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A comprehensive profile of awareness in Mild Cognitive Impairment

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A thesis submitted to the School of Psychology, Bangor University, in partial fulfilment of the requirements of the degree of Doctor of Philosophy.

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Declarations

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed ………………………………………….. (candidate)

Date …………………………………………..

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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Summary

This thesis explores awareness in mild cognitive impairment (MCI). The limited research on this particular topic has yielded inconclusive results yet it suggests that awareness does vary in people with MCI. The heterogeneity across findings is as a result of conceptual and methodological differences which are discussed in chapter 2 (literature review). Much of the literature has focussed on the role and accuracy of subjective memory complaint (SMC) in predicting future dementia, whereas focussing on SMC alone excludes people who would meet the criteria for MCI but who do not present with SMC. The literature review highlights the importance of focussing on awareness rather than SMC alone. For the purpose of this thesis, awareness is conceptualised as ‘a reasonable or realistic perception or appraisal of a given aspect of one’s situation, functioning or performance, or of the resulting implications, which may be expressed explicitly or implicitly’. Awareness is also placed within a framework of different levels, specifically, meta-representation, evaluative judgment and performance monitoring.

Study 1(chapter 3) explores the meta-representation level of awareness in MCI by adopting a qualitative approach through interpretative phenomenological analysis (IPA). This study provides an exploratory model of the experience of MCI with a focus on the participants’ appraisal of their memory or cognitive difficulty. This study identified four themes, ‘fear and uncertainty’, ‘interdependence’, ‘life goes on as normal’ and ‘disavowal of difficulty’. Studies 2 (chapter 4) and 3(chapter 5) present quantitative data from a cross-sectional and longitudinal perspective respectively, and explore awareness in MCI at the level of evaluative judgment and performance monitoring. Overall findings support the biopsychosocial model which implicates the role of psychological and social factors as well as cognition in how people with MCI appraise their symptoms, which can result in a variety of context-dependent coping styles. Findings from these three studies are discussed with consideration of theoretical and practical challenges as well as future directions.

Chapter 1

A comprehensive profile of awareness in Mild Cognitive Impairment: An introduction

As we age, the risk of neurodegenerative conditions is increased. The worry of developing dementia is a reality for many older people and a noticeable decline in memory and/or cognitive function may serve to increase anxiety and reduce wellbeing. A wide body of literature exists which explores cognitive decline in older people whereby performance on neuropsychological tests show abnormality yet the clinical criteria for a disease process such as dementia are not met. The aetiology of such impairment has been discussed widely in the literature with varying classification systems which propose that such a decline either represents healthy aging, the early stages of Alzheimer's disease or a heterogeneous disorder with multiple possible outcomes (Collie & Maruff, 2002). The importance of an accurate classification system which identifies people at risk of or in the earliest stages of dementia lies in the possibility of the application of therapeutic interventions which may delay further decline which would impede on a persons' independence and wellbeing. This thesis will utilise the most prominent classification system, that of 'mild cognitive impairment' (MCI; Petersen, 1997, 1999, 2001) which is currently the dominant criteria used in research and in clinical settings. MCI is considered a prodromal stage for many dementias (Petersen & Negash, 2008) and would be classified as a heterogeneous disorder with multiple outcomes. MCI is currently being considered for inclusion in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (Petersen & O'Brien, 2006).

Historical perspectives

It is important to consider earlier constructs of cognitive decline which is not dementia in order to understand the history which underpins the current criteria. Notably, earlier classification systems view MCI as a normal part of aging with more recent constructs adopting a clinical definition. Differences across MCI classification systems relate primarily to inclusion and exclusion criteria although certain requirements remain constant, such as that of subjective memory complaint (SMC). A SMC would be defined as a negative statement about a persons' memory ability. Kral (1962) introduced the concept of benign senescent forgetfulness (BSF) defined as a difficulty with recall of factual information such as names or dates but with preserved global knowledge and intact awareness of deficits. BSF was distinct from a more progressive decline which Kral termed 'malignant senescent forgetfulness' (MSF), defined as rapid, progressive memory impairment in aging with loss of recent and remote memories, and a lack of awareness of deficits. As time progressed, the concept of benign senescent forgetfulness was re-named 'age-associated memory impairment' (AAMI) by the National Institute of Mental Health (NIMH; Crook et al., 1986). This criteria required subjective reports of memory difficulties in people aged over 50 which were qualified by impaired performance of memory tests at least one standard deviation below the mean of young adults. It was also required that impaired memory was not attributable to any medical or psychological condition.

In view of criticisms suggesting that AAMI criteria would apply to most people over 65 years (Bamford & Caine, 1988) an attempt was made to redefine AAMI by Blackford and LaRue, (1989) who introduced two subcategories termed 'age-consistent memory impairment' (ACMI) and 'late life forgetfulness' (LLF). An age restriction of 50-79 years was specified with LLF representing a more profound memory decline than ACMI. There is a requirement in both these categories for the person to have a SMC and for this to be corroborated by objective tests of memory which had age-related norms. Criticism of AAMI, ACMI and LLF criteria suggest that the specified exclusion criteria (current psychological and psychosocial stress, previous alcohol abuse and any disorder which would interfere with assessment) are too exclusive and that the term 'impairment' (AAMI & ACMI) is misleading as the criteria are specifically related to normal age-related changes (Smith et al,. 1991). Levy (1994) further proposed the classification of ‘aging-associated cognitive decline’ (AACD) which required a decline of at least one standard deviation in any area of cognitive functioning compared to age-matched norms. AACD criteria acknowledged that memory function is not the only domain affected by age.

As a result of dissatisfaction with age-related criteria of cognitive decline which fail to address the impairments associated with a diagnosis of dementia (Smith et al., 1996) the introduction of classifications which signify a disease-related process, specifically a prodomal stage of dementia, have been proposed. This could be regarded as a move towards a disease-based definition which would allow the opportunity for intervention (Ritchie, Artero & Touchon, 2001). The Canadian Study of Health and Aging (CSHA) used the term ‘cognitive impairment-no dementia’ (CIND) to describe individuals who had impaired cognitive function yet did not meet dementia criteria (Ebly et al., 1995) yet as a result of less restrictive criteria, high population prevalence rates are reported (16.8%; CSHA) which exceeds all types of dementia combined (Graham, Rockwood & Beattie, 1997). As the construct of CIND includes those with lifelong cognitive impairment and learning disabilities it naturally includes a larger subset of the population, although attempts have been made to define subsets of CIND which more closely resemble MCI (Fisk, Merry & Rockwood, 2003). The AAMI criteria were incorporated into CIND subcategories, where the presence of SMC was a requirement. Clearly, it was assumed that the person with cognitive impairment at the earliest stages would be aware of these changes.

At around the same time period as the development of earlier constructs, the term MCI was being used in the literature (Reisberg, Ferris, De Leon & Crook, 1982; Flicker, Ferris & Reisberg, 1991) to describe individuals with a Global Deterioration Scale (GDS) rating of 3. The GDS is a global rating scale which is used to summarise whether an individual has cognitive impairment which is consistent with a dementia process. Although the GDS is useful in defining the severity of cognitive impairment, it does not correspond to specific diagnoses (Petersen & Negash, 2008). The original clinical criteria for MCI were developed by Petersen (1999, 2001) and were designed to capture an Alzheimer-like process and were therefore focussed on memory difficulties (See Table 1.1). Evidence suggested (Petersen, 1999) that people who met criteria for MCI were at greater risk of developing Alzheimer's disease (10-15% annually) than older people without MCI (1-2% annually). The criteria for MCI have since evolved to reflect a heterogeneous condition with multiple outcomes such that impairments in other cognitive domains may indicate progression to non-Alzheimer's dementias (Petersen & Negash, 2008: Figure 1.1).

Table 1.1 MCI criteria (Petersen, 1999; 2001)

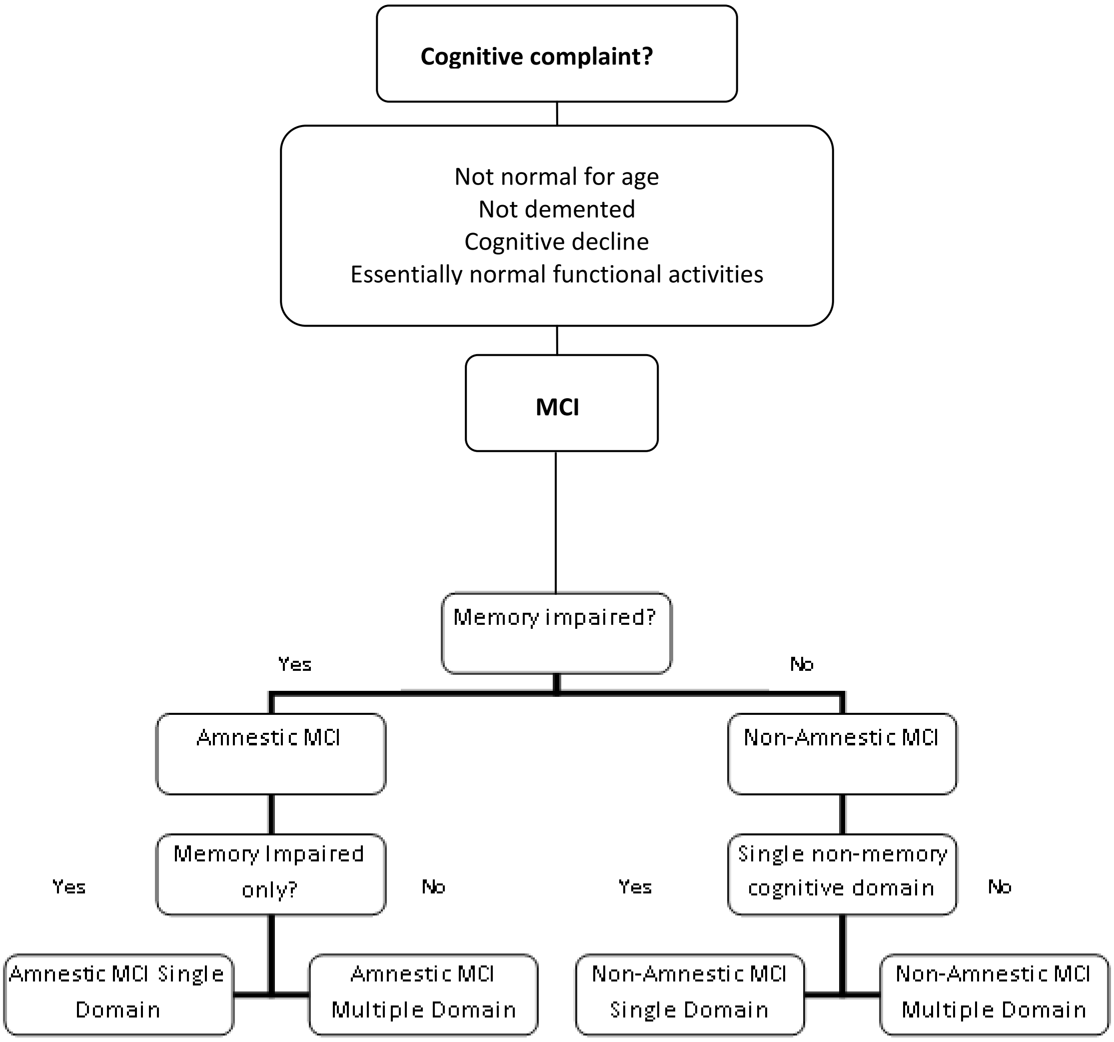
Subjective memory complaint, preferably corroborated by an informant
Memory deficit based on age-appropriate norms
Preserved general cognitive ability
Relatively intact activities of daily living
No dementia

The inclusion of SMC as a requirement of MCI criteria remained in the amnestic sub-classifications of MCI (single & multiple domain). It is of interest to note that SMC requires corroboration by objective testing in earlier constructs or an informant in the criteria specified by Petersen (1999, 2001) which would implicitly suggest that a persons' own perception of cognitive processes may not be an accurate appraisal of functioning. It is not the accuracy of appraisal which is the central issue; if a person experiences changes in memory or cognition which would otherwise meet the diagnostic criteria for MCI yet lacks awareness of these, they will not express SMC or seek appropriate advice. Specifically, a lack of awareness will diminishes the purpose of MCI criteria in identifying people who would benefit from early therapeutic intervention. In a recent meta-analysis of studies which explored the utility of cognitive interventions, it was found that people with MCI benefited across all areas of functioning (Li et al., 2011). It is therefore necessary to explore and identify the mechanisms underlying awareness in MCI in order to inform future work in this area.

Awareness

Awareness is most notable when it is absent in various neurological conditions such as head injury or stroke (McGlynn & Schacter, 1989). The study of awareness in neurodegenerative conditions such as dementia has been an area of much interest yet it is only in recent years that conceptual and methodological issues have been addressed in order to promote a better theoretical understanding of the awareness concept (Clare, 2004a, 2004b). In reviewing existing theoretical models of awareness it is apparent that awareness can be described at different levels and is influenced by neurological, psychiatric or psychosocial perspectives (Clare, 2004b). This is reflected in the use of conflicting terminology such as anosognosia, lack of insight and denial which causes further confusion. A further consideration when exploring awareness is that there has to be an awareness of something, whether it is of cognitive domains such as memory or behavioural domains such as apathy or functional ability. This is termed the object of awareness and will influence the elicited awareness phenomenon (Markova & Berrios, 2001). The term awareness offers a descriptive label which has been defined in this thesis as “a reasonable or realistic perception or appraisal of a given aspect of one’s situation, functioning or performance, or of the resulting implications, which may be expressed explicitly or implicitly" (Clare, Markova, Roth & Morris, pg 4, in press).

Figure 1.1 Diagnostic algorithm for diagnosing and sub-typing MCI (Petersen & Negash, 2008)



Awareness operates at different levels of increasing complexity, from simple behavioural indicators of awareness to the most complex awareness phenomena of self-awareness and sense of identity (Stuss, Picton and Alexander, 2001). A framework for understanding the different levels of awareness in AD and associated dementias has been proposed, with four levels of increasing complexity which are not exclusive although they are described separately for clarity (Clare, Markova, Roth & Morris, in press). The primary level is the most basic and is that of sensory registration, which reflects the capacity for attention to be directed at an object which allows appraisal or a behavioural response. The second level, performance monitoring involves monitoring on going task performance as it occurs and identifying errors. The third level is that of evaluative judgment, which reflects a judgment about symptoms, changes or impairments specific to the individual. The final, highest and most complex level of awareness is meta-representation. At this level awareness can be retrospective or prospective and may be directed internally (aspects of the self and identity) or externally (at the environment). Current models which involve cognitive processes and structures can be placed within this framework. This framework also focuses on motivational processes and social and environmental influences which shape awareness. Given the possible prodromal nature of MCI, and similarities between some features of MCI and dementia, the framework for understanding awareness in AD and associated dementias is likely to be equally relevant to MCI.

From a neurological perspective, Petersen et al. (1999) reported similar levels of impairment of verbal episodic memory in an MCI and a mild Alzheimer’s disease (AD) sample. Other cognitive domains such as naming and executive function were found to be similar to healthy older controls. As 48% of the MCI sample in Petersen’s study developed probable AD within 4 years of diagnosis, it would be logical to assume that verbal episodic memory is the initial cognitive domain affected in the AD process. Similar results have been reported by others (Grober et al., 2008; Guarch, Marcos, Salamero, Gasto & Blesa; Perri, Serra, Carlesimo & Caltagirone, 2007). From a neuropsychological perspective, a review by Apostolova and Cummings (2008) found that between 35-75% of people with

MCI across the reviewed studies had symptoms of apathy, anxiety, depression, irritability and agitation. Apostolova and Cummings suggest that such behavioural features could serve as clinical indicators of MCI as a prodromal state.

It is therefore indicated that both the neurological and neuropsychological elements associated with MCI will influence the presentation of elicited awareness phenomena. Difficulties with episodic memory could prevent the assimilation of new information relating to current self-knowledge, whereby the individual will refer to his/her earlier self in relation to a given domain and appear unaware of recent changes (Klein, Cosmides & Costabile, 2003; Klein, German, Cosmides & Gabriel, 2004). In considering the role of psychological factors, if a person is apathetic, depressed or is anxious, this influences their ability to reflect accurately on any given domain. Motivational factors will be influenced by beliefs, norms and expectations whether internal or external within a specific social context (Glaser & Strauss, 1965). Kitwood (1997) proposed a dialectical process of dementia which encompassed the neurological, psychological and social elements of the disease, which as discussed, is also likely to be relevant in MCI. It is equally relevant to apply the biopsychosocial model of disease to MCI (Engel, 1977) which places the experience of MCI within a synthesis of factors relating to the person and their social context.

Methodological issues

The process of measuring awareness is difficult as it does not lend itself to a single empirical measure which could capture all its various elements (Clare, Markova, Verhey & Kenny, 2005). Comparability across studies is difficult as a result of a lack of a clear definition of awareness in some studies with varying objects of awareness (Markova & Berrios, 2001) resulting in different awareness phenomena being elicited. The choice of methods should have a clear theoretical framework which clearly specifies which aspect of this framework is being measured (Clare et al, 2005). Current methods involve either a discrepancy framework or clinician ratings as a measure of awareness which do have certain limitations. Clinician ratings generally involve a global rating which does not account for clinician bias, individual responses or the social context in which the responses occur. Discrepancy methods can involve a comparison between self- and informant-rating on parallel measures which reflect the chosen object of awareness. Informants are usually partners or children who are themselves subject to psychological and social factors which may influence the objectivity and accuracy of their ratings. A discrepancy between tests of cognitive function and self-ratings offers an alternative approach, but would require comparability between both measures in order to be of value. Performance monitoring offers a further discrepancy measure of awareness between pre- or post-diction rating of performance on a task which may be influenced by mood or situational factors; it would also be imperative to ensure the ecological validity of the assigned task, in order to ensure that it can be generalised to everyday situations.

In response to the identified limitations inherent in different methods of measuring awareness, this thesis will utilise a combined approach. Discrepancy scores will be calculated between parallel forms of questionnaires administered to the participant and someone who knows them well as a measure of awareness from an evaluative judgment level. Discrepancy scores between a post-task self-rating scale and a matched ecologically valid memory task will provide a measure of awareness from a performance monitoring level. Neuropsychological measures will provide an overview of participants’ cognitive functioning and psychological and social variables will be assessed for both participants and informants in order to explore any factors which may influence responses. Appendix

A lists each measure employed in the thesis. A qualitative study will also allow the exploration of awareness from a meta-representational perspective.

Outline of thesis

The primary aim of this thesis was to explore the impact MCI symptoms have on individuals and how this is then appraised, what factors influence that appraisal and how this influences expressed awareness. Data collection occurred at two time points, approximately 12-15 months apart. Data for study 1 and 2 is from the initial visit with study 3 exploring data from the follow up visit. The same pool of participants contributed data to studies 1, 2 and 3. Participants were recruited from 4 separate memory clinics, and all had a clinical diagnosis of MCI of the amnestic form (see figure 1.1). See appendix B for ethical approval, appendix C for the study information sheet, and appendix D for the consent form. Both quantitative and qualitative methods were adopted in order to fully explore the complexity of the awareness phenomenon. The thesis is made up of a literature review (Chapter 2), a qualitative study employing interpretative phenomenological analysis (IPA; Chapter 3), a cross-sectional study (Chapter 4) and a longitudinal study (Chapter 5). These chapters are linked and explore different levels of awareness in MCI within a framework upon which the awareness construct can be understood (Clare, Markova, Roth & Morris, in press).

Chapter 2 is a systematic literature review exploring the limited literature on awareness in MCI. The aim is to gather evidence on whether levels of awareness of memory functioning varies amongst people with MCI and whether awareness is predictive of conversion to dementia. Conceptual and methodological differences across studies will be highlighted in relation to the concept of awareness as well as a discussion of the variation in the application of the MCI criteria. There will also be a focus on SMC and their utility as part of MCI criteria. Importantly, the systematic literature review gives an overview of the findings of the most recent body of literature in the area of awareness in MCI and provides a platform upon which to base the studies incorporated in this thesis.

Chapter 3, study 1, will explore the phenomenological nature of awareness in MCI, specifically at the meta-representational level where individuals' beliefs and values as well as motivational factors form internal (self-reflection) and external (perspective of others) elements of awareness which are further shaped within the individuals' social context. A qualitative approach was considered most suitable for exploring this level of awareness, specifically IPA. Questions posed by this study explored the nature of participants' understanding of MCI as a diagnosis and the associated implication of dementia risk, the psychological impact of living with MCI and what, if any, coping mechanisms are employed. This study also considers how people with MCI appraise their condition and how this influences their experience, understanding and adopted coping mechanisms. The results of this study confirmed the influence of psychological factors at the most complex level of awareness.

Chapter 4, study 2, adopts a quantitative methodology to explore the more basic levels of awareness of evaluative judgments and performance monitoring from a biopsychosocial perspective. The domains considered in this study were memory, functional ability and social functioning. A multiple methods approach was adopted which represented an individual's performance monitoring of memory by a discrepancy score between self-rating (postdiction) and objective memory test (ecologically valid) performance and evaluative judgment of memory, functional ability and social functioning by a discrepancy score between self- and informant-rating on parallel forms of domain specific questionnaires. Neuropsychological and psychological measures were administered to elicit a full biopsychosocial profile of participants' functioning. The final study, (3; Chapter 5) adopted a longitudinal methodology in order to explore how biopsychosocial factors influence the presentation of awareness over time. Study 3 adopted the same methodology as Study 2 for the purpose of continuity and comparability.

The discussion (Chapter 6) synthesises the findings from each study into a comprehensive framework (Clare, Markova, Roth & Morris, in press) which incorporates the most complex meta-representational level of awareness down to the more basic levels of performance monitoring and evaluative judgments. Theoretical and clinical implications are discussed.

Chapter 2

Literature review: Subjective memory complaints and awareness of memory functioning in mild cognitive impairment: a systematic review[1]

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[1] A version of this chapter has been published as 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*(2), 95-109.

Abstract

Objectives-Subjective memory complaint (SMC) is central to the diagnosis of mild cognitive impairment (MCI). People with MCI are at a higher risk of progressing to dementia and research on SMC is contradictory in terms of the accuracy of SMC and its predictive role for future dementia. Awareness goes beyond SMC as it acknowledges those who are unaware of any memory problem, which may account for the contradictory evidence within the SMC literature. Studies of SMC and awareness in MCI were reviewed in order to examine whether level of awareness of memory functioning varies amongst people classified as having MCI and whether there is support for the suggestion that the level of awareness in MCI predicts future progression to dementia.

Method-Sixteen studies were identified which evaluate awareness level in people classified as having MCI in either a clinical or research setting. In addition to the outcome of each study, the conceptualization of awareness, 'object' of awareness and methodology were also considered.

Results-There is evidence to show that level of awareness in MCI does vary, and this may have implications for future progression to dementia. This review identifies important considerations for future research in the area of SMC, awareness and MCI.

Conclusions- Given the increased risk of progression to dementia for those identified as having MCI, the role of awareness should be explored further with due consideration given to the conceptualisation of awareness and the methodology employed.

In Mild Cognitive Impairment (MCI), the individual functions adequately on a day to day basis and has fairly intact cognitive abilities, but shows evidence of cognitive decline in a given domain or domains beyond that which would be expected for his or her age (Petersen, 2004). Longitudinal follow up of people with MCI shows annual conversion rates to probable Alzheimer's disease (AD) as around 10-15%. This figure drops significantly to 1-2% per year for healthy older people (Petersen, 2000). The importance of MCI therefore lies in its possible role as a prodromal stage of dementia. Suggested predictive factors for progression from MCI to AD include pronounced decline on objective test scores in cognitive domains such as episodic memory (Grober, Hall, Lipton, Zonderman, Resnick & Kawas, 2008; Guarch, Marcos, Salamero, Gastó & Blesa, 2008; Perri, Serra, Carlesimo & Caltagirone, 2007), visual memory (Guarch et al., 2008), executive function and verbal intelligence (Gober et al, 2008). Behavioural markers which have been suggested as predictive of progression to AD include depression (Gabryelewicz, Styczynska, Luczywek, Barczac, Pfeffer, Androsiuk et al, 2007) and apathy (Robert, Berr, Volteau, Bertogliati, Benoit, Sarazin et al, 2006), and the personality variable of low levels of conscientiousness has also been implicated (Wilson, Schneider, Arnold, Bienias & Bennett, 2007). For a review of behavioural manifestations see Apostolova and Cummings (2008). Clearly, no definitive predictor has so far been identified.

While the term 'mild cognitive impairment' was first used in a study by Flicker, Ferris and Reisberg (1991), it was Petersen (1997) who first set out the diagnostic criteria for MCI as follows: (a) memory complaint, (b) intact activities of daily living, (c) intact general cognitive function, (d) memory impairment beyond that which would be expected for age, and (e) no dementia. Petersen (2004) went on to develop three sub-classifications of MCI, acknowledging the heterogeneity of the construct:

- The amnestic form – memory complaint, other cognitive domains normal, not dementia.
- Multiple domain MCI –impairment in more than one cognitive domain, not dementia.
- Single non-memory domain MCI –isolated impairment in one cognitive domain e.g. language, not dementia.

The amnestic and multiple domain criteria accord a central role to the presence of subjective memory complaint (SMC). The role of SMC was acknowledged by Petersen (1997) in the initial formulation of the diagnostic criteria for MCI. Later amendments (Petersen, 1999, 2001) suggest that any memory complaint should preferably be corroborated by an informant, although this is not a requirement. Thus, there is an implicit acknowledgment that the individual's own subjective evaluation of his/her memory functioning may not reflect an accurate appraisal of the actual memory deficit. An inaccurate appraisal could indicate a lack of awareness of changes in memory or of difficulties with memory. The key issue here is whether some individuals with memory changes amounting to MCI may lack awareness of these, and thus fail to express SMC, while meeting other aspects of the diagnostic criteria.

Different theoretical models underpin the understanding of awareness and each model defines awareness as occurring at different levels, whether it is from a neurological, psychiatric or psychosocial perspective (Clare, 2004a). For the purpose of this review, awareness can be defined as the ability to accurately appraise aspects of one's own situation or functioning and may be evaluated in relation to a range of domains, or 'objects', including memory (Markova & Berrios, 2001; Clare, 2007). SMC alone do not constitute an assessment of awareness of memory function. It is the comparison of SMC with a standard such as objective testing or informant rating which represents a measure of awareness (Clare, Marková, Verhey & Kenny, 2005). If SMC are present, it is important to identify to what extent this reflects an accurate appraisal of memory functioning, suggesting good awareness, or whether the complaints are inaccurate, suggesting greater or lesser difficulty than the actual memory deficit would indicate. If SMC are absent, this does not necessarily mean there is no memory problem; it could reflect either an absence of memory problems or an inaccurate appraisal of memory functioning that indicates poor awareness.

Awareness has been extensively researched within the field of dementia (for reviews see Clare, 2004a, 2004b, Clare et al 2005). While the conceptualisation of awareness and the specific assessment method adopted clearly impact on the phenomenon that is elicited, it seems evident that level of awareness of cognitive deficits varies considerably among individuals diagnosed with mild Alzheimer’s disease (AD). It is of interest to consider whether such variability in awareness also arises with more mild memory difficulties and whether it is evident among individuals otherwise meeting diagnostic criteria for MCI. If this is the case, then the further question arises as to whether low awareness in MCI could serve as a possible predictor of conversion to AD. The nature of awareness in those who are already showing cognitive impairment may provide valuable clues as to whether variability in awareness at the MCI stage suggests an increased likelihood of progression. Alternatively, if people with MCI show good awareness, then SMC could be regarded as a reliable predictor of dementia. Research on awareness in people with MCI largely focuses on SMC, their accuracy against objective test scores and their predictive role in progression to dementia.

Results are contradictory regarding the accuracy of SMC when compared to objective test performance. Clement, Beleville and Gauthier (2008) conducted a cross-sectional study to examine the nature and accuracy of SMC in MCI, AD and healthy older adults. The MCI group were selected from a memory clinic where a diagnosis of MCI was based on the Petersen (1999) criteria, thus requiring the presence of SMC. Correlation analysis indicated that there was a higher level of cognitive complaint in the MCI group than in the healthy older adult group, although this was restricted to certain circumstances and specific domains. There was little relationship between the domains of subjective memory complaint and the nature of the actual cognitive deficits as indicated by test scores, suggesting that SMC are based on an evaluation of general cognitive abilities rather than reflecting a precise assessment of memory performance. This in itself suggests that awareness may be compromised. However, other studies have found a strong association between SMC and objective test performance (Jonker, Geerlings & Schmand, 2000; Podewils, McLay, Rebok & Lyketsos, 2003).

Contradictory results can also be found in relation to the predictive role of SMC in progression to dementia. Jorm, Christensen, Korten, Henderson, Jacomb and Mackinnon (1997) selected a community sample of older people and examined whether SMC predicted a change in memory test performance. The study excluded those with dementia but did not specifically identify those who potentially had MCI. Indeed, 3.7% (28 of 721) had progressed to dementia during the time period of the study (3.6 years), implying that a proportion of the sample may already have had cognitive impairment. In this study SMC did not predict cognitive decline, which may in itself indicate that level of awareness was variable. As SMC were not a requirement for inclusion in the study, this sample may have included people with cognitive impairment who were unaware of any change. Schmand, Jonker, Geerlings and Lindeboom (1997) conducted a 4 year longitudinal study of 4051 older people living in the community, of whom 131 (6.2%) developed dementia over the course of the study. SMC predicted conversion to dementia more strongly than age.

Although the authors excluded those with dementia at the outset, as in the Jorm et al (1997) study, it is unclear which of the sample could have been classed as having MCI, thus making these results difficult to interpret. Geerlings, Jonker, Bouter, Adèr and Schmand (1999) used the same sample of volunteers to explore the predictive role of SMC. Based on Mini Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975), the sample were classed as either cognitively normal (n = 1956 of 2169 who were available for follow up) or as having borderline/impaired cognition (n = 213). Those classed as having normal cognition had scores between 26 and 30 on the MMSE whereas those with scores ≤ 25 were classed as borderline/impaired. An association was found between memory complaint and incident AD, which was modified by cognition. On further analysis, memory complaints were associated with incident AD for those with normal cognition but not for those with borderline/impaired cognition.

Differences in the outcomes of these studies could be accounted for by conceptual and methodological issues similar to those found in the research on awareness in dementia (Clare et al, 2005). Different methods are used across studies to elicit SMC, ranging from a battery of measures or a single question, and methods of objectively testing cognition also differ amongst studies. The heterogeneity of the MCI criteria and the sampling methods used clearly impact on outcome; in particular, by only including those participants with SMC, any individuals who are not aware of their memory difficulties will be missed. Within community samples there may be no clear demarcation between those who are considered cognitively healthy and those who would fit into the MCI criteria.

