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# Anxiety in Older People with Mild Cognitive Impairment and Early Dementia

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## Contents

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## Thesis Abstract

Little is known about the psychological experiences of older adults with mild cognitive impairment (MCI) although there is some evidence that they exhibit high levels of anxiety. The first paper of this thesis reviews some of the literature on MCI and goes on to explore possible explanations for anxiety within this group. There is some evidence that greater anxiety may be related to greater awareness of cognitive impairment, particularly in social situations. The literature on awareness is critically reviewed and the potential impact of social factors, particularly social phobia and social support on those with MCI and dementia is discussed. This paper concludes with a discussion of potential areas for future research.

The second paper of this thesis describes a study, which has aimed to explore factors potentially relating to the high levels of anxiety observed in individuals with MCI, using a mixed qualitative and quantitative methodology. This study found a nonsignificant trend towards greater anxiety in a group of individuals with MCI when compared to a group with early dementia (ED) and, as predicted, a significant relationship between anxiety and awareness. No evidence was found for specific roles for social anxiety or social support in relation to anxiety or awareness in those with MCI and ED. The qualitative analysis highlighted areas of concern for individuals with cognitive impairment, including social interactions, loss of skills and fears for the future. The implications for clinical practice of these findings are also discussed.

**Literature Review Paper:**

# Anxiety in Older People with Mild Cognitive Impairment: The Role of Awareness and Social Factors.

Philippa M. A. Wilson

Prepared as if for submission to 'Age and Ageing'

# Anxiety in Older People with Mild Cognitive Impairment: The Role of Awareness and Social Factors.

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**Abstract**

Mild cognitive impairment (MCI) is a relatively new and controversial diagnosis that is frequently given to older individuals who show some degree of impairment of cognitive function, usually memory, but do not meet criteria for a diagnosis of dementia. There is very little research which has investigated the psychological experiences or needs of this group, although two studies have found that they have shown high levels of anxiety compared both to those with dementia and those without cognitive impairment. As yet no explanations have been provided for these high levels of anxiety. This review considers possible explanations, mainly drawn from the literature on anxiety in individuals with dementia.

Research into anxiety in individuals with dementia has suggested that there may be a relationship between increased anxiety and retained awareness of difficulties. This may be relevant for those with MCI given that their awareness is typically intact. The current research base on awareness in dementia is reviewed and limitations are discussed, particularly the difficulties in measuring awareness and the role of other psychological factors such as denial.

Research into anxiety and dementia has raised the possibility that anxiety may relate specifically to social situations, particularly in those with retained awareness. The implications of this for those with MCI and the potential roles of social support in relation to anxiety within this group are considered.

Areas for future research are discussed both in relation to enhancing current understanding of anxiety in MCI and in terms of considering possible psychological interventions for anxiety in those with cognitive impairment.

**Keywords:** mild cognitive impairment, dementia, anxiety, awareness, social support.

## Introduction

This paper considers the diagnosis of 'mild cognitive impairment' (MCI), including the controversy around the diagnosis and the uncertain prognosis it presents for those who receive it. The review will go on to discuss the lack of psychological research in this group, particularly in ight of the evidence that individuals with MCI present with high levels of anxiety. Explanations for this anxiety will be sought, first by considering research which has looked at anxiety in those with dementia and then by considering possible links with levels of awareness of cognitive deficits. The review will then consider the relevance of social factors, and particularly the potential social anxiety that might result from awareness of deficits and the role of social support. Finally, there is a brief consideration of how these suggestions might fit within the current cognitive model of anxiety and a discussion of areas for future research.

## The concept of mild cognitive impairment

### *What is mild cognitive impairment?*

The term 'mild cognitive impairment' refers to a state in which an older individual is experiencing impairment of a single cognitive function, usually memory, to a degree greater than that which would be expected considering their age, but without meeting the criteria for dementia [1]. Diagnoses of dementia, such as that for dementia of the Alzheimer's type, require impairment of memory plus a second cognitive function, such as language, praxis or executive functioning, plus evidence of impairment of social or occupational functioning and continuing decline [2].

MCI remains a controversial diagnosis, mainly due to the lack of an established consensus around diagnostic criteria, but also due to disagreements about the existence of a state between normal ageing and dementia. The debate centres

around the competing ideas that either MCI represents one stage on a continuum of memory functioning which ranges from normality to severe dementia, or it represents a distinct pathological state [3].

There is evidence in older people of a general decline of recent memory, and particularly recall [4] . Several terms have been used to describe this memory loss which is not part of dementia but can occur with age, such as 'benign senescent forgetfulness', 'age-related cognitive decline' and 'late-life forgetfulness'. There are limitations to all these terms [5]. The most commonly used terms in research literature are those of 'age-associated memory impairment' and 'mild cognitive impairment'. These will be considered further.

*Age-associated memory impairment*

The term 'age-associated memory impairment' (AAMI) was first used by a US National Institute of Mental Health group [6]. This group proposed that this term should apply to individuals over the age of 50 who report subjective memory loss, exhibit performance at least one standard deviation below the mean established for younger adults on a specific test of memory functioning, have an adequate IQ level and do not have any obvious medical or psychiatric cause for their memory problems [5]. This definition has been criticised particularly for the requirement that the individual performs simply one standard deviation below the mean for younger adults on a neuropsychological test, since for some tests this would mean that 90% of older adults would fall into this category [7]. It also means that a diagnosis of AAMI is more likely to be given to individuals with poorer educational attainment [8]. A more appropriate comparison might be with individuals of a similar age and educational level. The AAMI concept also limits possible cognitive decline to

memory, when in reality age-related changes may involve other domains of cognitive functioning [5].

*Mild cognitive impairment*

While AAMI is intended to define memory changes, which can be part of the normal ageing process, the concept of MCI has been developed to describe a more extreme and potentially pathological process [9]. MCI has been defined as a transitional state between normal ageing and dementia, which in many cases leads on to dementia [7]. There is no overall consensus over a definition of MCI although many studies use the definition offered by Petersen and colleagues [10]. This definition requires individuals with a diagnosis of MCI to show evidence of memory complaint as well as objective memory impairment within the context of normal activities of daily living, otherwise normal cognitive functioning and no diagnosis of dementia. Most research studies use definitions similar to this, although some suggest that minor impairments of cognitive functioning other than memory are permissible within the diagnosis [e.g. 9]. This review will use the term MCI since it is the most widely used within research and within clinical settings such as memory clinics in which these individuals frequently receive assessment and treatment.

*Prevalence*

It is extremely difficult to estimate the prevalence of MCI due to the lack of consensus around diagnostic criteria [11]. Prevalence rates vary depending upon the definitions and criteria used. For example one study found that in a sample of 60-64 year olds in good health, 13.5% met criteria for AAMI, 6.5 % met criteria for age-consistent memory impairment (ACMI) and only 1.5% for late-life forgetfulness

[12]. However, this study did not consider individuals aged over 64, nor did it appear to consider any of the helpful definitions of MCI itself, such as that given by Petersen et al. [10]. A further study found the prevalence of AAMI to vary from 5.8% to 18.5% in a sample of individuals aged over 50 dependent on alterations to the criteria used [13]. A more recent population-based study estimated the prevalence of MCI to be 3.2% [14]. It seems that it will not be possible accurately to predict the prevalence of MCI amongst older people until a general consensus has been reached with regards to a definition and criteria to define this disorder. The need for neuropsychological tests specifically aimed at diagnosing MCI has also been highlighted [15].

One further complication is that estimates of MCI prevalence may include those suffering from cognitive impairment due to a reversible cause, such as physical illness, depression or medication [5].

Evidence from one Memory Disorders Clinic suggests that MCI (at least as defined by Petersen et al., [10]) is a very common diagnosis, being present in approximately 37% of those attending for an initial appointment [16].

*Prognosis*

Most studies looking at the prognosis of individuals with MCI have been concerned with the likelihood of these individuals going on to develop dementia [e.g. 10, 17]. One study looked at mortality rates [18]. This study found, over a 7-year period, that mortality rates for a group of individuals with MCI were midway between the higher mortality rates for those with Alzheimer's disease (AD) and the lower rates for those without any cognitive impairment. The authors were unable to provide an explanation for this finding.

It has frequently been suggested that MCI is a prodromal or preclinical stage of dementia, usually AD [1,11]. However, a number of studies have refuted this suggestion. One study found that for a sample of individuals with MCI each year 12% converted from their MCI diagnosis to one of AD, meaning that within 4 years almost 50% had gone on to develop AD, but 50% had not [10]. This is much higher than the rate for those of a similar age without a diagnosis of MCI for whom the conversion rate to either MCI or AD would be 1 to 2% per year [10]. It is not known what happened to the remaining 50% without AD after the time period of the study. It is also not known from these results whether any of the participants went on to develop dementias other than AD such as vascular dementia (VAD) or Lewy Body dementia (LBD). In general there is very little consideration in the research of MCI as a precursor of dementias other than AD. This is particularly surprising in the case of VAD since clinical experience suggests that MCI is frequently seen in older adults with a history of transient ischemic attacks (TIAs) [19, 20].

A further study found three distinct groups in following up individuals with MCI an average of 2.7 years after their diagnoses [17]. In this study 20% of those with MCI went on to develop dementia while 20% returned to normal cognitive functioning and 60% remained stable. However, this study did not give the range of times between original diagnosis and follow-up, just an average of this period so this may have influenced the rate of conversion and a longer follow up period might have been useful. In combination, these findings suggest that individuals with MCI are a heterogeneous group. Currently, the diagnosis of MCI does not provide any certainty with regard to prognosis and cannot be assumed to be a transitional state between normal cognitive functioning and dementia.

Some research has sought to investigate factors which may be predictive in identifying which individuals will progress to AD. Early diagnosis is a particularly important issue now that there are pharmacological treatments available for AD [11]. It has been suggested that severity of episodic memory deficit is predictive of decline to dementia [21] and that the presence of mild impairments of other areas of functioning, such as language and executive functioning may be a warning sign [11]. However, this last finding is less useful since for most diagnostic criteria for MCI, one of the criteria is that memory is the sole area of cognitive impairment. It has also been suggested that presence of the apoE4 gene protein [7] and evidence of reduced volume [11] or functioning [21] of the hippocampal area of the brain may be predictors of the development of AD. A recent study [22] has found evidence that impaired olfactory identification may be predictive of the development of AD amongst a sample of 90 individuals diagnosed with MCI. In general these research findings are theoretically interesting, but more research is necessary to elucidate how they might be used clinically. No research has focused specifically on the subgroup of those diagnosed with MCI who do not go on to develop dementia [23].

*Interventions for MCI*

Based on the assumption that in some cases MCI may be a preclinical period of AD, research has begun to investigate the efficacy of pharmacological interventions proven useful in AD for this group [1, 23]. It has been suggested that the desire to promote MCI as a separate clinical category has been fuelled by drug companies keen to identify a new market for their products [9]. However, this pathologising of MCI does at least open the way for treatments for this group.

Little consideration has been made of non-pharmacological interventions for this group, although it has been suggested that some individuals with MCI might benefit from cognitive training techniques, such as learning mnemonics [5].

*Characteristics of individuals with MCI*

A study investigating the relationship between MCI and poor health [20] found that individuals with MCI (aged 75 to 95) were more likely to be depressed as well as having a higher incidence of physical health problems when compared with individuals without any cognitive impairment. This connection between poor health and MCI remained even when cerebrovascular disease had been controlled for. There are limitations of this study, particularly the poor definition used for MCI, which considers only a reduced performance on the Mini-Mental State Examination [24]. However, the study did use a very large sample and was population based, thus giving credibility to the findings.

In addition to this study, high levels of both anxiety and depression were found in a sample of individuals diagnosed with MCI [25] in comparison to both individuals with dementia and those without any cognitive impairment. However, the definition of MCI used in this study included the need for subjective memory complaint and an association has been found between memory complaint and affective state [26].

Another recent study [27] found that those diagnosed with MCI showed higher rates of both anxiety and depression than a group diagnosed with dementia. This was an unexpected finding in a study concerned with investigating the impact on memory clinic patients of being informed of their diagnosis and the MCI sample is small (n = 7). Also the measure of anxiety used in this study, the Beck Anxiety

inventory [28] is perhaps not the most appropriate for use with this population who have a high rate of physical health problems [20] given that it includes a large number of somatic symptoms. Despite the limitations of this study, the finding that anxiety was high in individuals with MCI, particularly in the light of the previous findings [25] is worthy of further investigation. Maguire and colleagues [27] suggested that this increase in anxiety may have related to the greater awareness of impairment in individuals with MCI. Importantly this hypothesis had not, as yet, been tested directly. Therefore, while there is evidence that there may be a psychological impact of experiencing MCI, particularly in terms of anxiety, no research has been carried out to attempt to understand why this is the case or to propose possible interventions aimed at easing anxiety for this group.

*Summary*

It is now widely accepted that there exists a state between normal ageing and dementia in which memory is impaired but otherwise functioning remains relatively normal. This state of MCI has been the subject of research looking at prevalence, prediction of prognosis and potential pharmacological interventions. Individuals with MCI are thought to be a heterogeneous group in terms of prognosis, but there is no evidence that their psychological experiences are heterogeneous. Little research has looked at these psychological experiences although several recent studies have suggested that anxiety is high in this group [25, 27]. To the best of the author's knowledge, no research has sought to understand the aetiology of this anxiety in people with MCI, other than the suggestion that awareness may be a factor. It is important to consider this anxiety further, since it suggests that there may be a need for the development of appropriate psychological intervention within this group.

There is some literature relating to the experience of anxiety in individuals with dementia which may be relevant to consider in seeking an understanding of anxiety in MCI, particularly since in at least a section of cases of MCI, the disorder represents a preclinical stage of dementia. Following a consideration of how this fits within the wider model of dementia research, this review will examine literature relating to anxiety in dementia.

**Context of dementia care**

Over the last ten years there has been a shift in terms of understanding and treating people with dementia from a medical model to a more psychological, person-centred model. The traditional medical model of dementia [e.g. 29] views dementia only as a disease process, concerned with neuropathological changes in the brain and the impact of these upon discrete areas of an individual's functioning. This model is very useful in promoting research and particularly the development of pharmacological treatments which have been shown to halt cognitive decline on a temporary basis in some people with dementia [30]. However, there have been criticisms of this model, specifically that people with dementia are seen only in terms of their disease and not as holistic individuals with personalities, life histories and their own individual social environments and who also happen to have dementia [31].

Kitwood proposed an alternative model of dementia which promotes the 'personhood' of individuals with dementia, defined as the 'standing or status that is bestowed upon one human being, by others, in the context of relationships and social being' [31, p8]. An appreciation of this personhood requires knowledge and understanding not just of an individual's disease process but their personality and life history. He proposed that this understanding is essential in avoiding processes of

'malignant social psychology' which undermine the personhood of people with dementia and, he believed, have been rife within dementia care settings [31]. This model has led to attempts to improve the experience of individuals with dementia by promoting their quality of life as opposed to simply trying to relieve their symptoms. There is currently a lack of good empirical evidence for this model [32] although it is widely accepted to have good face validity. This shift towards understanding the psychological experiences in individuals with dementia care has led to a growth in research addressing these issues, such as that which has applied attachment theory to dementia [33] and has looked at the sense of loss experienced by people with dementia [34]. In addition to these considerations of the internal psychological experiences of individuals with dementia, recent work has also emphasised the importance of investigating the social environment and relationships of those with dementia, and the impact of their difficulties on this aspect of their lives [35].

As yet, there is no research taking this approach with individuals with MCI. Given that that many individuals with MCI will go on to develop dementia, it seems appropriate to apply the principles proposed for person-centred care in dementia to this group. It is therefore appropriate to take a psychological approach in understanding the experiences of individuals with MCI - in this case, their elevated levels of anxiety.

## Anxiety and dementia

### *Anxiety in older adults*

Research looking at the prevalence of anxiety in older adults has found a prevalence of between 3 and 5% for generalised anxiety disorder [36-38] in large population samples. The prevalence of individual symptoms of anxiety amongst this population

is thought to be much higher, with one study giving a figure of 25% [36]. These authors also suggest that while prevalence of anxiety disorders decreases with age, individual anxiety symptoms do not. There is evidence for a high level of comorbidity between anxiety and depression [36, 39] and a suggestion that an external locus of control is particularly predictive of anxiety in this older age group [40].

*Prevalence of anxiety in dementia*

There have been several attempts to estimate the prevalence of anxiety symptoms amongst individuals with dementia. One large community study, in which anxiety was assessed by observation of symptoms of emotional distress thought to be associated with anxiety, found that 70% of the sample showed at least one symptom of anxiety [41]. This very high figure may relate to the rating method which relied on subjective interpretation of symptoms which may be due to anxiety, but may also have another explanation, such as physical illness. Further evidence comes from a study investigating anxiety within a memory clinic sample of those diagnosed with dementia. This found that 29.4% of those assessed using a structured questionnaire with participants and their informants exhibited one or more symptom of anxiety while 12.8% showed two or more symptoms [42]. Two other studies, one in a sample of individuals with dementia recruited from a day hospital and one in individuals with dementia found that 31% of the former met 'Research Diagnostic Criteria' for generalised anxiety disorder [43] and 5 to 6% of the latter met DSM-IV criteria for generalised anxiety disorder [44]. The diagnostic rate from this second study was similar to that found in the general population. However, this same study

found that 71% of participants showed some evidence of anxious mood, based on clinician or carer rating.

In a study which used a questionnaire, and was therefore limited to participants in the early stages of dementia, 38% of individuals (most of whom had AD) showed evidence of anxiety on the Hospital Anxiety and Depression Scale [45] compared to a rate of 9% in those without dementia [46].

One study found anxiety to be higher in individuals without dementia when compared to those with mild to moderate dementia [47]. However, this sample consisted only of depressed psychiatric patients with a diagnosis of dementia and therefore cannot be generalised to the population of dementia sufferers.

It is likely that the variation in the estimates of prevalence between the studies reflects both the different methods used to estimate anxiety and the different samples used. Despite this, these studies consistently report higher rates of anxiety or anxiety symptoms than those found in population samples of older adults.

*Difficulties in assessing anxiety in dementia*

In general there are difficulties in assessing anxiety in people with dementia. Firstly, symptoms perceived to represent anxiety, such as lack of concentration and sleep problems, may actually be part of the dementia [42, 48]. Secondly, it is not easy to measure cognitive states such as worry and rumination in people with dementia who may have expressive difficulties [44].

Until recently there has been no standardised method of measuring anxiety in dementia. However, the 'rating anxiety in dementia' (RAID) scale has now been developed [49]. This is an 18-item scale rated by clinicians following interviews with

the individual with dementia and a carer. It has been shown to have good reliability and validity [49]. As yet, the RAID has not been used to assess anxiety in MCI.

*Explanations for anxiety in dementia*

A number of studies have sought to explain the anxiety found in dementia. One study has found anxiety to be higher in individuals diagnosed with VAD (71%) when compared with AD (38%) as measured on a checklist of anxiety symptoms developed from DSM-IV criteria [50]. In those with VAD, anxiety was found to increase with a decrease in MMSE scores whilst the opposite was true in individuals with AD [50]. This finding leads to the suggestion that anxiety may relate to the extent of disease pathology in VAD while it is related to psychosocial factors in dementia. This suggestion could explain why some studies have found anxiety to increase with cognitive impairment [e.g. 44] while others have found it to be higher in those with mild impairment [e.g. 51] and others have found no correlation [e.g. 46]. These differences may reflect the different proportions of those with particular dementia types within the samples used in these studies, or the different methods used for assessing anxiety.

