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**The role of social & psychological factors in
unawareness of current functioning in
dementia.**

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Abstract

A person-centred, social psychological model of dementia was used as a framework for considering the role of psychological and social factors in unawareness of current functioning in dementia. Historically, unawareness has been considered to arise from neuropsychological impairment. Neuropsychological theories, however, cannot account for all aspects of unawareness (e.g. the observed variability in awareness). The study's central aim was to investigate the role of psychological factors such as patients' pre-morbid personality and coping strategies and social factors such as style of communication with significant others in unawareness in dementia. The study also re-investigated the association between unawareness and increased carer burden.

A cross-sectional correlational design was used to study unawareness in a sample of 49 individuals with a 'non-frontal' dementia. All participants and their partners completed a number of standardised self-report questionnaires relating to patients' awareness of current functioning, pre-morbid personality, coping strategies, style of communication between patient and partner, and carer burden. The relationship between these variables and awareness was explored, while controlling for pre-morbid marital satisfaction, patients' and partners' level of depression and anxiety, and disease severity and duration.

Patients' awareness was significantly better for language function than for memory and general cognitive and executive function. Greater awareness was associated with self-reported depressive symptoms, and there was a non-significant trend for increased awareness to be associated with self-reported anxiety symptoms. Reduced awareness

was related to increased age of the patient, and there was a non-significant trend for unawareness to be associated with longer duration of disease. No significant relationship was found between unawareness and disease severity. It was suggested that this pattern of relationships is not wholly consistent with an exclusive neuropsychological model of unawareness in dementia, and the need to consider additional non-biological factors was highlighted. Pre-morbid personality factors, in particular negative attitudes towards emotional expression were related to patients' use of avoidant coping strategies in managing the experience of dementia. However, neither negative attitudes towards emotional expression nor avoidant behavioural coping related to unawareness. The study did detect an overall relationship between patients' pre-morbid conscientiousness and unawareness, but this was not significant in a regression analysis after disease-related variables and emotional factors were controlled for. The study's findings were interpreted with reference to the literature on denial and denial-like processes. It was suggested that a distinction should be made between the processes of conscious behavioural avoidance and unconscious defensive denial and that these two processes have different implications for the assessment of unawareness and for clinical practice. The study also replicated the finding that unawareness was related to higher carer burden, but this effect was not independent of spouses' depression and anxiety.

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1. Introduction

Damage to different areas of the brain can lead to cognitive and behavioural changes, of which individuals may sometimes seem unaware. This phenomenon was first documented by Babinski (1914), who coined the term 'anosognosia' to refer to hemiplegic patients who appeared unaware of paralysis on one side of their body following stroke. Since this description the phenomenon has been confirmed and described in a wide range of neurological syndromes and conditions (McGlynn & Schacter, 1989). A lack of awareness has also been reported as a clinical feature of dementia (DeBettignies et al., 1990; Wagner et al., 1997; Verhey et al., 1995).

This review will first consider general conceptualisations of awareness before turning attention specifically to unawareness in dementia and its associated factors. Unawareness is an abstract concept, which has been operationalised and measured in different ways, therefore it is important that a review of awareness in dementia considers methodological issues involved in its assessment.

In terms of theoretical conceptualisations of unawareness in dementia, the overriding school of thought has been that unawareness is a facet of neurological deterioration. Therefore, the contribution of neuropsychological models to understanding unawareness in dementia will be critically appraised. Neuropsychological theories cannot account for the variability in awareness (for example, some people become more aware over time). It seems that there are individual differences in awareness pointing to the role of other factors.

Social psychological approaches to dementia highlight the importance of considering dementia within a neurological, psychological and social context (e.g. Kitwood, 1997). Traditional neuropsychological models have provided a thorough examination of unawareness within a neurological framework but the role of psychological and social factors in unawareness has only been given a cursory mention in the literature. Therefore, this study will consider dementia and more specifically unawareness predominantly within a psychological and social context.

Psychological conceptualisations of dementia (e.g. Cheston & Bender, 1999; O'Connor, 1993; Solomon & Szwabro, 1992; Cohen et al., 1984) highlight the losses involved and the threat of future losses. Within this framework, lack of awareness in some individuals could be considered to reflect the use of defensive denial. Although there is a large body of literature on defensive denial and stress and coping, theoretical considerations and measures developed in these fields of research do not seem to have been applied to unawareness in dementia. Therefore, the theoretical underpinnings of denial, and research regarding coping and defensive processes in older adults and dementia, will be discussed. Empirical studies of the role of psychological factors, and specifically denial in unawareness in dementia, are scarce. Weinstein (1994) seems to be one of the very few who has studied this. He acknowledges the role of neuropsychological factors in unawareness in dementia as well as the role of defensive denial. On the basis of his research and clinical work with brain-injured patients, he has described the 'prototypical denial personality'. Consideration of this personality description within the area of

personality research suggests that Weinstein's description of someone who tends to deny their disability corresponds to the personality trait of conscientiousness and someone who is controlled and reserved with their feelings. Research on the stability of personality traits in old age and dementia, the measurement of personality in individuals with dementia, and the relationship of personality traits with coping will be discussed.

Dementia and lack of awareness will subsequently be considered within a social, interactional context. Indeed, it seems likely that low awareness may relate to psychosocial and relationship factors, such as how the dementia patient communicates and approaches problems with significant others.

Finally, unawareness will be considered from the perspective of the family caregiver. The concept of carer burden and its hypothesised relationship with unawareness will be discussed.

1.1. Awareness: manifestations and terms used

There is lack of clarity in the literature regarding awareness. Studies have operationalised this complex construct in different ways and have used a variety of terms to describe the phenomenon. Anosognosia has been defined as "lack of knowledge, awareness, or recognition of disease" (McGlynn & Schacter, 1989). However, this broad definition covers a range of levels of awareness. At one extreme an individual may verbally deny any difficulty. However, some individuals may acknowledge some difficulty but attribute it to something else or minimise the severity. Awareness may also be context-dependent, with

acknowledgment of difficulties in one context but not another. Alongside explicit verbal denial, there may be some implicit knowledge expressed behaviourally. Awareness may also be modality-specific with acknowledgement of some disabilities but denial of others. Finally, acknowledgement of difficulties may be accompanied by lack of emotional reaction or concern. Studies have operationalised and measured the construct in different ways. Consequently, it is not always clear what aspect of awareness is being assessed.

A number of terms have been used in the preceding paragraph to describe the phenomenon of unawareness: anosognosia, unawareness, denial. Indeed, the language used in the literature and the meaning attached to it varies. Marková, (1997) concludes that the language often depends on the 'object' of insight and the theoretical framework used. Anosognosia is often used to refer to lack of awareness of neurological deficits in the context of a neurological or neuropsychological model. In contrast, lack of insight is often used to refer to unawareness of patients with psychiatric disorders, within a psychiatric or psychodynamic model.

1.2. Unawareness in dementia

One disorder where unawareness has been described is dementia. Dementia involves a progressive, global deterioration in cognitive functioning, which may be accompanied by deterioration in emotional control, social behaviour or motivation. Specific subtypes of dementia include dementia of the Alzheimer type (DAT), vascular dementia or multi-infarct dementia (MID), Lewy-body dementia (LBD) and frontal lobe dementias.

Dementia of the Alzheimer type is probably the most common form of dementia. Episodic memory loss is usually the presenting symptom, however, cognitive deficits become widespread with most higher cortical functions affected within a few years (Rossor, 1993). In vascular dementia a series of infarcts occur, leading to a characteristic stepwise deteriorating course and a 'patchy' distribution of cognitive deficits (Corey-Bloom et al., 1995). More recently, Lewy-body dementia has been described as a specific subtype. Features include a fluctuating cognitive state, visual or auditory hallucinations and extrapyramidal symptoms (McKeith et al., 1996). Less commonly, dementia can be due to frontal lobe damage. Correspondingly, the early features in this type of dementia are those controlled by the frontal lobes (personality change, loss of social awareness, disinhibition, distractibility, impulsivity, stereotyped and perseverative behaviour, and mental rigidity and inflexibility; The Lund and Manchester Groups, 1994). Early loss of insight has been reported as characteristic of frontal dementias (Gustafson & Nilsson, 1982) however it has also been reported in Alzheimer's disease and multi-infarct dementia (DeBettignies et al., 1990; Wagner et al., 1997; Verhey et al., 1995). As Lewy-body dementia has only been considered as a distinct illness in the last few years, it is unsurprising that there is a scarcity of research considering unawareness in this condition.

The majority of studies have focused on unawareness of cognitive deficits (Reed et al., 1993; Michon et al., 1994). Although cognitive difficulties are the earliest and most widely recognised problems in dementia, there can also be behavioural changes, functional deficits and emotional disturbances. Therefore, in dementia there are a number of different, possible 'objects of insight'. It would seem important to consider awareness

separately for these different modalities, but studies looking at such dissociations in unawareness in dementia are relatively sparse. Vasterling (1995) reported less awareness for memory and self-care abilities and better awareness for depression and health status. Similarly, Kotler-Cope & Camp (1995) concluded that there was less awareness for cognitive problems relative to psychiatric and behavioural problems.

Therefore, in dementia there are a number of different, possible 'objects of insight'. It is also a field where there is a convergence of different professions who bring different theoretical frameworks to the study of unawareness. Marková's (1997) assertion that the conceptualisation and study of unawareness varies according to the 'object' of insight, the language used and the theoretical context is, therefore, particularly relevant to dementia. With this in mind the current study will use the term unawareness, as this seems to be the most atheoretical term.

1.3. Unawareness in dementia: associated factors

Studies have considered the association between unawareness and variables such as demographic factors, disease severity, and duration of disease, psychiatric variables, and neuropsychological and neuroanatomical correlates. However, studies have generally produced conflicting results regarding factors associated with unawareness in dementia.

1.3.1. Age of the individual

It might be hypothesised that awareness may be related to age. Younger people with dementia may be subject to different experiences compared to older people, which could

influence awareness. Younger people may be more likely to be at work, which may mean that they are confronted with more direct feedback regarding their level of functioning. In terms of society's attitudes, cognitive decline is to some extent expected in older people, whereas in younger people it is less expected and may therefore be more noticeable to others. Consequently, it is possible that in younger people there are more confrontative experiences and more opportunities for awareness. In addition, a family history is more common in younger-onset cases, which may mean that the person has more personal knowledge of dementia, which could influence their own responding. Empirically, there have been mixed results regarding the relationship between age and awareness. Lopez, (1994) found older people showed less awareness. However, several studies have found no correlation between age and awareness (Auchus, 1994; DeBettignies, 1990; Vasterling, 1995). In a similar vein, there have been mixed results regarding the relationship of unawareness to the age of onset of disease (Migliorelli et al., 1995; Sevush & Leve, 1993; Vasterling et al., 1995).

1.3.2. Pre-morbid level of functioning

It might be hypothesised that highly educated individuals are more likely to have occupied occupational positions requiring a high level of cognitive skill. It could also be hypothesised that such individuals may be more likely to engage in more intellectual recreational pursuits during retirement, and may also be in more demanding social situations. Both these scenarios might suggest that such individuals may have more experiences and opportunities to evaluate their cognitive functioning, and hence more opportunity to develop an awareness of their difficulties. However, empirical studies have

found no influence of educational level or pre-morbid IQ on awareness (Auchus, 1994; DeBettignies, 1990; Migliorelli et al., 1995).

1.3.3. Dementia severity and duration of disease

It has been widely hypothesised that as the dementia progresses, there is reduced awareness as part of the neurological deterioration. Whilst a number of studies have found a significant correlation between low awareness and increased dementia severity (Zanetti et al., 1994; Lopez, 1994; McDaniel, 1995; Migliorelli, 1995; Verhey et al., 1993; Sevush & Leve, 1993; Vasterling, 1995), other studies have found no relationship (DeBettignies et al., 1990; Reed et al., 1993; Auchus, 1994). However, when considering awareness at different severities and therefore at different stages of the disease, there is also the variable of time and duration of the disease. It could be hypothesised that there is initially less awareness as the person is coping to register their deficits, and that awareness increases over time as the person adjusts to and accepts their situation. In terms of longitudinal empirical studies, Vasterling (1997) found a decline in Alzheimer's disease patients' awareness over 12-20 months, which was not correlated with a decline in MMSE scores. McDaniel et al. (1995) found more variability in how awareness changed over time. Subjective clinical ratings of awareness indicated that after two years, 33% of Alzheimer's disease cases showed a decline in awareness, 57% showed no change and 10% showed more awareness. Weinstein (1994) also found individual differences in awareness over time. A follow-up study over three years found that 33 patients showed no change in their level of awareness, 5 patients became less aware, 2 became more aware and in 1 patient awareness seemed to fluctuate. On balance, the progressive nature of

dementia makes it difficult to separate the effect of disease severity and duration of disease, and it is currently difficult to draw conclusions as to how unawareness is related to dementia severity or duration of disease. Not only does there seem to be variability in the findings between different studies, there also appears to be variability in awareness between individual participants within studies.

1.3.4. Emotional factors

Depressive symptoms are relatively common in dementia, (Haupt et al., 1995). Depression in dementia could be viewed as a psychological reaction to the experienced cognitive loss. In this case, depression would be expected to be associated with increased awareness. It could be hypothesised that awareness is a vulnerability factor for depression, and that unawareness of cognitive difficulties is actually protective of depression. An alternative consideration should be the finding that depression is associated with increased self-report of memory difficulties in healthy people (O'Connor et al., 1990), as this suggests that depressed dementia patients may be hyperaware and over-report cognitive deficits. In this case, depressed dementia patients would appear to be more aware relative to non-depressed patients. Empirical studies have produced mixed results regarding the relationship between awareness and depression. Some studies support the co-occurrence of depression with increased awareness (O'Connor et al., 1990; Sevush & Leve, 1993), and Migliorelli et al. (1995) found awareness to be correlated with dysthymia but not clinical depression. However, other studies have found no significant association (Verhey et al., 1993; Reed et al., 1993; DeBettignies et al., 1990). These contradictory results may be partly due to differences in the assessment of depression.

Some studies have assessed for symptoms, some have applied diagnostic criteria to diagnostic interviews whilst others have used clinical ratings or self-report questionnaires. Migliorelli (1995) also found low awareness was associated with lower levels of anxiety, and Verhey et al. (1993) found that a score from an item of 'psychic anxiety' showed a weak but significant correlation with level of awareness. In a similar vein to depression, it is possible that unawareness protects against anxiety.

1.3.5. Neuropsychological and neuroanatomical variables

- A number of studies have considered the relationship between awareness and memory. It could be hypothesised that memory problems are a contributing factor to low awareness. However, there have been mixed results, with some studies finding evidence of a relationship (Feher, 1991), and some finding a significant association on some types of memory tests but not others (Reed, 1993; Migliorelli et al., 1995), whilst other studies have found no significant association (Michon, 1994; Auchus, 1994).
- Awareness is assessed by a patient's verbal report of their difficulties, therefore it could be hypothesised that language difficulties are linked to unawareness. Sevush & Leve (1993) found that low awareness in Alzheimer's disease was linked with a test of object naming.
- The link between unawareness and clinical symptoms associated with frontal lobe pathology has been documented (Weinstein et al., 1994; Migliorelli et al., 1995). The relatively few imaging studies which have been completed also highlight the involvement of the frontal lobes in unawareness (Reed et al., 1993; Starkstein et al.,

1995; Ott et al., 1996). However in terms of neuropsychological tests thought to involve frontal lobe functioning, results have again been mixed (Michon et al., 1994; Starkstein et al., 1995; Lopez, 1994; Migliorelli et al., 1995).

1.3.6. Carer burden

It might be hypothesised that unawareness in people with dementia also impacts on caregivers. Individuals who are less aware of their difficulties may become involved in activities (for example, physical or financial), which may involve a higher level of risk given their level of cognitive impairment. People with dementia who are less aware of their condition may also be less accepting of support. Both these scenarios might lead to an increase in the level of stress experienced by a carer. Empirical studies have found evidence for a link between patients' unawareness of difficulties and reported carer burden (DeBettignies et al., 1990; Seltzer et al., 1997). The results of these studies are significant as they suggest that unawareness has clinical implications for carers as well as for patients. This important relationship of patient unawareness with carer burden will be considered more fully later on.

1.4. Methodological approaches to studying awareness

On balance, studies looking at the prevalence and correlates of unawareness in dementia have produced mixed results. Such discrepancies may in part be due to methodological variation between studies. Sample sizes have varied considerably (some studies have used very small samples), studies have used a range of dementia severities (this is not always systematically assessed), and the 'object of insight' also varies between studies. In

addition, studies do not usually elaborate on the context of the assessment of unawareness. However, the nature of the relationship between the patient and the assessor may affect the outcome. For example, there may be a motivation for the patient to present himself or herself in a certain way depending on the context of the assessment. Finally, an important source of variability is the way unawareness is operationalised and measured.

Several studies have assessed unawareness using subjective clinical ratings made on the basis of an interview with the patient (e.g. Verhey et al., 1993; Sevush & Leve, 1993; Weinstein, 1994; Reed, 1993). However, this approach is limited in how much it can differentiate levels of awareness/unawareness. The objectivity of such an approach is also questionable. Although, Zanetti et al. (1999) showed that two different interview-based rating scales of awareness had a good interrater intra-class correlation and good test-retest reliability, the majority of studies do not present data regarding the validity and reliability of this approach.

A number of studies have operationalised unawareness as the discrepancy between self-report of cognitive functioning and performance on objective test measures. For example, Anderson (1989), DallaBarba (1995) and Wagner et al. (1997) compared patients' self-ratings of their cognitive and everyday functioning with performance on specific cognitive tests. Although this approach involves a more objective, quantitative methodology than clinician ratings, it seems questionable to define awareness as the discrepancy between two

such different kinds of measures. Indeed it seems unclear how equivalent self-report estimates of everyday cognitive functioning are to performance on specific cognitive tests.

Another approach has been to operationalise unawareness as the discrepancy between patients' self-report of difficulties compared to informants' report of patients' difficulties (e.g. DeBettignies et al., 1990; Feher et al., 1991; Migliorelli et al., 1995). A number of studies have used standardised questionnaires to compare patients' self-report and informants' report (Migliorelli et al., 1995; Feher et al., 1991; Marková, 1997). There are, however, potential problems in defining unawareness in this way. There may be a discrepancy in ratings not only because patients underestimate difficulties but also because carers may overestimate (or indeed underestimate) difficulties. Carers' responses may be influenced by the nature of the patient-carer relationship, their personality, or the degree of carer burden experienced. Indeed, Jorm (1996) noted that informants' responses on questionnaires regarding patients' cognitive deficits were affected by their own emotional states and by the quality of the relationship with the patient. Despite these potential problems, there is substantial support for the validity of such an approach. A number of studies have shown that caregiver questionnaire ratings correlated with objective measures of patients' cognitive functioning (e.g. Feher et al., 1991; Koss et al., 1993). In addition, Jorm's (1997) meta-analysis concluded that informant questionnaires were as effective as brief cognitive tests at screening for dementia. Generally, caregivers have been shown to be accurate in estimating their relatives' disability. On balance, this approach is currently the most widely accepted method of evaluating awareness.

1.5. Neuropsychological models of unawareness in dementia

Over the years there have been various attempts to consider the theoretical underpinnings of awareness, and a number of models have been suggested using a neuropsychological conceptual framework. Some of the more detailed, well-thought out theories include Stuss & Benson's (1986, 1991) model, Schacter's (1989) DICE model, and Agnew and Morris's (1998) developed version of the DICE model.

1.5.1. Stuss & Benson (1986, 1991) advocate an integrated, hierarchical organisation of brain function in which self-awareness is viewed as the 'highest' of brain activities located in the frontal lobes. It is thought that a disturbance in awareness can arise from damage to different levels in the system. Impairment may occur at a lower level interrupting output from a specific psychological module (such as language, memory or motor function) to the higher level of self-awareness leading to a disturbance in awareness for a specific psychological function. Damage to the prefrontal cortex is thought to lead to a disturbance in awareness at a higher level of the system. It is suggested that this type of impairment leads to a disorder of self-awareness, which manifests as deficient monitoring and impaired self-regulation of behaviour.

1.5.2. Schacter's (1989) DICE model (dissociable interactions and conscious experience) also has a hierarchical framework. It is one of the more detailed models which has been used as a framework to consider unawareness in dementia. A central monitoring system is proposed (a 'conscious awareness system', CAS), which is thought to be located in the parietal lobes, and which receives input from different modules for specific psychological

processes. It is suggested that the CAS has an output connection to an executive system located in the frontal lobes. Modality-specific unawareness would result from selective disconnection of the CAS from specific input modules, whereas damage to the CAS itself would result in a more global unawareness for all neuropsychological deficits. Damage at the higher-level executive system would lead to disturbed awareness of more complex systems requiring executive processes. Impairment at this level is thought to lead to unawareness for more complex changes in functioning such as personality or behavioural change. This model does account for some of the ways that unawareness is manifested in dementia, for example the modality-specificity sometimes seen, as well as unawareness for more complex changes such as personality and behavioural changes. However, it does not consider the role of memory impairment in unawareness.