In summary, there is evidence to suggest that the ability to accurately appraise aspects of one’s own functioning, and in particular memory functioning, may be affected in some people who otherwise meet diagnostic criteria for MCI. This has implications for the emphasis placed on SMC in diagnostic criteria. It may also have implications for the likelihood of conversion to dementia, such that lower levels of awareness are predictive of progression. This review will systematically examine quantitative studies providing information about awareness in MCI in order to determine the nature of awareness in MCI and its role in progression to dementia. For the purposes of the review, awareness will be defined as the ability to accurately appraise one's own functioning in a given domain. The focus here will primarily be on awareness of memory functioning, although other aspects of awareness will be considered where information is available, in order to provide a broader picture. The following specific questions will be addressed:

1. Does level of awareness of memory functioning vary among people diagnosed with MCI?
2. Do lower levels of awareness of memory functioning in people diagnosed with MCI predict conversion to dementia?

Method

Searches of Psychinfo, Medline, Science Direct, Web of Knowledge and Ovid were conducted on the 9th September 2008 using the search terms 'mild cognitive impairment' and 'cognitive impairment' combined with 'awareness', 'anosognosia', 'metamemory' 'insight', 'self-knowledge', 'self-report', 'evaluation', 'experience', 'memory complaints' or 'knowing'. Further studies were identified from the references cited in each selected study and examined for suitability. Criteria for inclusion in the review were that:

(a) the study considered awareness in people with a diagnosis of mild cognitive impairment; and

(b) the study measured participants' awareness of memory functioning and/or other aspects of awareness.

There was no limit on year of publication, although given that the term MCI was not used prior to 1991, it was not expected that there would be studies dated earlier than this.

Results

Twenty-three studies were identified as potentially relevant and examined in detail. Of these, sixteen studies met the inclusion criteria for the review. These studies are summarised in Table 2.1. We will first consider methodological and conceptual issues relating to participant selection, concepts and definitions employed, and the aspects of awareness elicited. We will then evaluate the evidence regarding inter-individual variability in awareness and the possible role of awareness as a predictor of conversion to dementia.

Table 2.1 Table of studies examining awareness in MCI.

Name & Year	Participants & mean age(SD).	MMSE	'Object' of Awareness.	Measures used in assessing awareness	Methods of assessing awareness	Results
1. Cook & Marsiske (2005)	16 MCI (amnestic) Age-76.94(7.62). 57 no MCI Age-74.77(5.03).	MCI = 26.63 (1.82 SD) No MCI = 28.70 (1.18 SD)	Memory function.	Memory Functioning Questionnaire (MFQ; Gilewski et al, 1990); Metamemory in Adulthood Questionnaire (MIA; Dixon, Hultsch & Hertzog, 1988).	Comparison between self-rating and objective testing.	A relationship was found between subjective memory beliefs and performance on tests of capacity beliefs, verbal memory and trails.
2. Crowe, Andel, Wadley, Cook, Unverzagt, Marsiske and Ball (2006).	55 MCI Age-76.	26.1 (2.0 SD)	Cognitive function.	Attitude Toward Intellectual Aging Scale from the Personality in Intellectual Aging Contexts(PIC; Lachman et al, 1982) and Everyday Forgetting (Fourteen items from the MFQ; Gilewski et al, 1990).	Comparison between self-rating and objective testing.	People with amnestic MCI have some insight into cognitive function. Predictive role of subjective cognitive function dependent on question used.

3.	Farias, Mungas and Jagust (2005).	111 community dwelling older adults of which: 59 normal Age-72.12(8.27). 21 MCI (amnestic) Age-76.54(8.41). 25 MCI (non-amnestic) Age-73.73(7.35). 6 Demented Age-74.83(3.83).	Modified MMSE used to aid diagnosis, no figures given in study.	Everyday functioning.	Assessment of everyday functioning (DFQ) based on the IQCODE (Jorm & Jacomb, 1989)	Discrepancy score from parallel forms of questionnaire.	MCI participants over-report functional change when compared to an informant as opposed to those with dementia who under-report functional change.
4.	Hanyu , Sakurai and Iwamoto (2006).	37 AD Age-77.9(6.5). 44 MCI (amnesic) Age-78.0(5.7).	AD = 22.4 (1.8 SD) MCI = 25.9 (1.4 SD)	Memory function.	Everyday Memory Checklist (EMC; Kazui et al, 2003).	Discrepancy score from parallel forms of questionnaire.	Found MCI participants showed impaired awareness of memory deficit.
5.	Hanyu, Sakurai, Hirao, Shimizu and Iwamoto (2007).	43 MCI (amnesic) AD pattern Age-77.6(5.7). non AD pattern Age-78.4(5.8). (AD and non AD pattern identified via SPECT).	AD pattern = 25.8 (1.4 SD). Non AD pattern = 25.9 (1.6SD).	Memory function.	Everyday Memory Checklist (EMC; Kazui et al, 2003).	Discrepancy score from parallel forms of questionnaire.	Unawareness scores in the AD pattern group were higher than the non-AD pattern group.

6. Kalbe et al (2005)	82 AD Age-70.2(8.7) 79 MCI Age-67.7(8.3)	AD = 25.5 (1.3 SD) MCI = 27.0 (19 SD)	Cognitive function.	A complaint interview covering 13 cognitive domains administered to patients and caregivers.	Discrepancy score from parallel forms of questionnaire.	MCI group overestimated their cognitive deficits when compared to informant assessment.
7. Marri, Modugno, Iacono, Renzetti, De Vreese and Neri (2001)		MCI = 28.1 (1.3 SD)	Memory function.	Metamemory Questionnaire – Memory scale of Sehulster (1981) and Age Associated Memory Impairment measure (MAC-Q; Crook et al, 1992).	Comparison between self rating and objective testing.	Reliable information can be obtained from a single metamemory item, assessing a change in memory function over time.
8. Okonkwo et al (2008)	74 MCI Age 68.32(6.54) 73 Healthy older controls Age 66.44 (8.57)	MCI = 28.38(1.63) HOC = 29.46(0.97)	Everyday functioning-financial abilities.	Current Financial Capacity Form (CFCF; Marson, 2001) & Financial Capacity Instrument (FIC; Marson, 2000)	Combined methodology-Comparison between self and objective rating & discrepancy score from parallel forms of questionnaire.	Those with MCI vary in levels of awareness of their financial abilities-this is influenced by cognitive status and depression.

9.	Onor, Trevisiol, Negro and Aguglia (2006).	61 AD Age-74.81(6.61) 60 MCI Age-77.10(7.35)	AD = 23.63 (1.43 SD) MCI = 27.90 (1.37 SD)	Cognitive function, Behavioural and everyday functioning.	Schedule for the Assessment of Insight (SAI; David et al, 1992 and Clinical Insight Rating Scale (CIRS; Ott et al, 1996).	Combined methodology- Clinician rating & semi-structured interview.	MCI participants do lack insight but not to the same extent as those with AD.
10.	Perrotin, Belleville and Isingrini (2007).	20 MCI Age-67.45(8.42) 20 Controls Age-68.55(7.84)	MCI = 28.25 (1.07 SD) Controls = 28.85 (1.04 SD)	Memory function.	Episodic feeling of knowing (FOK) procedure.	Comparison between self-rating and objective testing.	MCI group made less accurate FOK predictions than controls.
11.	Purser, Fillenbaum and Wallace (2006).	10 year longitudinal study. 1004 with memory complaint Age- 74.6(6.3). 1920 without. Age-74.0(6.4) Of the total sample (2924), 25% met MCI diagnostic criteria.		Memory function.	Short Portable Mental Status Questionnaire (SPMSQ; Pfeiffer, 1975), an ADL measure and a twenty-item word recall task.	Comparison between self-rating and objective testing.	A similar proportion of those with and without memory complaint could be objectively classified as MCI-SMC found to be unreliable.

12. Ready, Ott and Grace (2006).	AD (n34) and MCI (n34) both combined for testing in this study. Combined Age-77.9(7.2)	Both AD and MCI = 24.4 (4.5 SD)	Situation, memory deficit, functional deficits & disease progression.	Clinical Insight Rating Scale (CIR).	Clinician rating.	Level of awareness did not predict agreement between participant and informant on a QOL measure.
13. Ries et al (2007).	16 MCI Age-73.4(7.1) 16 Controls Age-74.4(6.4)	MCI = 27.4 (2.2 SD) Controls = 29.7 (0.4)	Cognitive function.	IQCODE (Jorm & Jacomb, 1989). fMRI task and scan.	Discrepancy score from parallel forms of questionnaire.	MCI participants found to be heterogeneous in their ability to make accurate self-appraisal.
14. Robert et al (2002).	60 AD Age-74.90(7.11) 12 Parkinsons Age-64.1(11.9) 24 MCI Age-71.67(5.92) 19 Controls Age-70.68(8.21)	AD = 22.55 (3.98 SD) Parkinsons =27.2 (3.5 SD) MCI = 28.2 (1.06 SD) Controls = 29	Apathy.	Apathy Inventory (IA; Marin et al, 1991).	Discrepancy score from parallel forms of questionnaire.	IA found to be a reliable method of assessing some dimensions of apathy and the person’s awareness of these symptoms.

15. Tabert et al (2002).	107 MCI Age-67.6(10.1) 46 Controls Age-63.8(9.7)	MCI = 27.5 (2.2 SD) Controls = 29.4 (0.78 SD)	Everyday functioning.	Pfeffer FAQ (Pfeffer et al, 1982) & Lawton IADL (Lawton et al, 1969).	Discrepancy score from parallel forms of questionnaire.	Under-reporting of functional deficit by MCI participants as compared to informant report strongly predicted future AD.
16. Vogel, Stokholm, Gade, Andersen, Hejl and Waldemar (2004) & Vogel, Hasselbalc, Gade, Ziebell and Waldemar (2005).	36 Mild AD Age-76.4(6.3) 30 MCI Age-74.4(4.8) 33 Controls Age-73.4(5.3)	Mild AD = 24.04 (2.5 SD) MCI = 26.07 (2.06 SD) Controls = 29.3 (0.85 SD)	Memory function.	Anosognosia rating scale (four point scale from Reed et al.,1993) and memory questionnaire (Michon et al. 1994, adapted from Squire and Zouzounis, 1988).	Combined methodology- Clinician rating & Discrepancy score from parallel forms of questionnaire.	Significant heterogeneity found in clinical presentation of awareness and impaired awareness in both MCI and AD groups.

Methodological and conceptual issues

Participant selection

MCI was either a construct applied to a group of healthy volunteers from the community (e.g. Cook & Marsiske, 2006; Crowe et al, 2006; Farias et al, 2005), or a diagnosis made in a clinical setting (e.g. Hanyu et al, 2006; Hanyu et al, 2007; Kalbe et al, 2005). In the clinical samples, mean MMSE scores ranged from 25.9 (Hanyu et al, 2006) to 28.38 (Okwonkwo et al, 2008) with an average mean across studies of 27.2. Ready et al (2006) based their results on a mixed sample of people with AD and MCI, and MMSE data is not provided separately for the MCI group. Four studies recruited participants from the community, with only two reporting MMSE scores for the MCI groups; the mean MMSE scores were 26.63 (SD 1.82) (Cook & Marsiske, 2006) and 26.1 (SD 2.0) (Crowe et al, 2006). Purser et al (2006) did not use MMSE and Farias et al (2005) did not report overall MMSE scores for their MCI group. Thus, for those studies where data is available, there does not appear to be any major difference in cognitive status arising from the sampling method employed. Numbers of participants ranged from sixteen (Cook & Marsiske, 2005) to 107 (Tabert et al, 2002). Purser et al (2006) used an epidemiological database and extracted data for 2924 individuals. Average age across MCI participants was 73.45 years (range 67.45-78; SD 3.93). Methods for diagnosing MCI differed amongst studies, but the most frequently-used criteria were those of Petersen et al (1999; 2001). Table 2.2 provides an overview of the diagnostic criteria employed in each study.

Table 2.2 MCI diagnostic criteria used in reviewed studies.

	Winblad (2004)	Petersen (2001)	Impaired memory criteria for AMCI[1]	Petersen (1999)[2]	Petersen (1999)[3]	Below 10th percentile on Verbal Memory	Below 10th percentile on non-memory measures	ICD-10 criteria.	Deficits in neuropsych testing and/or memory complaint and functional impairment
Cook & Marsiske (2005)			√						
Crowe et al (2006)					√				
Farias et al (2005)						√	√		
Hanyu et al (2006)		√							
Hanyu et al (2007)		√							
Kalbe et al (2005)				√					
Marri et al (2001)				√					
Okonkwo et al (2008)		√							
Onor et al (2006)		√							
Perrotin et al (2007)		√							
Purser et al (2006)				√					
Ready et al (2006)		√							
Ries et al (2007)	√							√	
Robert et al (2002)									
Tabert et al (2002)									√
Vogel et al (2004) & (2005)		√							

Note. [1]Age consistent memory impairment. [2]With SMC. [3]Without SMC.

Concepts and definitions

Awareness is a multidimensional concept with no single clear conceptual and theoretical model or definition. This is reflected in the different terms used and can be explained to some extent by the range of disciplines working towards an understanding of awareness, in relation to their philosophical foundations. The one study which did use the term 'awareness', Okwonkwo et al (2008) does not offer a definition for the term. Other studies employed different terminology.

Several studies use the term 'insight'. Cook and Marsiske (2006) describe insight as the "ability to elaborate on the experience of a disease, label the symptoms of the disease as pathological…." (pg 413). Ready et al (2006) conceptualize insight as "awareness of situation, memory deficit, functional deficits and disease progression" (pg242), which merely defines insight as awareness. Crowe et al (2006) refer to insight in their conclusion, but do not offer a definition of the concept. Based on research on insight in psychosis, Onor et al (2006) identified two types of insight, emotional and cognitive. The authors describe emotional insight as the psychological response to the illness whereas cognitive insight is described as the recognition of symptoms without reference to psychological and emotional influence. The authors acknowledge that awareness is complex and multifaceted, and refer to literature which contradicts their definition e.g. Kessler & Supprian (2003) who acknowledge that awareness influences both behavioural and cognitive functions. Such contradiction highlights the difficulties in conceptualising such a broad concept, adding little to the existing literature on the subject.

The term 'metamemory' is used by Marri et al (2001) to describe a general knowledge of cognitive functioning and processes. Perrotin et al (2007) also use the term metamemory in relation to 'metamemory judgments' which are an evaluation of performance made whilst engaging in a specific memory task. Although both studies refer to ‘metamemory’, there is little similarity in their definitions and this is reflected in the different methods and focus of both studies. The term ‘anosognosia’ is used by Kalbe et al (2005) to refer to unawareness of cognitive dysfunction. Ries et al (2007) use the term anosognosia to refer to unawareness of loss of function, specifically in the area of cognition. While these studies share similar conceptualisations of anosognosia and describe this as a lack of awareness, their methodology and focus differ and their conclusions on awareness in MCI are conflicting. Vogel et al (2004) use anosognosia synonymously with unawareness of deficits and lack of insight.

The studies in this review employ a range of different terms to describe the phenomenon of interest, and even where the same term is used, the meaning assigned to it is often variable. Different terms may be used interchangeably. In some instances, definitions are lacking, while in other studies a definition is provided but is contradicted by other cited material. This heterogeneity and lack of clarity necessarily results in studies with a range of different outcomes.

‘Objects’ of awareness

Awareness has to be understood in relation to something. This is termed the object of awareness. Awareness is expressed in relation to a given object, and the selection of the object of awareness to be investigated influences the nature of the awareness phenomenon that is elicited clinically (Marková & Berrios, 2001). Objects can range from the broad, such as awareness of having an illness, to the specific, such as awareness of having memory impairment or making an error on a memory task. The object of awareness may be cognitive or behavioural in nature or may be an affective state, such as apathy. The implications of this are that the phenomenon of awareness which is elicited will not be comparable across objects as these reflect different aspects of a wider awareness concept. The studies included in this review focused on a range of objects including memory, general cognitive dysfunction, everyday functional abilities and apathy.

Seven studies assessed awareness in relation to memory functioning. Cook and Marsiske (2006) compared participants' subjective memory beliefs against neuropsychological testing as a representation of awareness of memory function. They specifically focussed on subjective memory beliefs rather than complaints, as they claimed memory beliefs were better predictors of memory performance. Hanyu, et al (2006) investigated unawareness of memory impairment in order to test the utility of SMC as a diagnostic entity, while Hanyu et al (2007) investigated the correlation between awareness of memory deficit and cerebral perfusion. In a prospective cohort study, Purser et al (2006) compared the self-ratings of participants with and without SMC against objective test scores in order to determine the accuracy of SMC, thus providing an indication of level of awareness. This study specifically considered the predictive utility of SMC in predicting decline in functional disability, word recall and general cognition over a ten year period. Vogel et al (2004) focussed on awareness of memory impairment in participants with MCI, mild AD and healthy controls in order to examine the nature of awareness in these groups. Using the same prospective memory clinic cohort, Vogel et al (2005) examined correlations between awareness of memory function and behavioural symptoms, executive test performance and regional cerebral blood flow in the frontal cortex.

Marri et al (2001) used a metamemory questionnaire to measure participants' beliefs about memory in everyday life, and explored correlations with measures of self-perceived health and memory test performance. In this case it is the relationship between responses on the metamemory measure and scores on the memory test that constitute a measure of awareness. Perrotin et al (2007) used an experimental metamemory paradigm, eliciting feeling of knowing (FOK) judgments as a means of evaluating the accuracy of participants' estimation of their memory performance whilst engaged in a memory task.

Four studies used functional abilities as the 'object' of awareness. Onor et al (2006) compared perceptions held by people with MCI and mild AD regarding cognitive difficulties, functional problems and behavioural disturbances. These perceptions were also compared to those of caregivers. Farias et al (2005) focused on the lack of agreement between people with dementia and their caregivers regarding cognitive and functional abilities, and examined this phenomenon in participants classified as having MCI and dementia. Tabert et al (2002) specifically focused on functional deficits, again comparing self- and informant reports of functional deficits in people identified as having MCI and AD. Okwonkwo et al (2008) focussed on financial ability as the object of awareness.

Three studies assessed awareness of cognitive function through the use of questionnaires covering various cognitive domains. Crowe et al (2006) hypothesised that poorer subjective cognitive function at baseline would predict future decline over the two year period of the study, comparing subjective cognitive function with a measure of global cognitive status at baseline and subsequent follow up. Kalbe et al (2005) and Ries et al (2007) focussed on awareness of cognitive dysfunction. Kalbe et al compared level of awareness cognitive dysfunction to a global measure of cognitive status, while Ries et al compared level of awareness of cognitive dysfunction to the brain pathology of participants engaged in an fMRI task involving self-appraisal (the participants selected trait adjectives which related to them). This particular study highlights the difficulty inherent in the comparison of different objects of awareness. Awareness of cognitive dysfunction, based on informant and participant rating of change over a 10 year period, bears little relationship with self-appraisal of ability on an experimental task. Each specific awareness measure will elicit a different awareness phenomenon, rather than a global indication of awareness.

Ready et al (2006) examined the relationship between awareness level and the reliability and validity of self-reported quality of life from people with MCI and AD, as compared to informant rating of the participant’s quality of life. They used a clinician rating of awareness where the ‘object’ was awareness of situation, memory deficit, functional deficits and disease progression. Again, there is little relationship between clinician rating of awareness in cognitive domains and the subjective response to questions about quality of life.

Robert et al (2002) examined awareness of apathy in order to establish the reliability and validity of the Apathy Rating scale. A questionnaire assessing emotional, behavioural and cognitive dimensions of apathy was administered to the participant and informant, the awareness of these symptoms of apathy being the ‘object’ of awareness. A comparison was made between participants with AD, MCI and Parkinson’s disease. The relationship between awareness and apathy is complex, in that the symptoms of apathy can directly affect a person’s expressions of awareness. If an individual is apathetic, this is likely to be reflected in their responses on the questionnaire. This does not, however, indicate that the person is necessarily unaware.

What is clear from these studies is that the chosen ‘object’ of awareness directly influences the nature of the phenomenon that is elicited. The variation in selection of objects makes it difficult to draw comparisons across studies. Even where the object is the same, different research questions and the use of different methods to assess awareness create difficulties in making comparisons.

Measurement of awareness

Clare (2004a) identified three main methodological approaches to measuring awareness in AD, which are typically used either singly or in combination:

- Awareness rating by a clinician.
- Discrepancy score between self and informant rating on parallel forms of questionnaires.
- Discrepancy score between self-rating and actual performance on an objective task.

The same methods of assessing awareness were found in the studies of MCI included in this review. We will discuss each method in terms of its advantages and limitations.

Only Ready et al (2006) relied on clinician rating alone. The clinician rated the participants according to a four item scale, the clinical insight rating scale (CIRS) (Ott, LaFleche, Whelian, Buongiorno, Albert & Fogel, 1996), which yields scores ranging from 0 (fully aware) to 8 (totally unaware). This scale relates to awareness of situation, memory deficit, functional deficits and disease progression. Clinician rating is subjective and relies on the participant and clinician having a reciprocal relationship, where the participant understands the questions asked and is able to respond in a way which is understandable to the clinician. It is assumed that the clinician has some knowledge of awareness and is able to assess this accurately. Clinicians will also have the advantage of talking to the individual and treating them as such, picking up subtle cues, whereas questionnaires will not. However, the patient may present themselves to a clinician in a certain way which may not reflect the reality of their situation.

Seven studies used a discrepancy score between self and informant rating on parallel questionnaires as a measure of awareness. In some cases validated questionnaires were used (e.g. Hanyu et al, 2006; Hanyu et al 2007) but other studies used non-validated measures (e.g. Kalbe et al, 2005). These questionnaires were selected with regard to the chosen ‘object’ of awareness. It is important to note that the method of questioning used is likely to have an impact on the kind of responses that are elicited (Markova et al 2005). The questionnaire discrepancy method also assumes that the informant is accurately assessing the abilities of the person with MCI, which may not necessarily be the case. Ries et al (2007) acknowledge this limitation, noting that even those informants who have known the person with MCI for many years may tend to over- or under-report symptoms or be unaware of the extent of cognitive decline. Five studies used a comparison between self-rating and performance on objective testing as a measure of awareness. These studies focussed on subjective memory complaints or memory beliefs (Cook & Marsiske, 2006; Crowe et al, 2006; Purser et al, 2006), or metamemory (Marri et al, 2001; Perrotin et al 2007). Each of these studies used questionnaires to elicit a self-rating of memory (e.g. Cook & Marsiske, 2006) or cognitive function (e.g. Crowe et al, 2006). The objective testing ranged from a broad, global test of cognitive function such as the MMSE (Cook & Marsiske, 2006: Crowe et al, 2006), to a more comprehensive memory test such as the Randt memory test (Randt et al, 1980) used by Marri et al (2001).

Purser et al (2006) used data from an epidemiological database to inform a prospective cohort study over a ten year period. The MCI group were split between those with and those without memory complaints and a comparison was made with objective scores on the seven item Short Portable Mental Status Questionnaire (SPMSQ; Pfeiffer, 1975), an ADL measure and a twenty-item word recall task. The nature of the specific memory complaints is not described, and it is questionable to what extent these complaints are related to the objective items tested. For example, a twenty-item word recall task would not necessarily reflect the problems an individual may have in everyday situations. If awareness is measured by the level of agreement between the self-rating and objective test, there should be a similar focus between the two in order to assess awareness correctly, thus highlighting a need for isomorphic measures (Clare et al, 2005). Perrotin et al (2007) acknowledge the need for similarly focussed measures based on difficulties they encountered in comparing SMC with a specific experimental paradigm. Their results show that their MCI participants had a higher level of SMC compared to healthy controls, whereas the MCI group over-estimated their predicted performance on the experimental task. They provide various possible explanations for these results but acknowledge the methodological limitations of using such divergent measures.

Three studies used a combined methodology. Clinician rating on the CIRS was used by Onor et al (2006) together with the Schedule for the Assessment of Insight (SAI; David, Buchanan & Reed, 1992), a semi-structured interview scale developed for measuring awareness in psychosis. Onor and colleagues acknowledge that the SAI is not ideal, given that the questions relate to symptoms of psychosis. Having a combined methodology offers the possibility of cross-validating different methods of assessing awareness, but given that the SAI is more suited to psychotic conditions it is unclear why this particular scale was chosen for studying participants with MCI. Vogel et al (2004) used discrepancy scores on parallel forms of a memory questionnaire and clinician rating of awareness on the Anosognosia Rating Scale

(ARS; Reed, Jagust & Coulter, 1993). This is a four category scale (‘full awareness’, ‘shallow awareness’, ‘no awareness’, ‘denies impairment’). Vogel et al, acknowledging the lack of a ‘gold standard’ in awareness rating, compared clinician ratings with discrepancy scores. The awareness rating based on discrepancy scores between participant and informant on a memory questionnaire corresponded well with clinician ratings, providing support that they both measure similar things. Although the authors conclude that in a clinical situation, this provides evidence for the accuracy of the clinician rating of awareness, they acknowledge the need for multiple methods of assessing awareness in research situations.

Okonkwo et al (2008) used a discrepancy score between participant and informant on a parallel measure of financial capacity in addition to a performance based psychometric instrument for assessing the financial ability of older adults. This allowed the authors to compare the participant self-report with a performance based measure in addition to assessing the accuracy of informant report against objective testing. The performance based measure in this study was developed using the same conceptual model as the measure of financial ability, thus ensuring isomorphism. The performance based task was also something which was familiar to the participant. The development of methods which are isomorphic and use familiar situations are recommended (Clare, 2005). In the studies included in this review, a variety of methods were used to measure awareness. The choice of method is influenced to some extent by the conceptualisation of awareness and the selected object of awareness. There are issues relating to the subjectivity of clinician ratings, the accuracy of informant ratings and the comparability of subjective and objective rating measures. Although a combined methodology may appear preferable, this may add further complications if the limitations inherent in each method are not acknowledged and accounted for.

Evidence for individual variability in awareness of memory functioning in MCI

Despite the limitations outlined above, the studies included in this review provide evidence to suggest that people diagnosed with MCI differ in level of awareness, and that some individuals with MCI have low levels of awareness. In general, some participants with MCI did show reduced awareness of memory impairment, but not to the same extent as people with dementia (e.g. Hanyu et al, 2006). Hanyu et al (2007) used single photon emission computed tomography (SPECT) to identify MCI participants with reduced cerebral perfusion in bilateral parietotemporal or posterior cingulate areas, who were defined as having AD pattern brain pathology. The group showing AD pattern brain pathology had lower levels of awareness than the non-AD pattern group.

Onor et al (2006) found that informants reported more cognitive and behavioural impairment than did individuals with MCI, suggesting reduced awareness among people with MCI. Vogel et al (2004) found that people with MCI showed similar levels of impaired awareness to people with mild AD. Within both MCI and AD groups, however, there was a full spectrum of awareness, with some participants showing good awareness and others poor awareness. Some of the participants with MCI showed a significant lack of awareness.

Purser et al (2006), in a sample including people with and without SMC, focussed on the validity of SMC and found these to be an unreliable measure of cognitive impairment. This implies inaccurate judgments, and thus supports the idea that level of awareness is variable in MCI. Crowe et al (2006), who did not use presence of SMC as a criterion for inclusion in their MCI group, also included people with and without SMC. In this study the MCI group showed some awareness regarding memory and cognitive difficulties, with measures of change in cognitive function and a single question about change in memory predicting significant change in MMSE scores at two year follow up. Questions relating to frequency of problems with memory in everyday situations did not predict significant change. The authors conclude that asking about ‘change’ is preferable to asking about ‘problems’, given that a participant may be aware of a decline in memory but not perceive this as a problem.

Kalbe et al (2005) suggest that low awareness as measured by a discrepancy score between participant and informant is a frequent symptom of AD but not MCI. However, their results also indicate that people with MCI demonstrate low awareness. With regard to their discrepancy scores, positive values reflected unawareness whilst negative values implied good awareness. Discrepancy scores were not always negative for people with MCI (median = - 1, range – 19 to 12). This range of scores suggests that level of awareness varies, with some participants showing limited awareness and others reporting significantly more dysfunction than their informants. In this study, SMC were required for the MCI diagnosis, so that people who did not complain of memory dysfunction but did have impairments may have been excluded.

Over-estimation of dysfunction is also found in the samples reported by Farias et al (2005), Tabert et al (2002) and Okwonkwo et al (2008). Farias et al suggest that people with MCI are fairly accurate in reporting their functional status, as there were few discrepancies between participants and informants. However, they acknowledge that informant- and participant-reported functional change becomes more discrepant in dementia and notes that their community sample may have shown less functional change than would be found in a clinical sample (e.g. Tabert et al, 2002). Despite using different measures of functional ability, both studies found that the MCI group over-reported functional change compared to informants. Okwonkwo et al found that those who over-reported dysfunction in financial ability when compared to results from an objective measure of performance had higher level of depressive symptoms.

Although it is difficult to generalise given the incomparability across studies, there is evidence to suggest that awareness in MCI is individually variable with some suggestion that a proportion of people with MCI may tend on average to over-estimate dysfunction. This apparent over-estimation of dysfunction may be as a result of disparity between participant and informant, where the informant does not acknowledge the participants difficulties, or the participant may be influenced by factors other than awareness when faced with an objective measure. This warrants further investigation in order to establish the factors involved in these inaccurate judgments and how these factors influence the elicited awareness phenomenon.

Evidence for low awareness as a predictor variable in conversion to dementia

Only one study directly considered the role of awareness in progression from MCI to dementia. Tabert et al (2002) found strong evidence to support the view that low awareness of functional deficits in MCI predicts future dementia. Specifically, under-reporting of functional deficits compared to informant reports strongly predicted future progression to dementia. Tabert and colleagues evaluated 107 participants with MCI at baseline, 23 of whom were incident dementia cases at follow up (mean duration 24.5 months, SD 14.3 months). Informants for those who converted to dementia reported greater deficits than informants for those who did not.

