AN INVESTIGATION OF THE RELATIONSHIP BETWEEN ANXIETY AND AGITATION IN DEMENTIA

Thesis submitted to

The University of Leicester

Centre for Applied Psychology - Clinical Section

Faculty of Medicine

in partial fulfilment of the degree of

Doctor in Clinical Psychology

Helen Twelftree

2001

UMI Number: U149694

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



UMI U149694

Published by ProQuest LLC 2013. Copyright in the Dissertation held by the Author.

Microform Edition © ProQuest LLC.

All rights reserved. This work is protected against

All rights reserved. This work is protected against unauthorized copying under Title 17, United States Code.



ProQuest LLC 789 East Eisenhower Parkway P.O. Box 1346 Ann Arbor, MI 48106-1346

Contents

		Page
	List of Tables	iii
	Abstract	1
	Acknowledgements	2
1.	Introduction	3
1.1.	Dementia	3
1.2.	Well-Being in Dementia	5
1.3.	Challenging Behaviour in Dementia	8
1.4.	Anxiety	9
1.4.1.	Prevalence of anxiety in older adults	10
1.4.2.	Anxiety in dementia	13
1.5.	Agitation	15
1.6.	The Relationship Between Anxiety and Agitation	17
1.7.	Depression	20
1.8.	Summary and Purpose of the Current Study	22
1.9.	Hypotheses	23
2.	Method	25
2.1.	Design of Study	25
2.2.	Use of Self Report Measures	25
2.3.	Assessment of Anxiety	25
<i>2.3.1</i> .	Anxiety measures chosen	28
2.4.	Assessment of Agitation	29
<i>2.4.1</i> .	Informant rated measures	29
2.4.2.	Observational measures	32
2.4.3.	Mechanical devices	33
2.4.4.	Agitation measure chosen	33
2.5.	Assessment of Depression	33
<i>2.5.1</i> .	Depression measure chosen	34
2.6.	Assessment of Dementia	35
2.7.	Procedure	36
2.8.	Participants' Demographics	37
3.	Results	38
3.1.	Participants	38
3.2.	Measures	38
<i>3.2.1</i> .	Cohen-Mansfield Agitation Inventory	38
<i>3.2.2.</i>	Rating Anxiety in Dementia	39
<i>3.2.3</i> .	State Anxiety Inventory	39
<i>3.2.4</i> .	Geriatric Depression Scale	39
<i>3.2.5.</i>	Mini Mental State Examination	39

Contents

		Page
3.	Results (continued)	
3.3.	Hypothesis One	40
3.4.	Hypothesis Two	41
3.5.	Hypothesis Three	42
3.6.	Hypothesis Four	43
3.7.	Hypothesis Five	43
3.8.	Hypothesis Six	43
3.9.	Hypothesis Seven	43
3.10	Additional Analyses	44
4.	Discussion	46
4.1	Methodology	46
<i>4</i> .1.1.	Representativeness of sample	46
<i>4.1.2.</i>	Participants	47
4.2.	Measures	48
4.2.1.	Cohen-Mansfield Agitation Inventory	48
<i>4.2.2</i> .	Rating Anxiety in Dementia	49
<i>4.2.3</i> .	State Anxiety Inventory	50
4.2.4.	Geriatric Depression Scale	51
4.2.5.	Mini Mental State Examination	52
4.3.	Hypothesis One	53
4.4.	Hypothesis Two	53
4.5.	Hypothesis Three	54
4.6.	Hypothesis Four	54
4.7.	Hypothesis Five	55
4.8.	Hypothesis Six	55
4.9.	Hypothesis Seven	55
4.10	Additional Analyses	56
4.11	Conclusions	56
4.12	Clinical Implications	59
5.	References	60
6.	Appendices	69
Α	Participant Information Sheet and Consent Form	
В	The Rating Anxiety in Dementia Scale	
C	The State Anxiety Inventory	
D	The Cohen-Mansfield Agitation Inventory	
E	The Geriatric Depression Scale	

List of Tables

		Page
Table 1	Spearman's correlations between total scores for each measure.	40
Table 2	Spearman's correlations between RAID total scores and 10 CMAI items, with the item on restlessness removed from both.	42
Table 3	Spearman's correlations between the STAI-S, CMAI and the RAID subscales.	43
Table 4	Mean scores on all measures for participants grouped by sex, living arrangements and informant.	44

Abstract

An Investigation of the Relationship Between Anxiety and Agitation in Dementia

Helen Twelftree

Introduction

Separate lines of research into well-being in dementia have identified anxiety and agitation as indicators of ill-being. Both are common disorders of older adults with dementia and their consequences can be severe, including increased mortality rates and institutionalisation. Anxiety in this population has been under-researched and there are difficulties with its measurement. Despite the importance of anxiety and agitation in dementia care there is confusion between these concepts in the literature. Some studies have assumed that agitation is the same as anxiety in dementia, while others have attempted to differentiate between them.

The primary aim of the study was to investigate whether there was an association between anxiety and agitation in older adults with mild to moderate dementia. A secondary aim was to compare a recently developed anxiety measure for older adults with dementia with one validated for use with older adults without dementia.

Method

A cross-sectional correlational design was used. Forty older adults with dementia who were using mental health services participated in the study. Agitation, anxiety, depression and level of cognitive impairment were assessed.

Results

Significant positive correlations were found between agitation and anxiety, and between the two anxiety measures. Previous findings were replicated with a correlation found between anxiety and depression. Differences were found in the reporting of behaviours by professional and family informants.

Conclusions

The main finding of this study was that anxiety is associated with agitation and could be one of its causes in individuals who have dementia. The moderate correlation found suggests that anxiety and agitation cannot be treated as the same in this population and that other factors associated with agitation should also be considered in clinical practice. The study supported the use of the new measure of anxiety. These findings require extending to clients with more severe cognitive impairment.

Acknowledgements

I would like to thank all of the clients and their carers who participated in this study. I am extremely grateful to them for their time and willingness to help. I would also like to thank all the clinicians who identified and referred clients to participate in the study. I am particularly grateful to the staff in the day hospitals who identified clients and gave their time to complete the carers questionnaires.

I would like to thank all the people who have provided support throughout the study. I would like to thank Professor Ed Miller for his guidance and support in his role as academic supervisor. I would like to thank Gail Scothern in her role as field supervisor, for facilitating the introduction of the study to clinicians, the recruitment of participants, and for her support and encouragement.

I would also like to thank my friends and family who have supported and encouraged me throughout this research. I would like to thank Janet Procter for her proof-reading of the thesis. I would particularly like to thank my partner Nick for all his support and practical help, without which the research process would have been considerably more difficult.

1. Introduction

1.1. Dementia

Dementia is a behavioural syndrome characterised by progressive losses in intellectual functioning which can lead to difficulties in remembering, making decisions, thinking through complex ideas, carrying out practical tasks, retaining information and acquiring new skills (Bond, 1999). Diagnostic criteria for dementia from the Diagnostic and Statistical Manual of Mental Disorder (DSM-IV; American Psychiatric Association, 1994) have several factors which are common to all dementias and can be used as a way of defining the syndrome. These include multiple cognitive deficits including both memory impairment and one of: aphasia, apraxia, agnosia, or disturbance in executive functioning. Each of these deficits must cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning. They must also not occur exclusively during the course of delirium.

The prevalence of dementia has been widely found to be related to age, but different prevalence rates have been reported. Krasucki, Howard and Mann (1998) in their review paper reported one month prevalence rates for severe cognitive impairment of 2.9% for adults aged 65-74, 6.8% for adults aged 75-84, and up to 15.8% for those aged 85 and above. However, Jorm, Korten and Henderson (1987) reported that dementia affects approximately 6.6% of people aged 65 and this prevalence doubles for every 5.1 years of age. The differences in these rates may be accounted for by the different populations studied, assessments used and the cut-offs for dementia or cognitive impairment. With increasing numbers of people living into old age the numbers of people affected by dementia will also increase. It is therefore essential to further our understanding of the disorder so that appropriate interventions for it can be developed.

Dementia has been described purely in terms of the neurological changes in the brain and as an interaction between the neurological changes and the effects of personal and social interaction. The neurological degeneration in the brain is thought to lead to the changes in intellectual, linguistic and cognitive functioning. The behaviours associated

with dementia are perceived as symptoms of the underlying organic changes. Several organic processes have been defined, including Alzheimer's disease, Lewy body disease and multiple infarctions.

One of the difficulties encountered by understanding dementia purely as a disease of the brain is that there does not appear to be a direct relationship between the amount of neurodegeneration and the level of cognitive impairment. Studies have consistently found that there is a large area of overlap in the level of neurodegeneration between people who were identified as having dementia and people identified as not having dementia. If the diagnosis of dementia were to be made on the level of neurodegeneration, up to twenty per cent of participants would be misdiagnosed (for the original studies see Blessed, Tomlinson & Roth, 1968; Roth, 1980; or Jacoby & Levy, 1980). Across these studies approximately 70% of the variance in level of dementia is not accounted for by the amount of neurodegeneration (Jorm, 1990). One explanation for these findings is that current neurological measurement techniques are not sufficiently sensitive to small changes in function. An alternative explanation is that there are processes in addition to the organic changes involved in the syndrome of dementia.

There are several frameworks which have considered the effect of personal or social interactions in dementia. Cheston and Bender (1999) and Bond (1999) have reviewed these. Of particular interest is the framework described by Kitwood and colleagues (Kitwood, 1990, 1993, 1997; Kitwood & Bredin, 1992). In this approach, the neurological changes are seen to interact with changes in relationships with others. The cognitive changes in the person with dementia are thought to attract negative, dehumanising behaviour. This has been termed Malignant Social Psychology (MSP). MSP compounds the individual's difficulties and reduces their personhood (a concept defining what it means to be human in terms of social interactions) which leads to illbeing. Kitwood defined ten types of MSP, based mainly on observation of what happens in institutional care settings. From this he developed interventions which attempt to decrease the MSP in the environment of the person with dementia and hence enhance their personhood and well-being.

There are several positive aspects to this approach. It construes individuals with dementia primarily as people, each of whom is unique and is worthy of respect. It focuses on the social interactions surrounding people with dementia and how they affect the dementing process. Since social interactions are potentially amenable to change, this suggests a positive approach to dementia care and clearly suggests ways in which positive change could be achieved. As a framework it includes the effects of the changes in the brain since neurological impairment is postulated to attract and interact with MSP. In addition, the effect of MSP in dementia suggests an explanation for the lack of correlation between the extent of neurodegeneration and the degree of impairment.

There are several difficulties with Kitwood's work. Cheston and Bender (1999) point out that the impact of Kitwood's ideas has so far been confined to institutional settings. Since 80% of people with dementia live in their own homes, interventions in institutions do not address the needs of the majority. Further work is needed to develop ways to help informal carers develop effective and sustainable patterns of interaction with the person with dementia in their own homes (Cheston & Bender, 1999). The interventions based on Kitwood's work have shown improvements in the interactions surrounding the person with dementia but have been evaluated using his techniques for measurement. There has been a lack of evaluation of Kitwood's work by other measures. Sustained improvement in functioning or quality of life has also not been clearly demonstrated for individuals. A further difficulty with this framework is the concept of personhood (Kitwood & Bredin, 1992). Personhood has not been adequately defined, Kitwood appears to suggest that the essence of being human is purely defined in terms of the person's interactions and relationships with others. This appears to leave little room to include the individual's personality, previous experiences, strengths or weaknesses. Kitwood's work also does not address the effects of the physical environment in enabling or disabling the person with dementia and the effects this has on them.

1.2. Well-Being in Dementia

It is from studies of well-being in dementia that the importance of studying anxiety and agitation has been suggested. As a concept, psychological well-being has proved difficult to define. This is primarily because it is a personal and subjective judgement,

SPECIAL NOTE

ITEM SCANNED AS SUPPLIED PAGINATION IS AS SEEN

Lawton, Kleban, Dean, Rajagopal and Parmelee (1992) considered psychological well-being in older adults without dementia by using a combination of observation and subjective reports. This method was adapted for use with people with dementia where subjective reports would not be possible (Lawton, Van Haitsma and Klapper, 1996). Two factors were generated in the analysis: 'positive affect' (which included happy, interested and energetic) and 'negative affect' (which included sad, annoyed and worried). Volicer, Hurley and Camberg (1999) have extended this research and proposed a model of psychological well-being in dementia.

Volicer et al (1999) used an observational method with nursing home residents who had dementia. They reported that they had repeated the previous findings of factors for positive and negative affect and extended this to six indicators of well-being. Their model conceptualises well-being along three dimensions of happy to sad (recognised by facial expression), engaged to withdrawn (recognised by engagement with the environment), and calm to agitated (expressed by body movements and vocalisations). They described the observational methods they used to measure each of these dimensions.

The model proposed by Volicer et al (1999) goes beyond the three dimensions to show progressive changes in emotion from 'normal' functioning to the terminal stages of dementia. They state that

'with the progression of dementia, the range of and capacity to express emotions become more restricted. Eventually, in a terminal stage of dementia, the individual may lose most of the contact with the environment and become unable to express emotions' (Volicer et al, 1999, p87).

It appears that they are suggesting that people with dementia do not experience the same range of emotions as people without dementia. No support is provided for this, either empirical or theoretical. Verbal reporting of emotion is likely to become restricted in dementia in line with losses of cognitive and linguistic function. There is no evidence however that the range of emotion experienced by an individual with dementia changes or becomes restricted. It may be that each of the three dimensions described by Volicer et al (1999) encompasses several of the emotions reported by people without dementia, but which it is impossible to differentiate by observational means.

so the factors which constitute it are unique to each individual. Because of this, measurement of well-being usually depends on the person's self report. As the dementia progresses this becomes increasingly problematic due to the individual's difficulties with speech and short term memory. Although there are difficulties with the measurement of well-being, it does not appear that ill-being is a necessary consequence of dementia. Kitwood and Bredin (1992) found that variations in well-being between individuals with dementia do not appear to be related to levels of cognitive impairment. It is therefore important to consider the factors which influence well-being in dementia.

Kitwood and Bredin (1992) defined twelve indicators of well-being in dementia: assertiveness, bodily relaxation, expressing a range of emotions (positive and negative), sensitivity to the emotional needs of others, humour, creative self-expression, demonstrating pleasure, helpfulness, initiating social contact, affection, self respect (e.g. being concerned about appearance), and acceptance of others who have a dementing illness. They also defined ten indicators of ill-being: unattended distress, sustained anger, anxiety, fear, boredom, cultural alienation, apathy and withdrawal, despair, physical discomfort or pain, and oppression (the imposition of power, whether physical or psychological). Of particular interest is their inclusion of relaxation as an indicator of well-being and of anxiety as an indicator of ill-being.

One advantage of this method of assessing well-being is that the indicators are designed to be assessed by observation, so are applicable to all individuals regardless of the severity of their dementia. The indicators also do not require complex cognitive skills on the part of the person with dementia for them to be demonstrated. One of the difficulties is that several assumptions are made about what constitutes well-being or ill-being. Some areas of well-being may be included which a particular individual has never expressed. The assessment method attempts to address this by recording the frequency of any behaviours which indicate well-being or ill-being, as well as the range of behaviours displayed. Another difficulty is that anxiety is not defined theoretically or in behavioural terms so that the measurement of anxiety would be based on the observer's subjective judgement.

The three dimensions proposed by Volicer et al (1999) have good face validity. However, they were based on results from a small study (N = 57) so would benefit from further evaluation. Their article also did not include any information on the selection of participants, or of characteristics such as level of dementia or psychiatric diagnoses, nor did they report the actual results or analyses used in the study. It is therefore necessary to treat their conclusions with caution. However, their dimension of calm to agitated appears to be describing a similar concept to that suggested by Kitwood and Bredin (1992) of relaxation indicating well-being and anxiety indicating ill-being. This convergence of two separate lines of enquiry suggests that these ideas should be investigated further.

1.3. Challenging Behaviour in Dementia

Further support for the importance of anxiety and agitation in ill-being comes from research into challenging behaviour. There is a large literature concerning dementia-related challenging behaviours (reviewed by Burgio & Stevens, 1999; Cohen-Mansfield & Werner, 1994). Challenging behaviour is often a poorly defined term which makes comparisons between studies difficult. In the broadest definition, it is a set of behaviours which formal or informal carers find difficult to manage. These behaviours can indicate ill-being in the individual and may increase the likelihood of institutionalisation (O'Donnell et al, 1992).

Allen-Burge, Stevens and Burgio (1999) divided challenging behaviours into behavioural excesses (disruptive vocalisation, wandering, physical and verbal aggression) and behavioural deficits (excess dependency, lack of social interaction or communication, and lack of functional abilities). Many other behaviours could be included in these categories. In terms of the indicators of well-being and ill-being suggested by Kitwood and Bredin (1992) and the dimensions of well-being in Volicer et al (1999) many challenging behaviours suggest a lack of well-being. In particular, disruptive vocalisation, wandering and excess dependency could all be expressions of anxiety or agitation. The literature reviewed so far has indicated that anxiety and agitation are both important indicators of ill-being for individuals with dementia. They may also be linked to behaviours which are difficult to manage and increase the risk of institutionalisation.

The definition of challenging behaviour as 'behaviours which are difficult to manage' shows that a behaviour is judged to be challenging because of its effects.

These can be dependant on the situation, environment and perceptions of others. A particular behaviour may be challenging in one environment but not in another.

Challenging behaviour includes both behavioural excesses and deficits of behaviour such as social withdrawal or a lack of functional abilities. Deficits of behaviour would not be considered indicators of agitation.

The most widely used definition of agitation is 'inappropriate verbal, vocal, or motor activity which is not explained by needs or confusion per se' (Cohen-Mansfield & Billig, 1986, p712). This definition is extremely broad and encompasses many forms of behaviour, some of which could be considered challenging. However, the emphasis is on inappropriate levels of activity not on the effect of the behaviour. While specific behaviours could be both challenging and agitated, agitation and challenging behaviour refer to qualitatively different constructs. Agitation refers to the nature of the behaviour while challenging behaviour refers to its effects.