1.5.3. Agnew and Morris (1998) have proposed an elaborated, developed version of the DICE model, which also considers the role of metacognition in self-awareness. Three different forms of unawareness are described. A 'primary anosognosia' is thought to result from damage to the CAS, giving rise to unawareness for all neuropsychological deficits and therefore for the dementia as a whole. A 'mnemonic anosognosia' is described as resulting from the memory impairment and a failure to update semantic memory, and individuals believing that they are functioning as they have always done. In contrast, 'executive anosognosia' is thought to result from damage to part of the central executive system, and therefore some accompanying executive problems might be expected as well as possibly a 'frontal' clinical presentation.

In short, there have been a number of well thought out models proposed, some of which view unawareness as part of a specific deficit in self-awareness (Stuss & Benson, 1986, 1991; Schacter, 1989), and others which also consider the role of generalised metacognitive deficits (Agnew and Morris, 1998). However, these neuropsychological models all fail to consider the role of psychosocial variables. Agnew and Morris (1998) consider the research on the role of pre-morbid characteristics in unawareness in dementia but subsequently fail to incorporate it in their model.

Although neuropsychological models (such as those described above) have made a valuable contribution to our understanding of unawareness in dementia, they cannot account for all manifestations of unawareness. Research reviewed previously has shown that there is considerable variability in unawareness. This variability in awareness between individuals cannot be explained by neuropsychological variables; Clare (2000) has found that level of awareness cannot be predicted by neuropsychological performance. In addition, neuropsychological theories cannot account for changes in awareness sometimes observed over time. Neuropsychological models would predict that unawareness increases over time as the dementia progresses and brain damage becomes more widespread. However, contrary to this prediction it has been found that some individuals actually become more aware over time (McDaniel et al., 1995; Weinstein, 1994). Clinical observation of people with dementia suggests that on a shorter time-scale, apparent expressed awareness can fluctuate from day to day and even from the beginning to the end of a conversation. This type of variability would also seem problematic for an organic model.

Research has shown that expression of awareness in dementia is often dependent on context (Weinstein, 1994). However, neuropsychological models do not consider this, which seems surprising as individuals do not exist in isolation. We are all part of complex systems and subject to external influences, which affect our thoughts and feelings. Such social factors would seem particularly relevant to people with dementia, who are struggling to make sense of their world despite a loss of cognitive functioning. It seems likely that the way someone communicates and interacts with others will affect their level of awareness of functioning.

As well as social factors, it also seems vital to consider the role of psychological factors in awareness in dementia. An individual's personality and the way they have coped with difficulties or changes in the past is undoubtedly going to affect how they respond to the onset of dementia. For example, if a person has tended to cope with difficulties by using avoidant coping strategies or defensive denial then they may be more likely to use such strategies to cope with the onset of dementia and may consequently appear less aware of their current difficulties.

Historically, social and psychological aspects of dementia have been broadly recognised. Sixty years ago, Rothschild (1937) pointed out that neuropathological changes in the brain do not always map on to clinical, functional presentation and that person-centred factors need to be considered. He wrote:

“extensive [pathological] changes are unquestionably present in cases of senile psychosis and are an essential part of the picture. But they are occurring in a living organism and it is necessary to ask, what is the person doing about them? senile patients should be studied, not merely as anatomic specimens, but as living persons who are growing old and who are struggling to adjust to personal problems”. (p.780, 1937)

However, despite such references to psychosocial factors in the presentation of dementia, there have been (until relatively recently) few attempts to incorporate them into a theoretical framework. Dementia has until recently been conceptualised within an organic, medical model, and an individual’s clinical presentation has been viewed essentially in terms of neurological deterioration. Therefore, given this historical context it is not surprising that theories of unawareness in dementia have also emphasised cognitive and biological factors. However, in the last ten years the limitations of a pure organic conceptualisation of dementia have been increasingly recognised.

1.6. Social psychological approaches to dementia

1.6.1. Kitwood’s dialectical framework for dementia

One of the fiercest critics of a purely organic model of dementia has been Kitwood (e.g. 1997, 1996). He refers to the organic model as the ‘standard paradigm’ and argues that it conceptually ignores the question of how the mind and brain relate. He highlights a number of empirical challenges for the ‘standard paradigm’. Firstly, there is sometimes a weak correlation between measures of dementia and the extent of neuropathology.

Secondly, he emphasises that in some individuals, level of functioning deteriorates faster than can be attributed to the consequence of progressive neurological deterioration. Indeed, Kitwood has been one of the strongest proponents of a growing move to consider psychological and social aspects of dementia.

Kitwood (1996, 1997) emphasises the close, relationship between psychological and neurological aspects of the mind. He asserts that any ‘event’ or ‘state’ that is experienced psychologically (ψ) is also a ‘brain state’ or ‘event’ (b).

This is represented as: $\psi \equiv b$

He describes such ‘brain events’ as occurring within an ‘apparatus’, whose architectural structure provides certain parameters regarding brain functioning. The developmental aspects of brain structure, and the influence of learning and experience on brain development, are highlighted (B^d). Secondly, in dementia there is usually loss of neurones and synaptic connections, and such pathology is represented as B_p .

Kitwood describes the relationship between these factors as:

$$\underline{\psi \equiv b}$$

$$B^d, B_p$$

“Any psychological event or state is also a brain event or state, ‘carried’ by a brain whose structure has been determined by both developmental and pathological factors.” (p. 18, 1997)

Dementia is conceptualised as a continuing, dialectical interplay between social, psychological and neuropathological factors. As an individual moves from one state to another there may be varying contributions made in any of these components.

If this theoretical framework is applied to the phenomenon of unawareness in dementia, it would suggest that unawareness is delineated to a certain extent by brain pathology (as described by neuropsychological models). However, at different points in time unawareness may reflect the varying contributions of social, psychological and neurological factors. This person-centred approach, therefore, emphasises that unawareness in dementia needs to be considered within neurological, psychological and social contexts. Unawareness will first be considered within a personal, psychological framework, after which it will be thought of within a social context.

1.7. Dementia and unawareness within a personal, psychological context

A person-centred approach reframes dementia as a personal experience. Cheston & Bender (1999) describe dementia as a terrifying ordeal, which generates an emotional reaction and sense of insecurity. However, the neurological degeneration itself is going to affect an individual’s ability to defend against the trauma and anxiety caused by the deterioration. Within this framework, unawareness in dementia could be viewed as the

defence mechanism of denial, which would protect against information too traumatic to be consciously assimilated. Denial would protect the self from being overwhelmed by anxiety and unbearable emotions regarding losses and the threat of future losses. O'Connor (1993) considers this process within a psychodynamic framework, and suggests that in the earlier stages individuals may use defence mechanisms to protect the self from acknowledging the losses.

Models of bereavement have also been drawn on to understand the personal, subjective process of dementia. Cheston & Bender (1999) highlight Cohen's (1984) and Solomon & Szwabro's (1992) stage models, which consider the grief process involved in dementia. Cohen et al. (1984) describe people with dementia as going through a series of stages: pre-diagnosis there may be recognition and concern, whilst following diagnosis there may initially be denial, followed by reactions of anger, guilt and sadness before coping and maturation and finally separation from self. Cohen et al. suggest that progression through these psychological changes depends on factors such as personality and social influences. Therefore, according to this model lack of awareness could be thought of as an individual who is 'stuck' in the denial stages following diagnosis, with personality and social influences playing a role.

Solomon & Szwabro (1992) describe a similar model of grief for people with dementia using a psychodynamic framework. Dementia is thought to trigger a grieving process whereby the person moves through a number of stages including denial, disorganisation and reorganisation, but limited cognitive functioning may mean that some people are not

able to progress through to the final stages, and indeed some individuals may get stuck in the stage of denial.

Stage models have received criticism for being too rigid and mechanistic. Not all individuals will pass through the listed stages in such a neat sequential order. It seems more likely that individuals move in and out of these different psychological modes in a more interactive way, with some modes of operation being more prominent in some individuals. However, at a broad conceptual level these models do provide good insights into some of the processes that may be experienced by individuals facing dementia, and the possible role of denial in this process.

In summary, historical over-reliance on organic models of dementia has led to the behaviour of people with dementia being explained by neurological damage without reference to its context and without consideration of non-biological explanations. However, the preceding psychological conceptualisations of dementia point to the need to take psychological variables into account when considering unawareness. At the heart of dementia is loss and threat of future losses, and within this context it seems possible that some lack of awareness could be conceptualised as a defence mechanism (denial) or as a coping strategy (possibly more akin to avoidance). Denial would serve the function of preservation of self and sense of identity in the face of extreme stress and threat. It would also defend against intolerable feelings otherwise manifested such as depression. Lazarus (1983) argues that processes of coping and defence mechanisms are not fixed entities but instead functional and changeable depending on variables within and outside of the person.

Therefore, within this framework it would be expected that denial would appear in some social contexts and at some times but not others, and it may also concern some aspects of cognitive function but not others. In short, it seems likely that neurological factors and psychological factors are involved in lack of awareness in dementia and that the proportions of these factors will vary between individuals. Given the hypothesised role of denial in unawareness in dementia, it would be useful to consider its conceptual and theoretical underpinnings.

1.7.1. Denial: conceptual and theoretical underpinnings

Denial is an abstract, complex concept, which has acquired different meanings depending on the theoretical context. The concept of denial will first be considered within a psychoanalytical framework in which it has its theoretical roots, after which it will be considered within the context of the relatively more recent literature on stress and coping. Different manifestations and categories of denial will also be discussed. The chapter will then review research regarding coping and defensive processes in older adults and people with dementia.

1.7.1.1. Denial and psychodynamic theory

The concept of defence mechanisms originated with Sigmund Freud (e.g. 1923). Defence mechanisms are defined as mental processes operating outside conscious awareness, which reduce painful emotions such as anxiety, depression or loss of self-esteem. In particular, denial refers to defence against painful aspects of external reality. Traditionally psychoanalysts considered denial to be a primitive defence as it was viewed as relatively

crude and simplistic. Anna Freud (1936) also considered it to be a 'pre-stage defence' as it occurs early in development. Salander & Windahl (1999) highlight that Freud actually discussed two different defence mechanisms in relation to external reality: the more commonly mentioned denial, which relates to the repudiation of reality, and disavowal, where the perceptual image is registered and acknowledged but where its significance or affective meaning is disregarded through distortion, rationalisation or misinterpretation.

1.7.1.2. Denial and stress and coping research

In the 1960s a new line of research labelled as 'coping' grew out of the traditional psychoanalytical approach to defence mechanisms. Some authors started to label certain more mature, reality oriented, 'adaptive' defences (such as humour and sublimation) as coping (e.g. Haan, 1965). Later coping research became more distinct from the older psychoanalytic literature on defence mechanisms as more emphasis was placed on active, conscious efforts at managing stressful situations. Lazarus & Folkman's (e.g. 1984) stress coping model is the most widely used in the field of stress and coping with illness. They define coping as:

"constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person". (p. 141, 1984)

Two stages of cognitive appraisal are thought to take place when confronted with a stressor. Initially there is primary appraisal, which involves evaluation of the threat or danger to self posed by the stressor. This is followed by secondary appraisal where a

person evaluates what can be done to overcome or to manage the threat or loss. In the case of illness, individuals need to manage external demands relating to the disease itself, with internal demands related to emotional reactions to the illness (Maes et al., 1988). Coping is viewed as a dynamic process, which varies with time, across contexts, and from person to person. A process conceptualisation of coping seems particularly relevant to dementia, as the stress involved is of a relatively long duration, and its nature changes over time as the disease progresses. Therefore, it would seem helpful to consider variables such as duration of disease or time since diagnosis when considering how people with dementia cope.

Lazarus & Folkman (e.g. 1984) make a distinction between problem-focused coping (efforts to alter the situation) and emotion-focused coping (efforts to regulate emotional distress). When appraisal indicates that little can be done to alter the situation (as is sometimes the case with illness) there is a tendency towards emotion-focused coping. Denial or escape-avoidance is clearly an emotion-focused form of coping. It has been found to form an important part of coping with chronic illnesses such as cancer (Salander & Windahl, 1999) and heart disease (Croog et al., 1971). Therefore, it also seems likely that denial will form an important part of coping with dementia for some individuals.

With regard to terminology, there is often an interchange of terms, with 'denial' being used to refer to the traditional psychoanalytic defence mechanism as well as a range of coping strategies, such as behavioural avoidance. Lazarus (1983) poses the question of whether it is useful to distinguish between different forms of denial as well as related

processes such as avoidance, or whether the term denial should be used to consider a more generalised process and a range of specific patterns.

1.7.1.3. Forms of denial: categories & frameworks

A number of attempts have been made to impose some form of categorisation on different forms of denial and denial-like processes in the literature.

Breznitz (1983) proposes a model which considers a framework of various kinds of denial. He describes seven kinds of denial each related to a different stage in the processing of threatening information, with each level of denial representing a more extreme attempt to protect the self from threat. He distinguishes denial of personal relevance, denial of urgency, denial of vulnerability or responsibility, denial of affect, denial of the relevance of affect, and at a more extreme level, denial of threatening information and finally denial of information in its totality (as in the case of psychotic withdrawal).

Salander & Windahl (1999) draw on their clinical experiences in oncology to categorise denial-like processes into avoidance, disavowal and denial. Avoidance refers to the conscious behavioural act of avoiding information. Disavowal is thought to be a preconscious process, which involves distortion of meaning. This process could be considered to occur at a more cognitive level as an individual is aware of their threatening situation, in that they perceive it correctly but the personal meaning of the threat is elaborated or dissociated from its personal impact. Denial is conceptualised in the

traditional psychoanalytic sense as an unconscious defensive act in the perceptual process that leaves the basics of the threat outside the individual.

In summary, these models suggest that denial-like processes can occur at a perceptual, cognitive or behavioural level. In terms of measurement, denial at a perceptual level would probably be virtually impossible to measure through self-report, and instead it would probably have to be detected through observation or implicit tasks. However, in the case of dementia the outcome of defensive denial at a perceptual level could be measured through self-report by assessing awareness of functioning. Measurement at the behavioural level of avoidance seems more straightforward as this is more conscious and deliberate.

1.7.1.4. Changes in defensive and coping processes in older adults

A study of the role of denial in unawareness in dementia is going to be predominantly assessing coping and defensive processes in older people. It has been assumed that coping changes over the course of life. Vaillant (1977) suggested that healthy older people make greater use of effective, realistic coping mechanisms and decreased use of 'immature' mechanisms such as projection, denial and repression. Empirically, however, coping *per se* has not been found to change with age. Folkman & Lazarus (1980) and McCrae (1982) found no clear differences in coping patterns in older people. However, Folkman & Lazarus's (1980) sample only went up to the age of sixty-four years, and McCrae's (1982) sample was characterised by relatively affluent older adults with good mental and physical health. It is possible that although coping *per se* does not change with age, the

stresses that people face change. Older adults may be more likely to face psychological, social and material losses, and these new stresses may affect coping strategies used. Indeed, dementia seems particularly relevant to this point.

1.7.1.5. Defensive and coping processes in dementia

When models of coping are applied to dementia, it needs to be remembered that people with dementia have to cope in the context of reduced cognitive resources. As cognitive difficulties progress there may also be a reduction in the coping strategies available to the individual. Kitwood (1997) suggests that individuals use whatever resources are still available to cope with the process of dementia, but that cognitive deterioration may mean that more sophisticated coping actions are no longer a possibility, and that instead individuals may resort to more basic strategies learnt in childhood. As has been previously discussed, denial has been considered to be a relatively primitive, crude defence, and so within this context it might be hypothesised that denial is increasingly used as there is increasing cognitive deterioration and more habitual defence mechanisms are no longer available. In contrast to this hypothesis, Chester & Bender (1999) suggest that people initially respond using escape-avoidance coping strategies, but that as the threat becomes more evident it gradually becomes incorporated into the person's sense of self. Although there is considerable research on how families cope with caring for someone with dementia, there are relatively few empirical studies considering how patients cope with the experience of dementia. Keady et al.'s (1995) qualitative study interviewed six individuals in the early stages of dementia and their family supporters. They concluded that in the early stages there is often fear associated with a feeling of not knowing and of being out of

control, and that individuals often cope by concealing difficulties. If conceptualised within Lazarus's model (e.g. Lazarus & Folkman, 1984) this may be viewed as avoidant coping. In the later stages, the authors conclude that although there is anger and fear, the dominant coping response is acceptance and 'making the best of a bad job'. It seems that there is a need to make the most of available time and to preserve intact functions. Bahro et al. (1995) described their clinical experience with patients with mild-moderate Alzheimer's disease and concluded that a number of patients coped with their illness using some form of denial (avoiding naming the illness, not seeking information out, dissociation of affect, vagueness in discussing their condition, minimising the severity of their disabilities). Other coping strategies highlighted were somatisation (shifting attention to other physical symptoms) and self-blame.

1.7.2. Empirical studies relating to the role of psychological factors in unawareness in dementia

Although literature in the field of dementia makes reference to the role of defensive denial in unawareness, there have been relatively few empirical studies of this.

Weinstein (e.g. 1955, 1994, 1996) is one of the few who has considered denial in his theoretical and clinical writings on disorders of self-awareness. He acknowledges the role of neuropsychological factors in unawareness but also argues for the role of defensive denial. Weinstein & Kahn (1955) initially investigated the role of pre-morbid personality factors in unawareness in patients with brain tumours, head injuries, strokes, and ruptured aneurysms. This study involved clinical descriptions of various manifestations of

unawareness or denial. Informants gave an account of patients' pre-morbid personality in terms of attitudes, character, reactions to stress, and interpersonal communication patterns prior to illness. Weinstein concluded that differences in expressions of awareness relate to the way in which a person adapts to and represents their disability following brain damage, and that this is determined by the neuropathology involved, the meaning of the disability as determined by pre-morbid personality and the context in which behaviour is elicited. He describes the 'prototypical denial personality' as follows, suggesting that people showing this pattern:

“tended to deny and ignore illness, regarding it as a sign of weakness or failure involving a loss of personal integrity and status ... highly work-oriented, conscientious, efficient and organised with emphasis on willpower, self-sufficiency, self-improvement and achievement. Relatives described them as stubborn, dogmatic, unwilling to admit mistakes and as controlled and reserved rather than open with their feelings”. (p. 178, 1994)

These pre-morbid personality factors were also found to be important in determining awareness of impairments in Alzheimer's disease (Weinstein, 1994). However, Weinstein concluded that the effect of pre-morbid personality was important in predicting lack of awareness when initial presentation indicated parietal or frontal involvement but not when it indicated posterior brain involvement. This is possibly an artefact of the study's small sample size as the project only used a small sample of 41, and only 7 of these cases started with a presentation indicating posterior brain damage. Other criticisms of the study

involve the method of assessing awareness, which was via clinical ratings, which has questionable validity and reliability. In addition, pre-morbid personality was only assessed by interviewing relatives. Relying on relatives' views without corroboration from the patient means that the relatives' personal feelings about the patient and his illness may have affected the results.

Jacque and Jackson's (2000) clinical observations of how different personality types react to dementia provide some insight as to why an individual with a rather 'obsessional' personality (as described by Weinstein) might cope through defensive denial. They suggest that such an individual would find the experience of dementia particularly distressing as they would be faced with a loss of control and a disintegration of order. It might be expected that in such cases there is a particular need for denial to protect the self from disintegration and chaos.

Cottrell & Lein's (1993) small qualitative study also looked at the role of pre-morbid personality and coping strategies in awareness and denial in Alzheimer's disease. The results indicated that the majority of people reacted to their illness in a way that was consistent with pre-illness characteristics. Those who had coped with earlier difficulties by blocking out reality also expressed denial of Alzheimer's disease. The conclusions of the study can only be tentative as it included only a very small sample of five, and also only interviewed informants.

Clare's (2000) qualitative study considers the different ways in which individuals with early Alzheimer's disease react to and manage the losses and threats to their sense of self. She describes a process of registering problems followed by reacting, explaining, experiencing and adjusting. This is conceptualised as an interactive cycle of developing awareness. Clare emphasises the interpersonal negotiation which contributes to the 'growing realisation' of problems, and how pre-existing ways of coping also affect the way a person with dementia thinks about the changes, and how s/he deals with the potential threats involved. Differences in the way that individuals experience the emotional impact of dementia is seen to be influenced by preferred ways of dealing with emotions, attitudes and beliefs regarding illness and responses of others. If people tend to minimise, normalise or cover up the experience, this seems to be consistent with previous traits. She suggests that this way of responding to the threat of dementia could reflect a 'preference for covering up, preventing limitations being exposed and avoiding loss of face'. However, it seemed in many cases that this unawareness represented a strongly motivated defensive response, which covered up deep fears of the future.