Not every person with a diagnosis of MCI will convert to dementia, but for those who do, the decline in functional ability would occur at the point of progression. Indeed, it is the lack of functional deficits which is often a key discriminator in the decision to assign an MCI rather than dementia diagnosis. Tabert and colleagues identified two groups of MCI participants, those with a Clinical Dementia Rating (CDR; Hughes, Berg, Danziger, Coben & Martin, 1982) status of 0 (n=39) and those with a CDR status of 0.5 (n=53). The higher CDR rating would be thought of by many as moving into questionable dementia territory, and thus one would expect a higher rate of progression. It is unclear however whether participants with higher CDR ratings were more likely to have converted. Petersen (1999) highlights the difficulty with the heterogeneity of a 0.5 CDR rating, and suggests that those falling into this category that remain within the MCI classification would have significant memory impairment but retain fairly normal cognition in other areas and only be slightly affected in activities of daily living. Petersen suggests that those with functional impairment would be distinguishable to clinicians as having AD.

Findings regarding the role of low awareness in progression from MCI to dementia are limited to one study, where the object of awareness is functional ability. The issue here is the demarcation between an MCI diagnosis and probable dementia. If an individual with MCI is to progress to dementia, decline in functional ability will occur at some point along the continuum of the disease. However, it is also probable that many of those with an MCI diagnosis may have some degree of functional difficulty (Farias et al, 2005; Tabert et al, 2002), which may or may not be as a result of cognitive impairment. The findings of the Tabert study should not be discounted on this basis alone. Indeed, this study highlights the importance of examining whether low levels of awareness in MCI do predict future conversion to dementia and should be the focus of future research in the field.

Discussion

The overall questions of this review were firstly whether level of awareness varies among people diagnosed with MCI, and secondly whether low levels of awareness in people with MCI predict conversion to dementia. This review has found strong evidence for variability in level of awareness among individuals with MCI. The included studies indicated that some individuals with MCI have limited awareness. There was also evidence to show that some individuals overestimate their dysfunction, which can be viewed as reflecting heightened or even hyper-awareness. Such over-estimation of deficits can also be found in people with AD (e.g.Michon, Deweer, Pillon, Agid & Dubois, 1994). As regards the role of awareness as a predictor of progression, however, there is an absence of evidence. Although Tabert et al (2002) found that unawareness of functional deficit predicted future progression to dementia, methodological issues may have affected the reliability of this finding, and further studies are required in this area. The fact that level of awareness in MCI has been found to vary in this review supports the idea that its role in the progression from MCI to dementia should be explored further. Future studies would need to examine the profile of awareness in MCI that is most indicative of progression to dementia.

The conclusions that can be drawn from the present review are limited given the lack of comparability between the included studies. A range of theoretical foundations underpinning the study of awareness are reflected in the range of terms used and the contradictory explanations offered. The broad nature and complexity of awareness is acknowledged by some although not by all. SMC when compared to some kind of standard such as objective testing reflects the accuracy of complaint and is therefore a measure of awareness, but excludes those who may have memory problems but who are not aware. Future research should consider focussing on awareness level rather than SMC in order to address this issue. It is clear that further work is required on the theoretical conceptualisation of awareness in order to ensure the comparability of future work.

The choice of the object of awareness to be assessed influences the nature of the awareness phenomenon elicited. The ‘objects’ chosen by the studies in this review include both cognitive domains, for example, memory or cognitive dysfunction, and behavioural domains, for example, apathy or everyday functional abilities. Affective states can be problematic when considering awareness. Apathy and awareness are linked in that expressions of awareness will be influenced by symptoms of apathy and the demarcation between the two should be considered when interpreting results. This also highlights the issue of the neurological and psychological interplay within expressions of awareness. Although the complexity of the concept of awareness is acknowledged in some studies, little consideration is given to how this relates to the awareness phenomena elicited in the studies included in this review.

Issues relating to the measurement of awareness in MCI are similar to those discussed in the dementia literature and future research should seek to address these issues through the development of new methods. These could include taking account of participant and informant factors which influence results, the use of isomorphic rating scales with objective tasks, and the use of familiar situations when examining functional ability. Studies could be improved with clearer descriptions of sample characteristics and selection procedure and additional approaches could be considered when examining awareness (Clare, 2004a). Given that MCI may precede the onset of dementia, there is a need for homogeneity of research methods when examining factors relative to both conditions.

Affective states can be problematic when considering awareness. Depression is common in people with MCI (Apostolova & Cummings, 2008). Kumar, Jorm, Parslow and Sachdev (2006) found depression to be a predictor of MCI with motivation related symptoms being significant predictors. Kumar et al suggest that depression may mistakenly be diagnosed in those exhibiting symptoms of apathy. If unmotivated, subjective opinion may well be compromised and the relationship between SMC and depression should therefore be considered. Schmand, Jonker, Geerlings and Lindeboom (1997) found that the relationship between SMC and depression is reciprocal, where one would expect an increase in complaints about memory as a result of depression and where recognition of failing memory could lead to depression. This has implications for the study of awareness, as expressions of awareness may well be influenced by depression. This could account for over-reporting of functional difficulty as compared to objective testing or informant report which is evident in some of the studies included in this review. The presence of depression will enhance negative attributions, thus making the memory problems seem worse than they are.

It is also important to consider the psychological impact of living with MCI rather than having a diagnosis of dementia. Awareness is likely to be affected by psychological factors as well as neurological causes, since receiving such a diagnosis may directly impact on the individual’s expression of awareness. Lingler (2006) studied the impact of living with MCI over a six month period, using a grounded theory approach. Emotional reactions included distress and anger, relief at the absence of a dementia diagnosis, satisfaction at having the cognitive impairment objectively verified and acceptance of the condition. The authors acknowledge the potential role of awareness in accounting for why some individuals did not acknowledge the possibility that MCI could progress to dementia, while others believed MCI would inevitably result in dementia. The label of MCI is vague and does not indicate to the person receiving the diagnosing whether it is a disease entity or part of normal aging (Corner & Bond, 2006). The effect of a MCI diagnosis on the individual requires further exploration, given that the term MCI is not known to many (Dale, Hougham, Hill and Sachs, 2006) and lack of information accompanying the diagnosis may impact on coping responses (Banningh, Vernooij-Dassen, Rikkert, Teunisse, 2008). This could lead to expressions of unawareness which result from confusion about MCI rather than from a person's appraisal of their memory.

Alongside the complexity surrounding the study of awareness, there are also complex issues relating to the construct of MCI. This is demonstrated by the range of diagnostic criteria adopted by studies in this review. Although the diagnostic criteria proposed by Petersen (1999; 2000) dominate, there are differences in the use of these criteria, highlighting issues relating to interpretation. Alladi, Arnold, Mitchell, Nestor and Hodges (2006) examined the applicability of research criteria for MCI in a memory clinic population and concluded that MCI case definition is highly dependent upon the neuropsychological tests used and parameters applied. Thompson and Hodges (2002) conclude that MCI is a clinically useful concept, but identify three areas which require clarification in research settings:

1. Consistency of tests used to identify memory impairment and the threshold used.

2. The exclusion of non-amnestic deficits in some cases.
3. The need for better methods of assessing functional impairment and clarification as to the nature of functional impairment in MCI.

These issues contribute to the lack of comparability across studies in this review

Conclusions

This review has demonstrated that level of awareness varies amongst individuals diagnosed with MCI. Further work is required to determine whether low awareness is predictive of future progression to dementia, given the limited evidence in this area. There is some acknowledgment in the literature of the complexity surrounding the awareness concept, although further clarification is required in this area. In addition to the conceptual and measurement issues already raised, future work could usefully acknowledge both neurological and psychological aspects of awareness. As the construct of MCI may vary, a global set of criteria should be adopted, leading to consistency of diagnosis amongst researchers and clinicians. Such action may lead to better understanding of the nature of SMC and awareness in MCI which could ultimately result in better outcomes for clinicians, researchers and people affected by MCI.

Chapter 3

Study 1: An IPA study of the meta-representational level of awareness in Mild Cognitive Impairment

Abstract

Objectives: Awareness in MCI has been studied primarily from a quantitative perspective which has yielded inconclusive results. A qualitative approach may provide a more in depth profile of awareness in MCI, specifically, at the meta-representational level. Few qualitative studies have considered awareness in MCI therefore the focus here will be on the nature of participant understanding of MCI as a diagnosis, the psychological impact of living with memory difficulties and how awareness of memory difficulties impacts in daily life.

Method: Twenty five participants with a clinical diagnosis of MCI were interviewed. Interpretative phenomenological analysis was used to analyse interview transcripts.

Results: Four higher order themes were identified. An exploratory model is proposed with a dominant theme of ‘Fear and uncertainty’ which underpins ‘Interdependence’, ‘Life goes on as normal’ and ‘Disavowal of difficulty’ which are representative of coping responses resulting from appraisal of memory and cognitive difficulties.

Conclusions: The label of MCI had little meaning for the participants interviewed in this study yet the need for a definitive label to which the acknowledged memory and cognitive difficulties could be attributed is suggested. The themes elicited from participant accounts indicate that the symptoms of MCI are perceived as a threat to psychological wellbeing which results in context specific appraisal.

Mild cognitive impairment (MCI) represents an attempt to identify a discrete state between healthy aging and dementia. Identifying MCI allows the clinician to monitor those at risk of future dementia and the researcher an opportunity to explore factors which may be predictive of future dementia. Around 10-15% of cases will progress to dementia annually, as compared to 1-2% of the healthy older population (Petersen, 2001). The term MCI is unfamiliar to the general public and may not be meaningful to people who are given this diagnosis. (Dale, Houghham, Hill & Sachs, 2006). A lack of knowledge about the term can create uncertainty and can lead to an increase in worry over future dementia, an increase in isolation, or a tendency to under-estimate the significance of further decline (Lingler et al., 2006; McIlvane, Popa, Robinson, Houseweart & Haley, 2008; Moody & Whitehouse, 2004). Clinical assessment and subsequent diagnosis can result in one of two outcomes; the uncertainty faced by PwMCI can be resolved or result in unresolved questions relating to what the symptoms of MCI actually represents (Koppel & Dallos, 2007). Possible reasons for these negative outcomes following clinical assessment could be the lack of significance attributed to difficulties arising from MCI, the person with MCI forgetting information provided at assessment or insufficient feedback at the time of diagnosis.

MCI is a heterogeneous condition which can affect not only memory (amnestic form) but also other cognitive domains (multiple domain MCI; single non-memory domain MCI; Petersen, 2004). Subjective memory complaint (SMC) is central to the diagnostic criteria for amnestic and multiple domain MCI and requires an appraisal of memory functioning.   The ability to accurately appraise one’s own situation, performance or functioning in a given domain is described as having awareness (Clare, 2007). Petersen (1999, 2001) included in diagnostic criteria for

MCI the desirability of informant corroboration of SMC, which implies that there may not always be an accurate appraisal of memory functioning. This could indicate a lack of awareness on the part of people with MCI (PwMCI). A review exploring awareness in PwMCI (Roberts, Clare & Woods, 2009) found that PwMCI vary in the extent to which they acknowledge awareness of difficulties across cognitive and functional domains in comparison to informant report or objective testing. A lack of awareness could therefore lead to less information seeking during clinical assessment leading to uncertainty and less significance attributed to memory difficulties.

Awareness can relate to internal states such as symptoms or external stimuli such as changes in functioning or interactions with family. Therefore, awareness is assessed in relation to a given object (Markova & Berrios, 2001) and this object determines the nature of the awareness phenomenon. Expressions of awareness occur at different levels; (1) from a basic state of sensory registration which involves the ability to attend to an object; (2) a higher level of performance monitoring with the ability to identify errors; (3) a more complex level of evaluative judgment towards symptoms, changes or impairment and; (4) the most complex level of meta-representation which encompasses aspects of self-identity and the environment (Clare, Markova, Roth & Morris, in press). More recent literature acknowledges the role of biopsychosocial factors in expressed and elicited awareness in neurodegenerative conditions such as dementia (Clare et al., 2010) which encompasses the role of social, behavioural and psychological elements in ill health (Engel, 1977). As the nature of cognitive impairment will be milder in PwMCI it is crucial to consider the social and psychological effect of MCI and how this impacts on expressions of awareness in order to fully capture the complex nature of the awareness phenomenon.

Conclusions as to the nature of awareness in PwMCI from a quantitative perspective remain inconclusive as a result of methodological and conceptual differences across studies (Roberts et al, 2009). It is also possible that quantitative measures do not capture certain levels of the awareness phenomenon; specifically the meta-representational level of living with MCI, which could account for the variable results in these studies. Limited attention has been given to the meta-representational level of awareness which involves the personal implications of being diagnosed and living with MCI. Only two studies were identified which considered the awareness of PwMCI when exploring the experience of MCI from a qualitative perspective. It should also be noted that the observations of awareness in these studies were not an intended aim; the authors refer to awareness as an adjunct to the main focus of the study. Frank et al. (2006) describe a lack of help-seeking behaviour in PwMCI as a manifestation of poor awareness; some PwMCI only sought professional help following prompting by relatives. Lingler et al (2006) suggest that a lack of pre-diagnostic awareness of cognitive changes results in neutral reactions from PwMCI following diagnosis. Given that there is such limited research into how PwMCI reflect on their situation and changes, and how this impacts on their self-identity or with interactions with others, this study will focus on the meta-representational level of awareness in MCI.

In considering the most appropriate method to explore meta-representational expressions of awareness for PwMCI, the method used will be interpretative phenomenological analysis (IPA; Smith, Flowers & Larkin, 2009). It is a process oriented method which is inductive in nature and focussed on the interpretation of meaning made by individuals. Awareness at a meta-representational level occurs as a reflection on one’s situation and consideration of changes experienced as well as consideration of the perspective of others, thus it is the experience of living with MCI which is of interest here. IPA explores individuals' perceptions of what they are experiencing (phenomenological) and acknowledges the role of the researcher in placing his/her own understanding of the meanings expressed in participant accounts into the analysis (interpretative).

In summary, PwMCI respond to the experience of memory difficulties in different ways and the way in which they do so will be influenced primarily by the way in which they are aware of their memory difficulties. Focus has been on performance monitoring and evaluative judgments in quantitative studies of awareness in people with MCI. This may exclude the more complex level of meta-representation, which can provide an awareness profile which incorporates self-perspective. At this level of awareness the objects of awareness under consideration will be internal in terms of appraisal of symptoms and external in terms of difficulties with functioning and relationships with others. In the absence of qualitative research directly exploring the awareness phenomenon in PwMCI, the current study will focus on the following research questions:

1. What is the nature of participants' understanding of MCI as a diagnosis and its implications with regard to the risk of developing dementia?
2. What is the psychological impact of living with MCI and how do PwMCI cope with this?
3. How do participants appraise their memory difficulties and how does this influence their experience of the condition, their understanding of the condition and the way in which they cope?

Method

This qualitative interview study forms part of a wider investigation of awareness in MCI, the Memory Impairment and Dementia Awareness Study (MIDAS). MIDAS is a longitudinal study of awareness in people with MCI and early-stage dementia, with MCI participants assessed on entry and again 12 months later. The interview data reported here were collected at initial assessment. Ethical approval was granted by the relevant University and NHS ethics committees.

Participants

Participants were recruited from across 4 specialist Memory Clinics in North Wales. Clinical staff identified potential participants who would be willing to take part in research and had received a diagnosis of MCI based on the Petersen (2001) criteria. Memory clinic records were examined in order to ensure that participants met study criteria. Inclusion was dependent on a clinical diagnosis of MCI and the ability to communicate verbally in English. Exclusion criteria for the PwMCI were the presence of major depressive disorder or a current or past history of psychosis or other neurological disorder, stroke or brain injury. The participants, 16 men and 9 women, had a mean age of 76years (SD 9.15 range 60 – 97 years). They all lived in their own homes and were of white European origin.

Procedure

Participants were interviewed either at home or at the University depending on participant preference. Of the 25 participants who took part in this study, one chose to be seen at the University. The digitally recorded interviews were later transcribed by the interviewer. Interviews followed a semi-structured format, and lasted between 11 and 30 minutes. If no changes were acknowledged the interview was typically shorter than if changes were acknowledged. Each participant gave consent at the beginning of the interview and were made aware that should they wish to stop recording at any point, they could do so. The aim of the interview was to elicit the participants' understanding of their condition. The term 'mild cognitive impairment' was not used at any point unless introduced by the participant.

The interview process (see appendix E for the interview schedule) began with an introductory conversation covering topics such as how the participant felt that day, what they did on a typical day, how life had changed for them since they had become older, their family and/or where they were from. The interview then addressed their current situation and functioning with a focus on any changes they had noticed in their memory, thinking, activities, interests, interactions and relationships. If the participant spoke of changes, s/he was asked to what they attributed these changes or how they would explain them. If the participant did not refer to any changes, the interviewer focused on daily life and activities. Following a conversation about changes, questions were then asked about what led the participant to the memory clinic, what happened at the memory clinic, and what s/he was told. If the participant spoke directly about the diagnosis of MCI, the interviewer asked about what this meant to the participant, how it had affected them and the implication of this diagnosis for the future. If no mention of MCI was made, the interview proceeded to questions about how they felt about any identified changes or, if no changes were acknowledged, whether they felt that they were the same person. If changes were acknowledged, questions were asked about how they deal with the situation, what information they had been given and what information they felt they needed. At this stage of the interview, the participant would be asked whether family and friends had noticed any changes and about the effects these reactions had on them. Finally, the conversation turned to what the participant felt about the future. The interview was ended on a positive note. The participants were told that should they wish to discuss any issue further, they could contact the interviewer.

Data analysis

The interviews were transcribed and analysed using IPA (Smith et al, 2009). This process began with an analysis of each individual interview, which involved reading and re-reading the transcript and making key notes in the right margin, relating to what the participant was conveying and remaining close to the participants own words. Additional memos relevant to the aim of the study were also noted at this time. The margin notes were then listed and grouped into themes, which were made up of clusters of margin notes. Theme headings stayed close to the participants’ own words. Themes were noted on the interview transcript which ensured that every instance of the theme had been identified. A final summary list of themes was then made. See appendix F for a list of themes from an individual transcript.

Once transcripts had been analysed individually, analysis moved to the group level. Theme summaries for each interview were grouped together, arriving at an overall list. These overall themes were grouped, with an emphasis on similarities and differences. Themes which did not appear on at least two thirds of the interviews were dropped. Each transcript was coded with the overall themes, to ensure that they were of good fit. A full list of extracts relating to each theme was then completed (see appendix G for a list of extracts relating to one theme). In order to support the validity of the analysis and interpretation, the data and analyses were scrutinised at each stage by two researchers working independently. Consensus was reached through discussion in areas of disagreement, which resulted in minor changes. Reflexivity was integral to the analysis in order to acknowledge any pre-conceived ideas or beliefs held by the researcher which may influence the outcome (Brocki & Wearden, 2006).

Results

Analysis identified four higher-order themes which encapsulate the experience of living with MCI and how this interacts with expressed awareness of difficulties. Higher-order themes which emerged from the analysis were ‘Interdependence’ ‘Life goes on as normal’, ‘Disavowal of difficulty’ and ‘Fear and uncertainty’. All participants had statements relating to each of these higher-order themes, with some individual interviews having extracts relating to them all (see appendix H).

Interdependence

This theme reflects how participants appraised their memory or cognitive difficulties in relation to their perceived support network. The context in which participants lived shaped their responses to questions about their memory and everyday functioning. Participants demonstrated a withholding of explicit acknowledgment of difficulty in certain social situations which was dependent upon their living situation. For those living alone, retaining their sense of independence appeared extremely important, especially in light of changes to memory and the possible perceived risk of that independence being taken away. Betty was keen to demonstrate that she was more than capable of living alone and preferred it that way:

Betty (70yrs) *“I do loads of stuff like that* (travelling abroad) *and I like doing it by myself.*

Those participants who had support available displayed sensitivity to how others perceived them in light of their difficulties, especially in social situations. Their apparent reluctance to acknowledge memory difficulties to others resulted in a masking of those difficulties when in company, demonstrating the negative attributions they associated with such difficulties. Jerry relied on his wife to remind him of people's names when out in the community rather than his difficulty with people's names being explicitly acknowledged in conversation:

Jerry (70yrs) *"…there was a man and I knew the way he was looking at me that he knew me. I couldn't work out who he was so I asked* (wife) *quietly.*

Jack spoke of the embarrassment resulting from forgetting names when he met people socially:

Jack (77 years) *"Well my relationships with other people, er, again that's loss of memory. Er I have great difficulty remembering names and putting a person to a name, you know my memory just won't hold the names and I find that very, very difficult like, you know".*

Negative attributions regarding memory difficulties were also perceived by PwMCI in those closest to them. In the following extract it appears that Joan felt that there would be little support from her husband should she talk about her difficulties. Joan explains why she feels her husband does not want to know. It is interesting to note her reference to Alzheimer's in the latter stages and that this frightens her husband; this may reflect her own feelings towards the subject:

Joan (79yrs) *"probably not because the changes are all in my head you see and I don't talk to him about it because what's the point"* …………………… "*His way of dealing with it* (husband) *is to ignore it completely, he doesn't want to know but you see he only knows about Alzheimer's from people in the latter stages….and I think that frightens him".*

This higher-order theme represents the impact of relationships with others on expressions of awareness of memory and functional difficulties. Participants who lived alone strove to retain their independence, suggesting that they are fearful of losing autonomy in light of their memory difficulties. For those participants who live with a significant other, the masking of difficulties in social situations or within a marriage as a response to self-generated negative attributions or the negative attributions of others is evident.

Life goes on as normal

In this theme, participants' perceptions of memory difficulties, and the subsequent assessment of the symptoms of MCI, are expressed as a normal part of aging. Betty demonstrates this expectation by attributing the symptoms of MCI to her age. It is also notable that in her attempt to normalise her memory difficulty, the use of the word 'submitting' is suggestive of her perceiving memory difficulties as something which should be fought:

Betty (70yrs) *"not quite submitting to the fact that my, that my memory is absolutely defunct, I'm seventy so expect a deterioration you know……I view it in the context* *mainly, in the interest of the that context, as you get older your brain isn't dancing about so much and you've got to stop and think"*

References to forgetting were made within all interviews but some participants did not acknowledge global changes in memory, as shown by Thomas:

Thomas (78yrs) *"Yesterday I noticed something and I can't remember what the hell it was now*..(Later in the transcript)..*Well nothing has changed actually" (referring to a question about changes in memory).*

Visits to the memory clinic were predominantly seen as routine, with some apparent confusion shown by some participants as to why the assessment took place. This could reflect lapses in memory concerning the memory clinic visit or could demonstrate the lack of information given at the time of referral and during the memory clinic assessment. Equally, this could reflect a choice to appraise the situation in a way which would minimise the psychological impact resulting from acknowledging the need for and subsequent outcome of assessment at a memory clinic. Alice appeared ambivalent towards her visit to the memory clinic and had perceived the event as resulting in a positive outcome, indicating that everything was all right, despite being clinically assessed as having MCI:

Alice (88yrs) *"I didn't even know there was such a thing (memory clinic). Erm, it must have been one of these routine check-ups for something, you know…*(later on in the transcript, when describing what happened at the memory clinic) *..interview's* *done, like you were here and she said, "Oh , oh, you better go home", she said, "There's no point in me seeing you", she said".*

In some instances, direct reference was made to the lack of information supplied at the time of the memory clinic assessment. Shirley blamed herself for not asking what the outcome of assessment could mean for her. This could be interpreted as an avoidance of information at the time of assessment, information which Shirley might have perceived as impacting on her psychological wellbeing:

Shirley (64yrs) *"It's my fault, I never asked, I said nobody's actually explained"* (when asked about the memory clinic assessment outcome).

Although this higher-order theme represents some acknowledgment of difficulty, the nature and impact of those difficulties are diminished by participants choosing to evaluate them as a normal part of aging.

Disavowal

The term disavowal reflects the participants' explicit and implicit attempts at disassociating memory difficulties from negative outcomes, whether emotional or tangible. Rather than seeking to normalise the situation, as seen in the theme 'life goes on as normal', the acknowledgment of impact and/or the presence of the memory difficulty is implicit in participant accounts for this theme, yet the presence of memory difficulty is either diminished or denied. David appears to acknowledge memory difficulties, yet diminishes their impact. His extract suggests that memory difficulty is something which has to be accepted; implicitly emphasising the impact and threat yet explicitly stating that it is acceptable:

David (77years) *"Well you've got to – you've got to accept it. You can't fight it, th-n- there's nothing you can do about it. You just gotta accept that it's happened and it's happened and that's it innit."*

Humour is used by some interviewees to divert the conversation from serious, possibly upsetting occurrences in participants' lives, as demonstrated by Charles when responding to a question relating to a situation where he was lost, which had prompted his referral to the memory clinic:

Charles (81years) *"I can't really remember it, you see about having a bad memory, you don't remember the bad things (laughs)."*

The use of humour in the following extract deflects the interviewer from the fact that Nancy is actually upset at having memory difficulties. Nancy clearly states that living with memory difficulties is upsetting yet in couching such a statement in laughter, deflects further discussion of the topic:

Nancy (85 years) *"It's no use being upset is it (laughs)."*

Patricia acknowledged that she would occasionally miss something, but related this to her busy life. When asked why she was assessed at the memory clinic, she attributed this to her son, who she felt was overly concerned with her well-being and who was instrumental in the initial referral to the memory clinic. Objective testing had demonstrated that Patricia had memory difficulties consistent with a diagnosis of MCI. However, she did not acknowledge the presence of any memory difficulty during the interview.

Patricia *"I don't know, he- he (son) just seemed to think that my memory wasn't good and..as I've said before you- you- when you've got everything to do you can't help it if you occasionally miss something a bit, you know, and I don't, you know...I see to everything that has to be seen to and I keep my appointments and such like, you know."*

Rather than directly acknowledge any limitations resulting from MCI, Roger implies that it is his wife who will not let him drive outside the immediate locality.

Roger (86 years) *"Oh I do drive, but my wife won't let me drive very far."*

Central to the higher-order theme of disavowal is the disconnection between the memory difficulty and impact on daily life. Roger demonstrates this by implying that it is his wife who limits his activities, not the impact of MCI. It is unclear whether or not the use of strategies such as humour, minimising the impact of memory difficulties and placing the responsibility of limited activities on others is conscious or not. What is does suggest is that there is at some level at least an awareness of change.

Fear and uncertainty

Extracts relating to the theme of fear and uncertainty dominated the analysis, and this appears to be central to the overall experience of people living with MCI. Whereas the other themes appear to reflect coping efforts in light of memory and functional difficulties, extracts which demonstrate the theme of fear and uncertainty are suggestive of a perceived threat to psychological wellbeing. In appraising the memory difficulty, it appears that there is a dynamic process where the individual moves between active coping efforts which are demonstrated by the themes of ‘Interdependence’, ‘Life goes on as normal’ and ‘Disavowing of difficulty’ which are in response to the experience of ‘Fear and uncertainty. The acknowledgment of possible risk of future dementia and present limitations resulting from memory difficulties appears to underpin active coping efforts. Such acknowledged limitations affect activities such as reading, as expressed by Jack:

Jack (77 years) *“I get trouble reading it and what actually happens I’ll read a line and then go to the next line, the trouble is when I go to the next line, I’ve missed a line and I go back on the line I’ve already read”.*

Throughout the interviews the term MCI was not adopted by any of the participants. Whether or not this reflects the level of information provided at diagnosis, or a lack of knowledge surrounding the MCI term, the absence of a label seemed to increase the uncertainty. Although some participants opposed the use of a label, the fact that they acknowledged the issue highlights that they believed there to be something which needed a label, demonstrated by the following comment made by Betty.

Betty (70 years) *"…because I think you can't live just under a label, there's other, surrounding, you can have a label, can't you, you know, but it, that isn't the whole thing, it needs context".*

Regardless of the absence of a known label, participants knew there was something wrong and strived to place some meaningful framework on what they were experiencing, as shown in the following extract from Joan.

Joan (79 years) *"…sometimes things would get muddled in my brain and the only way I can explain it is..er..take a ball of wool or a ball of string, you know, the ball of string and you can just pull the string along an it just unravels, however, er supposing that was my brain, instead of the ball of string just unravelling, it'd all be completely knotted up and it wouldn't unravel it was all in a big tangle".*

Although some participants feared receiving a definitive label, others wanted to know why they were having memory difficulties, as was the case for Shirley:

Shirley (64 years) *"I always think well there's got to be a cause for something, why is my memory going?"*

Some participants also felt that others viewed them unfavourably as a result of their memory difficulties. Paul, although in good humour, spoke of limits to activities involving other people and how the impact of memory difficulties affects his relationship with friends. His terminology of 'going round the bend' suggests that he views his memory difficulty as negative and as something to be feared:

Paul (71 years) *"…because a lot of people put two, two together say, oh he's going round the bend he is, you what I mean (laughs) you know what I mean so people so I-I-I just don't go down that road no more*

Participants also felt that they were different people and that they couldn't be relied upon in the way that they once were. Rather than seeing themselves as having memory difficulties resulting in unreliability, they saw themselves as unreliable, as demonstrated by Evelyn:

Evelyn (97 years) *"Do you know, I don't know uh…it's not long..not eh…(sigh) if I say something it could not be true".*

Not only do the limitations of living with MCI cause uncertainty in the absence of a definitive label or knowledge about the condition, but also there is a fear that the memory and cognitive difficulties highlight the beginning of dementia. This is further influenced by having seen others with dementia such as family or friends, or depictions in the media. Harold fears dementia following media representations of the disease:

Harold (65 years) *"…the programmes on the television about men or women who's had it (Alzheimer's) and their partners are looking after them and the things that happens..because they've got it..well that's…something I wouldn't like…to be".*

Within this higher-order theme there was a sense of trying to cope. Rather than perceiving that life goes on as normal or disavowing the memory difficulty, participants in this instance appeared to be covering up their sense of fear. Nancy lived alone and was supported by her son.

Nancy (85 years) *"No I've just got to manage best I can and (son) is very good to me, you know".*

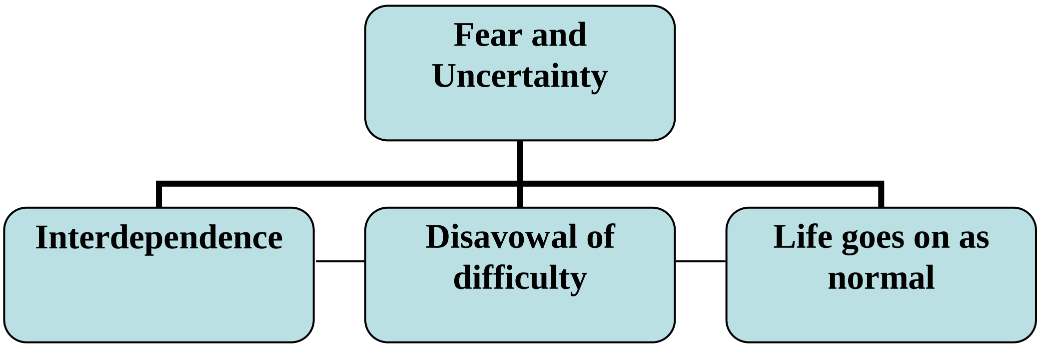
Jack also felt that his current situation was one that he had to cope with. These statements suggest that living with MCI is a burden to these particular participants.