1.4. Anxiety

Anxiety consists of subjective, somatic and behavioural symptoms. It includes worries, over-concern with future events, tension, sleep disturbance, headaches, restlessness, avoidance, irritability, palpitations, sweating, dizziness, panic attacks, and phobias. These are the main symptoms of anxiety, if a sufficient number and severity of these are present the individual may be considered to have an anxiety disorder, of which there are several types. Research into the consequences of anxiety symptoms in older adults suggests that they are: associated with lower quality of life; can be mistaken for the first stages of dementia or medical illness (Wetherell, 1998); may negatively affect physical health and lead to increased mortality rates (Grasbeck, Rorsman, Hagnell & Isberg, 1996); and have been associated with increased healthcare costs (Lloyd, Jenkins & Mann, 1996). Older adults who receive treatment are mainly treated with anxiolytics. Benzodiazepine use has been found to be between 14% and 37% for community dwelling older adults and higher rates of use were found in nursing homes (reviewed by Wetherell, 1998). In addition to this, the side-effects of anxiolytics are more common in older adults. These can include addiction, falls, daytime sedation, disinhibition,

impaired cognitive functioning, sleep disorder, ataxia, dysarthria, uncoordination, gait disturbance, and slowed reaction time (Sadavoy & LeClair, 1997; Wetherell, 1998). The consequences of anxiety symptoms in later life can therefore be severe and the most common treatments for them can produce extra difficulties which may interact with, or be mistaken for, dementia.

1.4.1. Prevalence of anxiety in older adults. While there is a large literature on the concept and prevalence of anxiety in younger adults, there is much less concerning older adults, particularly those who have dementia. Anxiety in older adults has been found to be less prevalent than in younger adults (e.g. Christensen et al, 1999; Flint, 1994) with rates of prevalence for all types of anxiety disorder varying from 0.7% to 18.6% (studies reviewed by Flint, 1994). When significant anxiety symptoms which do not reach criteria for a specific disorder are considered, prevalence rates among older people increase to 20-25% in community samples (Copeland et al, 1987; Himmelfarb & Murrell, 1984). There have been several suggestions for the apparently lower prevalence rates of anxiety in older adults, including that this may be a cohort effect rather than an effect of the ageing process. Generalised anxiety and phobias may also be attributed to normal ageing processes (Lindesay, Briggs & Murphy, 1989), or to physical illness (Knauper & Wittchen, 1994) and so be under reported.

Flint (1994) review prevalence rates for different anxiety disorders across the eight available random-sample community studies which reported data for older adults. Prevalence rates were reported for phobic disorders, panic disorder, generalised anxiety disorder (GAD) and obsessive compulsive disorder, although not all of these were measured in every study. The one month prevalence rate of phobic disorders was found to be between 0.0% and 10% across four studies with a female to male ratio of approximately 2:1. A further study combined phobic and panic disorder and reported a prevalence rate of 3.1%. The rate of 0.0% was found by Copeland et al (1987) who used a hierarchical approach to the diagnosis of anxiety disorders and generally found lower rates of all anxiety disorders compared to other studies. The prevalence rate of 10% was found by Lindesay et al (1989) who used a non-standardised questionnaire to identify phobic disorders. They found agoraphobia to be the most common disorder (7.8%), with simple phobia and social phobia less common (2.1% and 1.3% respectively).

Panic disorder was found to a have a prevalence rate between 0.0% and 0.3% across the three studies in which it was reported. It was generally found to be the least common of the anxiety disorders. In each of the studies it was only found to be present in women although prevalence data was combined for both sexes. GAD was the most common disorder, prevalence rates were found to be between 7.1% and 0.7% across three studies with slightly higher rates reported for women than for men. It was concluded that generalised anxiety disorder accounted for over half of the anxiety disorders in older adults (Flint, 1994). The only exception to this was the Lindesay et al (1989) study where it only accounted for one third of cases but who found a considerably higher rate of phobic disorders than the other studies.

Obsessive compulsive disorder was found to have prevalence rates between 1.5% and 0.0%, with little difference in the rate in men and women across studies. It was concluded that this disorder was rare in older adults and required future investigation. The prevalence of post traumatic stress disorder (PTSD) has not been investigated in the general older adult population. Flint (1994) reported studies of its prevalence in Holocaust survivors and former prisoners of war where it was found that 20%-29% continued to meet criteria 40 years after the trauma. This suggests that it affects older adults but its prevalence has not been investigated.

A critical review by Fuentes and Cox (1997) highlighted the variations in anxiety measurement in the studies reviewed by Flint (1994), with many using assessment instruments which were designed for younger adults and which had not been validated for use with older populations. They suggested that the variations in prevalence rates across studies could be due to the different assessments used to identify anxiety disorders. Further problems noted were that studies which used community samples were compared with those using participants from institutions (where the prevalence and severity of all psychiatric disorders would be expected to be higher). There was also variation in the criteria for older adults from age 55 years to 65 years old.

The effect of diagnostic criteria on the prevalence of anxiety have been highlighted by several authors (e.g. Fuentes & Cox, 1997; Lindesay et al, 1989). In diagnostic criteria a hierarchical approach is used and other diagnoses (including depression and dementia) take precedence over anxiety. Some prevalence studies have used a

hierarchical approach where individuals with depression were excluded. Others have used co-morbid diagnoses and included individuals with depression. Individuals with dementia were usually excluded, but in some studies this was not clarified. Since anxiety has been found to be more common in people who have a depressive or dementing disorder (Lindesay et al, 1989; Wands et al, 1990) these differences may have led to under reporting of anxiety in some studies.

It was not clear from many studies cited in Flint (1994) whether they were considering anxiety disorder or anxiety symptoms. Diagnostic criteria identify anxiety disorder rather than anxiety symptoms. The use of cut-offs for anxiety disorders may underestimate anxiety and ignore aspects of anxiety which are specific to older populations and not included in current diagnostic criteria (McEwan, Donnelly, Robertson & Hertzman, 1991). Fuentes and Cox (1997) argue that anxiety symptoms in older adults should have further research and be better understood before diagnostic cut-offs are determined for this population. They suggest that research at present should consider anxiety symptoms rather than disorders until research into diagnostic cut-offs for older adults has been carried out and any changes made.

One area which requires further research is whether the theoretical definitions and diagnostic criteria of anxiety disorders are applicable to older adults. Stanley and Beck, G. (2000) reviewed research on this issue. They concluded that older adults appear to experience anxiety differently from younger adults, which may be due to differences in thinking about emotional terms. In particular, emotional terms assessing guilt loaded more heavily on an 'anxiety-guilt' factor for younger than older adults. Older adults were generally found to report fewer negative emotional states compared to younger adults, but showed few differences for reporting positive emotional states. However, diagnosed anxiety disorders appear to be associated with similar characteristics in older and younger adults (Stanley & Beck, G., 2000).

Further research by Shapiro, Roberts and Beck, G. (1999) suggested differences in the cognitive and affective dimensions of depression and anxiety in older and younger adults. In particular, that the cognitive dimensions of affect were not related to symptoms of anxiety or depression in older adults but were in younger adults. A large scale study of differences in anxiety symptoms with age concluded that anxiety in older

adults may be characterised by a reduced level of complaint about pain and physical tension (Christensen et al, 1999). Other researchers have found no evidence to suggest that anxiety presents differently between younger and older adults (Fuentes & Cox, 2000). These conceptual controversies about the nature of anxiety in older adults support the suggestion that prevalence rates and diagnostic cut-offs for older adults require further investigation. At the present stage, research into anxiety symptoms rather than disorders may be appropriate. It also highlights the importance of using anxiety measures which have been specifically designed or validated for use with older adults.

Krasucki et al (1998) suggested a dimensional model of anxiety in older adults, in which anxiety could be divided into psychic, somatic and behavioural dimensions. They suggested that specific anxiety disorders would load to varying degrees on the different anxiety dimensions and discussed ways in which this could change with age. They also suggested that this type of model could be useful in dementia where

- '... [anxiety] was manifest predominantly as psychic symptoms in mild to moderate dementia and as behavioural symptoms, currently described as agitation, in severe dementia' (Krasucki et al, 1998, p96).
- 1.4.2. Anxiety in dementia. Given the difficulties of investigating anxiety disorders in older adults it is hardly surprising that there has been little systematic investigation in this area for older adults with dementia. Cohen (1998) suggested that part of this may be due to the emphasis on cognitive aspects of anxiety which could lead to doubt over whether anxiety exists in the presence of severe cognitive impairment, and to the lack of understanding of the difference between anxiety and agitation. One difficulty for measuring anxiety in dementia is that it is an internal state, defined by thoughts (e.g. apprehensions, worry), emotions (e.g. anxiety, fear), physical sensations (e.g. muscle tenseness, palpitations), and behaviours (e.g. avoidance, restlessness). Assessment usually involves the person answering questions or providing an account of their experiences. Impairments in concentration, memory, and verbal abilities may affect the responses of people with dementia to questionnaires and rating scales. It has been suggested that symptoms such as restlessness should be excluded from rating scales and diagnostic criteria for anxiety in dementia to prevent overlap with agitation (Ballard,

Boyle, Bowler & Lindesay, 1996). In addition, the investigation of prevalence rates of anxiety in this group is subject to the same methodological difficulties as for older adults without dementia.

There is some research into the prevalence of anxiety in dementia. There are difficulties with these studies in the measures used and the populations studied. Hocking and Koenig (1995) found anxiety symptoms in 38% of individuals with early dementia and with Parkinson's disease. Their participants were all medically ill older adults so may not represent levels of anxiety found generally in older adults with dementia. Wands et al (1990) attempted to measure prevalence rates for anxiety in older adults with dementia. Their sample was drawn from a cohort analytic study of Alzheimer's disease and other dementias, in which care was taken to be representative of the general population of older adults with dementia. They found 38% of individuals with mild dementia had possible or probable anxiety disorder. However, anxiety was measured using the Hospital Anxiety and Depression Scale (HADS; Zigamond & Snaith, 1983), which has not been validated for use with individuals who have dementia and has mixed support for its use with older adults.

Ballard, Mohan, Patel and Graham (1994) used research diagnostic criteria for GAD. They found GAD in 31% of people with dementia. Their participants were all attending a day hospital so may not be representative of the general population of older adults with dementia. They did not include other anxiety disorders such as phobias which may be common in older adults. Shanker, Walker, Frost and Orrell (1999), using the recently developed informant rated Rating Anxiety in Dementia (RAID; Shanker et al, 1999) found a prevalence rate of 36% in individuals with dementia. Although they stated that they attempted to recruit a representative sample of participants with dementia, they recruited from acute inpatient wards, day hospitals, day centres and long-stay continuing care wards. This meant that all participants were receiving psychiatric services and 61% were inpatients. It would be expected that the prevalence of all psychiatric disorders would be higher in this population. The studies which have attempted to measure prevalence rates of anxiety in older adults with dementia all have difficulties so their results should be treated with caution. However, they support the suggestion that anxiety symptoms and disorders are more common in older adults who have dementia.

James (1999) attempted to conceptualise anxiety in dementia using a cognitive rationale. In line with other cognitive conceptualisations, perceptions of a given situation are influenced by an individual's mental health status, history, personality, current environment and physical status. These are then filtered through the person's current cognitive abilities. In this model the effects of dementia interact with mood consistent biases found in anxiety or depression, and with previous experiences. The person with dementia is seen as continually attempting to make sense of their world, using similar processes to do this as people without dementia. However, in dementia the perception and interpretation of the world is chaotic and confused, leading to apparently dysfunctional behaviours.

The model described by James (1999) has several positive aspects. It is based on cognitive theory which has been well validated in clinical practice. As pointed out in the article, there is not yet empirical evidence to confirm its applicability to dementia. As a starting point, it appears reasonable to assume that dementia does not change the nature of cognitive processes used by a person, but that it interferes with their function. The model includes the importance of the individual's history, environment and personality as well as stressing the effects of mental and physical health. Potentially, it allows the use of cognitive therapies with this population and their carers.

1.5. Agitation

Agitation has been shown to be a significant problem for older adults, their families and carers. It has been found to occur in 70-90% of individuals who have dementia at some point during the disorder and has been found to increase as the dementia progresses (Cohen-Mansfield & Billig, 1986; Reisberg et al, 1987; Swearer, Drachman, O'Donnell & Mitchell, 1988; Teri, Larson & Reifler, 1988). Agitation has been shown to impair the quality of life of the individual with dementia, increase their likelihood of entering a residential facility, increase the use of medication, and require high carer to client ratios (Cohen-Mansfield & Billig, 1986; Cohen-Mansfield, Marx & Werner, 1992; Kopecky & Yudofsky, 1999; O'Donnell et al, 1992). It has been suggested that anti-psychotic medications, which are often used to treat agitated behaviours, may accelerate cognitive decline (McShane et al, 1997). Traditionally, the majority of research into agitation and its treatment has been pharmacological (Cohen-Mansfield, 1986; Kopecky & Yudofsky, 1999), although other studies are becoming more common.

Cohen-Mansfield and colleagues have carried out research into agitation in older adults, including those with cognitive impairment, both in nursing homes and in the community (Cohen-Mansfield, 1986; Cohen-Mansfield & Billig, 1986; Cohen-Mansfield, Marx & Rosenthal, 1989; Cohen-Mansfield et al, 1992; Cohen-Mansfield, Werner, Watson & Pasis, 1995). Agitation was defined as 'inappropriate verbal, vocal, or motor activity which is not explained by needs or confusion per se' (Cohen-Mansfield & Billig, 1986, p712). There are several difficulties with this definition of agitation. It is subjective, depending on the observer to judge the appropriateness of a behaviour and identify the presence of needs. It is also extremely broad and appears to encompass many forms of behaviour which are difficult to manage. However, it does include all behaviours which would be recognised clinically as agitation, including those which have been studied separately in the literature, such as wandering or aggressive behaviour.

A different approach to the construct and measurement of agitation has come from the work of Yudofsky, Kopecky and colleagues (Kopecky, Kopecky & Yudofsky, 1998; Kopecky & Yudofsky, 1999; Yudofsky, Kopecky, Kunik, Silver & Endicott, 1997). They have conceptualised agitation as "objective vocal and motor behaviours on a continuum of behavioural expressions that extend from anxiety to aggression" (Kopecky & Yudofsky, 1999). There is little discussion of the theoretical basis or implications of this conceptualisation of agitation. It is categorised as

'a progressive set of neurobiological and anatomical/functional behavioural phenomena, including inappropriate vocalisations and oral/facial movements, upper torso and upper extremity movements and lower extremity movements' (Kopecky & Yudofsky, 1999, pA33).

This defines agitation purely in terms of the movements which make up agitated behaviours. While this will allow more objective measurement, it may be less accessible to staff involved in clinical practice and more appropriate for research studies.

Although agitation is a widely used term clinically, it does not refer to a clinical diagnosis, but to a group of behavioural signs and symptoms. Published studies of agitation have been concerned with its measurement and treatment. There has been little discussion of its causes and correlates (Cohen-Mansfield & Billig, 1986; Cohen-

Mansfield & Marx, 1988; Mintzer & Brawman-Mintzer, 1996). Mintzer and Brawman-Mintzer (1996) state that the aetiology of agitation in individuals with dementia is unknown. They reviewed studies suggesting that it is related to a number of factors including social interactions, medication, physical problems or pain, and can be a misinterpretation of confusion. In their conceptual review of agitation Cohen-Mansfield and Billig (1986) state that agitation has been linked in previous research to dementia, senility, depression, anxiety, and sleep disturbance. A staff survey of the factors thought to be associated with agitation was reported in a second, related paper (Cohen-Mansfield, 1986). The factors were grouped into four categories of moods and needs, external events, disabilities, and past issues. In the category of moods and needs were included depression, frustration, loneliness, boredom, and need for attention.

The main difficulty with the article by Mintzer and Brawman-Mintzer (1996) is their widely quoted assertion that GAD-like symptoms are currently defined as agitation (see section 1.6. below for a more detailed discussion of this). They provide a useful review of studies of agitation but do not discuss its relationship with internal states such as anxiety. The results from the survey of staff attributions in Cohen-Mansfield (1986) has apparently been taken by some authors to indicate that no association was found between anxiety and agitation (Shanker & Orrell, 2000; Shanker et al, 1999). However, a survey of staff's attributions for agitation is not an investigation of an association between agitation and anxiety, or of agitation and any other factors. Cohen-Mansfield's work has been concerned with defining and measuring agitation. It has not considered the causes or correlates of agitation and has not involved any measurement of anxiety. Agitation is acknowledged to be a significant problem for older adults with dementia, their families and carers, but there has been little research to investigate its relationship with other factors and its possible causes.

1.6. The Relationship Between Anxiety and Agitation.

There is little theoretical discussion in the literature about the relationship between anxiety and agitation. Cohen (1998) suggests that the lack of discussion of anxiety in dementia reflects confusion around the difference between anxiety and agitation. Shanker and Orrell (2000) state that "anxiety is often expressed as agitation in demented patients" but provide no support for this statement. In younger adults with depression, anxiety has been found to be significantly associated with agitation (Katz et al, 1993).

In older adults definitions have been unclear. Hersen and Van Hasselt (1992) describe the importance of differentiating between anxiety and agitation in behavioural assessment but do not define either, nor suggest how differentiation might be achieved.

