impairments and their partners?

Introduction

As the population continues to age, increasing emphasis is being placed on the early detection of cognitive impairments that could signal the onset of dementia (NICE Guidelines, 2006; National Dementia Strategy, 2009). Estimates show that up to 6% of people over the age of 65 suffer from dementia, rising to 20% in those aged over 85 (British Psychological Society, 2002). It has been suggested that subjective cognitive complaints may predict future cognitive decline, preceding the onset of mild cognitive impairment (MCI) or dementia by up to 15 years (Gauthier et al., 2006; Reid & MacLullich, 2006; Reisberg, Schulman, Torossian, Leng & Zhu, 2010). It has also been suggested that MCI is on a continuum with dementia, and although prevalence rates for conversion from MCI to dementia vary, it has been found that people with MCI deteriorate more rapidly than unimpaired people (Petersen et al., 1999).

Previous research indicates that there is great variability in the extent to which impaired individuals complain of cognitive change. Awareness of such changes is difficult to conceptualise, but has been defined as 'the recognition of the fact, degree and implications of one's own illness' (see Clare, 2004a). Clare (2004a) has described the discrepancy between self and informant ratings of functioning as one of the main methods of assessing awareness. Generally, people with cognitive impairments overestimate their ability compared to an informant, often a family member, though some studies have demonstrated cases of 'hypergnosia' where people with cognitive

decline perceive themselves as more impaired than their informant (Michon, Deweer, Pillon, Agid & Dubois, 1994).

Previously, a lack of awareness was thought to be an inevitable consequence of progressive neurological damage (Cheston & Bender, 1999). However, awareness does not always decrease linearly with cognitive deterioration, and recent psychosocial research has challenged exclusively neurological explanations (Aalten, Van Valen, Clare, Kenny & Verhey, 2005; Clare, 2004b; Marková, Clare, Wang, Romero, & Kenny, 2005). For people with cognitive impairment, increased awareness has been found to be associated with mild depression and anxiety (Aalten et al., 2005; Roberts, Clare & Woods, 2009). Studies focusing upon carers have found larger discrepancies in ability ratings to be associated with increased carer burden, anxiety, and depression (DeBettignies, Mahurin & Pirozzolo, 1990; Jorm et al., 1994). This suggests informant ratings may also be influenced by subjective psychosocial factors

Carers with high levels of emotional distress have also been found to be high in expressed emotion (EE). EE refers to the attitude of an individual towards a family member with a disorder or impairment (Barrowclough & Hooley, 2003). High EE carers are characterised by greater levels of criticism or emotional over-involvement (EOI) towards their relatives than low EE carers. Most EE research into cognitive decline was conducted before the concept of MCI was introduced. Subsequently, the research has focused on carers of people with dementia, where it has been observed that most high EE is attributable to criticism rather than EOI (Wearden, Tarrier, Barrowclough, Zastowny, & Rahill, 2000). EE also takes into account the overall quality of the relationship (Magana et al., 1986). The general importance of interpersonal

relationships in dementia has been demonstrated by reviews such as Ablitt, Jones and Muers (2009) who reported an association between relationship quality and the psychological well-being of both carers and people with dementia. Moreover, Quinn, Clare and Woods (2009) report that carer perceptions of relationship quality are influenced by how much help the person with dementia needs.

Previous research has found that high EE carers rate their partners as more impaired than low EE carers, even after controlling for objective cognitive decline (Tarrier et al., 2002; Vitaliano, Becker, Russo, Magana-Amato & Maiuro, 1988). Vitaliano et al. (1988) found that high EE spouses rated their partners' functioning for instrumental activities of daily living (IADL) as more impaired than either low EE spouses or independent interviewers. This trend has been replicated with other family carers on behavioural measures (Tarrier et al., 2002; Vitaliano, Young, Russo, Rommano & Magana-Amato, 1993), although this finding has not been replicated with measures of cognitive ability (Tarrier et al., 2002; Gilhooly & Whittick, 1989; Vitaliano et al., 1993; Wagner, Logsden, Pearson & Teri, 1997). However, in these studies cognitive ability was measured using an objective test, rather than carer ratings.

Research to date has largely focused on how aware an individual is of their cognitive changes and the factors which may be associated with this. In a separate line of research, emphasis has been placed on the negative factors associated with being a carer, including emotional distress and the changing interpersonal relationship with the person cared for. However, no research has examined the extent to which relationship quality is associated with discrepancies between self and informant reports of ability. This discrepancy is important, particularly in clinical practice,

because the difference between these reports is often taken to indicate the degree of awareness a person has, which in turn has consequences for their assessment, diagnosis and care (Clare, Marková, Verhey & Kenny, 2005). Moreover, if discrepant estimates of ability are an indication of relationship difficulties, clinicians may wish to consider ways of reconciling the couple to reduce associated burden, distress and relationship quality.

This study aimed to investigate the relationship between carer EE and the degree of discrepancy between ratings of ability made by older people with cognitive impairments and their partners. It was not the purpose of this research to consider the objective accuracy of the reports of people when assessing ability, but to contribute to an understanding of the factors which affect the perception of ability within a couple affected by cognitive impairments in later life. The main research question was whether carer EE is predictive of discrepant estimates of ability. In order to further clarify the relationship between carer EE and perceptions of ability, the study also investigated the association between EE and individual ratings made by carers and older people with cognitive impairments. The main hypotheses are summarised as follows;

1) For couples where the carer is high in EE there will be a larger discrepancy in ratings of abilities than for couples where the carer is low in EE.
2) Consistent with previous research, high EE carers will rate their partners as more impaired than low EE carers rate their partners.

In the absence of previous research, it was not possible to hypothesise how people with cognitive impairments from high and low EE couples would rate themselves. The link between EE and discrepant ratings of ability was explored in two domains (or 'objects' of awareness, see Clare et al., 2005); cognitive ability and for IADL. As previous EE research has not used carer ratings of cognitive ability, an additional aim of the study was to explore whether the pattern of results would be consistent for both cognitive and IADL measures.

Method

Design

This study employed a cross-sectional, survey-based design. Data was collected at one point in time using standardised questionnaires and a brief interview with the partners of people with cognitive difficulties. A power calculation based on the primary research question indicated that 50 couples would yield a power of 0.81, allowing for the detection of a 0.1 variance being attributable to EE, where control variables were assumed to account for 0.3 of the variance and alpha was set to 0.05.

Participants

Participants were voluntarily recruited through specialist NHS mental health services for older people in the North of England. As relationship quality differs according to type of familial relationship (e.g. Quinn et al., 2009), participation was restricted to spouses living together in the community. Participants were at least 65 years old, had a diagnosis of MCI, Alzheimer's or vascular dementia, and a mini mental state examination score ≥18 (MMSE; Folstein, Folstein & McHugh, 1975). Couples were excluded if either partner lived in residential care, or if both partners had a diagnosis

of cognitive impairment. Couples were also excluded if the person with cognitive difficulties had a co-morbid psychiatric illness, or a diagnosis of fronto-temporal dementia or dementia with Lewy Bodies. Previous research has focused mainly upon Alzheimer's disease, and although awareness may be comparable in vascular dementia, it has been argued that generalisations to other dementias cannot be made (Aalten et al., 2005).

In total, 46 of 54 eligible couples were successfully recruited to participate in the study. One couple stated that it was not a convenient time, for five couples only one partner was willing to participate, and for two couples neither wished to participate. For the cognitively impaired group, there were 33 males, and 13 females, the mean age was 76.98, (s.d. 5.35, range 66-87). Of these nine had a diagnosis of MCI, 20 of Alzheimer's disease, five of vascular dementia, and 12 of mixed vascular/Alzheimer's dementia. The mean MMSE score was 24.61, (s.d. 2.79, range 18-30). The mean duration of symptoms as reported by partners was 31.11 months, (s.d. 24.4, range 6-96, *n*=44). The mean age of partners was 74.04, (s.d. 7.09, range 57-89), including 13 males and 33 females.

Measures

Appraisal of ability

The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE: short version; Jorm, 1994; 2004) was used to assess cognitive ability. Respondents are asked to compare current functioning to 10 years ago for 16 common situations using memory and intelligence. For each one, respondents indicate on a five point scale whether they feel functioning has improved, stayed the same or become worse.

Answers are summed and divided by 16 to gain the final score; higher scores indicate greater impairment. The short version correlates 0.98 with the long version, has comparable validity, and is the recommended version for use in English (Jorm, 2004). A self-report version for people with dementia demonstrated acceptable homogeneity (Cronbach's alpha, 0.94) and construct validity on a sample of 4823 participants (Jansen et al., 2008).

The Instrumental Activities of Daily Living Scale (IADL scale: Lawton & Brody, 1969) was used to assess ratings of functional ability. This scale has eight items, with 3-5 hierarchical responses indicating the subject's level of functioning. Each item was scored using polytomous summation (Vittengl, White, McGovern & Morton, 2006) where lower scores indicate greater functioning. The items were summed to give a total score from 8-31. The scale has a test-retest coefficient of 0.94 and the scale's validity has been established by correlating it with other measures of functional status, (Lawton & Broody, 1969). This scale has been used previously in discrepancy based awareness research (DeBettignies et al., 1990; Mangone et al., 1991).

Assessment of expressed emotion

EE was assessed using the Five Minute Speech sample (FMSS; Magana et al., 1986). The FMSS is briefer than the 'gold standard' Camberwell Family Interview (CFI; Vaughn & Leff, 1976), and has been found to be an acceptable alternative in a review of EE measures (Van Humbeeck, Van Audenhove, De Hert, Pieters & Storms, 2002). Respondents are instructed to speak for five minutes about their relationship with a specific person, and then the speech sample is rated according to emotional content and tone. This yields one of two overall statuses: low or high EE (the latter

incorporating critical, emotional over-involvement, or mixed subtypes). The FMSS has a reported internal consistency of ≥0.80, a test-retest reliability of 0.64 (Van Humbeeck et al., 2002) and has previously been used with dementia carers (Vitaliano et al., 1988, 1993; Wagner et al., 1997).

Although recommended for measuring EE, the FMSS has been criticised for underestimating levels of high EE and it has been argued that it should not be used as the only alternative to the CFI (Van Humbeeck et al., 2002). Subsequently, partners were also asked to complete the Quality of Carer-Patient Relationships scale (QCPR; Spruytte, Van Audenhove, Lammertyn & Storms, 2002) which is a more general measure of relationship quality, previously used with dementia carers. It has 14 items, which require respondents to answer on a five point scale from 'totally disagree' to 'totally agree'. It has two subscales, warmth and absence of criticism, the latter being similar to the concept of criticism in high EE. Higher scores indicate a better relationship. The authors demonstrated an internal consistency of 0.82 and acceptable validity by correlating the QCPR with the Perceived Criticism Scale (Hooley & Teasdale, 1989), also developed from the literature on EE.

Assessment of control variables

To control for the possible confounding effect of depression on ability ratings, people with cognitive impairments were asked to complete the Geriatric Depression Scale (GDS-15: Sheikh & Yesavage, 1986). The GDS-15 requires respondents to answer 15 yes/no questions and has been recommended for both screening and rating severity of depression in mild-moderate dementia (Isella, Villa, & Appollonio, 2001). In people with mild impairments (MMSE ≥18), an internal consistency of 0.83 and a validity

coefficient of 0.7 with the Cornell Scale for Depression in Dementia has been demonstrated (Alexopoulos, Abrams, Young & Shamoian, 1988; Müller-Thomsen, Arlt, Mann, Maβ & Ganzer, 2005).

To control for the possible confounding effect of emotional distress on partner ratings, partners were asked to complete the General Health Questionnaire-12 (GHQ-12: Goldberg, 1992). This 12 item self-report questionnaire is intended to detect non-psychotic psychiatric disorder. Respondents are asked to indicate on a four point scale whether they have experienced certain symptoms/behaviours recently. Goldberg and Williams (1988) report an internal consistency between 0.82 and 0.90, split-half reliability of 0.83 and test-retest reliability of 0.73. Validity has been established via sensitivity, 93.5% and specificity, 78.5%. The GHQ-12 was scored using the Likert scoring system, which produces a score from 0-36 allowing for the detection of a greater degree of variation.