Empirically, it seems that pre-morbid personality, ways of dealing with emotions and ways of coping all contribute to unawareness in dementia. This chapter has already reviewed literature regarding defence mechanisms and models of coping in the context of denial. However, the preceding empirical studies also indicate that it is important to consider personality when considering an individual's response to the threat of dementia.

1.7.3. Personality

In the 1960s the predominant approach to studying personality was trait theory. Personality traits are considered to be the more stable, enduring aspects of personality, which lead to characteristic patterns of behaviour. Hampson (1999) emphasises that despite Mischel's (1968) critique of traits, which argues that people do not behave consistently regardless of the situation, trait approaches remain popular and influential in the field of personality. Different numbers of traits have been proposed, but there seems to be emerging consensus for a five-factor model known as the 'Big Five' (e.g. Hampson, 1999; McCrae & Costa, 1997). These five factors are: Neuroticism (N), Extraversion (E), Openness (O), Agreeableness (A) and Conscientiousness (C). The conscientiousness trait seems to map most closely on to Weinstein's description of the prototypical denial personality. Pervin & John (1997) describe individuals who score highly on the conscientiousness scale as tending to:

“lead very well-ordered lives, striving to meet their goals in a planned and deliberate manner. They are neat, punctual, well organised and can be counted on to carry through on commitments they make. They take moral, civic and personal obligations quite seriously and put business before pleasure. They have good self-discipline and have developed a number of competencies. [Significant others] describe them as careful, reliable, hard-working and persevering.” (p. 275, 1997)

Although this captures most of Weinstein's description, it does not capture his reference to someone who is controlled and reserved with their feelings. Joseph et al.'s (1994) work on 'attitudes towards emotional expression' following exposure to a stressful life-

event seems relevant to this. They highlight that negative attitudes towards emotional expression may block processing of emotionally charged information following exposure to a traumatic event. The authors have developed a measure of attitudes towards emotional expression, which would seem relevant to Weinstein's description.

It has been claimed that personality (as defined by trait scores) remains relatively stable in adulthood and does not seem to change much when someone is over the age of thirty years (McCrae & Costa, 1990). However, there seems to be less research specifically considering whether such stability continues into old age. Indeed, very few longitudinal studies appear to have been completed. In terms of cross-sectional studies, Goldberg et al. (1998) and Costa and McCrae's (1994) review suggests that older adults rate themselves as slightly higher on the trait of conscientiousness compared to younger adults. However, it is difficult to disentangle the role of sampling biases and cohort effects in interpreting the results of cross-sectional studies. Overall, however it is most likely that a personality rating which describes how an individual has been over the course of their life will influence how s/he responds to the threat of dementia. As well as ageing, it is also important to consider the relationship between dementia and personality, as this may affect how personality is assessed in people with dementia.

1.7.3.1. Personality and dementia

Historically, it has been suggested that personality differences, in particular 'rigid and static habits', may be a contributory factor to the development of dementia (Noyes & Kolb, 1958, cited in Oakley, 1965; Oakley, 1965). More recently, Meins & Dammas

(2000) found that patients with Alzheimer's disease were rated by relatives as being relatively high in pre-morbid neuroticism and rigidity compared to controls. Although informants indicated that these traits were present before the onset of the disease, it is unclear whether these obsessional features constitute risk factors for Alzheimer's disease or a pre-clinical sign. Alternatively, the results could also reflect a selection bias. If obsessional features are a pre-morbid risk factor, then a study looking at the contribution of pre-morbid conscientiousness to use of denial and unawareness of deficits might find that as a group, dementia patients score higher on this factor compared to healthy controls. However, it should still be possible to investigate whether relatively higher scores are associated with less awareness.

What does seem to be clearer is the finding that there is personality change as a concomitant of dementia. Studies investigating personality change in dementia have found a decrease in openness and conscientiousness and an increase in neuroticism on the NEO-Personality Inventory (Siegler et al., 1991), and a reduction on the extraversion and rigidity scales of the Munich Personality Test (Michalski, 1991, cited in Romero, 1997). These personality changes can be thought of as secondary to the cognitive changes experienced. Indeed Kitwood (1997) argues that many of the changes observed are due to a loss of resources and a breakdown in psychological defences. He suggests that there is a general continuity of personality during the course of dementia with some characteristics that were always present becoming more exaggerated. However, frontal lobe dementia is an important exception to this, as there is often significant change in personality and little insight into difficulties (The Lund and Manchester Groups, 1994).

The frontal lobe damage means that the lack of awareness in this dementia subtype is more likely to be due to neurological factors rather than psychological factors. Therefore, it is important that a study looking at the psychological factors contributing to unawareness in dementia excludes people with a diagnosis of frontal lobe dementia or looks at them as a separate group because their frontal lobe damage is likely to mean that neurological factors are playing a more significant role in awareness compared to people with a non-frontal dementia. The finding that there is exaggeration or reduction in certain personality features in non-frontal dementia indicates that a study should consider the role of pre-morbid personality rather than current personality in unawareness, as pre-morbid personality is more likely to shape an individual's response to the illness.

1.7.3.2. Measurement of personality in dementia

Most studies of patients' personality in dementia have used informant ratings as it seems to be generally assumed that self-report has some limitations regarding validity. Measures of personality such as the NEO-Personality Inventory (Costa & McCrae, 1992) have been standardised for self-report and informant-report, and reliability studies demonstrate substantial agreement of self-ratings with peers and spouses on all five factors (McCrae & Costa, 1990). Strauss et al. (1993) specifically consider the validity of using relatives' ratings of personality in dementia by examining the agreement between a first and second informant. The interrater intraclass correlation was less for conscientiousness compared to other traits. The authors speculate that this is because conscientiousness is particularly context-dependent, and the second informant (usually a friend of the patient) may have a different observational context compared to the spouse.

Overall, the validity of relatives' ratings of personality is generally accepted in studies of dementia. However, Strauss et al.'s (1993) study does indicate that there may be some potential limitations in this approach regarding the trait of conscientiousness. Therefore, it would seem particularly important to use spouse ratings of personality in a study investigating the role of pre-morbid conscientiousness in use of defensive denial and unawareness in dementia. However, if a patient has sufficient language skills there seems no reason why they should not also give a self-rating of pre-morbid personality to enable triangulation of data sources and to increase the validity of the data. Episodic memory for events in the distant past tends to be better than for memory for more recent events, and therefore it seems likely that people with dementia will be able to describe their pre-morbid personality as traits which have been relatively constant over the past thirty or forty years as opposed to current personality which possibly involves registering more recent changes.

1.7.4. The relationship of personality with coping

A person-centred approach to dementia highlights that an individual's personality will influence how a person copes with the threat of dementia. Kitwood (1997) takes an ethogenic approach viewing personality as resources for action. Implicit to this view is the notion that personality is inextricably linked with ways of coping. In addition, Weinstein's (1994) empirical study of awareness in Alzheimer's disease indicates that pre-morbid personality relates to how an individual responds to dementia. Therefore, it seems

reasonable to hypothesise that there is a relationship between personality traits and ways of coping with the onset of dementia.

Historically, the field of coping research has suggested that little of the cross-sectional consistency in coping is attributable to person variables (Folkman & Lazarus, 1980). Coping was seen as a transactional process which depended on the nature of the stressor. However, Parker & Endler (1996) point out that early coping research tended to involve highly stressful situations, and that extreme, possibly life-threatening situations tend to lead to a narrower range of coping behaviours, and therefore it is not surprising that these studies found the stressor to be a better predictor of coping compared to personality. More recently the importance of personality traits in coping behaviour has been acknowledged, and Lazarus (1990) has also conceded that personality traits together with environmental factors do contribute to the appraisal and coping process.

Empirically, there seems to be growing evidence that there is some consistency in coping behaviour, however, most research relating coping to personality has focused on the trait of neuroticism. There has been little research regarding the link between conscientiousness and coping. Costa et al. (1996) considered personality correlates of coping in older adults facing a life event. However, only a limited subset of data was available for the conscientiousness factor. Positive associations were found with two individual ways of coping: 'becoming stronger as a result' and 'concentrating on the next step'. Hooker et al. (1994) found that in a sample of caregivers of spouses with dementia, conscientiousness was positively related to problem-focused coping and negatively related

to emotion-focused coping. However, conscientiousness was not found to be a significant predictor of coping strategy in multiple regression analyses.

In summary, the scarcity of research studies means that the link between personality traits, and specifically conscientiousness, and ways of coping has not been sufficiently investigated at this time. As yet there is little in the way of evidence to support or dispute the hypothesis that the personality trait of conscientiousness influences the way an individual copes with the threat of dementia in terms of their use of defensive denial or avoidant coping strategies.

1.8. Dementia and unawareness within a social, interactional context

Person-centred approaches (e.g. Kitwood, 1996, 1997; Chester & Bender, 1999) emphasise that dementia needs to be considered within a social frame as well as a personal frame. In terms of social psychological factors pertinent to dementia, Kitwood (1996, 1997) describes a 'malignant social psychology' (MSP), which often surrounds people who have a diagnosis of dementia. Examples of MSP include disempowerment, infantilisation and intimidation. It is argued that such changes in a person's social world combine with neurological factors to erode a person's sense of being or 'personhood'. Kitwood draws on the work of the philosopher Martin Buber (1937) conceptualising 'personhood' as a standing or status which is bestowed upon an individual in the context of their interactions with others. Therefore, the social roles that an individual occupies can be viewed as supporting their sense of self or 'personhood'. Within this context,

dementia can be thought of as posing a threat to a person's sense of self as it can lead to changes in an individual's social world and loss of role.

Cheston and Bender (1999) consider the process of loss involved in dementia and the threat that is posed to self-identity. They point out that a loss of cognitive skills can make it harder to maintain the necessary social interactions. Changes in relationships and loss of social roles are seen as representing 'potential destruction of the person [and] damage to the sense of self'. Therefore, the onset of dementia can be conceptualised as a stressor, which poses a threat to the sense of self and an individual's schemas and cognitive structures. However, at the same time it is this crumbling sense of self that needs to cope with the threat posed.

Charmaz's (1983) research regarding losses experienced by the chronically ill seems particularly relevant to individuals facing dementia. She identifies a number of key issues and points out that the chronically ill tend to live a restricted life with restrictions in everyday choices. This is especially relevant to people with dementia where restrictions in every day life can challenge previous self-images. A major consequence of a restricted life is social isolation. Charmaz highlights that social isolation and losses of social role can also lead to a loss of sense of self. In addition, social experiences of embarrassment, discreditation or shame can lead to further experiences of loss of self-concept. Such discrediting experiences may cause individuals to withdraw from social situations. In people with dementia, it has been suggested that withdrawal can lead to decreased stimulation and decreased use of cognitive resources and social skills (Cheston & Bender,

1999). This may in turn lead to fewer opportunities for an individual to assess their own functioning thus leading to reduced awareness. If an individual is also less socially grounded in reality, there may be further disorientation, which presents as cognitive decline. In short, Charmaz argues that chronic illness can lead to individuals depending more on others for self-definition and value; however, illness can also mean that individuals are less able to maintain significant relationships. In addition, she points out that people may be concerned about openly revealing their suffering as this may risk estranging those who still take an interest in them. In dementia this might involve a certain amount of covering up, and 'seeming unawareness' may be a means of protecting significant relationships.

Generally, these models highlight that an individual's subjective experience of dementia occurs within a social context, and that it is important to consider systemic factors when considering how dementia manifests itself in a given individual. Expression of awareness or unawareness in dementia is also likely to be influenced by such factors. The interpersonal relationships between people with dementia and their families in terms of what they feel, how this is expressed, and what is communicated is very complex and is likely to affect an individual's awareness of their condition. For example, it may be that some individuals feel less able to explore and communicate their feelings and worries with their families, and denial may be a way of coping that is used within the relationship. This method of coping may also mean that individuals receive less feedback regarding their level of functioning from family members, and therefore have fewer opportunities to develop awareness. Alternatively, in line with Charmaz's (1983) suggestions, dementia

patients may also 'cover up' their difficulties to protect significant others from distress, and therefore to protect important relationships. This 'covering up' may also present as a form of unawareness.

There has been very little research which considers how partners and families communicate with patients about dementia, and how feelings and worries regarding diagnosis, symptoms and future needs are discussed (if at all). There have been some studies which consider the effect of dementia on the family, for example Garwick et al.'s (1994) study on family perceptions of living with Alzheimer's disease. However, these studies tend to exclude the patient and his/her perspective. Two areas of research regarding the interpersonal interactions of people with dementia which may be relevant to the level of awareness are the study of expressed emotion and research on the patterns of communication between patients with dementia and care staff in nursing homes.

The concept of 'expressed emotion' originated with Brown et al.'s (1958) work on the resettlement of men with schizophrenia into the community, and the finding that prognosis appeared to be related to the emotional atmosphere within the family. Relatives with a high level of expressed emotion were described as overtly critical, hostile and blaming towards the patient. Relatives with a low level of expressed emotion were described as not expressing overt criticism or hostility and more accepting of the patient's condition. A few studies have applied this concept to families caring for relatives with dementia (e.g. Gilhooly & Whittick, 1989). The concept of expressed emotion can be thought of as relevant to the level of awareness in people with dementia. If an individual experiences

critical comments or hostility from relatives regarding their difficulties, there may be more of a need for defensive denial or to 'cover up' problems as a way of managing some of the interpersonal difficulties. Therefore, it may be useful to consider how often a patient experiences negative interactions such as arguments with their families when considering the role of social, psychological factors in awareness.

Research on staff-patient communication patterns in nursing homes has indicated that people with dementia may take on a 'non-person' status and that communication with patients often only involves a few formulaic exchanges (Smithers, 1977, cited in Hamilton, 1994). Lubinski's (1981, cited in Hamilton, 1994) investigation into communication patterns in nursing homes noted that people find it difficult to talk to individuals with cognitive difficulties and that this can lead to reduced opportunities for people with dementia to interact meaningfully. Although these studies are concerned with individuals in a relatively more advanced stage of dementia in nursing homes, it seems likely that people with a less severe dementia who are still living at home may also have diminished opportunities for communication and fewer chances to discuss feelings, fears or worries. This may contribute to use of avoidant coping regarding the threat of dementia. It may also mean that people with dementia receive less discursive feedback regarding their difficulties which could impact on their awareness.

Clare's (2000) qualitative study considers interpersonal factors in the development of awareness of difficulties. She suggests that the development of awareness involves interpersonal negotiation with significant others, and that the quality of the relationship

and how communication has been negotiated earlier in the relationship will affect this process.

As well as personal, psychological factors contributing to lack of awareness, social factors may also play a role as it seems likely that communication and interaction with others will affect level of awareness.

1.9. Clinical implications of defensive denial

Lack of awareness in people with dementia is sometimes viewed as having negative clinical implications. Research has suggested that individuals who are less aware of their memory difficulties make poorer treatment gains following cognitive rehabilitation (Clare, 2000; Koltai et al., in press). However, the role of defensive denial in unawareness in dementia suggests that it should not necessarily be viewed negatively or as a simple obstacle to rehabilitation, but rather as a positive, motivated process that is protective and adaptive. An understanding of awareness is important so that clinicians are able to respond appropriately to the individual needs of the patient and their families. Clinicians need to understand where the person is at and what they can or cannot cope with at a given stage. Careful consideration of unawareness is important because if it is partly due to defensive denial, detailed information regarding diagnosis, prognosis or cognitive rehabilitation may be a threatening, confrontational experience. Lazarus (1983) points out that in the early stages of coping, when someone may not have the physical or psychological resources to cope in a more problem-focused way, it may provide

temporary relief from trauma and prevent an individual from being overwhelmed by feelings of grief, depression or anger.

1.10. The need for further research: a possible model & hypotheses

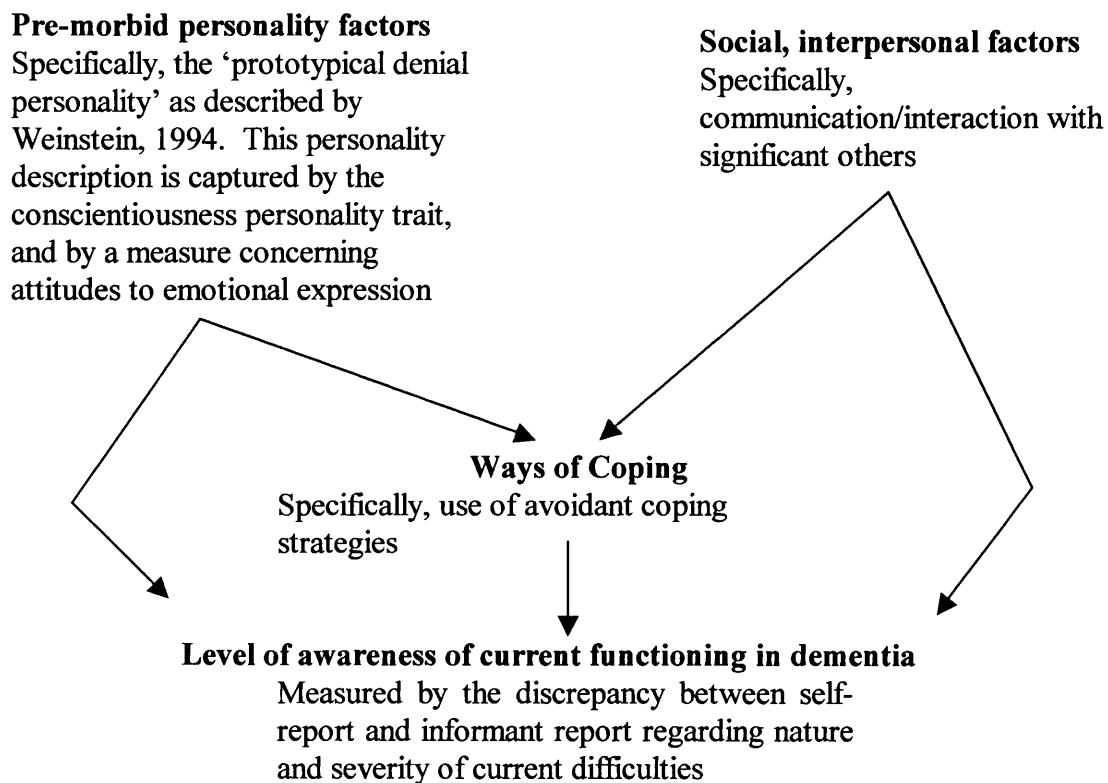
It seems that the study of awareness in dementia needs to consider individual psychological factors as well as neuropsychological factors. This is also in line with the growing move towards a person-centred approach to dementia and the need to consider the individual's subjective experience (Kitwood, 1997). The person with dementia is still going to rely on coping mechanisms and their personality is undoubtedly going to affect how they cope. Although there is a large body of research on personality, defence mechanisms, and stress and coping, no study has systematically investigated the contribution of personality and coping to awareness using well-researched, valid and reliable measures which have been developed in the fields of personality and coping.

Person-centred approaches to dementia also highlight the relevance of social context to the presentation of dementia. Within this framework, it might also be expected that low awareness relates to psychosocial and relationship factors, such as how the person communicates with significant others and how they approach problems with significant others.

The current study proposes to investigate the role of pre-morbid personality, coping strategies and style of communication with significant others in unawareness in dementia.

A diagrammatic representation of the hypothesised relationship between these variables is depicted in Figure 1.1.

Figure 1.1: Diagram illustrating the hypothesised relationships between awareness and psychological and social variables



1.11. Carer burden and its relationship with unawareness

Whilst some people in the more advanced stages of dementia are placed in nursing homes, the majority of people (particularly in the earlier stages) live at home with their families. Family members (most frequently spouses) provide most of the care that is needed, which

can lead to considerable stress. The chronic, progressive nature of dementia means that these stresses may persist for several years, as there is increasing dependency on others to fulfill basic needs. As the disease progresses there may be new and complex challenges for the carer. Some studies have reported increased carer burden with higher care recipient impairment (e.g. Pearson et al., 1988), however Zarit et al. (1980) found that carer burden was not related to severity of cognitive impairment, behavioural problems or functional impairment. Therefore, although it seems that carer burden is influenced by the status of the person with dementia, there are individual differences. It seems that caregiving is a complex process involving multiple variables.