GAD is defined in DSM-IV (American Psychiatric Association, 1994) as: Excessive anxiety and worry occurring more days than not for at least six months; The person finds it difficult to control the worry; The anxiety and worry are associated with at least three of these six symptoms, restlessness or feeling keyed up or on edge, being easily fatigued, difficulty concentrating or mind going blank, irritability, muscle tension, sleep disturbance; The focus of the anxiety is not confined to features of another disorder such as panic attacks, phobias, or PTSD; The anxiety, worry or physical symptoms cause clinically significant distress or impairment; The disturbance is not due to a substance, a medical condition, or occurs exclusively during a mood disorder or psychotic disorder. This has a number of differences from the definition of agitation as 'inappropriate verbal, vocal, or motor activity which is not explained by needs or confusion per se' (Cohen-Mansfield & Billig, 1986). The definition of agitation does not contain any constraints about how long it should be present for, the level of control the person has over it, or whether it causes distress or impairment to the person. There is also no mention of the causes of the behaviour or that it should not be considered agitation if it is related to another disorder, substance use, or medical condition. The main areas of overlap are in the symptoms of GAD and of agitation. Restlessness and irritability are common to both GAD and agitation. Sleep disturbance and being easily fatigued were not included in the definition of agitation because they can have multiple causes in older adults. Difficulty concentrating was also not included because it can be caused by dementia. The definition of agitation includes verbal behaviours which are not included specifically in GAD. There are difficulties with applying the DSM-IV criteria for GAD to older adults with dementia. These include the exclusion criteria for a medical condition (which could include dementia), difficulties in assessing the person's level of control, and in assessing the distress or impairment caused by the anxiety, worry, or symptoms.

Mintzer and Brawman-Mintzer (1996) investigated GAD in older adults with dementia. They considered a group of symptoms thought to indicate GAD which included excessive worry, restlessness, irritability, being easily fatigued, and sleep difficulties. They stated that some of these symptoms were included in the definition of agitation proposed by Cohen-Mansfield (1986) and concluded that GAD-like symptoms were currently defined as agitation. As previously discussed, Cohen-Mansfield's definition of agitation appears to include most types of difficult behaviour, of which anxiety symptoms would only be part. As noted later in Mintzer and Brawman-Mintzer's article, agitation was found to be related to difficulties in communicating needs, excess demands on the individual with dementia, the side effects of medication, physical problems or pain, and it can be a misinterpretation of confusion. This suggests that agitation is not specific to anxiety. Also, some symptoms of anxiety would not be included in this definition, for instance fears, feelings and physical symptoms. There is therefore little evidence that all agitated behaviours can be used to measure anxiety in individuals with dementia.

Kopecky and Yudofsky (1999) have conceptualised agitation as being on a behavioural continuum from anxiety to aggression. This suggests an area of overlap between anxiety and agitation, but they state that '[agitation] differs from anxiety that is subjective and verbalised through a variety of somatic complaints' (Kopecky & Yudofsky, 1999; pA33). The work on agitation by Cohen-Mansfield and colleagues (e.g. Cohen-Mansfield, 1986; Cohen-Mansfield & Billig, 1986) has been used in research on anxiety (Mintzer & Brawman-Mintzer, 1996) and also in research on aggression (Patel & Hope, 1993). There is however, no discussion in Cohen-Mansfield's work of a relationship, or areas of overlap, between anxiety and agitation.

A different approach has been to differentiate anxiety from agitation in people with dementia. Ballard et al (1996) proposed that agitation covered a range of symptoms and that there were areas of overlap with anxiety. In their study anxiety symptoms were assessed by a standardised questionnaire which included questions concerning the subjective and physical aspects of anxiety. Problems with the study included that participants were not a representative sample of older adults with dementia and that the questionnaire used was not formally validated. Ballard et al (1996) suggested the overlap between anxiety and agitation could be minimised by concentrating on

subjective, situational, muscular, and autonomic symptoms of anxiety. They excluded restlessness and sleep disturbance on the basis that these could have multiple causes in individuals who have dementia. Panic was associated with anxiety but there were too few participants reporting panic for any conclusions to be drawn from this. Irritability was not found to be associated with anxiety. Overall, 29.4% of participants experienced one or more symptoms of anxiety. This is a lower rate than that found in other studies (Ballard et al, 1994; Hocking & Koenig, 1995; Wands et al, 1990) which may have been due to their exclusion of restlessness and sleep disturbance.

1.7. Depression

Depression in older adults has been widely studied. It has been found to be more common in individuals with dementia than those without dementia. Forsell and Winblad (1998b) found that 11.8% of older adults with dementia had depression compared to 3.9% of those without dementia. Other studies have found varying prevalence rates. Greenwald (1995) summarised the findings and concluded that: major depression occurs in 5-15% of individuals with Alzheimer's disease and in 20-25% of individuals with multi-infarct dementia; minor depression occurs in 25% and depressive features occur in 50% of individuals with dementia.

Depression has been found to co-occur with anxiety (Fuentes & Cox, 2000). In the Epidemiological Catchment Area (ECA) survey in the United States (Regier et al, 1988) 21% of younger adults who were diagnosed as having an anxiety disorder also met criteria for an affective disorder, and 33% who were diagnosed as having an affective disorder were also diagnosed with at least one anxiety disorder. Similar data have not been presented for older adults from the ECA survey. In Britain, Lindesay et al (1989) found that 91% of older adults living in the community who received a diagnosis of generalised anxiety disorder also met criteria for depression. In the same study, 39% of individuals who were diagnosed as having a specific phobia were also diagnosed as having depression. These results included older adults with and without cognitive impairment. No relationship was found between cognitive impairment and either anxiety or depression (Lindesay et al, 1989). A large scale study investigating anxiety in very old adults (aged 78-99, mean age 84.2) found 13% of participants with anxiety symptoms had a depressive disorder, compared to 1.9% of participants without anxiety

symptoms (Forsell & Winblad, 1998a). These studies suggest a high level of comorbidity between anxiety and depression in older adults, including those with cognitive impairment.

Shapiro et al (1999) examined the cognitive and affective dimensions of anxiety and depression in community dwelling older adults. They found that cognitive dimensions of affect (such as fear of future events in anxiety and feelings of worthlessness in depression), were not specifically related to symptoms of anxiety or depression in their sample. They suggest that cognitive aspects are less useful for distinguishing between anxiety and depression in older adults than younger adults.

Depression has also been found to be associated with agitation. Agitation is included as a symptom of depression in several rating scales which have been used with older adults including the Hamilton (Hamilton, 1960) and Zung (Zung, 1965) depression scales. Depressed older adults have been found to experience irritability, sleep disturbance, and psychomotor agitation to a greater degree than younger depressed adults (reviewed by Shapiro et al, 1999). These symptoms were found to be no more common in non-depressed older adults than in younger adults, which has been taken to suggest that this is due to the depression rather than increased physical illness in old age. However, these symptoms are also associated with anxiety. The effects of comorbidity between depression, anxiety and physical illness were not discussed. Depression has been found to correlate with verbal agitation, but not physical agitation or aggression (Cohen-Mansfield & Marx, 1988). In their study, verbal agitation was associated with participants who were cognitively intact. Physical agitation and aggression were only associated with participants who had dementia. As noted by the authors there were difficulties in this study with their measure of depression. They used a scale which had not been validated and which relied on carers perceptions of the participants mood. It may have been that more cognitively intact participants were more able to express themselves and so were more likely to be perceived as being depressed. The study suggests that depression may be associated with verbal agitation rather than other types of agitation, but only for cognitively intact individuals.

1.8. Summary and Purpose of the Current Study

Research into well-being in dementia has shown that ill-being is not a necessary consequence of dementia. Kitwood and Bredin (1992) suggested that relaxation was an indicator of well-being and anxiety an indicator of ill-being. A separate line of research by Volicer et al (1999) suggested one dimension of well-being in dementia was from calm to agitated. Further support comes from research into challenging behaviours, many of which indicate ill-being and could be expressions of anxiety or agitation. These separate lines of enquiry all suggest that anxiety and agitation are important factors in the well-being of people who have dementia.

Anxiety and agitation are common disorders affecting older adults with dementia and can have severe consequences for the individual affected. Anxiety has been found to affect approximately 31% to 38% of people who have dementia at any one time. Agitation affects 70% to 90% of people at some point during the course of their dementia. The consequences of anxiety and agitation include increased mortality rates, increased healthcare costs, increased risk of institutionalisation, decreased quality of life, and increased use of medication. The medication used may be addictive, accelerate cognitive decline, and increase the risk of falls, daytime sedation, disinhibition, confusion and sleep disorder.

Despite the importance of anxiety and agitation in dementia care there is confusion about these concepts in the literature. While some researchers into anxiety in dementia assume that agitation is the same as anxiety in this population, others try to differentiate or minimise the overlap between them. One difficulty is that anxiety is an internal feeling or a psychiatric diagnosis, while agitation is a behavioural syndrome which may be caused by a number of factors, but is not a psychiatric diagnosis.

There is overlap in the symptoms included in anxiety and agitation. In particular restlessness and irritability are symptoms of GAD and are also included in agitated behaviours. From this it could be considered that agitation is a symptom of anxiety and one which remains possible to assess in the presence of dementia. However, the definition of agitation is much broader than the restlessness and irritability included in anxiety. It also does not include aspects of anxiety such as worry, sleep disturbance, being easily fatigued, or the level of distress caused by these symptoms.

Further research is required to clarify the relationship between anxiety and agitation rather than attempt to differentiate between them. The current study proposes to measure anxiety and agitation in a sample of older adults who have dementia. It will investigate correlations between anxiety and agitation measures and consider specific agitated behaviours which are associated with anxiety. Due to the difficulties with measuring anxiety in this population, two measures will be used and a secondary aim of the study is to compare them.

1.9. Hypotheses

The main hypotheses in this study concern the association between anxiety and agitation and comparison of the two anxiety measures.

- 1.9.1. <u>Hypothesis one</u>. Anxiety and agitation are associated. This will be shown by a positive correlation between measures of anxiety and agitation.
- 1.9.2. <u>Hypothesis two.</u> Some agitated behaviours will show a greater association with anxiety than others.
- 1.9.3. <u>Hypothesis three</u>. The two anxiety measures will be measuring the same construct. Specifically, they will be associated with each other and will behave similarly with other measures.

The remaining hypotheses are related to repeating previous findings reported in the literature.

- 1.9.4. <u>Hypothesis four.</u> There will be an association between anxiety and depression. This has been widely found in previous studies of older adults with and without dementia (e.g. Forsell & Winblad, 1998a; Fuentes & Cox, 2000; Lindesay et al, 1989; Shanker et al, 1999; Wands et al, 1990).
- 1.9.5. <u>Hypothesis five.</u> There will be no association between depression and agitation. Depression and agitation have been found to be associated in younger adults

and older adults without dementia (Shapiro et al, 1999), but no association has been found with older adults with dementia (Cohen-Mansfield & Marx, 1988).

- 1.9.6. <u>Hypothesis six.</u> There will be no association between level of cognitive impairment and depression or anxiety (Forsell, Jorm & Winblad, 1993; Shanker et al, 1999; Wands et al, 1990).
- 1.9.7. <u>Hypothesis seven.</u> There will be an association between level of cognitive impairment and agitation (Cohen-Mansfield & Billig, 1986; Reisberg et al, 1987; Swearer et al, 1988; Teri et al, 1988).

2. Method

2.1. Design of Study

To test the hypotheses it was decided to use a cross-sectional correlational design. The study measured agitation, anxiety symptoms, depression, and level of cognitive impairment. Agitation was assessed using a well validated measure designed for use with older adults with dementia. Due to the difficulties with measuring anxiety in older adults with dementia two measures were used: a measure of anxiety designed for use with older adults with dementia; and a standardised measure of anxiety which has been well validated for use with older adults and has been used successfully with older adults with dementia. Depression and level of cognitive impairment were assessed using screening measures.

2.2. <u>Use of Self Report Measures</u>

Several studies have used self report measures with individuals who have dementia. Gottlieb, Raquel and Ruben (1988) studied the reliability of self rating and rateradministered psychiatric scales with individuals who had Alzheimer's disease. They found that individuals with low severity, but not those with high severity dementia, showed a good correlation between self rating and rater-administered depression scales. This suggests that people with mild to moderate dementia are able to reliably complete self rating scales. A number of other studies have reported using self report measures successfully with older adults with mild to moderate dementia (e.g. Ballard et al, 1996; Fuher, Larrabee & Crook, 1992; Parmelee, Lawton & Katz, 1989; Wands et al, 1990; Ward, Wadsworth & Peterson, 1994; Yesavage, 1986; Yesavage et al, 1983).

2.3. Assessment of Anxiety

The main methods used to assess anxiety are interview schedules, rating scales, diagnostic criteria, behavioural observation, self report, and informant-rated measures. For reviews see Beck, G. and Stanley (1997), Fuentes and Cox (1997), or Hersen and Van Hasselt (1992). There are difficulties with a number of these methods. Interview schedules, rating scales and diagnostic criteria are usually based on anxiety disorders in younger adults and have not been widely used with older adults with dementia. They tend to use hierarchical diagnoses, which may not be suitable for use with older adults

with dementia until further research has been carried out and appropriate cut-offs have been determined for this population. At the present stage, research into anxiety symptoms may be more appropriate. Observational approaches have been used but these are likely to miss symptoms of anxiety related to thoughts or emotions and would be difficult to distinguish from current measures of agitation. In view of the difficulties with these methods, it was decided that self report and informant-rated measures would be the most appropriate to use. Some examples of these will be considered in more detail.

The recently developed Rating Anxiety In Dementia (RAID; Shanker et al, 1999) appears to be the only validated instrument developed specifically for this population. Items on the scale were derived from widely used concepts of anxiety and its presentation in older adults with and without dementia. The RAID has 18 items rated on a four point scale from 0=absent to 3=severe, using information from both the participant and an informant. A score of 11 or more suggests significant clinical anxiety. The items make up four subscales of worry, apprehension and vigilance, motor tension, and autonomic hypersensitivity. There are two additional items on phobias and panic attacks which are not included in the total score. Items on worry were taken from the literature and were designed to be observable by verbal behaviour. There were no references to the Worry Scale (Wisocki, Handen & Morse, 1986) included in this section, even though the Worry Scale was designed specifically for use with older adults. Items on sleep disturbance, irritability and restlessness were included in the RAID.

Good reliability and validity was found for the RAID. Internal consistency measured by Cronbach's alpha was 0.83, inter-rater reliability was 82% to 100%, and test-retest reliability was 84 to 100%. It showed reasonable correlation with other informant rated measures of anxiety: Spearman coefficient of 0.54 with the Clinical Anxiety Scale (Snaith, Baugh, Clayden, Husain & Sipple, 1982); and 0.62 with the Anxiety Status Inventory (Zung, 1971), although neither of these measures has been widely used or validated for use with older adults. Using a cut-off score of 11, the sensitivity of the RAID was 90% and the specificity was 78.5% compared to the modified DSM-IV (American Psychiatric Association, 1994) criteria for anxiety. The DSM-IV criteria were modified so that the restriction criteria on anxiety due to other axis I disorders, or

due to direct effect of a substance or medical condition, were not applied. The RAID was found to be acceptable to participants and staff, there were no problems reported with its administration.

There have been a number of measures of anxiety which have been used and validated for use with older adults. For reviews of measures see Beck, G. and Stanley (1997), Fuentes and Cox (1997), Hersen and Van Hasselt (1992), or Stanley and Beck, G. (2000). One of the most widely used self report measures with older adults is the Speilberger State-Trait Anxiety Inventory (STAI: Speilberger, Gorsuch & Lushene, 1970; Speilberger, 1983). Stanley and Beck, G. (2000) concluded that good validity and internal consistency had been demonstrated across several studies. Test-retest reliability was good for the trait subscale, but moderate for the state subscale, as would be expected. High correlations were reported between the state and trait subscales. In a recent study of anxiety symptoms, Fuentes and Cox (2000) used the trait subscale of the STAI (STAI-T) with groups of older and younger adults. They reported Cronbach's Alpha for the STAI-T to be 0.87 with older adults and 0.94 with younger adults. This demonstrated good internal consistency and suggested that there was little effect of age on the internal consistency of the scale.

The STAI has been used with older adults in mental health services. It was found that some participants had difficulty completing the measure but were able to use the simpler, child's version of the STAI (Patterson, O'Sullivan & Spielburger, 1980). It has also been used in a study of older adults with dementia. Ward et al (1994) used self report measures with a group of older men with dementia. They used the state questionnaire of the STAI (STAI-S; form Y-1; Speilberger, 1983), modified so that the answers were in a yes/no format instead of the usual four point scale. The twenty items were read to the participants and their answers recorded by the interviewer. They chose this procedure to reduce the effects of low education, diminished cognitive abilities, limited stamina and motivation, and impaired visual acuity, all of which are common in this group of people. They reported good internal consistency (Cronbach's alpha 0.91) with these procedures for the STAI-S.

Wands et al (1990) used self rating scales with adults with mild to moderate dementia who were judged able to complete a self rating scale with minimum difficulty.

The HADS (Zigamond & Snaith, 1983) was used. No difficulties using the scale were reported, however they did not report any data on the internal consistency or reliability of the HADS with this population. It has not been validated for use with individuals who have dementia in any other studies. There is some support for its validity for use with older adults (Kenn, Wood, Kucyj, Wattis & Cunane, 1987) however, Davies, Burn, McKenzie, Brothwell and Wattis (1993) found that it did not satisfactorily detect anxiety in older medical inpatients.

The Beck Anxiety Inventory (BAI; Beck, A. & Steer, 1993) has had some support for its use with older adults. Stanley and Beck, G. (2000) summarised three studies in which it had shown good internal consistency. It was also reported to measure a distinct construct to depression as measured by the Beck Depression Inventory (BDI; Beck, A., Rush, Shaw & Emery, 1979) or the Geriatric Depression Scale (GDS; Yesavage et al, 1983). It has not been used with older adults with dementia.

The Worry Scale (Wisocki et al, 1986) was developed specifically for use with older adults. It focuses on concerns which have special significance for older adults. Wisocki et al (1986) provided evidence of concurrent validity with the anxiety subscale of the Hopkins Symptom Checklist (SCL-90; Derogatis, Rickles & Rock, 1976), a widely used measure with younger adults. This was extended by Stanley, Beck, G. and Zebb (1996) who showed Worry Scale to have good internal consistency and convergent validity, and adequate test-retest reliability, with the exception of the health subscale. However, the Worry Scale has not been widely used in published research and no information was found on its use with individuals who have dementia.