Jack (77 years) *"To me it's living with it and, er, trying as best I can to cope with it like, you know".*

An exploratory model

The themes elicited from this analysis suggest that participants are fearful and uncertain about MCI symptoms which are appraised as a threat to psychological well-being resulting in context-specific coping responses. Figure 3.1 is an exploratory model, demonstrating how the higher-order themes of 'Interdependence', 'Life goes on as normal' and 'Disavowal of difficulty' which represent forms of context-specific coping responses resulting from the dominant theme of 'Fear and uncertainty' which underpins appraisal of memory and cognitive difficulties. The coping response themes are not distinct and represent context specific areas which demonstrate the variations in expressed awareness of difficulties.

Figure 3.1 An exploratory model of the experience of living with MCI



Discussion

The current study aimed to explore the nature of participants' understanding of MCI as a diagnosis, the psychological impact of MCI and how PwMCI appraise their memory and cognitive difficulties. The results show that there was some awareness shown by each participant at a meta-representational level. The experience of MCI results in active context-specific coping efforts upon which the expression of awareness is dependent, whether in relation to self or others.

In the current study, according to available memory clinic records, the diagnosis of MCI was disclosed following assessment at the memory clinic, yet no participants used the term MCI. Only 1 of 11 participants used the term MCI in the Lingler et al (2006) study. The authors conclude that this is possibly a result of a failure to own, reflect or identify with the condition, which confirms the lack of knowledge surrounding this concept; it is not possible to own, reflect or identify with something that we have no knowledge of. The ability to own, reflect or identify with the concept could also depend on how PwMCI appraise their condition and whether the presence of a label has any impact on this. The utility of a label such as MCI within a clinical setting raises ethical issues such as the possible distress of the individual or family on being told the diagnosis and subsequent stigmatization (Werner & Korczyn, 2008). Various arguments are put forward for and against the disclosure of MCI as a diagnosis. Dale, Hougham, Hill and Sachs (2006) studied the willingness of participants (*n* = 149) over the age of 35 (71% ≥ 65 years) to be screened and treated for MCI following information about the condition. The authors found their participants to have a strong interest in the screening and subsequent treatment of MCI, yet raised issues of caution with regard to the effects of 'labelling'.

Although it was noted in the clinical record for each participant that the diagnosis of MCI had been disclosed, it was unclear as to the nature and content of what was said to the individual at the time of diagnostic feedback. This has certain implications when considering the lived experience of MCI as what PwMCI have been told will influence their understanding of their memory and/or cognitive difficulties. Although the information about MCI given may include a comprehensive account of the condition, the perception of the individual will be influenced by their memory and/or cognitive difficulty in addition to their mood state at that time. It is also necessary to consider whether PwMCI have received the feedback in the presence of family or someone close to them in order to consider the impact these interpersonal relationships will have on expressed awareness. The current study found that the label of MCI in itself had little meaning to the participants interviewed. However, participants did express a wish for a definitive label to which they could attribute their acknowledged difficulties. It would appear that the label of MCI in its current form does not fulfil this need. With regard to future risk of dementia, this was referred to under the theme of 'fear and uncertainty' yet it was related to familial knowledge or media representations and rose from difficulties with memory rather than the diagnostic label of MCI.

All the themes in the current study suggest that PwMCI perceive the symptoms of MCI as a threat to psychological wellbeing, whether implicitly or explicitly, and three of the themes involve active coping strategies (interdependence, life goes on as normal and disavowal of difficulty) in response to the perceived threat. Coolidge, Segal, Hook and Stewart (2000) found that dysfunctional strategies such as mental and behavioural disengagement were more likely to be relied upon by anxious rather than non-anxious older adults. Given the ambiguity of the MCI concept, and the presence of fear and uncertainty in participant accounts, the theme of 'Disavowal of difficulty' supports the findings of Coolidge and colleagues. In a study of PwMCI and their care partners, McIlvane, Popa, Robinson, Houseweart and Haley (2008) found that dysfunctional coping strategies which include behavioural disengagement and denial were used to a lesser extent than emotion-focussed and problem-focussed coping strategies. In contrast, the current study found that 'Disavowal of difficulty', which could be deemed a dysfunctional coping strategy, was predominant. This difference could be attributed to the contrasting methodology, since McIlvane and colleagues adopted a questionnaire-based study where coping responses were defined for the participants prior to eliciting their responses. In the current study, the nature of coping responses was elicited naturally using phenomenological methods where there were no assumptions about what those coping responses would be.

When talking of relationships with others, participants' responses reflected the context in which they live which appeared to influence their expression of difficulty to the researcher and to people they know in social situations. Where continued independence is the primary aim of PwMCI who live alone, an emphasis is put on evidence suggesting that they do not need or wish for the support of others. From a phenomenological view, this suggests that their difficulties do not impact on their functional abilities. However, in interpreting this stance, the avoidance of overtly acknowledging memory or cognitive difficulties for fear of losing their independence could demonstrate a lack of awareness attributable to this fear rather than a lack of awareness resulting from a cognitive impairment. If support is available, a more explicit negative appraisal is elicited which features overt references to embarrassment in social situations. Social networks are considered central to wellbeing in older adults, where a diversity of networks, not restricted to marriage, has been found to be beneficial (Fiori, Smith & Antonucci, 2007). It would appear that where close familial support is available the negative appraisal of difficulty is more apparent, which may restrict social networks through reliance on significant others. A study by Blieszner and Roberto (2010) found an increase in depressive symptoms in care partners of people with MCI as well as distress at behavioural changes attributable to MCI which are consistent with the findings of the current study. It is therefore important for clinicians and researchers to consider the context in which PwMCI live and how this may influence appraisal of difficulty in PwMCI and the impact that MCI has on significant others.

This study adds to the current literature on awareness in MCI by focussing on one aspect of the framework of awareness (Clare, Markova, Roth & Morris, in press), specifically the meta-representational level of awareness. In considering awareness at a this level, the results of the current study show that appraisal of memory or cognitive difficulty shape the coping responses adopted and thus influence the awareness phenomenon elicited. This is further influenced by the nature and content of diagnostic information conveyed to the individual and how the memory and/or cognitive difficulty in addition to mood impacts on the individuals understanding of the diagnostic information conveyed. This has important implications for clinical assessments which rely on self-reported memory or cognitive difficulty as well as the importance of how and when the diagnosis of MCI is explained to the individual by clinicians. Although cognitive neuropsychological models of awareness (e.g. Agnew and Morris, 1998) provide some explanation as to the way in which PwMCI appraise their difficulties, the current study demonstrates a complex interplay between social and psychological factors which mediate expressions of awareness. The current study also demonstrates the interplay between internal and external objects of awareness (Markova & Berrios, 2001) across the elicited themes (talking about symptoms and interpersonal relationships). The profile of awareness at a meta-representational level is therefore a multi-dimensional construct which is influenced by a range of factors.

The advantage of the current study was the depth of analysis and understanding of the lived experience of MCI through IPA. This provided a phenomenological account of the experience of MCI as well as the opportunity to interpret participant responses which were elicited in a manner free from the influence of prior assumptions. The current study was conducted thoroughly and systematically with each stage of analysis being validated by a second researcher who was not involved in interviewing participants. Central to IPA is the acknowledgement that the researcher is subject to his/her own assumptions and views which could influence their interpretation of participant accounts which would influence the reported results. In acknowledging prior assumptions the researcher is attempting to remain as objective as possible in the interpretation of participant accounts (Yardley, 2000). For the purpose of the current study, reflexivity was achieved through keeping reflective notes and by discussing interpretative ideas at each stage of the analysis with a second researcher who was not involved in interviewing participants. In doing so, any assumptions and views could be made explicit with appropriate adjustment made to the analysis as necessary.

A limitation of this study is the short length of some interviews, although as the number of participants is considered large (*n* = 25) for an IPA study, it is felt that sufficient data contributed to the analysis and subsequent findings. A second limitation could be the absence of direct questions about MCI. However, the diagnosis of MCI was disclosed to participants following memory clinic assessment and should the term have been introduced by the participant, the interviewer would have questioned this further. If the interviewer had introduced the term MCI, this may have influenced the participant response and would have been ethically questionable. Thirdly, informant accounts are not included in this study. This would provide further information with regard to perceptions of memory clinic assessment and provide a third person perspective as to the experience of MCI. Although informant experience of MCI has been considered in other studies (Blieszner, Roberto, Wilcox, Barham & Winston, 2007; Blieszner & Roberto, 2010), it would be useful to examine the experience of the individual with MCI from a different standpoint, in the form of triangulation (Cohen & Manion, 1986). The inclusion of informant accounts in the analysis would help to minimise interviewer bias in interpreting the themes and provide supporting evidence to participant accounts. Future studies could also consider the qualitative experience of people living with subjective memory complaints in the community, in order to explore the influence of clinical input.

Conclusions

The current study found the dominant theme of living with MCI to be one of ‘Fear and uncertainty’. Participants implicitly perceived the difficulties of MCI as a threat and adopted context-specific coping strategies which were represented by themes of ‘Interdependence’, ‘Life goes on as normal’ and ‘Disavowal of difficulty’. All participant accounts suggest that there is awareness of memory and cognitive difficulty at a meta-representational level, yet expressed awareness is influenced by a range of factors which may result in a less than accurate appraisal. This has important implications for clinical practice, which relies on subjective accounts of difficulty, in particular everyday functional ability, upon which the demarcation between a diagnosis of dementia and a diagnosis of MCI lies.

Chapter 4

Study 2: A biopsychosocial approach to assessing awareness of memory, everyday activities and social functioning in Mild Cognitive Impairment

Abstract

Objective: It is acknowledged within the literature that awareness can be impaired in MCI which may result in people with MCI not recognising difficulty with cognition, everyday tasks or relationships with others. The aim of this study was to consider awareness in MCI from a biopsychosocial perspective across the domains of memory function, memory performance, functional ability and social functioning as well as to identify which psychosocial and neuropsychological factors best predict discrepancy indices of awareness.

Method: Thirty participants with a clinical diagnosis of MCI were recruited in addition to an informant who knew the participant well. Discrepancy indices of awareness across memory, functional ability and social functioning were calculated. Participants completed a short neuropsychological battery. Participants and informants completed measures of individual psychological and social variables.

Results: The relevance of the biopsychosocial framework is supported. Awareness in MCI is influenced by a range of social and psychological factors as well as neuropsychological factors.

Conclusion: Awareness in MCI is variable across the domains of memory, functional ability and social functioning and each domain is influenced separately by a range of factors. Affective states and quality of relationships are important in considering self- and informant-evaluative ratings.

Awareness can be broadly defined as the ability to accurately appraise one’s own situation or functioning in response to the nature or impact of a health condition such as Alzheimer’s disease (Clare, 2007). The importance of accurate appraisal in the context of clinical phenomena lies in its pivotal role in influencing help-seeking behaviour and in determining appropriated response to intervention. The study of awareness has been prevalent within the dementia literature in recent years, focussing on concepts, models, assessment methods, awareness measures (Clare, 2004; Clare, 2005; Agnew & Morris, 1998) and objects of awareness (Marková & Berrios, 2001). Appraisal of memory functioning has also been considered in relation to age-related cognitive decline associated with normal ageing (Perrig-chiello, Perrig & Stahelin, 2000). Primarily, such research stems from a developmental viewpoint and has focussed on metamemory, the ability to monitor memory ability in performance-related tasks (Perlmutter, 1978). Awareness is therefore relevant to both age-related neurodegenerative conditions and the cognitive decline associated with normal ageing. Consequently it is also highly relevant for the area of uncertainty that lies between normal ageing and dementia, currently conceptualised primarily within the construct of Mild Cognitive Impairment (MCI).

Petersen (1999, 2001) describes MCI as a transitional state between the cognitive changes normally associated with getting older and the onset of early dementia. The primary aim of applying MCI criteria is to identify cases of cognitive decline over and above what would be considered normal for age. Variations exist as to the precise criteria used for identifying MCI in research and clinical practice, although the most prevalent are those specified by Petersen (2001): (a) Memory complaint, preferably qualified by informant report; (b) Intact activities of daily living; (c) Intact general cognitive function; (d) Memory impairment beyond what would be expected for age; and (d) No dementia. It is debated from an ethical standpoint whether MCI as a diagnostic label should be used in clinical practice (Werner & Korczyn, 2008). However, the aim of such a diagnosis is to capture a prodromal stage of dementia which from a clinical perspective can lead to increased support from appropriate services at the earliest stage of cognitive decline (Petersen, 2006).

Petersen (1999, 2001) acknowledges within the MCI diagnostic criteria that subjective memory complaint (SMC) should preferably be corroborated by an informant. This implies that people with MCI (PwMCI) may not be accurate in their appraisal of memory. This inaccurate appraisal may indicate a lack of awareness of difficulties or changes in memory. Although awareness in MCI may be influenced by the neuropsychology of the condition, negative affective states have been associated with SMC in PwMCI (Minett, Da Silva, Ortiz & Bertolucci, 2008; Jorm, Christensen, Korten, Jacomb & Henderson, 2001; Schmand, Jonker, Geerlings & Lindeboom, 1997) which suggests that social and psychological factors are also implicated. The biopsychosocial model, originally proposed by Engel (1977) to encompass the social, psychological and behavioural elements of ill health and described by Clare (2004) in relation to awareness in early-stage Alzheimer's disease is a useful framework against which to place MCI. What is crucial to consider is that some individuals, who meet all aspects of the diagnostic criteria for MCI yet have impaired awareness, may not express SMC and will fail to seek appropriate professional help at the earliest opportunity.

Awareness of memory in PwMCI has been the subject of research into the accuracy of SMC against objective measurement (Cook & Marsiske, 2006; Hanyu, Sakurai & Iwamoto, 2007), metamemory (Marri, Modugno, Iacono, De Vreese &

Neri, 2001; Perrotin, Belleville & Isingrini, 2007) and awareness of memory as part of a wider cognitive function battery (Ries et al., 2007; Crowe et al., 2006). Central to the demarcation between an MCI diagnosis and that of dementia is how functionally able the person is. Awareness of functional ability has received attention in the literature given its pivotal role in dementia diagnosis (Farias, Mungas & Jagust, 2005; Okonkwo et al, 2008; Onor, Trevisiol, Negro & Aguglia, 2006; Tabert et al, 2002). Comparison across these studies of awareness of memory decline and functional ability have proved difficult as a result of conceptual and methodological differences, although there is evidence to suggest that levels of awareness do vary amongst PwMCI in the domains of memory and functional ability (Roberts, Clare & Woods, 2009).

Informants generally report greater deficits in the cognitive and functional ability of PwMCI than PwMCI do themselves, and the accuracy of informant report of PwMCI ability is supported by its association with objective measures (Schinka, 2010). Often, it is a family member who initiates professional help and his/her input in clinical assessment is often used as a measure of a persons' awareness. How the PwMCI presents on a social and emotional level and its subsequent effects on personal relationships is likely to be influenced by social awareness and empathy towards others. Ausén, Edman, Almkvist and Bogdanovic (2009) found that PwMCI were withdrawn and less interested in connecting with others and reported higher level of stress susceptibility when compared to healthy older controls. However, at the time of writing, no studies exploring awareness of social and emotional functioning in PwMCI have been found.

Awareness is a complex phenomenon which is challenging to assess. Issues of measurement have already been discussed within the dementia literature (Clare, 2004) as well as in a review of studies exploring awareness in MCI (Roberts et al., 2009). Markova & Berrios (2001) highlight the importance of defining the object of awareness as this determines the awareness phenomenon which is elicited. Okonkwo, Spitznagel, Alosco & Tremont (2010) examined associations between the results obtained by measuring awareness from different perspectives: clinician rating, participant-informant discrepancy, and participant-test discrepancy. They found that each of these methods captured unique properties of the complex awareness phenomenon, and suggested that clinician rating is preferable in cases of uncertainty. As noted by Clare (2004), limitations exist with each of these methods, such as the subjectivity of clinician rating, the accuracy of informant rating and comparability between subjective and objective rating measures. From a research perspective, a combined approach is therefore indicated, with consideration given to the identified issues pertaining to each method.

In summary, MCI as a diagnostic category aims to capture the prodrome of dementia in order that people can seek appropriate professional help at the earliest opportunity. Evidence suggests that awareness can be impaired in MCI, which may impede PwMCI recognising difficulties with cognition, everyday tasks or relationships with others. The purpose of this study is therefore to provide a comprehensive profile of awareness in MCI within a biopsychosocial framework across different objects of awareness addressing previously noted methodological issues. The specific research questions are:

1. What is the profile of awareness in patients identified as MCI with regard specifically memory functioning, memory performance, functional ability and social functioning?

2. Which psychosocial and neuropsychological factors relate to and best predict discrepancy indices of awareness for each domain?

Method

Design

This study was part of the Memory Impairment and Dementia Awareness Study (MIDAS) which is a longitudinal study of awareness in people with dementia and MCI. This paper presents a cross-sectional analysis of the MCI data at the first time-point, and explores awareness of memory, functional ability and socio-emotional functioning in participants diagnosed with MCI. The relevant NHS and University ethics committees granted approval for the study.

Participants

Participants were recruited across 4 NHS memory clinics in North Wales, UK. Inclusion was dependent on a diagnosis of MCI, a score of 18 or above on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), the ability to communicate verbally in English and the presence of an ‘informant’ who knew the participant well. The informant could be a spouse, child or friend able to communicate verbally in English, with adequate eyesight and hearing and without cognitive impairment as judged by the researcher. Exclusion criteria for the PwMCI were the presence of major depressive disorder or a current or past history of psychosis or other neurological disorder, stroke or brain injury. This information was confirmed by medical records and discussion with the clinicians involved with the participant. Demographic data covering ethnicity, marital status and socio-economic status were recorded along with the use of acetylcholinesterase-inhibiting medication.

Measures

Assessment of awareness

- The Memory Awareness Rating Scale (MARS; Clare, Wilson, Carter, Roth & Hodges, 2002) provides parallel versions for self- and informant evaluated memory ability in everyday tasks and separate postdiciton ratings which can be compared to objective test performance on the Rivermead Behavioural Memory Test (RBMT; Wilson, Cockburn & Baddeley, 2003). The RBMT is an ecologically-valid memory test which assesses performance on analogues of everyday performance such as remembering a name, remembering faces and remembering a short news item. The MARS questionnaire items for self- and informant evaluated memory ability relate to RBMT items. Postdiction ratings which are made immediately after each RBMT task are pro-rated and adjustments made to the weighting of sub-test contributions to the Standardised Profile Score ensuring a corresponding numerical scale.

- Functional Activities Questionnaire (FAQ; Pfeffer, Kurosaki, Harrah, Chance & Filos, 1982) administered to both PwMCI and informants in parallel form provided self- and informant-reported functional ability. Originally a 10 item version consisting of tasks related to shopping, paying bills and cooking a meal, a question relating to telephone use was added for this study.

- Socio-Emotional Questionnaire (SEQ; Bramham, Morris, Hornak & Rolls, 2003) administered in parallel to PwMCI and informants as a measure of empathic reactions to social situations and ability to recognise emotions in self and others.

The parallel forms of the above measures produced discrepancy scores between PwMCI and informants which were corrected for scaling effects by taking the difference between self- and informant scores and dividing this by the mean of the two scores (Clare, Whitaker & Nelis, 2010). This produced a memory functioning difference (MFD) score, a functional activity difference (FAD) score and a socio-emotional functioning difference (SED) score. Scores close to zero indicate good agreement between the PwMCI and informant. Positive scores indicate a higher rating by PwMCI than informants and negative scores indicate a higher informant score than PwMCI.

A memory performance score (MPS) was calculated in order to reflect any discrepancy between objective testing (RBMT) and postdicton self-rating. Ratio scores were calculated to counteract differences in baseline scoring levels (Clare et al, 2010). The calculation of the ratio was dependent on score values not being zero on the MPS and pro-rated RBMT standardised profile score, and therefore a value of 0.5 was added to the individual participant scores of each. The memory performance ratio (MPR) was then calculated by dividing the MPS by the pro-rated RBMT standardised profile score. Ratio scores close to 1 indicate good agreement. Ratio scores above 1 indicate a positive self-rating in comparison to test score and ratio scores below 1 indicate a negative self-rating in comparison to test score. MPR scores were log transformed for the purposes of statistical analysis.

Neuropsychological assessment

Cognitive status was measured by the Mini-Mental State Examination (MMSE; Folstein et al, 1975). Estimated pre-morbid intelligence was measured with the National Adult Reading Test (NART; Nelson, 1991). Memory function was assessed with the Rivermead Behavioural Memory test (RBMT-2; Wilson, Cockburn & Badderley, 2003). Episodic memory was measured by the immediate recall score from the Word List subtest of the Wechsler Memory Scale (WMW-III; Wechsler, 1997). Executive function was measured by the Delis-Kaplan Executive Function System (D-KEFS; Delis, Kaplan & Kramer, 2001), specifically the verbal and category fluency sub-tests. Language ability was measured with the Graded Naming Test (GNT; McKenna & Warrington, 1983) and the Pyramids and Palm Trees Test (P & PT; Howard & Patterson, 1992) measured semantic knowledge.

Assessment of psychological and social variables.

Quality of life was measured with the Qol-AD (Logsden, Gibbons, McCurry & Teri, 1999), mood was measured with the Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmond, 1994), self-concept was measured with the Tennessee Self Concept Scale (TSCS; Fitts & Warren, 1996), quality of relationship between PwMCI and informants was measured with the Positive Affect Index (PAI; Bengston, 1982), and conscientiousness was measured with the relevant scale from the NEO Five-Factor Inventory (NEO-FFI).

Informant measures

Informants rated any behavioural symptoms shown by PwMCI, together with their own level of distress on the Neuropsychiatric Inventory Questionnaire (NPI-Q; Kaufer, Cummings, Ketchel, Smith, MacMillan, Shelley, Lopez & DeKosky, 2000). Carer well-being in terms of mood, coping and quality of relationship between PwMCI and informants was assessed with the General Health Questionnaire, 28-item version (GHQ; Goldberg, 1992), Relatives' Stress Scale (RSS; Green, Smith, Gardiner & Timbury, 1982) and Positive Affect Index (PAI; Bengston, 1982).

Procedure

Participants and informants were seen at the University or visited at home by the researchers, depending on their preference. The study required two to three sessions with the participant, and awareness measures were administered first followed by the other tests and measures. Informants were seen separately, typically over one to two sessions, with the awareness measures administered last following the other tests and measures.

Data analysis

SPSS v16 was used to analyse all data in the current study. Associations amongst awareness measures and between awareness measure scores and other variables were explored with correlational analysis. No further analysis was conducted on variables showing no association with scores on awareness measures. Associated variables were explored with multiple regression analysis in order to identify which variables most accounted for a significant proportion of the variance in self- and informant ratings and discrepancy/ratio scores, thus developing a predictive model in each case. All associated variables were initially entered together in a backward regression analysis and the model showing the highest adjusted R^2 (R_a^2) was identified.

Results

Thirty individuals diagnosed with the amnestic form of MCI (MCI participants) and 30 informants were included in the study. All were white European: MCI participants were 12 females and 18 males with a mean age of 76 years (SD 8.55 range 60-97). Informants were 23 females and 7 males with a mean age of 66 years (SD 11.87 range 37-88). Twenty-three of the 30 dyads lived together; the co-resident informants were 21 spouses, one son/daughter and one friend. Of the 7 informants who lived apart, 6 were a son/daughter and one was a friend. Two of the MCI participants were receiving acetylcholinesterase-inhibiting medication, which had been prescribed previously based on an earlier diagnosis of probable dementia. This previous diagnosis had since been reclassified as MCI prior to recruitment for this study, although medication was continued. Mean MMSE score for the MCI participants was 25.93 (SD 3.45 range 18-30): MCI participants had an average of 10.68 years of education (SD 1.93 range 6-14), and informants had an average of 11.76 years of education (SD 1.51 range 9-15.5). Some measures were not completed by some MCI participants/informants, as a result of task difficulty, physical/sensory impairment or personal preference.

Table 4.1a shows the mean scores on psychosocial and neuropsychological measures for MCI participants and informants and Table 4.1b shows mean MCI participant and informant ratings of memory functioning, functional ability, socio-emotional functioning and memory performance, together with self- and informant corrected discrepancy scores for memory (MFD), functional ability (FAD) and socio-emotional functioning (SFD).

MCI participants rated their memory functioning much more positively than informants, and perceived their functional ability and socio-emotional functioning as better than informants. Their ratings of memory performance following objective testing were lower than their ratings of memory functioning, but this still represented an over-estimation as compared to their test score. Although overall mean scores on all three awareness measures represent an over-estimation of ability, the range of scores indicates that some individuals under-estimated their ability. Table 4.2 explores this range of over- and under-estimation by comparing MFD and MPR scores to percentile-based norms derived from healthy older people (Clare, Whitaker & Nelis, 2010).

Table 4.1

(a) Mean scores on individual psychosocial, neuropsychological and informant measures

	N	Mean	SD	Range	Min.-Max.
MCI participant psychosocial measures					
HADS anxiety	30	4.60	4.17	0 – 17	0-21*
HADS depression	30	3.97	2.62	0 – 11	0-21*
TSCS self-concept	29	75.69	9.55	55 – 94	20-100
NEO-FFI conscientiousness	28	37.86	6.70	20– 47	0-48
MCI participant neuropsychological measures					
NART errors**	30	21.37	10.20	1 – 37	0 – 50*
WMS-III-WL recall score	27	19.63	6.37	7 – 35	0-48
Pyramids and Palm Trees	30	50.33	1.65	45 – 52	0-52
Graded Naming Test	30	17.37	5.15	5 – 25	0-30
DKEFS verbal fluency:					
Letter fluency	29	32.69	14.19	9 – 70	
Category fluency	29	26.86	9.38	7 – 45	
Informant rating of MCI participant					
NPI symptom rating	30	4.50	2.66	0 – 11	0-12*
NPI severity rating	30	7.50	5.54	0 – 23	0-36*
Informant self-ratings					
NPI distress rating	30	7.27	6.67	0 – 29	0-60*
GHQ-12	28	11.96	4.12	4 – 19	0-36*
Relatives’ Stress Scale	28	19.39	11.67	3 – 47	0-60*
Positive Affect Index	28	20.79	4.95	12 – 29	5-30

**Higher scores represent poorer functioning.*

***NART error scores represent levels of pre-morbid IQ functioning.*

Key to abbreviations: HADS = Hospital Anxiety and Depression Scale; TSCS = Tennessee Self-Concept Scale; NEO-FFI = NEO Five-Factor Inventory; NART = National Adult Reading Test; WMS-III-WL = Wechsler Memory Scale, 3rd edition, Word List subtest; DKEFS = Delis-Kaplan Executive Function System; NPI = Neuropsychiatric Inventory; GHQ = General Health Questionnaire.

(b) Mean scores on measures of awareness

	N	Mean	SD	Range	Min-Max
MARS Memory Functioning Scale:					
Self-rating	30	39.00	7.37	23 - 50	0-52
Informant rating	29	24.90	10.04	4 - 42	0-52
MFD (corr)	29	.48	.48	-.32 - 1.60	
MARS Memory Performance Scale:					
Postdiction	30	33.57	7.48	20 - 48	0-52
RBMT Standardised Profile Score	30	27.33	11.56	4 - 48	0-52
MPR	30	1.50	.94	.65 – 5.50	
FAQ:					
Self-rating	28	2.64	2.92	0 – 11	0-33
Informant rating	29	10.59	7.87	0 – 30	0-33
FAD (corr)	27	.96	1.12	-2 – 2	
SEQ:					
Self-rating	30	63.93	11.49	45 – 93	30-150
Informant rating	29	78.03	15.02	48 – 111	30-150
SFD (corr)	29	.18	.21	-.25 - .55	

For the MARS, higher scores reflect better perceived functioning or performance. For the RBMT, higher scores reflect better test performance. For the FAQ and SEQ, lower scores reflect better perceived functioning. For the MFD, MPR, FAD and SFD higher scores mean greater discrepancies between the two sets of scores being compared.

Discrepancy scores between self- and informant rating were greatest for FAD, with PwMCI rating their functional ability higher then informants. MFD shows some overestimation for memory for PwMCI in comparison to informant report and SFD shows the least discrepancy with PwMCI rating their socio-emotional function as slightly higher than informants.

Table 4.2

Percentile ranked MFD and MPR scores in the MCI sample: numbers scoring at each level

Percentile range	MFD (n 29)	MPR (n 30)
>99		
95-99		2
90-95	2	
75-90		4
50-75	2	4
25-50	1	5
10-25	2	5
5-10	2	2
1-5	5	5
<1	15	3

Close agreement between participant and informant rated memory function (MFD) or agreement between test score and self-rating of performance (MPR) is represented by the 50th percentile. Low scores represent an overestimation of memory ability and high scores represent an underestimation of memory ability relative to either informant rating or objective test score.

The majority of scores fall below the 50th percentile showing an overestimation of memory ability across MFD and MPR. There is greater agreement between self-rating of performance and objective test score (MPR) than between self- and informant rated memory ability (MFD). It is interesting to note that the distribution of scores on the MPR reflects what was found in the healthy older population whereas the distribution of scores on the MFD reflects the pattern seen in people with dementia (Clare et al., 2010).

Correlation analyses

Bivariate correlations among the measures of awareness are shown in Table 4.3. Memory functioning discrepancy (MFD) was significantly correlated with memory performance ratio (MPR) and social functioning discrepancy (SFD) although not with the functional activities discrepancy (FAD).

Table 4.3 Bivariate correlational analysis between measures of awareness.

	MFD	MPR	FAD	SFD
MFD	1			
MPR	.649**	1		
FAD	.260	.119	1	
SFD	.412*	.209	.292	1

***Correlation is significant at the 0.01 level (2-tailed)*
** Correlation is significant at the 0.05 level (2-tailed)*
Key to abbreviations: MFD = Memory functioning discrepancy; MPR = Memory performance ratio; FAD = Functional activities discrepancy; SED = Social functioning discrepancy

Bivariate correlations between each measure of awareness and background variables, psychosocial factors and neuropsychological scores are shown in Table 4.4. MFD was significantly correlated with age, MMSE score, episodic memory test score (WMS-III-WL) and an informant rated general health questionnaire (GHQ). FAD was significantly correlated with the anxiety score (HADS). SFD was significantly correlated with the language ability test score (GNT), informant age, symptom and severity stress scale (NPI), informant completed general health questionnaire (GHQ), informant completed stress scale (RSS) and informant completed quality of relationship questionnaire. The log MPR was significantly correlated with participant age and MMSE score.