Pearlin et al. (1990) conceptualise caregiver stress as involving multiple variables: background and contextual factors (such as the quality of the pre-morbid relationship and socio-economic resources) and primary and secondary stressors. Primary stressors are considered to be stresses directly related to caregiving, and are therefore linked to the cognitive status of the patient, behavioural problems and level of functioning in everyday tasks. Primary stressors may lead to secondary stressors, as stress encroaches on other areas of the caregivers' life. The carer may experience role strain as stress is experienced in other areas (e.g. family conflict, work, social roles). If there is considerable change in the caregiver's roles and if the identity and life of the caregiver have been closely bound to that of the patient, there may also be damage to the caregiver's self-concept. Pearlin et al. (1990) label this intrapsychic strain. The model highlights coping and social support as variables, which mediate at different points in the stress process. Within this model, unawareness on the part of the patient could be viewed as increasing carer burden at

different levels. Lack of awareness may mean that the individual with dementia is resistant to help and support from their carer. This would lead to an increase in primary stress as providing help and assistance is probably more difficult when someone is resistant and thinks that they are still capable of functioning independently. Reduced awareness in the patient may also increase carer burden by having an effect on the mediating variables of coping and social support. It may be that the carer previously coped with difficulties by gaining emotional support from the care recipient, however unawareness on the part of the individual with dementia might reduce opportunities for such discussion and emotional support.

Vitaliano et al. (1991) consider similar variables in their conceptualisation of carer burden:

$$\text{“Distress (burden) = } \underline{\text{exposure to stressors + vulnerability}} \\ \text{psychological resources + social resources”}$$

(p. 392, 1991)

Within this model, unawareness may contribute to burden at the level of ‘exposure to stressors’, which are thought to include factors such as impairment in the patient as well as other life stressors. As discussed in Pearlin’s (1990) model, unawareness in the patient may also affect coping strategies open to the carer, which in this model would involve a decrease in ‘psychological resources’.

The relationship between patient unawareness and carer burden has received only limited attention, however existing studies provide empirical support for a link. Although

DeBettignies et al. (1990) found that unawareness was associated with higher levels of carer distress, the study only considered awareness of impaired independent living skills. As has been discussed earlier, in dementia there can be difficulties in a number of domains of function, and therefore there can be a number of 'objects of insight'. Seltzer et al. (1997) consider the relationship of carer burden with unawareness of memory deficit, self-care skills and social function. Increased carer burden was found to be associated with unawareness of memory deficit (irrespective of disease severity or duration) but not unawareness for self-care skills or social function. The authors suggest that this may be due to relative preservation of these skills in their sample of people with mild to moderate dementia.

Empirically, there is support for the mediating effect of social support (e.g. Zarit et al., 1980) and coping strategies (e.g. Vitaliano et al., 1991) on carer burden. There is also evidence for a relatively high incidence of mental health symptoms (depression and anxiety) in carers (Vitaliano et al., 1991). Depression could be conceptualised as an outcome of caregiving. However, the circular interactive nature of the process also means that depression and anxiety could be a vulnerability factor for increased levels of burden. Models such as that of Pearlin et al. (1990) hypothesise that the quality of the pre-morbid relationship between carer and care recipient is relevant to carer burden. Indeed, it could be hypothesised that conflict or lack of affection or closeness in the pre-morbid relationship may reduce a relative's willingness to be a carer, and increase resentment about the personal sacrifices involved. Williamson & Schulz (1990) found that carers who

had enjoyed a close relationship with the patient prior to the onset of dementia felt less burdened.

The role of the patient's unawareness in carer burden has not received considerable attention. However, a link between these variables would indicate that unawareness (whether it is due to neurological or psychological factors) has clinical implications for family caregivers as well as the individual with dementia in terms of clinical management. Therefore, as an adjunct to the study of the role of psychological and interpersonal factors in unawareness, the relationship of awareness to carer burden will also be considered. As carer burden has also been found to relate to the quality of the pre-morbid relationship, symptoms of depression and anxiety in the carer as well as disease severity of the patient, these variables should be controlled for in the analysis.

1.12. Aims and research questions

The present study proposes to investigate awareness of current functioning in dementia. In particular, awareness will be examined in various subtypes of 'non-frontal' dementias. The literature review highlighted that although there are a number of different possible 'objects of insight' in dementia, only a limited number of studies have considered awareness for different modalities of function. Therefore, the study will explore the possibility of dissociations in awareness by looking at awareness for different functional domains. Studies have produced mixed results regarding factors associated with unawareness in dementia. Therefore, the correlates of unawareness in terms of

demographic factors, disease-related and psychiatric variables will be considered in this study.

The central aim of the study is to investigate the role of psychological and social factors in unawareness of current functioning in dementia. This aim draws on a number of theoretical frameworks. The subjective experience of dementia is considered within a person-centred, social psychological framework, and within this model it is hypothesised that in some individuals lack of awareness might serve to protect the self from overwhelming feelings related to the threat and loss represented by dementia. It is suggested that within this context lack of awareness might relate to the psychological defence mechanism of denial. Weinstein's (1955, 1994, 1996) research on pre-morbid personality factors in disorders of awareness suggests that individuals who score highly on the personality trait of conscientiousness and who are controlled and reserved with their feelings may be more likely to deny their disability. Therefore, the study hypothesises that individuals who score highly on the personality trait of conscientiousness and who are controlled and reserved in their emotional expression may appear less aware of their condition and level of function. It is hypothesised that such individuals may also be more likely to cope with the threat of dementia at a behavioural level by using avoidant coping strategies, which may also impact on their awareness. Therefore, it is proposed that pre-morbid personality factors may directly influence expressed level of awareness as well as having an impact through use of avoidant coping strategies. However, it is also important to keep in mind that in some individuals some aspects of unawareness may be due to neurological factors. It might be expected that the role of neurological factors in

unawareness increases as the dementia progresses and there is increased loss of brain function. Therefore, it would seem prudent to control for dementia severity when considering the role of psychological factors in unawareness. Another important factor which may need to be controlled for in an analysis is duration of symptoms. It may be that it takes time for a person to consciously register their difficulties and that awareness takes time to develop. It may also be that those who have experienced symptoms for longer have had more clinical assessments, which may also serve to increase awareness. In addition, it may be important to consider symptoms of depression and anxiety when investigating the role of psychological factors in unawareness. Depression might be expected to be associated with higher awareness, however, it may also lead to over-reporting of symptoms and hyperawareness. The relationship of depression to unawareness is, therefore, possibly quite complex and may need to be controlled for in an analysis.

Social psychological models of dementia also highlight that the presentation of dementia in an individual is influenced by social factors. The study draws upon this model to consider unawareness in dementia, and hypothesises that unawareness will also be related to the style or level of communication with significant others such as partners. For example, those who confide in or discuss issues with their partners may receive more feedback regarding their level of functioning and may consequently have more opportunities to increase their level of awareness. Therefore, it is suggested that level of communication with partners may directly impact on patients' awareness of current functioning. In addition, the concept of 'expressed emotion' and the level of expressed hostility that

patients experience with their partners can be thought of as relevant to awareness. For example, individuals who experience more confrontations and arguments and less open communication with their partners may have an increased need to 'cover up' problems as a way of coping within the relationship. Such individuals may be more likely to use avoidant coping strategies and appear less aware of their condition. Therefore, it is suggested that these interpersonal factors may have a direct impact on level of awareness as well as an indirect impact by influencing patients' use of avoidant coping strategies.

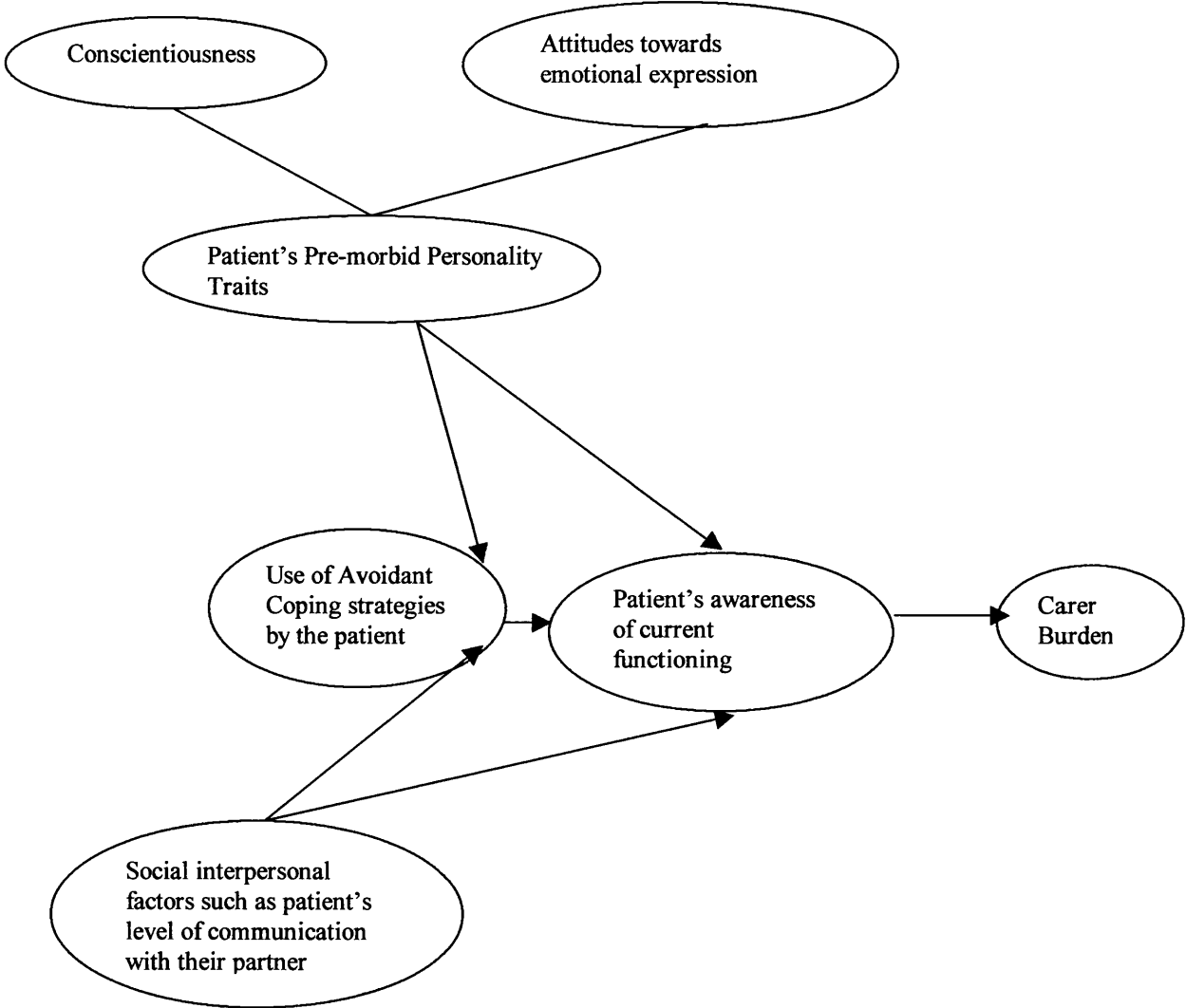
A model is proposed in Figure 1.2 which illustrates how the psychological variables of pre-morbid personality features and coping strategies, and social, interpersonal factors, may impact on level of awareness of current functioning in individuals with dementia.

The study also proposes to re-investigate the association between low awareness and increased carer burden. When considering this association, however, it is important to control for certain factors in the analysis; for example, dementia severity may be related to increased unawareness due to neurological variables and may therefore indirectly influence carer stress. In addition, dementia severity may influence carer stress directly as it means that the care recipient requires more supervision and help. It may also be useful to include a measure of quality of the pre-morbid relationship in the control variables as this has been found to influence carer stress. Symptoms of depression and anxiety in the carer also need to be controlled for in an analysis because depression can be conceptualised as an outcome of caregiving as well as contributing to carer burden. In addition, depression could lead to an over-reporting of patient difficulties by the carer. Alternatively, lack of awareness in

the patient may be causally related to depression in the carer, as it may impact on the couple's relationship.

The hypothesised relationship of unawareness to carer burden is also featured in Figure 1.2.

Figure 1.2: Proposed model regarding the relationship between level of awareness and psychological and social factors and carer burden



1.13. Specific research questions

The following specific research questions will be addressed in the study.

Part 1

What is the profile of awareness regarding current functioning in a sample of individuals with 'non-frontal' dementia?

In particular, the following will be considered:

- 1.a. Awareness in different subtypes of 'non-frontal' dementias
- 1.b. Awareness for different functional modalities
- 1.c. Correlates of unawareness (e.g. demographic, disease-related and psychiatric variables)
- 1.d. The effect of context on the expressed level of awareness

Part 2

Do psychological and social factors affect level of awareness in dementia?

More specifically:

- 2.a. Do psychological factors, in particular pre-morbid personality features and coping strategies employed by individuals with dementia, affect level of awareness of current functioning?
- 2.b. Do social factors, in particular level of communication with partners, affect patients' awareness of current functioning?

Part 3

Does patients' level of awareness contribute to carer burden?

2. Method

2.1 Design

The study used a quantitative cross-sectional correlational design. The research questions were addressed by administering standardised self-report and informant-report questionnaire measures of patient's awareness of current level of functioning, patient's pre-morbid personality, coping strategies employed by the patient, style of communication between the patient and partner, pre-morbid marital satisfaction and carer burden. The patient and carer also completed questionnaire measures of anxiety and depression so that these variables could be controlled for in the analysis. Data regarding dementia severity were obtained from patients' clinical assessments so that this could also be controlled for in the analysis.

As has been discussed in the previous chapter, awareness is a complex concept which has been operationalised and measured in different ways, with each methodology having its own advantages and limitations. The literature reviewed in the introductory chapter suggested that currently the most widely-used method of evaluating awareness is by considering the discrepancy between patient self-report and informant report of difficulties. Although it has been suggested that the carer's appraisal of patients' difficulties may be influenced by factors such as the quality of the relationship with the patient and their own emotional state, there seems to be substantial evidence supporting the validity of this methodological approach (Feher et al., 1991; Koss et al., 1993; Jorm, 1997). Therefore, in this study, patients' level of awareness of current functioning was operationally defined as the discrepancy between patient self-report of level of functioning

the patient may be causally related to depression in the carer, as it may impact on the couple's relationship.

The hypothesised relationship of unawareness to carer burden is also featured in Figure 1.2.

mean that neurological factors are playing a more significant role in unawareness compared to ‘non-frontal’ dementias. It seemed acceptable to include a mixed group of ‘non-frontal’ cortical dementias in the study because it seems likely that the role of psychological factors in unawareness will be broadly similar across these diagnostic subgroups. Additionally, in clinical practice it can often be very difficult to confirm a specific diagnosis of dementia of the Alzheimer type, Vascular dementia or Lewy-body dementia until post-mortem.

It was decided to only include those individuals with dementia who had partners, as research in the area of personality measurement has shown that partners’ ratings of personality correlate more highly with self-ratings compared to other informant ratings (Costa & McCrae, 1992). In addition, it was thought that communication within the marital relationship (or partners’ relationship) would probably be more significant in terms of relating to awareness than communication with friends or other relatives.

2.3.1 Inclusion & exclusion criteria

Inclusion criteria

- Diagnosis of a ‘non-frontal’ progressive cortical dementia.
 - The NINCDS/ADRDA criteria were used to diagnose Dementia of the Alzheimer type (McKhann et al., 1984).
 - The NINDS/AIREN criteria were used to diagnose Vascular dementia (Roman et al., 1993).

- McKeith et al.'s (1996) work was used to aid diagnosis of Lewy-body dementia
- Sufficient cognitive skills to be able to complete the questionnaire measures. A minimum Mini-Mental State Examination score of 16-18 was used as a guide (MMSE; Folstein et al., 1975).

Exclusion criteria

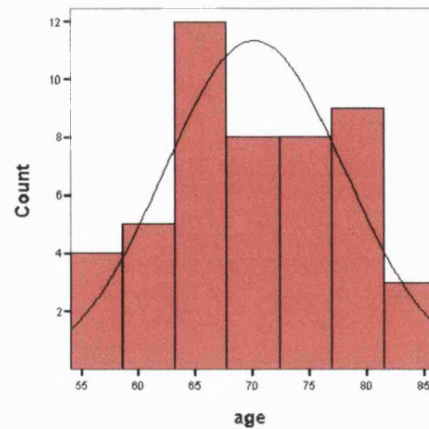
- Diagnosis of a frontal dementia
- History of alcoholism, head injury or developmental disability
- Diagnosis of current severe psychiatric disorder
- Non-fluent in English.

2.3.2 Demographic variables of the participants

2.3.2.1 Age

The average patient age was 70.1 years (SD = 7.9, range 54-86). Figure 2.1 shows the frequency distribution of age in the study.

Figure 2.1: Distribution of age of the participants



2.3.2.2 Gender

In terms of gender distribution, only 16 (32.7%) of the patients participating in the study were female. A Chi-square test showed that this represents a significant gender imbalance in the sample (with more males) given that there is no effect of gender on diagnosis of dementia, $\chi^2(\text{df})=5.9$, $p=0.02$. This gender distribution may reflect a selection bias as previous studies have found that females (if anything) are actually at greater risk (e.g. Lindsay et al., 1989).

2.3.2.3 Ethnicity

There was some diversity in the ethnicity of the participants as summarised in Table 2.1.

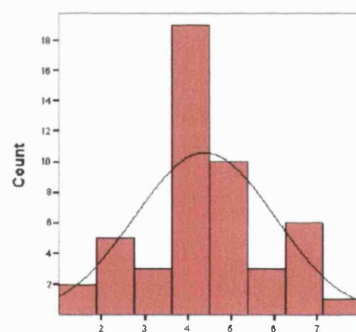
Table 2.1: Ethnic distribution of the patients

Patient ethnic group		Number of patients	Percentage of patients
	White UK	43	87.8%
	White American	1	2.0%
	White European	2	4.1%
	Black African	2	4.1%
	Indian	1	2.0%

2.3.2.4 Socio-economic class/pre-morbid occupational status

Socio-economic class of the patient was classified by coding the patient's occupation according to the Occupational Classifications of the OPCS (Office of Population Censuses and Surveys, 1995). The majority of the participants were retired, so classification was made in terms of the patient's best level achieved prior to retirement. For participants who were married housewives, the occupation of their husband was classified. The modal score in the sample was 4 (SD=1.6), which places the average patient at a social stratum equivalent to professional workers (employees). Figure 2.2 illustrates the frequency distribution of socio-economic class as determined by the OPCS Occupational Classification (See Appendix 1 for details of the OPCS Occupational Classification).

Figure 2.2: Distribution of occupational groups in the sample



Occupational group as defined by the OPCS Occupational Classifications

2.3.3 Disease-related variables

2.3.3.1 Diagnosis

The distribution of the 'non-frontal' dementia diagnostic subtypes in the study's sample is detailed in Table 2.2.

Table 2.2: Distribution of the dementia subtypes in the study

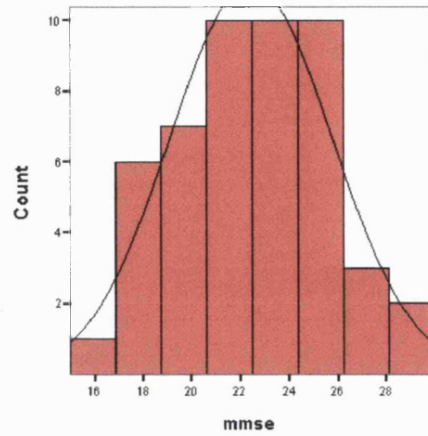
	Number of patients	Percentage of patients
Dementia subtype: Alzheimer's disease	32	65.3%
Familial Alzheimer's disease	4	8.2%
Vascular dementia	9	18.4%
Lewy-body dementia	2	4.1%
Mixed Vascular/Alzheimer's	2	4.1%

The diagnostic proportions in the study's sample are broadly representative of relative prevalence rates in the general population. Cheston & Bender's (2000) review suggests that Alzheimer's disease is the most common form of dementia accounting for up to two-thirds of all dementias, Vascular dementia is thought to account for 10 to 20% of all forms of dementia, whereas it is suggested that Lewy-body dementia accounts for 7 to 30% of diagnosed dementias.

2.3.3.2 Severity

Dementia severity was assessed with the Mini-Mental State Examination (MMSE; Folstein et al., 1975). The mean score was 22/30 (SD 3.3), which is below the widely reported cut-off score of 24, which is said to distinguish between impaired and normal subjects (Folstein et al., 1975). Figure 2.3 depicts the frequency distribution of MMSE scores in the sample.

Figure 2.3: Distribution of MMSE scores in the sample



2.3.3.3 Duration of symptoms

The average duration of symptoms as reported by the patient's partner was 3.8 years (SD 1.8, range 1-9 years).

2.3.3.4 Medication

Information regarding medication relevant to the symptoms of dementia was also collected and is detailed in Table 2.3.