2.3.1. Anxiety measures chosen. For the current study it was decided to use two of the better validated measures of anxiety. This was due to the limited data on the validity of anxiety measures for older adults with dementia. The two measures chosen were the RAID (Shanker et al, 1999) (see Appendix B), and the STAI-S (Speilberger, 1983) (see Appendix C). The RAID was chosen because it appears to be the only measure designed specifically for older adults with dementia and has good reliability and validity reported from its initial study. The STAI (Speilberger, 1983) was chosen because it has been widely used and validated for use with older adults. It was decided to use the STAI-S with the responses and procedure modified for use with individuals

with dementia as reported by Ward et al (1994). The state questionnaire, asking participants how they felt at the moment, was used because it was unlikely to be affected by memory problems. The trait questionnaire was not used because it requires information on how participants generally feel, which has a greater memory component.

2.4. Assessment of Agitation

There are various means of assessing agitation, which can be grouped into informant ratings, observational methods, and technological devices. Self report or interview based methods are not commonly used because people with more severe dementia would be unable to communicate effectively and are unlikely to be able to recall their behaviours accurately. A further difficulty is that individuals are often unaware of behaviours they carry out routinely so these may be most accurately assessed by another person. Contained in the definition of dementia suggested by Cohen-Mansfield, agitated behaviour must be inappropriate and not result directly from apparent needs or confusion, 'the definition refers to agitation as being in the eyes of the beholder' (Cohen-Mansfield, 1996; p234). Kopecky and Yudofsky (1999) in their definition also stress the importance of objective, observable behaviours. Neither of these indicates the use of self report or interview based methods for the assessment of agitation.

2.4.1. Informant rated measures. The most widely used and validated measure of agitation in older adults who have dementia is the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield et al, 1989). The CMAI consists of an informant questionnaire with ratings of the frequency of each item on a seven point scale from 1=never to 7=several times an hour. There are different versions of the CMAI, the original 29 item questionnaire was designed for use in a nursing home (Cohen-Mansfield et al, 1989). There is a community version developed for use with formal and informal carers (Cohen-Mansfield, Werner et al, 1995). This includes five extra questions and is available in two formats, one for staff and one for relatives, containing the same questions but in a different layout and order. Using the original and community CMAI four factors have been found for agitation: physical aggression, physical non-aggression, verbal aggression, and verbal non-aggression. Some variations have been found in this structure, with different analyses resulting in three rather than four factors. This is the result of all the aggressive behaviours forming one factor or all the verbal behaviours forming one factor (Cohen-Mansfield, 1991; Cohen-

Mansfield, 1996; Cohen-Mansfield et al, 1989; Cohen-Mansfield et al, 1992; Cohen-Mansfield, Werner et al, 1995). It was suggested that the four factor model be used until further research had been carried out (Cohen-Mansfield, Werner et al, 1995).

Various studies have reported on the reliability and consistency of the CMAI. The internal consistency, measured by Cronbach's alpha has been found to be between 0.83 and 0.91 (Finkel, Lyons & Anderson, 1992; Finkel, Lyons & Anderson, 1993; Shah, Evans & Parkash, 1998). Test-retest reliability using Spearman's correlation coefficient (two tailed) was found to be 0.97 (Shah et al, 1998). Inter-rater reliabilities for the CMAI in a nursing home and in the community were 0.92 (Cohen-Mansfield, 1996) and in an inpatient setting was 0.80 (Shah et al, 1998). However, in a nursing home study by Finkel et al (1992) it was found to be 0.41. This lower reliability appears to be driven by variation across inter-rater reliabilities for different subtypes of agitated behaviours. They found these to be 0.66 for physical aggression, 0.61 for verbal agitation, and 0.26 for physical non-aggression. They suggested that in their study, physical non-aggressive behaviours were some of the least frequently reported so may be the least reliably assessed.

A short version of the CMAI has been developed: the Brief Agitation Rating Scale (BARS; Finkel et al, 1993). The BARS consists of ten items from the CMAI which were selected on the basis of their correlations with the total CMAI score and to represent each of the types of agitated behaviour identified. The BARS showed good internal consistency, validity, and high inter-rater reliability. It was concluded that it was a suitable measure for assessing the presence and severity of agitated behaviours in older adults in a nursing home. No information was provided about levels of cognitive impairment in the participants.

The CMAI has been compared to other measures of behaviour in people who have dementia. Weiner et al (1998) compared the CMAI to the Behaviour Rating Scale for Dementia (BRSD; Tariot et al, 1995) in a community sample of people with Alzheimer's disease. High correlations were found between the CMAI and the BRSD subscales of irritability/aggression and behaviour dysregulation (r = 0.63 and 0.71 respectively). Low correlations were found between the CMAI and the BRSD subscales of depression, inertia, and vegetative symptoms (r = 0.37, 0.23, and 0.33

respectively). This provides some evidence of convergent and divergent validity for the CMAI, showing correlations with related constructs and a lack of correlation with unrelated constructs.

In a study by Shah et al (1998) the CMAI, BARS and the Rating Scale for Aggressive Behaviour in the Elderly (RAGE; Patel & Hope, 1992) were compared with a sample of older adult inpatients. All three scales were found to have good internal consistency, test-retest reliability, and inter-rater reliability. They were also significantly correlated with each other, suggesting evidence for concurrent validity. However, there were several methodological difficulties with this study. The data was collected as three repeat measures of only thirteen participants, all of whom were admissions to an acute psychogeriatric ward. They also found low rates of aggressive and agitated behaviours. This may mean that the results are not generalisable to longer-stay settings, or to those with higher levels of aggressive or agitated behaviour.

A recently developed measure of agitation is the Agitated Behaviour in Dementia Scale (ABID; Logsdon et al, 1999). This was designed for use with older adults with mild to moderate dementia in community settings. It includes 16 items, each of which is rated by the main carer for its frequency and the carer's level of distress about each behaviour. Logsdon et al (1999) report internal consistency measured by Cronbach's alpha of 0.70 for both frequency and carer distress ratings. Validity was examined by the ABID's correlation with other measures. It correlated positively with the CMAI (r=0.62) and with overall behavioural disturbance as measured by the BRSD (r=0.65). These initial findings suggest good reliability and validity for the ABID, although further studies using it are needed.

Agitation has also been assessed using general rating scales of behaviour in people who have dementia. One example of these is the BRSD (Tariot et al, 1995). The BRSD includes subscales on depressive symptoms, psychotic symptoms, inertia, vegetative symptoms, irritability/aggression, and behavioural dysregulation. Scales such as this include only a few items on agitated behaviours. They are therefore less appropriate for studies where agitation is the main behaviour considered than the many rating scales developed specifically for agitation.

2.4.2. Observational measures. Observational measures involve the individual with dementia being observed and their behaviours rated. They have the advantage of increasing objectivity by ensuring that only observable behaviours are rated. A major difficulty with them is that many behaviours do not happen frequently so would only be detected by long or frequent observation periods. This is especially true of behaviours such as physical aggression which may be infrequent but have an important impact on others.

The Overt Agitation Severity Scale (OASS; Yudofsky et al, 1997) was developed from the work of Yudofsky, Kopecky and colleagues on agitation. This is an observer rated behaviour scale, filled out after a 15 minute observation period. It was developed for use with older psychiatric inpatients who had a variety of diagnoses and difficulties. One difficulty with this scale is that in the short period of observation it is unlikely that a representative frequency and severity of behaviours would be observed and the final rating may be heavily dependent on the time of day and situation. Some support for difficulties with the observation period is suggested by the finding of considerable differences in mean scores from 15 minute and 1 hour agitated observation periods (56.21 and 89.5 respectively), and 8 hour and 16 hour non-agitated observation periods (17.79 and 43.29 respectively). There are further difficulties with the OASS including the allocation of severity ratings, which depend on the type of behaviour. There was little explanation or justification for these allocations. Reliability of the OASS was evaluated by comparison with the Pittsburgh agitation scale (PAS; Rosen et al, 1994). Correlations of 0.82 and 0.81 were found respectively with the two raters. The PAS has not been widely used in published research.

The PAS (Rosen et al, 1994) is designed to be short and easy to use. It is aimed at busy nursing staff who fill it in at the end of a naturally occurring observation period such as an eight hour shift, although shorter time periods can be used. It is made up of four groups of behaviours: aberrant vocalisation, motor agitation, aggressiveness, and resisting care. Each of these is rated on a five point severity scale depending on the behaviour's intensity, disruptiveness, and amenability to re-direction. Inter-rater reliability was reported to be 0.82 for the total score. Validity was investigated by comparison of PAS scores for periods when interventions for agitation of medication or restraint were used and for periods when they were not used. A highly significant

correlation was reported. The PAS is concerned with the severity and effect of agitated behaviours in a particular environment, which may make it particularly suitable for treatment outcome research. It was not designed to measure types of agitated behaviour.

- 2.4.3. Mechanical devices. These devices are attached to the person with dementia, they sense and record particular movements or vocalisations. They are occasionally used in research studies but a number of difficulties have been found with them. These include participants fidgeting with the device, difficulty putting the device on the participant, difficulty transferring the information from the device, and concerns over the validity of the measurements obtained (Cohen-Mansfield, Culpepper, Werner, Wolfson & Bickel, 1995).
- 2.4.4. Agitation measure chosen. For this study it was decided to use the community version of the CMAI (Cohen-Mansfield, Werner et al, 1995) (see Appendix D). It was chosen because it is the most widely used and validated measure of agitation for older people with dementia. It has a large and inclusive list of agitated behaviours, which is an advantage over the shorter alternative measures. It was decided to use a single format of the CMAI for all informants to increase consistency. The format for relatives was chosen because it is designed to be self-administered so was the clearest and easiest to use.

2.5. Assessment of Depression

The most widely used measure of depression in older adults is the Geriatric Depression Scale (GDS; Yesavage et al, 1983) which is available in the original 30 item version and a 15 item short form (Sheikh & Yesavage, 1986). The GDS is a self report measure developed specifically for older adults. Each item is answered in a yes/no format. For the 15 item version scores greater than five have been suggested to indicate possible or mild depression and scores greater than ten to indicate probable or moderate depression (Yesavage, 1988). It has been used successfully with older adults who have dementia (Fuher et al, 1992; Parmelee et al, 1989; Ward et al, 1994; Yesavage, 1986; Yesavage et al, 1983). Fuher et al (1992) investigated the validity of using the GDS with older adults who have dementia. They concluded that the GDS was valid when used with mild to moderate dementia. Its validity was not affected by the presence of memory

problems but may be attenuated when used with clients who deny their memory problems because they may also deny depressive symptoms. Internal consistency of the GDS was not reported but it correlated significantly with the Hamilton depression scale (Hamilton, 1960) an interview based depression measure, suggesting convergent validity (Fuher et al, 1992). Ward et al (1994) used the 30 item GDS as well as the STAI-S with 40 older men with dementia. Items on each scale were read out and responses recorded by the interviewer. They reported no difficulties in administering the GDS with these procedures and found an internal consistency of 0.90 (Cronbach's alpha).

The Hamilton rating scale for depression (Hamilton, 1960) and the Zung self rating depression scale (Zung, 1965) were used with individuals with Alzheimer's disease (Gottlieb et al, 1988). Good correlations were found between the two scales for individuals with low severity but not for those with high severity dementia, supporting their validity for use with mild to moderate dementia. Data on the internal consistency of these measures were not reported for this population.

Other measures of depression have been developed specifically for people with dementia. The Dementia Mood Assessment Scale (DMAS; Sunderland & Minichiello, 1996) is based on direct observation and a semi-structured interview with the participant. It was partly derived from the Hamilton depression scale (Hamilton, 1960). It consists of 24 items, seven of which can be used for differentiating between depression and dementia. The Cornell Scale for Depression in Dementia (Alexopolous, Abrams, Young & Shamoian, 1988) is a 19 item measure, which uses information from the participant and an informant. It was based on a literature search on depressive symptoms in people with and without dementia, and information from clinicians working in the field. The Cornell Scale has been found to be more reliable than either the Hamilton or the DMAS (Camus et al, 1993). These measures provide a more detailed assessment of depression and are not limited to use with people with mild to moderate dementia.

2.5.1. <u>Depression measure chosen.</u> In this study it was decided to use the GDS (Sheikh & Yesavage, 1986) (see Appendix E) because it is widely used and has good validity and reliability with older adults with dementia. It was not considered necessary

to use one of the more detailed depression measures developed for individuals with dementia because depression was not part of the main hypotheses of the study. The 15 item version of the GDS was used to minimise the number of questions asked of the participants and help reduce fatigue effects. The GDS was read to the participants and the answers recorded by the researcher. The procedure was the same as that used by Ward et al (1994).

2.6. Assessment of Dementia

There are several well validated measures for assessing level of cognitive impairment. It was decided to use the Mini Mental State Examination (MMSE; Folstein, Folstein & McHugh, 1975). This was chosen as a brief, well validated, widely used and easy to administer screening measure. It was considered whether to use a more comprehensive assessment of level of cognitive impairment than the MMSE. For instance, the Middlesex Elderly Assessment of Mental State (MEAMS; Golding, 1989) or the cognitive assessment of the revised Cambridge Examination for Mental Disorders of the Elderly (CAMCOG-R; Roth, Huppert, Mountjoy & Tym, 1998). These both give more information about cognitive impairment but take considerably longer to complete. Interactions with level of cognitive impairment were not the main aims of this study so it was not felt that the extra asked of participants would be justified.

If the MMSE had been carried out in the previous three months it was not repeated and the recorded score was checked and used. Participants with MMSE scores greater than 22 were only included if they had a definite diagnosis of dementia based on results from scans (either MRI or CAT) and other information. This was usually from screening for suitability for anti-dementia medication (Aricept) where strict guidelines for the diagnosis of dementia are used.

The diagnosis of dementia was established from medical notes. All participants were known by the service to have cognitive impairment and their length of difficulties with memory or cognitive impairment was recorded from their medical notes. All participants fulfilled criteria for dementia from DSM-IV. Participants with severe depression (operationally defined as a GDS score greater than nine) were excluded to

avoid the possibility of including participants with depressive 'pseudodementia'. These precautions helped to ensure that clients with delirium or cognitive impairment due to other causes were not included in the sample.

2.7. Procedure

The study was first discussed with clinicians in the Leicestershire Elderly Directorate, who felt that it was viable and agreed to support the study. The protocol was submitted to the Research Committee for Clinical Psychology at Leicester University. Their suggestions were incorporated into the study. Ethical approval for the study was granted from the Leicestershire Health Authority Research Ethics Committee via the Trust Research Office.

All consultant psychiatrists in the Elderly Directorate were contacted by letter, informed of the nature of the study and invited to contact the researcher if more information was required. Meetings were arranged between the researcher and each Community Mental Health Team (CMHT) and Day Hospital in the Elderly Directorate in Leicestershire. In the meetings the nature of the study and the criteria for recruiting participants were explained. Potential participants were identified by a clinician directly involved in their care who asked if they were willing to discuss the study with the researcher. They were given a copy of the information sheet and consent form (see Appendix A) to consider and discuss with others. Participants were then contacted by the researcher who explained the study and ensured informed consent was given.

Inclusion criteria for participants were that the person was currently resident in the community and was known to have mild to moderate cognitive impairment.

Participants were excluded if they were considered unable to give informed consent to take part in the study, were clearly unable to understand or answer the questions, or if they had severe depression. Depression was measured using the GDS, participants who scored more than nine were excluded from the study. Levels of anxiety or agitation were not part of the inclusion criteria. This was decided on for several reasons. It would have led to a biased sample of participants with high levels of anxiety or agitation, which would have prevented findings from this study being applicable to the general population of older adults with dementia. It is also important in a study considering correlations that participants with both high and low levels of anxiety and

agitation were included. In particular, this ensures the inclusion of any participants who scored highly on one measure but not on the other, which would affect any correlation between the measures.

Physical complaints were recorded because of their interaction with agitation and the similarity between some symptoms of physical problems and anxiety. Where a participant had a physical complaint such as hypertension, angina, or chronic obstructive airways disease it was ensured that the symptoms of these were not scored as anxiety symptoms.

All participants completed the measures in the following order, MMSE (if it had not been completed in the previous three months), GDS, STAI-S, and RAID. When the informant was present during the interview they completed the CMAI while the participant completed the MMSE, GDS, and STAI-S. The RAID was then completed with both the participant and the informant. When the informant was not present they were interviewed afterwards and completed the RAID and the CMAI. This is in accordance with instructions for the RAID and the CMAI. Whether the informant was present during the participant's interview was dependent on the participant's and informant's wishes. Where the informant was present they did not assist the participant to answer questions on the MMSE, GDS, or STAI-S. The interviews were usually completed in a single session and took between forty and sixty minutes for both the participant and the informant. Each participant was allocated a code and the list of names and codes was kept in secure facilities used for clients' files. The data was entered into a SPSS database for analysis, in which responses from individual participants were identifiable only by code.

2.8. Participants' Demographics

The participants were 40 older adults with dementia resident in the community. They were in the care of either a CMHT or a day hospital for older adults in Leicestershire. Their mean age was 79.4 (SD = 7.03, range 64 to 93), 28 (70%) were female. The ethnicity of the sample was: 36 (90%) white British, 2 (5%) Polish, 1 (2.5%) Latvian, and 1 (2.5%) Spanish. Other ethnic groups were not represented in the sample.

3. Results

3.1. Participants

All participants were known to have cognitive impairment, although this was not necessarily the main reason for their involvement with the older adult service. Dementia diagnosis was recorded from medical notes: 17 (42.5%) had Alzheimer's dementia, 12 (30%) had vascular dementia, and 11 (27.5%) did not have their type of dementia recorded. The mean length of time for the participants' problems with their memory or cognitive difficulties was 34.4 months (SD = 22.4, range 4 to 96).

All participants were resident in the community, 21 (52.5%) were living alone (including warden controlled accommodation) and 19 (47.5%) were living with their spouse or adult child. Of the individuals who filled in the informant-rated measures 32 (80%) were a nurse or other member of staff, 3 (7.5%) were a spouse, 2 (5%) were an adult child, and 3 (7.5%) were another relative.