Procedure

Following ethical approval by a local NHS Research Ethics Committee, suitable couples were initially identified and approached by members of their health care team. Interested couples were provided with an information pack about the study and were contacted one week later by the researcher. For couples who wished to participate, a one off home visit was arranged, lasting approximately one hour. After completing the informed consent procedure, each partner was seen separately to complete the individual measures as part of a semi-structured interview. During this time people with cognitive impairments completed the IQCODE, the IADL scale and GDS in a counterbalanced order. For partners, the two relationship measures, the FMSS and

the QCPR, were also counterbalanced against the three other questionnaires, the IQCODE, the IADL scale and the GHQ-12. Demographic information was gathered from the partner at the end of the interview.

Data analysis

Continuous variables were first checked using the Kolmogorov-Smirnov test, which confirmed that each variable could be assumed to be normally distributed. The control variables, patient depression and partner distress were checked for multicollinearity using Pearson's correlation, which indicated acceptable relationships. To test the relationship between EE and ability ratings/discrepancies, high and low groups as determined by the FMSS were first compared using t-tests. Where Levene's test for equality of variances was found to be significant, the unequal population variances form of the t-test is reported. This was then repeated using analysis of covariance to include the control variables. Given the limitations of the FMSS, the analyses were then repeated using the continuous scores from the subscales of the QCPR. The control variables were entered in a hierarchal multiple linear regression at the first step, followed by warmth and absence of criticism at the second step. All significance tests used an alpha of .05.

Results

Discrepancy scores

Discrepancy scores were calculated by subtracting the total rating score made by people with cognitive impairments from their partner's total rating score. Positive scores indicate that the person with cognitive impairment overestimated their ability relative to their partner, whilst negative scores indicate that they underestimated. For

IQCODE ratings, 43 (93.48%) people overestimated, and three (6.52%) underestimated. On the IADL scale, 38 (82.61%) overestimated, four (8.70%) gave equal estimates, and four (8.70%) underestimated.

Expressed emotion

The FMSS were coded by the main author (CH). Ten samples were independently coded by a second rater (PP), trained in the assessment and scoring of EE. The inter-rater reliability using the Kappa statistic was found to be 0.85 (p<.001) indicating a good level of agreement. In total, 28 partners were rated as low EE, 10 as critical, six as EOI, and two as combined critical-EOI. Subsequently the QCPR data was analysed separately.

Variables

For the total sample, 36 (78.26%) people with cognitive impairment scored below the cut-off for depression, whilst 10 (21.74%) scored in the depression range. For their partners, the original GHQ-12 scoring was used with a cut-off of three for psychiatric distress, as cut-offs using Likert scoring have not been validated. Twenty-four (52.17%) scored below the cut-off for psychiatric distress, whilst 22 (47.83%) scored at or above the cut-off. The mean score on the QCPR warmth scale was 33.37 (s.d. 3.73, range 25-40), and for absence of criticism the mean was 21.46 (s.d. 4.33, range 10-29). Table one summarises the main scores for the predictor and dependent variables by EE groups. For control variables, there was no significant difference between the high and low EE couples.

Table 1. Means (and standard deviation) of the main variables by low and high expressed emotion (EE) groups.

	Low EE *n*=28	High EE *n*=18	Range	Significance
PwCI Depression	2.82 (1.74)	3.94 (3.75)	0-13	*p*=.247
Partner Distress	11.00 (4.78)	13.94 (5.79)	0-27	*p*=.067
IQCODE Discrepancy	0.72 (0.50)	1.08 (0.75)	-0.38-2.63	*p*=.055
IADL Discrepancy	4.04 (3.83)	6.67 (4.64)	-2-12	*p*=.042
PwCI IQCODE	3.44 (0.37)	3.35 (0.53)	2.19-4.50	*p*=.510
PwCI IADL	14.25 (5.43)	14.06 (4.17)	8-28	*p*=.898
Partner IQCODE	4.16 (0.45)	4.43 (0.46)	3.31-5.00	*p*=.051
Partner IADL	18.29 (6.09)	20.72 (5.75)	10-29	*p*=.183

Abbreviations: PwCI People with cognitive impairment

Expressed emotion and discrepant estimates of ability

For both IQCODE and IADL, high EE couples were found to a have larger discrepancy than low EE couples. An initial t-test demonstrated this difference was approaching significance for IQCODE ratings ($t_{(44)}$=−1.968, *p*=.055), and significant for IADL ratings ($t_{(44)}$=−2.09, *p*=.042). After adjusting for depressive symptoms in people with cognitive impairments and partner distress, the effect of EE upon IQCODE discrepancy became significant ($F_{(1,42)}$=4.42, *p*=.041). This analysis also showed that less depression in people with cognitive impairments and greater partner distress made a significant contribution to greater discrepancy size ($F_{(1,42)}$ =11.32, *p*=.002; $F_{(1,42)}$=6.41, *p*=.015 respectively). For IADL, no factors were found to be significant after adjusting for

depression and partner distress, although the effect of EE was approaching significance ($F_{(1,42)}$=3.84, p=.056).

Expressed emotion and self-estimates of people with cognitive impairments

Figures one and two demonstrate the relationship between self-estimates of ability and EE. There was no significant difference for either IQCODE ($t_{(44)}$=0.67, p=.510) or IADL ($t_{(44)}$=0.13, p=.898). When the analysis was repeated to adjust for depression and partner distress, only depression was found to have a significant effect ($F_{(1,42)}$=22.42, p<.001). People with higher self-reported depression symptoms rated themselves as more impaired than those with less depression symptoms. No factors were significant in the controlled model for IADL.

Expressed emotion and estimates of abilities made by partners

Figures one and two also demonstrate the relationship between partner estimates of ability and EE. For IQCODE, the difference between high and low EE carers was approaching significance ($t_{(44)}$=−2.00, p=.051). However, in the controlled model, only greater carer distress significantly contributed to lower carer estimates of ability ($F_{(1,42)}$=10.53, p=.002). For IADL there was no significant difference between high and low EE carers ($t_{(44)}$=−1.35, p=.183). No other factors were found to be significant in the controlled model.

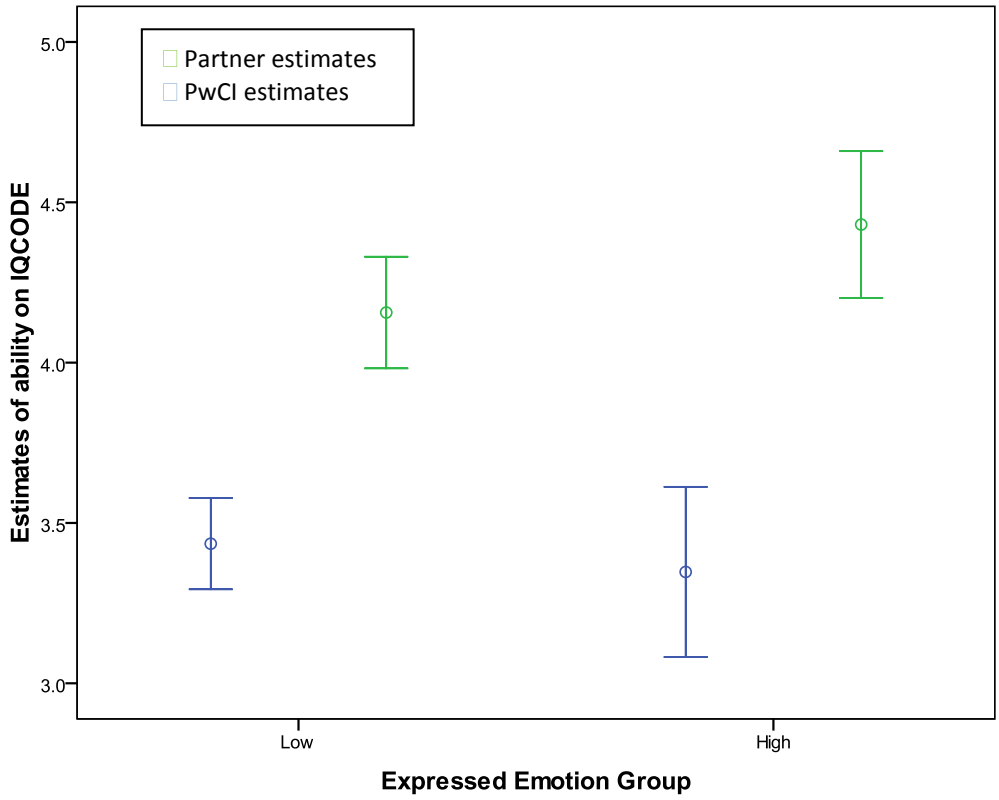


Figure 1*:* Means (and 95% confidence intervals) for estimates of ability on the IQCODE by people with cognitive impairments (PwCI) and partners for the high and low expressed emotion groups, higher scores indicate poorer ratings.

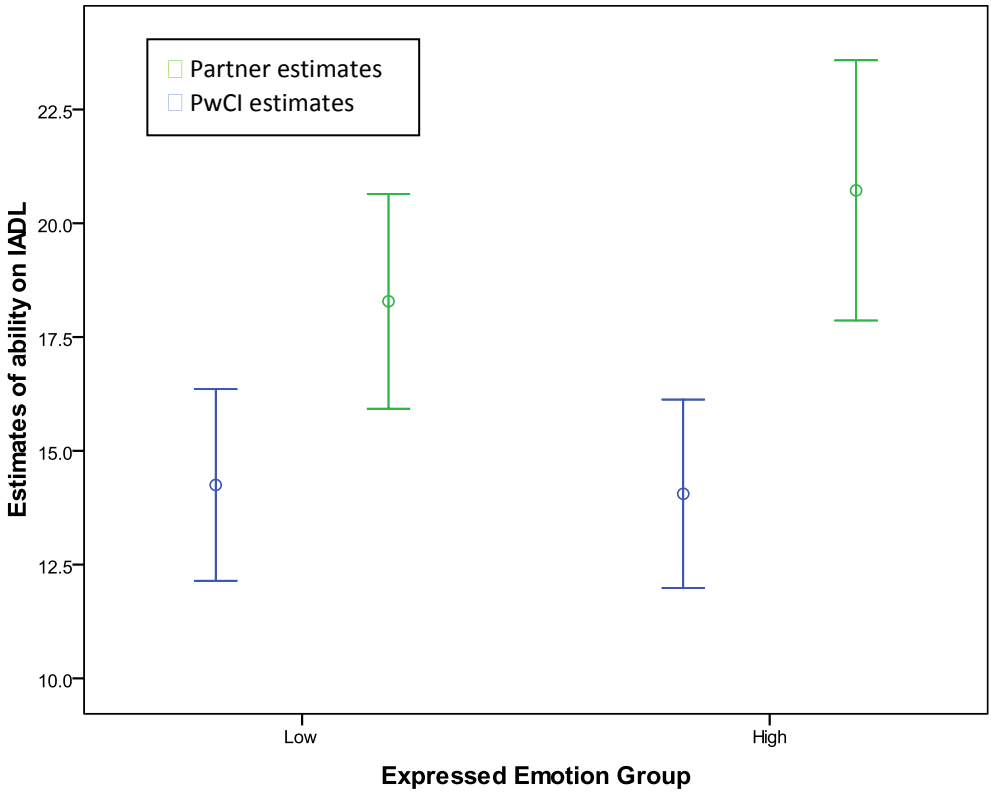


Figure 2: Means (and 95% confidence intervals) for estimates of ability on the IADL by people with cognitive impairments (PwCI) and partners for the high and low expressed emotion groups, higher scores indicate poorer ratings.

Secondary analyses using the QCPR subscales

Initial analyses were conducted using Pearson's correlation coefficient to look for individual relationships between the independent variables (depression, partner distress, warmth, absence of criticism) and each of the dependent variables. For IQCODE, this showed that greater depression was significantly correlated with smaller discrepancy (r=-.29, p=.05), and poorer self-ratings (r=.57, p<.001), whilst greater partner distress was significantly correlated with poorer partner ratings (r=.50, p<.001). Pearson's correlation coefficients between these factors and the IADL variables did not find any significant relationships.