Table 2.3: Relevant medication taken by patients in the study

Type of medication:		Number of patients	Percentage of patients
Acetylcholinesterase inhibitors		19	38.8%
Trial (drug or placebo) ¹		7	14.2%
Aspirin		2	4.1%
Antidepressant		2	4.1%
No relevant medication		19	38.8%

¹ The trial was a double-blind placebo trial of the efficacy of Donepezil in Vascular dementia

2.4 Ethical Issues

Individuals with dementia represent a potentially vulnerable population; therefore, careful consideration of ethical issues was central in planning the study's research protocol. Special consideration was given to the language of the participant information sheet to ensure that someone with reduced cognitive skills could understand it.

In addition, disclosure of diagnosis to patients is not always straightforward. Patients may show reduced awareness of their condition, and relatives may want to protect the patient from knowledge of their diagnosis. With this in mind, the project had a participant title which did not refer to a diagnosis ("How do people attending clinic and their partners cope with memory problems?"). In addition, careful attention was given to the wording of the information sheet so that it only referred to memory problems rather than dementia or specific diagnoses (See Appendix 2 for participant information sheets and consent forms).

The process of consent is another issue particularly pertinent to individuals with dementia. Participants were encouraged to discuss the possibility of taking part with their families in private and to take their time in deciding whether to participate. During completion of the questionnaires, participants were reminded at two separate time points that they were free to withdraw from the study if they wished to discontinue. It was hoped that this sympathetic, cautious approach would increase participants' autonomy in deciding whether to take part.

In order to ensure confidentiality, participants were not required to write their names on the questionnaires. All participants and their partners signed consent forms, after which each set of questionnaires was given a number, and the data was subsequently stored on computer in a coded form.

Ethical approval was sought and obtained from the National Hospital for Neurology & Neurosurgery and Institute of Neurology Joint Medical Ethics Committee, and the Hounslow District Research Ethics Committee (Appendix 3). The information sheets for the two centres differed slightly because of the different requirements of the ethics committees.

2.5 Recruitment

The majority of participants were recruited from the Cognitive Disorders clinic at the National Hospital for Neurology and Neurosurgery. Participants who fulfilled the study's inclusion/exclusion criteria were told about the study and given an information sheet during their clinical appointments. In some cases, the questionnaires were completed during their clinic appointment at the hospital. However, in most cases (especially first clinic visits) patients had a lot to think about and were undergoing lengthy assessment procedures, and were therefore encouraged to take more time to decide whether to take part in the project. In these cases, if participants expressed an interest in taking part, they were asked whether it was acceptable for the researcher to contact them at a later date. The questionnaires were then completed at a later date. Usually the researcher visited the participant and their partner at home to complete the questionnaires; however, in a few

cases this was done during a subsequent hospital visit. Occasionally, organisational issues meant that it was not possible to raise the possibility of participating in the research project with potential participants in the clinic. In these cases, an invitation letter and information sheet were sent, and potential participants were asked to return a reply slip in a stamped addressed envelope if they would like to discuss the possibility of taking part in the project.

2.5.1 Difficulties in recruitment

Recruitment was hindered by a number of different factors. A significant number of possible participants had been widowed and attended the clinic with other family members, and therefore had to be excluded. Referrals of cases of frontal dementias were also over-represented in the clinic (possibly due to the Consultant's clinical and research interests). In addition, the majority of individuals attending the clinic had Mini-Mental Scores of below 16-18, and would therefore have struggled to complete the questionnaire measures. For patients with a MMSE of above eighteen, it was often one of their first clinic visits. Initial clinic visits tended to involve lengthy assessment procedures and therefore it was usually too much to consider completing the project during this visit. Indeed, the refusal rate was higher for patients who were attending the clinic for the first time, with the most common reason being that the patient felt overwhelmed and as if they had too much to think about. In total, twenty participants declined to take part. These difficulties meant that actual recruitment levels were only about 50% of the estimate initially made by clinic staff.

As these recruitment difficulties emerged, ethical approval was sought and obtained from Hounslow District Research Ethics committee so that further participants could be recruited from the memory clinic at the West Middlesex Hospital in order to make up the anticipated shortfall. However, review of individuals attending this memory clinic during the time period of the project revealed that only three people out of a possible nineteen cases fulfilled the study's criteria. Eleven cases were excluded as they had lost their partner, and in seven cases the MMSE score was below eighteen at the initial appointment. Of the three individuals who fulfilled the criteria, two refused because of other physical health problems.

In addition, four cases had to be excluded from the analysis after recruitment and (in some cases) after testing. In two cases, despite fulfilling the inclusion/exclusion criteria at the time of recruitment, it became apparent during administration of the questionnaires that cognitive functioning had deteriorated such that the participant could no longer cope with the demands of completing the formal measures. One case had to be excluded after administration of the questionnaires as diagnosis was subsequently changed to a frontal dementia. Finally, one case was excluded as it became apparent that the partner had misapplied the instructions thus invalidating the data.

2.5.2 Potential biases in recruitment

The Cognitive Disorders clinic at the National Hospital for Neurology and Neurosurgery is a specialised, tertiary level service. Therefore, use of this clinic as a target sample may not be representative of the general population of people with dementia. It could be

speculated that individuals who are more aware of their difficulties may be more likely to seek a referral to a specialist clinic. Indeed, Weinstein (1994) concluded that individuals with dementia who were less aware of their condition were slower to go to the doctor. The process of the referral itself may also have an impact on an individual's level of awareness. In addition, it might be hypothesised that people who attend the clinic at an early stage in their condition are less likely to cope using avoidant coping strategies. It was hoped that these biases might be addressed to a certain extent by recruiting from the memory clinic at the West Middlesex Hospital which is a secondary level service serving the needs of the local community. However, individuals attending this clinic tended to have a lower MMSE score at their initial visit, which often meant that they were too severely affected to take part in the study. This observation may be supportive of the hypothesis that people who are less aware of their difficulties are not referred to the clinic until a later stage in their condition. However, as it is often carers who bring individuals to the clinic even if they are unaware, this observation may be more suggestive of a possible need to educate referrers in recognising the early signs of dementia and to encourage earlier referrals.

These potential biases in recruitment need to be kept in mind as they may influence the generalisability of the results of the study, and therefore the external validity.

2.6 Measures

A number of measures were used to investigate the study's hypotheses. The Memory Insight Questionnaire (MIQ; Marková, 1997) was used to assess patients' awareness of

level of functioning. Pre-morbid personality features were assessed using the Conscientiousness scale of the NEO Five-Factor Personality Inventory (NEO; Costa & McCrae, 1992) and the Attitudes to Emotional Expression questionnaire (Joseph et al., 1994). Coping strategies employed by the person with dementia were assessed using the Ways of Coping Checklist – revised (Vitaliano et al., 1985). The quality of the pre-morbid relationship and the style of communication between the patient and the partner were assessed using the Dyadic Adjustment Scale (DAS; Spanier, 1976). Carer burden was measured with the Burden Interview (Zarit & Zarit, 1987). Other measures included the Hospital Anxiety and Depression Scale (HAD; Zigmond & Snaith, 1983) and the Mini-Mental State Examination (MMSE; Folstein et al., 1975), which were used to assess for levels of anxiety and depressive symptomatology in the patient and partner and dementia severity respectively.

2.6.1 Patients' awareness of current level of functioning: Memory Insight Questionnaire (MIQ; Marková, 1997)

This questionnaire operationalises and measures unawareness as a function of the discrepancy between patients' and informants' views on patients' current level of functioning. The patient completes one version of the questionnaire, and a parallel version phrased in the third person is given to the informant.

The MIQ consists of nineteen items covering four main areas likely to be affected by memory difficulties:

- General functioning (items 3,10,19)

- Memory (general, autobiographical and procedural) (items 1,2,4,5,6,7,8,16)
- Language function (items 9,11,18)
- Cognitive (general and executive function) (items 12,13,14,15,17)

The questionnaire asks the patient and informant to rate functioning using a four point scale (improvement [1], no change [2], mildly worse [3] and much worse [4]). Level of awareness is calculated as the sum of the differences between patients' ratings and ratings by their partner on each item. Therefore, a discrepancy of zero indicates a good agreement between patient and partner, which suggests that the patient has good awareness of his/her level of functioning. A positive discrepancy indicates that the patient's difficulties were rated as more severe by the partner, thus suggesting a lower level of awareness on the part of the patient regarding his/her level of functioning. Finally, a negative discrepancy indicates that the patient's problems were evaluated as more severe by the patient than by the partner, suggesting that the patient is hyperaware of his/her difficulties.

One reason for the questionnaire being chosen for the current study is that it is particularly user-friendly. The items are very carefully worded and reference to dementia or specific diagnoses are minimal. The questionnaire was designed for use with individuals with mild to moderate cognitive impairment, and therefore is very clear and easy to understand.

In terms of psychometric properties, reliability as measured by Cronbach's alpha coefficient was acceptable (>0.80) for both versions of the scale. Support for the validity

of this methodological approach for measuring awareness was discussed in the previous chapter. In summary, there is evidence to suggest that on balance informants are relatively accurate in their ratings of patients' cognitive functioning (Feher et al., 1991; Koss et al., 1993; Jorm, 1997). In particular, the MIQ examines fairly overt functional difficulties with little emphasis on subjective feelings, which should be relatively easier for the informant to evaluate. The MIQ was developed for use with mildly to moderately cognitively impaired patients attending a memory clinic, whose memory difficulties were attributable to both organic and non-organic causes (Marková, 1997)

2.6.2 Patient's pre-morbid personality: NEO, Five-factor Personality Inventory (Costa & McCrae, 1992) and Attitudes to Emotional Expression questionnaire (Joseph, Williams, Irwing & Cammock, 1994)

2.6.2.1 NEO, Five-factor Inventory (Costa & McCrae, 1992)

The NEO Five-factor Personality Inventory (NEO PI-R) is a widely used comprehensive measure of the five domains of personality (Neuroticism [N], Extraversion [E], Openness [O], Agreeableness [A] and Conscientiousness [C]). The questionnaire has been standardised for self-report and completion by a spouse or peer (informant-report).

The questionnaire involves a number of statements, which are worded both positively and negatively, to control for the effect of acquiescence. Responses to each statement are made on a five-point scale (strongly agree, agree, neutral, disagree, strongly disagree) so that it best describes the person being rated (either self-report or the rating of another person as in the case of informant-report).

The NEO PI-R measures traits which have an approximate normal, bell-shaped distribution in the normal population. The psychometric properties of the NEO PI-R have been extensively investigated. Normative data for the NEO PI-R self-report form is based on a composite of three samples: a group of 405 men and women in the Augmented Baltimore Longitudinal Study of Ageing (ABLSA), an additional 329 participants also completed the form by computer administration, and also 1539 men and women who participated in an American study of job performance. Normative data for the informant-report version is based on a combination of spouse and peer ratings. Internal consistency as calculated by coefficient alpha is acceptable for the NEO PI-R. Retest reliability for NEO-PI ranged from 0.66 to 0.92 for the different factors. In terms of validity, the NEO PI-R factors show strong evidence of convergent and discriminant validity with adjective-based measures of personality. NEO-PI-R scores also correlated well with sentence completion measures of related constructs.

The 48-item conscientiousness scale was selected for the purposes of this study as it captures Weinstein's (1994) description of the prototypical denial personality most closely. The conscientiousness scale (like the other scales) is composed of six more specific scales, which measure facets of the domain. These are as follows:

- C1 (competence). This refers to the sense that one is capable, sensible, prudent and effective. (Items 1, 7, 13, 19, 25, 31, 37, 43)
- C2 (order). Individuals who score highly on this facet tend to be neat, tidy and well organised. (Items 2, 8, 14, 20, 26, 32, 38, 44)

- C3 (dutifulness). This refers to the sense that one is governed by one's conscience. Individuals who score highly on this scale tend to adhere strictly to their ethical principles and scrupulously fulfil their moral obligations. (Items 3, 9, 15, 21, 27, 33, 39, 45)
- C4 (achievement striving). People who score highly on this facet usually have a high level of aspiration, and work hard to achieve their goals. They are usually diligent, purposeful and have a sense of direction in life. (Items 4, 10, 16, 22, 28, 34, 40, 46)
- C5 (self-discipline). Individuals who obtain a high score on this dimension often have the ability to begin tasks and carry them through to completion despite boredom and other distractions. (Items 5, 11, 17, 23, 29, 35, 41, 47)
- C6 (deliberation). People who rate themselves highly on this facet have a tendency to think carefully before acting, and are thus cautious and deliberate. (Items 6, 12, 18, 24, 30, 36, 42, 48)

In terms of psychometric properties of the conscientiousness scale, internal consistency of the individual facet scales as calculated by coefficient alpha ranged from 0.67 to 0.75 for the self-report form, and 0.70 to 0.82 for the informant form. Over a period of three years, the test-retest coefficient was 0.79 for a brief version of the conscientiousness scale.

The NEO Five-factor Personality Inventory has been used previously in studies of personality in individuals with dementia (e.g. Strauss et al., 1993; Siegler et al., 1991). However, these studies seem exclusively to use informant ratings of patients' personality. Research has shown that there may be some changes in personality in non-frontal

dementias (Siegler et al., 1991; Michalski, 1991, cited in Romero, 1997). With this in mind, the study asked spouses to rate the patient's pre-morbid personality. The following instructions were given:

“Please fill out this questionnaire so that it best describes your partner. Rather than thinking about how they are now, try and think more generally how they have been over the course of life. For example, you might want to use 10 years ago as a reference point.”

There is a paucity of studies which ask the person with dementia to rate their own pre-morbid personality. The participants in the current study only have mild to moderate cognitive impairment; therefore, within this group (as long as there are sufficient language skills) individuals should be able to describe their pre-morbid personality as a trait which has been relatively constant over their adult life. Indeed, in the earlier stages of dementia memory difficulties are often greater for recent events, whereas episodic memory for events in the distant past may be relatively more preserved. With this in mind, individuals with dementia were also asked to complete this measure so as to triangulate data sources. The full length NEO PI-R was piloted on three individuals with dementia, however their cognitive difficulties meant that the full questionnaire took too long to complete. It was, therefore, decided to use the briefer NEO Five-factor Personality Inventory (NEO-FFI) with patients but to keep using the full length NEO PI-R with partners. The NEO-FFI is a shorter version of the self-report form of the NEO PI-R. The conscientiousness scale of this version only includes 12 items, and does not include information on specific facets

within the domain. Internal consistency as measured by coefficient alpha was good (0.81) for this version of the conscientiousness scale. Retest reliability over a three-month period was also found to be good for the conscientiousness scale (0.83, $p < 0.001$). The NEO-FFI also shows good evidence of convergent validity. For example, the conscientiousness scale correlated significantly with adjective self-reports (0.61, $p < 0.001$). In addition, cross-observer correlations of the NEO-FFI self-report conscientiousness scale with the conscientiousness scale of the informant version of the NEO PI-R are good (self/spouse 0.44, $p < 0.001$; self/peers 0.33, $p < 0.001$; Costa & McCrae, 1992).

2.6.2.2 Attitudes to Emotional Expression Questionnaire (Joseph, Williams, Irwing & Cammock, 1994) [Appendix 4]

The Attitudes towards Emotional Expression Questionnaire was used to capture Weinstein's (1994) description of someone who is controlled and reserved with his/her feelings. This 20-item scale measures negative cognitions and behaviours concerning emotional expression. At a more detailed level, the measure has four 5-item subscales: beliefs about the meaning of emotional expression (for example "I think getting emotional is a sign of weakness"); behavioural style (for example, "When I'm upset I bottle up my feelings"); beliefs about expression (for example, "I think you should always keep your feelings under control"); and beliefs about the consequences of emotional expression (for example, "other people will reject you if you upset them"). Participants are asked to rate themselves on a 5-point scale ranging from 'disagree very much' to 'agree very much'. Higher scores indicate more stoical, controlled and reserved attitudes and behaviours towards emotional expression.

In terms of psychometric properties, internal reliability of the total scale was high (Cronbach's $\alpha=0.90$), thus confirming that the measure is assessing a single construct characterised by stoical attitudes, beliefs and behaviours. Responses on the measure were not significantly associated with gender or age (however the study's sample only ranged in age from 18 to 40 years). Convergent validity of the scale was demonstrated by the finding that higher scores on the measure were associated with lower scores on a measure of seeking social support ($r=-0.46$, $p<.001$).

Only the person with dementia completed this measure, as the questionnaire has not been standardised for completion by an informant, and most of the attitudes and beliefs which are asked about are not overt, observable behaviours. The participant was again asked to complete the questionnaire so that it described his/her pre-morbid personality, with the following instructions:

"Please fill out this questionnaire so that it best describes how you have been as a person throughout life."

This measure has only been developed relatively recently and as yet has not specifically been used with an older adult population, or more specifically with individuals with dementia. However, the items are written in a clear style with relatively simple language, and as such should be comprehensible to someone with mild to moderate cognitive impairment.

2.6.3 Patient's use of coping strategies: Ways of Coping checklist – revised (Vitaliano et al. 1985) [Appendix 5]

The Ways of Coping checklist (WCCL) is a measure of coping derived from Lazarus's (e.g. 1984) transactional model of stress. It is a 42-item scale made up of five subscales concerning different ways of coping (problem-focused coping, seeking social support, blames self, wishful thinking and avoidance). Transactional models of stress tend to view coping as a multidimensional rather than a unidimensional process, and therefore it is important that the WCCL subscales are considered to be relatively independent dimensions. Participants are asked to respond to the measure with respect to a current serious stressor, and to check 'yes' or 'no' for each item depending on whether they tried this way of coping.

The psychometric properties of this revised scale have been assessed using samples from three different types of populations: psychiatric patients referred for management of anger problems, spouses of patients with Alzheimer's disease, and medical students. The internal consistency of the revised scale was either greater or unchanged relative to the original version. In addition, the revised subscales were found to overlap substantially less than the original scales. For example, among the spouses of Alzheimer's disease patients there was a 40% drop in the average shared variance of the revised scales compared to the originals. Construct validity of the revised scale was demonstrated by the finding that depression was positively correlated with the revised wishful thinking scale and negatively associated with the problem-focused scale consistently across the three samples. Anxiety

correlated less significantly with these scales, however, it showed a strong positive association with the seeking social support scale across the three samples. Further evidence for the construct validity of the scale came from the finding that medical students receiving group therapy had significantly higher scores compared to those who were not participating in therapy.

Although the measure has been used with older adults who are spouses of patients with dementia, it has not previously been used specifically with individuals with dementia. A slight amendment was made in how the measure was administered to accommodate the memory difficulties experienced by the participants in this study. The WCCL was piloted on three individuals with mild to moderate dementia, and it was found that participants found it difficult to remember and think about how they dealt with a specific, recent stressful experience due to their episodic memory difficulties. Participants in the study found it easier to think more generally how they coped with the onset of memory difficulties rather than tying this to a specific event which needed to be remembered.

In order to obtain a quantitative measure of avoidant coping style for each participant, the number of avoidant ways of coping that each individual used was expressed as a fraction of their total number of ways of coping.

2.6.4 Style of communication and marital satisfaction: Dyadic Adjustment Scale (Spanier, 1976) [Appendix 6]

The Dyadic Adjustment Scale (DAS) is one of the most widely used measures of marital adjustment. It is a 32-item measure, which assesses satisfaction within an intimate relationship. A higher score indicates greater marital adjustment. At a more detailed level it has four subscales: dyadic satisfaction, dyadic cohesion, dyadic consensus and affectional expression. The measure was selected for the current study because of its brevity, its applicability to non-married couples and its good psychometric properties. Discriminant validity of the DAS has been demonstrated by the finding that it distinguishes between married and divorced couples, and concurrent validity has been shown by the finding that it significantly correlates with the Marital Adjustment Scale (Locke & Wallace, 1959). Carey et al. (1993) found the scale to have high internal consistency (Cronbach's alpha coefficient of the whole scale was 0.95), and good test-retest reliability over a two-week interval (0.87, $p < .0001$).

This measure was only completed by the patient's partner, as it is the partner's perception of the pre-morbid relationship which is most likely to influence carer stress. The study specifically considers the role of the quality of the pre-morbid relationship in influencing carer stress. It was thought that it was important to consider the nature of the pre-morbid relationship as the experience and stress of dementia may actually alter marital adjustment. With this in mind the following instructions were given:

“Every relationship has its ups and downs, but please consider how your relationship has generally been in the past, and indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.”

In order to obtain a brief measure of the style or level of communication between the patient and significant others (more specifically partners), four items from the Dyadic Adjustment Scale which specifically consider communication within the relationship were given to the patient. The patient was asked to consider these questions in terms of current levels of communication with their partner, as it was thought that current style of communication was most likely to influence patients' awareness of their current difficulties.