The medications which participants were taking at the time of assessment were recorded: 9 (22.5%) were taking dementia medication (Aricept), 7 (17.5%) were taking a benzodiazepine, 20 (50%) were taking an antidepressant, 9 (22.5%) were taking an anti-psychotic medication (often prescribed to control agitated behaviours), and 33 (85%) were taking medication for a physical complaint. Participants' physical complaints included hypertension, angina, osteoporosis, arthritis, chronic obstructive airways disease, diabetes, shingles and kidney disease.

3.2. Measures

3.2.1. Cohen-Mansfield Agitation Inventory. The CMAI mean score was 46.98 (SD = 14.55, range 34 to 82). The internal consistency (Cronbach's alpha) was 0.87 (34 items, based on 39 cases, one case was not used due to a missing item). Participants taking anti-psychotic medication (which is often prescribed for agitated behaviour) had a higher mean CMAI score (N = 9, M = 58.44, SD = 16.85) compared with those who were not (N = 31, M = 43.65, SD = 12.19), which was significant at the 0.05 level (t = 10.55) = 2.46, t = 10.05 (t = 10.05). The scoring of the CMAI gives a frequency score

of 1 to 7 on each of 34 items. No cut-off score for agitation is given. Instead, participants carrying out a physical or verbal non-aggressive behaviour at least once a day or an aggressive behaviour at least several times a week are categorised as agitated (Cohen-Mansfield, 1991). Using these criteria, 25 (62.5%) of the participants were agitated.

- 3.2.2. Rating Anxiety in Dementia. The RAID total mean score was 11.85 (SD = 6.91, range 0 to 30). Sixteen (40%) of the participants scored above the cut-off of 11, which indicates clinically significant anxiety. Internal consistency (Cronbach's alpha) was 0.79 (18 items, using 40 cases). Participants who were taking benzodiazepines had higher mean scores on the RAID (N = 7, M = 18.57, SD = 9.13) compared to those who were not (N = 33, M = 10.42, SD = 5.53). This difference was significant at the 0.01 level (t = 33, t = 10.42, SD = 5.53).
- 3.2.3. State Anxiety Inventory. The STAI-S mean score was 3.65 (SD = 4.20, range 0 to 17). Internal consistency (Cronbach's alpha) was 0.88 (20 items, based on 39 cases, one case was not used due to a missing item). Twelve (30%) of the participants scored zero on the STAI-S. There was a trend for participants taking benzodiazepines to have a higher mean STAI-S score (N = 7, M = 7.29, SD = 7.04) than those who were not (N = 33, M = 2.88, SD = 2.96). This difference did not reach significance (t (38) = 1.626, p = 0.15, 2-tailed).
- 3.2.4. Geriatric Depression Scale. The GDS mean score was 3.62 (SD = 2.61, range 0 to 9). Eight (20%) of the participants scored more than five, which indicates possible or mild depression. Participants who scored greater than nine were excluded from the study. The internal consistency using Cronbach's alpha was 0.58 (15 items, based on 38 cases, 2 cases were not used due to missing items). There was a trend for participants taking antidepressants to have a higher mean GDS score (N = 20, M = 4.40, SD = 2.56) compared to those who were not (N = 20, M = 2.85, SD = 2.48), but this did not reach significance (t = 1.95, t = 0.06, 2-tailed).
- 3.2.5. <u>Mini Mental State Examination</u>. The MMSE total mean score was 20.45 (SD = 4.89, range 10 to 29) which indicated that participants had a mild to moderate level of dementia. There were 13 participants who had definite diagnoses of dementia but

scored greater than 22 on the MMSE. Participants taking medication for dementia had a higher mean MMSE score (N = 9, M = 23.89, SD = 3.02) compared with those who were not (N = 31, M = 19.45, SD = 4.90), this difference was significant at the 0.05 level (t (38) = 2.563, p = 0.014, 2-tailed).

3.3. Hypothesis One

The primary hypothesis of this study was that there would be a correlation between anxiety and agitation. The distributions of the CMAI, RAID, STAI-S, GDS and MMSE scores were investigated for normality. Their skewness statistics were 1.27, 0.71, 1.48, 0.66, and -0.19 respectively (standard error = 0.37). The CMAI and the STAI-S had particularly skewed distributions so non-parametric correlations were used. Spearman's correlation co-efficients were calculated between the total scores on each of the measures and the results are presented in Table 1. Multiple comparisons were carried out so the Bonferroni correction was used.

<u>Table 1</u>: Spearman's correlations between total scores for each measure.

	MMSE	GDS	STAI-S	RAID
GDS	.04			
STAI-S	12	**.60		
RAID	24	.40	**.60	
CMAI	32	.14	.10	**.51

^{**} Correlation is significant at the 0.01 level (2 tailed) using Bonferroni correction.

A significant correlation between the RAID and the CMAI was found but the correlation between the STAI-S and the CMAI was not significant. There were no instances of three measures correlating significantly with each other. This indicates that the correlations found between measures were not due to their correlation with a third measure. The use of partial correlations to investigate further was therefore not appropriate.

The relationship between the CMAI and the RAID was investigated further. The CMAI and the RAID had one item which was very similar on both measures, this was removed to ensure that it was not driving the correlation. The CMAI item was 'General restlessness, fidgeting, always moving around' and the RAID item was 'Restlessness (fidgeting, cannot sit still, pacing, wringing hands, picking clothes)'. The totals for the RAID and the CMAI were re-calculated excluding these items. The Spearman's correlation co-efficient for the new totals was significant at the 0.01 level (r (38) = .41, p = 0.009, 2-tailed), which suggests that the correlation was not due to the shared item.

3.4. Hypothesis Two

The second hypothesis was that some agitated behaviours would be more closely associated with anxiety than others. One way in which to investigate this was an item by item correlation of the CMAI with the RAID total score (with the item on restlessness removed from both). Many of the questions in the CMAI were rarely or never endorsed by this group of participants, which suggested that some items should not be included in this analysis. Kline (1986) recommends including only those items in a scale which correlate highly with the total score and which have endorsement rates of between 20% and 80%. Applying these guidelines to the CMAI results, 22 items were excluded because less than 20% of participants endorsed them. One item 'Hiding or Hoarding Things' was excluded because it did not correlate significantly with the total score, although it was endorsed by 22.5% of participants. The remaining 10 items were: Pacing, Handling Things Inappropriately, Relevant Verbal Interruptions, Unrelated Verbal Interruptions, Repetitive Sentences or Questions, Constant Requests for Attention or Help, Verbal Bossiness or Pushiness, Complaining or Whining, Negativism, and Temper Outbursts. Correlations were calculated between these CMAI items and the RAID and are presented in Table 2.

The results suggest that Constant Requests for Attention or Help, Unrelated Verbal Interruptions, Complaining or Whining, and Handling Things Inappropriately may be the agitated behaviours most closely associated with anxiety. Application of the Bonferroni correction to the significance levels meant that none of these correlations reached significance.

<u>Table 2</u>: Spearman's correlations between the RAID total scores and 10 CMAI items, with the item on restlessness removed from both.

CMAI Items	Correlation with RAID	Significance level	
	(df = 38)	(2-tailed)	
Pacing, wandering	.31	.06	
Handling things inappropriately	.33	.04	
Relevant verbal interruptions	.20	.23	
Unrelated verbal interruptions	.32	.04	
Repetitive sentences or questions	.30	.06	
Constant requests for attention or help	.41	.009	
Verbal bossiness or pushiness	.10	.53	
Complaining or whining	.34	.03	
Negativism	.19	.24	
Temper outburst	.09	.57	

3.5. Hypothesis Three

A further aim of the study was to compare the two anxiety measures. The third hypothesis was that the anxiety measures would correlate and would behave similarly with other measures. From Table 1 it can be seen that the STAI-S and the RAID did correlate, but did not behave similarly. The RAID correlated with the CMAI but the STAI-S did not and the STAI-S correlated with the GDS but the RAID did not.

Post hoc analyses were carried out to investigate the differences in the STAI-S and the RAID. It was hypothesised that the STAI-S may measure one aspect of anxiety whereas the RAID measures several, this would be shown by differences in the degree of correlation found between the STAI-S and the RAID subscales. If the CMAI correlated more highly with some subscales of the RAID and the STAI-S correlated more highly with others, this could explain the lack of correlation between the STAI-S and the CMAI. Table 3 shows correlations between the STAI-S, CMAI and the RAID subscales. The item on panic is included but the item on phobias is not included because it was only endorsed by 3 (7.5%) of the participants. The STAI-S correlates significantly with the Worry subscale of the RAID but not with any of the other

subscales. The CMAI correlates significantly with the Apprehension and Vigilance and Motor Tension subscales of the RAID and has no correlation with the autonomic hypersensitivity subscale.

Table 3: Spearman's correlations between the STAI-S, CMAI and the RAID subscales.

	Worry	Apprehension	Motor tension	Autonomic	Panic
		and vigilance		hypersensitivity	attacks
STAI-S	**.51	.43	.41	.42	.41
CMAI	.36	**.51	*.46	.05	.34

^{**} Correlations significant at the 0.01 level (two tailed) using Bonferroni correction.

3.6. Hypotheses Four

Hypothesis four predicted that there would be a positive correlation between depression and anxiety. Table 1 shows that the GDS correlated significantly with the STAI-S but not with the RAID.

3.7. Hypothesis Five

Hypothesis five predicted that there would be no association between depression and agitation. Table 1 shows that the correlation between the GDS and the CMAI was not significant.

3.8. Hypothesis Six

Hypothesis six predicted that there would be no association between level of cognitive impairment and depression or anxiety. Table 1 shows that the correlations between the MMSE and the GDS, RAID and STAI-S were not significant.

3.9. Hypothesis Seven

Hypothesis seven predicted that there would be an association between level of cognitive impairment and agitation. Table 1 shows that the correlation between the MMSE and the CMAI was not significant.

^{*} Correlations significant at the 0.05 level (two tailed) using Bonferroni correction.

3.10. Additional Analyses

It is possible that some of the participants' characteristics interacted with the measures used. Of the possible characteristics: sex, living arrangements, and whether the informant was a professional or family carer were investigated. The sample was split by each of the three characteristics in turn and the means calculated for each new group. The differences in mean scores were tested for significance using independent samples t-tests. The results are presented in Table 4. It should be noted that these are exploratory analyses and are not directly related to the hypotheses the study set out to investigate. Ethnicity was not investigated because there were too few participants who were not white British for meaningful comparisons to be made.

<u>Table 4</u>: Mean scores on all measures for participants grouped by sex, living arrangements and informant (standard deviations in brackets).

	Sex		Living arrangements		Informant	
	Female	Male	Alone	With family	Professional	Family
	N=28	N=12	N=21	N=19	N=32	N=8
MMSE	21.61*	17.75 *	22.10*	18.63*	20.91	18.63
	(4.73)	(4.29)	(4.81)	(4.41)	(4.75)	(5.34)
GDS	3.64	3.58	3.76	3.47	3.50	4.13
	(2.79)	(2.23)	(2.79)	(2.46)	(2.51)	(3.09)
STAI-S	4.25	2.25	3.24	4.11	3.31	5.00
	(4.66)	(2.49)	(3.11)	(5.21)	(3.57)	(6.28)
RAID	12.82	9.58	9.90	14.00	10.56*	17.00*
	(7.44)	(4.05)	(5.46)	(7.82)	(6.42)	(6.76)
CMAI	48.83	46.18	40.62**	54.00**	42.66**	64.25 **
	(16.99)	(13.64)	(7.93)	(17.02)	(11.01)	(14.71)

^{*} Difference significant at 0.05 level (2-tailed)

The comparisons in Table 4 suggest that female participants had a higher mean MMSE score than males; participants who lived alone had a higher mean MMSE score and a lower mean CMAI scores than those who lived with family; and participants who had family informants had higher mean CMAI and RAID scores than those with

^{**} Difference significant at 0.01 level (2-tailed)

professional informants. Using the Bonferroni correction for multiple comparisons the only difference which remained statistically significant was that participants with family informants had higher mean CMAI scores than those with professional informants. These results should also be treated with caution because there were unequal group sizes and some variables may have been contaminated by others.

4. Discussion

4.1. Methodology

4.1.1. Representativeness of sample. The selection of participants attempted to achieve a representative sample of older adults with mild to moderate dementia who use mental health services. Participants were selected on the basis of their cognitive impairment and those reporting high levels of depressive symptoms were excluded. Scores greater than five on the GDS have been suggested to indicate possible or mild depression and scores greater than ten to indicate probable or moderate depression (Yesavage, 1988). Participants who scored greater than nine were excluded from the study. It is likely that some of the participants scoring between five and nine on the GDS in this study had a mild level of depression. The aim of setting the GDS cut-off at more than nine was to exclude participants who may have a depressive 'pseudodementia' and to ensure that the relationship between anxiety and agitation was considered rather than the relationship between depression and agitation. Depression has been found to be common in dementia, with major depression occurring in 5-25% and depressive features occurring in 50% of individuals (Greenwald, 1995). Previous research has also found high levels of co-morbidity between anxiety and depression in older adults, including those with dementia (Forsell & Winblad, 1998a; Fuentes & Cox, 2000; Lindesay et al, 1989). Although it was necessary to exclude participants with high levels of depression, excluding all participants with mild depression would have lead to a non-representative sample of participants with dementia and anxiety.

To increase the representativeness of the sample, anxiety and agitation were not made inclusion criteria. Clinicians were aware however that anxiety and agitation were being investigated. This could have affected their referrals to the study, resulting in an over representation of anxious or agitated participants. Based on the RAID, 40% of participants scored as clinically anxious, which is similar to the prevalence of 38% found in previous studies of anxiety symptoms in older adults with dementia (Hocking & Koenig, 1995; Wands et al, 1990). Both of these studies used less stringent criteria for the presence of anxiety symptoms than the RAID cut-off. Shanker et al (1999) found a prevalence rate of 36% using the RAID with individuals with dementia

receiving psychiatric services. Over 61% of their participants were inpatients, who would be expected to have a greater degree of psychiatric difficulty than the community based participants in this study. These comparisons suggest that participants in this study may have had higher levels of anxiety than is representative of older adults with dementia. Participants do not appear to have been more agitated than would be expected. The CMAI categorised 62.5% of participants as agitated. This is lower than the prevalence of 70-90% found during the course of dementia (Cohen-Mansfield & Billig, 1986; Reisberg et al, 1987; Swearer et al, 1988; Teri et al, 1988), which is expected when comparing a point prevalence to prevalence over a longer time period. The prevalence in this study is similar to the 62.9% found by Cohen-Mansfield, Werner et al (1995) in a day care centre.

Previous community studies have found rates of benzodiazepine use between 14% and 37% (Wetherell, 1998). The rate of 17.5% found in this study was comparatively low, which may reflect reduced prescribing since previous studies were carried out. The finding that 50% of participants were taking an antidepressant appears high. Some antidepressants are known to have anxiolytic effects which may have affected the prescription rate for this sample of more anxious individuals. Anti-psychotic medication was taken by 22.5% of participants. In Britain this is often prescribed to control agitated behaviours in people who have dementia, as well as for psychotic symptoms.

4.1.2. Participants. The participants had a mean age of 79.35, one client was 64 years old which is below the usual older adult cut-off of 65 years. He was included because he had a definite diagnosis of multi-infarct dementia and was in the care of the older adult services. Women were over-represented in the sample, as were individuals of white British ethnic origin. Leicester has large Asian and Eastern European populations, however Asian clients are under represented in mental health services in Leicester. None were included in this study because those eligible did not have good enough understanding of spoken English to complete the measures. The four participants for whom English was not their first language had been resident in Britain for over 50 years and had good comprehension and use of English. All participants were resident in the community and were living alone or with family members.

The mean length of time for the participants' problems with their memory or cognitive difficulties was found to be nearly three years. In some cases it was not clear how long the difficulties had been present, so length of time since referral or the first mention of cognitive difficulties was recorded. This would have led to an underestimate because in most cases it would be expected that difficulties would predate referral by several months. A specific dementia diagnosis was recorded for 72.5% of participants. Where it was not recorded this was due to lack of information in the notes or because some assessments were not complete (e.g. waiting for MRI scans). Participants were only included in these circumstances if they scored less than the cutoff of 22 on the MMSE. These precautions make it unlikely that participants had cognitive impairment due to causes other than dementia.

4.2. Measures

4.2.1. <u>Cohen-Mansfield Agitation Inventory</u>. The CMAI has been widely used and validated. In this study its internal consistency was good (Cronbach's alpha 0.87) and is similar to that found in other studies (Finkel et al, 1992; Finkel et al, 1993). It was not compared to another measure of agitation, but the finding that participants taking antipsychotic medication had a significantly higher mean CMAI score than those who were not suggests some convergent validity.

One difficulty with the CMAI in this study was the fact that many of its items were rarely or never endorsed for this group of participants. This may have reflected the fact that the CMAI was developed for more severely disturbed nursing home residents and many of its items are less appropriate for community dwelling individuals with mild to moderate dementia. This is supported by the fact that the items which were rarely or never endorsed were predominantly the more severe or aggressive behaviours. Cohen-Mansfield, Werner et al (1995) using the CMAI in the community also found that physically aggressive behaviours were very rare. Although actual frequencies were not given, they reported that the items most frequently endorsed in their study were very similar to those most frequently endorsed in the present study. The item 'Hiding or hoarding things' did not correlate highly with the total score. This item was also found to have a low correlation with the total score by Finkel et al (1993).