Multiple regressions were then conducted to investigate the combined associations between these factors and each of the dependent variables. For IADL, the regression models were not significant for either the control variables alone or with the addition of warmth and absence of criticism scores. For IQCODE discrepancy, the overall model was significant ($F_{(4,41)}$=4.07, p=.007), but neither absence of criticism nor warmth were found to be significant predictors. However, lower depression and greater partner distress were found to significantly contribute to greater discrepancy (β=-.42, t=-.3.00, p=.005; β=.362, t=2.53, p=.015 respectively). For IQCODE self-estimates, the overall model was significant ($F_{(4,41)}$=4.15, p<.001). Increasing absence of criticism significantly contributed to more impaired self-ratings (β=.345, t=2.27, p=.028), along with greater depression (β=.577, t=4.56 p<.001). For IQCODE ratings made by partners, the overall model was significant ($F_{(4,41)}$=3.50, p=.015) but only greater partner distress significantly predicted poorer ratings (β=.489, t=3.35 p=.002).

Discussion

The aim of this study was to investigate how EE is related to the amount of agreement between people with cognitive impairment and their partners on ratings of ability. Using the FMSS to create high and low EE groups, the results indicated a larger discrepancy on both IQCODE and IADL for couples characterised by high EE. There was no difference between the high and low EE groups for either self-ratings or partner ratings. In addition to this, greater depression was found to be significantly related to smaller discrepancies and to poorer self-ratings on the IQCODE. Greater partner distress was found to be significantly related to greater discrepancies and poorer partner ratings on the IQCODE. When the analyses were repeated using the subscales

of the QCPR, the pattern of results was found to differ. Whilst the association of the control variables to each of the dependent variables remained the same, the QCPR subscales were not found to predict discrepancy size. Moreover, absence of criticism was found to predict self-ratings on the IQCODE, such that poorer self-ratings were associated with less criticism.

Due to the design of the current study it is not possible to infer causal relationships between EE, the subscales of the QCPR, and the other variables. However, the findings for factors associated with discrepancy size are in line with previous research. This indicates that people with depression appear to have more insight into their difficulties than those without depression (Aalten et al., 2005) and that carers report more distress when awareness is low (DeBettignies et al., 1990; Jorm et al., 1994). In the present study, depression was also found to predict poorer self-ratings of cognitive ability. However as Aalten et al. have acknowledged it is not possible to determine the direction of causality. Although it could be argued that insight into one's cognitive deterioration increases vulnerability to depression, depression is also known to be associated with increased subjective memory complaints. The results for partners' ratings appear more mixed. Previous research has shown high EE is associated with increased carer distress and with poorer ratings of IADL ability (e.g. Tarrier et al., 2002; Vitaliano et al., 1988, 1993; Wagner et al., 1997). In the present study, these findings weren't replicated, however both carer distress and high EE were found to be associated with larger IQCODE discrepancies.

The overall pattern of results for IADL differed from IQCODE ratings in this study. One possible explanation is that most participants with cognitive impairments were male, and it could be argued that the scale used in this study to measure IADL has a gender bias which may be open to cohort effects in this generation. All eight items of the Lawton and Brody (1969) scale were used in this study, though some researchers (see Vittengl et al., 2006) have argued that with males, the three items pertaining to domestic activities should be excluded. An alternative explanation is that there was little opportunity to observe functional impairment in this study. The mean MMSE score indicated most participants had only mild difficulties. A much larger and more varied sample would be needed to detect a clearer relationship with any of the predictor variables.

The variation in results between the FMSS and the QCPR analyses could be explained by their different properties. Although both measures consider similar areas (e.g. criticism) the QCPR was designed as a more general relationship measure (Spruytte et al., 2002), and has not been validated against interview measures of EE. Moreover, there are difficulties with comparing results derived from a continuous measure with those from a categorical measure. For example, whilst the QCPR criticism scale yields a score between 1 and 30, participants only need to make one critical comment during the FMSS to be categorised as high critical EE. Furthermore, the regression analyses may have been limited by the sample size in this study. There may also be additional limitations of using the FMSS, particularly with older people. The EE literature and the development of the FMSS originally grew out of research with family carers of people with psychosis (Wearden et al., 2000). Typically these involved parent-child or sibling relationships, which are known to differ from spousal

relationships in dementia (Quinn et al., 2009). Moreover, EE research traditionally focused upon likelihood of relapse in psychosis. Dementia is different to psychosis in that it is a progressive illness, not an episodic condition, and subsequently EE research has focused upon the association with symptomatic factors. However it is not yet clear if EE has a different pattern of association to progressive and episodic conditions.

In the current study EOI was present in 44% of the high EE couples, which was greater than expected. This may partially be explained by the recent conceptualisation of EE as an adaptation to loss. Patterson, Birchwood & Cochrane (2005) argue that, for psychosis, high EOI and criticism are natural reactions as part of a grieving process following diagnosis. Over time, they found that high EOI carers evolved into critical carers. Subsequently, it could be argued the high EOI rate reflects the inclusion of participants at an earlier stage of cognitive decline than previous research, which has included people at later stages of the illness. Inclusion of people at an earlier stage of decline might also account for the failure to replicate greater carer distress in high EE couples. This raises the issue of whether including both people with MCI and mild dementia in the study is a limitation, as it was not possible to analyse these as separate groups. It could be argued that a diagnosis of dementia carries a different meaning to that of MCI. For example, a diagnosis of dementia may be associated with greater perceived loss. Clare (2003) describes the threat to self that people with dementia face, and Corner and Bond (2004) have described the negative stigma that surrounds dementia; the fear and poor expectations that have come to be associated with the label. Given that MCI is a newer, less well known concept, this could be seen as less

threatening and may have influenced both appraisals of ability and levels of EE reported in this study.

Although the main focus of this study was the size of discrepancy between people with cognitive impairments and their partners, some impaired people were found to underestimate their ability relative to their partner's rating. This poses a challenge to how the concept of awareness is ordinarily conceptualised. It could be argued that carers are more accurate in their ratings and therefore underestimating indicates equally poor awareness as overestimating. Alternatively it could be argued that underestimation is qualitatively different, in that the impaired person may actually be more aware of their difficulties than their carer. Such people may differ from 'over-estimators' in terms of psychosocial factors such as depression and EE. Unfortunately, due to the limited sample size in the present study it was not possible to compare the results of under- and over-estimators.

The results of the study indicate that high EE is associated with poorer agreement between people with cognitive impairments and their partners for ratings of cognitive and IADL functioning. Clinically, this suggests that where disagreement is greater, the affective environment towards the person with cognitive impairment is characterised by either criticism, EOI or both. In order to help the couple adapt to a diagnosis and/or symptoms related to cognitive deterioration, clinicians may need to consider how the couple can come to a shared understanding of problems. Additionally, clinicians may wish to consider the quality of the relationship between a couple, both prior to, and within the context of cognitive impairment. Ablitt et al. (2009) concluded that overall relationship quality will deteriorate as a consequence of

dementia. However for couples with a particularly poor relationship history, carers are more likely to experience distress which may negatively influence the well-being of their partner. Subsequently, it may also be beneficial for clinicians to focus on supporting couples to manage any relationship difficulties, depression or distress.

Future research in this field might consider how the direction of disagreement is associated with EE and affective functioning in couples. In particular, it may be of interest to consider whether differences in ratings and scores between the EE groups also vary by direction of disagreement. In addition to this, it may also be useful to investigate the potential confounding effect of diagnosis, and the influence of perceptions that people have regarding a particular illness upon EE and ratings of ability. This would further our understanding of the overarching concept of awareness. Moreover, it would be helpful to clarify the concept of EE in older people. For example it may be of value to investigate the relationship between EE and the course of illness in episodic and progressive conditions. Finally, research aimed specifically at the way in which EE is affected by aging and different familial relationships would enhance our understanding of how EE manifests and evolves across the lifespan.

References

Aalten, P., Van Valen, E., Clare, L., Kenny, G., & Verhey, F. (2005). Awareness in dementia: a review of clinical correlates. *Aging & Mental Health, 9*, 414-422.

Ablitt, A., Jones, G.V., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging & Mental Health, 13,* 497-511.

Alexopoulos, G.S., Abrams, R.C., Young, R.C., & Shamoian, C.A. (1988). Cornell scale for depression in dementia. *Biological Psychiatry, 23,* 271-284.

Barrowclough, C & Hooley, J. (2003). Attributions and expressed emotion: A review. *Clinical Psychology Review, 23,* 849-880.

British Psychological Society (2002). *Clinical psychology services for older people in primary care.* Leicester: British Psychological Society.

Cheston, R., & Bender, M. (1999). *Understanding dementia: The man with the worried eyes.* London: Jessica Kingsley Publishers.

Clare, L. (2003). Managing threats to self: Awareness in early stage Alzheimer's disease. *Social Science and Medicine, 57,* 1017-1029.

Clare, L. (2004a). Awareness in early stage Alzheimer's disease: A review of methods and evidence. *British Journal of Clinical Psychology, 43,* 177-196.

Clare, L. (2004b). The construction on awareness in early-stage Alzheimer's disease: A review of concepts and models. *British Journal of Clinical Psychology, 43,* 155-175.

Clare, L., Marková, I., Verhey, F., & Kenny, G. (2005). Awareness in dementia: A review of assessment methods and measures. *Aging & Mental Health, 9,* 394-413.

Corner, L. & Bond, J. (2004). Being at risk of dementia: Fears and anxieties of older adults. *Journal of Aging Studies, 18,* 143-155.

DeBettignies, B.H., Mahurin, R.K., & Pirozzolo, F.J. (1990). Insight for impairment in independent living skills in Alzheimer's disease and multi-infarct dementia. *Journal of Clinical and Experimental Neuropsychology, 12,* 355-363.

Department of Health (2009). *Living well with dementia: A national dementia strategy*. London: Department of Health.

Derouesne, C., Thibault, S., Lagha-Pierucci, S., Baudouin-Madec, V., Ancri, D., & Lacomblez, L. (1999). Decreased awareness of cognitive deficits in patients with mild dementia of the Alzheimer's type. *International Journal of Geriatric Psychiatry, 14*, 1019-1030.

Folstein, M.F., Foldstein, S.E., & McHugh, P.R. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Psychiatry Research, 12,* 189-198.

Gauthier, S., Reisberg, B., Zaudig, M., Petersen, R.C., Ritchie, K., Broich, K., et al. (2006). International psychogeriatric association expert conference on mild cognitive impairment. *Lancet, 367,* 1262-1270.

Gilhooly, M.L.M., & Whittick, J.E. (1989). Expressed emotion in caregivers of the dementing elderly. *British Journal of Medical Psychology, 62,* 265-272.

Goldberg, D. (1992). *General Health Questionnaire (GHQ-12).* Windsor: NFER-Nelson.

Goldberg, D., & Williams, P. (1988). *A user's guide to the general health questionnaire.* Windsor: NFER-Nelson.

Hardy, R.M., Oyebode, J.R., & Clare, L. (2006). Measuring awareness in people with mild to moderate Alzheimer's disease: Development of the memory awareness rating scale – adjusted. *Neuropsychological Rehabilitation, 16,* 178-193.

Hooley, J. M., & Teasdale, J. D. (1989). Predictors of relapse in unipolar depressives: Expressed emotion, marital distress and perceived criticism. *Journal of Abnormal Psychology, 98*, 229-235.

Isella, V., Villa, M.L., Appollonio, I.M. (2001). Screening and quantification of depression in mild-to-moderate dementia through the GDS short forms. *Clinical Gerontologist, 24,* 115-125.

Jansen, A.P.D., van Hout, H.P.J., Nijpels, G., van Marwijk, H.W.J., Gundy, C., de Vet, H.C.W., et al. (2008). Self-reports on the IQCODE in older adults: A psychometric evaluation. *Journal of Geriatric Psychiatry and Neurology, 21,* 83-92.

Jonker, C., Geerlings, M.I., & Schmand, B. (2000). Are memory complaints predictive for dementia? A review of clinical and population-based studies. *International Journal of Geriatric Psychiatry, 15,* 983-991.

Jorm, A.F., Christensen, H., Henderson, A.S., Korten, A.E., Mackinnon, A.J., & Scott, R. (1994). Complaints of cognitive decline in the elderly: a comparison of reports by subjects and informants in a community survey. *Psychological Medicine, 24,* 365-374.