2.6.5 Carer Burden: The Burden Interview (Zarit & Zarit, 1987) [Appendix 7]

The Carer Burden Interview is a composite measure, which provides a summary measure of the stresses experienced by family caregivers of elderly and disabled persons. The 22-item measure can be administered as an interview or as a self-report questionnaire. Carers consider the impact of the care recipient's disabilities on their life in areas such as health, finances, social life and interpersonal relations. Questions are answered using a five-point scale according to how often they have felt that way (never [0], rarely [1], sometimes [2], quite frequently [3], nearly always [4]). Therefore, a higher score indicates greater carer stress. Factor analysis has led to the delineation of two subscales: personal strain and role strain.

Vitaliano et al.'s (1991) review indicates that the Burden Interview has high internal consistency (Cronbach's alpha was found to be 0.91 by Gallagher et al., 1985). Good test-retest reliability (0.71) has also been demonstrated by Gallagher et al. (1985). Construct validity has been examined by correlating the Burden Interview score with a single global rating of burden (0.71) and with the Brief Symptom Inventory (0.41) (Zarit & Zarit, 1987).

Some of the other measures of carer stress which were considered for use in the study seemed more relevant for family members caring for someone who is severely impaired (e.g. Vitaliano et al., 1991; Robinson, 1983). The Burden Interview seemed more suitable for the current study because it includes a wide range of situations as sources of burden, which seem relevant to a carer of someone who is only mildly to moderately impaired.

2.6.6 Anxiety and Depression: Hospital Anxiety & Depression Scale (Zigmond & Snaith, 1983)

The Hospital Anxiety and Depression Scale (HAD scale) is designed to detect anxiety and depression in general medical outpatients. It consists of seven depression items and seven anxiety items. Participants rate the frequency or intensity of their experiences in the last week on a four-point scale, ranging from absence of a symptom or presence of positive features (0 points) to maximal symptoms or the absence of positive features (3 points). Therefore, a higher score indicates more severe depressive or anxiety symptoms. Zigmond & Snaith (1983) use their data gathered on 100 clients to suggest the following categories: scores of less than 8 on either subscale are associated with individuals with no

clinically significant anxiety or depression, scores of between 8 and 10 are likely to be obtained by mildly disturbed individuals, and scores of between 11 and 21 are thought likely to indicate definite anxiety or depression.

Criterion validity of the measure has been demonstrated by the finding that the scale significantly correlates with the authors' twenty-minute interview of clients (0.54 for anxiety and 0.79 for depression).

The HAD scale was selected for the current study because it provides a measure of both anxiety and depression which is quick and easy to complete. The measure has also been previously used with older adults, for example Clare (2000) used it with carers of people with dementia.

2.6.7 Measure of dementia severity: Mini-Mental State Examination (MMSE; Folstein et al., 1975)

Data regarding dementia severity was gathered by collating participants' MMSE scores as this measure was routinely administered during their clinic appointments. The MMSE is one of the most widely used and studied screening measures of cognitive impairment (Hodges, 1994). The measure is scored out of a possible thirty points, with a lower score indicating more severe cognitive impairment.

2.7 Procedure

After information had been given about the study, information sheets had been read, questions had been answered and consent forms had been completed, a number of initial questions were asked before the questionnaires were administered. Demographic information regarding age and occupation was gathered for the person with dementia and their partner. Questions were also asked about who first noticed the memory problems (whether it was the patient, the partner or somebody else). This was thought to be important as it gave an indication of how aware the partner was of the patient's difficulties and hence provided some check on the validity of using the partner to provide an objective measure of the patient's level of functioning on the Memory Insight Questionnaire. Partners were also asked how long ago the difficulties started, as duration of difficulties in terms of time as well as severity may affect the development of awareness.

In terms of administration, the partner completed the questionnaires on his/her own in a separate room from the patient to ensure that the questionnaires represented independent views. The researcher took the patient through the questionnaires item by item to ensure that the questions had been understood correctly. In practice, questions sometimes needed to be clarified or occasionally re-phrased so that someone with reduced cognitive resources could understand what was being asked. For the questionnaires where participants had to respond using a five point scale (the NEO Five-Factor Personality Inventory and the Attitudes towards Emotional Expression Questionnaire), this sometimes had to be simplified as some participants found it difficult to keep the five possible

response options in mind. In some cases, it was sufficient to use a visual analogue as follows:

Strongly agree.....Agree..... Neutral.....DisagreeStrongly disagree

Occasionally, however the response process had to be broken down into stages as follows: a three-point response scale of agree, neutral and disagree was used initially, and if the participant selected agree or disagree this was subsequently rated further as strongly agree/disagree or just agree/disagree.

The questionnaires were completed in the following orders:

Patients' questionnaires

- 1 Memory Insight Questionnaire
- 2 Attitudes towards Emotional Expression Questionnaire
- 3 Conscientiousness scale of the NEO-FFI
- 4 Ways of Coping Checklist - revised
- 5 Selected items of the Dyadic Adjustment Scale
- 6 Hospital Anxiety and Depression Scale

Partners' questionnaires

- 1 Memory Insight Questionnaire
- 2 Conscientiousness scale of the NEO PI-R
- 3 Burden Interview

- 4 Hospital Anxiety and Depression Scale
- 5 Dyadic Adjustment Scale

After completion of the questionnaires the researcher took time to explain the purpose of the study in more detail and to answer any queries. In a number of cases clinical concerns or management issues came up, which were directed to the clinician responsible for the case. Participants were debriefed at the end of the appointment and asked how they had found the experience, and checks were made to ensure that they had not found the experience intrusive. All participants said that they had not found the experience intrusive, and some individuals reported finding the experience helpful as it made them consider aspects of their condition and the ways they manage which they had not considered before.

In total, the appointment took approximately 1¼ hours if it took place at the clinic. However, in the majority of cases the appointment took place at the participant's home, which usually took between 1½ to 2 hours.

3. Results

Overview

The study's results are divided into the following three sections:

1. The profile of awareness in the study's sample of dementia patients will first be considered, and level of awareness of current functioning in the different dementia subtypes will be examined. The possibility of dissociations in unawareness will also be investigated by considering awareness separately for different functional modalities. Previous studies have produced conflicting results regarding factors associated with unawareness. The correlation of relevant factors with unawareness (e.g. disease-related variables, demographic and psychiatric factors) will, therefore, be examined. Finally, the introductory chapter noted that the context of the assessment of awareness is not usually detailed in studies. However, there may be a motivation for the patient to present himself or herself in a certain way depending on the context. The locations of the assessments will be detailed and compared to see if there is any associated difference in level of expressed awareness.
2. The second section will address the question, 'Do psychological and social factors affect level of awareness in dementia?' More specifically the psychological factors of the patient's pre-morbid personality and use of avoidant coping strategies, and social factors such as the patient's level of communication with partners will be considered. Data on measures of patients' pre-morbid personality, use of avoidant coping, and level of communication with partners will be presented. The methodological validity of using patients' self-ratings of pre-morbid personality will be checked by looking at the level of agreement with partners' ratings. In addition, patients' pre-morbid

personality ratings will be compared to published normative data to see if there are any specific pre-morbid personality differences in people who go on to develop dementia compared to the general population.

3. The final section will focus on the question, 'Does patients' level of awareness contribute to carer burden?' Data on relevant measures will also be detailed.

Data preparation

Exploratory data analysis was conducted prior to all analyses. Data was inspected for normality by visual inspection, examination of skewness and kurtosis, and the Kolmogorov-Smirnov test of deviations from normality. Tests for outliers were also done, and cases with scores of more than three standard deviations from the mean were excluded from the analysis. In each section, the exploratory data analysis will only be mentioned if variables were found to significantly deviate from normality and if transformation was required.

For all regression analyses, checks were made to ensure that the assumptions of the regression were met. The errors of prediction (the residuals) were inspected to ensure that they were normally distributed around a mean of zero. In order to check the assumption of *homogeneity of variance in arrays*, a plot of the residuals against the predicted values of the dependent variables was visually inspected to confirm that the scatter was evenly distributed. Finally, Cook's distance values (Cook & Weisberg, 1982) were calculated and inspected for multivariate outliers. Cook's distances are a measure of

outliers which heavily influence the regression. For all the regressions performed there were no problems with any of these points.

In three cases there were incomplete data sets due to time constraints on completing the questionnaires during clinic visits (in two cases the NEO-FFI self-rated questionnaire was not completed fully, in one case the Ways of Coping Checklist could not be finished and in three cases partners did not finish completing the Burden Interview). In addition, one couple did not feel that the Dyadic Adjustment Scale was applicable to their living situation, as they described themselves as platonic, long-term, live-in partners.

3.1. Part 1: Profile of awareness in the study's sample of individuals with dementia

Awareness was measured with the Memory Insight Questionnaire (MIQ), which asks the person with dementia and an informant (the partner in this study) to rate the patient's level of functioning in a number of different areas. Patients' level of awareness is defined by the discrepancy between patient and informant ratings on the MIQ. For each respondent scores on the self-rated and informant-rated scales were totalled. An awareness discrepancy score was derived for each participant by subtracting the overall MIQ self-report score from the overall partner-report score. Therefore, larger awareness discrepancy scores indicate a lower level of patient awareness regarding level of functioning. The sample's MIQ scores are summarised in Table 3.1.

Table 3.1: MIQ descriptive statistics

	Mean	SD	Minimum	Maximum
Self-rated: total MIQ score	50.3	7.9	36	70
Partner-rated: total MIQ score	57.8	5.6	44	72
Awareness discrepancy score ¹	7.5	8.3	-8	28

¹ a score of 0 is taken to indicate good awareness of level of functioning on the part of the patient. A positive score indicates lower levels of awareness. A negative score indicates hyperawareness.

Exploratory data analysis showed that the MIQ awareness discrepancy scores were normally distributed about the mean and that there were no outliers. A paired samples t-test indicated that partners rated patients as having significantly more difficulties on the MIQ compared to patients' self-report on the questionnaire [$t(48)=-6.32, p<0.001$].

3.1.1. Comparison of level of awareness in different subtypes of dementia

Awareness discrepancy scores for the different subtypes of dementia are detailed in Table

3.2. It was not possible to conduct statistical analyses to investigate differences in the level of awareness in different dementias due to the small numbers of participants in each group.

Table 3.2: Awareness discrepancy scores for the different subtypes of dementia

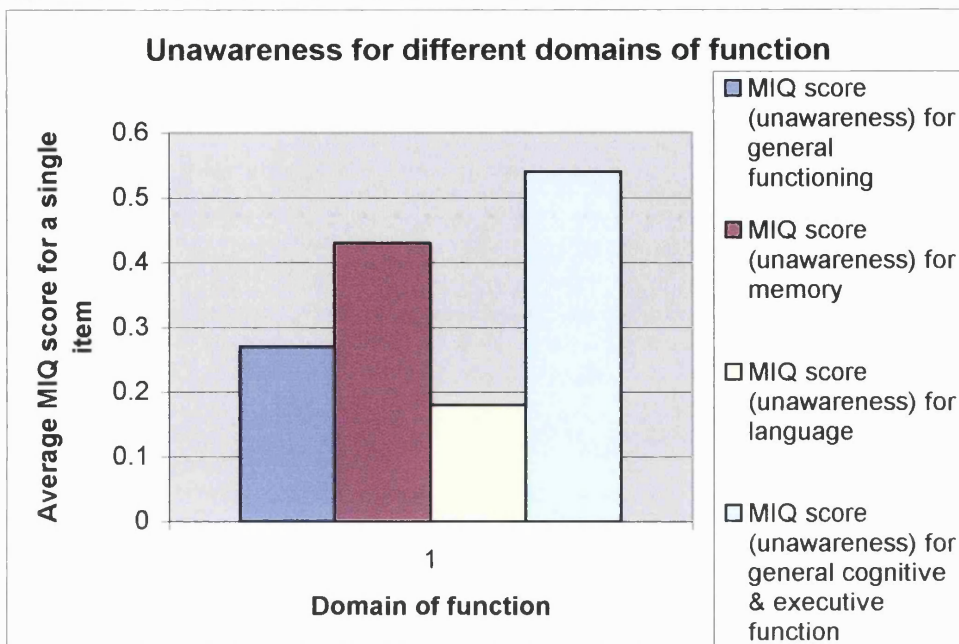
Diagnostic subtype	Mean	SD	Minimum	Maximum
Alzheimer's disease (N=32)	7.2	9.0	-8	28
Familial Alzheimer's disease (N=4)	4.0	4.1	1	10
Vascular dementia (N=9)	11.0	7.5	0	24
Mixed Vascular/Alzheimer's (N=2)	8.5	5.0	5	12
Lewy-body dementia (N=2)	3.0	8.5	-3	9

Note: a lower awareness discrepancy score indicates a higher level of awareness in the patient. A negative score indicates hyperawareness.

3.1.2. Comparison of level of awareness for different functional modalities

The Memory Insight Questionnaire requires patients and their partners to rate patients' level of functioning in four main areas: general function, memory (general, autobiographical and procedural), language function and cognitive function (general and executive function). As there are different numbers of items in these different areas, an average awareness discrepancy score for a single item was calculated for each participant in these four functional domains. Figure 3.1 depicts these relative awareness discrepancy scores for the different modalities of function on the MIQ.

Figure 3.1: Unawareness for the different functional domains on the MIQ



Note: a lower awareness discrepancy score indicates a higher level of awareness in the patient.

To explore whether there were any significant differences in awareness in these different functional modalities, average awareness discrepancy scores for each MIQ domain were subjected to a repeated measures one-way ANOVA. Prior to the analysis being performed, exploratory data analysis showed that there was an outlier data point in the MIQ – language domain which was excluded from the analysis. The ANOVA analysis revealed that average awareness discrepancy scores differed significantly according to functional modality [$F(3,45)=6.98$, $p=0.001$; this F value was based on Wilks' Lambda - a multivariate approach was used in the repeated measures ANOVA as it does not make the assumptions of univariate tests]. Subsequent comparisons with t-tests on all possible pairwise combinations indicated that average awareness discrepancy scores in the language domain were significantly lower than for the memory domain [$t(47)=3.35$, $p=0.002$] and the cognitive (general and executive function) modality [$t(47)=-4.35$, $p<0.001$]. These

results are still significant even if interpreted at the more stringent significance level of 0.01, in order to control for the increased familywise error rate resulting from multiple comparisons. This suggests that awareness for language function was significantly better than awareness for memory function or general cognitive and executive function.

3.1.3. Factors associated with lower levels of awareness

To explore the correlates of unawareness, simple two-tailed Pearson's correlations were performed between awareness discrepancy scores and age of the patient, occupational status (as defined by OPCS), dementia severity (MMSE), duration of symptoms (as reported by the partner), patients' level of depression (Hospital Anxiety & Depression Scale, HADS-depression) and anxiety (HADS-anxiety). The results, which are detailed in Table 3.3, indicate that patient unawareness is associated with increasing age [$r=0.29$, $p<0.05$]. In addition, higher levels of awareness are associated with increased levels of depressive symptoms (as self-reported by patients on the HADS) [$r=-0.32$, $p<0.05$]. Although not statistically significant at a 0.05 level, there was a trend for higher levels of awareness to be associated with higher levels of anxiety symptoms (as self-reported by patients on the HADS), and for lower levels of awareness to be associated with a longer duration of symptoms. No significant relationship was found between levels of awareness and disease severity or occupational status.

Table 3.3: Pearson's correlation coefficients between awareness discrepancy scores and possible associated factors.

	Awareness discrepancy score	
	Pearson's correlation coefficient	Significance level
Age	0.29	0.04*
Occupational status	0.05	0.74
MMSE	-0.09	0.54
Symptom duration	0.25	0.08
HADS-depression	-0.32	0.03*
HADS-anxiety	-0.28	0.05

Occupational status, as classified by the Office of Population Censuses and Surveys, 1995; MMSE, Mini-mental State Examination; HADS-depression, depression scale of the Hospital Anxiety & Depression Scale; HADS-anxiety, anxiety scale of the Hospital Anxiety & Depression Scale

* Significant at the level $p < 0.05$

All patients completed the Hospital Anxiety and Depression Scale. 'Clinical caseness' was defined as a minimum score of 11 on the anxiety and depression scale. On the anxiety scale, 8.1% of patients reached the criterion for 'caseness' and on the depression scale 4% reached the criterion.

3.1.4. The effect of context on the expressed level of awareness

It was observed in the introductory chapter that studies do not usually give detail regarding the context of the assessment of awareness. In this study, 37% of the participants completed the research during clinic visits, whilst the remaining 63% of participants were visited at home. An independent samples t-test indicated that there was no significant difference in the mean awareness discrepancy scores between these two different testing locations [$t(47) = -0.77, p = 0.45$].

3.2. Part 2: Do psychological and social factors affect level of awareness in dementia?

2.a. Do pre-morbid personality factors (in particular conscientiousness and stoical and reserved attitudes towards emotional expression) and use of avoidant coping strategies contribute to unawareness in people with dementia?

2.b. Do social, interpersonal factors such as level of communication with partners contribute to unawareness in people with dementia?

The model relevant to this section is illustrated in Figure 3.2 (on page 101). However, before the questions above are considered, data on measures of patients' pre-morbid conscientiousness, attitudes towards emotional expression, use of avoidant coping strategies and level of communication with partners will be examined.

In terms of personality factors, patients' pre-morbid conscientiousness was rated using self-ratings on the conscientiousness scale of the short NEO five-factor Personality Inventory (NEO-FFI) and partner-ratings on the conscientiousness scale of the full length NEO Five-factor Personality Inventory (NEO PI-R). Patients' attitudes towards emotional expression were self-rated on the Attitudes towards Emotional Expression Questionnaire. Patients' use of avoidant coping strategies to manage their condition was measured using the self-rated Ways of Coping checklist (WCCL). The number of avoidant coping strategies used was expressed as a proportion of the total number of ways of coping employed. Interpersonal factors in terms of patients' level of communication with partners was measured (and rated by patients) using selected items from the Dyadic

Adjustment Scale (DAS). Descriptive statistics for these measures are summarised in Table 3.4.

Table 3.4: Descriptive statistics for measures relevant to Part 2

Measure	Mean	SD	Minimum	Maximum
Conscientiousness scale, NEO-FFI (self-rated) (<i>max 48</i>)	36.04	7.32	21	48
Conscientiousness scale, NEO-PI-R (partner-rated) (<i>max 192</i>)	127.29	30.15	33	185
Attitudes to emotional expression (self-rated) (<i>max 100</i>)	52.94	12.38	30	79
Proportion of avoidant coping strategies used (self-rated)	0.15	0.11	0.00	0.42
Selected items from the DAS (<i>max 20</i>) (self-rated)	13.49	2.23	9	19

The validity of using dementia patients' ratings of pre-morbid personality can be checked by examining the level of agreement between self-ratings and partner-ratings on the conscientiousness scale of the NEO-FFI and NEO PI-R. Pearson's correlation coefficient (two-tailed) was significant [$r=0.51$, $p<0.001$] suggesting that dementia patients in the current study were able to accurately rate their pre-morbid personality, thus lending support for the validity of the methodological approach in this study. It was not possible to calculate an intra-class correlation coefficient, which measures agreement in terms of the linear relationship between scores (like Pearson's correlation coefficient) as well as differences in mean scores between raters, because the dementia patient completed a short version (NEO-FFI) whilst the partners completed the full-length version (NEO PI-R).

3.2.1. Comparison of the sample's scores on measures of personality with published normative data

One sample t-tests showed that the mean ratings for the personality trait of conscientiousness in the study's sample of people with dementia (rated pre-morbidly) was not significantly different from published normative data (Costa & McCrae, 1992) [NEO-FFI, self-rated, $t(46)=1.38$, $p=0.17$; NEO PI-R, partner-rated, $t(48)=-1.54$, $p=0.13$].

The conscientiousness scale of the full-length version of the NEO PI-R (rated by the partner) has six subscales: C1 competence, C2 order, C3 dutifulness, C4 achievement striving, C5 self-discipline, C6 deliberation. In a similar vein, the Attitudes towards Emotional Expression Questionnaire has four subscales: beliefs about the meaning of emotional expression, behavioural style, beliefs about expression and beliefs about the consequences of emotional expression. The short, self-rated NEO-FFI does not have separate subscales. The research questions in this section consider patients' pre-morbid personality in terms of the total conscientiousness scale and the total Attitudes towards Emotional Expression scale rather than focusing on specific individual subscales. Entering the specific subscales (a total of 10 variables) into the analysis would reduce the power of the study and increase the probability of a type II error occurring. However, it is still useful to examine the sample's profile on these subscales and to check that they do not significantly differ from published normative data. Descriptive statistics of the conscientiousness subscales (as rated by the partner on the NEO PI-R) and the subscales of the self-rated Attitudes towards Emotional Expression Questionnaire are listed in Table 3.5.