Anxiety has also been found to be higher in those who have awareness of their condition [49]. However, Shankar et al. [49], used only a simple 'present' or 'absent' categorisation of awareness in this study without any consideration that awareness might represent a continuum. Ballard et al., [42] attempted to categorise 11 of the individuals found to be highly anxious in their study into three groups depending on the apparent cause of their anxiety. Two were found to be suffering from comorbid depression and two to be experiencing psychotic symptoms. Of the remaining seven, six exhibited anxiety confined to specific social situations. All of

these had awareness of their problems. This suggests that awareness of difficulties may lead to anxiety in social situations, perhaps because these individuals are embarrassed by their impairments in front of others. This may be particularly relevant in people with MCI, who due to the milder nature of their impairments are likely to retain awareness. This study also found a trend towards an association between awareness and anxiety in the sample as whole [42].

*Comorbidity*

Several studies have found high levels of correlation between anxiety and depression in this group, for example 54% in one study [41]. A correlation has also been found between anxiety and both impairment of activities of daily living and other behavioural disturbances such as wandering, sexually inappropriate behaviour and physically and verbally threatening actions [41]. The direction of causation within these relationships is not clear.

*Interventions*

Little research has looked at the management of anxiety in dementia, although it has been suggested that medications such as anticholinesterase inhibitors recently licensed for use in AD may have an anxiety-reducing affect [52]. There have also been reports of case studies in which cognitive-behavioural therapy (CBT) has been used to treat anxiety in dementia with modifications such as simplified explanations and the use of carers in developing behavioural programmes [53]. There is evidence that interventions involving carers can reduce agitation and anxiety in individuals with dementia, even if they are not themselves involved in the intervention [54]. It is possible that a modified CBT approach, particularly involving carers, might be useful

in treating anxiety not only in individuals with dementia but in those with MCI and it is certainly an interesting area for future research.

*Summary*

In conclusion it appears that some degree of anxiety symptomatology is common amongst individuals with dementia, although actual anxiety disorders do not appear to occur at a rate higher than in the general population. Several possible explanations for these high rates of anxiety have been proposed – firstly that there is a relationship between type of dementia and anxiety [50] and secondly there is again the suggestion that awareness may be related to anxiety [42, 49]. The suggestion that anxiety is somehow explained by awareness in both MCI and dementia is worthy of further consideration. The next section of this review will examine literature on awareness and cognitive impairment.

**Awareness and cognitive impairment**

*Definition of awareness*

The terms insight and awareness, used within the context of psychiatry, refer to an individual's understanding and knowledge of their symptoms of mental illness [55]. Insight is the most widely used term to describe this, although other terms used interchangeably with insight include awareness [56] and anosognosia [57]. The latter term, anosognosia, refers to unawareness of specific neurological deficits.

Awareness in dementia has been the subject of a great deal of recent research and is considered an important issue due to the implications of lack of awareness on dementia sufferers in terms of their safety such as when driving [58], compliance with treatment and interactions with carers [59]. Reduced awareness has been found

to relate to increased carer burden independently of dementia stage or severity [60, 61].

*Assessment of awareness*

Several different methods have been used to assess levels of awareness in people with dementia and there remains no well-validated measure for this purpose. There is also a lack of consensus around what should be measured in studies of awareness.

Generalised clinician ratings have been used in assessment of awareness [e.g. 62, 63, 64], often in conjunction with other assessment measures [e.g. 65]. These usually involve the clinician making an overall rating such as 'no impairment of awareness', or 'mild', 'moderate' or 'severe' impairment, based on interviews with patients and carers. The criteria used by Verhey and colleagues [63] have been used in a number of other studies and have more validity than those criteria which are more idiosyncratic. However, the problem remains that these measures are largely subjective, and clinicians and researchers need to ensure that this kind of global assessment incorporates the various dimensions which make up awareness before drawing conclusions relating to it [58].

Several studies have estimated awareness level by calculating the discrepancy between a person with dementia's scores and an informant's ratings on a scale such as a measure of activities of daily living [e.g. 60, 66, 67] or a scale of memory functioning [e.g. 65, 68]. This method requires a certain level of functioning and language skills within individuals with dementia since it requires them to respond appropriately to questions regarding their beliefs about their level of functioning. It is therefore not appropriate for use with individuals with severe dementia or with particular aphasic difficulties. A difficulty with the use of carer ratings in assessing

awareness is the possibility that carers may overestimate the impairments of the person for whom they are caring due to the burden they feel as a result of the caring role and possible associated depression [66]. Alternatively, it may lead to negative scores, suggesting that the individual with dementia has rated themselves as more impaired than their carer. This could be explained by an underestimation or denial of the dementia sufferer's deficits by their carer or by anxiety within the individual with dementia [56].

Some studies have measured awareness by asking individuals with dementia to rate their cognitive abilities and then look at the discrepancy between these ratings and their performance on neuropsychological tests [e.g. 67, 69]. This mixed methodology lacks validity due to the possibility that what is being rated by the participants and then what is subsequently measured by the neuropsychology is not the same concept.

There have been attempts to develop questionnaires explicitly for use in measuring awareness, such as the Awareness of Memory Impairment Scale (AMIS), a simple six-item scale asking individuals to answer 'yes' or 'no' to questions about the presence of deficits [70]. The author of this measure proposes that it is more helpful than measures reliant on the ratings of carers or clinicians which may be open to bias [70]. However, the simplicity of this measure is likely to reduce its sensitivity and it does not give much allowance for the degrees of awareness suggested in other research. Another study used the anosognosia questionnaire for dementia (AQ – D) which is completed by both dementia sufferers and their carers [57]. A further proposal for use in this area is the 'Assessment of Impaired Insight' questionnaire which is also a measure to be completed by both patients and carers [71]. These questionnaires all remain in an early stage of development and, although promising,

currently lack the reliability and validity data to back up their use. In addition those which rely on both patient and carer report are likely to face the same problems as the use of established questionnaires with carers, as outlined above.

A comparison of several different methodologies for assessing awareness [72] found that there was no difference in terms of predicting awareness between the results for the 4-point scale used by Verhey [63], discrepancy scores on an ADL scale rated by both patients and carers and the use of ratings by patients on a number of dimensions such as memory ability, mood, independence and confidence rated for the present and in terms of change from past functioning. This suggests that the different methodologies are at least measuring the same thing. However, there remains a need for a well validated and consistently used measure of awareness level and the lack of one is the greatest weakness of all the research which has currently been carried out in this area.

*Relationship between awareness and severity and type of dementia*

There is evidence to suggest that awareness decreases as severity of dementia increases [62, 66-68, 70] although these studies have only included patients with AD. Interestingly, no significant correlation has been found between length of illness and awareness level [56] although this might be explained by the difficulty in pinpointing the starting point of an insidious illness like AD. Studies looking at changes in awareness over time have found inconclusive results. One study following up AD patients over 2 years found that a third of them declined in terms of awareness as rated by a clinician following a structured interview with this decline more likely to be associated with more severe dementia [62].

It has been found that awareness is more impaired in individuals with a diagnosis of AD when compared with individuals with VAD, controlling for severity of dementia in terms of ADL [60] and cognitive functioning [69]. This is particularly interesting when considered alongside the finding that anxiety increases with a decrease in MMSE scores in VAD but not in AD [50]. Another study did not back up this research, finding no difference between AD and VAD participants in terms of levels of awareness, depression and personality change [64]. This contrasting result could be explained by the fact that this latter study only included those in the early stages of dementia and it may be that the different presentations of AD and VAD do not appear until later on in the disorders. In the early stages it is likely that most individuals retain some degree of awareness, regardless of their dementia type. A study comparing small groups of individuals with AD and MCI [73] found that the MCI group showed no diminished awareness of their memory impairments, in contrast to the AD group. This study also found no deficits of metamemory skills such as correcting intrusion errors on memory testing amongst the MCI group [73]. This suggests that individuals with MCI retain awareness to a greater degree than those with dementia.

*Relationship between awareness and affective state*

There is evidence that greater awareness is associated with low mood in individuals with AD [68, 71, 74], although there is also evidence that under-reporting of depressive symptoms is more frequent amongst those who lack awareness [75]. Some studies have failed to find an association between depression and awareness [e.g. 76] although this may have been because this study was looking for major

depression in individuals with dementia and not just depressive symptomatology, which is thought to be most prevalent [71].

A recent study [71] also found that depression may be a mediating factor between impaired awareness and dementia severity. These authors found that awareness level was only related to severity of dementia when depression had been controlled for, leading to the suggestion that depression might improve awareness, although the direction of this relationship is by no means fully understood. There is also evidence that awareness does not explain the higher rate of depression amongst those with AD, when compared with those with other types of dementia and those without dementia [63]. However, this study also found that one item entitled 'psychic anxiety' on the measure used correlated negatively with impaired awareness [63]. This suggests the need for further research more fully addressing the role of anxiety in maintained awareness.

Some studies have supported the view that there is a negative correlation between impairment of awareness and anxiety level [56, 74] although these studies have looked only at individuals with AD. The study carried out by Harwood and colleagues [74] also needs replicating with a more balanced sample since theirs was 92% male, particularly since there is evidence that women show greater impairment of awareness than men [77].

There is also evidence of a strong correlation between impaired awareness and apathy [56, 57]. A possible explanation for this is the idea that individuals who are highly apathetic may be less reactive to their environments and therefore less able to make judgements about their abilities [57].

Finally, there has been criticism of the use of questionnaires in studies of affective state and awareness, in particular that awareness is a pre-requisite for

questionnaire completion [65]. However, it may be that awareness of emotional state involves different levels of processing than awareness of cognitive state. There is evidence that individuals with dementia may retain memory for events which are strongly emotionally salient for them, as illustrated by the remarkable memory for a Japanese earthquake amongst a group of dementia sufferers [78].

*Dimensions of awareness*

There is strong evidence to support the view that awareness is not a state which is either present or absent but something which exists on a continuum. Studies have suggested that awareness may vary within individuals for different types of functioning. For example, Ott et al, [65] found that awareness of ADL functioning was more impaired than awareness of memory functioning for a small group of AD sufferers. Another study suggested that there are two domains of awareness – that which relates to cognitive functioning and that which relates to behavioural abilities [57]. The first of these domains correlates with cognitive deficits, delusions and apathy while the second does not correlate with any cognitive factors although it does show an association with manic symptoms, suggesting a link with inhibition [57].

*Explanations for loss of awareness*

A range of explanations for loss of awareness have been proposed. These include neurological factors as well as more psychological theories, which propose the potential benefits of having reduced awareness of deficits. In terms of neurological explanations, there is some evidence that impaired awareness is related to reduced functioning in the frontal lobes of the brain, particularly the right frontal lobe, as

measured by use of SPECT (single photon emission computed tomography) scanning techniques [56, 79].

A more psychological view holds that loss of awareness is in fact functional for individuals with dementia [80], in that it provides them with a coping strategy to avoid having to think about the abilities they have lost, thus reducing depression [57]. An argument against this idea of lack of awareness as a coping strategy comes from the finding that awareness decreases with increased cognitive impairment. It seems unlikely that more impaired individuals would be able to implement a coping strategy more effectively than those who are less impaired [68].

An alternative psychological explanation proposes that awareness in some cases may not be true unawareness but a denial of difficulties of which they are really aware, possibly at a subconscious level. They may deny difficulties which they perceive as a threat to their sense of identity [34]. This denial may be a temporary stage in the course of the illness, resolved when the individual feels ready to emotionally process the reality of his or her impairment and the associated losses. It may be that denial of difficulties presents differently from a lack of awareness of these difficulties. For example, an individual who is denying his or her problems may respond to questioning with hostility and resistance whereas an individual who is not aware of their difficulties may respond with genuine puzzlement about the questions rather than an emotional response [58]. This kind of emotional denial may also be most likely to occur in the earliest stages of the disorder, when the experience of memory loss is most threatening.

In attempting to understand this relationship between lack of awareness and denial of difficulties, one study has investigated premorbid personality traits associated with denial and compared this 'Denial Personality Rating' with current

levels of awareness [81]. This study found that those with a higher rating on this measure showed greater unawareness, suggesting a link between lifelong personality traits and coping styles and the appearance of impaired awareness in AD. There are limitations of this study, particularly the somewhat subjective measure used in the denial personality rating. However, it is an interesting area for future research and highlights the need to consider an individual's premorbid characteristics and life experiences when carrying out an assessment of awareness. This fits with Kitwood's [31] ideas of a 'person-centred care' approach to dementia, which promotes the need to view an individual with dementia within the context of their whole lives, including their premorbid personality and personal history as well as their current difficulties.

There is also an assumption in the literature that awareness is something relatively stable, which may decline over the course of an illness but does not fluctuate on a day-to-day basis. Clinical experience suggests that this is not the case and that levels of awareness may vary over the course of a conversation. This variation may be due to the environment in which an individual is asked about their impairment. They are more likely to reveal their fears about their level of functioning in a non-threatening environment with a professional with whom they feel safe and have developed a relationship [58]. This is important to consider when carrying out research in this area. Clinical experience also suggests that this may relate to what is happening during an interview. For example, an individual with dementia may display greater awareness of their difficulties if asked about them directly after performing poorly on a memory task than if asked before completing any tasks.

The understanding of an illness may also be dependent upon the extent to which an individual has been provided with information and feedback about their levels of functioning. Pre-existing beliefs and knowledge may also be important. In

some cases, individuals with dementia are protected, usually by family members, who do not wish to use words such as 'dementia' or 'Alzheimer's disease'. Whilst the motivation behind this is understandable, it may be that this lack of knowledge maintains a level of unawareness [58].

The possibility of providing interventions to promote awareness in individuals with dementia has been raised [58]. While this might be beneficial in terms of promoting treatment compliance and easing the burden on carers, there is a need to consider the ethics behind such interventions since there is a very real possibility that promotion of awareness might also increase symptoms of distress, specifically depression and anxiety.

There is a need formally to address the psychological possibilities relating to awareness discussed in this section through methodologically sound research.

*Summary*

There is evidence that awareness is frequently impaired in dementia and that this impairment of awareness increases with increased cognitive impairment. This fact coupled with the evidence that deficits in frontal lobe functioning accompany this decline support the argument for a pathological basis for awareness loss. However, what are less clear are the psychological correlates of impairment of awareness or indeed retained awareness. There is also a need to understand the role of denial.

There are several main limitations of this research. Firstly, there remains a lack of a good, validated measure for assessing awareness. Secondly, most of the literature on awareness has limited itself to studies of individuals with AD. There is a need to broaden this research to consider other types of dementia, such as VAD and

LBD, in which patterns of awareness may be different. There is also a need to understand more about awareness in MCI.

There have been some attempts to understand the experience of losing awareness in people with dementia, from both a biological and a psychological perspective but there remains a need for a biopsychosocial model incorporating all of these factors to promote a full understanding of the phenomenon [82].

While there is some evidence of a relationship between anxiety and awareness, with anxiety higher in those with more awareness, so far research into this association has been limited to individuals with AD. There is a need to replicate these findings in other groups, such as those with VAD and MCI using validated measures of anxiety.

The process by which anxiety is related to awareness is also not clear, although one suggestion might be that increased awareness of impairments of functioning leads to increased embarrassment and worry related to these impairments in social situations [42]. The next section of this review examines how these social factors may relate to the experience of anxiety in individuals with cognitive impairments.

**Social factors in anxiety and cognitive impairment**

Other than the suggestions made in the study previously described [42], there has been no research, to the best of the author's knowledge, related to the particular experience of social anxiety in individuals with any type of cognitive impairment. However, it may be useful to see how recent understanding of social anxiety, and specifically the phenomenon of social phobia can be applied to individuals with MCI.

*Cognitive model of social phobia*

The cognitive model of social phobia is currently the best-researched and most widely used model. Social phobia as operationalised by this model refers to a 'marked and persistent fear of social or performance situations in which embarrassment may occur' (DSM-IV). This model proposes that individuals with social phobia experience an excessive fear that they will behave in an inappropriate way leading to the negative evaluation by others in social situations [83, 84]. They become pre-occupied with these fears and their constant self-evaluation coupled with symptoms of anxiety may lead to impaired functioning, thus validating their fears. They are also likely to replay social events in their minds after they have occurred, focusing on the negative aspects of these events and catastrophising about their meanings. People with social phobia are known to have more negative thoughts about social situations [85] and it is thought that they will have more relevant long-standing beliefs and dysfunctional assumptions, activated by these social situations [84]. The development of social phobia is thought to relate to events in early life, with later events possibly acting as triggers to activate the beliefs and assumptions which maintain the disorder [83].

It is unlikely that the anxiety felt by individuals with cognitive impairment in social situations is sufficient to warrant a diagnosis of social phobia, and indeed they would be excluded from this diagnosis since the cause of their embarrassment is an illness [83]. However, it is possible that a similar process may be occurring for some individuals. For example, it is likely that in the earliest stages of cognitive decline, individuals with MCI may notice negative reactions in those they meet to their initial symptoms such as forgetting names, repeating questions or being unable to find a correct word. If they have awareness of their difficulties, they may feel

embarrassment about this happening and over-estimate the reactions of other people. This could develop into a severe source of anxiety, maintained by repeated social contacts and the fact that anxiety further reduces cognitive abilities [e.g. 86]. It is possible that this will relate to premorbid experiences and beliefs, with past anxieties re-activated by a new situation perceived as threatening. There is a need for further research in this area, firstly assessing the prevalence of symptoms of social anxiety amongst those with cognitive impairments and then looking for associations between these symptoms and current awareness of impairment, and premorbid anxieties and personality characteristics.

*Social factors in dementia*

In addition to the suggestion that a subgroup of individuals with dementia might experience anxiety within the context of retained awareness [42], a number of studies have investigated social factors in individuals with dementia. One study found that high levels of social contact predicted anxiety in a group of dementia sufferers in hospital [87]. This suggests that quality of support may be more important than quantity with the high levels of social care from relative strangers within a hospital setting proving anxiety-provoking. This is an opposite pattern to older individuals without dementia, who show increased anxiety in the absence of social contacts [88]. It was also found that both difficulties in the relationship between an individual with dementia and their primary carer, and severe life events predicted anxiety in dementia [87]. These authors went on to conclude that the relationship between severe life events and anxiety is mediated by depressive symptoms. While these conclusions are interesting and highlight the need to consider the impact of social

factors, this research would have been greatly enhanced if awareness had also been measured.

*Social support*

In general, social support is thought to act as a buffer, blunting the effects of stress and enabling individuals to cope better with stress [89]. Anxiety in a general sample of older adults has been associated with having a smaller social support network [39] and with dissatisfaction with the social network [36]. There is evidence that increased mortality in individuals with dementia is associated with lack of social support [90], although this study also found that increased mortality was associated with poor physical health in the same group. However, these positive effects of social support may not always be the case with individuals with dementia [87] perhaps because increased social support provides wider opportunities for embarrassment. There is also evidence that increased cognitive impairment is associated with reduced social support [91] although this is thought to be explained by the disability resulting from the impairments of cognitive functioning leading to reduced social participation. In the early stages of cognitive impairment, it is unlikely that any disability would be so severe that social participation becomes impossible. Therefore while social support and interactions remain as they did before the difficulties began, the potential for social embarrassment and anxiety remains, particularly while awareness is also retained.