Jorm, A. F. (1994). A short form of the informant questionnaire on cognitive decline in the elderly (IQCODE): development and cross-validation. *Psychological Medicine, 24*, 145–153.

Jorm, A.F., (2004). The informant questionnaire on cognitive decline in the elderly (IQCODE): A review. *International Psychogeriatrics, 16,* 1-19.

Lawton, M.P., & Brody, E.M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist, 9,* 179-186.

Magana, A., Goldstein, M.J., Karno, M., Miklowitz, D.J., Jenkins, J., & Falloon, I.R.H. (1986). A brief method for assessing expressed emotion in relatives of psychiatric patients. *Psychiatry Research, 17,* 203-212.

Mangone, C.A., Hier, D.B., Gorelik, P.B., Ganellen, R.J., Langenberg, P., Boarman, R., et al. (1991). Impaired insight in Alzheimer's disease. *Journal of Geriatric Psychiatry and Neurology, 4,* 189-193.

Marková, I., Clare, L., Wang, M., Romero, B., & Kenny, G. (2005). Awareness in dementia: conceptual issues. *Aging & Mental Health, 9*, 386-393.

Michon, A., Deweer, B., Pillon, B., Agid, Y., & Dubois, B. (1994). Relation of anosognosia to frontal lobe dysfunction in Alzheimer's disease. *Journal of Neurology, Neurosurgery, and Psychiatry, 57,* 805-809.

Müller-Thomsen, T., Arlt, S., Mann, U, Maβ, & Ganzer, S. (2005). Detecting depression in Alzheimer's disease: evaluation of four different scales. *Archives of Clinical Neuropsychology, 20,* 271-276.

National Institute for Clinical Excellence (2006). *Dementia: Supporting people with dementia and their carers in health and social care*. London: NICE.

Patterson, P., Birchwood, M., & Cochrane, R. (2005). Expressed emotion as an adaptation to loss: Prospective study in first-episode psychosis. *British Journal of Psychiatry, 187*(Supple. 48), 59-64.

Petersen, R.C., Smith, G.E., Waring, S.C., Ivnik, R.J., Tangalos, E.G., & Kokmen, E. (1999). Mild cognitive impairment: Clinical characterization and outcome. *Archives of Neurology, 56,* 303-308.

Quinn, C., Clare, L., Woods, B. (2009). The impact of the quality of the relationship on the experiences and wellbeing of caregivers of people with dementia: A systematic review. *Aging & Mental Health, 13,* 143-154.

Reid, L.M., & MacLullich, A.M.J. (2006). Subjective memory complaints and cognitive impairment in older people. *Dementia and Geriatric Cognitive Disorders, 22,* 471-485.

Reisberg, B., Shulman, M.B., Torossian, C., Leng, L., & Zhu, W. (2010). Outcome over seven years of healthy adults with and without subjective cognitive impairment. *Alzheimer's and Dementia, 6,* 11-24.

Roberts, J.L., Clare, L., & Woods, R.T. (2009). Subjective memory complaints and awareness of memory functioning in mild cognitive impairment: A systematic review. *Dementia and Geriatric Cognitive Disorders, 28,* 95-109.

Sheikh, J.I., & Yesavage, J.A. (1986). Geriatric Depression Scale (GDS). Recent evidence and development of a shorter version. In T.L. Brink (Ed.) *Clinical Gerontology: A Guide to Assessment and Intervention* (pp. 165-173). New York: The Haworth Press.

Spruytte, N., Van Audenhove, C., Lammertyn, F., & Storms, G. (2002). The quality of the caregiving relationship in informal care for older adults with dementia and chronic psychiatric patients. *Psychology and Psychotherapy: Theory, Research and Practice, 75,*295-311.

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

Vaughan, C.E. & Leff, J.P. (1976). The influence of family and social factors on the course of psychiatric illness: A comparison of schizophrenic and depressed neurotic patients. *British Journal of Psychiatry, 129,* 125-137.

Van Humbeeck, G., Van Audenhove, C., De Hert, M., Pieters, G., & Storms, G. (2002). Expressed emotion: A review of assessment instruments. *Clinical Psychology Review, 22,* 321-341.

Vitaliano, P.P, Becker, J., Russo, J., Magana-Amato, A., & Maiuro, R.D. (1988). Expressed emotion in spouse caregivers of patients with Alzheimer's disease. The *Journal of Applied Social Sciences, 13,* 215-250.

Vitaliano, P.P., Young, H.M., Russo, J., Romano, J., & Magana-Amato A. (1993). Does expressed emotion in spouses predict subsequent problems among care recipients with Alzheimer's disease? *Journal of Gerontology, 48,* 202-209.

Vittengl, J.R., White, C.N., McGovern, R.J., & Morton, B.J. (2006). Comparative validity of seven scoring systems for the instrumental activities of daily living scale in rural elders. *Aging & Mental Health, 10,* 40-47.

Wagner, A.M., Logsden, R., Pearson, J.L., & Teri, L. (1997). Caregiver expressed emotion and depression in Alzheimer's disease. *Aging & Mental Health, 1,* 132-139.

Wearden, A.J., Tarrier, T., Barrowclough, C., Zastowny, T.R., & Rahill, A.A. (2000). A review of expressed emotion research in health care. *Clinical Psychology Review, 20,* 633-666.

Part Three: Appendixes

Appendix 1: Guidelines for Submission to Psychology & Aging

Retrieved from: http://www.apa.org/pubs/journals/pag/index.aspx

Description

Psychology and Aging publishes original articles on adult development and aging. Such original articles include reports of research that may be applied, biobehavioral, clinical, educational, experimental (laboratory, field, or naturalistic studies), methodological, or psychosocial.

Although the emphasis is on original research investigations, occasional theoretical analyses of research issues, practical clinical problems, or policy may appear, as well as critical reviews of a content area in adult development and aging. Clinical case studies that have theoretical significance are also appropriate. Brief reports are acceptable with the author's agreement not to submit a full report to another journal.

Instructions to Authors

Please consult APA's Instructions for All Authors for information regarding

- Manuscript Preparation
- Submitting Supplemental Materials
- Abstract and Keywords
- References
- Figures
- Permissions
- Publication Policies
- Ethical Principles

Submission

Submit manuscripts electronically through the Manuscript Submission Portal (.rtf, .doc, or .pdf files).
Fredda Blanchard-Fields, PhD
School of Psychology
Georgia Institute of Technology
Atlanta, GA 30332-0170

General correspondence may be directed to the Editor's Office.
In addition to addresses and phone numbers, please supply e-mail addresses and fax numbers, if available, for potential use by the editorial office and later by the production office.
Keep a copy of the manuscript to guard against loss.

Masked Review Policy

Masked reviews are optional, and authors who wish masked reviews must specifically request them at submission. Authors requesting masked review should make every effort to see that the manuscript itself contains no clues to their identities. Authors' names, affiliations, and contact information should be included only in the cover letter.

Length
Manuscripts should not exceed 8,000 words (approximately 27 double-spaced pages in 12-point Times New Roman font). Shorter manuscripts are equally welcomed.

The word count does not include references, tables, and figures. If you feel that you need extra space, please contact the editor. For example, you may have a complex methodology or statistical approach or a new theoretical framework that requires more text.
Please include the word count for the main text below the keywords.

Brief Reports
Use 12-point Times New Roman type and 1-inch (2.54-cm) margins; include an abstract of 75–100 words; do not exceed 265 lines of text, not including references; and include no more than two tables or figures.

Instructions for all authors

Overview
The following instructions pertain to all journals published by APA and the Educational Publishing Foundation (EPF).
Please also visit the web page for the journal to which you plan to submit your article for submission addresses, journal-specific instructions, and exceptions.

Manuscript Preparation
Prepare manuscripts according to the *Publication Manual of the American Psychological Association* (6th edition). Manuscripts may be copyedited for bias-free language (see Chapter 3 of the *Publication Manual*).
Double-space all copy. Other formatting instructions, as well as instructions on preparing tables, figures, references, metrics, and abstracts, appear in the *Manual*.
If your manuscript was mask reviewed, please ensure that the final version for production includes a byline and full author note for typesetting.
Review APA's Checklist for Manuscript Submission before submitting your article.

Submitting supplementary materials
APA can now place supplementary materials online, available via the published article in the PsycARTICLES database. Please see Supplementing Your Article With Online Material for more details.

Abstract and Keywords
All manuscripts must include an abstract containing a maximum of 250 words typed on a separate page. After the abstract, please supply up to five keywords or brief phrases.

References
List references in alphabetical order. Each listed reference should be cited in text, and each text citation should be listed in the References section.
Examples of basic reference formats:

Journal Article:
Herbst-Damm, K. L., & Kulik, J. A. (2005). Volunteer support, marital status, and

the survival times of terminally ill patients. *Health Psychology*, *24*, 225–229. doi: 10.1037/0278-6133.24.2.225

Authored Book:

Mitchell, T. R., & Larson, J. R., Jr. (1987). *People in organizations: An introduction to organizational behavior* (3rd ed.). New York, NY: McGraw-Hill.

Chapter in an Edited Book:

Bjork, R. A. (1989). Retrieval inhibition as an adaptive mechanism in human memory. In H. L. Roediger III & F. I. M. Craik (Eds.), *Varieties of memory & consciousness* (pp. 309–330). Hillsdale, NJ: Erlbaum.

Figures

Graphics files are welcome if supplied as Tiff, EPS, or PowerPoint files. The minimum line weight for line art is 0.5 point for optimal printing.

When possible, please place symbol legends below the figure instead of to the side.

Original color figures can be printed in color at the editor's and publisher's discretion provided the author agrees to pay

- $255 for one figure
- $425 for two figures
- $575 for three figures
- $675 for four figures
- $55 for each additional figure

Permissions

Authors of accepted papers must obtain and provide to the editor on final acceptance all necessary permissions to reproduce in print and electronic form any copyrighted work, including, for example, test materials (or portions thereof) and photographs of people.

Publication Policies

APA policy prohibits an author from submitting the same manuscript for concurrent consideration by two or more publications.

See also APA Journals Internet Posting Guidelines.

APA requires authors to reveal any possible conflict of interest in the conduct and reporting of research (e.g., financial interests in a test or procedure, funding by pharmaceutical companies for drug research).

Download Disclosure of Interests Form (PDF: 38KB)

Authors of accepted manuscripts are required to transfer the copyright to APA.

Download Publication Rights (Copyright Transfer) Form (PDF: 83KB)

Ethical Principles

It is a violation of APA Ethical Principles to publish "as original data, data that have been previously published" (Standard 8.13).

In addition, APA Ethical Principles specify that "after research results are published, psychologists do not withhold the data on which their conclusions are based from other competent professionals who seek to verify the substantive claims through reanalysis and who intend to use such data only for that purpose, provided that the confidentiality of the participants can be protected and unless legal rights concerning proprietary data preclude their release" (Standard 8.14).

APA expects authors to adhere to these standards. Specifically, APA expects authors to have their data available throughout the editorial review process and for at least 5 years after the date of publication.
Authors are required to state in writing that they have complied with APA ethical standards in the treatment of their sample, human or animal, or to describe the details of treatment.

Download Certification of Compliance With APA Ethical Principles Form (PDF: 26KB)

The APA Ethics Office provides the full Ethical Principles of Psychologists and Code of Conduct electronically on their website in HTML, PDF, and Word format. You may also request a copy by e-mailing or calling the APA Ethics Office (202-336-5930). You may also read "Ethical Principles," December 1992, *American Psychologist*, Vol. 47, pp. 1597–1611

Other Information

- Appeals Process for Manuscript Submissions
- Preparing Auxiliary Files for Production
- Document Deposit Procedures for APA Journals

Appendix 2: Guidelines for Submission to Aging & Mental Health

Retrieved from www.tandf.co.uk/journals/journal.asp?issn=1360-7863&linktype=44 on 30th May 2010.

Journal Details: Aging & Mental Health

Instructions for Authors

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

Manuscripts

Manuscripts may be in the form of: (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to **10,000 words**); or (ii) short reports not exceeding **2,000 words**. These word limits **exclude** references and tables.

All submissions should be made online at Aging & Mental Health's ScholarOne Manuscripts site. New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre.