In retrospect it was considered whether another agitation measure would have been more suitable for this study, such as the BARS (Finkel et al, 1993) or the ABID (Logsdon et al, 1999). The BARS contains ten items from the CMAI but as five of these were rarely or never endorsed in this study, it is unlikely that this would have been a more appropriate measure to use. The ABID was designed specifically for community dwelling older adults with mild to moderate dementia. It was not used in this study because it had not been widely used or validated. With respect to this study, six of its sixteen items are very similar to items in the RAID. These are: Arguing, Irritability, or Complaining; Restlessness, Fidgetiness, Inability to Sit Still; Worrying, Anxiety and/or Fearfulness; Waking and Getting up at Night; Incorrect, Distressing Beliefs; Seeing, Hearing, or Sensing Distressing People or Things Which are not Really Present. These would have led to an overlap in the symptoms measured by the RAID and the ABID and the remaining items may have been insufficient for a correlation to be found. In summary, although not all of the items in the CMAI were relevant to this group of participants it was the most comprehensive measure available to identify a relationship between anxiety and agitation.

4.2.2. Rating Anxiety in Dementia. The RAID was easy to administer and the questions appeared to be understood by the participants and informants. It had good internal consistency (Cronbach's alpha, 0.79), which was similar to the 0.83 found in the original validation study (Shanker et al, 1999). The total mean score (11.85) was above the suggested cut-off for anxiety of 11 and higher than the mean of 9.3 (SD=7.1) found by Shanker et al (1999). This suggests that this was a more anxious group of participants than used in the validation study, which could have been due to differences in recruitment of participants. Shanker et al (1999) attempted to recruit a representative sample of older adults with dementia. In this study there may have been an over representation of anxious participants. The finding that participants who were taking benzodiazepines had significantly higher RAID scores than those who were not, provides some evidence of convergent validity. The RAID also correlated significantly with the other anxiety measure, the STAI-S.

The RAID was developed from widely used concepts of anxiety from the older adult and dementia literature. It has items on subjective, muscular and autonomic symptoms of anxiety, use of which has been suggested to reduce overlap with agitation when assessing anxiety (Ballard et al, 1996). However, items on restlessness and sleep disturbance were included, which it was also suggested should not be used on the basis that they could have multiple causes in older adults who have dementia (Ballard et al, 1996). Irritability was also included, although it has previously been found not to be associated with anxiety (Ballard et al, 1996). Item by item analysis of the RAID was not reported in the original study (Shanker et al, 1999). The factor structure reported in their study suggested that several items including 'Sleeplessness' did not load heavily on the two main factors found. Several items were also included in the measure despite being endorsed by less than 20% of their participants (Shanker et al, 1999). Current results support the use of the RAID but further research is needed into its psychometric properties and further refinement of its items may be necessary.

4.2.3. State Anxiety Inventory. The STAI-S was found to have a positively skewed distribution of results and 30% of the participants scored zero. The STAI-S had a mean score of 3.65 which was lower than the 8.65 (SD = 5.82) found by Ward et al (1994) using the same modifications and procedure. The internal consistency found in this study was similar to that found by Ward et al (1994) (Cronbach's alpha 0.88 and 0.91 respectively). The higher STAI-S scores in the Ward et al (1994) study could have been due to differences between participants in the two studies. The participants in their study were male and were referred for psychological evaluation, rather than solely for research. Older men have been found to have a lower prevalence of anxiety than women (Lindesay et al, 1989). Participants in this study were predominately women, so the results would have been affected if women scored significantly lower on the STAI-S than men. However, Table 4 showed no significant difference between men and women on the STAI-S, men tending to have a slightly lower score. The higher mean levels of anxiety in the study by Ward et al (1994) could have been due to the difference in selection procedures. Participants referred for psychological assessment could have had higher levels of anxiety than the participants in this study who were referred for research into anxiety and agitation. There was a trend in this study for participants taking benzodiazepines to have higher mean STAI-S scores but this did not reach significance, which may have been related to the large standard deviations and skewed distribution of results.

The STAI-S mean score appears to be low compared to the RAID mean score for the same group of participants. One reason for this may have been that the STAI-S asked how participants felt at that moment whereas the RAID asked how they had been over the previous two weeks. During administration of the STAI-S several participants stated that they often felt a symptom of anxiety but that they did not at the moment, so answered accordingly. This could have led to the discrepancy in the STAI-S and RAID scores.

In summary, the findings for the use of the STAI-S were mixed. There were no difficulties noted with its acceptability to participants, or its administration, and its internal consistency was good. However, it gave a skewed distribution of results. Its mean score also appeared to be low compared to previous research and to the RAID mean score. Difficulties may also have resulted from the time period the STAI-S was based on. The STAI-S was chosen for this study because this was the only subscale of the STAI used previously with individuals who have dementia and because it does not have a memory component. In retrospect, the trait subscale may have been more similar to the other measures used and may have given a more representative picture of anxiety symptoms. Further research is needed to investigate the use of the STAI with older adults with dementia.

4.2.4. Geriatric Depression Scale. The internal consistency for the GDS in this study was relatively low, which may have been due to having 15 items in this measure. Internal consistency is usually less for measures with less than twenty items (Kline, 1986). It has not been possible to find other studies for comparison which have used the short form of the GDS and reported the internal consistency. The GDS was found to be generally easily to administer and well understood, although it was noticed that participants with more severe cognitive impairment had a tendency to talk about the questions rather than give a yes/no answer. This could have been due to a lack of understanding of the instructions for the measure or to distractibility. It could also be related to the administration of the GDS in this study, where the questions were read out and participants' answers recorded. The presentation of the information verbally rather than visually may have affected participants' distractibility and understanding of the type of response required. These considerations affected the length of time needed to administer the GDS and it is not clear to what extent they affected its validity. The use

of the GDS with older adults with dementia has been questioned (Burke, Houston, Boust & Roccaforte, 1989), while other studies support its validity (Feher et al, 1992; Parmelee et al, 1989; Yesavage, 1986; Yesavage et al, 1983). These studies have generally used the 30 item version and have given it to the participants to fill in (standard administration), although some report reading the items out for participants who were not able to read the items themselves. No comparisons of these administration procedures have been found.

The difficulties found with the GDS for participants who were more cognitively impaired suggests that it may be more appropriate for use with individuals with mild cognitive impairment. In conclusion, while there are concerns about the use of the GDS with this population, it is widely used and several studies support its validity within certain parameters. The GDS was adequate for the purposes of this study, which was to provide a brief screening measure of depression. Had the study required a more detailed assessment of depression the use of another measure such as the Cornell scale for depression in dementia (Alexopolous et al, 1988) would have been considered in addition to the GDS.

4.2.5. Mini Mental State Examination. The MMSE is designed as a brief screening measure and does not give detailed information about cognitive functioning. It has difficulties with ceiling effects, particularly for individuals who had a high pre-morbid level of cognitive ability. In this study a significant proportion (32.5%) of the participants scored above the cut-off of 22 on the MMSE, but had definite diagnoses of dementia based on other sources of information. This suggests that ceiling effects were found in this study. The MMSE was chosen for this study because it is quick to administer, widely used in research and well validated. It was also used routinely by services in Leicestershire, which meant that it often had been administered recently and did not have to be repeated. This reduction in the amount asked of participants was important given the effects of fatigue and reduced concentration in this population.

It was considered whether a more comprehensive assessment of cognitive impairment should have been used. Both the MEAMS (Golding, 1989) and the CAMCOG-R (Roth et al, 1998) suffer from fewer difficulties with ceiling effects but take longer to complete and would have had to be carried out for all participants.

Interactions with level of cognitive impairment were not part of the main hypotheses for this study so it was not felt that the extra asked of participants would have been justified.

4.3. Hypothesis One

The primary hypothesis of a relationship between anxiety and agitation was supported by the significant positive correlation between the CMAI and the RAID. It was further shown that the correlation was not due to an item on restlessness common to both measures.

The CMAI did not correlate with the STAI-S. This difference between the behaviour of the STAI-S and the RAID was investigated further. The findings suggested that the difference may have been due to the CMAI correlating more highly with some subscales of the RAID and the STAI-S correlating more highly with others. As discussed previously, there were difficulties with using the STAI-S in this study: the STAI-S had a skewed distribution of scores; and the items asked how participants felt at that moment whereas the CMAI asked how they had been over the previous two weeks. There were also differences due to the STAI-S being a self report measure and the CMAI an informant rated measure. The lack of correlation could therefore have been due to differences in the subscales of the RAID with which the STAI-S and the CMAI correlated, difficulties with the STAI-S, the different time periods the two measures were based on, or to their different types of administration.

4.4 Hypothesis Two

Hypothesis two predicted that some agitated behaviours would show greater association with anxiety than others. There was little support for this, item by item analysis suggested that 'Constant requests for attention or help', 'Complaining or whining', 'Handling things inappropriately' and 'Unrelated Verbal Interruptions' were the agitated behaviours which correlated most highly with the RAID. However, none of these correlations were significant after application of the Bonferroni correction so these results should be treated with caution. The correlations in Table 2 suggest that 'Temper Outburst' and 'Verbal Bossiness or Pushiness' do not correlate with the RAID. This is similar to previous findings that irritability is not associated with anxiety (Ballard et al, 1996).

4.5. Hypothesis Three

A secondary aim of the study was to compare the two anxiety measures, in particular to consider whether the recently developed RAID correlated with a widely used measure of anxiety, the STAI. A high correlation was found between the STAI-S and the RAID scores. This supports the use of the RAID with this population and provides some evidence of concurrent validity. The finding of a high correlation between the self-rated STAI-S and the informant-rated RAID also supports the use of self-rating scales with this population.

The mean STAI-S score was low compared to the mean RAID score for the same group of participants. A possible reason for this was that the STAI-S items asked how participants felt at that moment whereas the RAID asked how they had been over the previous two weeks. A further difference between the measures was that the STAI-S is a self report measure and the RAID is based on information from the participant and an informant. The discrepancy in the STAI-S and RAID scores could have been due to these differences or to the difficulties with the STAI-S discussed previously.

4.6. Hypotheses Four

In previous research, correlations have been found between measures of anxiety and depression in older adults (e.g. Forsell & Winblad, 1998a; Fuentes & Cox, 2000; Lindesay et al, 1989; Shanker et al, 1999; Ward et al, 1994). In the current study a significant positive correlation was found between the GDS and the STAI-S, but not with the RAID. The STAI-S correlation with the GDS was 0.60, which is lower than the 0.80 found by Ward et al (1994) using similar procedures for administration. They used the 30 item form of the GDS and did not exclude participants with high levels of depression. This may account for the greater correlation found. As discussed previously, there were also differences in the participants between this study and the Ward et al (1994) study. The STAI-S and the GDS are both self report measures and it may be that the correlation was in part due to similarities in their administration. It could also have been due to co-morbidity between anxiety and depression as found in other studies (Forsell & Winblad, 1998a; Fuentes & Cox, 2000; Lindesay et al, 1989) or to lack of differentiation between the constructs of anxiety and depression as measured by the STAI-S and the GDS.

The correlation between the GDS and the RAID was 0.40 which was not significant. The RAID has not previously been compared with the GDS. Shanker et al (1999) found a correlation of 0.69 between the RAID and the Cornell Scale for Depression in Dementia (Alexopolous et al, 1988), which reduced to 0.20 when similar items were removed. The lack of significant correlation between the RAID and the GDS suggests that the RAID is not measuring the same construct as the GDS.

4.7. Hypothesis Five

Hypothesis five predicted that there would not be an association between depression and agitation in this study. The GDS and the CMAI did not correlate significantly. Cohen-Mansfield and Marx (1988) also failed to find an association between depression and agitation in individuals with dementia, although they were associated in cognitively intact older adults. This suggests that at present agitation should not be considered a symptom of depression in older adults with dementia.

4.8. Hypothesis Six

Hypothesis six predicted that level of cognitive impairment would not correlate with depression or anxiety. The level of cognitive impairment was measured by the MMSE. No significant correlations were found between the MMSE and any of the other measures. The lack of correlation between the MMSE and the GDS, STAI-S and RAID was predicted from previous studies which have found no correlation between level of cognitive impairment and depression or anxiety (e.g. Forsell et al, 1993; Shanker et al, 1999; Wands et al, 1990).

4.9. Hypothesis Seven

Hypothesis seven predicted that there would be an association between level of cognitive impairment and agitation, which has been found in previous studies (Cohen-Mansfield & Billig, 1986; Reisberg et al, 1987; Swearer et al, 1988; Teri et al, 1988). The expected correlation between the CMAI and the MMSE was not found in this study. This may have been because participants were selected to have a relatively narrow range of mild to moderate cognitive impairment. It could also have been due to the ceiling effect in the MMSE scores.

4.10. Additional Analyses

The additional analyses were not part of the planned comparisons and were based on unequal sized groups so should be treated with caution. They suggested that the mean score for the CMAI was higher and the MMSE score lower for participants who lived with family members compared to those who lived alone. It may be that individuals who are agitated or have greater cognitive impairment and live alone are more likely to be admitted to care facilities. Those who live with family are more likely to be managed at home.

Mean scores on the informant rated measures, particularly the CMAI, were higher for participants who had family informants. Cohen-Mansfield, Werner et al (1995) found that family informants reported more agitated behaviours and at greater frequencies than professional informants. They interpreted this as a difference in the behaviours manifested at home and at day care centres. It could also be related to the increased amount of time family informants spent with the participant, or to differences in the perception of behaviours by family and professional carers. In the study by Cohen-Mansfield, Werner et al (1995) different formats of the CMAI were used for professional and family informants. This could also have affected the differences between informants. Shanker et al (1999) used both professional and family informants with the RAID but comparisons were not made between the two types of informant. There were insufficient family informants in this study to investigate the effect of the informant further. A weakness of this study is that both family members and professional care-givers were used as informants. Both of the informant rated measures were designed to be used in this way, but differences in informants' reporting of behaviours require further investigation. Future research would benefit from having both family and professionals complete measures.

4.11. Conclusions

The primary aim of this study was to investigate the relationship between anxiety and agitation in older adults who have dementia. A significant, positive correlation was found between anxiety and agitation with the RAID and the CMAI but not with the STAI-S and the CMAI. There was tentative support for the agitated behaviours of Constant Requests for Attention, Complaining, Unrelated Verbal Interruptions and Handling Objects Inappropriately being more closely associated with anxiety than other

behaviours. The relationship between anxiety and these behaviours requires further research before firm conclusions can be drawn. There was support for previous findings of a lack of correlation between anxiety and irritability. Further research is needed to investigate the relationship between anxiety and agitation and to extend studies to individuals with more severe cognitive impairment.

The correlation found between anxiety and agitation in this study was moderate. Once a similar item had been removed, the correlation remaining accounted for approximately 17% of the variance. This suggests that while anxiety and agitation are associated in dementia, they cannot be considered as the same. No correlation was found between the CMAI and the RAID subscale of autonomic hypersensitivity. This suggests that the anxiety symptoms of autonomic hypersensitivity could be used to differentiate between anxiety and agitation if this was required. These findings are contrary to the conclusion that 'GAD-like symptoms are currently defined as agitation' (Mintzer & Brawman-Mintzer, 1996, p.61), but is supported by the finding from the same study that agitation is related to a number of factors including social interactions, side effects of medication, and physical problems or pain (Mintzer & Brawman-Mintzer, 1996). The suggestion that symptoms of anxiety are replaced with agitated behaviours as dementia progresses (Krasucki et al, 1998) was not directly investigated in this study. It would be expected from this hypothesis that as the level of cognitive impairment increased, levels of anxiety would decrease and levels of agitation would increase. In the current study no correlations were found between level of cognitive impairment and either anxiety or agitation. This does not support the suggestion by Krasucki et al, but the results may be due to the narrow range of cognitive impairment considered in this study.

A secondary aim of the study was to compare the two anxiety measures. The measurement of anxiety in dementia presents a number of difficulties. The RAID is currently the only instrument designed to measure anxiety in this population. As a recently developed instrument it has not yet been widely used or validated. This study provides further support for its use. It was found to be easy to use, had good internal consistency, and correlated highly with the STAI-S, a widely used measure of anxiety

which has been validated for use with older adults. Current results support the use of the RAID to measure anxiety in older adults with dementia, but further research is needed into its psychometric properties.

The conclusions from this study about the use of the STAI-S with older adults with dementia are mixed. It was easy to use and appeared to be well understood by participants using the modified administration procedure and yes/no answers. Good internal consistency was found and it correlated highly with the other anxiety measure, the RAID. However, there was a skewed distribution of scores and the comparatively low mean score found may have been due to the use of the state subscale which is only concerned with how the participant feels at the moment.

The use of the GDS with older adults with dementia had some support from this study. The principle concern was that participants with greater cognitive impairment appeared to have difficulty completing the scale and took a long time to answer yes or no to the items. It is unclear whether this was due to the verbal administration of the scale or to it being too complex for use with more cognitively impaired participants. Findings from other studies were replicated with a correlation found between the GDS and the STAI-S, but the correlation between the GDS and the RAID was not significant. The expected correlation between the level of cognitive impairment and agitation was not found.

Participants in this study were more anxious and less depressed than may be representative of older adults with dementia. Women and participants of white British ethnic origin were also over-represented. The findings were also based on individuals with mild to moderate cognitive impairment so may not be applicable to those with more severe cognitive impairment. Further research is required to extend these findings to more representative samples of older adults with dementia, including those with severe cognitive impairment. Differences in the reporting of behaviours by professional and family informants should also be investigated further and incorporated into any future research in this area.

4.12. Clinical implications

When considering the association between anxiety and agitation it should be remembered that they are qualitatively different constructs. In clinical terminology anxiety refers to an internal feeling or psychiatric diagnosis, while agitation is a behavioural syndrome. The challenge is therefore to investigate which factors are associated with agitation and if agitated behaviours can be used to identify different causes for any one individual. The findings of this study show that anxiety is associated with agitation and could be one of its causes in individuals who have dementia. The findings do not support the use of agitation purely as an indicator of anxiety. Clinically, it remains important to consider several possible causes of agitated behaviour, of which anxiety may be one.

Agitation was not supported as a symptom of depression in older adults with dementia. This could be due to limitations of the measures used, but is similar to findings in previous studies. An association between anxiety and depression in this population was partially supported by this study. It is not clear whether this was due to co-morbidity, a lack of differentiation between the disorders in older adults with dementia, or to difficulties with the measures used. Until this is investigated further, it suggests that in clinical practice co-morbidity between these difficulties should be considered.