**Synthesis of explanations for anxiety in MCI and dementia**

This review has examined some of the literature which may be useful in understanding why levels of anxiety are so high in individuals with MCI. Due to the

lack of literature looking at the psychological experiences of people with MCI, this review has inevitably drawn considerably upon literature relating to dementia. However, due to the overlap between the two conditions both diagnostically and in terms of their psychological experience, it is likely that there are similarities between the anxiety experiences of the two groups. To gain further understanding, it may be useful to consider these anxiety experiences within the context of the current cognitive model of anxiety.

*Cognitive model of anxiety*

The cognitive model of anxiety, based on the work of Beck [92], proposes that anxiety develops due to an individual's overestimation of a situation as dangerous, and an underestimation of their ability to cope [93]. The model proposes that individuals are prone to anxiety due to particular beliefs and assumptions they have developed, possibility due to negative experiences in early life and possibly related to the situation which is now feared. These beliefs and assumptions are activated by the feared situation leading to symptoms of anxiety and further thoughts incorrectly appraising the danger inherent in the situation and the individual's ability to cope [83]. These anxiety symptoms may also be interpreted as more dangerous than they really are, thus maintaining the anxiety. The individual may develop maintaining behaviours, such as avoidance of the feared situation.

It is possible to see how individuals with cognitive impairment may view their difficulties as a threat. There is now much media awareness of dementia and many people have personal experience of a friend or relative with the disorder. Therefore, those in the early stages are likely to have some knowledge of how dementia can develop and are likely to fear this outcome. In the case of MCI the

prognosis is less clear cut, leaving those given this diagnosis with a sense of uncertainty. This uncertainty itself may contribute to anxiety. A parallel finding in a group of people with cancer suggested that those for whom imminent death from their disease was certain showed lower anxiety than a group for whom death was probable [94]. It has also been found that telling individuals with dementia their diagnoses does not increase their anxiety levels [27]. There is a great deal of mystery around the diagnosis of dementia, with many patients not being told their diagnoses. It is possible to see how incorrect beliefs and assumptions could develop within this context. It is also important within the context of this model to consider how the experience of cognitive impairment could activate beliefs and assumptions established long before the illness.

*Factors contributing to anxiety in MCI and dementia*

This review has identified a number of factors that may contribute to the development and maintenance of anxiety in MCI. One issue which has not been given much consideration is the idea that this anxiety might have a physiological basis. There have been suggestions that depression, which occurs frequently in dementia [95], may not relate just to psychological factors, but also to biochemical [29] or neurological factors [96]. There is no evidence that this is the case in anxiety, and indeed it would be surprising since it would be expected that anxiety would increase with greater physiological damage and increased impairment. Since this is not thought to be the case [51], psychological explanations may be more appropriate.

The finding that anxiety decreases with increased cognitive impairment in a similar way to awareness is suggestive of a relationship between anxiety and awareness. Intuitively, it makes sense that an increased awareness of deficits would

lead to greater anxiety about the possible development of those symptoms, the current implications of the symptoms and an individual's ability to cope, given those symptoms. This leads onto the idea of the importance of social factors, since social anxiety may result from an awareness of potentially embarrassing deficits. While social support may protect against the negative effects of anxiety, it is also possible to see how a wide social network might increase this anxiety by providing an individual with a range of different potential environments for embarrassment.

**Directions for future research**

There are several areas that require further research. There is a need for a more widespread study of the prevalence of anxiety amongst MCI and comparison between anxiety levels in this group and other groups, particularly individuals with dementia and older adults who lack any kind of cognitive impairment. There is also a need for exploratory studies, possibly using qualitative methodology to explore the nature of anxiety within this group and produce hypotheses for future research. It would also be appropriate to investigate the possible relationships between anxiety and awareness, and the role of social factors in this relationship as highlighted in previous research.

In addition, there is a need for further research to establish and validate reliable measures for assessing awareness in those who are cognitively impaired.

Once a clearer understanding of the causes and consequences of anxiety in MCI have been established, this paves the way for future studies investigating psychological interventions for alleviating anxiety in those with cognitive impairment. This might involve the adaptation of established therapies, such as

cognitive-behavioural interventions for anxiety, or the development of new interventions, especially designed for this group.

## Conclusion

Individuals with MCI pose a new challenge for clinicians and researchers alike. MCI is a relatively new diagnostic category and one about which there remains controversy, due to the heterogeneous prognosis and the lack of consistent diagnostic criteria. At present, there is little understanding of the psychological processes involved in MCI, and particularly in the high levels of anxiety shown by those with MCI. Research into anxiety in individuals with dementia has suggested that anxiety in this group may relate to increased awareness of deficits. This may be particularly relevant in those with MCI given the high levels of awareness in this group, although there may be a number of factors contributing to an individual's awareness of their deficits, both neurological and psychological. It has also been suggested that awareness may increase anxiety particularly in social situations, since these situations provide opportunities for embarrassment and those with MCI, because of their relatively preserved functioning, are likely to remain engaged with their social networks. The role of social support in protecting against anxiety in those with cognitive impairment is not clear although it may be the case that a larger support network promotes anxiety because it provides more opportunities for embarrassment while a high quality emotionally supportive system protects against it. It is important to develop a good understanding of anxiety in MCI so that this group can be offered appropriate support. This review has highlighted several areas which may be useful for researchers in reaching an understanding of anxiety in relation to cognitive impairment and has proposed areas for future research.

**Key points**

- Little is known about the psychological experiences of individuals with mild cognitive impairment, although some research has suggested that their anxiety levels are high in comparison to those with dementia and those without cognitive impairment.
- This high anxiety level may relate to the relatively preserved levels of awareness in those with MCI, as has been found in dementia, although there are limitations of this research.
- Anxiety in MCI may relate particularly to social situations, since they are likely to be more aware of evidence of their impairment in front of others.
- Social support is thought to protect against anxiety in older adults generally although this may not be the case in those with cognitive impairment.
- There is a need for further research to fully understand the role of anxiety in MCI and to identify and develop appropriate treatment packages.

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**Empirical Paper:**

# Anxiety in Older People with Mild Cognitive Impairment and Early Dementia

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# Anxiety in Older People with Mild Cognitive Impairment and Early Dementia

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# Anxiety in Older People with Mild Cognitive Impairment and Early Dementia


## Abstract

Previous research has found that anxiety levels are high in individuals with mild cognitive impairment (MCI) when compared to those with dementia and those without impairment. It may be that greater awareness of cognitive deficits relates to greater anxiety and that this is particularly apparent in social situations. It is also possible that social support protects against anxiety if it is of high quality but that a large social network increases anxiety. No prior research has investigated possible psychological explanations for anxiety in MCI.

This study explored anxiety in those with MCI and in the early stages of dementia, first by use of a brief semi-structured interview, and then by use of questionnaires to test hypotheses related to the roles of awareness and social factors within this anxiety.

Anxiety was not found to be significantly higher in the MCI group when compared to those with dementia, although there was a trend in this direction. The study did find a positive correlation between anxiety and awareness of deficits, although no relationship was found between social anxiety and awareness or between anxiety and social support. Qualitative analysis of the semi-structured interviews highlighted common areas of worry for those with cognitive impairment, including social interactions, loss of skills and worries about the future. Interestingly, none of the participants appeared aware of their specific diagnoses.

The implications of these findings and potential areas for future research are also discussed.

# Anxiety in Older People with Mild Cognitive Impairment and Early Dementia

## Introduction

The term 'mild cognitive impairment' (MCI) refers to a condition, usually occurring in older adults, in which there is some kind of cognitive impairment, almost always of memory, with objective evidence of a decline from a previous level of functioning, but where the difficulties are not so severe or generalised that a diagnosis of dementia is warranted (Petersen *et al.*, 1999). It is a diagnosis frequently given in memory clinics, although it remains controversial, due to the lack of consistent diagnostic criteria for the diagnosis (Jones & Ferris, 1999) and the question of whether it identifies a group of individuals truly separate both from those experiencing the affects of normal ageing and those suffering from dementia (Ritchie & Touchon, 2000). It has often been suggested in the literature (e.g. Celsis, 2000; Sherwin, 2000) that MCI represents a preclinical phase of a dementia such as Alzheimer's Disease (AD). However, evidence suggests that this is not always the case and that while a subgroup of those diagnosed with MCI progress to developing dementia, a considerable number also do not (Petersen *et al.*, 1999; Wolf *et al.*, 1998). These studies have found that approximately 20-25% of those diagnosed with MCI progress to dementia after two years with almost 50% having moved into dementia after 4 years (Petersen *et al.*, 1999). This suggests that the group of individuals with MCI is a pathologically heterogeneous group, some in the early stages of a degenerate dementia and others suffering from a stable cognitive impairment of different origin. This also suggests that it is a diagnosis given with an uncertainty of prognosis.

Some research has attempted to identify factors which might predict the development of dementia in those with MCI, such as specific areas of brain

dysfunction using scanning techniques (Collie & Maruff, 2000), a pattern of cognitive deficits including severe episodic memory deficit (Collie & Maruff, 2000) and olfactory deficits (Devanand *et al.*, 2000). However, there is no evidence at present of any differences between those who will go on to develop dementia and those who will not in terms of their psychological processes in response to the diagnosis. Indeed, very little psychological research has focused on this clinical group at all, with most research taking a medical perspective and investigating underlying pathology (e.g. Collie & Maruff, 2000) or potential pharmacological intervention (e.g. Sherwin, 2000; Sramek *et al.*, 2000). There is some evidence that anxiety is high in those with MCI, both in comparison to non-impaired elderly controls (Christensen *et al.*, 1995) and those with dementia (Christensen *et al.*, 1995; Maguire *et al.*, submitted). This is an interesting finding, although in need of replication since the study by Christensen and colleagues did not use the standard definition of MCI and that of Maguire *et al* found their significant result with a sample of only 7 individuals diagnosed with MCI. Despite the methodological difficulties of these studies, the strength of the results suggest that this is worthy of further investigation.

A further understanding of anxiety within this group is important to ensure that clinicians develop a greater awareness of the possibility of anxiety when assessing individuals with MCI and in pointing towards the development of appropriate interventions. Research emphasising the psychological and social experiences of individuals with cognitive impairment fits within the psychosocial model of dementia care (Cheston & Bender, 1999a; Kitwood, 1997). Research into anxiety in this group may also enhance understanding of anxiety in those with dementia, since there is thought to be an overlap between these two groups.

It is necessary to consider the possibility that there is some kind of neuropathological process leading to both cognitive impairment and anxiety in those with MCI and dementia. However, if this were the case, it would be expected that anxiety would increase or at least remain stable as impairment progresses, when the reverse appears to be the case (Christensen *et al.*, 1995). It is also unlikely that a physiological process could account for the high levels of anxiety in MCI given that there is not thought to be a common underlying pathology in the disorder and the heterogeneity of prognosis (Wolf *et al.*, 1998). It is therefore appropriate to consider the possibility of a psychological explanation for this anxiety.

One possibility is that this anxiety is due to the uncertainty around the future prognosis of MCI and the possibility of developing dementia. In individuals with cancer, anxiety has been found to be associated with an uncertain prognosis (Hinton, 1999). However, it has been found that telling individuals with dementia their diagnosis does not increase their levels of anxiety or depression (Maguire *et al.*, submitted). Despite this, it is possible to see how this diagnosis and its implications present a threat to those who receive it, in terms of potential future cognitive decline and associated losses, including possible loss of an individual's sense of identity (Cheston & Bender, 1999b) and that anxiety is a possible response to this type of threat.

There is evidence of high anxiety amongst individuals with dementia (e.g. Ballard *et al.*, 1996; Ballard *et al.*, 1994; Teri *et al.*, 1999) and higher rates of anxiety in comparison to those without dementia (Wands *et al.*, 1990). One study has found that anxiety is higher in those who have awareness of their impairment (Shankar *et al.*, 1999) and several others have suggested this as a possible explanation for anxiety in those with cognitive impairment (Ballard *et al.*, 1996; Maguire *et al.*, submitted).

None of these studies have directly addressed this relationship and yet it is worthy of further consideration. There is thought to be a strong negative association between awareness of deficits and impairment of functioning (Mangone *et al.*, 1991; McDaniel *et al.*, 1995; Sevush, 1999). Since the milder nature of MCI is suggestive of a higher level of awareness than that found in those with dementia, this could explain the discrepancy in anxiety between these two groups. There are some difficulties with this research, mainly due to the lack of a standardised measure of awareness (Mangone *et al.*, 1991) and the need to ensure that research takes place in an environment in which participants feel comfortable enough to reveal potential awareness of their difficulties (Cotrell, 1997).

The nature of this relationship between anxiety and awareness is not widely discussed in the current literature. However, one important issue has been raised in a study addressing anxiety in dementia (Ballard *et al.*, 1996) which identified a subgroup of anxious participants, who displayed anxiety particularly associated with social situations and all of whom retained awareness of their difficulties. It may be that this awareness of difficulties makes social situations particularly anxiety provoking for those with MCI, because they fear potential embarrassment and the reactions of others. It is also likely that those with MCI will still be maintaining their social functioning because their impairment remains mild. While social support is usually thought to act as a buffer against stress in general (Taylor, 1999) and social anxiety in particular (Furmark *et al.*, 1999), it may be that a wider social network in those with MCI actually increases anxiety due to the increased opportunity for embarrassment provided by a range of social opportunities. High levels of social contact have been found to predict anxiety in dementia (Orrell & Bebbington, 1996) while social support protects against anxiety in older adults without dementia

(Forsell & Winblad, 1998). It may be that cognitive impairment reduces the protective effect of social support because of the difficulties this impairment leads to in social situations. It may also be useful to separate the ideas of quality, which may reduce anxiety, and quantity, which may increase anxiety, when discussing the role of social support in this relationship.

In summary, there is evidence that individuals with MCI experience high levels of anxiety in comparison to both those with dementia and those without any type of impairment (Christensen *et al.*, 1995). As yet, no explanation has been found for this high level of anxiety. One possibility is that the uncertainty surrounding the prognosis of MCI contributes to the anxiety. It may also be that an awareness of cognitive deficits is an important factor since decreased awareness has been found to correlate negatively with anxiety in dementia (e.g. Shankar *et al.*, 1999) and awareness is known to be relatively preserved in MCI in comparison to dementia (Correa *et al.*, 1996). Anxiety in social situations may explain anxiety in a subgroup of those with MCI since observation of a very small group suggested that this linked with awareness (Ballard *et al.*, 1996) and it is also possible that high levels of social contact increase this anxiety (Orrell & Bebbington, 1996).

The present study planned to examine the question of why anxiety has been reported to be so high in individuals with MCI and considered some of the possibilities suggested in the literature as to why this might be the case. The study initially aimed to replicate the previous finding that anxiety is higher in those with a diagnosis of MCI than in those with dementia by assessing this in a larger sample than the most recent study (Maguire *et al.*, submitted) and using measures validated for these groups. The present study also aimed to explore possible causes of anxiety by asking participants about their anxiety in a semi-structured interview and carrying

out a qualitative analysis of the transcriptions of these interviews, with a view to the development of hypotheses for future research. Finally, the study aimed to investigate a number of specific hypotheses related to the roles of awareness of deficits and social factors in the development of anxiety in those with MCI and those with early dementia (ED). These hypotheses were developed from a review of the relevant literature.

To the best of the author's knowledge, this study is the first time that research has addressed the psychological experiences and needs of individuals with MCI and particularly their experiences of anxiety. While previous research has established a link between anxiety and level of awareness of cognitive functioning in those with dementia, this association has never previously been examined in those with MCI. No previous study has investigated the possible role of social anxiety in either those with MCI or those with dementia, or the links between this and awareness level and social support.

The study predicted that anxiety would be higher in a group diagnosed with MCI than in a group diagnosed with ED and that greater anxiety would be associated with greater awareness of cognitive deficits across both groups. The study also expected that social anxiety would be higher in the MCI group than in those with ED and that greater awareness would be associated with greater social anxiety. Finally the study predicted that increased perceived quality of social support would be associated with lower anxiety while increased quantity of this support would be associated with greater anxiety.

To control for the potentially high comorbidity of anxiety and depression (Teri *et al.*, 1999), depression was also measured to ensure that group differences in depressive symptoms could not account for differences in anxiety.

## Method

*Design*

The study involved a mixed design, with a between groups comparison of anxiety levels and a correlational analysis across the two groups of factors potentially contributing to this anxiety. The study also involved some qualitative analysis, incorporating thematic analysis (Boyatzis, 1998) of the transcriptions of semi-structured interviews in which participants were asked about their anxiety.

*Participants*

There were 36 participants in total, forming 2 groups. Eighteen of the participants had a diagnosis of MCI and 18 a diagnosis of dementia in the early stages. Only those with early dementia (ED) were included in the study to ensure they could openly discuss and reflect upon their experiences of anxiety.

The participants in this study were recruited from two memory disorders clinics, known as A and B. All those referred to either clinic received a thorough assessment of their memory complaints. This involved taking a detailed medical history from the individual referred and an informant, a physical examination, a neuropsychological assessment, a number of blood tests and a CT scan. During the neuropsychological assessments, patients completed the National Adult Reading Test (NART; Nelson & Willison, 1991), which provides an estimate of premorbid IQ level.

Those diagnosed with probable Alzheimer's disease (AD) or probable vascular dementia (VAD) met the diagnostic criteria for these conditions according to DSM-IV (American Psychiatric Association, 1994). A diagnosis of mild cognitive

impairment (MCI) was made using a common sense combination of the principles inherent in the literature referring to this condition, namely objective evidence of impaired cognitive performance, usually memory insufficient for a diagnosis of dementia and without evidence of another reversible cause (Petersen et al, 1999). There is likely to be some degree of error in these diagnoses, of approximately 10% (Katzman *et al.*, 1988) due to the lack of a definitive test, other than at autopsy, for identifying dementia.

All participants were aged 50 years or over. The ED group included those with a diagnosis of either probable AD, probable VAD or mixed dementia and with a Mini-Mental State Examination (MMSE; Folstein *et al.*, 1975) score of eighteen or more. Only those who had attended the clinics within the last six months for either an initial or follow up appointment were approached to ensure reliability of diagnosis.

Individuals with a history of serious psychiatric illness or evidence of a bereavement or other significant life event within the past six months were excluded. Potential participants with comorbid life-threatening physical health problems, such as malignant conditions, were excluded. However, individuals with chronic and stable physical conditions, such as arthritis and diabetes were included due to the prevalence of these conditions within this population.

Participants were approached by letter and followed up by telephone in memory clinic A. In memory clinic B they were approached either by a doctor while attending the memory clinic or by letter and asked to respond positively by phone if they wished to participate. See figure 1 for more details on recruitment. All participants were provided with an information sheet both for themselves and for a friend or relative who would act as an informant on their behalf in the study (see

Appendix III). Those who agreed to participate were contacted and a convenient time arranged to visit them at home.

Amongst those who declined to participate, some said they thought participation might be distressing and some were too busy. In some cases relatives of potential participants declined on behalf of potential participants as they thought the research might distress their relatives.