Authors should prepare and upload two versions of their manuscript. One should be a complete text, while in the second all document information identifying the author should be removed from files to allow them to be sent anonymously to referees. When uploading files authors will then be able to define the non-anonymous version as "File not for review".

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

All submissions should be in the style of the **Publication Manual** of the American Psychological Association (6th edition, 2009). Papers should be double spaced throughout (including the references), with margins of at least 2.5 cm (1 inch). All pages must be numbered.

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

more than 250 words. The third page should repeat the title as a heading to the main body of the text.

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

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

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

Style guidelines
Description of the Journal's article style
Description of the Journal's reference style, Quick guide
Any consistent spelling style is acceptable. Use single quotation marks with double within if needed.

If you have any questions about references or formatting your article, please contact authorqueries@tandf.co.uk (please mention the journal title in your email).

Word Templates
Word templates are available for this journal.
If you are not able to use the template via the links or if you have any other queries, please contact authortemplate@tandf.co.uk

Units of measurement
All measurements must be cited in SI units.

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

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

Tables
Tables should be submitted on separate pages, numbered in Arabic numerals, and their position indicated in the text (e.g. Table 1). Each table should have a short, self-explanatory title. Vertical rules should not be used to separate columns. Units should

appear in parentheses in the column heading but not in the body of the table. Any explanatory notes should be given as a footnote at the bottom of the table.

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

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Corresponding authors will receive free online access to their article through our website (www.informaworld.com) and a complimentary copy of the issue containing their article. Reprints of articles published in this journal can be purchased through Rightslink® when proofs are received. If you have any queries, please contact our reprints department at reprints@tandf.co.uk

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Aging & Mental Health has a new editorial e-mail address: amh@ucl.ac.uk. General enquires can be sent to m.orrell@ucl.ac.uk.

Title of Paper:
Author: Reviewer:

Section		Question	Yes (1)	No (0)	Unable to determine (0)
Abstract	1	Does the study provide in the abstract an informative and balanced summary of what was done and what was found?			
Introduction	2	Does the study explain the scientific background and rationale for the investigation being reported?			
	3	Is the hypothesis/aim/objective of the study clearly described?			
Methods *Design*	4	Have the main potential confounders been identified and taken into account in the design?			
	5	Are the main outcomes to be measured clearly described in the introduction or methods section?			
	6	Were the main outcome measures used in the study valid and reliable?			
	7	Does the study describe a power calculation to determine the sample size?			
Participants	8	Does the study give the eligibility criteria, and the sources and methods of selection of participants?			
	9	Are the characteristics of the participants included in the study clearly described?			
	10	Has the study reported on the cognitive status of eligible participants and how this was defined?			
	11	Were the participants asked to participate in the study representative of the entire population from which they were recruited?			
	12	Were those participants who were prepared to participate representative of the entire population from which they were recruited?			
Results	13	Were the statistical tests used to assess the main outcomes appropriate?			
	14	Was there adequate adjustment for confounding variables in the analyses from which the main findings were drawn?			
	15	Have actual probability values been reported *(e.g. 0.035 rather than <0.05)* for the main outcomes except where the probability value is less than 0.001?			
Discussion	16	Does the study summarise key results with reference to study objectives?			
	17	Does the study discuss the clinical relevance and generalisability of the results?			
	18	Does the study discuss limitations?			

Appendix 3: Methodological Quality Checklist

Section		Question	Type	Original Source*
Abstract	1	Does the study provide in the abstract an informative and balanced summary of what was done and what was found?	Reporting	STROBE
Introduction	2	Does the study explain the scientific background and rationale for the investigation being reported?	Reporting	STROBE
	3	Is the hypothesis/aim/objective of the study clearly described?	Reporting	D&B
Methods *Design*	4	Have the main potential confounders been identified and taken into account in the design?	Internal validity	D&B *(adapted)*
	5	Are the main outcomes to be measured clearly described in the introduction or methods section?	Reporting	D&B
	6	Were the main outcome measures used in the study valid and reliable?	Internal validity	D&B
	7	Does the study describe a power calculation to determine the sample size?	Power	D&B/STROBE *(adapted)*
Participants	8	Does the study give the eligibility criteria, and the sources and methods of selection of participants?	Reporting	STROBE
	9	Are the characteristics of the participants included in the study clearly described?	Reporting	D&B
	10	Has the study reported on the cognitive status of eligible participants and how this was defined?	Reporting	Specific extension of question above
	11	Were the participants asked to participate in the study representative of the entire population from which they were recruited?	External validity	D&B
	12	Were those participants who were prepared to participate representative of the entire population from which they were recruited?	External Validity	D&B
Results	13	Were the statistical tests used to assess the main outcomes appropriate?	Internal Validity	D&B
	14	Was there adequate adjustment for confounding variables in the analyses from which the main findings were drawn?	Internal validity	D&B
	15	Have actual probability values been reported *(e.g. 0.035 rather than <0.05)* for the main outcomes except where the probability value is less than 0.001?	Reporting	D&B
Discussion	16	Does the study summarise key results with reference to study objectives?	Reporting	STROBE
	17	Does the study discuss the clinical relevance and generalisability of the results?	Reporting	STROBE
	18	Does the study discuss limitations?	Reporting	STROBE

'Type' of question derived from the Downs and Black Checklist for measuring study quality, *D&B = Downs & Black Quality Checklist; STROBE = STrengthening the Reporting of OBservational studies in Epidemiology statement

Quality Checklist: Rater 1, CH

Authors	Item																		Total
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	
Chung & Man (2009)	1	1	1	1	0	1	0	1	1	1	1	0	1	1	1	1	1	1	15
Dux et al. (2008)	1	1	1	1	1	1	0	1	1	1	1	0	1	1	0	1	1	1	15
Jessen et al. (2007)	1	1	1	1	1	0	0	1	1	1	1	0	1	1	0	1	1	1	14
Potter & Hartman (2006)	1	1	1	1	1	1	0	1	1	1	0	0	1	1	1	1	1	1	15
McDougall et al. (2006)	1	1	1	1	1	1	0	1	1	1	1	0	1	0	1	1	1	0	14
Cook & Marsiske (2006)	1	1	1	1	1	1	0	1	1	1	1	0	1	1	1	1	1	1	16
Minett et al. (2005)	1	1	1	1	1	1	0	1	1	1	1	0	1	1	1	1	1	1	16
Jungwrith et al. (2004)	1	1	1	1	1	0	0	1	0	1	1	0	1	0	0	1	1	0	11
Harwood et al. (2004)	1	1	1	1	1	1	0	1	1	1	1	0	1	1	1	1	1	1	16
McDougall (2004)	1	1	1	1	1	1	0	1	1	1	1	0	1	1	0	1	1	0	14
Mattos et al. (2003)	1	1	1	1	1	1	0	1	1	1	0	0	1	1	1	1	1	1	15
Dik et al. (2001)	1	1	1	1	1	0	0	1	1	1	1	0	1	1	1	1	1	1	15
Wang et al. (2000)	1	1	1	1	1	0	0	1	1	1	1	1	1	1	1	1	1	1	16
Pálsson et al. (2000)	1	1	0	1	1	1	0	1	0	1	1	0	1	1	1	1	1	1	14
Jonker et al. (1996)	1	1	1	1	1	0	0	1	1	1	1	0	1	1	0	1	1	1	14
Hãnninen et al. (1994)	1	1	1	1	1	0	0	0	1	1	1	0	1	0	0	1	1	1	12
Gagnon et al. (1994)	1	1	1	1	1	0	0	1	1	1	1	0	1	1	0	1	1	1	14
Poitrenaud et al. (1989)	1	1	1	1	1	0	0	1	0	0	1	0	1	1	0	1	1	1	10
Larrabee & Levin (1986)	1	1	1	1	0	0	0	0	0	0	0	0	1	1	0	1	1	0	8

Key: 1 = Criteria met, 0 = Criteria missing or unable to determine

Quality checklist: Rater 2, RA

Authors	Item																		Total
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	
Chung & Man (2009)	1	1	1	1	1	1	0	1	1	1	0	0	1	1	1	1	1	1	15
Dux et al. (2008)	1	1	1	1	1	1	0	1	0	1	0	0	1	1	1	1	1	1	14
Jessen et al. (2007)	1	1	1	1	1	1	0	1	1	1	0	0	1	0	1	1	1	1	14
Potter & Hartman (2006)	1	1	1	1	1	1	0	0	0	1	1	1	1	1	1	1	1	1	15
McDougall et al. (2006)	1	1	1	1	1	1	0	0	1	1	0	0	1	0	1	1	1	0	12
Cook & Marsiske (2006)	1	1	1	1	1	1	0	1	1	1	0	0	1	1	1	1	1	1	15
Minett et al. (2005)	1	1	1	1	1	1	0	1	0	0	1	1	1	1	1	1	0	1	14
Jungwrith et al. (2004)	1	1	1	1	1	1	0	1	0	1	1	1	1	0	0	1	0	0	12
Harwood et al. (2004)	1	1	1	1	1	1	0	1	1	1	0	0	1	1	1	1	1	1	15
McDougall (2004)	1	1	1	1	1	1	0	1	1	1	0	0	1	1	1	1	0	0	13
Mattos et al. (2003)	1	1	1	0	1	1	0	1	1	0	1	1	1	1	1	1	1	1	15
Dik et al. (2001)	1	1	1	1	1	1	0	0	0	1	0	0	1	1	1	1	1	1	13
Wang et al. (2000)	1	1	1	0	1	1	0	0	0	0	0	0	1	1	1	1	1	1	11
Pálsson et al. (2000)	1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	1	1	1	17
Jonker et al. (1996)	1	1	1	1	1	1	0	0	0	0	1	1	1	1	1	1	0	0	12
Hãnninen et al. (1994)	1	1	1	1	1	1	0	0	0	0	0	0	1	0	1	0	0	1	9
Gagnon et al. (1994)	1	1	1	1	1	1	0	0	1	0	1	1	1	1	0	1	0	1	13
Poitrenaud et al. (1989)	1	1	1	0	1	1	0	0	0	0	0	0	1	0	0	1	0	0	7
Larrabee & Levin (1986)	1	1	1	1	1	1	0	0	0	0	0	0	1	1	0	1	1	0	10

Key: 1 = Criteria met, 0 = Criteria missing or unable to determine

Inter-rater reliability

Table 1: Intraclass correlation coefficient

	Intraclass Correlation[a]	95% Confidence Interval		F Test with True Value 0			
		Lower Bound	Upper Bound	Value	df1	df2	Sig
Single Measures	.684[b]	.345	.865	5.325	18	18	.000
Average Measures	.812[c]	.513	.928	5.325	18	18	.000

Two-way mixed effects model where people effects are random and measures effects are fixed.

a. Type C intraclass correlation coefficients using a consistency definition-the between-measure variance is excluded from the denominator variance.

b. The estimator is the same, whether the interaction effect is present or not.

c. This estimate is computed assuming the interaction effect is absent, because it is not estimable otherwise.

Single measures reported.

Appendix 5: Ethical Approval Letter

NHS

National Research Ethics Service
York Research Ethics Committee

Learning and Research Centre
York Hospital
Wigginton Road
York
Y031 8HE

Telephone: 01904 725125
Facsimile: 01904 731297

02 July 2009

Miss Christine Hanson
Department of Clinical Psychology
Hertford Building
University of Hull
HU6 7RX

Dear Miss Hanson

Study Title:	**How is expressed emotion related to discrepant estimates of ability in dementia dyads?**
REC reference number:	**09/H1311/52**
Protocol number:	**5.3**

Thank you for your letter of 11 June 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.

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. The Committee's concern regarding supervision arrangements has now been clarified and I enclose a copy of my letter to Dr Clarke dated 2nd July 2009 confirming this.

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).

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.