Variables which showed the greatest strength of association as indicated by correlational analysis were initially entered together in a backward regression analysis and the model showing the highest adjusted R^2 (R_a^2) was identified (see table 4.5). This identified which variables most accounted for a significant proportion of the variance in self- and informant ratings and discrepancy/ratio scores, thus developing a predictive model in each case. Variance inflation factors (VIF) confirmed the absence of multicollinearity between the predictor variables used in each regression model.

Regression analyses

Memory functioning discrepancy (MFD): Awareness of memory function.

A significant model emerged for self-ratings which consisted of age and MMSE score ($F_{2, 26}$ =10.048, $p < 0.05$, $R_a{}^2 = .393$), with both variables being individually significant. The positive association between age and MFD suggests that greater age is associated with poorer awareness. With regard to informant variables the significant model consisted of GHQ score alone ($F_{1, 26}$ =7.686, $p < 0.05$, $R_a{}^2 =$ .198). Informants with lower well-being scores gave ratings which were more discrepant from those of the PwMCI. Among the neuropsychological variables, WMS-III-WL recall score and DKEFS category switching produced a significant model ($F_{2, 23}$ =5.469, $p < 0.05$, $R_a{}^2 = .263$), with WMS-III-WL individually significant. Lower scores on these tests were associated with low awareness. The strongest predictive variables were participant age and MMSE as shown by the highest $R_a{}^2$ for this model which accounts for 39% of the variance in MFD.

Functional ability discrepancy (FAD): Awareness of functional ability.

When considering self-ratings and their relationship with FAD, HADS anxiety score emerged as the only significant predictor ($F_{1, 25}$ =7.292, $p < 0.05$, $R_a{}^2 = .195$). This was individually significant and was negatively associated indicating that a low anxiety score is related to greater variance in FAD, suggesting poorer awareness. Informant and neuropsychological variables did not produce a significant model.

Social functioning discrepancy (SFD): Awareness of social and emotional functioning.

For participants, only the GNT score however, significantly predicted SFD ($F_{1, 26}$ =6.555, $p < 0.05$, R_a^2 = .171). This was a negative association indicating that a lower score on the GNT is linked to a higher discrepancy score for social functioning. Informant variables of GHQ score, NPI severity score and informant reported quality of relationship score resulted in a significant model ($F_{3, 24}$ =6.978, $p < 0.05$, R_a^2 = .399) with informant rated quality of relationship score individually significant and negatively associated. Thus informants reporting a lower perceived quality of relationship produce ratings which are more discrepant from those of PwMCI. Informant variables produced the strongest predictive model which accounted for 40% of the variance in SFD.

Memory performance rating (MPR): Awareness of memory performance.

Age and MMSE score significantly predicted MPR ($F_{2, 27}$ =15.572, $p < 0.05$, R_a^2 = .501) with both variables being individually significant. Age was positively associated suggesting that with increasing age, participants rate their memory performance more highly compared to objective testing. MMSE score was negatively associated indicating that a lower MMSE score is associated with a more positive rating of memory performance compared to objective test scores. Older PwMCI with lower MMSE scores have poorer awareness. DKEFS category fluency also produced a significant model ($F_{1, 25}$ =4.976, $p < 0.05$, R_a^2 = .133) with this variable being negatively associated and individually significant. This suggests that a lower score on DKEFS category fluency is associated with a more positive rating of memory performance compared to objective test scores, thus poorer awareness. Age and

MMSE produced the strongest predictive model which accounted for 50% of the variance in MPR.

Table 4.4 Bivariate correlational analysis between measures of awareness and other variables.

	MFD	FAD	SFD	Log MPR
MCI participant background				
Age	.536**	.230	.203	.449*
MMSE score	-.509**	-.048	-.131	-.650**
Years of education	-.009	.266	-.052	-.175
MCI participant psychosocial				
HADS anxiety	-.315	-.475*	-.098	-.244
HADS depression	.046	-.280	.227	-.083
NEO-FFI conscientiousness self-rating	-.004	-.052	.066	.220
TSCS self-concept self-rating	.239	.263	-.066	.292
MCI participant neuropsychological				
NART errors	-.112	-.276	.191	.081
WMS-III-WL recall score	-.532**	-.168	-.179	-.372
GNT raw score	-.249	-.324	-.449*	-.234
Pyramids & Palm trees raw score	-.315	-.140	-.339	-.188
DKEFS letter fluency total	-.130	-.187	-.184	-.140
DKEFS category fluency total	-.318	-.211	-.199	-.320
Informant background				
Age	-.156	-.076	-.392*	-.200
Informant ratings of MCI participant				
NPI symptom score	.238	.109	.490**	.081
NPI severity score	.293	-.005	.470*	.117
Informant self-ratings				
NPI distress score	.075	-.146	-.353	-.090
GHQ	.478*	.067	.518**	.319
Relatives’ Stress Scale	.230	.163	.486**	.193
Quality of relationship with MCI participant	-.225	-.325	-.518**	-.028

*Significance levels are given as indicative only since they are not corrected for multiple comparison; they are included to facilitate a full presentation of the data. *=significant at 0.05 level (two tailed), **=significant at 0.01 level (two tailed). Key to abbreviations: MMSE = Mini-Mental State Examination; HADS = Hospital Anxiety and Depression Scale; TSCS = Tennessee Self-Concept Scale; NEO-FFI = NEO Five Factor Inventory; NPI = Neuropsychiatric Inventory; RSS = Relatives’ Stress Scale; GHQ = General Health Questionnaire; NART = National Adult Reading Test; WMS-III-WL = Wechsler Memory Scale, 3rd edition, Word List subtest; GNT = Graded Naming Test; P&PT = Pyramids and Palm Trees Test; RSS = Relatives’ Stress Scale; DKEFS = Delis-Kaplan Executive Function System.*

Table 4.5 Regression analysis

Beta, p values and R_a^2 values for each model

	MFD		FAD		SFD		MPR	
SELF RATINGS FOR PERSON WITH MCI								
R_a^2 for model	*.393*		*.195*		*.050*		*.501*	
	ß	p	ß	p	ß	p	ß	p
Age	.435	.008					.381	.009
MMSE	-.398	.015					-.548	.000
HADS anxiety			-.475	.012				
Quality of life					-.199	.318		
Quality of relationship					-.235	.240		
	MFD		FAD		SFD			
INFORMANT RATINGS								
R_a^2 for model	*.198*		*.070*		*.399*			
	ß	p	ß	p	ß	p		
NPI severity rating					.251	.139		
GHQ	.478	.010			.304	.083		
Quality of relationship			-.325	.098	-.374	.025		
	MFD		FAD		SFD		MPR	
NEUROPSYCHOLOGICAL VARIABLES								
R_a^2 for model	*.263*		*.085*		*.171*		*.133*	
	ß	p	ß	p	ß	p	ß	P
WMS-III-WL recall score	-.415	.049						
GNT			-.351	.085	-.449	.017		
DKEFS Category fluency							-.407	.035
DKEFS Category switching	-.230	.260						

Key to abbreviations: MMSE = Mini-Mental State Examination; HADS = Hospital Anxiety and Depression Scale; NPI = Neuropsychiatric Inventory; GHQ = General Health Questionnaire; WMS-III-WL = Wechsler Memory Scale, 3rd edition, Word List subtest; GNT = Graded Naming Test; DKEFS = Delis-Kaplan Executive Function

Discusson

The aim of this study was to consider the profile of awareness in PwMCI within a biopsychosocial framework, exploring the social and psychological factors which in addition to neuropsychological variables influence evaluative judgments and performance monitoring over three objects of awareness: memory, functional ability and socio-emotional functioning. This was supported, providing evidence of the relevance of the biopsychosocial framework.

Neuropsychological factors had the most influence on the memory discrepancy indices of awareness. MMSE produced the strongest predictive model for MFD which indicates that more cognitively impaired PwMCI will have poorer awareness. Lower scores on measures of episodic memory (WMS-III-WL) and executive function (DKEFS category switching) also produced a significant predictive model for MFD variance. Orfei et al. (2010) found a similar relationship between poor scores in verbal episodic tasks and poor awareness of cognitive difficulties in PwMCI. The authors suggest that episodic memory deficits would result in poor recall of recent events and hence inaccurate self-report of cognitive difficulties. Lower scores on the executive function task of category fluency were also predictive. PwMCI have been shown to have poorer recall of episodic material than healthy older controls (Anderson & Schmitter-Edgecombe, 2010) and show higher levels of dysfunction in fluency measures than healthy older controls (Kramer et al., 2006). Both MFD and MPR implicate the role of episodic memory and executive function in levels of awareness, as well as general severity of impairment as shown by MMSE score.

Most PwMCI in the current study over-estimated their subjective memory function and performance following and objective memory task, with closer agreement between post-diction rated performance and actual performance on a memory task. Perrotin, Belleville and Isingrini (2007) found that their MCI sample had more SMC than the control group, yet over-estimated their predicted performance on an episodic memory task, which reflects the divergent awareness constructs being examined. SMC relate to global, retrospective judgements which may reflect certain negative attributions associated with becoming forgetful and getting older. Post-diction performance monitoring, however, relies on current, ‘in the moment’ opinions of memory which aids the accuracy of perceived ability. This would add support to the difference in MFD and MPR in the current study and it would support the hypothesis put forward by Perrotin et al (2007) that the people who over-estimated their performance were influenced by response-bias and adopted a self-defence mechanism which would account for the influence of affective states.

No PwMCI in the present study reported clinical levels of depression and 2 participants had clinical levels of anxiety as measured by the HADS. A lower level of anxiety was the only significant predictor of greater variance in the functional ability discrepancy (FAD) score which suggests that even with low levels of reported anxiety, this influences self-rating on a functional ability measure. Informants of those with MCI experience increased depressive symptoms, have more perceived burden and offer narrative accounts of stress, strain and frustration (Blieszner & Roberto, 2009) Lower informant well-being as measured by the GHQ, was predictive of the degree of MFD, but to a lesser extent than MMSE score, age and neuropsychiatric variables. Caregiver burden for informants of PwMCI has been found to cause distress (Garand, Dew, Eazor, DeKosky & Reynolds, 2005) which lessens the accuracy of informant report when compared to objective testing (Zanetti, Geroldi, Frisoni, Bianchetti & Trabucchi, 1999). The variance in awareness of social and emotional behaviour (SFD) was significantly predicted by a low quality of relationship score. Additionally, poorer language function predicted greater variance in the SFD. Marital quality has been found to be reduced when a spouse has MCI particularly as a result of communication difficulties (Garand et al., 2007).

Patterns of over- and under-estimation of memory function were compared to percentile-based norms derived from healthy older people (Clare, Whitaker & Nelis, 2010). MFD in the current study show similar patterns of over-estimation as people diagnosed with Alzheimer’s disease (AD), whereas the pattern for MPR is similar to data collected from healthy older people. This would suggest that the pattern of awareness for subjective memory in PwMCI is similar to people with AD yet awareness of memory performance is retained to the same level as healthy older people. This reflects the intermediate nature of MCI between healthy older adulthood and the onset of dementia and would account for the conflicting evidence across studies exploring awareness in MCI. Normative data on discrepancy indices of awareness for functional ability and socio-emotional functioning are not available. Okonkwo et al. (2009) compared self-reported functional ability to an isomorphic objective task and found similar discrepancies across groups of PwMCI and healthy older controls. A comparison between PwMCI and the profile of discrepancy between self- and informant rating in functional ability and socio-emotional functioning for people of similar age and background without MCI would allow better understanding of the nature of awareness within discrete areas of functional ability and socio-emotional functioning.

When considering the results of this study in relation to an overall understanding of the nature of awareness in MCI, it is awareness at the performance monitoring and evaluative judgment level which is considered here (Clare, Markova, Roth & Morris, in press). A discrepancy score between postdiction self-rating and performance on an ecologically valid memory test represented a measure of performance monitoring whereas a discrepancy between PwMCI and informants on parallel forms of domain specific questionnaires provided indices of awareness representing evaluative judgments. These aspects of the framework of awareness (Clare et al., in press) are not distinct from the meta-representational level of awareness which is the most complex form and involves aspects of the self and identity and environmental factors. It is therefore necessary to consider awareness as a complex interplay between psychological and environmental factors which influence the nature of the awareness phenomenon elicited at a performance monitoring and evaluative judgment level.

The current study is limited in the conclusions that can be drawn as this was a small sample. The recruitment of MCI participants is challenging as rates of MCI in the community can vary between 3 and 36% (Busse, Bischkopf, Riedel-Heller & Angermeyer, 2003) and this is dependent on the criteria applied (Luck, Luppa, Briel & Riedel-Heller, 2010). Recruitment for the current study occurred within a memory clinic setting and therefore did not access people in the community who would meet the criteria for MCI but who had not come forward for assessment (Stephan et al., 2008). Reasons for this could be the absence of SMC resulting from poor awareness (Lin et al., 2010), the narrow definition of MCI in a clinical setting (Jungwirth, Weissgram, Zehetmayer, Tragl & Fischer, 2005) or monitoring of the individual by the GP. Despite this, the assessment of awareness in the current study was thorough and used multiple methods across different domains, utilising corrected discrepancy scores and ratios for indices of awareness. Although the conclusions are tentative given the sample size, the thorough methods of assessing awareness offer a way forward for future research in the area of awareness in MCI which can build on the findings of the current study.

Conclusion

The current study found that awareness levels in PwMCI as demonstrated by evaluative judgments across the domains of memory, functional ability and socio-emotional functioning as well as performance monitoring of memory are variable across domains and are influenced separately by a range of factors. Affective states and the quality of relationship are important factors when considering self- and informant evaluative ratings of memory, functional ability and informant ratings of socio-emotional functioning. The role of the biopsychosocial framework is therefore supported in the understanding awareness in MCI. It is therefore essential to consider the role of the environment in addition to neuropsychological functioning when assessing awareness levels of PwMCI across different domains.

Chapter 5

Study 3: The longitudinal trajectory of awareness in Mild Cognitive Impairment

Abstract

Objective: Evidence as to the profile of awareness in MCI over time is absent. Awareness is a multi-dimensional construct which is subject to the influence of biopsychosocial variables, which may change over time. A longitudinal methodology was therefore adopted to explore what patterns of change occur in discrepancy indices of awareness over time, specifically in the domains of memory, activities of daily living and socio-emotional functioning over a period of 12-15 months. The influence of cognitive change and psychosocial variables are considered.

Method: Thirty participants with a clinical diagnosis of MCI were recruited initially and a short neuropsychological battery administered, as well as measures of awareness to participants and an informant who knew them well. Measures of psychological and social variables were also administered. This process was repeated 12-15 months later with eighteen participants and informants who remained in the study.

Results: No significant change in discrepancy indices of awareness were observed over time despite a significant decline in verbal episodic memory and executive function. Significant increases were observed for self- and informant reported decline in activities of daily living and informant reported socio-emotional functioning.

Conclusions: It is suggested that there is little association between level of awareness when measured by discrepancy indices and cognition. Psychosocial factors remained stable over time which may be important influences on the presentation of awareness. Changes in everyday functioning were more readily acknowledged by people with MCI than changes in memory or socio-emotional functioning although to a lesser extent than informants. Clinical implications are discussed.

The concept of mild cognitive impairment (MCI) aims to bridge the gap between cognitive changes associated with normal aging and the progressive decline associated with dementia. How older people perceive a decline in cognition will influence whether they present for assessment and how they present to clinicians in a clinical assessment. People classified as having MCI (PwMCI) are at higher risk of progressing to dementia when compared to the normal aging population (Petersen, 2001) and therefore the accurate identification of MCI is important for the individual so that continued assessment can monitor any further deterioration. Inherent in the most widely used criteria for MCI (Petersen 1999,2001) is the suggested requirement of corroboration by an informant of any reported subjective memory complaint (SMC) which implies that the individual's own subjective rating of memory functioning may not be accurate. If a person with MCI is unable to accurately appraise his/her memory functioning s/he may not acknowledge difficulties and will not seek appropriate professional assessment (Lin et al., 2010). Equally, those presenting for assessment may not give an accurate subjective appraisal of their functioning, which could result in an inaccurate diagnosis. Therefore, awareness of functioning is an important consideration in regard to people with MCI.

Awareness is defined as an accurate appraisal of a person's situation, functioning, performance or outcome in any given domain (Clare, 2007). This can be in relation to different objects of awareness (Marková & Berrios, 2001) such as memory or functional ability, and the selected object influences the nature of the awareness phenomenon elicited. Cross-sectional studies exploring the nature of awareness in MCI in relation to memory and functional ability have produced conflicting results. Some studies find that PwMCI do not under-report cognitive or functional deficits to the same degree as individuals with Alzheimer's disease (AD) when using self- and informant discrepancy as a measure of awareness (Farias, Mungas, Jagust, 2005; Kalbe et al., 2005) whereas others have found that PwMCI show similar levels of impaired awareness to people with early-stage dementia (Vogel, Stockholm, Gade, Andersen, Hejl & Waldemar, 2004; Vogel, Hasselbalch, Gade, Ziebell & Waldemar, 2005; Lin et al., 2010; Tremont & Alosco, 2011). Conflicting results amongst studies have been attributed to methodological and conceptual issues although the majority of studies in this area suggest that PwMCI have different levels of awareness (Roberts, Clare & Woods, 2009). Given the conceptual difficulties within the classification of MCI and the fact that many PwMCI do not progress to dementia (Luck, Luppa, Briel & Riedel-Heller, 2010) the relationship between awareness and the cognitive changes in MCI is complex. It is likely that the expression of awareness in PwMCI is influenced by a range of factors which can be encompassed in a biopsychosocial framework, empirical evidence of which has been produced in relation to dementia (Clare et al., 2011)

If awareness is to be considered within a biopsychosocial framework, it would be of interest to explore the influential nature of psychosocial and neuropsychological factors which may change over time. In doing so, associations between any changes or lack of change in the elicited awareness phenomenon and other variables could be identified. A longitudinal approach is therefore likely to be most helpful. There are few longitudinal studies exploring awareness in MCI. Greenop et al. (2011) conducted an 18 month study of awareness in community-dwelling older adults classed as being cognitively impaired-no dementia (CIND). The focus of this study was on the predictive value of awareness in relation to cognitive decline rather than change in awareness over time. The authors' findings did not support their hypothesis that people with CIND who were classed as unaware would have poorer cognition or a higher rate of cognitive decline. Importantly, the study by Greenop and colleagues acknowledges that MCI classification may miss people with cognitive impairment where there is no SMC or informant complaint. However, the median MMSE score of 29 (SD 2.00) of their sample suggests that they were not representative of PwMCI who were clinically-diagnosed with MCI. At the time of writing, no longitudinal studies of changes in patterns of awareness over time have been found.

To summarise, evidence relating to awareness in PwMCI over time is absent. As the biopsychosocial view of awareness encompasses variables which may change with time, thus influencing the presentation of awareness, a longitudinal methodology was adopted. This study aims to explore changes in patterns of awareness by using discrepancies between PwMCI and informant scores on parallel questionnaires at initial assessment and at a 12-15 month follow up. Specifically, the study will focus on three objects of awareness - memory, activities of daily living and socio-emotional functioning. Methodological limitations of discrepancy scores will be dealt with by correcting for scaling effects, and the self- and informant ratings which make up the discrepancy score will also be examined individually. PwMCI scores on cognitive and psychosocial measures will also be considered as well as psychosocial factors relevant to the informant. The following research questions were addressed:

- What patterns of change occur in self- and informant ratings and discrepancy scores in the domains of memory, activities of daily living and socio-emotional functioning over a period of 12-15 months?
- Does change in awareness over time relate to changes in cognitive functioning, and do changes in PwMCI and informant ratings of awareness relate to changes in psychosocial variables?

Method

Design

This study was part of the Memory Impairment and Dementia Awareness Study (MIDAS), a longitudinal study of awareness in people with dementia and MCI. This paper presents a longitudinal analysis of the MCI data. Participants were assessed on awareness of memory ability, functional ability and social functioning on entry and at a second 12-15 month time point. The relevant NHS University ethics committees granted approval for the study.

Participants

Participants were recruited across 4 NHS memory clinics in North Wales, UK. Inclusion was dependent on a diagnosis of MCI, a score of 18 and above on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), the ability to communicate verbally in English and the presence of a spouse, partner or other family member or friend who knew the participant well. Exclusion criteria for the person with MCI were the presence of major depressive disorder or a current or past history of psychosis or other neurological disorder, stroke or brain injury. This information was confirmed by checking medical records and discussion with relevant clinicians at the memory clinic.

Measures

Awareness of memory

Both participant and informant completed parallel forms of the Memory Awareness Rating Scale (MARS; Clare, Wilson, Carter, Roth and Hodges, 2002). This scale gives a self-rating (MFS-Self) and informant rating (MFS-Informant) of participant memory ability and from these a corrected memory functioning discrepancy (MFD) score was calculated. To correct for scaling effects, MFD was calculated by taking the difference between self and informant score and dividing this by the mean of the two scores. A corrected score close to zero shows good agreement between participant and informant. A positive score indicates that participant rating is higher than informant rating, whereas a negative score indicates that informant rating is higher than participant rating.

Awareness of functioning

Parallel forms of the Functional Activities Questionnaire which measures functional ability in activities of daily living such as paying bills, shopping and household tasks (FAQ; Pfeffer, Kurosaki, Harrah, Chance & Filos, 1982) provided self-ratings of functional ability (FAQ-self) and informant ratings of participant functional ability (FAQ-informant). A corrected discrepancy score, the functional activity difference (FAD) score, was calculated using the same method as outlined for MFD.

Awareness of social behaviour

Parallel forms of the Socio-Emotional Questionnaire (SEQ; Bramham, Morris, Hornak & Rolls, 2003) which measures empathic reactions to social situations and ability to recognise emotions in self and others provided self-ratings (SEQ-self) and informant ratings of participant social and emotional behaviour (SEQ-informant). A corrected socio-emotional functioning discrepancy (SFD) score was calculated using the same method as for MFD and FAD.

Neuropsychological measures

Cognitive status was measured by the Mini-Mental State Examination (MMSE; Folstein et al, 1975). Episodic memory was measured by the immediate recall score from the Word List subtest of the Wechsler Memory Scale (WMW-III; Wechsler, 1997). Executive function was measured by the verbal and category fluency sub-tests of the Delis-Kaplan Executive Function System (D-KEFS; Delis, Kaplan & Kramer, 2001). Language ability was measured with the Graded Naming Test (GNT; McKenna & Warrington, 1983).

Measures of psychological and social variables

The Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmond, 1994) gave scores for depression and general anxiety. Quality of life was measured with the Quality of Life in Alzheimer's disease (Qol-AD) scale (Logsdon Gibbons, McCurry & Teri, 1999).

Informant measures

Informants rated any presenting neuropsychiatric symptoms and the severity of those symptoms which they had observed in the participant by completing the Neuropsychiatric Inventory Questionnaire (NPI-Q; Kaufer, Cummings, Ketchel, Smith, MacMillan, Shelley, Lopez & DeKosky, 2000). This also provided an informant rating of distress at each identified neuropsychiatric symptom. Informants' mood was measured with the General Health Questionnaire (GHQ; Goldberg, 1978) and level of stress with the Relatives' Stress Scale (RSS; Green, Smith, Gardiner & Timbury, 1982).

Procedure

Participants and informants were seen at their home or at the University, depending on their preference. Informed consent was obtained from both participant and informant at each time point. All measures were completed by the participant and informant separately and administration typically took two to three sessions to complete at entry point, with the follow up assessments typically taking one to two sessions.

Data analysis

Random effects regression analyses were used to measure change in awareness and other variables over both time points of the study by examining hierarchical linear models. This was achieved with the linear mixed-effects model (West, 2009) procedure in SPSS. West states that this method relaxes the assumption of simple regression models, which assume zero covariance of the dependent variable. This is important as longitudinal studies generally introduce non-zero covariance between random errors associated with test scores from the same individual. The linear-mixed effects model in SPSS allows the estimation of covariance structure of the random errors. In this study, participant identification number was used as the ‘subject’ variable, test score as the dependent variable and time interval (months) as a covariate. A significant time effect indicated that test scores changed over time. Three models (same slope, same intercept; same slope, different intercept; different slope, different intercept) were fitted for each variable. The model with the lowest Akaike’s Information Criterion (AIC; Akaike, 1974) was identified in each case as the best fitting model.

Results

Thirty PwMCI of the amnestic form, 18 men and 12 women, took part in the study and were assessed at Time 1. At follow up, 18 of those original participants (9 male, 9 female) remained. Demographic data at entry (T1) into the study and at follow up (T2) are shown in Table 5.1. Time between T1 and T2 averaged 12.65 months (SD .99; range 12-15). Between T1 and T2, attrition resulted in 10 participants dropping out as a result of self-withdrawal (5), ill health (4) and death (1), with 2 participants being excluded as a result of progression to and subsequent diagnosis of vascular dementia and Alzheimer's disease respectively. No significant mean differences at T1 in age [F (1, 29) = .002, p = .965] or MMSE score [F (1, 29) = 1.10, p = .303] were found between participants who remained in the project at T2 and those who did not.

Change over time in PwMCI and informant variables

Scores on PwMCI and informant variables at both T1 and T2 are shown in Table 5.2. All neuropsychological variables, anxiety, informant wellbeing (GHQ) and stress (RSS) show poorer functioning at follow up. Random regression analyses were carried out on all variables to explore whether any changes were significant, the results of which are shown in Tables 5.3 and 5.4.

The chosen model for all variables, based on the lowest AIC score, was that of same slope and different intercept, which implies that the trajectory is similar across time for all participants yet individual scores differ for each variable. MMSE score, language (naming), anxiety, depression and quality of life scores did not show significant change over time. There was a significant reduction in scores for measures of episodic memory (word list learning), and executive function in verbal letter fluency (verbal category fluency). Informant measures at T1 and T2 did not show any significant change over time in reported neuropsychiatric symptoms, the severity of those symptoms or informant distress in response to the symptoms. Carer mood and levels of stress showed no significant change over time.

Table 5.1 Participant characteristics

Variable	T1 (n = 30) Mean (SD)	T2 (n = 18) Mean (SD)
PwMCI		
Age (yrs.)	76.00 (8.54)	77.72 (8.22)
Sex (M: F)	18:12	9:9
MMSE	25.93 (3.45)	26.17 (3.76)
Education (yrs.)	10.68 (1.93)	10.86 (2.25)
Informant		
Age (yrs.)	66.34 (11.87)	68.88 (11.45)
Sex (M: F)	7:23	6:12
Reside with PwMCI (Yes: No)	23:7	13:5
Relationship (partner:child:friend)	21:7:2	12:5:1

**MCI diagnosis according to Petersen (2001) criteria*

Table 5.2 Scores on PwMCI and informant variables across the two time-points (mean, sd, range)

Measures (min – max)	Time 1 (n = 30)	Time 2 (n = 18)
PwMCI Neuropsychology		
WMS-III word list recall (0-48)	19.63 (6.37) 7-35	19.22 (8.58) 10-37
Graded Naming Test (0-30)	17.37 (5.15) 5-25	17.00 (6.56) 4-28
D-KEFS letter fluency (n/a)	32.69 (14.9) 9-70	31.56 (16.04) 7-65
D-KEFS category fluency (n/a)	26.86 (9.38) 7-45	25.39 (9.25) 14-47
PwMCI Psychosocial		
HADS anxiety* (0-21)	4.60 (4.17) 0-17	5.44 (4.25) 1-18
HADS depression* (0-21)	3.97 (2.62) 0-11	3.67 (2.63) 0-9
QoL-AD (13-52)	36.90 (5.29) 22-27	36.50 (5.03) 22-46
Informant rating of PwMCI		
NPI symptoms* (0-12)	4.50 (2.66) 0-11	4.53 (2.88) 1-9
NPI severity* (0-36)	7.50 (5.54) 0-23	7.07 (5.85) 1-18
Informant self-ratings		
NPI distress* (0-60)	7.27 (6.67) 0-29	7.33 (6.84) 0-24
GHQ-12* (0-36)	11.96 (4.12) 4-19	13.33 (2.72) 8-17
RSS* (0-60)	19.39 (11.67) 3-47	20.27 (8.70) 10-42

**Higher scores represent poorer functioning.*

Key to abbreviations: WMS-III = Wechsler Memory Scale, 3rd edition; D-KEFS = Delis-Kaplan Executive Function System; HADS = Hospital Anxiety and Depression Scale: Qol-AD = Quality of Life –Alzheimer's disease; NPI = Neuropsychiatric Inventory Questionnaire; GHQ = General Health Questionnaire; RSS = Relatives Stress Scale

Table 5.3 Random regression models for PwMCI variables across the two time points

Variable	**Slope**	**Intercept**	**Variance (s.e) for intercept**	**Change over time**
MMSE	-.051 (.037) *t* (17.513) = -1.376, p = .186 CI -.13 - .03	25.804 (.663) *t* (33.142) = 38.903, p < .001 CI -.13 - .03	2.050 (.715) Wald z 2.865, p < .05 CI 1.03 – 4.06	No Change
WMS-III Word list total	-.217 (.097) *t* (9.511) = -2.236, p = .05 CI -.43 - .00	19.602 (1.302) *t* (27.782) = 15.051, p < .001 CI 16.93 – 22.27	7.468 (3.622) Wald z 2.062, p < .05 CI 2.89 – 19.32	Significant reduction
Graded Naming test total	-.074 (.062) *t* (14.339) = -1.188, p = .254 CI -.21 - .06	17.363 (.964) *t* (31.926) = 18.015, p < .001 CI 15.34 – 19.33	4.386 (1.712) Wald z 2.562, p < .05 CI 2.04 – 9.43	No Change
D-KEFS Letter Fluency	-.268 (.159) *t* (18.882) = -1.682, p = .109 CI -.60 - .07	32.61 (2.700) *t* (31.881) = 12.074, p < .001 CI 27.11 – 38.11	38.594 (12.989) Wald z 2.971, p < .05 CI 19.95 – 74.64	No Change
D-KEFS Category Fluency	-.297 (.0804) *t* (17.337) = -3.692, p < .05 CI -.47 - -.13	26.828 (1.792) *t* (29.498) = 14.970, p < .001 CI 23.17 – 30.49	9.677 (3.353) Wald z 2.886, p < .05 CI 4.91 – 19.09	Significant reduction
HADS anxiety	.078 (.056) *t* (20.452) = 1.379, p = .183 CI -.04 - .20	4.589 (.749) *t* (35.516) = 6.124, p < .001 CI 3.07 – 6.11	4.951 (1.636) Wald z 3.026, p < .05 CI 2.59 – 9.46	No Change
HADS depression	.014 (.035) *t* (19.152) = .396, p = .696 CI -.06 - .09	3.960 (.479) *t* (34.360) = 8.261, p < .001 CI 2.99 – 4.93	1.934 (.661) Wald z 2.929, p < .05 CI .99 – 3.78	No Change
QoL-AD	-.119 (.062) *t* (17.439) = -1.908, p = .073 CI -.25 - .01	36.901 (.968) *t* (31.527) = 38.108, p < .001 CI 34.93 – 38.87	5.566 (1.966) Wald z 2.831, p < .05 CI 2.79 – 11.12	No Change

Key to abbreviations: as for Table 5.2

Table 5.4 Random regression models for informant variables across the two time points

Variable	**Slope**	**Intercept**	**Variance (s.e) for intercept**	**Change over time**
NPI symptoms rated by carer	.038 (.046) *t* (16.111) = .815, p = .427 CI -.06 - .14	4.495 (.506) *t* (34.408) = 8.891, p < .001 CI 3.47 – 5.52	2.940 (1.146) Wald z 2.565, p < .05 CI 1.37 – 6.31	No Change
NPI severity rated by carer	.094 (.086) *t* (15.008) = 1.089, p = .293 CI -.09 - .28	7.493 (1.058) *t* (32.580) = 7.080, p < .001 CI 5.34 – 9.65	10.015 (3.959) Wald z 2.530, p < .05 CI 4.62 – 21.73	No Change
NPI carer distress	.110 (.108) *t* (15.831) = 1.022, p = .322 CI -.12 - .34	7.260 (1.247) *t* (33.685) = 5.822, p < .001 CI 4.72 – 9.79	15.822 (6.149) Wald z 2.573, p < .05 CI 7.39 – 33.89	No Change
GHQ	.098 (.092) *t* (41) = 1.072, p = .290 CI -.09 - .28	12.000 (.700) *t* (41) = 17.137, p < .001 CI 10.59 – 13.41	13.775 (3.042) Wald z 4.528, p < .001 CI 8.94 – 21.24	No Change
RSS	.084 (.114) *t* (14.884) = .739, p = .471 CI -.16 - .33	19.413 (2.045) *t* (29.015) = 9.493, p < .001 CI 15.23 – 23.60	16.728 (6.341) Wald z 2.638, p < .05 CI 7.96 – 35.17	No Change

Key to abbreviations: as for table 5.2

Change over time in measures of awareness

Scores on awareness measures at T1 and T2 are shown in Table 5.5. Random regression analyses are shown in Table 5.6. For all variables, the lowest AIC scores were for the model involving same slope and different intercept. No significant changes over time were found for self-rating of memory (MFS), informant rating of PwMCI memory, or the corrected discrepancy between these scores. For functional ability (FAQ), a significant increase was found in self-rated functioning and informant rated functioning over time, suggesting a perceived decline in functional ability by both the PwMCI and the informant. The corrected discrepancy score for functional ability showed no significant change. No significant change was shown for self-reported social behaviour (SEQ) whereas a significant increase in score occurred for informant reported social behaviour, suggesting that informants report a greater degree of decline in social behaviour in comparison to PwMCI. However, the corrected discrepancy score for social behaviour did not show a significant change over time.