*Measures*

*Semi-structured interviews.* Participants were asked a number of questions in a semi-structured interview to explore possible causes of anxiety in a non-directive way. These questions were developed based on previous research and in consultation with researchers experienced in qualitative research. Participants were asked about sources of anxiety, including issues specifically related to their memory problems and particularly anxiety-provoking situations. They were also asked about recent changes in anxiety, their feelings about the future, what they believed to be the cause of their memory problems and the extent to which they found their memory changes to be a problem (see Appendix V). During the interviews, the researcher did not just follow the interview schedule, but pursued interesting areas of discussion, gently persuading participants to expand upon their answers. The need for both sensitivity and flexibility was paramount during these interviews.

In addition to the scheduled questions, further questions and probes were used in interviews if the participants did not appear to have fully understood a question or if their answers appeared incomplete. These involved rephrasing of questions, or additional questions such as 'do you have any other worries?'.

Questions of this type were asked in 7 of the interviews with MCI participants and in 10 interviews with ED participants, usually on only one occasion and never on more than three. In addition, extra questions aimed at clarifying participants' responses were asked in 11 of the MCI interviews and 13 of the ED interviews. Again these questions were typically asked once or twice during an interview, with three clarifying questions asked in two interviews.

*Mini-Mental State Examination (MMSE; Folstein et al, 1975).* Participants completed this brief test of cognitive functioning which is well validated and widely used in dementia research as a gold standard of level of functioning. It yields a maximum score of 30.

*Measures of awareness of cognitive deficits.* There is no standard measure for assessing awareness levels. Past research has used a mixture of methods including global clinician ratings (e.g. McDaniel *et al.*, 1995; Verhey *et al.*, 1993) and calculations of discrepancies between participants' and informants' ratings on scales of functioning (e.g. McGlynn & Kaszniak, 1991; Seltzer *et al.*, 1995). In this latter method there is no consistency in the literature with regard to the questionnaires selected to create these discrepancies.

This study used a mixture of these two methods to establish convergent validity. Participants and informants completed a short form of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) which is based on the original. Both the original and the shortened IQCODE have been shown to have good validity and reliability within dementia samples (Jorm & Jacomb, 1989; Jorm, 1994). The short version has been found to have psychometric properties very similar

to the long version, including good item-total correlations, test-retest reliability and correlations with other tests of cognitive functioning (Jorm, 1994). Since the IQCODE was originally designed for completion by informants, the wording of questions was changed slightly for completion by participants, with 'he/she' replaced with 'I'. A test of internal consistency was carried out to ensure the validity of this participant completed version of the short IQCODE.

Secondly, a global rating of awareness was used with judgements made by the researcher on the 4-point scale suggested by Verhey *et al.* (1993). This scale provides criteria for categorising participants as having 'adequate awareness', 'mildly impaired awareness', 'moderately impaired awareness' or 'severely impaired awareness' (See Appendix VI). This judgement is made on the basis of an interview with participants and their carers.

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

This is a well-validated 14-item scale that provides a brief measure of both anxiety and depression. It is a useful measure for older people, as it does not include many items relating to the somatic symptoms of anxiety and has been validated for use in this population (Kenn *et al.*, 1987). It has also been used in previous research into anxiety in individuals with dementia (Wands *et al.*, 1990).

*The Brief version of the Fear of Negative Evaluation Scale (FNE; Leary, 1983).*

This brief measure of social anxiety has been adapted from the full version of the FNE, both of which have been shown to have good reliability and validity and to correlate highly together (Leary, 1983; Watson & Friend, 1969). For the purposes of this study the scoring of the brief FNE was simplified from a 5-point scale to a

dichotomous scale identical to that used in the full-length version of the FNE, to ensure that the measure could be adequately completed by those with cognitive impairment. It was not thought that this simplification would affect the psychometric properties of the scale (Leary, personal communication, 2001).

*The Short Form Social Support Questionnaire (SSQ6; Sarason et al., 1987).* This brief scale provides measures both of number of social supports and perceived satisfaction with social support. It has been found to be valid and reliable (Sarason et al., 1987). No norms are currently available for this scale, but it can be used to make comparisons between and within groups.

*Measures with informants*

In addition to completion of the IQCODE as previously described, further measures of anxiety and depression were also completed by the researcher based on interviews with an informant of each participant in the research, as follows:

*The Rating Anxiety in Dementia Scale (RAID; Shankar et al., 1999).* The RAID is a recent measure, developed specifically for use with individuals with dementia. It is scored by a clinician based on informant interview. It has been shown to be valid and reliable (Shankar et al., 1999)

*Cornell Scale for Depression in Dementia (Alexopoulos et al., 1988).* The Cornell scale has been developed to assess levels of depression in individuals with dementia, based on a clinician's interview with an informant. It has been used widely and has been found to be valid and reliable (Alexopoulos *et al.*, 1988).

*Trait anxiety measure.* Lifelong participant anxiety was estimated using a crude measure in which informants were asked to mark on an analogue scale where they perceived their relative or friend to fall between two extremes of 'never anxious' and 'very anxious'. These marks were measured in millimetres from the 'never anxious' end of the scale and higher scores interpreted as suggestive of higher trait anxiety. This measure was used to ensure that differences in lifelong anxiety could not account for differences in present anxiety as measured in the study.

*Procedure*

Participants were visited in their homes by the researcher. They were initially asked to complete a consent form (see Appendix IV).

Following screening for inclusion and exclusion criteria, suitable participants then completed the semi-structured interview. Following this the MMSE was administered and the questionnaires completed with the researcher on hand to answer queries and explain ambiguous questions. The researcher was also alert to both verbal and non-verbal signs of distress throughout the participation as has been recommended in carrying out research with cognitively impaired individuals (Berghmans & TerMeulen, 1995).

In most cases the informant completed the IQCODE and the interview on which the RAID and Cornell were scored directly after the participant had completed his or her questionnaires. However, in several cases, carers completed their questionnaires and returned them to the researcher by post, with further explanation given by the researcher by telephone if necessary.

*Data analysis*

The semi-structured interviews were transcribed and analysed using a process of thematic analysis and coding as described by Boyatzis (1998). Goodness of fit tests were carried out to ensure the data fitted within a normal distribution and non-parametric tests (Mann-Whitney tests and Spearman's rank correlations) used for those that did not. The rest of the data were analysed by use of between groups t-tests, analysis of variance tests, an analysis of covariance test and by use of bivariate correlational statistics.

## Results

*Goodness of fit tests*

Kolmogorov-Smirnov tests were conducted on the data to ensure they met the assumption of normal distribution (see table 1). There was no evidence that any of the variables were not normally distributed, with the exception of years of education ($Z = 1.54$, $p < 0.05$) and the SSQ6 – satisfaction scores ($Z = 1.54$, $p < 0.05$). Therefore parametric statistics were used for all tests other then those involving these two variables.

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Insert Table 1 about here

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*Demographic data*

There were 18 participants in each of the MCI and ED groups. Of those with a diagnosis of dementia, 14 had a diagnosis of probable AD, 3 had a diagnosis of probable VAD and one had a diagnosis of probable mixed dementia. Demographic data relating to these two groups can be seen in table 2.

Insert Table 2 about here

There were no significant differences between the groups on years of education ($U = 134$, $p > 0.05$), NART scores ($t = 1.07$, $df = 33$, $p > 0.05$) or gender ($\chi^2 (1, n=36) = 1.03$, $p > 0.05$). There were also no differences between the two groups on the HADS depression subscale ($t = 0.93$, $df = 34$, $p > 0.05$) or the Cornell ($t = 0.69$, $df$ 33, $p > 0.05$), although there was a significant correlation between these two measures ($r = 0.45$, $p < 0.05$). There were no differences between the two groups on the trait anxiety measure ($t = 1.90$, $df = 33$, $p > 0.05$) although this measure did correlate significantly with both the HADS anxiety scale ($r = 0.57$, $p < 0.05$) and the RAID ($r = 0.40$, $p < 0.05$). As expected, the early dementia group was significantly older than the mild cognitive impairment group ($t = -2.87$, $df = 34$, $p < 0.05$) and had significantly lower MMSE scores ($t = 3.23$, $df = 34$, $p < 0.05$).

*Anxiety measures*

There was a significant correlation between the two anxiety measures used in this study, the HADS anxiety subscale and the RAID ($r = 0.38$, $p < 0.05$).

In order to compare anxiety levels between the MCI and ED groups, t-tests were performed on the two anxiety measures. There were no significant differences between the two groups on either of these measures; the HADS anxiety subscale ($t = 1.88$, $df = 34$, $p > 0.05$) and the RAID ($t = 1.08$, $df = 33$ $p > 0.05$). However there was a trend towards a significant difference between the groups on the HADS ($p = 0.07$) with anxiety levels higher in the MCI group. See table 3 for descriptive data for the anxiety measures.

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Insert Table 3 about here

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Since there were significant differences between the MCI and ED groups on age and MMSE scores, correlations were carried out between these two variables and the anxiety measures to determine whether they had influenced the results of the t-tests. The only significant correlation was between the HADS anxiety measure and MMSE ($r = 0.37$, $p < 0.05$). Therefore, the comparison between the groups for the HADS anxiety scale was repeated with MMSE score entered as a covariate. This only altered the result very slightly ($F[2, 33] = 3.16$, $p = 0.06$).

*Measures of awareness*

Patient/carer discrepancy method

The participant completed version of the IQCODE was found to have adequate internal consistency (Cronbach's alpha = 0.819).

Several methods were used to estimate participants' levels of awareness of their memory difficulties. One method sought to estimate awareness by subtracting the score given by each participant on each item of the IQCODE from the score given by their informant for that same item. This produced some negative scores, since participants sometimes rated themselves higher (suggesting greater impairment) than their informants. It is possible to argue that by summing these scores, including those which are both positive and negative, a score for awareness will be produced which cancels out the natural ups and downs in the reports of the participants and informants. These aggregated discrepancy scores were found to be significantly higher in the ED group than in the MCI group ($t = -2.70$, $df = 33$, $p <$

0.05). To test the hypothesis that greater awareness will be associated with greater anxiety, a correlation was carried out between these scores and the HADS anxiety subscale. This was found to be significant ($r = -0.56$, $p < 0.05$), thus supporting the hypothesis. However, there was no significant correlation between the aggregated discrepancy scores and the RAID ($r = -0.30$, $p > 0.05$).

An alternative interpretation of these discrepancy scores might suggest that any difference between the score of a participant and their informant represents a lack of awareness. Therefore it is appropriate to sum the total of these discrepancies regardless of whether they are positive or negative to create an absolute discrepancy score. This absolute discrepancy score was significantly higher for the ED group ($t = -2.86$, $df = 33$, $p < 0.05$). Again there was a significant negative correlation between these discrepancy scores and the HADS anxiety subscale ($r = -0.45$, $p < 0.05$) but no correlation with the RAID ($r = -0.10$, $p > 0.05$).

A further way of interpreting these scores involved looking at the differences between the mean of the informant's scores on the total 16 items of the IQCODE and the mean of the participant's scores on these items in terms of the standard deviation of the informant's scores. If this difference was greater than two standard deviations, the participant was considered to lack awareness ($\underline{M}$[participant] > $\underline{M}$[informant] + 2$\underline{SD}$[informant]). This was the case for 8 participants. This method of scoring also highlighted 3 participants for whom their mean score was more then two standard deviations higher than that of their informant, indicating that they considered themselves to be significantly more impaired than their informant did. One-way ANOVAs were carried out between these three groups (collapsed across diagnostic group), namely the group with participant scores more than two standard deviations above informant scores, the group with participant scores within two standard

deviations of informant scores and the group with participant scores two standard deviations below informant scores. These found a significant difference between the three groups on the HADS ($F[2,32] = 4.02$, $MS = 54.7$, $p < 0.05$). A post-hoc analysis found the differences between the three individual groups to be approaching significance on a Scheffé test. There were no significant differences between the groups on the RAID ($F[2,32] = 1.84$, $MS = 30.6$, $p > 0.05$).

Clinician rated method

Awareness was also rated according to the criteria suggested by Verhey *et al* (1993) with each participant assigned to a specific group as shown in table 4. Those three participants who rated their mean score on the IQCODE as more than two standard deviations above their informant's rating on the same score all fell into the 'adequate awareness' group. Of the eight participants that rated their performances more than two standard deviations below that of their informant's ratings, two fell into the 'mildly impaired awareness' group and the other six into the 'moderately impaired awareness' group. None of the participants were rated as having severely impaired awareness.

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Insert Table 4 about here

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A one-way ANOVA found a significant difference between the three levels of awareness (collapsed across diagnostic group) on the HADS anxiety subscale ($F[2,33] = 6.4$, $MS = 76.1$, $p < 0.01$). A post-hoc Scheffé test found there to be a significant difference between the adequate awareness and moderately impaired awareness groups, with anxiety higher in the adequate awareness group. There were

no differences between the mildly impaired awareness group and either of the other two groups.

There were no significant differences between the three groups on the RAID ($F < 1$).

*Social anxiety*

Analysis of the adapted brief FNE scale used in this study found it to have good internal consistency (Cronbach's alpha = 0.842).

A t-test carried out to determine if there was a difference between the MCI and ED groups on FNE score proved not to be significant (= 0.236, df = 34, $p > 0.05$).

To determine if greater awareness was associated with greater levels of social anxiety, awareness scores (both aggregated and absolute) were correlated with FNE scores. No evidence of a significant relationship was found (aggregated discrepancy score with FNE, $r = -0.26$, $p > 0.05$; absolute discrepancy scores with FNE, $r = -0.12$, $p > 0.05$).

Additionally, ANOVA comparing the three awareness groups as categorised using the standard score method and the Verhey criteria found no significant differences between the groups (standard score method, $F < 1$; Verhey rating criteria, $F < 1$).

*Social support*

There were no significant differences between the MCI and ED groups on the measure of number of social supports ($t = -0.41$, df = 34, $p > 0.05$) or the measure of satisfaction with social support ($U = 155.5$, $p > 0.05$).

To determine whether social support was associated with greater anxiety, correlations were carried out between both of the social support measures and the HADS anxiety subscale, the RAID and the FNE, for both the MCI or ED groups, and the total of all the participants (see table 5). None of these correlations were significant with the exception of that between SSQ6 satisfaction scale and the RAID (Spearman's rho = -0.49, $p < 0.05$). However, the use of repeated correlations requires a Bonferroni correction, which would leave this result nonsignificant.

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Insert Table 5 about here

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*Qualitative analysis*

Semi-structured interviews were carried out with 16 of the participants with MCI and 16 with ED. Data from the remaining four participants was unusable due to problems with recording equipment. The semi-structured interviews were transcribed and the researcher spent time reading and re-reading the transcripts, in order to become familiar with their content. The data were then analysed using the principles of thematic analysis as outlined by Boyatzis (1998). This involved selecting a random sub-sample of the transcripts. These were summarised and themes emerging from each section of the interviews were identified and compared across the sub-sample. These themes were developed into a series of codes to describe and identify the themes. One code was developed to describe the themes emerging relating to worries about memory problems, one for suggested causes of memory problems, one for severity of memory problems, one for changes in amount and type of anxiety and one for thoughts about the future. Once these codes had been developed they were

applied by both the researcher and an independent rater to the whole sample of interviews. Not all participants provided responses in each section of the interview. There was found to be good consistency between the two raters in identifying the themes with percentage agreement on the presence of each theme of 86% and a significant correlation in terms of frequencies of each theme (Spearman's rho = 0.96, $p < 0.01$). This suggests satisfactory interrater reliability. Discussions between the two raters around the definition of each category within the code aimed to establish the validity of the thematic code.

Themes for types of worries

Participants were initially asked about their worries in general terms. In addition to memory-related worries, many participants also identified worries related to their health, concerns about family members, environmental and social issues and financial matters. All of the participants with MCI went on to discuss specific areas of concern related to their cognitive failings, as did eleven of the sixteen ED participants. The remaining five denied any worries at all. Five themes for memory-related worries were identified from the analysis. These are described in order of the frequency with which they occurred within the sample. See table 6 for frequencies of all responses across both groups.

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Insert Table 6 about here

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1. Worries within a social context.

The most common type of worries were those relating to social interactions with others, such as forgetting names of friends and acquaintances, finding conversation to be limited and embarrassment relating to these limitations. For example:

> 'probably the most embarrassing thing is not remembering people's names. Now, I'm not talking about people I haven't seen for a long, long time, I'm talking about people I see every week... Someone I've known for a while and I just cannot remember their name. It's totally embarrassing' (Mrs A, MCI).

The consequences of this embarrassment was apparent in terms of social withdrawal:

> 'My conversation is limited. It's not as free as it used to be before the problem. So, I feel in some senses, I feel withdrawn from other people' (Mr B, MCI).

Similarly, concerns were expressed about the reactions of others and some participants mentioned trying to hide their difficulties:

> 'I'm playing golf three times a week but I find that when we're at lunch.... Well, I find that I'm not talking as much as I used to because I'm just a bit wary of, you know, slipping up and making a fool of yourself' (Mrs C, AD).

2. Worries about forgetting something important.

Participants commonly expressed a worry that their difficulties would lead them to forget something important, such as medical appointments or taking the necessary items when going out. These worries were often expressed with examples of past events when important things had been forgotten, such as the following example:

> 'I'm so used to wandering about the house without glasses, I jump in the car and drive to _____ or somewhere without even realising I haven't got my glasses on' (Mr D, AD).

This example shows the possible dangerous implications of forgetfulness in this context.

3. Loss of specific skills

Participants mentioned their worries about the loss of skills that had previously been important, and the limitations that the loss of these skills put upon their social and leisure activities. For example:

> 'I have lost interest in terms of reading, because I've just found that it's a waste of time. I'll read a book.... And two weeks later I can't remember anything that I've read about it' (Mr E, MCI).

In addition to reading, there were mentions of loss of skills in relation to driving, cooking, DIY and playing bridge. Again, these concerns often related to safety.

4. Worries about the future

Participants expressed their fears about the future. In some cases this was directly related to the potential decline of their memory problems:

> 'The thing I worry about is being ill or being bed bound or suddenly going completely bananas so one day they find me wandering in the street and have to lead me back to my wife' (Mr F, MCI)

These worries were sometimes related to past experiences of caring for someone with dementia:

> 'I have this worry about Alzheimer's disease because my mother died, she'd been suffering from senile dementia for five or six years before she dies... I remember the terrible time that it was, you know, how absolutely ghastly, her decline...' (Mr B, MCI).

In addition, participants worried about their abilities to cope in the future, and the possible burden upon family members of caring for them.

5. Worries about loss of professional skills

Some participants expressed concerns in relation to their difficulties coping with professional roles, either in a work or voluntary context. For example:

> 'I'm a group organiser for _____ holidays and people ask me sometimes, oh we went to so-and-so and they want to know some of the details and I can't remember at all. Who did I contact to organise it? Sometimes I just can't remember' (Mrs A, MCI).

These worries, which were only expressed by those with MCI, were often closely linked with worries relating to social situations.

A chi-square test was conducted to compare the frequencies of worries between the MCI and ED groups. This found no significant difference between the proportions of the different types of worries in the two groups ($\chi^2$ (4, n=32) = 3.41, p > 0.05). However, considerably more worries were identified in total in the MCI group (42 as opposed to 19).