This Research Ethics Committee is an advisory committee to Yorkshire and The Humber Strategic Health Authority

The National Research Ethics Service (NRES) represents the NRES Directorate within The National Patient Safety Agency and Research Ethics Committees in England

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*
Response to Request for Further Information		11 June 2009
Participant Information Sheet: Carer Information Sheet	3	04 June 2009
Participant Information Sheet	3	04 June 2009
Protocol	6	04 June 2009
Supervisors CV - Clarke		17 April 2009
Participant Consent Form: Participant	2	25 March 2009
Participant Consent Form: Carer	2	25 March 2009
Questionnaire: IQCODE		
Questionnaire: Mood Scale: Geriatric Depression Scale (GDS)		
Questionnaire: General Health Questionnaire (GHQ 12)		
Questionnaire: Lawton Instrumental Activities of Daily Living Scale: Self-report version (Participant)		
Questionnaire: Lawton Instrumental Activities of Daily Living Scale: Carer Version		
Peer Review		09 January 2009
Covering Letter		22 April 2009
Investigator CV		15 April 2009
Application	17165/34697 /1/967	15 April 2009
Instructions for administering the Five Minute Speech sample	1	09 March 2009
Questionnaire: Quality of Carer - Patient Relationship Scale (QCPR)		
Questionnaire: IQCODE-SR		
Questionnaire: Demographic Questionnaire	1	25 March 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/H1311/52	**Please quote this number on all correspondence**

Yours sincerely

pp **Mrs Alison Booth**
Chair

Email: Joanne.Holmes@York.NHS.UK

Enclosures: "After ethical review – guidance for researchers"

Letter to Dr Chris Clarke, Academic Supervisor dated 2nd July 2009

Copy to: Mr Stephen Walker
R& D Department, Trust HQ, Willerby Hill, Beverley Road, Willerby, Hull, HU10 6ED

Dr Chris Clarke
Academic Supervisor, Department of Clinical Psychology, Hertford Building, University of Hull, Cottingham road, Hull, HU6 7RX

Appendix 6: Research & Development Approval Letters

Humber Mental Health NHS
Teaching NHS Trust

Research & Development Department
Trust Headquarters
Willerby Hill
Beverley Road
WILLERBY
HU10 6ED

Our Ref: SW-15/07/09-Approval Letter.docx

15 July 2009

Christine Hanson
Trainee Clinical Psychologist
Department of Clinical Psychology
Hertford Building
University of Hull
Cottingham Road
Hull, HU6 7RX

Dear Christine

Re: How is expressed emotion related to discrepant estimates of ability in dementia dyads?

I can confirm that the research has been approved within the Humber Mental Health Teaching NHS Trust in the following locations

- **Hull Memory Clinic, Coltman Street, Hull**
- **In order to undertake research in other trusts you will need their specific approval**

Humber Mental Health Teaching NHS Trust conducts all research in accordance with the requirements of the Research Governance Framework, and the NHS Intellectual Property Guidance. In undertaking this study you agree to comply with all reporting requirements, systems and duties of action put in place by the trust to deliver research governance, and you must comply with the Trust information management and data protection policies. In addition, you agree to accept the responsibilities associated with your role that are outlined within the Research Governance Framework as follows:

- The study follows the agreed protocol
- Participants should receive appropriate care while involved in the study
- The integrity and confidentiality of clinical, other records and data generated by the study will be maintained
- All adverse events must be reported to the Trust and other authorities specified in the protocol
- Any suspected misconduct by anyone involved in the study must be reported
- You must notify the Trust when the study is complete

We would be grateful if you would copy the R&D Department into your annual and completions reports to the local ethics committee.

I would like to wish you every success with this project

Yours sincerely

Duncan Courtney
Acting Head of Clinical Governance

York Hospitals NHS
NHS Foundation Trust

North and East Yorkshire Alliance R&D Unit

Main Office: Learning and Research Centre
York Hospitals NHS Foundation Trust
York
YO31 8HE

Tel: (01904) 726996
Fax: (01904) 731297

www.northyorksresearch.nhs.uk

Project reference: NYY-P01401
Ethics ref: 09/H1311/52

Miss Christine Hanson
Department of Clinical Psychology
Hertford Building
University of Hull
HU6 7RX

21/05/2009

Dear Miss Hanson

Research Governance Approval
Project: How is expressed emotion related to discrepant estimates of ability in dementia dyads?

Thank you for submitting details of this project for Research Governance Approval by NHS North Yorkshire and York

On behalf of the Trust I confirm that the project can go ahead subject to assessment by the appropriate Ethics Committee. If you have not already done so, please supply me with a copy of the Ethics Committee's letter, either confirming its favourable ethical opinion or that full ethical review is not required.

Please note that as Site Principal Investigator you will be responsible for ensuring that the project is conducted in accordance with the Protocol, any Ethics Committee requirements, the Department of Health's *Research Governance Framework for Health and Social Care* (www.dh.gov.uk/assetRoot/04/10/89/65/04108965.pdf), the NHS Confidentiality Code of Practice (www.dh.gov/assetRoot/04/06/92/54/04069254.pdf) and any applicable legislation.

Please check that you are aware of the project sponsor's Standard Operating Procedures that are applicable to this project. If the sponsor does not have such procedures or there are gaps in them relating to local circumstances, please refer to the Standard Operating Procedures published on the Unit's website, where you will also find other useful information on research governance and related matters. The website address is www.northyorksresearch.nhs.uk

I would be grateful if you could send details of any publications and conference presentations that arise from this research for inclusion in our audit of research activity in due course.

Yours sincerely

Caroline Mozley
Head of Research and Development
On behalf of NHS North Yorkshire and York

cc: Veronica Mackley

Appendix 7: Participant Information Sheet: Version for people with cognitive impairment

Participant Information Sheet Version 3.1, 04.06.09

Exploring how older people and their families view memory changes

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
This research looks at how older people and their families view memory changes. For example looking at how people with memory problems view their abilities and how their families think about their abilities too. We are interested in how people's relationships are related to these views.

Why have I been invited?
We are asking people who have had contact with services following changes in their memory to help us with the research. Altogether, we are aiming to meet around 60 people with memory difficulties and also their partners.

Do I have to take part?
No, you do not have to take part. It is up to you to decide. We will describe the study and go through the information sheet. If after receiving this information you do not wish to take part then you do not have to. If you do decide to take part we will ask you to sign a consent form to show that you have agreed to take part. You are free to withdraw at any time, without giving a reason. If either you or your partner decides not to take part, your care and support from the NHS will not be affected in any way.

What will I have to do if I decide to take part?
You will be asked to take part in an interview which should last for about an hour. This can be at held at your home, or if you prefer, at a clinic or the University of Hull. In this interview you will be asked to fill in some short questionnaires. Your partner will also be asked to complete some questionnaires, and be asked to talk about their relationship with you. This will be recorded, so that it can be listened to later. All the questionnaires and recordings will be done in private. You will not have to tell anyone what you put on the questionnaires, unless you want to. As part of the study we will need some further information about your memory difficulties. With your permission we will get this information from the mental health team providing your care.

What are the possible disadvantages and risks of taking part?
In helping us you may find that some of the questionnaires make you think about things which are worrying for you. In the unlikely event that this happens, you will be able to discuss your concerns with the researcher who is a Trainee Clinical Psychologist. If you feel you need further support, the researcher can arrange this through other professionals involved in your care.

What are the possible benefits of taking part?
The research aims to understand how families see and cope with memory changes. This may help us to take into account different perspectives and will benefit the future care for older people who experience memory changes.

Will my taking part in this research be kept confidential?
All the information you give us in this study will remain strictly confidential. A number rather than your name will be used on the questionnaires so none of the information will be identifiable as you. The recordings will be listened to by the researchers but destroyed at the end of the study. Only people directly connected to this research will have access to any of the data in the study. All information will be securely stored, and after the study has finished it will be destroyed.

The involvement of your GP or other health care professionals
In most cases it will not be necessary to inform your GP or any other health professionals involved in your care that you are taking part. However, it may be that your answers to some of the questionnaires indicate that you are having difficulties that could be addressed by your doctor or mental health services. If this happens, then the researcher would discuss this with you fully. It may be necessary to inform a member of your care team if it comes to light that you are having severe problems that haven't been known about or addressed before. If you want, further support can then be arranged through your GP or another health professional.

What happens to the results of the research study?
The results will be written into a report, which we will try to publish so that other professionals will be able to use them to make a difference to people with memory changes in the future. Your individual results will not be identifiable. Unfortunately it is not possible to tell people their individual results. However, you can ask for a summary of the results of the study.

Who is organising the research?
The research is being organised as part of academic studies at the University of Hull. This is as part of a postgraduate doctoral qualification in clinical psychology.

Who has reviewed it?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed by the York Research Ethics Committee.

Expenses
Unfortunately, we can not reimburse you for any expenses incurred as part of the research. This means you will not be able to claim for your travel expenses if you choose to be seen outside your home.

Further information and contact details:

If you would like to take part in the research, or would like to ask any questions and find out further information about the study, please feel free to contact Christine Hanson, Trainee Clinical Psychologist, on _____ or by email at _____.

For more general information about participating in NHS research or for information about making any complaints, please contact the NHS Patient Advice and Liaison Service on 08000 688000 if you live in the York area or 01482 303966 if you live in the Hull area.

Appendix 8: Participant Information Sheet: Version for partners

Carer Information Sheet Version 3.1, 04.06.09

Exploring how older people and their families view memory changes

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
This research looks at how older people and their families view memory changes. For example looking at how people with memory problems view their abilities and how their families think about their abilities too. We are interested in how people's relationships are related to these views.

Why have I been invited?
We are asking people who have had contact with services following changes in their memory to help us with the research. Altogether, we are aiming to meet around 60 people with memory difficulties and their partners.

Do I have to take part?
No, you do not have to take part; it is up to you to decide. We will describe the study and go through the information sheet. If after receiving this information you do not wish to take part then you do not have to. If you do decide to take part we will ask you to sign a consent form to show that you have agreed to take part. You are free to withdraw at any time, without giving a reason. If either you or your partner decides not to take part, your care and support from the NHS will not be affected in anyway.

What will I have to do if I decide to take part?
You will be asked to take part in an interview which should last for about an hour. This can be at held at your home, or if you prefer, at a clinic or the University of Hull. In this interview you will be asked to fill in some short questionnaires and to briefly talk about your relationship with your partner. We would like to record this, so that it can be listened to again later. All the questionnaires and recordings will be done in private so, unless you want to, you will not have to tell anyone what you put or what you said.

What are the possible disadvantages and risks of taking part?
In helping us you may find that some of the questionnaires or discussions make you think about things which are worrying or upsetting to you. In the unlikely event that this happens, you will be able to discuss your concerns with the

researcher who is a Trainee Clinical Psychologist. If you feel you need further support, the researcher can arrange this through your GP or the professionals involved in the care of your other family member.

What are the possible benefits of taking part?
The research aims to understand how families see memory changes and how they cope with and respond to them. This may help us to take into account different perspectives and benefit future care for older people who experience memory changes.

Will my taking part in this research be kept confidential?
All the information you give us in this study will remain strictly confidential. A number rather than your name will be used on the questionnaires and to label any recordings, so none of the information will be identifiable as you. The recordings will be listened to by the researchers but destroyed at the end of the study. Only people directly connected to this research will have access to any of the data in the study. All information will be securely stored, and after the study has finished it will be destroyed.

The involvement of your GP or other health care professionals
In most cases it will not be necessary to inform your GP or any other health professionals involved in your partner's care that you are taking part. However, it may be that your answers to some of the questionnaires indicate that you are having difficulties that could be addressed by your doctor or mental health services. If this happens, then the researcher would discuss this with you fully. It may be necessary to inform your GP if it comes to light that you have severe problems that haven't been known about or addressed before. If you want, further support can then be arranged through your GP or another health professional.

What happens to the results of the research study?
The results will be written into a report, which we will try to publish so that other professionals will be able to use them to make a difference to people with memory changes in the future. Your individual results will not be identifiable. Unfortunately it is not possible to tell people their individual results. However, you can ask for a summary of the results of the study.

Who is organising the research?
The research is being organised as part of academic studies at the University of Hull. This is as part of a postgraduate doctoral qualification in clinical psychology.

Who has reviewed it?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed by the York Research Ethics Committee.

Expenses
Unfortunately, we can not reimburse you for any expenses incurred as part of the research. This means you will not be able to claim for your travel expenses if you choose to be seen outside your home.

Further information and contact details:

If you would like to take part in the research, or would like to ask any questions and find out further information about the study, please feel free to contact Christine Hanson, Trainee Clinical Psychologist, on _____ or by email at _____.