Further clinical implications from this study concern the use of the measures in this study with older adults with dementia. The CMAI contains a number of items which may be rarely endorsed for community based clients who have mild to moderate dementia. In clinical work it may be more appropriate to use a shorter measure designed for use with this population. The use of the RAID with this population has been supported, although further validation studies are needed. This study has provided mixed support for the use of the modified STAI-S. It did not appear to give extra information to that provided by the RAID. The GDS has been supported for use with clients with mild cognitive impairment. The effect of verbal and visual presentation of items require further investigation, especially with respect to clients who have greater cognitive impairment. The MMSE was found to have ceiling effects. This may mean that a significant proportion of clients who have dementia may score over the suggested cut-off of 22. It should therefore be used in conjunction with other assessments.

5. References

- Alexopolous, G. S., Abrams, R. C., Young, R. C. & Shamoian, C. A. (1988). Cornell scale for depression in dementia. <u>Biological Psychiatry</u>, 23, 271-284.
- Allen-Burge, R., Stevens, A. B. & Burgio, L. D. (1999). Effective behavioral interventions for decreasing dementia-related challenging behavior in nursing homes.
 <u>International Journal of Geriatric Psychiatry</u>, 14, 213-232.
- American Psychiatric Association. (1994). <u>Diagnostic and Statistical Manual of Mental</u>
 <u>Disorders.</u> (4th ed.). Washington: APA.
- Ballard, C., Boyle, A., Bowler, C. & Lindesay, J. (1996). Anxiety disorders in dementia sufferers. <u>International Journal of Geriatric Psychiatry</u>, 11, 987-990.
- Ballard, C., Mohan, R. N. C., Patel, A. & Graham, C. (1994). Anxiety disorders in dementia. <u>Irish Journal of Psychiatry</u>, 11, 108-109.
- Beck, A. T., Rush, A. J., Shaw, B. A. & Emery, G. (1979). <u>Cognitive Therapy of Depression</u>. New York: Guilford Press.
- Beck, A. T. & Steer, R. A. (1993). <u>Beck Anxiety Inventory Manual</u> (2nd ed.). San Antonio, TX: Psychological Corporation.
- Beck, G. J. & Stanley, M. A. (1997). Anxiety disorders in the elderly: The emerging role of behavior therapy. Behavior Therapy, 28, 83-100.
- Blessed, G., Tomlinson, B. E. & Roth, M. (1968). The association between quantitative measures of dementia and of senile change in the cerebral grey matter of elderly subjects. <u>British Journal of Psychiatry</u>, 114, 797-811.
- Bond, J. (1999). Quality of life for people with dementia: approaches to the challenge of measurement. <u>Ageing and Society</u>, 19, 561-579.
- Burgio, L. D. & Stevens, A. B. (1999). Behavioral interventions and motivational systems in the nursing home. In R. Schulx, G. Maddox & M. P. Lawton (Eds.).

 Annual Review of Gerontology and Geriatrics. (pp. 284-320). New York: Springer.
- Burke, W. J., Houston, M. J., Boust, S. J., & Roccaforte, W. H. (1989). Use of the geriatric depression scale in dementia of the Alzheimer's type. <u>Journal of the</u>
 American Geriatrics Society, 37, 856-960.

- Camus, V., Schmitt, L., Ousset, P. J., Micas, M., Sharlet, J. P., Vellas, B., Albarede, J.
 L., & Moron, P. (1993). A comparative study of Hamilton, Cornell and Sunderland depression rating scales in dementia. <u>Journal of the American Geriatrics Society</u>, 41 (Suppl 10), SA42.
- Cheston, R., & Bender, M. (1999). Brains, minds and selves: changing conceptions of the losses involved in dementia. <u>British Journal of Medical Psychology</u>, 72, 203-216.
- Christensen, H., Jorm, A. F., Mackinnon, A. J., Korten, A. E., Jacomb, P. A., Henderson, A. S., & Rogers, B. (1999). Age differences in depression and anxiety symptoms: a structural equation modelling analysis of data from a general population sample. Psychological Medicine, 29, 325-339.
- Cohen, G. D. (1998). Anxiety in Alzheimer's disease: theoretical and clinical perspectives. <u>Journal of Geriatric Psychiatry</u>, 31 (2), 103-132.
- Cohen-Mansfield, J. (1986). Agitated behaviors in the elderly, II: preliminary results in the cognitively deteriorated. <u>Journal of the American Geriatrics Society</u>, 34 (10), 722-727.
- Cohen-Mansfield, J. (1991). <u>Instruction Manual for the Cohen-Mansfield Agitation</u>
 <u>Inventory.</u> Rockville, MD: Research Institute of the Hebrew Home of Greater Washington.
- Cohen-Mansfield, J. (1996). Behavioral and mood evaluations: assessment of agitation. International Psychogeriatrics, 8 (2), 233-245.
- Cohen-Mansfield, J. & Billig, N. (1986). Agitated behaviours in the elderly I: a conceptual review. Journal of the American Geriatrics, Society, 34 (10), 711-721.
- Cohen-Mansfield, J., Culpepper, W. J., Werner, P., Wolfson, M., & Bickel, E. (1995).

 Assessment of pacing/wandering behavior in nursing home residents: a comparison of four commercially available devices. Monographs of the Research Institute of the Hebrew Home of Greater Washington, 121. Rockville, MD.
- Cohen-Mansfield, J. & Marx, M. (1988). Relationship between depression and agitation in nursing home residents. <u>Comprehensive Gerontology</u>, 2, 141-146.
- Cohen-Mansfield, J., Marx, M., & Rosenthal, A. (1989). A description of agitation in a nursing home. <u>Journal of Gerontology: Medical Sciences</u>, 44 (3), M77-84.
- Cohen-Mansfield, J., Marx, M., & Werner, P. (1992). Agitation in elderly persons: an integrative report of findings in a nursing home. <u>International Psychogeriatrics</u>, 4 (Suppl 2), 221-240.

- Cohen-Mansfield, J. & Werner, P. (1994). Verbally disruptive behavior in elderly persons: a review. In P. J. Garry & L. J. Fritten (Eds.). <u>Facts and Research in Gerontology: Dementia and Cognitive Impairment</u>. Alberede, Toulouse: Serdi.
- Cohen-Mansfield, J., Werner, P., Watson, V., & Pasis, S. (1995). Agitation among elderly persons at adult day-centres: the experiences of relatives and staff members. International Psychogeriatrics, 7 (3), 447-458.
- Copeland, J. R. M., Dewey, M. E., Wood, N., Searle, R., Davison, I. A., & McWilliam, C. (1987). Range of mental illness among the elderly in the community: prevalence in Liverpool using the GMS-AGECAT package. <u>British Journal of Psychiatry</u>, 150, 815-823.
- Davies, K. N., Burn, W. K., McKenzie, F. R., Brothwell, J. A. & Wattis, J. P. (1993). Evaluation of the hospital anxiety and depression scale as a screening instrument in geriatric medical inpatients. International Journal of Geriatric Psychiatry, 8, 165-169.
- Derogatis, L. R., Rickles, K., & Rock, A. (1976). The SCL-90 and the MMPI: a step in the validation of a new self-report scale. <u>British Journal of Psychiatry</u>, 128, 280-289.
- Finkel, S. I., Lyons, J. S. & Anderson, R. L. (1992). Reliability and validity of the Cohen-Mansfield agitation inventory in institutionalized elderly. <u>International</u> Journal of Geriatric Psychiatry, 7, 487-490.
- Finkel, S. I., Lyons, J. S., & Anderson, R. L. (1993). A brief agitation rating scale (BARS) for nursing home elderly. <u>Journal of the American Geriatrics Society</u>, 41, 50-52.
- Flint, A. J. (1994). Epidemiology and comorbidity of anxiety disorders in the elderly.

 <u>American Journal of Psychiatry. 151 (5)</u>, 640-649.
- Forsell, Y., Jorm, A. F., & Winblad, B. (1993). Variation in psychiatric and behavioural symptoms in different stages of dementia: data from physicians' examination and informants' reports. <u>Dementia</u>, 4, 282-286.
- Forsell, Y. & Winblad, B. (1998a). Feelings of anxiety and associated variables in a very elderly population. <u>International Journal of Geriatric Psychiatry</u>, 13, 454-458.
- Forsell, Y. & Winblad, B. (1998b). Major depression in a population of demented and nondemented older people: prevalence and correlates. <u>Journal of the American</u>
 <u>Geriatrics Society</u>, 46, 27-30.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. <u>Journal of Psychiatric Research</u>, 12, 189-198.

- Fuentes, K. & Cox, B. J. (1997). Prevalence of anxiety disorders in elderly adults: a critical analysis. <u>Journal of Behavior Therapy and Experimental Psychiatry</u>, 28 (4), 269-279.
- Fuentes, K. & Cox, B. (2000). Assessment of anxiety in older adults: a community-based survey and comparison with younger adults. <u>Behavior Research and Therapy</u>, 38, 297-309.
- Fuher, E. P., Larrabee, G. J. & Crook, T. H. (1992). Factors attenuating the validity of the geriatric depression scale in a dementia population. <u>Journal of the American</u> <u>Geriatrics Society</u>, 40(9), 906-909.
- Golding, E. (1989). <u>The Middlesex Elderly Assessment of Mental State manual</u>. Kent, UK: Thames Valley Test Company.
- Gottlieb, G. L., Raquel, E. G., & Ruben, C. G. (1988). Reliability of psychiatric rating scales in patients with dementia of the Alzheimer's type. <u>American Journal of Psychiatry</u>, 145 (7), 857-860.
- Grasbeck, A., Rorsman, B., Hagnell, O. & Isberg, P. E. (1996). Mortality of anxiety symptoms in a normal population. <u>Neuropsychology</u>, 33, 118-126.
- Greenwald, B. (1995). Depression in Alzheimer's disease and related dementias. In E. Lawlor (Ed.). <u>Behavioural complications in Alzheimer's disease.</u> (pp19-54). Washington: American Psychiatric Association Press.
- Hamilton, M. (1960). A rating scale for depression. <u>Journal of Neurology and Neurosurgery Psychiatry</u>, 23, 56-62.
- Hersen, M. & Van Hasselt, V. B. (1992). Behavioural assessment and treatment of anxiety in the elderly. Clinical Psychology Review, 12, 619-640.
- Himmelfarb, S. & Murrell, S. A. (1984). The prevalence and correlates of anxiety symptoms in older adults. <u>Journal of Psychology</u>, 116, 159-167.
- Hocking, L. B. & Koenig, H. G. (1995). Anxiety in medically ill older patients: a review and update. <u>International Journal of Psychiatry and Medicine</u>, 25, 221-238.
- Jacoby, R. J. & Levy, R. (1980). Computed tomograthy in the elderly: 2. Senile dementia: diagnosis and functional impairment. <u>British Journal of Psychiatry</u>, 136, 270-275.
- James, I. A. (1999). Using a cognitive rationale to conceptualise anxiety in people with dementia. <u>Behavioural and Cognitive Psychotherapy</u>, 27, 345-351.
- Jorm, A. F. (1990). <u>The Epidemiology of Alzheimer's Disease and Related Disorders.</u> London: Chapman and Hall.

- Jorm, A. F., Korten, A. E., & Henderson, A. S. (1987). The prevalence of dementia: a quantitative integration of the literature. <u>Acta Psychiar Scand</u>, 76, 465-479.
- Katz, M.M., Wetzler, S., Cloitre, M., Swann, A., Secunda, S., Mendels, J. & Robins, E. (1993). Expressive characteristics of anxiety in depressed men and women. <u>Journal of Affective Disorders</u>, 28, 267-277.
- Kenn, C., Wood, H., Kucyj, M., Wattis, J., & Cunane, J. (1987). Validation of the hospital anxiety and depression rating scale in an elderly psychiatric population. <u>International Journal of Geriatric Psychiatry</u>, 2, 189-193.
- Kitwood, T. (1990). The dialectics of dementia: with particular reference to Alzheimer's disease. Ageing and Society, 10, 177-196.
- Kitwood, T. (1993). Towards a theory of dementia care: the interpersonal process.

 Ageing and Society, 13, 51-67.
- Kitwood, T. (1997). <u>Dementia Reconsidered: the Person Comes First.</u> Buckingham, UK: Open University Press
- Kitwood, T. & Bredin, K. (1992). Towards a theory of dementia care: personhood and well-being. Ageing and Society, 12, 269-278.
- Kline, P. (1986). <u>A Handbook of Test Construction: Introduction to Psychometric</u>
 <u>Design.</u> Cambridge, UK: Cambridge University Press.
- Knauper, B. & Wittchen, H. U. (1994). Diagnosing major depression in the elderly: evidence for response bias in standardised diagnostic interviews? <u>Journal of Psychiatric Research</u>, 28, 147-164.
- Kopecky, H. J., Kopecky, C. R., & Yudofsky, S. C. (1998). Reliability and validity of the overt agitation severity scale in adult psychiatric inpatients. <u>Psychiatric</u> Quarterly, 69 (4), 301-323.
- Kopecky, H. J. & Yudofsky, S. C. (1999). Agitation: conceptualisation, measurement, and treatment. <u>Bulletin of the Menninger Clinic</u>, 63, (2) (Suppl. A) 31-52.
- Krasucki, C., Howard, R., & Mann, A. (1998). Review: the relationship between anxiety disorders and age. <u>International Journal of Geriatric Psychiatry</u>, 13, 79-99.
- Lawton, M. P., Kleban, M. H., Dean, J., Rajagopal, D., & Parmelee, P. A. (1992). The factorial generality of brief positive and negative affect measures. <u>Journal of Gerontology</u>, <u>Series B: Psychological Sciences and Social Sciences</u>, 47(4), 228-237.
- Lawton, M. P., Van Haitsma, K., & Klapper, J. (1996). Observed affect in nursing home residents with Alzheimer's disease. <u>Journal of Gerontology, Series B:</u>

 <u>Psychological Sciences and Social Sciences</u>, 51B, 3-14.

- Lindesay, J., Briggs, K., & Murphy, E. (1989). The Guy's/Age Concern survey: prevalence rates of cognitive impairment, depression and anxiety in an urban elderly community. <u>British Journal of Psychiatry</u>, 155, 317-329.
- Lloyd, K. R., Jenkins, R. & Mann, A. (1996). Long term outcome of patients with neurotic illness in medical practice. <u>British Medical Journal</u>, 313, 26-28.
- Logsdon, R. G., Teri, L., Weiner, M. F., Gibbons, L. E., Raskind, M., Peskind, E., Grundman, M., Koss, E., Thomas, R. G., & Thal, L. J. (1999). Assessment of agitation in Alzheimer's disease: the agitated behavior in dementia scale. <u>Journal of the American Geriatrics Society</u>, 47 (11), 1354-1358.
- McEwan, K. L., Donnelly, M., Robertson, D., & Hertzman, C. (1991). Mental Health

 Problems Among Canada's Seniors: Demographic and Epidemiological

 Considerations. Ottawa, ON: Department of National Health and Welfare, Mental Health Division.
- McShane, R., Keene, J., Geldling, K., Fairburn, C., Jacoby, R., & Hope, T. (1997). Do neuroleptic drugs hasten cognitive decline in dementia? Prospective study with necropsy follow up. British Medical Journal, 314, 266-270.
- Mintzer, J. E. & Brawman-Mintzer, O. (1996). Agitation as a possible expression of generalized anxiety disorder in demented elderly patients: toward a treatment approach. <u>Journal of Clinical Psychiatry</u>, <u>57</u>, <u>Suppl 7</u>, 55-63.
- O'Donnell, B. F., Drachman, D. A., Barnes, H. J., Peterson, K., Swearer, J., & Lew, R. A. (1992). Incontinence and troublesome behaviors predict institutionalization in dementia. <u>Journal of Geriatric Psychiatry and Neurology</u>. 5, 45-52.
- Parmelee, P. A., Lawton, M. P., & Katz, I. R. (1989). Psychometric properties of the geriatric depression scale among the institutionalised aged. <u>Psychological Assessment: A Journal of Consulting and Clinical Psychology</u>, 1, 331-338.
- Patel, V. & Hope, R. A. (1992). A rating scale for aggressive behaviour in the elderly—the RAGE. <u>Psychological Medicine</u>, 22, 211-221.
- Patterson, R. L., O'Sullivan, M. J. & Speilberger, C. D. (1980). Measurement of state and trait anxiety in elderly mental health clients. <u>Journal of Behavioral Assessment</u>, 2(2), 89-97.
- Regier, D. A., Boyd, J. H., Burke, J. D., Rae, D. S., Myers, J. K., Kramer, M., Robins, L. N., George, L. N., Karno, M., & Locke, B. Z. (1988). One-month prevalence of mental disorders in the United States: based on five epidemiologic catchment area sites. <u>Archives of General Psychiatry</u>, 45, 977-986.