Table 3.5: Descriptive statistics of conscientiousness subscales and Attitudes towards Emotional Expression subscales

Measure	Subscale	Mean	Published Normative mean ¹	SD	Published Normative SD
NEO PI-R	C1 competence (<i>max 32</i>)	22.8*	25.0	5.7	4.0
Partner-rated	C2 order (<i>max 32</i>)	18.3	19.4	6.4	4.7
	C3 dutifulness (<i>max 32</i>)	25.4	25.1	4.8	3.6
	C4 achievement striving (<i>max 32</i>)	19.6	20.7	6.0	4.2
	C5 self-discipline (<i>max 32</i>)	20.8	22.9	6.8	5.2
	C6 deliberation (<i>max 32</i>)	20.6	20.8	5.6	4.6
Attitudes towards Emotional Expression Q self-rated	Beliefs about meaning of emotional expression (<i>max 25</i>)	10.08*	6.39	3.74	2.73
	Behavioural style (<i>max 25</i>)	15.38*	12.21	4.64	4.60
	Beliefs about expression (<i>max 25</i>)	15.15*	8.94	3.62	3.50
	Beliefs about the consequences of emotional expression (<i>max 25</i>)	12.54*	10.62	3.64	3.27

¹ Normative data on the conscientiousness subscales of the NEO PI-R are based on an adult sample, with combined scores for men and women (Costa & McCrae, 1992). Normative data for the Attitudes towards Emotional Expression Questionnaire are based on a student population (Joseph et al., 1994)

* denotes subscale means which were significantly different from the published normative mean as determined by a one sample t-test with a significance level set more stringently at $p=0.005$ to control for possible increase in the familywise error rate resulting from multiple comparisons.

The study's sample of people with dementia were rated as significantly lower in pre-morbid competence by their partner compared to the published, normative mean. This may be because people with dementia are generally lower in the competence trait before they develop symptoms of dementia compared to the general population (this will be considered more fully in the next chapter). However, it may also be due to the current level of functioning of dementia patients distorting partners' ratings of pre-morbid competence. Of course, there is also always the possibility that the result could be due to a type I error, especially given the fact that multiple comparisons have been done.

Individuals with dementia in this study also scored significantly and consistently higher on every subscale of the Attitudes towards Emotional Expression Questionnaire compared to published normative means. This suggests that the study's sample of dementia patients were pre-morbidly less ready to express emotion compared to the sample of participants who were used in the development of the questionnaire. However, this questionnaire was developed and tested on a student population who grew up in a different generational culture compared to the older adults in this study; therefore, cohort effects could account for the increase in scores of this study's participants on this measure.

Exploratory data analysis revealed that the measure of avoidant coping was positively skewed and that there was an outlier which was more than three standard deviations from the mean. Therefore, the variable was subjected to a square root transformation and the outlier was removed to ensure that the data were normally distributed prior to performing analyses to test the hypotheses and model in this section.

The proposed model relevant to this section was discussed in 'Aims and research questions' and is depicted in Figure 3.2 (on page 101). The model makes a number of testable, falsifiable predictions:

3.2.2. The model predicts a relationship between pre-morbid personality variables in the person with dementia in terms of conscientiousness and attitudes towards emotional expression and their use of avoidant coping strategies in managing their condition.

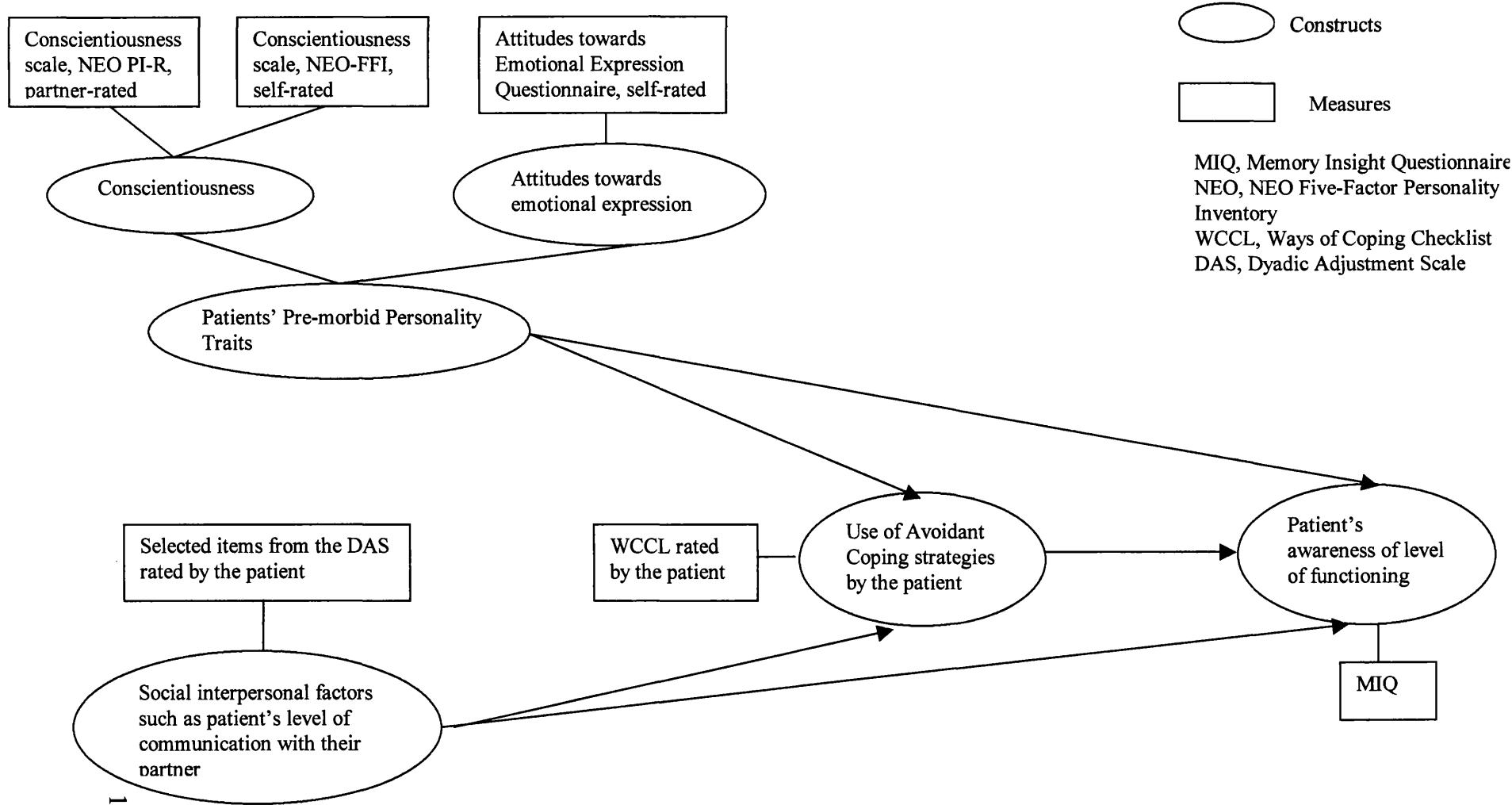
This will be investigated with a multiple regression analysis to assess the effect of

pre-morbid conscientiousness and attitudes towards emotional expression on use of avoidant coping strategies in the dementia patient.

3.2.3. The model also predicts a relationship between level of open, verbal communication and arguments that the dementia patient experiences with their partner and patients' use of avoidant coping strategies. The model predicts a negative correlation between level of communication and avoidant coping, with lower scores on selected items of the Dyadic Adjustment Scale (as rated by the patient) being associated with an increased use of avoidant coping strategies.

3.2.4. To investigate the three possible independent pathways to awareness, a multiple regression will be done with patients' level of awareness serving as the dependent variable and pre-morbid personality factors of conscientiousness and attitudes towards emotional expression, use of avoidant coping and level of communication with partners as independent variables. Other variables which have previously been found to relate to awareness will also be controlled for in the regression (e.g. dementia severity, duration, depression and anxiety in the patient).

Figure 3.2: Proposed Model



3.2.2. Prediction of a relationship between patients' pre-morbid personality and use of avoidant coping strategies

A multiple regression was performed in which the transformed avoidant coping variable served as the dependent variable and where pre-morbid conscientiousness (self-rated on the NEO-FFI and partner-rated on the NEO PI-R) and attitudes towards emotional expression (self-rated) were entered as three independent variables. The overall regression was significant [$F(3,42)=4.06$, $p=0.01$], with pre-morbid personality variables explaining around 22.5% of the variance in avoidant coping. Inspection of the regression coefficients revealed that only the attitudes towards emotional expression variable was significant [$\beta=0.47$, $t=3.38$, $p=0.002$], indicating that only attitudes towards emotional expression independently predict use of avoidant coping strategies. Indeed, calculation of Pearson's correlation coefficients (two-tailed) between pre-morbid personality variables and the transformed avoidant coping variable (See Table 3.6) also indicated that only attitudes towards emotional expression significantly correlated with use of avoidant coping. Measures of conscientiousness (both self-rated and partner-rated) showed very little relationship with avoidant coping.

Table 3.6: Pearson's correlation coefficients between pre-morbid personality variables and avoidant coping

	Patient's premorbid personality features		
	Attitudes towards Emotional Expression Questionnaire	Conscientiousness (NEO-FFI, self-rated)	Conscientiousness (NEO PI-R, partner-rated)
Patient's use of avoidant coping strategies	$r=0.44$ $p=0.002^*$	$r=-0.02$ $p=0.91$	$r=0.09$ $p=0.55$

3.2.3. Prediction of a relationship between patients' level of communication with partners and use of avoidant coping strategies

Pearson's correlation coefficient (two-tailed) showed that there was no significant association between level of communication with partners (as measured by selected items on the Dyadic Adjustment Scale, patient-rated) and patients' use of avoidant coping strategies [$r=-0.08$, $p=0.61$].

3.2.4. Prediction of a relationship between patients' pre-morbid personality, use of avoidant coping, level of communication with partners and patients' awareness of current functioning.

A hierarchical regression was performed with awareness discrepancy scores (from the Memory Insight Questionnaire) serving as the dependent variable. The variables of dementia severity (MMSE), duration of symptoms (as rated by the partner), patients' level of depression (HADS-depression scale) and anxiety (HADS-anxiety scale) were entered at the first step in order to control for their effect on awareness. The independent variables of patients' pre-morbid conscientiousness (self-rated, NEO-FFI), pre-morbid conscientiousness (partner-rated, NEO PI-R), attitudes towards emotional expression, avoidant coping and patients' ratings on selected items on the Dyadic Adjustment Scale were entered at the second step. The results are shown in Table 3.7.

Table 3.7: Relationship of key variables with patients' awareness

	R ²	F value	Associated P value	β	P associated with β
Step 1	0.21	2.76	For F, p=0.04		
MMSE				-0.03	0.86
No. of years of symptoms				0.28	0.05
HADS-depression				-0.19	0.25
HADS-anxiety				-0.26	0.12
Step 2	R ² change	F change	For F change,		
	0.12	1.30	p=0.29		
NEO-FFI				0.38	0.05
NEO PI-R				-0.25	0.19
Attitudes towards Emotional Expression				0.04	0.79
Transformed avoidant coping strategies				0.12	0.46
Selected items on the DAS				-0.11	0.45

These results indicate that the control variables together significantly predict patient's level of awareness [$F(4,41)=2.76$, $p=0.04$] and can explain around 21% of the variance in the dependent variable. However, inspection of the regression coefficients indicates that none of the control variables independently predict level of awareness (using $p<0.05$). The explanatory power of the regression model does not improve significantly when the independent variables of pre-morbid personality, use of avoidant coping and level of communication with partners are added [R^2 change=0.12, F change (5,36)=1.30, $p=0.29$]. Overall, the results of the regression do not support the broad hypothesis that psychological and interpersonal factors influence patients' level of awareness after controlling for disease severity and duration, and depression and anxiety in the patient. Pearson's correlation coefficients (two-tailed) between pre-morbid personality factors, use of avoidant coping, level of communication with partners and patients' level of awareness were subsequently calculated to see if there was any overall relationship between these factors and awareness. The results are detailed in Table 3.8. Only patients' pre-morbid

conscientiousness (as self-rated by the patient) correlated significantly with level of awareness, with higher self-ratings of conscientiousness associated with reduced awareness of level of functioning. No other significant relationships were found.

Table 3.8: Pearson's correlation coefficients between psychological and social variables and patients' awareness

	NEO-FFI (patient, self-rated)	NEO PI-R (partner-rated)	Attitudes towards emotional expression	Avoidant coping	Selected items from the DAD (patient-rated)
Awareness discrepancy score	r=0.31 p=0.03*	r=0.01 p=0.96	r=0.15 p=0.29	r=0.10 p=0.49	-0.08 0.59

*significance at level $p < 0.05$

3.3. Part 3: Does patients' level of awareness contribute to carer burden?

This section of the study is concerned with re-investigating the association between low awareness in the patient and increased carer burden, which has been reported in previous studies (e.g. Seltzer et al., 1997).

Carer burden was measured using the Burden Interview. Data regarding dementia severity (MMSE), the quality of the pre-morbid relationship as viewed by the partner (Dyadic Adjustment Scale, DAS) and anxiety and depression in the partner (Hospital Anxiety and Depression Scale, HADS) was also collated so that their contribution to carer burden could be controlled for in the analysis. Descriptive statistics for these variables are summarised in Table 3.9

Table 3.9: Descriptive statistics for carer burden, quality of pre-morbid relationship and partner's anxiety and depression

Measure	Mean	SD	Minimum	Maximum
Burden Interview (<i>max 88</i>)	32.07	15.13	10	68
DAS (<i>max 151</i>)	118.71	18.53	69	146
HADS-depression, partner (<i>max 21</i>)	5.04	3.93	0	16
HADS-anxiety, partner (<i>max 21</i>)	8.86	4.57	0	19

DAS, Dyadic Adjustment Scale; HADS, Hospital Anxiety & Depression Scale

3.3.1. Anxiety and depression in the partner

All 49 partners completed the HADS. On the anxiety scale 35% of partners reached the previously defined criterion for 'clinical caseness' and on the depression scale 12.2% reached the criterion.

Exploratory data analysis revealed no outliers in the variables relevant to this section's analysis. However, data on the Burden Interview and the HADS partners' depression scale was found to be positively skewed. Both variables were subject to a square root transformation prior to the analysis. Data on the DAS measure of the quality of the pre-morbid relationship was negatively skewed. Scores on this variable were transformed by reflection, adding the sample's maximum score and taking the square root of this.

3.3.2. Regression analyses

The question, 'Does patients' level of awareness contribute to carer burden?' was investigated using two regression analyses. The first regression considered whether patients' level of awareness predicted carer burden. The second regression considered whether level of awareness predicted carer burden after dementia severity, quality of pre-morbid relationship and partners' anxiety and depression levels were controlled for.

In the first regression Burden Interview scores were entered as the dependent variable with awareness discrepancy scores (from the Memory Insight Questionnaire) as the independent variable. The regression was significant [$F(1,44)=11.23$, $p=0.002$] with patients' level of awareness explaining around 20% of the variance in carer burden.

The second regression was conducted in a hierarchical manner with Burden Interview scores serving as the dependent variable. The variables of dementia severity (MMSE), quality of pre-morbid relationship (DAS) and partners' anxiety and depression (HADS-anxiety and HADS-depression) were entered in step 1 as control variables. The awareness

discrepancy score was entered as the independent variable in step 2. The results are shown in Table 3.10

Table 3.10: Relationship of key variables to carer burden

	R ²	F value	Associated P value	β	P associated with β
<u>Step 1</u>	0.54	11.88	For F, p=0.000		
MMSE				0.07	0.55
HADS – anxiety, partner				0.33	0.03*
HADS – depression, partner				0.46	0.00*
DAS				0.05	0.65
<u>Step 2</u>	R ² change	F change	For F change,		
	0.04	3.37	p=0.07		
MMSE				0.09	0.39
HADS – anxiety, partner				0.29	0.04*
HADS – depression, partner				0.40	0.01*
DAS				0.05	0.66
Awareness discrepancy score				0.21	0.07

MMSE, Mini-Mental State Examination; HADS, Hospital Anxiety & Depression Scale; DAS, Dyadic Adjustment Scale

Once control variables are included in the model, the value of R² change indicates that only a further 4% of the variance in carer burden is predicted by patients' level of awareness [R² change=0.04, F change(1,39)=3.37, p=0.07]. The significance of the proportion of the variance accounted for by patients' level of awareness after accounting for dementia severity, quality of the pre-morbid relationship and partners' anxiety and depression is much reduced. Inspection of the regression coefficients indicates that only partners' anxiety and depression predicts carer burden independently of the other independent variables. Therefore, it would appear that although patients' level of awareness does predict level of carer burden, this effect is not independent of partners' anxiety and depression.

The results of all three parts of the study (the profile of awareness in the study's sample of dementia patients; the question of whether psychological and social factors affect level of awareness in dementia; and the issue of whether patients' unawareness contributes to carer burden) will be fully summarised and discussed in the next chapter. Possible interpretations of the study's findings will also be considered.

Discussion

4.1. Summary of the findings

Part 1

In terms of the profile of awareness of current functioning in the study's sample of 'non-frontal' dementia patients, the salient results were:

- The study found different levels of awareness in different dementia subtypes. However, the small number of participants in each group did not allow formal statistical analysis of these differences.
- Level of awareness differed for different functional modalities.
- Level of awareness correlated significantly with patients' age and level of self-reported depression symptoms. There was a non-significant trend for awareness to be associated with anxiety symptoms and duration of disease. No significant relationship was found between awareness and disease severity or pre-morbid occupational status.
- There was no significant difference in level of expressed awareness according to the assessment's location.

Part 2

Do psychological and social factors affect level of awareness in dementia?

- Pre-morbid personality factors, in particular stoical and reserved attitudes towards emotional expression independently predicted patients' use of behavioural avoidant coping strategies in managing their condition.

- Higher self-ratings of patient pre-morbid conscientiousness were significantly associated with unawareness. However, conscientiousness was not found to be a significant predictor of unawareness in multiple regression analyses once disease severity, duration and patients' depression and anxiety were controlled for. There was no relationship between unawareness and patients' use of behavioural avoidant coping strategies.

Part 3

Does patients' level of awareness contribute to carer burden?

- Patients' level of awareness was found to predict level of carer burden (with unawareness predictive of higher levels of carer stress). However, this effect was not independent of partners' anxiety and depression.

4.2. Discussion & interpretation of the study's results

4.2.1. Part 1

The study's results confirm previous findings that dementia patients on average tend to over-rate their level of functioning compared to partners' ratings. In the current sample of dementia patients, 79.6% over-rated their performance compared to partners' ratings, 16.3% under-rated their level of functioning and 4.1% rated their level of functioning at the same level as partners.

4.2.1.1. Awareness in the different subtypes of ‘non-frontal’ dementias

In this study’s sample of dementia patients, there were different levels of awareness (as assessed by awareness discrepancy scores on the Memory Insight Questionnaire) in the different dementia subtypes. However, the study was not specifically designed to investigate levels of awareness in different diagnoses of ‘non-frontal’ dementias, and there were insufficient numbers of participants in each diagnostic group to conduct statistical analyses and to draw firm conclusions regarding level of awareness in different dementias. It is an area which may warrant further investigation, as previous studies have reported mixed results. DeBettignies et al. (1990) and Wagner (1997) found that a lower level of awareness was more common in Alzheimer’s disease compared to vascular dementia. In contrast, Verhey (1995) and Zanetti et al. (1999) found similar levels of unawareness in Alzheimer’s disease and vascular dementia. In addition, the *relatively* new diagnostic subtype of Lewy-body dementia has not yet been studied in terms of levels of unawareness.

4.2.1.2. Awareness for different functional modalities

Dementia can lead to changes in functioning in a number of different domains. There may be disturbances in various areas of cognitive functioning and general daily living skills, as well as emotional and behavioural functioning. In the current sample of dementia patients, awareness of language function was significantly better than awareness for memory and general cognitive and executive function. The statistical significance of this finding was relatively robust as it was significant even when evaluated at a more stringent significance level to control for multiple comparisons. This

finding supports the observation that there are a number of different, possible ‘objects of insight’ in dementia, which can lead to dissociations in awareness. These results could be considered to be in keeping with neuropsychological models of unawareness, which propose that modality-specific unawareness results from the disconnection of specific psychological modules for different cognitive functions to a central awareness system. However, social psychological factors could also explain this pattern of results. The communicative nature of language means that it could be thought of as the most socially based area of cognition. This might mean that dementia patients receive relatively more feedback and opportunities to evaluate language function compared to other cognitive skills, which could lead to relatively better awareness of language function compared to other cognitive abilities. Therefore, administering the Memory Insight Questionnaire through verbal self-report may actually affect patients’ awareness of their language function, thus biasing the measure. It might be useful if future research replicated the study of awareness for different functional modalities using different measures. The current study was limited in the domains of functioning which could be investigated as the Memory Insight Questionnaire only considers difficulties in the areas of general functioning, memory function, language function and general cognitive and executive functioning. There may also be emotional and behavioural changes which are potential ‘objects of insight’ and which can lead to further dissociations in awareness (e.g. Vasterling, 1995; Kotler-Cope & Camp, 1995).