Table 5.5 Scores on awareness measures across the two time points: self-ratings, informant ratings, and discrepancies (mean, sd, range)

Measure (min-max)	Time 1 N = 30	Time 2 N = 18
MFS self (0-52)	39.00 (7.37) 23-50	38.22 (7.88) 13-49
MFS inf (0-52)	24.90 (10.04) 4-42	27.69 (11.20) 5-48
MFD	.48 (.48) -.32–1.60	.35 (.55) -.94-1.58
FAQ self (0-33)	2.64 (2.92) 0-11	4.11 (3.29) 0-12
FAQ inf (0-33)	10.59 (7.87) 0-30	12.67 (7.70) 0-29
FAD	.96 (1.12) -2-2	.96 (.96) -2-2
SEQ self (30-150)	63.93 (11.49) 45-93	66.11 (11.26) 46-90
SEQ inf (30-150)	78.03 (15.02) 48-111	85.40 (13.91) 56-110
SFD	.18 (.21) -.25-.55	.22 (.17) -.03-.56

Key to abbreviations: MFS = Memory Functioning Scale; MFD = Memory Functioning Discrepancy; FAQ = Functional Activities Questionnaire; FAD = Functional Activities Discrepancy; SEQ = Socio-Emotional Questionnaire; SFD = Social Functioning Discrepancy

For the MFS, higher scores reflect better perceived functioning. For the FAQ and SEQ, lower scores reflect better perceived functioning. For the MFD, FAD and SFD higher scores mean greater discrepancies between the two sets of scores being compared. Positive discrepancies indicate that the PwMCI self-rating was more positive than the informant rating and vice versa.

Table 5.6 Random regression models for awareness measures across the two time points

Variable	**Slope**	**Intercept**	**Variance (s.e) for intercept**	**Change over time**
MFS self	-.121 (.118) *t* (18.779) = -1.022, p = .320 CI -.37 - .13	38.978 (1.399) *t* (35.608) = 27.857, p < .001 CI 36.14 – 41.82	22.248 (7.837) Wald z 2.839, p < .05 CI 11.15 – 44.37	No Change
MFS informant	.118 (.178) *t* (17.863) = .662, p = .517 CI -.26 - .49	24.827 (1.947) *t* (35.002) = 12.751, p < .001 CI 20.87 – 28.78	46.168 (16.978) Wald z 2.719, p < .05 CI 22.45 – 94.92	No Change
MFD	-.006 (.007) *t* (16.481) = -.916, p = .373 CI -.02 - .01	.482 (.095) *t* (31.623) = 5.080, p < .001 CI .29 - .67	.061(.022) Wald z 2.723, p < .05 CI .03 - .12	No Change
FAQ self	.124 (.061) *t* (20.714) = 2.043, p = .05 CI -.00 - .25	2.66 (.580) *t* (40.324) = 4.579, p < .001 CI 1.49 – 3.83	6.020 (2.139) Wald z 2.814, p < .05 CI 3.00 – 12.08	Significant Increase
FAQ informant	.250 (.084) *t* (14.601) = 2.98, p < .05 CI .07 - .43	10.631 (1.492) *t* (29.705) = 7.124, p < .001 CI 7.58 – 13.68	9.116 (3.494) Wald z 2.609, p < .05 CI 22.45 4.30 – 19.32	Significant Increase
FAD	-.006 (.027) *t* (40) = -.222, p = .826 CI .07 -.06 - .05	.990 (.205) *t* (40) = 4.821, p < .001 CI .58 – 1.41	1.143 (.256) Wald z 4.472, p < .001 CI .74 – 1.77	No Change
SEQ self	.227 (.169) *t* (19.407) = 1.344, p = .195 CI -.13 - .58	63.843 (2.087) *t* (35.497) = 30.588, p < .001 CI 59.61 – 68.08	44.923 (15.429) Wald z 2.912, p < .05 CI 22.92 – 88.07	No Change
SEQ informant	.490 (.180) *t* (15.511) = 2.727, p < .05 CI .11 - .87	78.054 (2.719) *t* (31.016) = 28.703, p < .001 CI 72.51 – 83.60	42.360 (15.962) Wald z 2.654, p < .05 CI 20.24 – 88.66	Significant Increase
SFD	.003 (.005) *t* (42) = .605, p = .549 CI -.01 - .01	.184 (.037) *t* (42) = 5.024, p < .001 CI .11 - .26	.0391 (.009) Wald z 4.583, p < .001 CI .03 - .06	No Change

Key to abbreviations: as for table 5.5
For MFS, a decrease in scores reflects perceived worsening of functioning. For FAQ and SEQ, an increase in scores reflects perceived worsening of functioning. For MFD, FAD and SFD an increase reflects a greater discrepancy between self and informant rating.

Discussion

This was the first longitudinal study of awareness in MCI which explored patterns of change in self- and informant-ratings and discrepancy scores in the domains of memory, activities of daily living and socio-emotional functioning over a period of 12-15 months. This study focuses on awareness at the evaluative judgment level (Clare, Markova, Roth & Morris, in press) and provides longitudinal data on this aspect of the awareness phenomenon. Associations between changes in discrepancy indices of awareness and changes in cognitive functioning were examined in addition to associations between changes in PwMCI and informant ratings of awareness and changes in psychosocial variables.

Longitudinal trajectories of discrepancy indices of awareness across the three domains did not change significantly over time, showing stability in the degree of discrepancy between self- and informant-report. The stability across domains remained despite a significant decline in verbal episodic memory as measured by the immediate recall score on a word list (WMS-III) and executive function as measured by the category fluency sub-tests from the Delis-Kaplan Executive Function System. The decline in verbal episodic memory is consistent with the findings of Collie and Maruff (2000) who suggest that this cognitive domain is affected earlier in PwMCI who subsequently progress to dementia. Such changes in cognition were not reflected in the memory awareness discrepancy index, suggesting that there is little association between level of awareness when measured in this way and a decline in cognition.

PwMCI symptoms of anxiety and depression remained constant over time with only one of two clinical anxiety cases at entry remaining above cut-off at follow up. No clinical cases of depression were noted at either time point. Scores on a measure of quality of life also remained constant over the period of the current study.

Neuropsychiatric symptoms as rated by the informant in terms of their presence and severity did not change over time, nor did informant distress at any noted symptoms. Informants were also questioned about their mood and levels of stress at entry and follow up and these scores did not change significantly over the study time period. These psychosocial factors, which remained stable along with the awareness indices, may be important influences on the presentation of awareness (Clare, 2004).

The only significant change across domains in PwMCI self-ratings was for functional ability. This demonstrates that perceptions of change in daily functioning are more readily acknowledged by PwMCI than those arising in domains of memory and socio-emotional ability, possibly due to the tangible evidence presented by such challenges to PwMCI and the subsequent reliance on informants. This could also reflect the trajectory of decline in PwMCI. A decline in memory will have been present at the time of diagnosis whereas a decline in functional ability will progressively become worse during the course of MCI if the individual progresses to dementia, making it more evident to PwMCI. Socio-emotional functioning may decline at a slower rate and to a lesser degree than memory and functional ability in MCI.

Informants reported a significant change in PwMCI functional ability and socio-emotional functioning. Informants may take a more predominant role in daily activities of PwMCI which may not be acknowledged overtly within the relationship and may induce the perception of greater burden. Informant rated socio-emotional functioning suggested that the informant observed significantly poorer functioning in this domain at follow up. As reflected in the acknowledged decline in functional ability by PwMCI, an increased reliance on others may lead to frustration or loss of confidence leading to a change in behaviour with others, specifically informants.

Personality alterations such as aggression-hostility have been noted in PwMCI (Ausén, Edman, Almkvist & Bogdanovic, 2009) with evidence suggesting that apathy is more frequently observed in PwMCI than depression and anxiety (Robert et al., 2006). Additionally, the effect behavioural change in MCI has on marital relationships (Garand, Dew, Urda, Lingler, DeKosky & Reynolds, 2007) and resulting caregiver burden (Blieszner & Roberto, 2010; Garand, Dew, Eazor, DeKosky & Reynolds, 2005) may give greater salience to socio-emotional functioning of PwMCI for informants.

When assessing awareness at the level of evaluative judgment, in particular when considering memory and functional ability, the discrepancy between participant and informant report is considered the gold standard approach. The relationship between participant and informant is an important consideration. As has been discussed, a change in the personality of the person with MCI along with their individual coping style will influence the nature of the relationship upon which discrepancy indices of awareness are formed. It is also relevant to consider whether the informant is living with the person with MCI and the type of relationship, whether spouse, child or friend. A spouse living with the person with MCI may be more negatively influenced than a friend who lives close by, whereas a marital relationship may provide a more supportive environment than that of a child living away, who may not fully appreciate the difficulties experienced by PwMCI or who may become overly concerned as a result of worry about their parent. Such issues are an important when considering the nature of discrepancies between participant and informant accounts, from a research and clinical perspective.

At both time points, measures in the three domains produced varying degrees of magnitude in discrepancy between self- and informant ratings. The greatest discrepancies between PwMCI and informant ratings were for functional ability. A moderate discrepancy was observed for memory with the smallest discrepancy being for socio-emotional functioning. Although PwMCI appear to recognise difficulties in functional ability, it is this domain which produces the greatest discrepancy between self- and informant report. As functional ability has the greatest influence on maintaining autonomy, PwMCI may adopt a greater response bias than in other domains.

Whether the discrepancy between self- and informant report reflects an inaccurate judgment by PwMCI, suggesting poor awareness, or an inaccurate judgment by the informant, either suggesting a lack of informed knowledge about the person or informant bias, or some combination of these, should be taken into account when interpreting these findings. A review of studies exploring discrepancies between PwMCI and informant reported functional ability and memory (Schinka, 2010) suggests that informant ratings are more reliable than the ratings of PwMCI when compared to objective measures. The absence of significant changes in informant measures of wellbeing, stress and distress over time in the current study suggest that these factors did not adversely influence the informant reports, which adds support to their accuracy.

One limitation of the current study is the conservative sample size at entry and the small number of participants left at follow up as a result of attrition. Prevelance rates of MCI amongst older adults in the community can vary between 3 and 36% (Busse, Bischkopf, Riedel-Heller & Angermeyer, 2003) and depend on which criteria are applied (Luck, Luppa, Briel & Riedel-Heller, 2010). Recruitment for this study took place in a memory clinic which potentially missed people in the community who would meet the criteria for MCI but had not come forward for assessment (Stephan et al., 2008) as a result of poor awareness and consequent absence of SMC (Lin et al., 2010). The low number of participants has implications for the conclusions which can be reached from any statistical analysis. However, linear mixed models analysis is designed for studies with unequal time points and unequal data for each participant at each time point (West, 2009).

Despite these limitations, the current study has explored the longitudinal trajectory of awareness in MCI across the objects of memory and functional ability which are the most prevalent studied domains in MCI with the addition of the object of socio-emotional functioning which has previously not been explored from a longitudinal perspective. Methodological issues already highlighted in the literature (Roberts et al., 2009) have been taken into account with a clear definition of awareness, the use of isomorphic measures and discrepancy scores corrected for scaling effects.

Conclusion

The current study found that despite a decline in certain areas of cognitive function in PwMCI, longitudinal trajectories of discrepancy indices of awareness across the domains of memory, functional ability and socio-emotional functioning remained stable over the time period of the study. Cognitive decline cannot therefore be solely associated with changes in awareness and other variables such as social and psychological factors should be considered as relevant. PwMCI are more likely to note changes in functional ability than in memory or socio-emotional functioning, but to a lesser extent than informants. A decline in functional ability can signal the transition from MCI to dementia; therefore clinicians should be particularly mindful of responses from PwMCI to questions about everyday activities.

Chapter 6

Discussion

Awareness is a complex phenomenon which has been the subject of much research in recent years yet conclusions as to its nature in people with MCI (PwMCI) remain unclear. This is a result of methodological limitations and a lack of clarity amongst research studies with regard to the specific aspect of awareness explored. These issues were considered in the literature review (chapter 2; Roberts, Clare & Woods, 2009). This provided a systematic evaluation of literature in this area, which informed the subsequent studies detailed in this thesis. This thesis aimed to provide a comprehensive profile of awareness in MCI with the main question focussing on the impact MCI symptoms have on individuals and how this is then appraised, what factors influence that appraisal and how this influences expressed awareness. Each chapter (3, 4 and 5) provides evidence relating to levels of awareness in MCI (Clare, Markova, Roth & Morris, in press), from the most complex meta-representational level explored in chapter 3 to levels of evaluative judgment and performance monitoring explored in chapters 4 and 5. These results will be synthesised in this chapter. The results of each study as well as theoretical challenges and clinical implications in relation to current research in this area will be discussed. Limitations of the thesis as well as possible future research in the area will also be considered. The research questions posed by this thesis were as follows:

Literature review (chapter 2)

1. Does level of awareness of memory functioning vary among people diagnosed with MCI?
2. Do lower levels of awareness of memory functioning in people diagnosed with MCI predict conversion to dementia?

IPA study (chapter 3)

3. How do PwMCI understand the diagnosis of MCI and its implications with regard to the risk of developing dementia?
4. What is the psychological impact of living with MCI and how do PwMCI cope with this?
5. How do PwMCI appraise their memory difficulties and how does this influence their experience of the condition, their understanding of the condition and the way in which they cope?

Cross-sectional quantitative study (chapter 4)

6. What is the profile of awareness in patients identified as MCI with regard specifically to memory functioning, memory performance, functional ability and social functioning?
7. Which psychosocial and neuropsychological factors relate to and best predict discrepancy indices of awareness for each domain?

Longitudinal study (chapter 5)

8. What patterns of change occur in self- and informant ratings and discrepancy scores in the domains of memory, activities of daily living and socio-emotional functioning over a period of 12-15 months?
9. Does change in awareness over time relate to changes in cognitive functioning, and do changes in PwMCI and informant ratings of awareness relate to changes in psychosocial variables?

Summary of research findings

Chapter 2 consists of a literature review which explored the association between subjective memory complaint (SMC) and awareness in studies exploring these concepts in PwMCI. The review highlighted conceptual issues demonstrated by inconsistent terminology, with varying definitions and theoretical foundations underpinning the awareness concept. Methodological issues were discussed and recommendations made for future research. The review also emphasised that although SMC is a measure of awareness when compared to some kind of standard such as objective testing, it excludes people who may meet the criteria for MCI yet who do not present with SMC. Although there is limited comparable evidence in the area, it was demonstrated that awareness does vary amongst PwMCI. The review showed that the role of awareness in predicting conversion to dementia is something which requires further study, due to there being only one study exploring this at the time of the review (Tabert et al., 2002). The subsequent chapters in the thesis explore what factors influence the variation in awareness level across PwMCI.

Chapter 3 explored the meta-representational level of awareness, which is considered the most complex level of awareness and incorporates judgments which can be directed at aspects of the self or towards the environment. As the meta-representational level of awareness concerns how an individual experiences a phenomenon and how this shapes their view of self and others, IPA was considered the most suitable method for this purpose (Clare, Markova, Roth & Morris, in press). There is limited qualitative research which examines awareness in MCI. Of the two studies identified which discuss this issue, the relevance of awareness was an adjunct rather than the focus of the study (Frank et al., 2006; Lingler et al., 2006). It was therefore indicated that the experience of MCI should be explored further with particular emphasis on the influence living with MCI has on expressed awareness. The IPA study suggested that the experience of MCI was perceived with fear and uncertainty resulting from appraisals made by PwMCI of their memory difficulties. This resulted in context-specific coping responses which influenced expressed awareness.

MCI as a diagnosis had little meaning for the participants, as evidenced by the absence of the term ‘mild cognitive impairment’ in participant interviews and the continued search by some for a definitive label. Themes elicited in this study were interpreted as demonstrating that PwMCI did perceive MCI symptoms as a threat to psychological wellbeing which was demonstrated by the over-arching theme of ‘fear and uncertainty’. The remaining three themes demonstrated the use of active coping strategies (interdependence, life goes on as normal and disavowal of difficulty). The theme of ‘Interdependence’ related to aspects of the environment, specifically relationships with others. This theme demonstrated how perceived support networks impact on appraisal of MCI symptoms. The theme ‘Life goes on as normal’ demonstrated the acknowledgement by participants of MCI symptoms. However, as all participants had experienced memory clinic assessment and subsequent feedback of MCI diagnosis, the attribution of MCI symptoms to what participants considered normal aging was suggestive of a coping method. In what could be considered a more dysfunctional strategy, the theme of ‘Disavowal of difficulty’ was interpreted as an explicit attempt by participants to dissociate from the perceived negative outcome of MCI symptoms.

Chapter 4 provides a profile of awareness of memory, functional ability and socio-emotional functioning from a quantitative perspective which focuses on awareness at the level of evaluative judgments and performance monitoring (Clare, Markova, Roth & Morris, in press). Evaluative judgments were represented by discrepancy indices of awareness between PwMCI and informants on parallel forms of domain specific questionnaires. Performance monitoring was represented by a discrepancy score between postdiction self-rating and performance on an ecologically valid memory test. In order to consider awareness from a biopsychosocial perspective, neuropsychological and psychological measures were administered and associations between these variables and indices of awareness explored. If informant reports were considered accurate, a greater discrepancy between self- and informant-report would be suggestive of poorer awareness for PwMCI. Impairments in episodic memory and executive function were predictive of a greater discrepancy between self- and informant-reported memory function in PwMCI which suggests that poorer cognition is associated with reduced awareness. There was a tendency for PwMCI to over-estimate their memory ability in comparison to informants and to a lesser extent when monitoring performance on a memory task. There was evidence to suggest that low levels of anxiety in PwMCI and lower informant wellbeing were associated with greater discrepancies between self- and informant rated functional ability, where PwMCI under-report difficulties. Poor relationship quality and poorer language function for PwMCI was predictive of PwMCI rating their socio-emotional functioning more positively than informants, which demonstrates the impact low awareness of functional ability and socio-emotional functioning has on relationship quality and informant wellbeing.

An important finding observed in chapter 4 was that patterns of over- and under-estimation of ability for evaluative judgments were similar to people with a diagnosis of Alzheimer’s disease (AD) whereas for performance monitoring, these patterns were similar to those found in data collected from healthy older people

(Clare, Whitaker & Nelis, 2010). This suggests that if MCI is considered an intermediate stage between healthy aging and dementia, the ability to make evaluative judgments deteriorate before the ability to monitor performance. Functional impairments are minimal in MCI; indeed, it is this which demarcates between MCI and a diagnosis of dementia. The ability to monitor performance may therefore be an important factor upon which to focus rehabilitative methods which aim to maintain or improve performance monitoring.

Chapter 5 is a longitudinal study which explores patterns of change over time of in awareness of memory, functional ability and socio-emotional functioning, focussing on cognitive change and the role of psychosocial variables. Indices of awareness for memory, functional ability and socio-emotional functioning remained stable over time, despite a significant decline in verbal episodic memory and executive function. It is therefore posited that although an association was found between poorer cognition (episodic memory and executive function) and reduced awareness for memory (Chapter 4), a significant deterioration in episodic memory and executive function is not associated with level of awareness for memory, functional ability and socio-emotional functioning in PwMCI over time. The involvement of other associated factors which influence awareness is therefore implicated. The only domain which showed a significant change for PwMCI was functional ability, where PwMCI showed greater recognition of changes in everyday ability, although these figures were still an over-estimation when compared to informants. This finding could reflect that tangible change in everyday life is a more salient occurrence than subsequent changes in memory or socio-emotional functioning. Functional ability would require the ability to monitor performance and could reflect the finding in chapter 4, that PwMCI have performance monitoring abilities similar to healthy older adults. Informants also reported significant change in functional ability as well as socio-emotional functioning over time. Both these variables have an impact on informant wellbeing and relationship quality which clearly give them greater salience for informants when making evaluative judgments.

A comprehensive profile of awareness in MCI

The primary aim of this thesis was to explore the impact MCI symptoms have on individuals and how this is then appraised, what factors influence that appraisal and how this influences expressed awareness. The literature on awareness in MCI was limited and as a result of methodological and conceptual differences across studies, comparison proved difficult. There was evidence, however, that levels of awareness vary in people with MCI although there was little agreement whether the degree of impairment of awareness in MCI was similar to people with dementia (Vogel et al., 2004) or not (Hanyu et al., 2006). The need to focus on awareness rather than SMC was specified with further exploration of the factors relating to poor awareness amongst people with MCI and how this influences the elicited awareness phenomenon. The biopsychosocial model of awareness in MCI is supported, with variables other than neuropsychology influencing the accuracy of expressed awareness. At the meta-representational level of awareness, the person with MCI may be resistant to acknowledge changes in memory, as a result of fear and uncertainty and in relation to their social circumstances. This thesis provides a comprehensive profile of awareness in MCI; however, the nature of the interaction between facets of the biopsychosocial model of awareness remains unclear. Specifically, it is difficult to distinguish between resistance/dissociation and the neurological aspects of awareness. Dissociative coping methods are employed to diminish the impact memory and cognitive difficulties have on daily life, which is a finding supported by others (Coolidge, Segal, Hook & Stewart, 2000). The label of MCI has little meaning for those meeting the criteria (Dale, Hougham, Hill & Sachs, 2006) which may increase negative attributions applied to MCI symptoms.

Neuropsychological factors are associated with awareness in MCI, specifically episodic memory and executive function, which is consistent with the literature (Anderson & Schmitter-Edgecombe, 2010; Orfei et al., 2010), although a decline in these neuropsychological functions does not influence discrepancy indices of awareness over a 12-15 month time period which suggests that other factors are relevant. Psychosocial factors found to be relevant in this thesis are level of anxiety and relationship quality (Garand et al., 2007).This supports the biopsychosocial model of awareness in MCI. At the level of evaluative judgment and performance monitoring, PwMCI over-estimate dysfunction in memory as compared to informant rating or an objective memory task although there is closer agreement in performance monitoring (Perrotin, Belleville & Isingrini, 2007). PwMCI acknowledge changes in functional ability more readily than for memory and socio-emotional functioning which is consistent with the similarities found in chapter 4 between PwMCI and healthy older controls in performance monitoring (Clare, Whitaker & Nelis, 2010).

Theoretical challenges

From a theoretical perspective, the challenges faced by researchers in the field of MCI relate to the heterogeneity of MCI across participants, heterogeneity across clinical outcomes, vagueness of the MCI criteria, and whether the participants are sourced from clinical or community populations (Petersen et al., 2009). This thesis has introduced a further challenge, which is that of awareness. The study of awareness is faced with its own set of challenges as already outlined, the acknowledgment of which has led to a clear definition of awareness and appropriate methodology throughout each of the studies detailed in this thesis. MCI is rather more complex as its identification in a clinical setting could not be influenced by the researcher in this instance. The thesis does, however, give an overview of a group of PwMCI who presented at memory clinic and the findings here are applicable to that population (participant numbers notwithstanding).

If a clear rationale for using a particular method for assessing awareness is given, and limitations of previously adopted methods accounted for, knowledge and theories of awareness can be expanded. The framework upon which awareness has been placed in this thesis, involves four levels, which are each subject to different processes; sensory registration, performance monitoring, evaluative judgments and meta-representation (Clare, Markova, Roth & Morris, in press). For the theory of awareness to evolve, the adoption of such a framework across studies is recommended. This thesis provides evidence relating to performance monitoring, evaluative judgments and meta-representation which provides an overall profile of awareness in MCI; the experience of MCI is uncertain for the individual resulting in context-specific coping responses, evaluative judgments often involve an over-estimation of ability when compared to an informant whereas performance monitoring has been shown to be at a similar level to healthy older controls.

Practice implications

There is evidence to suggest that MCI represents a prodrome of dementia for some individuals (Petersen et al., 2009). As a result of the variability across PwMCI, not all those identified as meeting the criteria for MCI will progress to dementia, with some people staying the same or less commonly, showing an improvement. It is not recommended that clinicians adopt any label which incorporates dementia in its title such as ‘incipient dementia’ as this may impact negatively on individuals and families. As evidenced by the findings in chapter 3, the core experience of MCI is one of fear and uncertainty. The aim of a label would be to offer some meaning to the person with MCI so that they could acknowledge the potential for progression to dementia and be mindful of their own ability and any observed changes. A neutral term such as ‘MCI’ is therefore preferable in providing a label for changes in cognition which are not severe enough to be termed a dementia (Petersen et al., 2009). The term MCI is not familiar to the general public (Dale, Hougham, Hill & Sachs, 2006) and the lack of knowledge about the term leads to uncertainty for PwMCI (Lingler et al., 2006; McIlvane, Popa, Robinson, Housewart & Haley, 2008; Moody & Whitehouse, 2004). Steps to promote knowledge of MCI would therefore encourage individuals and their families to seek advice at the earliest stage of decline, and provide a meaningful label to the symptoms experienced by PwMCI (Koppel & Dallos, 2007).

If the purpose of the MCI construct is to afford people who are at the earliest stage of a dementia process the opportunity to engage in occupational and preventative therapies, the awareness level of the individual will impact on the identification of people who meet MCI criteria by clinicians. This was demonstrated in the literature review (chapter 2; Roberts, Clare & Woods, 2009). The identification of PwMCI depends on the person recognising their symptoms and seeking appropriate medical advice. If SMC are acknowledged, even those people who may not have a quantifiable decline in cognition will in all probability seek advice. The key issue is the existence of those individuals who do not present for assessment but who would otherwise meet MCI criteria. If these individuals do not have someone close to them who would recognise a problem, they may well have developed a severe decline in cognition when presenting to services, thus removing the potential for intervention. Promoting knowledge of the MCI construct amongst non-health professionals working with older people may result in help and appropriate support for some people who would otherwise be missed at the earliest stage of decline. Better knowledge of MCI amongst the general public and those working with older people may then result in better outcomes for PwMCI who do not seek help as a result of poor awareness.

The themes elicited from the IPA study suggest the influence of social and psychological variables in determining the expressed appraisal of cognitive function made by PwMCI. The inclusion of statements relating to each of the coping strategy themes within some individual interviews indicate that clinicians should be mindful that even where a person sounds positive (e.g. makes a comment such as “life goes on as normal”), they may still perceive MCI symptoms as a threat to psychological wellbeing and this should be closely monitored, with appropriate support offered in each individual case. An explanation of MCI may be useful for some, with the possibility of future dementia discussed. This in itself may evoke positive coping responses. The willingness of PwMCI to engage in any type of intervention will also be influenced by their explicit awareness of MCI symptoms. Increasing awareness is not necessarily the aim of intervention; the improvement in symptoms attributable to psychosocial variables could, however, result in more accurate appraisal or recognition of there being a problem. The retention of performance monitoring ability suggests that interventions with a performance monitoring focus may be of particular benefit. Rehabilitative methods have been found useful (Li et al., 2011) and may support a longer period of independent functioning for those people who will eventually progress to dementia.