For more general information about participating in NHS research or for information about making any complaints, please contact the NHS Patient Advice and Liaison Service on 08000 688000 if you live in the York area or 01482 303966 if you live in the Hull area.

Appendix 9: Consent Form: Version for people with cognitive impairments

THE UNIVERSITY OF HULL

PARTICIPANT CONSENT FORM Version 2.1, 25.03.09

Title of Project: Exploring how older people and their families view memory changes
Name of Researcher: Christine Hanson
Please initial the boxes:

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that the researcher will ask my current care team for information about my problems and the help I receive, relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐
4. I understand that my GP or another member of my current health care team may need to be contacted if the research indicates that I might be suffering from a new mental health difficulty.	☐
5. I understand that an audio recording will be used as part of the research that contains information about my relationship. I understand that this will be listened to by the research team and that this will be destroyed once the study is completed.	☐
6. I agree to take part in the above study.	☐

_____ _____ _____
Name of Participant Date Signature

_____ _____ _____
Name of Person taking consent Date Signature

When completed, 1 for participant; 1 for researcher site file

Appendix 10: Consent Form: Version for partners

THE UNIVERSITY OF HULL

CARER CONSENT FORM Version 2.1, 25.03.09

Title of Project: Exploring how older people and their families view memory changes
Name of Researcher: Christine Hanson
Please initial the boxes:

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that my GP or another member of my current health care team may need to be contacted if the research indicates that I might be suffering from a new mental health difficulty.	☐
4. I understand that an audio recording will be used as part of the research that contains information about my relationship. I understand that this will be listened to by the research team and that this will be destroyed once the study is completed.	☐
5. I agree to take part in the above study.	☐

_____ _____ _____
Name of Participant Date Signature

_____ _____ _____
Name of Person taking consent Date Signature

When completed, 1 for participant; 1 for researcher site file

Appendix 11: Demographic Questionnaire

This information was obtained from the partners of people with cognitive difficulties as part of the semi-structured interview.

Demographic Questionnaire

People with memory difficulties:

Age	
Sex	
MMSE Score	
Diagnosis (Informed of diagnosis?)	
Duration of symptoms	
Current support (Sources of support & duration)	
Current medication (if any)	
Recruitment Site	

Partner:

Age	
Sex	

Appendix 12: IQCODE Measures

Removed for hard-binding

Appendix 13: Lawton& Brody IADL Measures

Removed for hard-binding

Appendix 14: General Health Questionnaire (GHQ-12)

Questionnaire removed for hard-binding

Scoring the GHQ-12

For the purpose of reporting prevalence rates, GHQ scoring was used. Responses are scored as 0,0,1,1, giving a final score of 0-12. The recommended cut-off for psychiatric disorder is 2/3. A cut-off of 3 was used in the present study, due to the sample comprising of older people who are more likely to have physical complaints which may be reflected in the GHQ scores. Cut-offs have not been validated for Likert scoring.

For the purposes of data analysis the GHQ-12 was scored using Likert scoring. Responses were rated as 0,1,2,3, giving a final score in the range 0-36.

Appendix 15: Geriatric Depression Scale (GDS: 15 item short form)

Removed for hard-binding

Appendix 16: Quality of Carer-Patient Relationships Scale (QCPR; Spruytte et al., 2002).

Removed for hard-binding

Appendix 17: The Five Minute Speech Sample (FMSS)

Removed for hard-binding

Instructions for scoring the five minute speech sample can be found in Magana-Amato, A., (1993). Manual for coding expressed emotion from the five minute speech sample. UCLA Family Project.

Five Minute Speech Sample for expressed emotion: Rater 1, CH

					Emotional Over-involvement					EE Profile	
					Emotional display	Statement of attitude	Self-sac / overprotect lack of obj.	Excess detail	Positive Remarks	FMSS Rating	
	Initial statement	Relationship	Criticism	Dissatisf action						EE Subgroup	EE
ID	+, n, -	+, n, -	#	P /A	P / A	#	P / A	P / A	#		
1	+	+	0	A	A	0	A	A	6	Low	Low
2	+	n	0	A	P	0	A	A	3	EOI	High
3	n	n	0	P	A	0	P	A	2	EOI	High
4	n	n	0	A	P	0	A	A	0	EOI	High
5	+	+	0	A	A	0	A	A	1	Low	Low
6	n	n	1	P	P	0	A	A	0	Critical-EOI	High
7	+	+	0	A	A	0	A	A	0	Low	Low
8	n	n	0	A	A	0	A	A	2	Low	Low
9	n	n	0	A	A	0	A	P	1	Low	Low
10	n	n	2	P	A	0	A	A	0	Critical	High

Key:
+ = Positive n = Neutral - = Negative # = frequency P = Present A = Absent
High expressed emotion subgroups: Critical, Emotionally over involved (EOI), combined critical-EOI

Five Minute Speech Sample for expressed emotion: Rater 2, PP

					Emotional Over-involvement					EE Profile	
					Emotional display	Statement of attitude	Self-sac / overprotect lack of obj.	Excess detail	Positive Remarks	FMSS Rating	
	Initial statement	Relationship	Criticism	Dissatisf action						EE Subgroup	EE
ID	+, n, -	+, n, -	#	P /A	P / A	#	P / A	P / A	#		
1	+	+	0	P	A	0	A	A	4	Low	Low
2	+	n	0	A	P	0	A	A	1	EOI	High
3	+	n	2	A	P	0	A	A	0	Critical	High
4	n	n	0	A	P	0	A	A	1	EOI	High
5	+	n	0	A	A	0	A	A	1	Low	Low
6	n	n	3	A	P	0	A	A	0	Critical-EOI	High
7	n	+	0	A	A	0	A	A	1	Low	Low
8	n	+	0	A	A	0	A	A	1	Low	Low
9	n	+	0	A	A	0	A	A	0	Low	Low
10	n	n	2	A	A	0	A	A	0	Critical	High

Key:
+ = Positive n = Neutral - = Negative # = frequency P = Present A = Absent
High expressed emotion subgroups: Critical, Emotionally over involved (EOI), combined critical-EOI

Calculation of Cohen's Kappa for inter-rater reliability

Table 1: Rater CH and rater PP crosstabulation.

Count

		rater PP				
		low	critical	eoi	critical and eoi	Total
rater CH	low	5	0	0	0	5
	critical	0	1	0	0	1
	eoi	0	1	2	0	3
	critical and eoi	0	0	0	1	1
Total		5	2	2	1	10

Table 2: SPSS output for Kappa statistic.

		Value	Asymp. Std. Error[a]	Approx. T[b]	Approx. Sig.
Measure of Agreement	Kappa	.848	.136	4.326	.000
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Table 1: *Descriptive Statistics and Kolmogorov-Smirnov test results for main study variables*

		PwCI IADL	PwCI IQCODE	Partner IADL	Partner IQCODE	Discrepancy IADL	Discrepancy IQCODE	QCPR Warmth	QCPR Absence of Criticism	PwCI Depression (GDS)	Partner Distress (GHQ-12)
N	Valid	46	46	46	46	46	46	46	46	46	46
	Missing	0	0	0	0	0	0	0	0	0	0
Mean		14.17	3.400815	19.24	4.263587	5.07	.862772	33.37	21.46	3.26	12.15
Std. Deviation		4.923	.4361240	6.012	.4682475	4.317	.6285482	3.732	4.329	2.728	5.337
Skewness		.829	.350	.157	-.362	.177	.352	.203	-.554	1.526	.511
Std. Error of Skewness		.350	.350	.350	.350	.350	.350	.350	.350	.350	.350
Kurtosis		.516	1.201	-1.200	-.929	-1.161	.447	-.319	-.169	3.298	1.046
Std. Error of Kurtosis		.688	.688	.688	.688	.688	.688	.688	.688	.688	.688
Range		20	2.3125	19	1.6875	14	3.00	15	19	13	27
Minimum		8	2.1875	10	3.3125	-2	-.3750	25	10	0	0
Maximum		28	4.5000	29	5.0000	12	2.6250	40	29	13	27
Percentiles	25	10.00	3.125000	14.00	3.937500	.175	.484375	31.00	18.75	1.75	8.75
	50	14.00	3.375000	18.50	4.312500	.450	.843750	33.00	22.00	3.00	12.00
	75	16.25	3.625000	25.00	4.687500	9.00	1.250000	36.00	25.00	4.00	15.00
Kolmogorov-Smirnov Z		.788	.952	.771	1.027	.778	.685	.872	.945	1.192	.752
Asymp. Sig. (2-tailed)		.563	.325	.592	.242	.580	.737	.432	.334	.116	.625

Abbreviations: PwCI People with cognitive impairment; IADL Instrumental activities of daily living: IQCODE Informant questionnaire on cognitive decline in the elderly; QCPR Quality of the Carer Patient Relationship scale

Multicollinearity: Table 2: *Pearson's correlation (and significance level) between all variables (n=46)*

Variable	PwCI Depression (GDS)	Partner distress (GHQ-12)	QCPR Warmth	QCPR Absence of criticism	Discrepancy IQCODE	Discrepancy IADL	Self-report IQCODE	Self-report IADL	Partner IQCODE	Partner IADL
PwCI depression (GDS)	1	.312 .035	-.125 .406	-.063 .677	-.291 .050	.002 .988	.567 .000	.025 .871	.139 .359	.022 .885
Partner distress (GHQ-12)		1	-.225 .133	-.235 .116	.284 .056	.110 .465	.122 .418	.025 .868	.495 .000	.100 .509
QCPR Warmth			1	.606 .000	-.174 .246	-2.48 .069	.045 .765	-.083 .582	-.192 .201	-.247 .098
QCPR Absence of Criticism				1	-.275 .064	-2.75 .064	.253 .089	.041 .787	-.133 .377	-.164 .276
Discrepancy IQCODE					1	.544 .000	-.668 .000	.182 .226	.721 .000	.540 .000
Discrepancy IADL						1	-.328 .026	-.158 .293	.424 .003	.588 .000
Self-report IQCODE							1	.097 .519	.035 .816	-.156 .300
Self-report IADL								1	.335 .023	.705 .000
Partner IQCODE									1	.579 .000
Partner IADL										1

Abbreviations: PwCI People with cognitive impairment; IADL Instrumental activities of daily living: IQCODE Informant questionnaire on cognitive decline in the elderly; QCPR Quality of the Carer Patient Relationship scale

ANCOVA output, main effects

Abbreviations: PwCI, people with cognitive impairment; EE, expressed emotion

Table 3: *Analysis of covariance for IQCODE discrepancy*

Source	Type III Sum of Squares	*df*	Mean Square	*F*	*p*
Corrected Model	5.552[a]	3	1.857	6.358	.001
Intercept	3.408	1	3.408	11.706	.001
EE	1.288	1	1.288	4.423	.041
PwCI GDS	3.293	1	3.293	11.314	.002
Partner GHQ-12	1.864	1	1.864	6.405	.015
Error	12.226	42	.291		
Total	52.020	46			
Corrected Total	17.778	45			

a. R Squared = .312 (Adjusted R Squared = .263)

Table 4: *Analysis of covariance for IADL discrepancy*

Source	Type III Sum of Squares	*df*	Mean Square	*F*	*p*
Corrected Model	80.786[a]	3	26.929	1.492	.231
Intercept	168.259	1	168.259	9.323	.004
EE	69.592	1	69.592	3.856	.056
PwCI GDS	4.204	1	4.204	.233	.632
Partner GHQ-12	1.922	1	1.922	.107	.746
Error	758.019	42	18.048		
Total	2019.000	46			
Corrected Total	838.804	45			

a. R Squared = .096 (Adjusted R Squared = .032)

Table 5: *Analysis of covariance for IQCODE self-report*

Source	Type III Sum of Squares	*df*	Mean Square	*F*	*p*
Corrected Model	3.169[a]	3	1.056	8.229	.000
Intercept	57.841	1	57.841	450.648	.000
EE	.385	1	.385	2.997	.091
PwCI GDS	2.877	1	2.877	22.415	.000
Partner GHQ-12	.001	1	.001	.005	.947
Error	5.391	42	.128		
Total	540.574	46			
Corrected Total	8.559	45			

a. R Squared = .370 (Adjusted R Squared = .325)