Causes of memory problems

Participants were asked what they believed to by the cause of their memory problems. Eleven said that they did not know what had caused their difficulties (four from the MCI group and seven from the ED group) and another eleven attributed their difficulties to 'old age' (five from the MCI group and six from the ED group). Several participants connected their memory problems with a physical illness or injury. For example:

> 'Well, I think they've got to go along with the fact that this started after I came out of hospital' (Mr G, AD).

In some cases, memory problems were explained as a consequence of not keeping the mind active. A number of participants also suggested that their difficulties might be due to a psychological cause, such as stress or worry:

> 'I thought it was stress related. I thought it was this sort of thing where you don't want to know, you really don't want to remember or easier to forget' (Mr F, MCI).

None of the participants said that they believed their difficulties to be due to a form of dementia.

Severity of memory problems.

When asked to rate how much of a problem they saw their memory difficulties as being, most of those participants who provided an answer stated that they saw their difficulties as small (6 with MCI and 7 with ED). Two participants from the MCI group and three from the ED group saw their difficulties as a medium problem. Only two participants, both with MCI, rated their difficulties as a big problem. Three participants, all from the ED group said that they did not see their memory changes as a problem at all.

Changes in amount and type of worrying.

Participants were asked if they felt that there had been any changes recently in the amount they worried or the things they worried about. Most participants (50% of those with MCI and 79% of those with ED) said there had been no change. Three participants (2 with MCI and 1 with ED) said there had been a reduction in their worrying while eight said there had been an increase. Of these, seven were from the MCI group. Most of these explained their increase in worrying by stating that they had new issues to worry about:

> 'I do worry more because I don't seem to be getting any better' (Mrs H, MCI).
>
> 'Well I suppose I worry more now than I used to a few years ago. It's just, you know, I didn't have any of these problems when I was younger' (Mr I, AD).

Typically, the increase in worrying was attributed to fears for the future, as discussed previously, and potential inability to cope with failing physical and mental health.

Thoughts about the future

Participants were asked how they felt about the future. Analysis of responses in this section of the interview resulted in the identification of four themes. These will be discussed in the order of the frequency with which they occurred (see table 6).

1. Acceptance

Participants made comments suggesting that they were resigned to the future, whatever it might bring:

> 'I feel as though I don't get any worse, you know, I can survive...whether I shall survive that long, well you don't know really... Well, nobody knows how long they've got to live' (Mr I, AD)

Some participants clearly accepted the inevitability of their own death and appeared to accept that the future involves uncertainty. Several participants suggested the need to 'take each day as it comes'.

2. Hope

Several participants expressed general feelings of hope and optimism about the future:

> 'Well, I look forward to a good future' (Mr J, MCI).

Some participants also mentioned looking forward to particular events, such as social activities and holidays.

3. Fear and despair

In contrast to the previous category, some participants expressed fear and despair about the future. Some described specific fears:

'It is on my mind. How much worse will I get?...I'll have to have things done for me, that horrifies me.' (Mrs C, AD).

Other participants expressed a more general negativity towards the future:

'I don't find I've got too many dreams and visions currently, so I'm not terribly optimistic about the future' (Mr E, MCI)

Six MCI and 2 ED participants made comments falling into this category.

4. Avoidance

A sub-group of participants, mainly from the ED category, said that they avoided thinking about the future and therefore were unable to comment on whether or not their viewed it positively or negatively. Most made comments such as:

'I don't really think about the future' (Mrs N, AD).

## Discussion

*Anxiety levels*

This study did not find a significant difference between the anxiety levels of individuals with MCI and individuals with ED as had been predicted based on previous research (Christensen *et al.*, 1997; Maguire *et al.*, submitted). However, a trend towards increased anxiety in the MCI group was found using the self-report measure, the HADS anxiety subscale. This may have been due to the relatively small sizes of the sample and the possibility of a type 2 statistical error. As has previously been mentioned, the diagnoses given within the memory clinics can only be considered to be 90% accurate (Katzman *et al.*, 1988) and therefore it is likely that some of these participants were wrongly categorised. Indeed, when the most impaired MCI participant and the least impaired ED participant were omitted from the analysis, the difference between the two groups became significant on the HADS

anxiety subscale ($t = 2.63$, $df = 32$, $p < 0.05$) with the MCI group significantly more anxious. It may, therefore, not be actual diagnostic criteria that are important, but severity of impairment. Since the majority of participants in this study seemed unaware of their diagnosis, their anxiety is likely to be based not on diagnosis, but on their subjective interpretations of their experiences.

The second measure of anxiety, the RAID, did not yield significant differences between the groups, and only correlated moderately with the HADS anxiety subscale. It could be argued that the participants were inaccurate in their completion of the self-report measure, as has been found previously with dementia participants on a self-report measure of depression (Burke *et al.*, 1996). However, the choice of only mildly impaired participants and a measure previously successfully used with individuals with dementia (Wands *et al.*, 1990) should preclude against this. In addition the trend towards significantly higher anxiety in the MCI group using the HADS anxiety scale is consistent with previous research supporting the validity of the HADS. It may be that the RAID, although developed for use with individuals with dementia, is not suitable for those in the earliest stages of the disorder, because of its reliance on explicit behavioural symptoms of anxiety that may not be so apparent in those with only mild impairments. It is also a measure which has only recently been developed (Shankar *et al.*, 1999) and has never previously been used with individuals with MCI.

The study did not find any significant differences between the groups in terms of the depression measures, which suggests that the trend towards a significant difference between the groups in terms of anxiety is independent of depression. In addition, no differences were found between groups on trait anxiety, although the measure used is both crude and subjective and lacks any reliability or validity data.

*Anxiety and awareness*

The study found evidence of a significant positive correlation between anxiety and awareness of deficits using the HADS anxiety scale and each of the methods of estimating awareness employed by this research, supporting previous research with individuals with dementia (e.g. Ballard *et al.*, 1996; Shankar *et al.*, 1999). This is the first time this association has been established in individuals with MCI, and considering the high levels of awareness in MCI individuals, may go some way towards explaining anxiety within this group. However, given the correlational nature of these results, it is not possible to establish the direction of this relationship. Since the participants in this study were not aware of their diagnoses, it seems that their awareness is of their actual deficits, not of a label put upon them. This suggests that the anxiety associated with awareness precedes knowledge of diagnosis, thus arguing against the view that individuals should be protected from their diagnosis because of the distress this knowledge may cause (see Marzanski, 2000).

Despite the previous criticisms of measures used in awareness research (Cotrell, 1997), the use of a number of different measures, with consistent results supports the validity both of the measures and the established association between awareness and anxiety.

The study identified an interesting subgroup of three participants who rated their levels of impairment to be significantly higher than the ratings given by their informants and showed high levels of anxiety. This may be due to the association between memory complaint and anxiety, which is true even in the absence of objective memory decline (Jorm *et al.*, 1997) or to an underestimation of impairment by a subgroup of informants, as has been previously observed (Derousné *et al.*,

1999). In this study this subgroup is very small and therefore further investigation would be necessary before it is appropriate to draw conclusions about them.

*Social factors*

The study did not find any significant difference in social anxiety levels between the two groups. Again, this may be because it is not diagnostic category that is important in understanding this relationship, but a combination of factors, including those not measured by this study, such as prior anxieties and coping.

The study also did not find a significant association between social anxiety and awareness of deficits as had been predicted. However, the qualitative analysis found that issues related to social interaction and embarrassment were the most frequently mentioned type of memory-related worries. It may be the brief FNE is not appropriate for detecting the specific subtle social anxieties that are particular to those with cognitive impairment and that population-specific measures are needed to establish the true nature of the relationship between this type of anxiety and awareness. It may also be the case that social anxiety is an issue for a subgroup of individuals with cognitive impairment.

The study also did not find any kind of relationship between social support and anxiety. Previous research has found both that social support protects against anxiety in older adults (Beekman *et al.*, 2000) and that increased levels of social contact predicts anxiety in a sample of dementia sufferers (Orrell & Bebbington, 1996). Neither of these patterns were evident within this sample, although this needs to be considered within the context of the measure used. This measure asked participants to identify individuals to whom they would turn for emotional support in times of anxiety and distress, but did not ask about the overall size of social network,

which may contribute more to anxiety. In addition, there are limitations in measures of satisfaction, as noted in previous research (Ross *et al.*, 1995). In this case, participants almost universally rated themselves as very satisfied with their social support, thus reducing the likelihood of any differences between groups or significant correlations. This may have been due to the poor sensitivity of the measure, or to the phenomenon of 'acquiescence', which suggests that participants tend to rate satisfaction as high, because they think this is what others want to hear. This has been found to be a particular problem in older research participants (Ross *et al.*, 1995). It is also possible that because participation in this research also involved the participation of an informant, those with the lowest levels of social support were not included.

*Semi-structured interviews*

The analysis of the semi-structured interviews carried out in this study suggested that individuals with MCI and ED worry about the social implications of their deficits, about forgetting important things, about loss of skills and about the future. However, the further analysis of the questions asked in the interview directly relating to the future suggest that only a subgroup, mainly consisting of those with MCI, voiced feelings of anxiety and despair in relation to the future. Interestingly some participants, mainly with ED, showed avoidance of thinking about the future. This could be construed as a form of denial of the current situation of these participants. There may be links between this apparent denial and the phenomenon of unawareness (Weinstein *et al.*, 1994).

Interestingly, none of the participants believed their difficulties to be due to dementia. In the case of the MCI group, it is likely that they had been reassured that

they currently did not have dementia, although this would not have been the case with those with AD or VAD. In some cases, it was apparent from discussions with carers that participants had been told their diagnosis. This again raises the question of denial as a coping strategy (Cotrell, 1997), although given that participants freely spoke about highly personal worries, it seems unlikely they would not reveal their diagnoses. It may be that diagnoses, if given, were forgotten, perhaps because they are merely labels and were not meaningful. Instead, it is the subjective experiences of these individuals which are meaningful.

The analysis of the semi-structured interviews found the pattern of worries to be similar across both groups, but that those with MCI spoke more about their worries. Although this may be because these worries are more important for those with MCI, other explanations need to be considered. For example, it may be that the more severe cognitive difficulties of the ED group prevented them from recalling such worries or speaking so fluently about them. Despite this, it was interesting to note that it was only amongst the MCI group that participants saw their difficulties as representing a big problem, and it was mainly MCI participants who noted a recent increase in their levels of worrying. These differences may relate to the increased awareness of the MCI group although they were not formally analysed.

*Limitations of the study*

In addition to the problems already identified relating to the use of specific measures, and accuracy of diagnoses, several other issues deserve consideration. In terms of the generalisability of the results, it must be remembered that this study did not include a population sample but one recruited from a memory clinic. It may be that those who attend a memory clinic are more anxious than is typical within the whole population

of those with cognitive impairment, although they are those most likely to be in need and in a position to receive services. Conversely, it is likely that the most anxious of those approached to participate were in fact too anxious to take part.

There may also be questions about the reliability of the responses of the participants. The importance of providing a safe and unthreatening environment for assessment of individuals with cognitive impairment has been highlighted (e.g. Cheston & Bender, 1999b; Cottrell, 1997). This study also raises questions about the capacity of individuals with cognitive impairment to complete self-report measures. There is some evidence that this may be a problem (Burke *et al.*, 1996). However, the decision to include participants only with a relatively mild level of impairment and the choice of relatively simple measures aimed to avoid this. In terms of the semi-structured interviews, it may have been the case that participants failed to recall significant areas of worry. However, there is evidence that memory is enhanced for emotionally salient events, even in those with moderate and severe dementia (Ikeda *et al.*, 1998).

*Areas for future research*

This study highlights a number of useful areas for future research. It would be helpful to repeat the comparison of anxiety levels between the MCI and ED groups in a larger sample, perhaps also including individuals with more severe dementia, and separating those with different forms of dementia. It would be interesting to see whether these sources of anxiety identified in the semi-structured interviews are shared by a wider sample of individuals with MCI and dementia, and to examine further the differences between these two groups. While awareness of deficits does appear to be relevant to anxiety, the exact nature of this relationship is not clear. For

example, does increased anxiety lead to greater awareness or vice versa? It may be that it will be easier to answer questions such as this if improved methods of measuring awareness are developed. It would also be useful to address the differences between unawareness and denial of deficits.

The relationship between social anxiety and awareness needs further consideration. This study did not find a significant relationship between these two factors, although the frequent mention of social worries in the semi-structured interviews suggests social concerns may be an important issue at least for a sub-group of those with cognitive impairment. Further research is also needed to investigate the role of social support in anxiety in this group, either to confirm the finding of this study, that there is no relationship, or through the use of better methodology to elicit the true nature of this relationship. There is also a need to consider the role of individuals' personal histories, particularly prior anxiety and coping styles in understanding the development of anxiety in those with cognitive impairment, particularly in terms of identifying those who are most at risk.

Finally, there is a need for research to assess the utility of psychological interventions, such as cognitive-behavioural therapy, in alleviating symptoms of anxiety in this group.

*Summary and implications*

This study goes some way towards supporting previous research which has suggested that anxiety levels are particularly high in individuals with MCI in comparison to those with dementia. It also shows a relationship between this anxiety and greater awareness of deficits, using a range of methodology to ensure the validity of these results. The role of social factors in contributing to anxiety remains unclear, although

analysis of the semi-structured interviews found this to be an important issue. The study did not elucidate the relationship between social support and anxiety in this group, possibly due to the limitations of the methodology used.

The results of this study have implications for those working with individuals with MCI and ED, for example underlining the importance of assessing for symptoms of anxiety when working with these individuals, particularly if they retain awareness. The qualitative analysis of the semi-structured interviews suggests issues that may be involved in these worries, highlighting areas for useful questioning in clinical assessment. There is also a need for clinical psychologists to consider interventions for anxiety with this group, and particularly the adaptations that will need to be made to accommodate their memory impairments.

Although this study is concerned with drawing conclusions about common patterns of psychological experience in individuals with MCI and ED, it also highlights areas that may be relevant only for a sub-group, such as concerns about social situations. This supports the view that individualised assessment of anxiety and relevant beliefs is important, and is in keeping with the person-centred care approach within dementia care (Kitwood, 1997). This work also represents the first study that has specifically addressed the psychological needs of individuals with MCI, and the first attempt at considering the anxiety experiences of individuals with memory impairment within the framework of a psychological model and not, as is the case with previous research, within medical or psychiatric models.

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Figure 1: Flow – diagram to illustrate recruitment of participants into this study.

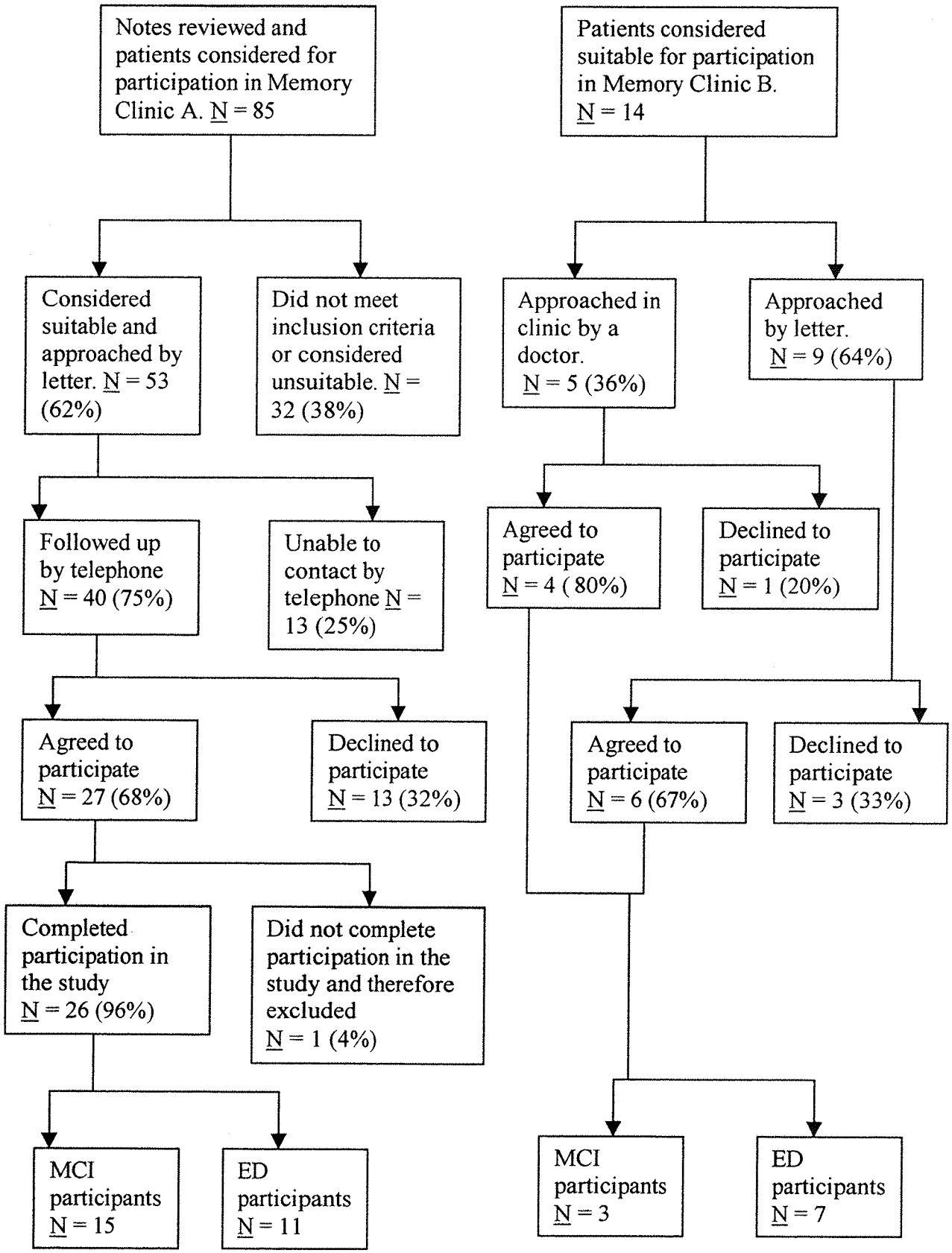

Table 1: Goodness of fit scores to demonstrate how well the data fit within the assumption of a normal distribution

| Variable | Kolmogorov-Smirnov Goodness of Fit Z Statistic | *p* (two-tailed) |
|---|---|---|
| Age | 0.75 | 0.62 |
| Years of education | 1.55 | 0.02* |
| NART predicted premorbid IQ scores | 0.99 | 0.28 |
| MMSE | 0.77 | 0.60 |
| HADS depression subscale | 1.15 | 0.14 |
| Cornell | 0.70 | 0.71 |
| HADS anxiety subscale | 0.63 | 0.82 |
| RAID | 0.90 | 0.39 |
| FNE | 0.72 | 0.68 |
| SSQ6 – support | 0.88 | 0.42 |
| SSQ6 – satisfaction | 1.54 | 0.02* |
| IQCODE discrepancy scores – aggregated | 1.19 | 0.12 |
| IQCODE discrepancy scores – absolute | 0.63 | 0.82 |
| Trait anxiety measure | 0.86 | 0.45 |

* $p < 0.05$. This suggests that these variables are not selected from a normally distributed population and it is inappropriate to use parametric statistics in analysis involving them.