Limitations

A limitation for the thesis was participant numbers. Thirty participants were recruited at the initial time point and eighteen remained at follow up. This limits the conclusions which can be drawn and may have limited the potential for statistical significance in some variables. The recruitment of MCI participants was particularly challenging for this thesis; in particular the requirement of an informant restricted the available pool of participants. The rate of diagnosis of MCI in memory clinic settings is small and may miss those who did not come forward for assessment (Stephan et al., 2008). This could be as a result of poor awareness (Lin et al., 2010). The Mayo Clinic Study of Aging found the prevalence rate for MCI in a non-demented community dwelling sample to be 15%, with a ratio of 2:1 for amnestic MCI and non-amnestic MCI (Roberts et al., 2008). Similar rates of between 14 to 18% have been found in community populations internationally (Petersen et al., 2009). It would be logical to presume that prevalence rates in clinical settings would be less as many people who would otherwise meet MCI criteria may be monitored by their GP and would not become known to memory clinics. Similarly, those with a great deal of familial support may not present to their GP as the impact of cognitive decline would be minimised.

Conclusions resulting from the studies which make up this thesis are subject to some limitations. The IPA study detailed in chapter 2 had relatively short interviews, between 11 and 30 minutes across 25 participants. It was felt, however, that there was sufficient data from the obtained interviews to conduct the analysis. Additionally, the term ‘mild cognitive impairment’ was not introduced by the researcher which may have influenced the apparent lack of knowledge about the construct in interviews. However, its introduction in the semi-structured interview may have been ethically questionable and the purpose of the interview was to elicit participant awareness of the construct in addition to the experience and subsequent appraisal of the symptoms of MCI. The opinions of family members are not included in the IPA study which may have offered further information relating to the awareness of the participant in the form of triangulation (Cohen & Manion, 1986). This would also help to minimise interviewer bias in interpreting the themes.

A further limitation, which resulted from the conservative sample size, was the absence of overt sub-classification of the sample into single or multiple amnestic domain forms of MCI. The purpose of the research was to develop a comprehensive profile of awareness in MCI, and as such, did not explore the nature of awareness across different MCI profiles. The objects of awareness included in the thesis concerned memory, functional ability and socio-emotional functioning. The conclusions reached with regard to memory could apply to both single and multiple domain amnestic MCI whereas those with multiple domain amnestic MCI may present differently on functional ability and socio-emotional functioning if, for example, their executive function or language was poor as opposed to a participant with single domain amnestic MCI who had good functioning in other cognitive areas. However, the use of discrepancy indices of awareness limits the relevance of symptom classification in profiling awareness and the inclusion of neuropsychological data allows inferences to be made about the relationship between cognitive profile and awareness. The sample included in this thesis did not include any participants with non-amnestic MCI.

Future directions

The systematic literature review (chapter 1: Roberts, Clare and Woods, 2009) has already informed current research in MCI (e.g. Calabria et al., 2011; Schinka, 2010; Kurt, Yener & Oguz, 2011; Thames et al., 2011; Greenop et al., 2011; Nobili et al., 2010). The clear rationale and clarity provided by the studies incorporated in this thesis can inform future research on methodological and conceptual issues concerning the study of awareness in MCI. Additionally, based on the findings of this thesis, future research could explore whether awareness influences progression from MCI to dementia, and build upon the only currently identifiable study which is suggestive of this (Tabert et al., 2002). The profile of awareness across sub-types of MCI would also be of benefit and may inform future work on the influence of awareness level on progression to dementia. The finding in chapter 3 of retained performance monitoring in PwMCI suggests that cognitive rehabilitative techniques with a performance monitoring focus may be of benefit in maintaining or improving current functioning for PwMCI; in particular this may delay the onset of dementia for those who would otherwise decline at a quicker rate. Rehabilitative techniques, specifically those which utilise performance monitoring ability are therefore worthy of further exploration which would add to current research in this area (for a review, see Lin et al., 2011).

The symptoms of MCI not only impact on the individual but also their partners and close family (Blieszner & Roberto, 2009; Garand, Dew, Eazor, DeKosky & Reynolds, 2005; Garand et al., 2007). Future qualitative research could explore how level of awareness in PwMCI impacts on personal relationships by interviewing both the PwMCI and their informant, which would offer a form of triangulation (Cohen & Manion, 1986). This would offer further evidence as to the profile of awareness in PwMCI and inform the design and implementation of rehabilitative interventions. The quantitative and qualitative exploration of awareness in PwMCI drawn from a community sample who do not present for memory clinic assessment may provide further information as to the nature of awareness in people who would otherwise meet MCI criteria but who do not feel their problems are of sufficient magnitude to warrant help seeking behaviour.

Conclusion

This thesis has produced a comprehensive profile of awareness in MCI, through the use of multiple and ecologically valid methods of measuring awareness, with the implementation of different study designs appropriate for measuring different aspects and objects of awareness. A specific definition of awareness was provided at the outset and each study has adhered to this definition. Implications are highlighted of using SMC in MCI diagnostic criteria, and it is suggested that the more inclusive concept of awareness is adopted than SMC in research studies so that those PwMCI who do not express SMC are identified. Importantly, this thesis demonstrates that changes in awareness level have little association with change in cognition over a 12-15 month period, which suggests that factors other than cognition impact on expressed awareness. Social and psychological factors are implicated as being essential in understanding a person's expressed awareness, findings which support the biopsychosocial model of awareness. However, it is unclear how to distinguish between an inaccurate level of expressed awareness as a result of conscious resistance/dissociation and an inaccurate level of expressed awareness as a result of neurological deterioration. The concept of MCI is clearly necessary as even at the milder stages of decline, MCI symptoms impact on the individual which has been demonstrated by the identified coping mechanisms employed. Equally, the thesis has demonstrated that there is a clinically significant impact on relationships which indicates the need for continued support following memory clinic involvement for PwMCI and their families in order to promote wellbeing for all concerned. It is therefore imperative that the work to further clarify MCI continues, in particular the specific biopsychosocial factors of awareness in MCI which are associated with the onset of dementia, with empirically validated rehabilitative methods employed to retain independent functioning in partnership with the immediate family.

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Appendix A

Measures used in study 2 and 3

Assessment of Awareness

The Memory Awareness Rating Scale (MARS; Clare, Wilson, Carter, Roth & Hodges, 2002)

Clare, L., Wilson, B. A., Carter, G., Roth, I., & Hodges, J. R. (2002) Assessing awareness in early-stage Alzheimer's disease: Development and piloting of the Memory Awareness Rating Scale. *Neuropsychological Rehabilitation*, *12*, 341-362.

This measure assesses memory awareness across two domains; (1). The memory function scale (MFS) assesses subjective views of everyday memory function and (2). The memory performance scale (MPS) assesses views of memory performance immediately following experience of an objective memory task, namely the Rivermead Behavioural Memory Test (RBMT). The RBMT tasks are analogues of the real-life situations covered in the MFS, thus allowing direct comparison across both domains. Both scales are rated from 0 to 4 where 0=Never and 4=Always. The MFS is available for both participants and informants where a discrepancy score represents an evaluative measure of awareness. A performance measure of awareness is calculated by subtracting RBMT profile scores from MPS scores. The MFS participant version can be seen in appendix I. Internal consistency for the MFS and MPS using Cronbach's alpha yielded scores of .94 and .93 respectively. For test-retest reliability, the MFS and MPS yielded scores of .91 and .97 respectively for participant self-rating.

Functional Activities Questionnaire (FAQ; Pfeffer, Kurosaki, Harrah, Chance & Filos, 1982)

Pfeffer, R.I., Kurosaki, T.T., Harrah Jr, C.H., Chance, J.M. & Filos, S. (1982) Measurement of functional activities in older adults in the community. *Journal of Gerontology*, **37** (3), 323-329.

Originally a ten item questionnaire of everyday functional ability, for the purposes of this study a further question related to telephone use was added. See appendix J for the version used. Scoring for each item consisted of (0a) Never did, but could do now (0b) Normal (1a) Have difficulty, but can do by myself (1b) Never did, and would have difficulty now (2) Require assistance and (3) Dependent. Over the eleven items, a maximum score of 33 could be achieved, with a lower score indicating better functioning. The original ten-item version showed validity compared to MMSE or r = -.71. Parallel versions of this questionnaire were administered to both PwMCI and informants and the discrepancy was considered a measure of awareness.

Socio-Emotional Questionnaire (SEQ; Bramham, Morris, Hornak & Rolls, 2003)

Bramham, J., Morris, R.G., Hornak, J. & Rolls, E.T (2003) Emotional and social consequences of orbitofrontal and non-orbitofrontal lesions of the prefrontal cortex. Rotman Research Institute abstracts. *Brain and Cognition*, **51**, 234-236.

This scale (see appendix K) was designed to measure social and emotional functioning with both self and informant rating. The discrepancy score between both self and informant rating is used as a measure of awareness. Respondents are asked to rate their socio-emotional functioning in terms of their ability to recognise emotions, the extent of their empathetic reactions and behaviour in social situations. There are 10 statements relating to emotion recognition and empathy of five basic emotions (happiness, anger, sadness, fear, and disgust). The remaining 20 items consist of statements concerning relationship skills, anti-social behaviour and public. Each response is rated on a 5 point scale (1 slightly agree, to 5 strongly disagree) and can be summed for sub-total scores and an overall score. Maximum possible score is 150 with lower scores demonstrating better socio-emotional functioning. Nine items are reverse scored to reduce systematic directional bias when rating. It has demonstrated reliability and validity with brain injury patients and with adolescents.

Neuropsychological Assessment

Mini-Mental State Examination (MMSE; Fostein et al, 1975)

Folstein, M.F, Folstein, S.E. & McHugh, P.R. (1975) “Mini-Mental State”: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, **12** (3), 189-198.

The MMSE was administered as a preliminary screening of cognitive dysfunction across the domains of orientation, registration, attention, recall and language. Scores can indicate severe (≤9 points), moderate (10-20 points) or mild (21-24 points) cognitive dysfunction. Scores range from 0-30 with higher scores representing better functioning. The MMSE has shown good reliability over 24hour and 28day periods where $r = .887$ following re-administration by the same examiner after 24hours and $r = .827$ following re-administration by a different examiner after 24hours.

National Adult Reading Test (NART; Nelson, 1991)

Nelson, H.E. (1991) *National Adult Reading Test: Second Edition*. NFER-Nelson, Windsor, UK.

The National Adult Reading Test (NART) is used for estimating premorbid intelligence levels. This measure consists of 50 English words which are read out loud and which are scored as either 0=correct or 1=incorrect for the pronunciation of each word. Scoring is therefore ranged from 0-50 with a lower score being indicative of better premorbid intelligence. The total error score is transformed into predicted full scale IQ, predicted verbal IQ and predicted performance IQ where IQ is then categorised as either below average, average or above average.

The Rivermead Behavioural Memory Test-2 (RBMT-2; Wilson, Cockburn & Baddeley, 2003)

Wilson, B.A., Cockburn, J. & Badderley, A. (2003) *The Rivermead Behavioural Memory Test Second Edition: Manual*. Harcourt Assessment: London

The RBMT was developed to detect impairments in memory function. Each sub test provides analogues of everyday memory situations such as remembering a name, an appointment and faces. There are four parallel versions of the RBMT (a,b,c,d) so that practice affects are avoided. Thirteen items measuring different aspects of everyday memory. For each sub test two scores are produced, a screening score, and a standardized profile score. The screening score ranges from 0 to 12 and the standardized profile score ranges from 0 to 24.

Weschler Memory Scale-word list subtest (WMS-III; Weschler, 1997)

Wechsler, D. (1997). *Wechsler Memory Scale: Third Edition*. San Antonio, TX: The Psychological Corporation.

The WMS-III is a battery of memory measures which evaluate working memory, learning and immediate and delayed recall. The word list subtest used in this study evaluated immediate and delayed recall which was representative of episodic memory and consisted of a list of 12 words. These words are read out and the participant asked to repeat all remembered words in any order. For each recalled word, the participant scores 1 point. There are 4 trials, with the first 3 trials being administered immediately and the 4th being administered after a 20 minute delay. Total recall score for all trials was calculated where the maximum score was 48 with lower scores representing poorer functioning.

Delis-Kaplan Executive Function System-verbal and category fluency subtest (D-KEFS; Delis, Kaplan & Kramer, 2001)

Delis, D. C., Kaplan, E. & Kramer, J. H. (2001). *Delis-Kaplan Executive Function System (D-KEFS).* London: Pearson.

In both subtests the participant is asked to either to produce as many words as possible which begin with a particular letter of the alphabet (Verbal fluency) or to produce as many words as possible which belong to a particular category (e.g. animals; Category fluency). The verbal fluency task is a means of evaluating the fluency with which the participant can generate words whilst simultaneously adhering to several rules. Scores on this test represent several fundamental and executive-function abilities which include verbal knowledge and processing and monitoring abilities. Category fluency shares many of the demands of Verbal fluency yet is a more familiar, overlearned task as it involves generating words belonging to a particular category rather than words beginning with a particular letter. If semantic knowledge were intact, Category fluency would yield better scores than Verbal fluency.

Graded Naming Test (GNT; McKenna & Warrington, 1983)

McKenna, P. & Warrington, E.K. (1983) *Graded Naming Test: Manual*. Cambridge Cognition Limited: Cambridge.

The GNT was created to measure impaired language function. A booklet with 30 line drawings is shown to the participant and they are asked to name each item they are shown. Less frequent items were used as they tend to be more vulnerable than more frequent, well-practised items in word retrieval difficulties. Therefore an individual with an extensive vocabulary may perform well despite having a language disorder if more frequent words were used to assess his/her memory. The graded naming test allows for individual differences while also measuring less frequent word finding ability. For each correct name given, the participant scores 1. Maximum score is therefore 30 on this test with a lower score representing poorer functioning. The NART and GNT have been found to be highly correlated (*r* = .62).

Pyramids and Palms Trees Test (P&PT; Howard & Patterson, 1992)

Howard, D., & Patterson, K. (1992) *The Pyramids And Palm Trees Test: A Test Of Semantic Access From Words To Pictures.* Harcourt Assessment: London.

This test consists of a booklet consisting of 52 pages with each page showing 3 pictures. Participants are asked to point to one of two pictures which relate to the remaining picture. Information from the test enables the tester to establish whether a subject's difficulty in pointing to a picture is due to a difficulty in retrieving semantic information from pictures. Scoring: 1 for each correct and 0.5 for each refusal. Maximum score is 52 with lower scores representing poorer functioning. 26/52 is expected by chance. 33 is better than chance at $p<0.05$, 35 at $P<0.01$ and 38 or better at $P<0.001$ (Binomial test, one tailed). If a patient scores 90% or better they do not have clinically significant impairment in this task. No patient norms, as pattern of impairment across the different versions of the test are more important than absolute score.

Assessment of psychological and social variables

Quality of Life-Qol-Ad (Logsden, Gibbons, McCurry & Teri, 1999)

Logsden, R.G., Gibbons, L.E., McCurry, S.M., & Teri, L. (1999) Quality of life in Alzheimer's disease: patients' and caregivers' reports. *Journal of Mental Health and Aging,* **5** (1), 21-32.

The Qol-Ad involves participants rating different aspects of their current situation in a number of areas including physical health, mood, memory, functional abilities, interpersonal relationships, financial situation, and global assessments of self as a whole and QOL as a whole. Response options are 4-point multiple choice options (1 = poor, 4 = excellent). Scale scores range from 13 to 52, with higher scores indicating greater QOL. This test has been found to have good internal reliability ($\alpha = 0.88\text{-}0.89$) and test-retest reliability after a week is $r = 0.76$.

The Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmond, 1994)

Snaith, R. P. & Zigmond, A. S. (1994). *The hospital and anxiety depression scale.* Windsor: NFER-Nelson.

The HADS (see appendix L) is a screening tool for anxiety and depression. There are two subscales (1) anxiety (scores 0-21) and (2) depression (scores 0-21). Higher scores suggest the presence or absence of clinically meaningful degrees of mood disorders. Bjellanda, Dahlb, Tangen Haugx and Neckelmann (2002) report HADS internal consistency for anxiety as mean Cronbach's $\alpha = .83$ (range .68 - .93) and depression as mean $\alpha = .82$ (range .67 - .90).

Bjellanda, I., Dahlb, A.A., Tangen Haugc, T. & Neckelmann, D. (2002) The validity of the Hospital Anxiety and Depression Scale: An updated literature review. *Journal of Psychosomatic Research,* **52**, (1), 69-77.

The Tennessee Self Concept Scale (TSCS; Fitts & Warren, 1996)

Fitts, W.H., Warren, W.L. (1996) *Tennessee Self-concept Scale Manual: Second Edition.* Los Angeles: Western Psychological Services.

The Tennessee Self Concept Scale is a measure of personality. The scale summarises an individual's feeling of self-worth, how realistic the self-image is, and whether or not that self-image abnormal. The version of the TSCS used in this study consisted of the first 20 items (out of 100) of the original measure. No subscales or validity scores are in the short form version.

The Positive Affect Index (PAI; Bengston, 1982)

Bengston, V. L. (1982). *Positive affect index. In Research Instruments in Social Gerontology, D. J. Mangen & W. A. Peterson, Eds.* University of Minnesota press: Minneapolis, MN, p. 154.

This questionnaire was used with both PwMCI and informants ratings obtained to provide an evaluation of the quality of the dyadic relationship. The PAI assesses the amount of positive affect that the respondent has for another person with five questions addressing communication quality, closeness, similarity of views on life, engagement in joint activities and overall relationship quality. Each response is rated on a 6 point scale (1 not well, to 6 extremely well) and summed for a total score. Possible scores range from 5-30, with higher scored indicating better quality of relationship.

The NEO Conscientiousness Scale- Five-Factor Inventory (NEO-FFI; Costa & McCrae, 1992)

Costa, P.T., Jr., & McCrae, R.R. (1992) *Manual for the Revised NEO Personality Inventory (NEO-PIR) and NEO Five-Factor Inventory (NEO-FFI).* Psychological Assessment Resources, Odessa, FL.

The NEO-FFI is a personality inventory. The short version, the NEO-Five Factor Inventory (NEO-FFI**)**, has 60 items (12 items per domain). For this study, the conscientiousness scale was used with 12 statements covering competence, order, dutifulness, achievement, self-discipline and deliberation. These were scored on a scale of 0 (Strongly disagree) to 4 (Strongly agree). Items 3,6,9,11 were reversed scored. Maximum score is 48 with a higher score indicating a higher level of the listed conscientiousness traits. The internal consistency of the NEO is reported as .90.

Informant Measures

The Neuropsychiatric Inventory Questionnaire (NPI-Q; Kaufer, Cummings, Ketchel, Smith, MacMillan, Shelley, Lopez & DeKosky, 2000)

Informants provided information in a questionnaire format on the presence or absence of 12 neuropsychiatric symptoms including delusions, hallucinations, aggression, depression, anxiety, elation, apathy, disinhibition, irritability, aberrant motor behaviours, night-time and appetite disturbances. Present behaviours are scored for severity (1-Mild to 3-Severe) and distress (0-No distress to 5-Extremely Distressing). Higher scores reflect greater frequency of symptoms, symptom severity and higher levels of caregiver distress associated with the symptoms. The NPI-Q is a shorter version of the Neuropsychiatric Inventory (NPI), which is a structured interview with established reliability and validity

The General Health Questionnaire-28 item version (GHQ; Goldberg, 1992)

Goldberg, D., & Williams, P. (1991) *A User's Guide To The General Health Questionnaire.* NFER-Nelson: Windsor.

The General Health Questionnaire (GHQ) is a measure of current mental health. The scale asks whether the respondent has experienced a particular symptom or behaviour recently. Each item is rated on a four-point scale (0=less than usual, 1=no more than usual, 2=rather more than usual, or 3=much more than usual) giving a maximum score of 36 (lower being better). Reliability, specificity and sensitivity are reported as follows: Split half reliability r = 0.83: Test-retest reliability r = 0.73: Specificity 78.5%: Sensitivity 93.5%

The Relatives' Stress Scale (RSS; Green, Smith, Gardiner & Timbury, 1982)

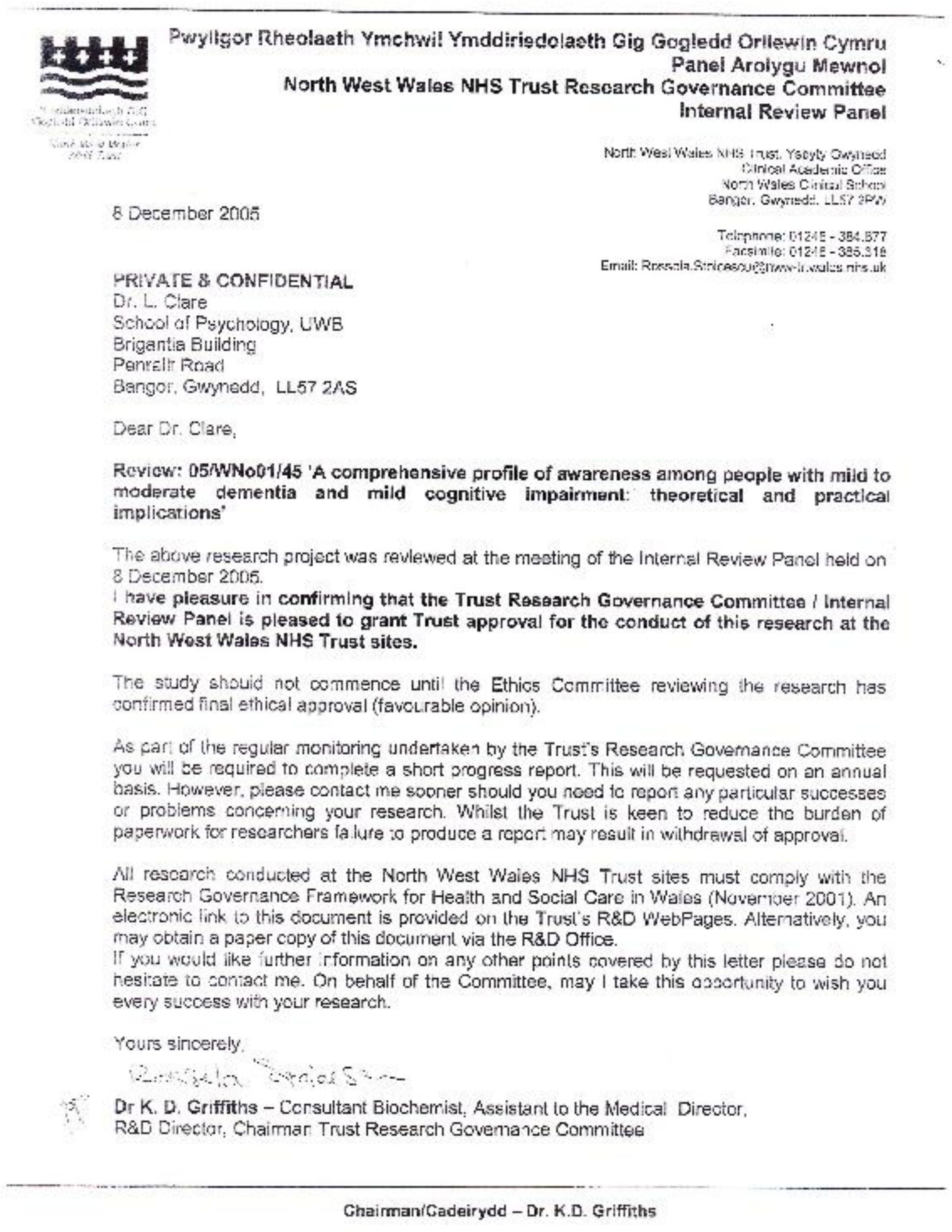
Green, J.G., Smith, R., Gardiner, M., & Timbury, G.C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effect on relatives. *Age and Ageing, 11,* 121-126.

A 15 item self-report measure designed to assess the degree of distress and social upset experienced by a relative as the result of caring for a person with physical and/or behavioural difficulties. Each item is assessed using a scale from 0 to 4 (never, rarely, sometimes, frequent, always), with higher scores indicating more severe stress.

The Positive Affect Index (PAI; Bengston, 1982)

See previous.

Appendix B



Pwyllgor Rheolaeth Ymchwil Ymddiriedolaeth Gig Gogledd Orllewin Cymru
Panel Arolygu Mewnol
North West Wales NHS Trust Research Governance Committee
Internal Review Panel

North West Wales NHS Trust, Ysbyty Gwynedd
Clinical Academic Office
North Wales Clinical School
Bangor, Gwynedd, LL57 2PW

Telephone: 01248 - 384.877
Facsimile: 01248 - 385.319
Email: Rossela.Stnicescu@nww-tr.wales.nhs.uk

8 December 2005

PRIVATE & CONFIDENTIAL
Dr. L. Clare
School of Psychology, UWB
Brigantia Building
Penrallt Road
Bangor, Gwynedd, LL57 2AS

Dear Dr. Clare,

Review: 05/WNo01/45 'A comprehensive profile of awareness among people with mild to moderate dementia and mild cognitive impairment: theoretical and practical implications'

The above research project was reviewed at the meeting of the Internal Review Panel held on 8 December 2005.
I have pleasure in confirming that the Trust Research Governance Committee / Internal Review Panel is pleased to grant Trust approval for the conduct of this research at the North West Wales NHS Trust sites.

The study should not commence until the Ethics Committee reviewing the research has confirmed final ethical approval (favourable opinion).

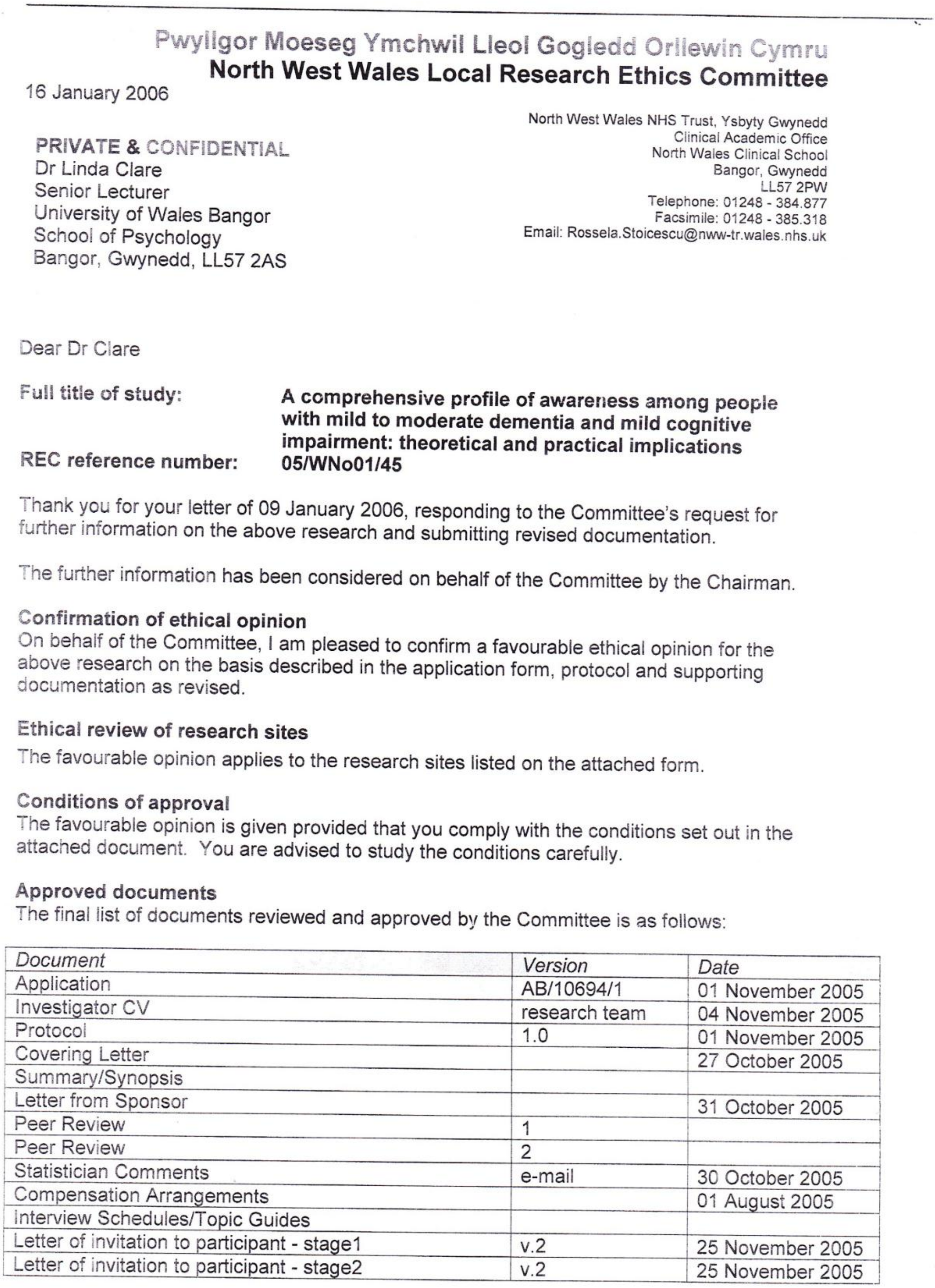
As part of the regular monitoring undertaken by the Trust's Research Governance Committee you will be required to complete a short progress report. This will be requested on an annual basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst the Trust is keen to reduce the burden of paperwork for researchers failure to produce a report may result in withdrawal of approval.

All research conducted at the North West Wales NHS Trust sites must comply with the Research Governance Framework for Health and Social Care in Wales (November 2001). An electronic link to this document is provided on the Trust's R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.
If you would like further information on any other points covered by this letter please do not hesitate to contact me. On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Yours sincerely,

Dr K. D. Griffiths – Consultant Biochemist, Assistant to the Medical Director,
R&D Director, Chairman Trust Research Governance Committee

Chairman/Cadeirydd – Dr. K.D. Griffiths



Pwyllgor Moeseg Ymchwil Lleol Gogledd Orllewin Cymru
North West Wales Local Research Ethics Committee

North West Wales NHS Trust, Ysbyty Gwynedd
Clinical Academic Office
North Wales Clinical School
Bangor, Gwynedd
LL57 2PW
Telephone: 01248 - 384.877
Facsimile: 01248 - 385.318
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16 January 2006

PRIVATE & CONFIDENTIAL
Dr Linda Clare
Senior Lecturer
University of Wales Bangor
School of Psychology
Bangor, Gwynedd, LL57 2AS

Dear Dr Clare

Full title of study:	**A comprehensive profile of awareness among people with mild to moderate dementia and mild cognitive impairment: theoretical and practical implications**
REC reference number:	**05/WNo01/45**

Thank you for your letter of 09 January 2006, 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 Chairman.