- Reisberg, B., Borenstein, J., Salob, S. P., Ferris, S. H., Franssen, E., & Georgotas, A. (1987). Behavioral symptoms in Alzheimer's disease: phenomenology and treatment. <u>Journal of Clinical Psychiatry</u>, 48, 9-15.
- Rosen, J., Burgio, L., Kollar, M., Cain, M., Allison, M., Fogelman, M., Micheal, M., & Zubenko, G. S. (1994). The Pittsburgh agitation scale: a user friendly instrument for rating agitation in dementia patients. <u>American Journal of Geriatric Psychiatry</u>, 2, 52-59.
- Roth, M. (1980). Senile dementia and its borderlands. In J. O. Cole and J. E. Barrett, (Eds.). <u>Psychopathology in the Aged.</u> New York: Raven.
- Roth, M., Huppert, F. A., Mountjoy, C. Q. & Tym, E. (1998). <u>The Cambridge Examination for Mental Disorders of the Elderly revised.</u> Cambridge, UK: Cambridge University Press.
- Sadavoy, J. & LeClair, J. K. (1997). Treatment of anxiety disorders in late life. Canadian Journal of Psychiatry, 42, Suppl 1, 28S-34S.
- Shah, A., Evans, H., & Parkash, N. (1998). Evaluation of three aggression/agitation behaviour rating scales for use on an acute admission and assessment psychogeriatric ward. International Journal of Geriatric Psychiatry, 13 (6), 415-420.
- Shanker, K. K. & Orrell, M. W. (2000). Detecting and managing depression and anxiety in people with dementia. <u>Current Opinion in Psychiatry</u>, 13(1), 55-59.
- Shanker, K. K., Walker, M., Frost, D., & Orrell, M. W. (1999). The development of a reliable and valid scale for rating anxiety in dementia (RAID). <u>Aging and Mental Health</u>, 3(1), 39-49.
- Shapiro, A. M., Roberts, J. E., & Beck, J. G. (1999). Differentiating symptoms of anxiety and depression in older adults: distinctive cognitive and affective profiles? Cognitive Therapy and Research, 23, 53-74.
- Sheikh, J. I. & Yesavage, J. A. (1986). Geriatric depression scale: recent evidence and development of a shorter version. In T. L. Brink (Ed.). Clinical Gerontology: A Guide to Assessment and Intervention. New York: The Haworth Press.
- Snaith, R. P., Baugh, S. J., Clayden, A. D., Husain, A. & Sipple, M. A. (1982). The clinical anxiety scale: an instrument derived from the Hamilton anxiety scale. <u>British Journal of Psychiatry</u>, 141, 518-523.
- Speilberger, C. D. (1983). <u>Manual for the State-Trait Anxiety Inventory (Form Y)</u>. Palo Alto, CA: Consulting Psychologists Press.

- Speilberger, C. D., Gorsuch, R. C. & Lushene, R. E. (1970). <u>Manual for the State-Trait</u>
 Anxiety Inventory. Palo Alto, CA: Consulting Psychologists Press.
- Stanley, M. A. & Beck, G. J. (2000). Anxiety disorders. <u>Psychology Review</u>, 20 (6), 731-754.
- Stanley, M. A., Beck, G. J., & Zebb, B. J. (1996). Psychometric properties of four anxiety measures in older adults. Behavior Research and Therapy, 34(10), 827-838.
- Sunderland, T. & Minichiello, M. (1996). Dementia mood assessment scale.

 International Psychogeriatrician, 8, (Suppl 3), 329-331.
- Swearer, J. M., Drachman, D. A., O'Donnell, B. F., & Mitchell, A. L. (1988).

 Troublesome and disruptive behaviors in dementia: relationships to diagnosis and disease severity. Journal of the American Geriatrics Society, 34, 711-721.
- Tariot, P. N., Mack, J. L., Patterson, M. B., Edland, S. D., Weiner, M. F., Fillenbaum,
 G., Blanzina, L., Teri, L., Rubin, E., Mortimer, J., & Stern, Y. (1995). Behavioral
 Pathology Committee of the Consortium to Establish a Registry for Alzheimer's
 Disease. The behavior rating scale of the consortium to establish a registry of
 Alzheimer's disease. <u>American Journal of Psychiatry</u>, 152, 1349-1357.
- Teri, L., Larson, E. B. & Reifler, B. V. (1988). Behavioral disturbance in dementia of the Alzheimer's type. <u>Journal of the American Geriatrics Society</u>, 36, 1-6.
- Volicer, L., Hurley, A. C. & Camberg, L. (1999). A model of psychological well-being in advanced dementia. Journal of Mental Health and Aging, 5, (1), 83-94.
- Wands, K., Merskey, H., Hanchinski, V. C., Fishman, M., Fox, F., & Boniferro, M. (1990). A questionnaire investigation of anxiety and depression in early dementia. Journal of the American Geriatric Society, 36, 535-538.
- Ward, C. L., Wadsworth, A. P., & Peterson, L. P. (1994). Concurrent validity of measures of anxiety, depression, and somatization in elderly, demented, male patients. Clinical Gerontologist, 15(1), 3-13.
- Weiner, M. F., Koss, E., Patterson, M., Jin, S., Teri, L., Thomas, R., Thal, L. J., & Whitehouse, P. (1998). A comparison of the Cohen-Mansfield agitation inventory with the CERAD behavioral rating scale for dementia in community-dwelling persons with Alzheimer's disease. <u>Journal of Psychiatric Research</u>, 32 (6), 347-351.
- Wetherell, J. L. (1998). Treatment of anxiety in older adults. <u>Psychotherapy</u>, 35, (4), 444-458.

- Wisocki, P. A., Handen, B. & Morse, C. K. (1986). The worry scale as a measure of anxiety among homebound and community active elderly. <u>Behavior Therapist</u>, 5, 91-95.
- Yesavage, J. A. (1986). The use of self-rating depression scales in the elderly. In L. W. Poon (Ed.). <u>Handbook for Clinical Memory Assessment of Older Adults.</u> (pp213-217). Washington, DC: American Psychological Association.
- Yesavage, J. A. (1988). Geriatric depression scale. <u>Psychopharmacology Bulletin, 24,</u> 709-710.
- Yesavage, J. A., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M. & Leirer, V. O. (1983). Development and validation of a geriatric depression screening scale: a preliminary report. <u>Journal of Psychiatric Research</u>, 17 (1), 37-49.
- Yudofsky, S. C., Kopecky, H. J., Kunik, M., Silver, J. M. & Endicott, J. (1997). The overt agitation severity scale for the rating of agitation. <u>Journal of Neuropsychiatry and Clinical Neurosciences</u>, 9 (4), 541-548.
- Zigamond, A. S. & Snaith, R. P. (1983). The hospital anxiety and depression scale. <u>Acta Psychiatr Scand</u>, 67, 361-370
- Zung, W. W. K. (1965). A self-rating depression scale. <u>Archives of General Psychiatry</u>, 12, 63-70.
- Zung, W. W. K. (1971). A rating instrument for anxiety disorders. <u>Psychosomatics</u>, 12, 371-379.

6. Appendices

Appendix A

Participant Information Sheet and Consent Form

Leicestershire and Rutland NHS

Healthcare NHS Trust

Psychiatry for the Elderly Directorate
Community Mental Health Team for North Charnwood
Town Hall Chambers, Town Hall Passage
Market Place, Loughborough,
Leics. LE11 3EB

Telephone: 01509 553901 Fax: 01509 553907

RESEARCH INTO THE RELATIONSHIP BETWEEN ANXIETY AND AGITATION.

I am a trainee Clinical Psychologist and I am carrying out some research into anxiety and agitation. I am writing to ask if you would be willing to take part in the research. The research will be looking at feelings of anxiety you might have and things you do which might show you are feeling anxious. I need to talk to you and to your carer, this is someone who knows how you are from day to day, they could be someone you live with, someone who visits you a lot, or the keyworker where you go for day care. Please take time to read the following information and discuss it with your friends, relatives, or anyone else if you wish.

What is the purpose of the research?

The purpose of this research is to find out if some behaviours are better at showing that people are feeling anxious than others. This could help to improve the service given to people who feel anxious.

What will it involve?

You will be seen individually at home or somewhere else if you prefer. I will ask you a few questions to see how you are managing at the moment. Then I will ask you about how you are feeling in terms of your mood and anxiety.

I will also ask your carer some questions about how they think you are in terms of anxiety and agitation.

It will probably take about 1 hour for you and about 30 minutes for your carer. You can do this in more than one session if you wish to.

Will my answers be confidential?

Everything discussed will be confidential. All written information will be given a number so that it can be kept together, but your name, address, or any other identifying information will not be used. If <u>you</u> choose to, you can talk about anything which is discussed with someone else but this will be up to you.

Will I be told the results?

If you wish, you will be told what your answers show and again, you can discuss this with whoever you choose. If you want to, you will also get a summary of the whole study when it has been completed.

Do I have to take part?

You do not have to take part, it is entirely up to you. If you do not want to take part it will not effect your treatment in any way.

If you would like to know more about the study please contact me, Helen Twelftree on 01509 553901.

What if I decide to take part?

The person who gave you this sheet will have asked you if you are willing to be contacted to talk about the research. If you agreed, I will be contacting you to arrange a convenient time and place to see you and discuss the research. If you decide to take part I will ask you to sign the consent form which is with this sheet. If you did not agree but have changed your mind please tell the person who gave you this sheet, or contact me on the above number.

If you decide to take part you can still stop later if you change your mind. You can also decide not to answer any questions. Again, your treatment will not be affected in any way.

Thank you for helping me with this research.

Helen Twelftree Trainee Clinical Psychologist. Supervised by Professor E. Miller Leicester University

Leicestershire and Rutland MFS

Healthcare NHS Trust

Psychiatry for the Elderly Directorate
Community Mental Health Team for North Charnwood
Town Hall Chambers, Town Hall Passage
Market Place, Loughborough,
Leics. LE11 3EB

Telephone: 01509 553901 Fax: 01509 553907

CONSENT FORM

RESEARCH INTO THE RELATIONSHIP BETWEEN ANXIETY AND AGITATION.

Researcher: Helen Twelftree.

Patient

I agree to take part in the above study as described in the information sheet.

I agree that Helen Twelftree may contact my carer as described in the information sheet.

I understand that Helen Twelftree may want to look at relevant sections of my medical records, but that all the information will be treated as confidential.

I understand that this research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

I understand that I can pull out of the study at any time without giving a reason and that I do not have to answer any questions that I do not want to answer.

I understand that my treatment will not be affected in any way and that all my answers will be confidential.

SignedDate
Please complete in BLOCK LETTERS
Name
Address
Telephone
Carer
I agree to take part in the above study as described in the information sheet. I understand that I can pull out of the study at any time without giving a reason and that I do not have to answer any questions that I do not want to answer. I understand that all my answers will be confidential.
SignedDate
Please complete in BLOCK LETTERS
Name
Address(if different)
Telephone

Appendix B

The Rating Anxiety in Dementia Scale

(RAID)

Shanker, K. K., Walker, M., Frost, D., & Orrell, M. W. (1999). The development of a reliable and valid scale for rating anxiety in dementia (RAID). <u>Aging and Mental Health</u>, 3(1), 39-49.

Number:

Anxiety Scale - RAID

Rating should be based on symptoms and signs occurring during the **two weeks** prior to the interview. No score should be given if symptoms result from physical disability or illness.

Scoring:

U - unable to evaluate

0 - absent

1 - mild or intermittent

2 - moderate

3 - severe

Score

			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	6	Frightened and anxious (keyed up and on the edge)	
and vigilance	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 (complains of headache, other body	
		aches and pains)	
	12	Restlessness (fidgeting, cannot sit still, pacing,	
		wringing hands, picking clothes)	
	13	Fatigability, tiredness	
Autonomic	14	Palpitations (complains of heart racing or thumping)	
hypersensitivity	15	Dry mouth (not due to medication), sinking feeling in	
		the stomach	
	16	Hyperventilation, shortness of breath (even when not	
		exerting)	
	17	Dizziness or light-headedness (complains as if going	
		to faint)	<u> </u>
	18	Sweating, flushes or chills, tingling or numbness of	
	<u> </u>	fingers and toes.	
		e excessive, that do not make sense and tend to avoid -	
like afraid of crow	ds, go	ing out alone, being in a small room, or being frightened	
by some kind of ar	nimal,	heights, etc.	
Describe:			
		of anxiety or dread that are so strong that they think they	
		a heart attack and they simply have to do something to	
stop them, like imr	nediat	ely leaving the place, phoning relatives, etc.	l
Describe:			
- · · · · · · · · · · · · · · · · · · ·	C	a 1 19 a score of 11 or more suggests significant clinical anxiety	

Total score is the sum of items 1-18, a score of 11 or more suggests significant clinical anxiety.

Appendix C

The State Anxiety Inventory

(STAI-S)

Speilberger, C. D. (1983). <u>Manual for the State-Trait Anxiety Inventory (Form Y).</u> Palo Alto, CA: Consulting Psychologists Press.

Number:

Self Evaluation Questionnaire

I am going to read some statements which people have used to describe themselves. Indicate how you feel right now, at the moment. There are no right or wrong answers. Do not spend too much time on any one statement, but give the answer which seems to describe your present feelings best.

		Yes	No
1	I feel calm	Y	N
2	I feel secure	Y	N
3	I am tense	Y	N
4	I feel strained	Y	N
5	I feel at ease	Y	N
6	I feel upset	Y	N
7	I am presently worrying over possible misfortunes	Y	N
8	I feel satisfied	Y	N
9	I feel frightened	Y	N
10	I feel comfortable	Y	N
11	I feel self-confident	Y	N
12	I feel nervous	Y	N
13	I am jittery	Y	N
14	I feel indecisive	Y	N
15	I am relaxed	Y	N
16	I feel content	Y	N
17	I am worried	Y	N
18	I feel confused	Y	N
19	I feel steady	Y	N
20	I feel pleasant	Y	N

Appendix D

The Cohen-Mansfield Agitation Inventory

(CMAI)

Cohen-Mansfield, J., Werner, P., Watson, V., & Pasis, S. (1995). Agitation among elderly persons at adult day-centres: the experiences of relatives and staff members.

<u>International Psychogeriatrics</u>, 7 (3), 447-458.

Cohen-Mansfield Agitation Inventory - Relatives

We would like to ask about specific behaviours. We have listed behaviours that are sometimes associated with elderly persons; they are arranged from physical to verbal and from benign to aggressive. We do not expect that all these behaviours will apply to your relative. Read each of the behaviours, and circle how often (from 1-7) each applied to your relative over the last 2 weeks:

FREQUENCY:

- 1- Never
- 2 Less than once a week
- 3 Once or twice a week
- 4 Several times a week
- 5 Once or twice a day
- 6 Several times a day
- 7 Several times an hour

1	General restlessness, fidgeting, always moving around	1 2 3 4 5 6 7
2	Performing repetitive mannerisms (tapping, rocking, rubbing)	1 2 3 4 5 6 7
3	Pacing, aimless wandering, constantly walking back and forth (including wandering while in a wheelchair)	1 2 3 4 5 6 7
4	Trying to get to a different place (sneaking out of room, out of house, off property)	1 2 3 4 5 6 7
5	Handling things inappropriately (rummaging through drawers, moving furniture)	1 2 3 4 5 6 7
6	Hiding or hoarding things	1 2 3 4 5 6 7
7	Grabbing things from others (food from other's plate)	1 2 3 4 5 6 7
8	Tearing things or destroying property	1 2 3 4 5 6 7
9	Inappropriate dressing or undressing (put on clothes in strange way or take off when in public)	1 2 3 4 5 6 7
10	Spitting, including at meals	1 2 3 4 5 6 7
11	Eating/drinking inappropriate substances	1 2 3 4 5 6 7
12	Grabbing onto people	1 2 3 4 5 6 7
13	Hitting (including self)	1 2 3 4 5 6 7
14	Kicking	1 2 3 4 5 6 7
15	Pushing, shoving	1 2 3 4 5 6 7
16	Throwing things, hurling, flinging	1 2 3 4 5 6 7

FREQUENCY:

1- Never

2 - Less than once a week

3 - Once or twice a week

4 - Several times a week

5 - Once or twice a day

6 - Several times a day
7 - Several times an hour

17	Biting people or things	1	2	3	4	5	6	7
18	Scratching people or self	1	2	3	4	5	6	7
19	Intentional falling (including from wheelchair or bed)	1	2	3	4	5	6	7
20	Hurting oneself (burns, cuts, etc)	1	2	3	4	5	6	7
21	Hurting others (burns, cuts, etc)	1	2	3	4	5	6	7
22	Making physical sexual advances, exposing self	1	2	3	4	5	6	7
23	Relevant verbal interruptions (i.e., cut short others who are speaking to relative; being rude - even if it does not seem to be intentioned)	1	2	3	4	5	6	7
24	Unrelated verbal interruptions (i.e., having nothing to do with ongoing conversation or activity)	1	2	3	4	5	6	7
25	Repetitive sentences or questions (do not include complaining)	1	2	3	4	5	6	7
26	Constant requests for attention or help (nagging, pleading, calling out)	1	2	3	4	5	6	7
27	Verbal bossiness or pushiness	1	2	3	4	5	6	7
28	Complaining, whining	1	2	3	4	5	6	7
29	Negativism, bad attitude, doesn't like anything, nothing is right (uncooperative, refusing)	1	2	3	4	5	6	7
30	Cursing or verbal aggression; threatening, insulting	1	2	3	4	5	6	7
31	Temper outburst (verbal or non-verbal expression of anger)	1	2	3	4	5	6	7
32	Strange noises (weird laughter, moaning, crying)	1	2	3	4	5	6	7
33	Screaming, shouting, howling	1	2	3	4	5	6	7
34	Making verbal sexual advances	1	2	3	4	5	6	7

Appendix E

The Geriatric Depression Scale

(GDS)

Sheikh, J. I. & Yesavage, J. A. (1986). Geriatric depression scale: recent evidence and development of a shorter version. In T. L. Brink (Ed.). <u>Clinical Gerontology: A Guide to Assessment and Intervention.</u> New York: The Haworth Press.

Number:

MOOD SCALE

Choose the best answer for how you have felt over the past week:

1. Are you basically satisfied with your life?	YES / NO
2. Have you dropped many of your activities and interests?	YES / NO
3. Do you feel that your life is empty?	YES / NO
4. Do you often get bored?	YES / NO
5. Are you in good spirits most of the time?	YES / NO
6. Are you afraid that something bad is going to happen to you'	YES / NO
7. Do you feel happy most of the time?	YES / NO
8. Do you often feel helpless?	YES / NO
9. Do you prefer to stay at home, rather than going out and doir	ng new things? YES / NO
10. Do you feel you have more problems with memory than mo	ost? YES / NO
11. Do you think it is wonderful to be alive now?	YES / NO
12. Do you feel pretty worthless the way you are now?	YES / NO
13. Do you feel full of energy?	YES / NO
14. Do you feel that your situation is hopeless?	YES / NO
15. Do you think that most people are better off than you are?	YES / NO