Table 2: Demographic data for participants

| | | Mild cognitive impairment (MCI) n = 18 | Early dementia (ED) n =18 |
|---|---|---|---|
| Age | M (SD), range | 69.8 (7.5), 60 - 82 | 76.7 (6.9), 63 - 91 |
| Years of ed. | M (SD), range | 10.8 (2.2), 8 - 16 | 10.2 (2.1), 9 - 16 |
| NART predicted premorbid IQ scores | M (SD), range | 109.2 (11.9), 89 - 123 | 104.8 (12.8), 85 – 127 |
| MMSE | M (SD), range | 25.0 (3.5), 17 - 30 | 21.4 (3.2), 15 - 27 |
| HADS depression subscale | M (SD), range | 5.4 (3.0), 1 - 10 | 4.6 (2.8), 1 - 13 |
| Cornell | M (SD), range | 6.1 (2.6), 2 - 12 | 5.5 (2.9), 1 - 12 |
| Trait anxiety measure | M (SD), range | 64.0 (27.7), 27 – 120 | 45.1 (28.7), 13-91 |
| Gender | Male (%), Female (%) | 9 (50)<br>9 (50) | 12 (67)<br>6 (33) |
| Marital status | Married (%),<br>Widowed (%),<br>Never married (%) | 16 (89)<br>2 (11)<br>0 | 13 (72)<br>4 (22)<br>1 (6) |
| Informants | Spouse (%)<br>Daughter (%)<br>Niece (%)<br>Friend (%)<br>No informant (%) | 15 (83)<br>2 (11)<br>1 (6)<br>0<br>0 | 14 (77)<br>2 (11)<br>0<br>1 (6)<br>1 (6) |

Table 3: Descriptive data for the MCI and ED groups on anxiety and depression measures.

| | | Mild cognitive impairment (MCI) | Early dementia (ED) |
|---|---|---|---|
| | | n = 18 | n =18 |
| HADS anxiety subscale | M (SD), range | 7.7 (3.7), 0 - 13 | 5.4 (3.9), 0 - 14 |
| RAID | M (SD), range | 9.2 (4.4), 3 - 20 | 7.7 (4.0), 3 - 15 |

Table 4: Distribution of awareness levels across the MCI and ED groups.

| | Mild cognitive impairment (MCI) | Early dementia (ED) |
|---|---|---|
| Adequate awareness | 11 | 3 |
| Mildly impaired awareness | 7 | 7 |
| Moderately impaired awareness | 0 | 8 |

Table 5: Results of correlations between social support and anxiety measures.

| Correlations between: | MCI n = 18 | ED n = 18 | Total participants n = 36 |
|---|---|---|---|
| SSQ6 – support + HADS anxiety subscale (Pearson's r) | 0.30 | -0.02 | 0.14 |
| SSQ6 – support + RAID (Pearson's r) | -0.05 | -0.22 | -0.12 |
| SSQ6 – support + FNE (Pearson's r) | -0.06 | 0.20 | 0.03 |
| SSQ6 – satisfaction + HADS anxiety subscale (Spearman's rho) | -0.24 | -0.08 | -0.16 |
| SSQ6 – satisfaction + RAID (Spearman's rho) | -0.49* | -0.22 | -0.32 |
| SSQ6 - satisfaction + FNE (Spearman's rho) | -0.17 | 0.28 | 0.01 |

* significant at the $p < 0.05$ level

Table 6: Frequencies of particular responses given in the semi-structured interviews for the MCI and ED groups (based on agreements between the two raters).

| | Mild cognitive impairment (MCI) n = 16 | Early dementia (ED) n = 16 |
|---|---|---|
| Memory related worries: | | |
| Worries within a social context | 11 | 6 |
| Worries about forgetting something important | 9 | 6 |
| Loss of specific skills | 9 | 4 |
| Worries about the future | 7 | 3 |
| Worries about loss of professional skills | 6 | 0 |
| Cause of memory problems | | |
| Unknown | 4 | 7 |
| Old age | 5 | 6 |
| Illness/injury | 2 | 4 |
| Psychological cause | 2 | 2 |
| Not keeping the mind active | 5 | 0 |
| Severity of memory problems | | |
| Not a problem at all | 0 | 3 |
| Small problem | 6 | 7 |
| Medium problem | 2 | 3 |
| Big problem | 2 | 0 |
| Changes in worrying | | |
| More worries | 7 | 1 |
| Fewer worries | 2 | 1 |
| No change | 8 | 11 |
| Thoughts about the future | | |
| Acceptance | 8 | 5 |
| Hope | 4 | 5 |
| Fear and despair | 6 | 2 |
| Avoidance | 3 | 5 |

## Appendices

Appendix I: Letters of Ethical Approval
- Swindon Research Ethics Committee
- North Bristol NHS Trust Research Ethics Committee
- University of Southampton Ethical Approval

Appendix II: Recruitment letters
- Kingshill Research Centre version (as approved by Swindon REC)
- BRACE Centre version (as approved by North Bristol REC)

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Appendix IV: Consent Form

Appendix V: Semi-structured interview schedule

Appendix VI: Clinician's ratings of awareness (based on Verhey *et al.*, 1993).

Appendix VII: Measures used in the study
- The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) – participants' version
- The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) – carers' version
- Mini-Mental State Examination (MMSE)
- Hospital Anxiety and Depression Scale (HADS)
- Brief Fear of Negative Evaluation Scale (FNE)
- Short Form Social Support Questionnaire (SSQ6)
- Rating Anxiety in Dementia Scale (RAID)
- Cornell Scale for Depression in Dementia

Appendix VIII: Examples of two transcripts of the semi-structured interview with research participants.
- MCI participant
- ED participant

Appendix IX: Instructions for authors of target journals
- Age and Ageing
- Aging and Mental Health

Appendix I: Letters of Ethical Approval

- Swindon Research Ethics Committee
- North Bristol NHS Trust Research Ethics Committee
- University of Southampton Ethical Approval

Wiltshire NHS
Health Authority

Ref: NB kp SW 44/2000

Southgate House
Pans Lane
Devizes
Wiltshire
SN10 5EQ

Tel: 01380 728899
Fax: 01380 722443
DX 121831
www.healthywiltshire.org.uk

27 November 2000

Ms Philippa Wilson
Ground Floor Flat
100 Cromwell Road
St Andrews
Bristol
BS6 5EZ

Dear Ms Wilson

SW 44/2000 (This number must be quoted in all correspondence)
**Anxiety in Older People with Mild Cognitive Impairment and Early Dementia**

The above application, which included the documents listed below, was considered at the meeting of the Swindon Research Ethics Committee on 13 November 2000:

a) Protocol
b) Application Form

The study was approved.

Any changes or extensions to the protocol, or additional investigators, should be notified to the Committee for approval. Adverse events should also be reported to the Committee. May we remind you of the Data Protection Act 1998, and the need to conduct the trial in accordance with the Good Clinical Practice guidelines.

The Committee is required to audit progress of research and to produce a yearly report to the Wiltshire Health Authority and Department of Health. You are therefore required to provide a brief yearly report and a short final report.

The Swindon Research Ethics Committee is fully compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects and undertakes to adhere to the relevant clauses of the guidelines for clinical practice adopted by the European Union in January 1997.

Yours sincerely

[redacted]

**Dr Norbert Blesing**
**Vice Chairman - Swindon Research Ethics Committee**

North Bristol NHS
NHS Trust

Clinical Governance Directorate
Executive Team Base
Frenchay Hospital
Beckspool Road
Frenchay
Bristol BS16 1JE

Tel: (0117) 918 6517
Fax: (0117) 9563880
E-mail: Kathy.Matthews@north-bristol.swest.nhs.uk

Our ref: app2001.10

6 April 2001

Ms P Wilson
Ground Floor Flat
100 Cromwell Road
St Andrews
Bristol BS6 5EZ

Dear Ms Wilson

Project 2001/10 **Anxiety in older people with mild cognitive impairment and early dementia** (Short title: Anxiety and memory problems)

Thank you for your letter of 1 April 2001 in response to the points raised by the members of the Avon Health Authority, North Bristol NHS Trust (Frenchay) Research Ethics Committee (the Frenchay Local Research Ethics Committee), regarding the above project, which Dr Dow e-mailed to you on 22 March 2001. I am pleased now to confirm the Committee's approval of the project subject to ratification at the next meeting of the Committee which is currently scheduled for 20 April 2001. We have assumed that the BRACE data only includes people who have signed a consent form for their clinical information to be used for research purposes. You may begin your project as soon as you have attended to the aspects in the following paragraphs. Unless there are any significant matters raised at the Committee's meeting regarding this project, I shall not need to write to you again in respect of it.

I would just draw your attention to the following paragraphs which are in respect of the standard requirements which apply to all projects approved by this Committee, **where appropriate.**

The Trust's Chief Executive has requested that the Trust's Directors for Clinical Services be advised of all research being undertaken within their Directorate to ensure that there are no operational implications affecting their departments and for their interest and information. You have obtained the signature of Dr J Pounsford. May I ask you as a matter of courtesy to advise any other relevant Directors for Clinical Services of the arrangements being made if you are undertaking any part of your project within their departments and seek their signatures of approval, if you have not already done so, on copies of your application form and provide copies bearing the signatures for the Committee's file.

The Committee is required to monitor research it has approved in accordance with Good Clinical Practice Guidelines of the European Community and the standard operating procedures for Local Research Ethics Committees. Also, in accordance with the ICH Harmonised Guideline for Good Clinical Practice, an annual, as well as end-of-study report is required. Therefore, it would be appreciated if you will report annually, and notify the Committee when your research is completed. We will be grateful if you would complete and return the enclosed form with your project report after each year and at the end of the study. Should the results be published, the Committee would like to receive a copy for information and for the benefit of any future research that may be undertaken in this field. Failure to notify outcome will be viewed seriously by the Committee.

In order to assist the Trust with its obligations in respect of reporting procedures, we ask that you complete and return the enclosed research project registration form to the Trust's R&D Office as information from your application may need to be extracted for the Trust's R&D Support Costs Funding and the submission to the National Research Registry. Unless we hear within two weeks of this letter, we will assume that you have no objections.

Please note that anyone mentioned as involved in this study who is not already a member of the Trust's staff may need an honorary contract. You would need to contact the Trust's Medical Manpower Department if they are medical and Mr K Spencer, Employment Services Officer, Frenchay Hospital, Frenchay Park Road, Bristol, BS16 1LE for everyone else.

I should also like to point out that if the project involves the use of drugs, it is necessary for you to notify and discuss the implications with the senior pharmacist in the hospital in which your research is being carried out and to ensure he is given:

(a) a copy of the protocol
(b) a copy of the randomisation schedule, and
(c) plans for the receipt, storage and issue of the drugs you will be using (i.e. where, how, etc.,) -it is incorrect to assume that the pharmacy will automatically store and issue trial medicines.

If the project is a clinical trial and it involves pathological or radiological investigations other than those which are being undertaken as part of normal patient care, please arrange this with the appropriate consultant.

Data Protection Act 1998 : If a project involves any data which relates to a living individual, we ask researchers to please contact Ms C Adams, Data Protection Officer, Information Management Department, Somerset House, Southmead Hospital, Westbury-on-Trym, Bristol, BS10 5NB; telephone No. (0117) 959 6205 (direct dial); e-mail: Adams_Ch@southmead.swest.nhs.uk.

May I just remind you that costs may be involved should you need Trust medical records to be pulled in connection with your project. If you do need medical records to be pulled, you should speak to the Operational Director of the directorate where carrying out your project and Miss R Wood, Senior Medical Records Manager to determine how these costs should be covered, whether or not you have made an application for funding which included this aspect.

Now that your project has been approved, we ask that you add "Frenchay LREC approved final version, dated 6 April 2001" to all the approved documents (ie the information sheet for patients, the information sheet for relatives/friends, the consent form, the GP letter, the letter from Professor G Wilcock) in the top left hand corner. Also, the information sheets enclosed with your letter of 1 April 2001 should be labelled Version 2 - April 2001 not Version 1 - February 2001 to differentiate them from the earlier versions which have been replaced. We would appreciate copies of your documents once this has been done, for our file.

Should you find you need to extend your project to the area of responsibility of the Southmead LREC you would need to send a copy of our approval letter with a copy of your application to Mrs S Bowman, the Southmead LREC Administrator and ask if the Southmead Chair's approval can be given.

Whenever contacting the Committee about this project, and/or any amendments or extensions which should be submitted for approval before initiating, it will be appreciated if you quote '**Project 2001/10**' as this will enable us to identify it easily. We should also be notified of any serious adverse events.

Yours sincerely

[redacted]

Mrs K M Matthews
Research Ethics Administrator
Encl.

cc Dr L Dow/Mr I Pople, Joint Chairs Frenchay LREC
R&D Office
Ms J Gibbs, Operations Director, Directorate of Medicine

University of Southampton

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Highfield
Southampton
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Email

3 November 2000

Philippa Wilson
Department of Clinical Psychology
University of Southampton
Highfield
Southampton SO17 1BJ

Dear Philippa,

**Re: Application for Ethical Approval**

I am writing to confirm you that your ethical application titled "Anxiety in older people with mild cognitive impairment", has been given approval by the department.

Should you require any further information, please do not hesitate in contacting me on (023) 80 593995.

Yours sincerely,

[redacted]

Kathryn Smith
Ethical Secretary

Appendix II: Recruitment letters

- Kingshill Research Centre version (as approved by Swindon REC)
- BRACE Centre version (as approved by North Bristol REC)

Kingshill
Research Centre

Victoria Hospital
Okus Road
Swindon
Wilts
SN1 4HZ

Telephone: (01793) 481182
Facsimile: (01793) 437521
Email: info@kingshill-research.org
Internet: www.kingshill-research.org

Dear

I am a trainee clinical psychologist from the University of Southampton and I am carrying out a research project with the support of the Kingshill Research Centre. As part of this project I would like to speak to people who have experienced difficulties with their memories.

The Kingshill Research Centre gave me your name and address because they thought that you might be interested in taking part in my project. I have enclosed an information sheet that you can read to help you decide if you would like to take part.

The Kingshill Research Centre also gave me your telephone number and I will phone you about a week after you receive this letter to see if you would like to be involved in my project and answer any questions you might have about it. If you would not like me to phone you, you can leave a message with someone from the psychology section of the Kingshill Research Centre and they will let me know that you would prefer it is I did not contact you.

I hope that you will find my project interesting and I look forward to speaking to you.

Yours sincerely

Philippa Wilson

Frenchay LREC approved final version, dated 6 April 2001

The BRACE Centre
Blackberry Hill Hospital
Manor Road
Fishponds
Bristol
BS16 2EW

Dear

One of my colleagues is carrying out a research project with the support of the BRACE Centre. Her name is Philippa Wilson and she is a trainee clinical psychologist from the University of Southampton. As part of her project she would like to speak to people who have experienced difficulties with their memories. She is particularly interested in the things which people with memory difficulties tend to worry about. Attached is an information sheet which explains more about the project.

If you would like to take part in this project, please contact the BRACE Centre on 0117-9186851 and ask to speak to Dr Judy Haworth. She will get in touch with Philippa who will then contact you to arrange a convenient time to visit you.

Thank you for taking the time to read this letter. I hope you will find the project interesting.

Yours sincerely,

Professor Gordon K Wilcock BSc., DM (Oxon.), FRCP
Consultant in Care of the Elderly

Appendix III: Information sheets (for participants and informants)

- Kingshill Research Centre version (as approved by Swindon REC)
- BRACE Centre version (as approved by North Bristol REC)

University of Southampton

Department of Psychology

Doctoral Programme in Clinical Psychology

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# INFORMATION SHEET

Project: Anxiety and Memory problems

My name is Philippa Wilson and I am a trainee clinical psychologist, based at the University of Southampton. I am carrying out a research project to find out more about anxiety in people who have difficulties with their memories. I want to find out what kinds of things people with memory problems worry about. I also want to look at how some other factors, such as how much support you get from other people, affects these worries.

I hope that by knowing more about what it is like to have memory problems, and the kinds of things which people with memory problem worry about, we will be able to develop better ways of helping people in a similar position.

If you would like to take part in the project, I will come to visit you at home. You will be able to ask me more questions about the project then and I will ask you to sign a consent form.

Taking part in the project will involve answering a few questions about the things that you worry about. I will be tape-recording the answers to these questions. These tapes will be kept in a safe place and no one apart from me will be able to listen to them. After the project is finished, the tapes will be wiped clean.

As part of the project, I will also ask you to complete some questionnaires. Each of the questionnaires comes with instructions and I will be there while you complete the questionnaires so that you can ask me about any questions that are unclear.

I will also ask a friend or relative who knows you well to complete some brief questionnaires.

If you decide to take part in the project, your results will be kept confidential. The questionnaires that you complete will be marked with a number and not your name, and the results will only be

used for this project. No one will find out what you have said to me as part of the project.

It is entirely your decision to take part in the project. If you choose to take part in the project but then change your mind, you can stop **at any time**. If you decide to stop, you don't have to give a reason. This will not affect any help you are getting now or might get in the future.

If you have any questions about the project or if there is anything you would like to talk about after completing the questionnaires, I can be contacted at the following address:

Philippa Wilson
Training Course in Clinical Psychology
Shackleton Building (44)
University of Southampton
Highfield
Southampton
SO17 1BJ

You can also contact me at this address if you would like to know the results of my project.

I will also be giving your friend or relative a sheet like this one so they will know how to get in touch with me as well.

**Thank you** very much for giving up your time to take part in this project. Your help is appreciated a lot and I hope you will find the questionnaires interesting.

University of Southampton

Department of Psychology

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## INFORMATION SHEET for relatives/friends

Project: Anxiety and Memory Problems.

I am a trainee clinical psychologist, based at the University of Southampton. As part of my training, I am carrying out a research project investigating anxiety in people who have memory problems.

I am planning to investigate kinds of things which people with memory problems tend to worry about and factors which contribute to these worries. This is what this research project intends to add to existing research. It is hoped that by understanding more about what it is like to experience memory problems, and by increasing our knowledge of common concerns in this group, we will be able to develop better ways of helping this group of people.

If your relative or friend decides to take part in the project, I will ask them to complete a consent form to make sure that they are clear about what the project will involve and that participation is entirely voluntary. Your relative or friend will be provided with an information sheet a bit like this one and will have the opportunity to ask questions about the project.

If your relative or friend gives their consent to take part in the project, I will visit him or her at home. Taking part in the project will involve answering a series of brief question about the kinds of things he or she worries about. The answers to these questions will be tape-recorded. These tapes will be kept in a safe place and will be marked with a number not a name. Results will be presented anonymously. The tapes will only be used for the project and will be wiped clean at the end of the project. No one other than myself will have access to the tapes.

As part of the project, I will also ask your relative or friend to complete some questionnaires. Each of the questionnaires comes with instructions and I will be there while he or she completes the questionnaires so that he or she can ask me about any questions that are unclear.

I will also be asking you to complete some questionnaires about your friend or relative. You can complete these at the same time as you friend or relative completes their questionnaires so you will be able to ask me questions about the questionnaires.