Table 6: *Analysis of covariance for IADL self-report*

Source	Type III Sum of Squares	*df*	Mean Square	*F*	*p*
Corrected Model	2.010[a]	3	.670	.026	.994
Intercept	1154.985	1	1154.985	44.561	.000
EE	.977	1	.977	.038	.847
PwCI GDS	.501	1	.501	.019	.890
Partner GHQ-12	.663	1	.663	.026	.874
Error	1088.598	42	25.919		
Total	10332.000	46			
Corrected Total	1090.609	45			

a. R Squared = .002 (Adjusted R Squared = -.069)

Table 7: *Analysis of covariance for IQCODE partner ratings*

Source	Type III Sum of Squares	*df*	Mean Square	*F*	*p*
Corrected Model	2.689[a]	3	.896	5.245	.004
Intercept	89.326	1	89.326	522.710	.000
EE	.265	1	.265	1.549	.220
PwCI GDS	.014	1	.014	.082	.776
Partner GHQ-12	1.799	1	1.799	10.528	.002
Error	7.177	42	.171		
Total	846.063	46			
Corrected Total	9.867	45			

a. R Squared = .273 (Adjusted R Squared = .221)

Table 8: *Analysis of covariance for IADL partner ratings*

Source	Type III Sum of Squares	*df*	Mean Square	*F*	*p*
Corrected Model	70.486[a]	3	23.495	.634	.597
Intercept	2204.917	1	2204.917	59.520	.000
EE	54.081	1	54.081	1.460	.234
PwCI GDS	1.802	1	1.802	.049	.826
Partner GHQ-12	4.844	1	4.844	.131	.719
Error	1555.884	42	37.045		
Total	18653.000	46			
Corrected Total	1626.370	45			

a. R Squared = .043 (Adjusted R Squared = -.025)

Hierarchical Regression Output

Table 9: *Summary of hierarchical regression analysis for variables predicting IQCODE discrepancy (N=46)*

Variable	B	Standard error B	β	t	*p*
Step 1					
PwCI GDS	-.097	.032	-.420	-3.001	.004
Partner GHQ-12	.049	.016	.415	2.966	.005
Step 2					
PwCI GDS	-.097	.032	-.419	-3.003	.005
Partner GHQ-12	.043	.017	.362	2.528	.015
QCPR Absence of criticism	-.029	.024	-.203	-1.208	.234
QCPR Warmth	-.004	.028	-.023	-.137	.892

Step 1: R square = .240 (adjusted R square = .205), $F_{(2,43)}$=6.785, p=.003.
Step 2: R Square = .284 (adjusted R square = .214), $F_{(4,41)}$=4.071, p=.007.

Table 10: *Summary of hierarchical regression analysis for variables predicting IADL discrepancy (N=46)*

Variable	B	Standard error B	β	t	*p*
Step 1					
PwCI GDS	-.056	.252	-.036	-.223	.824
Partner GHQ-12	.098	.129	.122	.762	.450
Step 2					
PwCI GDS	-.065	.249	-.041	-.262	.794
Partner GHQ-12	.041	.131	.050	.311	.757
QCPR Absence of criticism	-.188	.189	-.188	-.995	.326
QCPR Warmth	-.148	.219	-.128	-.679	.501

Step 1: R square = .013 (adjusted R square = -.033), $F_{(2,43)}$=.291, p=.749.
Step 2: R Square = .089 (adjusted R square = .000), $F_{(4,41)}$=1.003, p=.417.

Table 11: *Summary of hierarchical regression analysis for variables predicting IQCODE self-report (N=46)*

Variable	B	Standard error B	β	t	*p*
Step 1					
PwCI GDS	.094	.021	.586	4.447	.000
Partner GHQ-12	-.005	.011	-.060	-.457	.650
Step 2					
PwCI GDS	.092	.020	.577	4.557	.000
Partner GHQ-12	.000	.011	.003	.026	.980
QCPR Absence of criticism	.035	.015	.345	2.272	.028
QCPR Warmth	-.011	.018	-.091	-.598	.553

Step 1: R square = .325 (adjusted R square = .294), $F_{(2,43)}$=10.363, p<.000.
Step 2: R Square = .411 (adjusted R square = .354), $F_{(4,41)}$=7.154, p=<.000.

Table 12: *Summary of hierarchical Regression Analysis for Variables predicting IADL self-report (N=46)*

Variable	B	Standard error B	β	t	*p*
Step 1					
PwCI GDS	.034	.289	.019	.116	.908
Partner GHQ-12	.018	.148	.019	.121	.904
Step 2					
PwCI GDS	.012	.295	.007	.041	.967
Partner GHQ-12	.019	.155	.020	.120	.905
QCPR Absence of criticism	.168	.223	.148	.752	.456
QCPR Warmth	-.221	.259	-.167	-.854	.398

Step 1: R square = .001 (adjusted R square = -.046), $F_{(2,43)}$=.020, p=.980.
Step 2: R Square = .021 (adjusted R square = -.075), $F_{(4,41)}$=.216, p=.928.

Table 13: *Summary of hierarchical Regression Analysis for Variables predicting IQCODE partner ratings (N=46)*

Variable	B	Standard error B	β	t	*p*
Step 1					
PwCI GDS	-.003	.024	-.018	-.126	.900
Partner GHQ-12	.044	.012	.501	3.594	.001
Step 2					
PwCI GDS	-.004	.024	-.025	-.177	.860
Partner GHQ-12	.043	.013	.489	3.346	.002
QCPR Absence of criticism	.005	.019	.050	.291	.772
QCPR Warmth	-.014	.021	-.115	-.675	.503

Step 1: R square = .246 (adjusted R square = .211), $F_{(2,43)}$=7.004, p=.002.
Step 2: R Square = .254 (adjusted R square = .182), $F_{(4,41)}$=3.496, p=.015.

Table 14: *Summary of hierarchical Regression Analysis for Variables predicting IADL partner ratings (N=46)*

Variable	B	Standard error B	β	t	*p*
Step 1					
PwCI GDS	-.023	.352	-.010	-.064	.949
Partner GHQ-12	.116	.180	.103	.646	.522
Step 2					
PwCI GDS	-.053	.352	-.024	-.151	.880
Partner GHQ-12	.059	.184	.053	.321	.750
QCPR Absence of criticism	-.020	.266	-.014	-.075	.941
QCPR Warmth	-.369	.309	-.229	-1.196	.238

Step 1: R square = .010 (adjusted R square = -.036), $F_{(2,43)}$=.219, p=.804.
Step 2: R Square = .064 (adjusted R square = -.028), $F_{(4,41)}$=6.696, p=.599.

Appendix 20: Reflective Statement

Introduction

This section is a reflection on the process of designing and completing the research presented previously. I intend to address different aspects of the research from initial ideas and planning, strengths and challenges, and what I have learned during the research process.

Background and Planning

One of the most difficult tasks in undertaking this work was settling on a research area. Having worked previously with older people with memory difficulties I was keen to develop research in this area, but was also considering neurological and health psychology projects. Eventually I decided to pursue a project in the area of memory difficulties. Under the guidance of my supervisor, my initial ideas about health locus of control and adjustment to memory impairment evolved into exploring ideas around self-integration and self-maintenance of identity, which lead to the topic of awareness. It quickly became apparent that awareness is a very complicated concept. It was never the focus of the empirical research to work directly with awareness, but rather to try and understand some of the peripheral issues, such as what it is like for a couple affected by memory difficulties. In the final empirical research proposal, the focus settled on one particular method of measuring awareness, comparing self-reports to informant reports. Rather than focus upon accuracy, which seems very difficult to define and conceptualise, the aim was to understand what it is like for a couple who don't agree about the amount of impairment. This opened up other research avenues

and eventually led to the inclusion of expressed emotion. Although there is no previous research spanning awareness and expressed emotion, this seemed relevant given the changing nature of relationships when someone develops a condition such as dementia or MCI.

Recruitment and Conducting Research

After planning and writing the proposal, taking the research forwards seemed very challenging at times. Of particular note, was beginning recruitment, at which point I became largely dependent upon others to approach potential couples. Recruitment spanned over a six month period and it felt difficult to keep the research fresh in the minds of clinicians who were working with suitable couples. With the recruitment sites consisting of six teams across York and Hull, it was not always possible to attend team meetings as regularly as I would have liked. In addition to this, some clinicians described finding it difficult to introduce the research to couples. In particular, some clinicians felt it was difficult to discuss research when they themselves were still trying to build up a relationship with the couple. In response to this, and following discussion with my supervisor, I provided all the individual members of teams with information about how to approach couples based on the methods that other clinicians had found useful.

Once in contact with potential participants, I found couples were very welcoming and keen to participate. For some couples, research appointments had to be rearranged due to bad weather conditions and other unforeseen circumstances, but couples were not deterred by this. Their commitment to taking part in research came as quite a

surprise, especially as I felt I was able to offer couples little in return for their participation. Some people had never taken part in research before, but described how they wanted to share their experiences for the benefit of others. Other participants were heavily involved in research and at least two participants were considering volunteering for autopsy research. At one meeting I attended, concerns were raised by professionals about the difficulties of gaining ethical approval to conduct research with people with cognitive impairments. It seems there is a fine balance between protecting people who are potentially very vulnerable, and with enabling them to enjoy their own voice and contribute to our understanding of this condition. Certainly as part of my own ethics review, questions were raised about capacity to consent and the number of questionnaires I intended to ask people to complete. In my opinion, the information leaflets were too long and complicated, but it seems this needed to be countered against the ethical need to tell participants everything they needed to know.

I have some reservations about the use of the five minute speech sample for measuring expressed emotion. Although it is well validated as a research tool, at times administering it seemed to run counter to clinical training. For instance the instructions are clear that researchers should not comment upon the information being provided by participants. It is also suggested to appear busy with papers whilst participants are talking so as not to disturb them. This meant at times listening to difficult information about how people's lives have changed, without really being able to demonstrate empathetic listening. It may be that this helps some participants to tell their story and share their thoughts and feelings, however most participants

maintained eye contact and once the recorder was turned off many people began to seek some acknowledgement and feedback about what they had said. Listening back to the recordings, I began to wonder about using the FMSS to gather information about relationships. In particular, many people seemed wary of appearing disloyal to their partner and seemed to be more reserved in their comments when being recorded than when they were talking freely. Moreover, the agreement between the FMSS and the QCPR was relatively weak, and upon examining this further it seems that some people may have found it easier to indicate a poorer relationship on a rating scale than to say so directly.

Systematic Literature Review (SLR)

Similar to the empirical paper, the SLR went through several ideas and changes of topic before settling on awareness of memory function in people who do not have dementia. This was partly due to the emergence of new reviews in the areas of relationships, adjustment and awareness. I had hoped to move away from deficit focused models of awareness which emphasise impairment, towards a more general understanding of memory processes in people without cognitive difficulties. However in conducting the literature review it became apparent that there is little research focused exclusively on cognitively healthy older people, except to make comparisons with younger people. Widening the search to include people with mild cognitive impairment meant incorporating an element of deficit, but this has perhaps helped to bridge the gap between awareness in people with, and those without, impairment.

Journals

For the empirical paper, I chose *Aging & Mental Health,* given the previous precedence for awareness literature to be published in this journal. This journal has also previously published studies of expressed emotion. The choice of *Psychology & Aging* for the SLR reflects that this is a more general review, and although it was written with a view to its clinical relevance, it may be applicable to fields beyond mental health.

Summary

In conducting this research, through from initial ideas to writing up the reports, I feel I have experienced both the negative and positive aspects of research. At times it has been frustrating, dealing with unforeseen difficulties and trying to maintain research as a priority when there are several other competing commitments. However, once past the planning and initial recruitment stages, the research became much more manageable. Although I have worked previously with people with memory difficulties, meeting participants for this study helped to widen the meaning and purpose of the research. Although as a result of planning and writing proposals I had a clear idea of what I wanted to achieve through the research, speaking to participants led me to reflect upon how it might be helpful for some people with cognitive impairments and their partners to contribute to research, and to reflect upon what they were hoping to achieve through taking part. I now wonder if there would have been scope to include participants in the earlier planning stages. I hope in future research that people with cognitive impairments will continue to have an opportunity to express their opinion and views on how they see their condition.