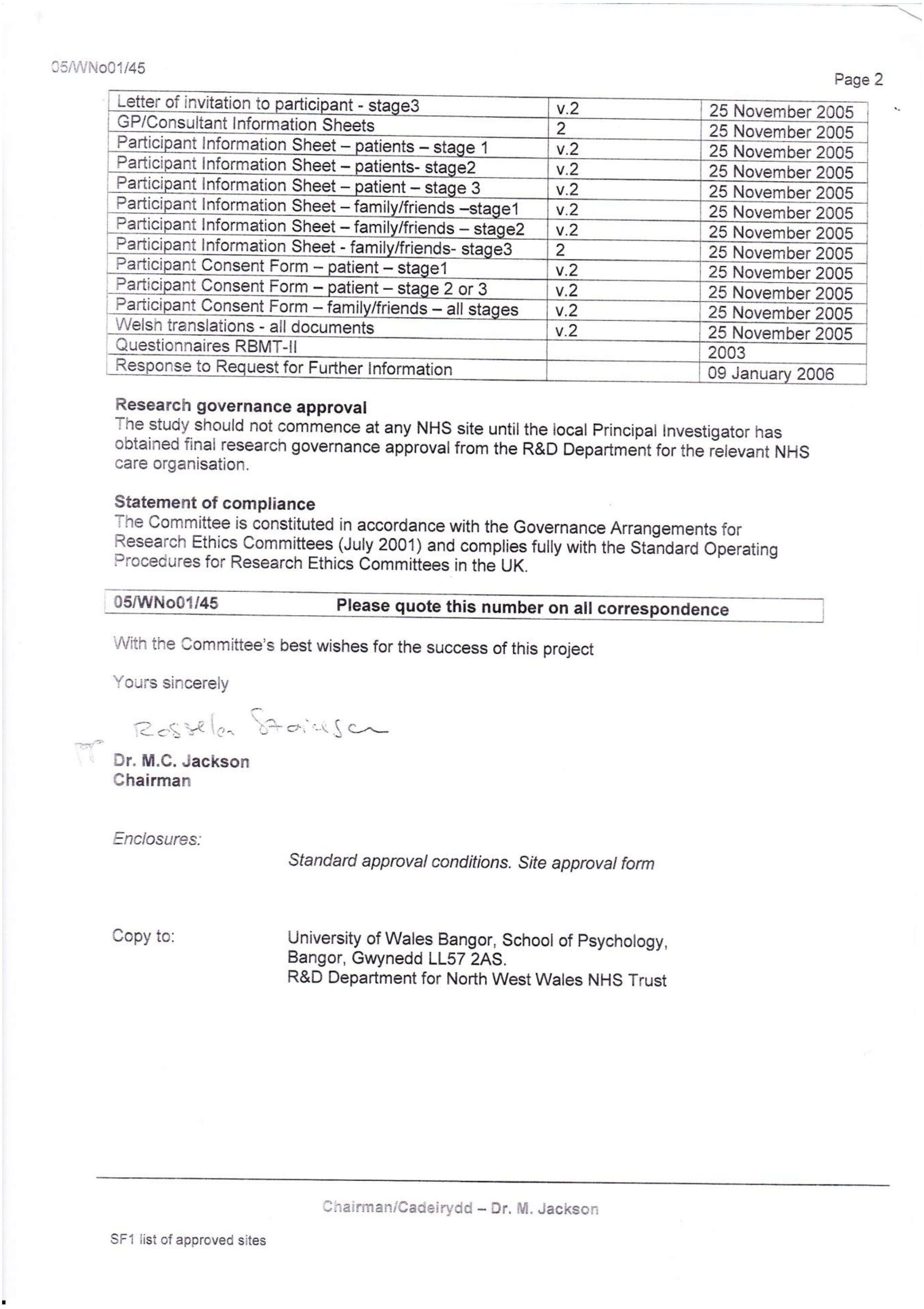
Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites
The favourable opinion applies to the research sites listed on the attached form.

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

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

Document	*Version*	*Date*
Application	AB/10694/1	01 November 2005
Investigator CV	research team	04 November 2005
Protocol	1.0	01 November 2005
Covering Letter		27 October 2005
Summary/Synopsis		
Letter from Sponsor		31 October 2005
Peer Review	1	
Peer Review	2	
Statistician Comments	e-mail	30 October 2005
Compensation Arrangements		01 August 2005
Interview Schedules/Topic Guides		
Letter of invitation to participant - stage1	v.2	25 November 2005
Letter of invitation to participant - stage2	v.2	25 November 2005



Letter of invitation to participant - stage3	v.2	25 November 2005
GP/Consultant Information Sheets	2	25 November 2005
Participant Information Sheet – patients – stage 1	v.2	25 November 2005
Participant Information Sheet – patients- stage2	v.2	25 November 2005
Participant Information Sheet – patient – stage 3	v.2	25 November 2005
Participant Information Sheet – family/friends –stage1	v.2	25 November 2005
Participant Information Sheet – family/friends – stage2	v.2	25 November 2005
Participant Information Sheet - family/friends- stage3	2	25 November 2005
Participant Consent Form – patient – stage1	v.2	25 November 2005
Participant Consent Form – patient – stage 2 or 3	v.2	25 November 2005
Participant Consent Form – family/friends – all stages	v.2	25 November 2005
Welsh translations - all documents	v.2	25 November 2005
Questionnaires RBMT-II		2003
Response to Request for Further Information		09 January 2006

Research governance approval

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

Statement of compliance

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

05/WNo01/45	**Please quote this number on all correspondence**

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

Yours sincerely

pp Rosselen Staiusen

Dr. M.C. Jackson
Chairman

Enclosures: *Standard approval conditions. Site approval form*

Copy to: University of Wales Bangor, School of Psychology,
Bangor, Gwynedd LL57 2AS.
R&D Department for North West Wales NHS Trust

SF1 list of approved sites

North West Wales Local Research Ethics Committee

LIST OF SITES WITH A FAVOURABLE ETHICAL OPINION

For all studies requiring site-specific assessment, this form is issued by the main REC to the Chief Investigator and sponsor with the favourable opinion letter and following subsequent notifications from site assessors. For issue 2 onwards, all sites with a favourable opinion are listed, adding the new sites approved.

REC reference number:	05/WNo01/45	**Issue number:**	1	**Date of issue:**	16 January 2006

Chief Investigator:	Dr Linda Clare
Full title of study:	A comprehensive profile of awareness among people with mild to moderate dementia and mild cognitive impairment: theoretical and practical implications

This study was given a favourable ethical opinion by North West Wales Local Research Ethics Committee on 16 January 2006. The favourable opinion is extended to each of the sites listed below. The research may commence at each NHS site when management approval from the relevant NHS care organisation has been confirmed.

Principal Investigator	*Post*	*Research site*	*Site assessor*	*Date of favourable opinion for this site*	*Notes* (1)
Dr. L. Clare	Senior Lecturer UWB Honorary Consultant	Ysbyty Gwynedd, North West Wales NHS Trust Department of Medicine – Neurology Pharmacy Department	North West Wales Local Research Ethics Committee	16/01/2006	

Approved by the Chair on behalf of the REC:

Rossela Stoicescu .... (Signature of ~~Chair~~/Administrator)
(delete as applicable)

ROSSELA STOICESCU .... (Name)

Ymddiriedolaeth GIG Siroedd Conwy a Dinbych
Conwy & Denbighshire NHS Trust

Date: 7 August 2007

PRIVATE & CONFIDENTIAL

Dr L Clare
Reader in Psychology
School of Psychology
University of wales Bangor
Bangor
Gwynedd LL57 2AS

Dear Dr Clare

Re: A comprehensive profile of awareness among people with mild to moderate dementia and mild cognitive impairment theoretical and practical implications.

Trust Ref: 2007/psych/372

The above research project was reviewed at the meeting of the Trust Research Governance Committee / Internal Review Panel held on 7 August 2007.

I have pleasure in confirming that the Internal Review Panel is pleased to grant Trust approval to proceed at the Conwy & Denbighshire NHS Trust site

The study should not commence until the Ethics Committee reviewing the research has confirmed final ethic approval (favourable opinion).

As part of the regular monitoring undertaken by the Trust's Research Governance Committee you will be required to complete a short progress report. This will be requested on a six monthly basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst the Trust is keen to reduce the burden of paperwork for researchers failure to produce a report may result on withdrawal of approval.

All research conducted at Conwy & Denbighshire NHS Trust site must comply with the Research Governance Framework for Health and Social Care in Wales (November 2001). An electronic link to this document is provided on the Trust's R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office. If you would like further information on any other points covered by this letter please do not hesitate to contact me. On behalf of the Committee, may I take this opportunity to wish you every success with your research.

Yours Sincerely

Lara Tudor Jones

pp Dr A B W Nethersell
Director R&D

Cc Julie Whitmore, Ethics Administrator, YGC

Ysbyty H. M. Stanley, Llanelwy, Sir Ddinbych LL17 0RS. Ffôn: 01745 583910 Ffacs: 01745 589717
H. M. Stanley Hospital, St. Asaph, Denbighshire LL17 0RS. Phone: 01745 583910 Fax: 01745 589717
Gwefan: www.ymdd-gig-cd.cymru.nhs.uk Website: www.cd-tr.wales.nhs.uk
Rydym yn croesawu yn y Gymraeg a'r Saesneg
We welcome correspondence in Welsh and English
Ymddiriedolaeth Ddi-fwg
A Smoke Free Trust
NHS WALES GIG CYMRU

Appendix C

Participant information sheet

UNDERSTANDING THE EXPERIENCE OF MEMORY DIFFICULTIES.

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others 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. Thank you for reading this information sheet.

What is the purpose of the study?

This study aims to explore the thoughts, feelings and experiences of people who have been to a memory clinic. In particular, we are interested in what people who have been to a memory clinic think about their memory. We would like to understand more about this in order to improve the future care and support of people who attend the memory clinic and who experience memory problems. For each person who has attended the memory clinic, we would also like to ask someone who knows the person well for their views on how that person is managing with his/her memory. Usually this will be a husband, wife, other family member, or close friend.

Why have I been chosen?

You have been invited to take part because you have attended a Memory Clinic in North Wales and have had a memory assessment.

Do I have to take part?

It is up to you whether or not you take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of medical care you receive.

What will happen to me if I take part?

If you take part in the study, a researcher will come to see you at your home (or if you prefer, you can meet the researcher at the university, or another location of your choice). The researcher will make two or three visits over the course of a few weeks, and will:

1. Talk with you about your experiences. This interview will be audio-taped to allow us to examine your views in detail. Some of your responses may be quoted when we write reports about the study but no-one will know who said what. It is worth considering that the interview might explore issues that you find upsetting or difficult to talk about, but the researcher will be sensitive to this. You will also be given a contact telephone number, so that you can talk to someone if you still feel upset once the researcher has left.
2. Help you to fill in several questionnaires that explore your thoughts and feelings about yourself and your current situation, including your quality of life, mood, and relationships.
3. Ask you to carry out some simple tasks that allow us to evaluate your memory, attention, and concentration abilities. These will involve looking at a variety of pictures, patterns and words; listening to stories; answering general knowledge questions; and solving problems.

4. With your permission, talk with a family member or someone else who knows you well to find out their views.

After these initial visits, we may like to see you and your relative/friend again after 12 months, and then again after 24 months. The researcher will contact you again to ask if you would be happy to be visited again. If so, the researcher will talk with you about how you are getting on and will ask you to fill in some questionnaires and carry out some memory tasks. These will be similar to the ones you completed initially.

What do I have to do?

If you decide to take part in the study, all you have to do is to be willing to set aside some time to meet with the researcher. The researcher will visit you at home, unless you prefer to meet at the University of Wales Bangor or at another location of your choice, in which case we will pay your travel expenses.

What are the possible disadvantages and risks of taking part?

We do not think that participation will involve any specific risks.

What are the possible benefits of taking part?

The information we get from this study may help us to understand and support people with memory difficulties better in the future. Participants who have taken part in this type of study in the past have said that they found the opportunity to talk about their experiences helpful

What if new information becomes available?

If any relevant information becomes available during the course of study, the researcher will advise you and ask you if you wish to continue with the study.

What if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence then you may have grounds for a legal action, but you may have to pay for it. Regardless of this, if you wish to make a complaint about any aspect of the way you have been approached or treated during the course of the study, the normal National Health Service complaints procedures should be available to you. If you are unhappy or dissatisfied about any aspect of your participation, we would ask you to tell us about this in the first instance, so that we can try to resolve any concerns and find a solution. Complaints can also be addressed to our Head of Department, Dr Oliver Turnbull, at the School of Psychology, Bangor University.

Will my taking part in the study be kept confidential?

We will ask your permission to send your GP and your hospital consultant a letter, explaining that you have agreed to take part in the study. All the information that you give us during the course of the study will be kept strictly confidential. If we use this information in preparing reports about the study we will make sure that you cannot be identified personally in any way.

What will happen to the results of the research study?

When the study is complete, the results will be presented at scientific conferences and published in scientific journals. We will also contribute articles to journals and newsletters aimed at people with memory difficulties, caregivers, practitioners and policy-makers. We will write to you individually to let you know the results of the study.

Who is organising the research?

The lead researcher is Professor Linda Clare, who is a senior lecturer in the School of Psychology at the University of Wales Bangor and a consultant clinical psychologist in the Memory Clinic at Ysbyty Gwynedd.

Who can I contact for further information?

Professor Linda Clare, School of Psychology, University of Wales Bangor,
Bangor, Gwynedd, LL57 2AS
Telephone: 01248 388178
E-mail: l.clare@bangor.ac.uk

Judith Roberts, School of Psycholgoy, University of Wales Bangor,
Bangor, Gwynedd, LL57 2AS
Telephone : 01248 388210
E-mail : judith.roberts@bangor.ac.uk

Thank you for considering taking part in this research study!

Appendix D

Participant consent form

Study Number:
Participant Identification Number:
Stage of study: Initial

What do people who have attended a memory clinic think about their memory?
Lead Researcher: Professor Linda Clare

Please initial box

1. I confirm that I have read and understood the information sheet for the above study, and have had the opportunity to ask questions. ☐
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 or legal rights being affected. ☐
3. I understand that sections of my medical notes may be looked at by the researchers where it is relevant to my taking part in the study. I give permission for these individuals to have access to my records. ☐
4. I agree to my GP and hospital consultant being informed by letter that I am taking part in this study. ☐
5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Name of Researcher	Date	Signature

1 for participant; 1 for researcher; 1 to be kept with hospital notes

Appendix E

Initial conversation: **I'd like to start by asking**

- How are you?
- How are you feeling in yourself – how have things been for you recently?
- How do you spend your time - what do you like to do - hobbies and interests?
- What do you do in a typical day?
- What things are important to you now?
    - How has that changed as you have gotten older?
- How is your life now compared to what it used to be like in the past?
    - What has changed for you?
- What is important to you and/or have your views changed on life between now and in the past?

If needed to build rapport more before start

- How is your family? (e.g. children/grandchildren)
- Where originally come from?
- What job did you do?

Current situation and functioning **I'm interested in how things change for us as we get older and go through life. I'm particularly interested in your experiences because you've been along to the memory clinic.**

Changes: (Have they noticed changes in themselves over time, and if so, what changes?)

- What changes have you noticed?

Have you noticed changes in?

- memory
- thinking
- activities of daily living
- general participation in activities and interests
- changes in interacting with people
- in relationships with family and friends

For any changes - ask what they attribute these to and what sense they make of this, to gain an idea of how they explain the changes to themselves.

- What do you attribute these changes to?
- How can you explain the changes
- What did you think it was at the time? How did you explain these changes?
- Who noticed the changes first?
- What led you to go to the Memory Clinic?
- Can you tell me what led up to your attendance at the clinic?
- What happened at the clinic?
- What you were told at the memory clinic?

If willing (acknowledge dementia)

- What does dementia mean to you?
    - How is it affecting you at the moment?
- What do you understand of the term?
    - What are your perceptions of dementia?

- What are its implications (both now and in the future)?
    - How has it already changed your life?
    - How do you think it will affect you in the future?

Emotional situation: How they react to any changes - (are they serious, or can they be dismissed or covered up)

- How do you now explain the changes - (part of normal ageing, or a sign of an illness?)
- How do you feel about the changes?
- How have you reacted to the changes?
- Does the situation bother you or upset you - How do you feel?
    - Do you prefer to avoid thinking about it?
- Do you feel that you are the same person, or different?
- Do you feel it has affected how other people treat/interact with you? If so – how?

Information:

- What information have you gained from other sources (media/internet) support groups
- Do you know of anyone else (family members/friends) who has had difficulties with their memory? Can you tell me about that?

How do they try to deal with their situation?

- How do you cope? - do you actively try to cope with it, or just let things develop?
- How do you compensate for any difficulties?
    - What things are you doing to help you remember? What strategies do you use?
- Do you take medication or use services?
- What help do you receive? Who helps?
- How do you see the future?
- What would you like to see in the future?

Summarise How do they react to and explain changes? (Serious or ignorable? Normal ageing or worse)

Explore what perspectives they think other people hold (spouse/son/daughter etc.)

- What do you think others think about the changes? (carers/family/friends etc)
- What changes have others noticed?
    - Can you tell me what they say/have noticed?
- How do you think others would explain the changes?
- How have they reacted to the changes?
    - What does it feel like for them?
- How are they coping with things?

- Do you talk with each other about the future? (How are things between you and your relative?).

End on a positive note

- Are there any questions you thought we may ask?
- Anything you would like to add?
- Returning to some of the themes elicited at the beginning.
- Emphasise areas for which the participant expressed enthusiasm or interest, or where the participant shows particular strengths.

Appendix F

Summary of themes from one interview transcript (participant 11)

11) I’ve got a thick head
11) Tired (can’t keep going for long)
11) Can’t sit for long
11) Can’t remember
11) Not interested (in TV)
11) Thing that I noticed first (names of things)
11) It’s just by chance (mentioned to doctor)
11) Bit bothered
11) Could be a bit of stress
11) Good and bad (not a steady downhill)
11) It is worse than others
11) Frustrating
11) I haven’t got lost (I know where I am)
11) Still think it’s funny
11) I don’t do a lot of (cooking) now
11) I don’t worry
11) A different type of dementia
11) Same questions (at MC)
11) Nobody’s explained (it’s my fault)
11) No way of knowing (the future)
11) I want to know
11) It’s not just a memory condition
11) There’s got to be a cause
11) People get to a certain age
11) Thunderstruck (about going to MC)
11) Not as if i’m on my own

Appendix G

List of interview extracts relating to the theme of 'it's all down to age'

1
Getting old.
I think it's cause I'm getting old.
I don't worry about getting old.
I tend to accept things you can do and you can't do as you get older.
Your body is breaking down isn't it.
We get different aches and pains at this time of life.
Where's all my muscles gone.

Natural deterioration.
There's nothing worse I think than being told that you, you know, oh it happens to everybody.
So, just a natural phenomenon
Perhaps there is nothing there.
You don't know, is it just natural deterioration?
Am I worrying over nothing.

9
Your brain isn't dancing about so much (as you get older)
all it does is draw attention to the fact that you forget stuff, but so do half the population.
not quite submitting to the fact that my, that my memory is absolutely defunct, I'm seventy so I expect a deterioration you know
I view it in that context mainly, in the interest of that context, as you get older your brain isn't dancing about so much and you've got to stop and think

Well I'm getting older

I don't know really because I just expect….you know, you go, well I'm getting older and I missed the bus at the wrong time
Age probably (why the memory problem?)
Well I remember, I used to teach bunches of students and I do remember the names uh, they remember mine which was a miracle you know cause it's a very odd name
It seems to me, as if the issue is being made out of a very normal uhm progressive part of living your life

11
People get to a certain age
You have to say oh it's old age y'know, alright yeah I'll have to accept that
But the way mine was going, I'm not that old, I'm reasonably fit y'know, I'm still active
People get to a certain age and sit in their chairs all day long and look out of the window
I'm fine no er I mean obviously the age throws you down a bit

13
When you get to our age
I sometimes wonder what's, who’s gunna go first [J] or myself cos you know when you get..to our age {laughs}.

16
You’re growing old
Well just that it's, it's you're growing old and that’s it {laugh}.

17
I can say it’s old age
Well, I can’t – I don’t really believe that it can be. Erm, I can say that it’s old age, it makes me feel good does that.
I know other people who are a lot older but I don’t know, at least I’m not aware that they have any problems with memory, they certainly don’t, you know, they don’t seem to

18
Just normal
Well I was just normal {laughs}.
Well I’ll put it down to old age actually

19
I don’t know
I don’t know unless – I really don’t know unless it's my age or what have you. You can't – you can't put – pinpoint it can I

20
A certain age
But you might just spend all your money and..just enjoy yourself I say. You know, when you get to a certain age.

22
It’s the cycle of old age
it’s maybe stupid but I put down to old age, it’s the cycle of old age, I don’t know now but I put down to that anyway like aye
I came to the conclusion that it’s part of old age and it’s one of the things
I know different people with different things as they get older and, you know what I mean, and I think this is just one of the things and I’ve got it
26
Because of age
my own family, they’re gradually dying off, you know, because of their ages
I took it for granted that these sort of things that I’m doing now is old age.
I just think it must be when you’re getting older
he’s left his thing, oh, well, yeah, yeah, you know, can’t help it. My mother used to say, “Well, he’ll do that, you know, because of his age.”
Well, I think they’re just like me, just, just that’s old age I suppose (what family thinks)

27
In the beginning I thought it was old age
Well, in the beginning I thought it was old age but it’s beyond that myself

everybody I talk to, “Oh, I’m the same, I forget things and I don’t recognise people.” Alright, I don’t know, I didn’t expect that.

29
It’s getting older isn’t it
Well I suppose it’s getting older isn’t it

Appendix H

PARTICIPANT	01/RB	02/PD	04/RC	05/JW	06/PE	07/DE	09/NH	11/BW	12/DS	13/AB	16/RJ	17/HA	18/JG	19/CC	20/LP	21/JK	22/JF	24/RF	25/WM	26/SH	27/JH	28/RJ	29/BL	30/KW	32/JG
INTERDEPENDENCE																									
They made me go to the memory clinic			X						X			X										X			X
It's not spoken about										X					X		X	X							
I am alone (do things by myself)							X		X								X						X		
It's done for me	X					X												X			X			X	X
There's concern from others		X										X													
Good to have others there for you		X						X		X					X					X			X		
DISAVOWAL OF DIFFICULTY																									
It's all down to age	X						X	X		X	X	X	X	X	X		X			X	X		X		
Nothing much happened at the memory clinic			X		X		X	X		X	X	X				X	X			X		X		X	X
I can't remember	X	X	X	X	X	X		X	X	X	X			X	X	X	X	X	X		X	X	X		
LIFE GOES ON AS NORMAL																									
Life is good!				X			X												X			X		X	
I just get on with life	X	X	X		X			X		X	X	X	X		X	X	X			X	X	X	X		X
I still do things							X	X	X							X				X		X		X	X
There is nothing wrong		X		X	X		X		X	X		X	X	X	X				X	X	X	X			X
It's quite amusing really	X						X	X																	
FEAR AND UNCERTAINTY																									
Not able to do things	X	X	X	X		X		X		X	X	X		X	X		X	X	X				X	X	
Feeling bad about it	X		X		X		X	X	X	X	X			X	X		X	X		X	X		X	X	
Trying to cope	X	X			X	X	X	X		X			X		X		X	X		X					
What is it?	X			X			X	X		X		X		X	X			X		X				X	
A different person	X	X	X		X	X	X	X		X		X	X		X		X	X			X	X	X		

Appendix I

Memory Functioning Scale (MFS-S) – Self-Report – Participant

Participant Number: P_____________ Name: _______________________________

Examiner: ________________________________ Date: _____________ Session: _____

I'm going to give you some examples of everyday situations where you might need to use your memory. I want you to think about your own memory, as it is now, and tell me how you think you would manage in that situation. I want you to choose the answer which best describes how you would do. The answers are on the card here. These are the situations.

SITUATION:	FREQUENCY 0 = Never 1 = Rarely 2 = Sometimes 3 = Often 4 = Always
1. You meet someone and are told their name. Later on you meet them again, and you need to remember their name.	0 1 2 3 4
2. You have made an appointment and need to remember to go along.	0 1 2 3 4
3. You have promised to do something later in the day and need to remember to do it at the right time.	0 1 2 3 4
4. You have got a set of items to sort out, some of which you have seen before and some of which are new to you. You need to pick out the ones you have seen before.	0 1 2 3 4
5. You hear a news item on the radio. a) One of your family comes in at the end and asks you what was said. b) Later on – say half an hour later – someone else asks you what you heard.	0 1 2 3 4 0 1 2 3 4
6. You meet up with a group of people. Some of them you've met before, others you haven't. You need to recognise which ones you've met before.	0 1 2 3 4
7. You go to a new building and you are learning to find the way around. Someone shows you a short route which you will need to remember. a) You need to retrace the route immediately. b) You need to retrace the route again later on – say half an hour later.	0 1 2 3 4 0 1 2 3 4
8. You have been given a message to deliver to someone. You need to remember to give that person the message when you see them. a) You see them right away. b) You see them later on.	0 1 2 3 4 0 1 2 3 4
9. You are being asked to give some information about yourself, such as age, address, date of birth, and so on, and to answer a few basic general knowledge questions.	0 1 2 3 4
10. Someone asks you for today's date.	0 1 2 3 4

Appendix J

Functional Activities Questionnaire (FAQ)

Participant Number: P_____________ Name: _______________________________

Examiner: ________________________________ Date: _____________ Session: _____

3 – Dependent
2 – Require assistance
1a – Have difficulty, but can do by myself
1b – Never did, and would have difficulty now
0a – Normal
0b – Never did, but could do now

1.	Can you write cheques, pay bills, and keep financial records?	………....
2.	Can you assemble tax records, make out business or insurance papers?	………....
3.	Can you shop alone for clothes, household necessities and groceries?	………....
4.	Can you play a game of skill (e.g. bridge, chess, cards, crosswords) or working on a hobby (e.g. gardening)?	………....
5.	Can you heat water for coffee or tea and turn off the stove?	………....
6.	Can you prepare a balanced meal?	………....
7.	Can you keep track of current events?	………....
8.	Can you pay attention to, understand and discuss a TV programme, book or magazine?	………....
9.	Can you remember appointments, family occasions and to take your medication?	………....
10.	Can you travel out of the immediate local area – driving, arranging to take buses etc.?	………....
11.	Are you able to use the telephone appropriately (e.g. finding & dialling correct numbers)?	………....
	Total ..	………..

Appendix K

Socio-emotional Questionnaire

Participant Number: P_____________ Name: _______________________________

Please circle the number to the right of the question that best describes you.

1	I express my feelings appropriately in public	1	2	3	4	5
2	I avoid arguments	1	2	3	4	5
3	When others are afraid, I reassure them	1	2	3	4	5
4	I speak my mind	5	4	3	2	1
5	I notice when other people are happy	1	2	3	4	5
6	I am critical of others	5	4	3	2	1
7	I am amusing	1	2	3	4	5
8	I notice when other people are frightened	1	2	3	4	5
9	When others are happy, I am pleased for them	1	2	3	4	5
10	I am not aggressive	1	2	3	4	5
11	I co-operate with others	1	2	3	4	5
12	I notice when other people are disgusted	1	2	3	4	5
13	I am impatient with other people	5	4	3	2	1
14	I am apologetic	1	2	3	4	5
15	When others are angry, I calm them down	1	2	3	4	5
16	I am confident meeting new people	1	2	3	4	5
17	I have difficulties making and keeping close relationships	5	4	3	2	1
18	I notice when other people are sad	1	2	3	4	5
19	I am sociable	1	2	3	4	5
20	When others are disgusted, I am appalled for them	1	2	3	4	5
21	I take a long time to make decisions	5	4	3	2	1
22	I do what I want to and do not care what others think	5	4	3	2	1
23	I notice when other people are angry	1	2	3	4	5
24	I do things without thinking	5	4	3	2	1
25	I have good manners	1	2	3	4	5
26	I am close to my family	1	2	3	4	5
27	I let someone know if I find them attractive	1	2	3	4	5
28	I keep in touch with old friends	1	2	3	4	5
29	I prefer being alone than with others	5	4	3	2	1
30	When others are sad, I comfort them	1	2	3	4	5
	Total					

Appendix L

Hospital Anxiety and Depression Questionnaire

Total A	
Total D	

This questionnaire asks about your feelings and well-being. Reply to which is closest to how you have been feelings in the past week. ***Do not take a long time over your answers; it is better just to give your immediate response.***

1	**I feel tense or 'wound up':**	
	Most of the time	**3**
	A lot of the time	**2**
A	**From time to time, occasionally**	**1**
	Not at all	**0**

2	**I still enjoy the things I used to enjoy:**	
	Definitely as much	**0**
	Not quite so much	**1**
D	**Only a little**	**2**
	Hardly at all	**3**

3	**I get a sort of frightened feeling as if something awful is about to happen:**	
	Very definitely and quite badly	**3**
	Yes, but not too badly	**2**
A	**A little, but it doesn't worry me**	**1**
	Not at all	**0**

4	**I can laugh and see the funny side of things:**	
	As much as I always could	**0**
	Not quite so much now	**1**
D	**Definitely not so much now**	**2**
	Not at all	**3**

5 **A**	**Worrying thoughts go through my mind:**	
	A great deal of the time	**3**
	A lot of the time	**2**
	From time to time, but not too often	**1**
	Only occasionally	**0**

6 **D**	**I feel cheerful:**	
	Not at all	**3**
	Not often	**2**
	Sometimes	**1**
	Most of the time	**0**

7 **A**	**I can sit at ease and feel relaxed:**	
	Definitely	**0**
	Usually	**1**
	Not often	**2**
	Not at all	**3**

8 **D**	**I feel as if I am slowed down:**	
	Nearly all the time	**3**
	Very often	**2**
	Sometimes	**1**
	Not at all	**0**

9 **A**	**I get a sort of frightened feeling like ‘butterflies’ in the stomach:**	
	Not at all	**0**
	Occasionally	**1**
	Quite often	**2**
	Very often	**3**

10 **D**	**I have lost interest in my appearance:**	
	Definitely	**3**
	I don't take as much care as I should	**2**
	I may not take quite as much care	**1**
	I take just as much care as ever	**0**

11	**I feel restless as I have to be on the move:**	
A	**Very much indeed**	**3**
	Quite a lot	**2**
	Not very much	**1**
	Not at all	**0**

12	**I look forward with enjoyment to things:**	
D	**As much as I ever did**	**0**
	Rather less than I used to	**1**
	Definitely less than I used to	**2**
	Hardly at all	**3**

13	**I get sudden feelings of panic:**	
A	**Very often indeed**	**3**
	Quite often	**2**
	Not very often	**1**
	Not at all	**0**

14	**I can enjoy a good book or radio or TV program:**	
D	**Often**	**0**
	Sometimes	**1**
	Not often	**2**
	Very seldom	**3**