Participation in the project is confidential. Participants will not be recognisable from their results and these results will only be used for research purposes. No distress or discomfort should be felt during the project. However, if your relative or friend does appear to be getting upset during participation in the project, I will stop at once. Participation is entirely

voluntary. If your friend or relative decides that he or she would not like to take part in the project, or if they would like to withdraw form the project **at any point**, they can do so. They do not need to give a reason. This will not affect their current or future medical care at all.

If you have any questions about this project, if there is anything that arises from completing these questionnaires that you would like to discuss further, or if you would like to receive information regarding the outcomes of the study, I can be contacted at the following address:

Philippa Wilson
Training Course in Clinical Psychology
Shackleton Building (44)
University of Southampton
Highfield
Southampton
SO17 1BJ

You can also contact me at this address if you would like to know more about the results of the project after it has been completed.

Your relative or friend also knows that I can be contacted at this address.

**Thank you** very much for giving up your time to take part in this project. I hope you will agree that it is a worthwhile and interesting project. Your help and that of your relative or friend is appreciated

University of Southampton

Department of Psychology

Doctoral Programme in Clinical Psychology

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SO17 1BJ
United Kingdom

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Fax +44 (0)23 8059 2588
Email



**Frenchay LREC approved final version, dated 6 April 2001**

**Contact number:**

# INFORMATION SHEET

Project: **Anxiety and Memory problems**

## Reasons for the project

My name is Philippa Wilson and I am a trainee clinical psychologist, based at the University of Southampton. I am carrying out a research project to find out more about anxiety in people who have difficulties with their memories. I want to find out what kinds of things people with memory problems worry about. I also want to look at how some other factors, such as how much support you get from other people, affects these worries.

I hope that by knowing more about what it is like to have memory problems, and the kinds of things which people with memory problem worry about, we will be able to develop better ways of helping people in a similar position.

## What does this mean for you?

If you would like to take part in the project, I will come to visit you at home. You will be able to ask me more questions about the project then and I will ask you to sign a consent form.

Taking part in the project will involve answering a few questions about the things that you worry about. I will be tape-recording the answers to these questions. These tapes will be kept in a safe place and no one apart from me will be able to listen to them. After the project is finished, the tapes will be wiped clean.

As part of the project, I will also ask you to complete some questionnaires. Each of the questionnaires comes with instructions and I will be there while you complete the questionnaires so that you can ask me about any questions that are unclear.

I will also ask a friend or relative who knows you well to complete some brief questionnaires.

If you decide to take part in the project, your results will be kept confidential. The questionnaires that you complete will be marked with a number and not your name, and the results will only be used for this project. No one will find out what you have said to me as part of the project. I will write a short letter to your GP, telling him or her that you have taken part in the project, but he or she will not have access to what you have said to me.

It is entirely your decision to take part in the project. If you choose to take part in the project but then change your mind, you can stop **at any time**. If you decide to stop, you don't have to give a reason. This will not affect any medical care you are getting now or might get in the future.

If you have any questions about the project or if there is anything you would like to talk about after completing the questionnaires, I can be contacted at the following address:

Philippa Wilson
Training Course in Clinical Psychology
Shackleton Building (44)
University of Southampton
Highfield
Southampton
SO17 1BJ

You can also contact me at this address if you would like to know the results of my project.

I will also be giving your friend or relative a sheet like this one so they will know how to get in touch with me as well.

**Thank you** for reading this information sheet. I hope that you will decide to take part in my project and that you will find it interesting.

University of Southampton

Department of Psychology

Doctoral Programme in Clinical Psychology

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**Frenchay LREC approved final version, dated 6 April 2001**

**Contact number:**

## INFORMATION SHEET for relatives/friends

Project: **Anxiety and Memory Problems.**

### Reasons for the project

I am a trainee clinical psychologist, based at the University of Southampton. As part of my training, I am carrying out a research project investigating anxiety in people who have memory problems.

I am planning to investigate kinds of things which people with memory problems tend to worry about and factors which contribute to these worries. This is what this research project intends to add to existing research. It is hoped that by understanding more about what it is like to experience memory problems, and by increasing our knowledge of common concerns in this group, we will be able to develop better ways of helping this group of people.

### What does this mean for your relative?

If your relative or friend decides to take part in the project, I will ask them to complete a consent form to make sure that they are clear about what the project will involve and that participation is entirely voluntary. Your relative or friend will be provided with an information sheet a bit like this one and will have the opportunity to ask questions about the project.

If your relative or friend gives their consent to take part in the project, I will visit him or her at home. Taking part in the project will involve answering a series of brief question about the kinds of things he or she worries about. The answers to these questions will be tape-recorded. These tapes will be kept in a safe place and will be marked with a number not a name. Results will be presented anonymously. The tapes will only be used for the project and will be wiped clean at the end of the project. No one other than myself will have access to the tapes.

As part of the project, I will also ask your relative or friend to complete some questionnaires. Each of the questionnaires comes with instructions and I will be there while he or she completes the questionnaires so that he or she can ask me about any questions that are unclear.

What does this mean for you?

I will also be asking you to complete some questionnaires about your friend or relative. You can complete these at the same time as you friend or relative completes their questionnaires so you will be able to ask me questions about the questionnaires.

## What will happen to the results of the project?

Participation in the project is confidential. Participants will not be recognisable from their results and these results will only be used for research purposes. I will write a brief letter to your friend or relative's GP, informing him or her that your friend or relative has taken part in the project.

No distress or discomfort should be felt during the project. However, if your relative or friend does appear to be getting upset during participation in the project, I will stop at once. Participation is entirely voluntary. If your friend or relative decides that he or she would not like to take part in the project, or if they would like to withdraw form the project **at any point**, they can do so. They do not need to give a reason. This will not affect their current or future medical care at all.

How can you find out more?

If you have any questions about this project, if there is anything that arises from completing these questionnaires that you would like to discuss further, or if you would like to receive information regarding the outcomes of the study, I can be contacted at the following address:

Philippa Wilson
Training Course in Clinical Psychology
Shackleton Building (44)
University of Southampton
Highfield
Southampton
SO17 1BJ

You can also contact me at this address if you would like to know more about the results of the project after it has been completed.

Your relative or friend also knows that I can be contacted at this address.

**Thank you** for reading this information sheet. I hope that your friend or relative will decide to take part in my project and that you will find it interesting.

Appendix IV: Consent Form

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## CONSENT FORM

Project: Anxiety and Memory Problems

I have spoken to ..... (name of researcher) about this project on.....

Have you read and understood the information sheet about this project? YES/NO

Have you had the chance to ask questions about the project? YES/NO

Do you understand that it is entirely your choice to take part in the project? YES/NO

Do you understand that if you take part in the project, you can stop at any time, without giving a reason? YES/NO

Do you understand that if you do not want to take part, or if you stop taking part, this will not affect any medical care you are getting now or in the future? YES/NO

Do you understand that as part of this project, your relative/friend ..... (name) will also be answering some questions? YES/NO

Do you agree to having a section of the interview with the researcher recorded on an audio-tape? YES/NO

Do you agree to your GP being informed that you are taking part in the project? YES/NO

Do you agree to take part in the project? YES/NO

Signed ..... Date.....

Name .....

Signed (researcher)..... Date.....

Name .....

Appendix V: Semi-structured interview schedule

Semi-structured interview schedule

These questions are asked by the researcher. The responses of the participants are then audio-taped.

1. What kinds of things do you worry about?

2. Do you have any worries that are particularly related to your health or memory problems?

3. What do you consider to be the cause of your memory difficulties?

4. How much of a problem do you see the difficulties with your memory as being? (rated as 'very much', 'a moderate amount', 'a little' or 'not at all')

5. What are the situations which make you feel particularly worried?

6. Have you noticed any changes recently in the amount you worry and the things you worry about?

7. How do you feel about the future?

Appendix VI: Clinician's ratings of awareness (based on Verhey *et al.*, 1993).

**Ratings of awareness (based on Verhay et al, 1993)**

4. Adequate awareness
Patient has adequate knowledge of his or her cognitive deficits. Spontaneous complaints about memory or other cognitive dysfunction.

3. Mildly disturbed awareness
Patient has some knowledge of his cognitive deficits, but with some gaps. Spontaneous complaints about memory. History of the patient shows some discrepancies with the history of the informant.

2. Moderately disturbed awareness
Patient has only vague and passive knowledge of cognitive deficits. No spontaneous complaints, admits to memory deficiencies only when questioned about them. Obvious discrepancies with the history of the informant.

1. Severely disturbed awareness
Denies any deficits. No complaints about memory whatsoever, even after explicit questioning.

Appendix VII: measures used in the study

- The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) – participants' version
- The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) – carers' version
- Mini-Mental State Examination (MMSE)
- Hospital Anxiety and Depression Scale (HADS)
- Brief Fear of Negative Evaluation Scale (FNE)
- Short Form Social Support Questionnaire (SSQ6)
- Rating Anxiety in Dementia Scale (RAID)
- Cornell Scale for Depression in Dementia

## The IQCODE – Short Form

Compared with ten years ago how are you at:

| | | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|---|
| 1. | Remembering things about family and friends, e.g. occupations, birthdays, addresses | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2. | Remembering things that have happened recently | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 3. | Recalling conversations a few days later | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 4. | Remembering your address and telephone number | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 5. | Remembering what day and month it is | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 6. | Remembering where things are usually kept | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 7. | Remembering where to find things which have been put in a different place from usual | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 8. | Knowing how to work familiar machines around the house | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 9. | Learning to use a new gadget or machine around the house | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 10. | Learning new things in general | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 11. | Following a story in a book or on TV | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 12. | Making decisions on everyday matters | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 13. | Handling money for shopping | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 14. | Handling financial matters, e.g. the pension, dealing with the bank. | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 15. | Handling other everyday arithmetic problems, e.g. knowing how much food to buy, knowing how long between visits from family or friends | Much improved | A bit improved | Not much change | A bit worse | Much worse |

| | | | | | | |
|---|---|---|---|---|---|---|
| 16. | Using your intelligence to understand what's going on and to reason things through | Much improved | A bit improved | Not much change | A bit worse | Much worse |

## The IQCODE – Short Form

Compared with ten years ago how is your friend or relative at:

| | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| 1. Remembering things about family and friends, e.g. occupations, birthdays, addresses | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2. Remembering things that have happened recently | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 3. Recalling conversations a few days later | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 4. Remembering her/his address and telephone number | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 5. Remembering what day and month it is | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 6. Remembering where things are usually kept | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 7. Remembering where to find things which have been put in a different place from usual | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 8. Knowing how to work familiar machines around the house | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 9. Learning to use a new gadget or machine around the house | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 10. Learning new things in general | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 11. Following a story in a book or on TV | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 12. Making decisions on everyday matters | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 13. Handling money for shopping | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 14. Handling financial matters, e.g. the pension, dealing with the bank. | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 15. Handling other everyday arithmetic problems, e.g. knowing how much food to buy, knowing how long between visits from family or friends | Much improved | A bit improved | Not much change | A bit worse | Much worse |

| | | | | | | |
|---|---|---|---|---|---|---|
| 16. | Using his/her intelligence to understand what's going on and to reason things through | Much improved | A bit improved | Not much change | A bit worse | Much worse |

## Mini-Mental State Examination

Section 1: Orientation

| | | |
|---|---|---|
| 1. What is today's date?<br>2. What is the year?<br>3. What is the month?<br>4. What day is it today?<br>5. Can you tell me what season it is?<br>6. What is the address of the place where we are?<br>7. What floor of this building are we on?<br>8. What town or city are we in?<br>9. What county are we in?<br>10. What country are we in? | | |

Section 2: Immediate Recall

Ask the participant to repeat the following three words:

| | | |
|---|---|---|
| Ball<br>Flag<br>Tree | | |

Section 3: Attention and Calculation

| | | | | |
|---|---|---|---|---|
| Start with 100 and take away '7' five times<br><br>AND spell the word 'world ' backwards. | 93<br>86<br>79<br>72<br>65 | | D<br>L<br>R<br>O<br>W | |

Section 4: Recall

Can you recall the words I said earlier?

| | | |
|---|---|---|
| Ball<br>Flag<br>Tree | | |

Section 5: Language

| | | |
|---|---|---|
| What is this? (Watch)<br>And this? (Pencil)<br>Repeat after me: 'No ifs, ands or buts'<br>'Take this piece of paper in your right hand,<br>Fold it in half,<br>And put it on your knee'<br>Read and do: 'Close your eyes'<br>Write a sentence<br>Copying pentagons | | |

Total:

## Hospital Anxiety and Depression Scale

This questionnaire is designed to help us understand more about how you feel. Read each item and circle the answer which comes closest to how you have been feeling in the past week. Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

1. **I feel tense or 'wound up'**
   - Most of the time
   - A lot of the time
   - From time to time, occasionally
   - Not at all

2. **I still enjoy the things I used to enjoy**
   - Definitely as much
   - Not quite so much
   - Only a little
   - Hardly at all

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

4. **I can laugh and see the funny side of things**
   - As much as I always could
   - Not quite so much now
   - Definitely not so much now
   - Not at all

5. **Worrying thoughts go through my mind**
   - A great deal of the time
   - A lot of the time
   - From time to time but not too often
   - Only occasionally

6. **I feel cheerful**

   Not at all

   Not often

   Sometimes

   Most of the time

7. **I can sit at ease and feel relaxed**

   Definitely

   Usually

   Not often

   Not at all

8. **I feel as if I am slowed down**

   Nearly all the time

   Very often

   Sometimes

   Not at all

9. **I get a sort of frightened feeling like 'butterflies' in the stomach**

   Not at all

   Occasionally

   Quite often

   Very often

10. **I have lost interest in my appearance**

    Definitely

    I don't take as much care as I should

    I may not take quite as much care

    I take just as much care as ever

**11. I feel restless as if I have to be on the move**

Very much indeed

Quite a lot

Not very much

Not at all

**12. I look forward with enjoyment to things**

As much as I ever did

Rather less than I used to

Definitely less than I used to

Hardly at all

**13. I get sudden feelings of panic**

Very often indeed

Quite often

Not very often

Not at all

**14. I can enjoy a good book or radio or TV programme**

Often

Sometimes

Not often

Very seldom

**Brief Fear of Negative Evaluation Scale**

| | | |
|---|---|---|
| 1. I worry about what people will think of me even when I know it doesn't make any difference | YES | NO |
| 2. I am unconcerned even if I know people are forming an unfavourable opinion of me | YES | NO |
| 3. I am frequently afraid of other people noticing my shortcomings | YES | NO |
| 4. I rarely worry about what kind of impression I am making on someone | YES | NO |
| 5. I am afraid that others will not approve of me | YES | NO |
| 6. I am afraid that people will find fault with me | YES | NO |
| 7. Other people's opinions of me do not bother me | YES | NO |
| 8. When I am talking to someone, I worry about what they may be thinking about me | YES | NO |
| 9. I am usually worried about what kind of impression I make | YES | NO |
| 10. If I know someone is judging me, it has little effect on me | YES | NO |
| 11. Sometimes I think I am too concerned with what others think of me | YES | NO |
| 12. I often worry that I will say or do the wrong things | YES | NO |

**Short form Social Support Questionnaire (SSQ6)**

## Instructions

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give each person's initials and their relationship to you. Do not list more than one person next to each of the numbers beneath each question. Do not list more than nine people per question.

For the second part, using the scale below circle how satisfied you are with the overall support you have.

| 6 | 5 | 4 | 3 | 2 | 1 |
|---|---|---|---|---|---|
| Very satisfied | Fairly satisfied | A little satisfied | A little dissatisfied | Fairly dissatisfied | Very dissatisfied |

If you have no support for a question, tick the words 'No one', but still rate your level of satisfaction.

1. **Whom do you feel that you can really count on to distract you from your worries when you feel under stress?**

| | | | |
|---|---|---|---|
| No one | 3. | 6. | 9. |
| 1. | 4. | 7. | |
| 2. | 5. | 8. | |

How satisfied?

| 6 | 5 | 4 | 3 | 2 | 1 |
|---|---|---|---|---|---|
| Very satisfied | Fairly satisfied | A little satisfied | A little dissatisfied | Fairly dissatisfied | Very dissatisfied |

2. **Whom can you really count on to help you feel more relaxed when you are under pressure or tense?**

| | | | |
|---|---|---|---|
| No one | 3. | 6. | 9. |
| 1. | 4. | 7. | |
| 2. | 5. | 8. | |

How satisfied?

| 6 | 5 | 4 | 3 | 2 | 1 |
|---|---|---|---|---|---|
| Very satisfied | Fairly satisfied | A little satisfied | A little dissatisfied | Fairly dissatisfied | Very dissatisfied |

**3. Who accepts you totally, including both your worst and best points?**

| | | | |
|---|---|---|---|
| No one | 3. | 6. | 9. |
| 1. | 4. | 7. | |
| 2. | 5. | 8. | |

How satisfied?

| 6 | 5 | 4 | 3 | 2 | 1 |
|---|---|---|---|---|---|
| Very satisfied | Fairly satisfied | A little satisfied | A little dissatisfied | Fairly dissatisfied | Very dissatisfied |

**4. Whom can you count on to care about you, regardless of what is happening to you?**

| | | | |
|---|---|---|---|
| No one | 3. | 6. | 9. |
| 1. | 4. | 7. | |
| 2. | 5. | 8. | |

How satisfied?

| 6 | 5 | 4 | 3 | 2 | 1 |
|---|---|---|---|---|---|
| Very satisfied | Fairly satisfied | A little satisfied | A little dissatisfied | Fairly dissatisfied | Very dissatisfied |

**5. Whom can you count on to help you feel better when you are feeling generally down-in-the-dumps?**

| | | | |
|---|---|---|---|
| No one | 3. | 6. | 9. |
| 1. | 4. | 7. | |
| 2. | 5. | 8. | |

How satisfied?

| 6 | 5 | 4 | 3 | 2 | 1 |
|---|---|---|---|---|---|
| Very satisfied | Fairly satisfied | A little satisfied | A little dissatisfied | Fairly dissatisfied | Very dissatisfied |

**6. Whom can you count on to console you when you are very upset?**

| | | | |
|---|---|---|---|
| No one | 3. | 6. | 9. |
| 1. | 4. | 7. | |
| 2. | 5. | 8. | |

How satisfied?

| 6 | 5 | 4 | 3 | 2 | 1 |
|---|---|---|---|---|---|
| Very satisfied | Fairly satisfied | A little satisfied | A little dissatisfied | Fairly dissatisfied | Very dissatisfied |

## RAID (Rating Anxiety in Dementia)

This questionnaire is rated by the researcher on the basis of a semi-structured interview with a friend, relative or carer of the individual with memory problems.

Scoring system:
U: unable to evaluate. 0: absent. 1: mild or intermittent. 2: moderate. 3: severe.
Rating should be based on symptoms and signs occurring during two weeks prior to the interview.
No score should be given if symptoms result from physical disability or illness.
Total score is the sum of items 1 to 18. A score of 11 or more suggests significant clinical anxiety.

| | | Score |
|---|---|---|
| Worry | | |
| 1. | Worry about physical health. | |
| 2. | Worry about cognitive performance (failing memory, getting lost when goes out, not able to follow conversation). | |
| 3. | Worry over finances, family problems, physical health of relatives. | |
| 4. | Worry associated with false belief and/or perception. | |
| 5. | Worry over trifles (repeatedly calling for attention over trivial matters). | |
| Apprehension and vigilance | | |
| 6. | Frightened and anxious (keyed up and on edge). | |
| 7. | Sensitivity to noise (exaggerated startle response). | |
| 8. | Sleep disturbance (trouble falling or staying asleep). | |
| 9. | Irritability (more easily annoyed than usual, short tempered and angry outbursts). | |
| Motor tension | | |
| 10. | Trembling | |
| 11. | Motor tension (complaints of headache, other body aches and pains). | |
| 12. | Restlessness (fidgeting, cannot sit still, pacing, wringing hands, picking clothes). | |
| 13. | Fatigueability, tiredness. | |
| Autonomic hypersensitivity | | |
| 14. | Palpitations (complains or heart racing or thumping) | |
| 15. | Dry mouth (not due to medication), sinking feeling in the stomach) | |
| 16. | Hyperventilating, shortness of breath (even when not exerting). | |
| 17 | Dizziness or light-headedness (complains as if going to faint). | |
| 18. | Sweating, flushes or chills, tingling or numbness of fingers and toes. | |
| **Phobias**: (fears which are excessive, that do not make sense and which involve avoidance – e.g. fear of crowds, going out alone, being in a small room, or being frightened by some kind of animals, heights etc). Describe: | | |
| **Panic attacks**: (feelings of anxiety or dread that are so strong that they think they are going to die or have a heart attack and they simply have to do something to stop them, like immediately leaving the place, phoning relatives etc). Describe: | | |
| | | Total: |

## Cornell Scale for Depression in Dementia

This questionnaire is rated by the researcher on the basis of a semi-structured interview with a friend, relative or carer of the individual with memory problems.

Scoring system:
a: unable to evaluate. 0: absent. 1: mild or intermittent. 2: severe.
Rating should be based on symptoms and signs occurring during the week prior to the interview.
No score should be given if symptoms result from physical disability or illness.
A score of 8 or more may indicate depression.

| | | |
|---|---|---|
| **Mood-Related Signs** | | |
| 1. | Anxiety (anxious expression, ruminations, worrying) | |
| 2. | Sadness (sad expression, sad voice, tearfulness) | |
| 3. | Lack of reactivity to pleasant events. | |
| 4. | Irritability (easily annoyed, short-tempered). | |
| **Behavioural disturbance** | | |
| 5. | Agitation (restlessness, hand wringing, hair pulling). | |
| 6. | Retardation ( slow movements, slow speech, slow reactions). | |
| 7. | Multiple physical complaints (Score 0 if GI symptoms only). | |
| 8. | Loss of interest (less involved in usual activities, score only if change occurred acutely, i.e. in < one month). | |
| **Physical signs** | | |
| 9. | Appetite loss (eating less than usual) | |
| 10. | Weight loss (score 2 if > 5lbs in one month). | |
| 11. | Lack of energy (fatigues easily, unable to sustain activities, score only if change occurred acutely, i.e. in < one month). | |
| **Cyclic functions** | | |
| 12. | Diurnal variation of mood (symptoms worse in the morning) | |
| 13. | Difficulty falling asleep (later than usual for this individual). | |
| 14. | Multiple awakenings during sleep. | |
| 15. | Early morning awakening (earlier than usual for this individual) | |
| **Ideational disturbance** | | |
| 16. | Suicide (feels life is not worth living, has suicidal wishes or makes suicidal attempt). | |
| 17. | Self-deprecation (self-blame, poor self-esteem, feelings of failure). | |
| 18. | Pessimism (anticipation of the worst). | |
| 19. | Mood congruent delusions (delusions of poverty, illness, loss). | |
| | | Total: |

Appendix VIII: Examples of two transcripts of the semi-structured interview with research participants.

- MCI participant
- ED participant

Participant A: Transcription of qualitative interview

(P = participant, R = researcher)

R: First of all, can you tell me a little bit about the kinds of things that you tend to worry about, just generally?

P: Mainly, as I said to you about, reading a book is not as easy as it was, because I just forget who the characters are. I've got to go back through the book, oh that's who that was. And another thing which is probably the most embarrassing thing, is not remembering people's names. Now, I'm not talking about people I haven't seen for a long, long time, I'm talking about people I see every week. We belong to the____, a crowd of us, we're in various groups and I organise group holidays for them. I just have a blank. Someone I've known for a while and I just cannot remember their name. It's totally embarrassing. I think, well, other people are like it probably. But I never used to be like this. Maybe it's just something to do with age. I don't know.

R: But it's a change?

P: Yes, certainly.

R: Do you have any other worries about your health or your memory difficulties?

P: No. I remember to take medication. I remember to remind _____ [husband] to take his. That sort of thing. Silly things. We've got a very old grandfather clock and it needs to be wound up every week and I have to put the key out to remind me to do it. Otherwise, things like that, I just wouldn't remember to do. I don't know. It has got worse, but I won't say it's getting worse now. But it's worse than it used to be when I was younger, but possibly everybody gets like it. And yet, some people appear not to.

R: We've talked about what the doctor thinks is going on with your memory, that they're not really sure, I think. But what do you consider to be the cause of your memory difficulties?

P: I don't know. Everybody tells me that Alzheimer's is not hereditary so.. but I thought well, I don't know. I mean nobody else in my mother's family had it. She came from a family of about twelve and she was the only one in the whole family so it obviously hasn't passed through their family. And hers came from shingles, after she had a very bad bout of shingles – whether that did something I don't know.

R: How much of a problem do you see the difficulties with your memory as being. Would you say they're not a problem at all or a little problem or a big one or somewhere in between?

P: An annoying problem. Because I'll tell you one thing now which I want to do. I want to go on a computer training course, because I bought a computerised sewing machine which is very with-it and if I had a computer and could use a computer, I could do ever such a lot more designing on it because it has all the technology but I

haven't got a computer. And I'd like to go on a course, but I'm sure I just wouldn't remember anything from one week to another and this is what – it's things like this. It's no good me going on a course. I wouldn't remember. It's hard taking the theory driving test now. Because when I took it the first time, you didn't do a theory paper, you only did a practical. But doing the theory now. I found that very very hard. In fact, in some ways it was worse than the practical. It's just remembering things like that.

R: You've answered this already really, but are there any other situations which make you feel particularly worried?

P: No, I don't... sometimes... I'm a group organiser for holidays for _____ groups, and people ask me sometimes, oh we went to so-and-so and they want to know some of the details of it and I can't remember at all. Who did I contact to organise it? Sometimes I just can't remember.

R: OK. Have you noticed any changes recently in the amount that you worry or the things that you worry about?

P: Well, since he's [husband] been like this, yes. There's more to worry about. You worry going out, that's he's not going to flake out or something's going to happen. I mean, you do worry. You know, I've not got the freedom I used to have. I make myself do things. I make myself travel the world with my friend. I've still got the confidence to do that.

R: And one final question for this section. How do you feel about the future?

P: Well, I feel that you just have to get on with it really. I must admit, to a certain extent, I feel when you feel yourself you've had enough, I wish you could say to the doctor, put me down, like an animal is put down. I don't agree with seeing the way my mother was. She'd have a few lucid moments. I arranged to go to hospital one day and she said can you take me to the toilet. She said can you take me to the toilet. She said I do hate the nurses having to do it. Oh god, I don't want to be like that. Who knows what, that sort of thing. If it happens..,. I suppose, people tell me if it happens I won't know. I suppose you don't, but new treatments are coming out, aren't they? New drugs to treat it?

R: They are, yes. I'll stop that now. Thank you.

Participant B: Transcription of qualitative interview

(P = participant, R = researcher)

R: First of all can you tell me a little bit about the kind of things, if anything, that you tend to worry about?

P: Quite worried about my health... erm.. At the moment I've had to write to the DVLA about my driving license, and er... Mr... worked at the _____, Professor _____, he said I had to do this, and so I've done it, and they've sent me off the form to fill in which I've sent back, and this is quite some time now and I haven't heard from them yet, so I'm wondering whether, you know, I shall be able to keep my driving license. It expires in January anyway, but you know, I'm a bit anxious about that, I want to go on driving if possible, but you know if they say I can't then that's it. They're going to approach Professor _____ and my doctor, my surgery doctor, to find out about my health in general. So I'm just waiting for something to happen really. So really that's my main worry at the moment.

R: Do you have any other worries connected with your memory at all?

P: Yes, I'm worried about my memory. The way I sort of go into a room for something, I think "well what did I come in here for", you know. Go back, find, you know, I've put something down and I can't find it, and, you know, silly little things really I suppose lots of people put up.. have to put up with this when they get to my age. I do look after the garden and everything. Erm, been a bit of a problem lately because we haven't had any rain for a long time. I go out watering it every evening.

R: OK, we talked about what the doctors think might be wrong with your memory. What do you think is the cause of your memory problems?

P: I suppose mainly it's getting old. I think that's the main thing really. And it's worrying me about my eyes, I'm finding it more and more difficult to read, especially in the evenings with the light, the artificial light. I can't read any small print now at all and there's nothing I can do about it. I can't get stronger lenses or anything. The only thing I can do I suppose is use a magnifying glass, which I do sometimes.

R: How much of a problem do you see the difficulties with your memory as being? Would you say that they're not really a problem at all, that it's a small problem, a medium problem, or a big problem?

P: Well, certainly a problem. I suppose it's... a small problem at the moment, but I suppose it will gradually get worse.

R: Are there any situations that make you particularly worried about your memory or about your health?

P: Hmm... Well remembering appointments and things like that... you know.. no... can't really think of anything.

R: Have you noticed any changes at all recently in the things that you are worrying about or the amount that you worry?

P: Well I suppose I worry more now than I used to a few years ago, it's just you know I didn't have all these problems when I was younger.

R: I've got one final question for this section. How do you feel about the future?

P: Well, I feel as though I don't get any worse, you know I can survive. I dare say of course I don't know. I'm 78 now, getting on for 80, whether I shall survive that long, well you don't know really when you get to... Well nobody knows how long they've going to live, but... No that's the only thing really.

R: OK, I'll stop that now... I'll stop recording, thank you very much for that.

Appendix IX: Instructions for authors of target journals

- Age and Ageing
- Aging and Mental Health

# Information for contributors

*Age and Ageing* is an international journal which presents an eclectic view of ageing and of sickness, disability and health in later life.

The target readership includes clinicians, who wish to be informed about new developments in medicine and related fields (including sociology, psychology, ethics, economics and politics); scientists (including biological gerontologists and social scientists); and other professionals who work in subjects related to the medicine of later life.

The journal is a forum for the dissemination and integration of knowledge. It aims to heighten understanding, highlight gaps in our knowledge — thereby promoting further research — and improve clinical care by promoting good practice and identifying needless, inappropriate and harmful activities.

Subjects covered include epidemiology, gerontology, physiology, sociological aspects of ageing, psychology, clinical trials, service delivery, pharmacology, and hospital as well as community care. We aim to publish well-written clinical and scientific research reports of the highest quality, which are original and relevant. Clinical trials are welcome. We also publish papers reporting negative results and meta-analyses. We are pleased to receive authoritative reviews and commentaries, which might be critical or constructive, selected case reports, provocative and lively letters, teaching points and other special pieces.

As well as presenting articles on the science, art and craft of gerontology and geriatric medicine, *Age and Ageing* wishes to stimulate, entertain and inform by including photographs of older people and age-related topics, aphorisms, poems and prose.

**Submission of manuscripts** Contributions and correspondence should be sent to Professor G. P. Mulley, Editor, *Age and Ageing*, Elderly Services Directorate, St James's University Hospital, Leeds LS9 7TF, UK. Tel/fax: (+44) 113 2469275.

Submissions to *Age and Ageing* should not have been previously published (except as an abstract, in which case details should be given). Similarly, the article should not be under consideration by another journal.

All authors must give signed consent to publication. (Credit for authorship requires important contributions to designing and doing the study, analysing and interpreting the data, and writing the article.)

Scientific research articles should be no longer than 2000 words (please give a word count). Submissions may be modified or shortened by the Editor before acceptance for publication.

**Manuscript preparation** Type all manuscripts in double spacing and number each page. The first page should include all authors' full names (clearly indicating which is the family or surname); the name of the centre where the work was done; address of each author; telephone, fax and e-mail details. There is no need to include academic awards but do include titles.

As articles are sent anonymously to referees, a page with the title only should be included.

Please send ***four*** copies (one for each reviewer and one for the Editor). Keep a copy yourself. Also include four copies of any figures or photographs. Do not send a disk until you have been informed that your paper has been accepted.

**Style** Manuscripts should conform to the Uniform Requirements of the International Committee of Medical Journal Editors (N Engl J Med 1997; 336: 309–15).

Please also include: (i) a structured abstract—headings might include: background, objective, design, setting, subjects, methods, results, conclusions; (ii) up to five keywords (please use terms from the Medical Subject Headings in *Index Medicus*); (iii) a running heading (a shortened version of the title); (iv) a Key Points box with 2–5 bullet points which summarize the main messages of your paper; (v) a title for each table or figure; (vi) no more than six tables or figures; (vii) details of sources of research funding or any possible conflict of interest; and (viii) details of informed consent of patients or volunteers studied and approval of an ethics committee, where appropriate.

Authors are encouraged to supply the names and addresses of two or three potential referees, although the Editor reserves the right of final selection.

Please ensure all abbreviations are defined at first usage, scientific measurements are in SI units, and approved names are used for drugs.

Try to avoid language that might be deemed unacceptable or inappropriate (e.g. 'older people' is preferable to 'the elderly'; the word 'senile' is best avoided). Take care with wording that might cause offence to ethnic or cultural groups.

Manuscripts not meeting these requirements may be returned to the authors for modification.

**References** should be numbered in order of citation and cited in the text by numbers in square brackets. They should be listed in the reference list in the form prescribed in the Uniform Requirements (giving the names and initials of all authors, unless there are more than six, when the first six should be given, followed by *et al.*).

**Illustrations** For diagrams, original artwork (black ink on white paper) is preferred, but glossy prints (not negatives or photographs) will usually be acceptable. Illustrations are best supplied larger than final printed size but lettering must be large enough to be legible after reduction. All illustrations should bear the author's name and number of the illustration on the reverse side. Degree of magnification should be indicated where necessary. Captions should be typed on separate sheets. It is the responsibility of the author(s) to ensure that any requirements of copyright and courtesy are fulfilled in reproducing illustrations and appropriate acknowledgements included with the captions.

**Review and Commentaries** Before submitting a Review or Commentary, please contact the Editor or Features Editor with an outline of your plans.

**Case reports** Clinically interesting cases should be written in 4–600 words with no more than one figure or table. Case reports should be of conditions which provide new insight, describe rare but modifiable disorders or present new treatments or understanding. All Case reports are peer-reviewed.

**Correspondence** We welcome lively, provocative, stimulating and amusing letters, as well as comments on and criticisms of articles previously published in the journal. Authors may be invited to re-submit shorter versions of manuscripts for publication in this section. Letters should be double-spaced and signed. Those including original data will be sent for peer review.

**Special sections** We will publish a range of article types: 'Grand round', with a focus on common problems and discussion from members of the inter-disciplinary team; 'Letter from...' giving details of developments in gerontology and geriatric medicine in different parts of the world; 'Personal view', expressing an individual opinion or approach to elderly care or biological or social gerontology; 'Physical sign', critically evaluating the validity and usefulness of clinical signs in geriatric medicine; 'Diogenes': summaries of and brief comment on interesting articles which have appeared in other journals.

**Fillers** We welcome photographs of older people or age-related subjects, drawings, anecdotes, aphorisms and poems on old age. Photographs should be submitted as black-and-white or colour prints. They should be unmounted and with an unmarked front surface. The subjects should sign a release form, confirming that they agree to their picture being published. It is considerate to inform the subject's family that the picture is to be printed.

**Proofs** are sent to authors for the correction of printer's errors only. Authors making extensive alterations will be required to bear resulting costs.

**Reprints** of articles can be ordered on the form supplied which should be returned to the publishers with payment. Twenty-five offprints are supplied free to the first named author on publication.

**Copyright** It is a condition of publication in the journal that authors assign copyright to the British Geriatrics Society. This ensures that requests from third parties to reproduce articles are handled efficiently and consistently and will also allow the article to be as widely disseminated as possible. In assigning copyright, authors may use their own material in other publications provided that the journal is acknowledged as the original place of publication, and Oxford University Press is notified in writing and in advance.

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# Notes for Contributors

*Aging & Mental Health* welcomes original contributions from all parts of the world on the understanding that their contents have not previously been published nor submitted elsewhere for publication. All submissions will be sent anonymously to independent referees. It is a condition of acceptance that papers become the copyright of the publisher. **Books for review** may be sent to either Editor.

### Manuscripts

Manuscripts may be in the form of: (i) regular articles (not exceeding 10,000 words), or, (ii) short reports for rapid publication (not exceeding 2,000 words). Four complete copies should be submitted to either Editor: Dr Martin Orrell, Department of Psychiatry, University College London Medical School, Wolfson Building, Middlesex Hospital, London W1N 8AA, United Kingdom, or Dan G. Blazer, J. P. Gibbons Professor of Psychiatry and Behavioral Sciences, Duke University Medical Center, School of Medicine, Box 3005, Durham, NC 27710, USA.

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

The first page should include the title of the paper, first name, middle initial(s) and last name of the author(s), and for each author a short institutional address, and an abbreviated title (for running headlines within the article). At the bottom of the page give the full name and address (including telephone and fax numbers and e-mail address if possible) of the author to whom all correspondence (including proofs) should be sent. The second page should repeat the title and contain an abstract of not more than 200 words. The third page should repeat the title as a heading to the main body of the text.

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

### References

References should follow APA style. All publications cited in the text should be listed following the text; all references listed must be mentioned in the text. Within the text references should be denoted by the author's name and year of publication in parentheses, e.g. (Woods, 1995) or (Mansell & McGill, 1995) or, if there are more than two authors, (Gallico *et al.*, 1986). Where several references are quoted consecutively within the text the order should be alphabetical, e.g. (Elford & Sherr, 1989; Folkman, 1992). Similarly, where several references are quoted within a single year, the order should be alphabetical (Mansell & McGill, 1995; Woods, 1995). If more than one paper from the same author(s) and year is listed, the date should be followed by (a), (b) etc., e.g. (Blazer, 1995a).

References should be listed at the end of the paper in alphabetical order, typed in double spacing. Responsibility for the references and their verification against the original documents lies with the author(s).

References should be listed on a separate sheet(s) in the following standard form, capitalization and punctuation:

(a) for periodical articles (titles of journals should not be abbreviated):

WOODS, B. (1995). Dementia care: progress and prospects. *Journal of Mental Health, 5*, 115–124.

(b) for books:

NORMAN, A. (1987). *Aspects of ageism.* London: Centre for Policy on Ageing.

(c) for chapters within multi-authored books:

ROBERTSON, I. T. (1994). Personality and personnel selection. In C. L. COOPER & D. M. ROUSSEAU (Eds.), *Trends in organizational behavior* (pp. 75–89). Chichester: Wiley.

### Units of measurement

All measurements must be cited in SI units.

### Illustrations

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

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

### Tables

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

### Proofs

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

### Offprints

Fifty offprints of each paper are supplied free, to the nominated author for correspondence for further distribution, together with a complete copy of the relevant issue of the journal. Additional offprints may be purchased and should be ordered when proofs are returned. Offprints are sent approximately two weeks after publication.

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