4.2.1.3. Correlates of unawareness

The study also considered the question of whether unawareness in dementia correlates with specific demographic, disease-related and emotional variables. These relationships are important as they may provide potential insights into the possible neurological and psychological mechanisms of unawareness in dementia. These potential associations have been considered in a number of studies, but widely different conclusions have been reached regarding the nature of these relationships. Variations in methodology may be responsible for some of these discrepancies. Indeed some studies have used relatively crude measures of awareness, for example making a categorical judgement of a patient's awareness based on their responses to only a few questions during a clinical interview (e.g. McDaniel et al. 1995; Auchus et al., 1994). The current study avoided certain biases associated with such methodology by using a standardised questionnaire measure to assess patients' awareness of level of functioning (the Memory Insight Questionnaire, MIQ), which defines awareness as the discrepancy between patients' ratings of their level of functioning in a number of different areas and partners' ratings. This measure has been found to have good reliability (Marková, 1997), and allows for a finer-grain discrimination regarding levels of awareness rather than a categorical judgement. It also captures different aspects of unawareness such as explicit verbal denial of difficulties, minimising of difficulties or attribution of them to something other than dementia, and awareness for different domains of function.

Unawareness (as measured by the MIQ) correlated significantly with age and with patients' self-report of depressive symptoms on the Hospital Anxiety and Depression

Scale. Reduced awareness was associated with increasing age, and patients with greater awareness were more likely to report depressive symptoms. There was a general trend for awareness to be associated with self-reported anxiety symptoms on the Hospital Anxiety and Depression Scale and with duration of disease (as rated by partners). No relationship was found between unawareness and disease severity (as assessed by scores on the Mini-Mental Status Examination) or pre-morbid occupational status (as defined by the Office of Population and Censuses and Surveys, 1995).

Regarding the age of the patient, the current results are in keeping with previous research which has also found that older people are more likely to show less awareness (Lopez, 1994). This result could be interpreted as supporting the relevance of social factors in the development of awareness in dementia. It was hypothesised in the introductory chapter that younger people with dementia may be subject to different experiences which could influence awareness. Younger people are more likely to be working which may mean that they are confronted with more direct feedback regarding changes in their level of functioning. Indeed, during the interviews a number of younger participants reported that changes in their cognitive functioning had led to problems in their performance at work and the need to confront their difficulties. The process of deciding whether to give up work was cited as having a major impact on the patient which possibly contributed to the development of awareness.

The finding that patients with greater awareness of their difficulties are more likely to report depressive symptoms has been reported in previous studies (e.g. O'Connor et al.,

1990; Sevush & Leve, 1993). However, other studies have found no significant relationship (Reed et al., 1993; DeBettignies et al., 1990; Zanetti et al., 1999). It should be noted that the current study assessed level of depressive symptoms using a self-report questionnaire and did not use clinical interviews to apply diagnostic criteria of clinical depression. Therefore, while it may be that awareness is associated with increased levels of self-reported depressive symptoms, the study cannot conclude that awareness is related to clinical depression (as defined by diagnostic criteria). This conclusion is reminiscent of Migliorelli et al.'s (1995) finding that awareness correlated with dysthymia but not major depression. The direction of causality in this relationship is not clear. The result could have significant clinical implications as it may be that greater awareness is a risk factor for depressive symptoms in dementia patients. However, the result could also be due to depression leading to over-reporting of cognitive deficits and a hyperawareness of difficulties.

The trend for increased awareness to be associated with higher levels of anxiety symptoms is consistent with previous research (Migliorelli et al., 1995). However, in a similar manner to the relationship between awareness and depression, the direction of causality is unclear. Future research to examine the nature of the relationship between awareness, depression and anxiety in more detail would be useful, as this may provide understanding regarding the direction of causality. This relationship has potential implications for the assessment of awareness as well as clinical practice.

In the current study, there was a non-significant trend for duration of symptoms to covary with awareness, such that reduced awareness was associated with a longer duration of symptoms. Although non-significant (as defined by $p < 0.05$), this is potentially an important result. The study found a trend for these variables to be related even though many participants were in the relatively early stages of dementia and had thus experienced symptoms for a limited duration. This was a necessary feature of the study's design, as participants needed a certain level of cognitive functioning to complete the Memory Insight Questionnaire, and hence tended to be in the earlier stages of their condition. It is possible that a study which included a wider cross-section of patients with respect to duration of disease might find a more significant correlation with unawareness. Previous cross-sectional studies have also found that a longer duration of illness was associated with reduced awareness (Migliorelli et al., 1995). If a longer duration of disease is associated with reduced awareness, this may be due to a link between disease progression and unawareness which would point to the role of organic factors in unawareness. However, an association between unawareness and longer disease duration could also be due to psychological factors. It is possible that as dementia progresses the individual's capacity for coping is reduced and there is a need to rely on more basic psychological defence mechanisms such as denial. Indeed, Kitwood (1997) suggests that as dementia progresses more sophisticated coping actions may no longer be available to the individual, and there may be an increased need to rely on more basic strategies learnt in childhood.

In terms of the absence of a relationship between unawareness and disease severity, previous studies have also reported this result (DeBettignies et al., 1990; Reed et al., 1993; Auchus et al., 1994). This finding would appear to be at odds with an organic, biological conceptualisation of unawareness in dementia, which would predict that unawareness is associated with increasing neurological deterioration. Zanetti et al.'s (1999) study found that unawareness was associated with cognitive status in a nonlinear manner. More specifically, the study reported no association between unawareness and cognition in the early stages of dementia but a linear association was found between unawareness and severity when MMSE scores were in the range of 12 to 24. Although the mean MMSE score in the current study was within this range (mean MMSE score 24, SD 3.3), no relationship between awareness and severity was detected. However, the range of MMSE scores in the current study was narrower than in Zanetti et al.'s study (as a certain level of cognitive functioning was needed to complete the relatively sophisticated Memory Insight Questionnaire). Therefore, it is possible that the current study was less sensitive to the effect of disease severity and organic factors in unawareness. It could be the case that these factors are more important in determining level of awareness at a more advanced stage of the disease, and that at an earlier stage in the disease non-biological variables are more important in determining variations in awareness. Valid assessment of awareness in the later stages of the disease is more problematic. Therefore, it is also possible that the increased unawareness which has been reported in patients who are at a more severe stage of dementia is actually an artefact of measurement difficulties.

The lack of a relationship between pre-morbid occupational status and level of awareness in this study is in keeping with previous studies, which have found no influence of educational level or pre-morbid IQ on awareness.

Although a number of statistical analyses were conducted to examine the correlations between level of awareness and disease-related, emotional and demographic factors, it should be noted that these analyses were not conducted in an *ad hoc* manner. The correlations examined were based on theoretical hypothesising and previous research. It is important that research is planned in this way so as to reduce the possibility of finding a spurious result and thus incurring a type I error.

On balance, the pattern of relationships observed is not wholly consistent with an exclusively organic model of unawareness in dementia. It appears that a purely organic model of unawareness is inadequate. The associated factors of age and depression and particularly the lack of a relationship with disease severity point to the need to consider additional non-biological factors when considering unawareness in dementia.

4.2.1.4. The effect of context on level of expressed awareness

It was hypothesised in the introductory chapter that the context of the assessment might affect level of expressed awareness. This is linked to the phenomenon known as ‘reactivity of measurement’ and the fact that the act of measurement can sometimes change the response being measured (Barker et al., 1994). Indeed, it was hypothesised that an individual may be motivated to present himself/herself in a certain manner

depending on the context of the assessment and the nature of the relationship with the assessor. The only formal measure of context in the current study was the location of the assessment. This is obviously a relatively crude measure which captures only one aspect of the assessment's context. The present study found no significant difference in the level of expressed awareness as measured by the Memory Insight Questionnaire between participants who were tested during visits to the clinic and those who were tested in their own homes.

Informal observation of how the research interview affected participants gave some further insight as to the effect of other aspects of context on level of expressed awareness. It was noted that there was some fluctuation in the level of expressed awareness within an assessment, with participants admitting problems in one sentence and denying them in another sentence. For example, one participant denied any possibility that she had dementia earlier in the assessment on the Memory Insight Questionnaire and then later spontaneously admitted "I do worry about it, you know that word that you mentioned earlier, I can't remember it... it's gone". If there were fluctuations in the level of expressed awareness, it generally appeared that individuals admitted to greater awareness over the course of the assessment. Initially some individuals seemed to rate their level of functioning relatively highly on the Memory Insight Questionnaire but later on in the assessment admitted to more significant problems. For example, one individual who categorically denied any difficulties at the beginning of the assessment later said, "well I've got brain cell death, you know" and by the end of the assessment said, "I have actually got a touch of dementia". Such fluctuations in the level of expressed awareness

are also contrary to a purely organic conceptualisation of unawareness. It could be speculated that the process of going through the Memory Insight Questionnaire and encouraging individuals to think about their functioning actually increases their awareness. It is also possible that once a rapport has been established and the individual feels that their perspective is listened to and valued, they feel safe enough to disclose their fears. This has clinical implications for professionals working with dementia patients in terms of accessibility of therapy and counselling to explore these issues (this will be discussed later in more detail). These points also have implications for future research studies assessing level of awareness; it may be that a questionnaire is a more confrontative experience for some participants that prompts use of denial. A qualitative interview which involves talking with a researcher in depth may be a more 'containing experience' which elicits a higher level of expressed awareness. Clare (2000) considers the relationship between quantitative measures of unawareness and phenomenological accounts and reports a 'fairly good' agreement between these different methodological approaches. However, she also notes some evident discrepancies and suggests that detailed interviews, with triangulation of data sources provide a richer basis for evaluating awareness.

It should be noted that all the assessments had common contextual parameters which may have increased participants' willingness to admit to difficulties. It was emphasised in all assessments that the results were confidential and would not be put into medical files, so that the research interview was distinguished from clinical interviews.

4.2.2. Part 2: Do psychological and social factors affect level of awareness in dementia?

The previous results point to the need to consider other non-biological factors when studying unawareness in dementia. Indeed, the study's primary aim was to consider dementia within a person-centred, social psychological framework and thus to consider the contribution of social and psychological factors to unawareness.

A person-centred approach to dementia emphasises the need to consider individual differences in personality style and life experiences when thinking about how people respond to the threat of dementia (e.g. Woods, 2001). Historically, the field of coping research has argued that the nature of the stressor determines coping behaviours rather than personality variables (Folkman & Lazarus, 1980). However, more recently researchers in this field have conceded that personality traits together with environmental factors do contribute to the coping process (Lazarus, 1990). The results of the present study are supportive of the broad hypothesis that pre-morbid personality factors influence how individuals respond to and cope with the threat of dementia. In particular the current study found that individuals who were more stoical and reserved in their emotional expressions were more likely to cope with their condition by using avoidant coping strategies. This finding relates to Williams's (1993, cited in Joseph et al., 1994) conclusion that negative attitudes towards emotional expression may act to block processing of emotionally charged information following exposure to a traumatic event. This has clinical implications as individuals with negative attitudes towards emotional

expression may find it particularly difficult to come to terms with the threat of dementia and may find it difficult to confide in others.

There were significant differences in the sample's pre-morbid scores on the Attitudes towards Emotional Expression scale compared to the published means (Joseph et al., 1994). It is possible that more controlled and reserved attitudes towards the expression of emotions are more common in people who go on to develop dementia. However, this result may be due to cohort differences as the questionnaire measure was developed and tested on students (Joseph et al., 1994). This population have grown up in a very different generational culture compared to the older participants in the current study. Older adults are more likely to have grown up in a culture where a stronger emphasis was placed on solving one's own problems without outside help, and where controlled emotional expression and a 'stiff upper lip' were viewed as positive attributes. Such cohort differences may have contributed to the mean difference in scores of the current sample on this measure compared to published means.

In terms of other pre-morbid personality traits, conscientiousness was not related to use of avoidant coping. It may be that individuals who score highly on the trait of conscientiousness feel compelled to consider all the options and actually use a wider range of coping strategies. It may also be that individuals high in conscientiousness are more likely to take a problem-focused approach and be orderly and practical in their application of coping strategies. Indeed, Hooker et al. (1994) found that spouse

caregivers of dementia patients who were high in conscientiousness were more likely to use problem-focused coping strategies than emotion-focused coping.

It has been suggested that certain personality traits may have a role in the aetiology of dementia (e.g. Oakley, 1965). Recent research found that Alzheimer's disease patients were rated by relatives as being relatively high in pre-morbid rigidity and neuroticism compared to controls (Meins & Dammast, 2000). At a broad level the current study has not replicated these findings. Mean ratings of pre-morbid conscientiousness (which can be thought of as similar to rigidity) in the current sample of dementia patients were not significantly different compared to the general adult population, suggesting that generally conscientiousness or 'rigid and static habits' are not risk factors for dementia or pre-clinical signs. However, at a more detailed level, the study's sample of dementia patients was rated by spouses as pre-morbidly significantly lower on the competence subscale compared to published normative data. This might be because the more specific trait of competence is a risk factor for or pre-clinical sign of dementia, or it could be that patients' current level of functioning biased partners' ratings of this characteristic.

A social psychological framework for dementia emphasises that dementia needs to be considered within a social as well as a personal, psychological context. The introductory chapter suggested that social factors may relate to the manner in which people respond to and cope with the threat of dementia. It was hypothesised that individuals who experience less open communication with their partners may also be more likely to use avoidant coping strategies to manage their condition. In addition, the concept of

'expressed emotion' was considered, and it was hypothesised that individuals who experience more confrontations and arguments with their spouses may also be more likely to employ avoidant ways of coping as a way of 'covering up' problems and managing difficulties within the relationship. This mode of communication may have been a long-standing feature of the relationship, or it may be situational, emerging in response to the threat of dementia. However, it was hypothesised that both these scenarios could lead to an increase in use of avoidant coping in the dementia patient as it was suggested that the current level of communication is the determining factor. The study's results were not supportive of this hypothesis, as no significant correlation was found between selected items on the Dyadic Adjustment Scale relevant to level of communication and arguments (as rated by the patient) and use of avoidant coping strategies. However, it is possible that methodological issues may have affected the validity of the measure of communication and hence the significance of the result. The measure of level of communication and arguments between patient and spouse was four selected items from the Dyadic Adjustment Scale. The participants in this study seemed to have relatively more difficulties in giving accurate responses on this measure relative to the other questionnaires. Indeed, this measure is possibly more problematic for someone with episodic memory difficulties, as it requires patients to give very specific ratings of the incidence of certain types of recent communication with their partners. This may have led to a higher degree of error being associated with this measure. Informally, it was observed during the interviews that some participants said that their condition had made them more concerned as to how other people in their family were feeling and subsequently they reported attempting to cover up memory problems and to

avoid expressing their feelings as a way of protecting spouses and children. This observation is reminiscent of Charmaz's (1983) work which suggests that chronically ill people may be concerned about openly revealing their suffering as this may risk estranging those who still take an interest in them, and Keady et al.'s (1995) conclusion that in the early stages of dementia individuals often cope by concealing difficulties.

The central aim of the study was to investigate the contribution of psychological and social factors to unawareness in dementia. It was hypothesised that in some individuals some aspects of unawareness may be the outcome of defensive denial. Weinstein's (1955, 1994) research on disorders of awareness suggests that people who are very conscientious and reserved in their emotional expression may be more likely to use defensive denial. The current study's results indicate that individuals with stoical and reserved attitudes towards emotional expression are more likely to cope with their condition at a behavioural level by using avoidant coping strategies. Use of avoidant behavioural coping strategies may also be hypothesised to further influence level of awareness of functioning. However, the results of the study provide mixed support for Weinstein's (1994) research. Psychological factors related to pre-morbid conscientiousness, attitudes towards emotional expression and avoidant behavioural coping, and social factors related to level of communication with spouses, did not significantly influence patients' level of awareness after controlling for disease severity, duration of symptoms and patients' depression and anxiety. However, there did appear to be some overall relationship between pre-morbid conscientiousness (as self-rated by the patient on the NEO-FFI) and awareness discrepancy scores. In accordance with the

study's hypothesis, individuals with higher ratings of pre-morbid conscientiousness showed reduced awareness of their level of functioning (as defined by a greater awareness discrepancy score on the MIQ). This may be supportive of Weinstein's 'prototypical denial personality' as someone who is work-oriented, conscientious, efficient and organised. Jacque and Jackson (2000) suggest that people with 'obsessional' personalities find the experience of dementia particularly distressing as they are faced with a disintegration of order and control and a lowering of standards. Therefore, it may be that conscientious individuals have an increased need to defend against the threat of dementia using defensive denial, and thus show reduced awareness. It needs to be kept in mind that five correlation analyses were conducted in this section which potentially could increase the possibility of a type I error occurring. However, the analyses were not chosen in an exploratory *ad hoc* manner, and instead were based on the theoretical hypotheses of the study, which reduces the possibility of a spurious result. Contrary to Weinstein's (1994) work, the current study did not find that individuals with negative attitudes towards emotional expression were more likely to show reduced awareness. In addition, avoidant coping strategies did not predict level of awareness. Therefore, there was no evidence that behavioural avoidant coping strategies play a mediational role in the relationship of pre-morbid conscientiousness and level of awareness (Baron & Kenny, 1986).

It is interesting that self-reported pre-morbid conscientiousness as rated by the patient was significantly related to level of awareness, as partner-ratings of patient pre-morbid conscientiousness showed no such relationship. Although Pearson's correlation

coefficient showed that there was significant inter-rater agreement, it was not possible to calculate an intra-class correlation coefficient, which is a more complete measure of inter-rater reliability as it considers agreement in terms of means as well as the linear relationship between scores, because partners and patients completed different versions of the NEO Five-factor Personality Inventory. Therefore, it is possible that there was a difference in the level of conscientiousness as rated by patients and partners (which was not testable). This may explain why only self-ratings correlated with unawareness. Although the literature highlights a close agreement between self-ratings with peers and spouses on the different factors of the NEO Five-factor Personality Inventory (e.g. McCrae & Costa, 1990), closer inspection of studies indicates that there is more variability and possibly a lower level of agreement between self and peer or partner ratings on the conscientiousness scale compared to the other scales (Costa & McCrae, 1992). Indeed, Strauss et al. (1993) suggest that the trait of conscientiousness may be more context-dependent relative to other traits, and that partners and peers may have different contexts of observation, which could lead to more variability in inter-rater reliability. This highlights the importance of including the patients' perspective when measuring pre-morbid personality.

4.2.2.1. Proposal of a revised model

These results suggest that there may be two separate denial-like processes occurring in two different groups of people with dementia.

1. Pre-morbid personality does appear to relate to the coping strategies employed by individuals in managing the threat of dementia. In particular, stoical and reserved attitudes towards emotional expression are predictive of an increased use of avoidant behavioural coping strategies.

Salander & Windahl (1999) categorise denial-like processes into avoidance, disavowal and denial. They refer to avoidance as the conscious behavioural act of avoiding information. Interestingly, avoidant behavioural coping in this study was not linked to unawareness. This provides support for Salander & Windahl's assertion that avoidant behavioural coping is conscious despite being a denial-like process, and as such might not be expected to be associated with unawareness of current functioning. Indeed, it seems likely that an individual would need to be aware of their difficulties in order to consciously implement avoidant coping strategies and to be able to report their use of these strategies. Therefore, this group of dementia patients are individuals who have pre-morbidly tended to hold negative attitudes towards emotional expression. They are consciously aware of their difficulties and they tend to consciously employ avoidant coping strategies in a motivated attempt to manage their illness.

2. It seems that there are another group of individuals who are less aware of their condition and who were pre-morbidly conscientious individuals. This is in line with Weinstein's (1994) suggestion that highly conscientious individuals are more likely to manage the threat of dementia using defensive denial. It seems that in

this group the process is more one of denial in the traditional psychoanalytic sense. As Salander & Windhal (1999) suggest:

“Denial, when conceptualised in the traditional psychoanalytic sense (Kernberg, 1994) is a forceful unconscious defensive act in the perceptual process that leaves the basics of the threat outside the patient. It is an ‘unconscious selective perceptual blindness to the unpleasant facts’ (Page, 1975). It is not a distortion of meaning, it is a repudiation of meaning.” (1999, p. 276)

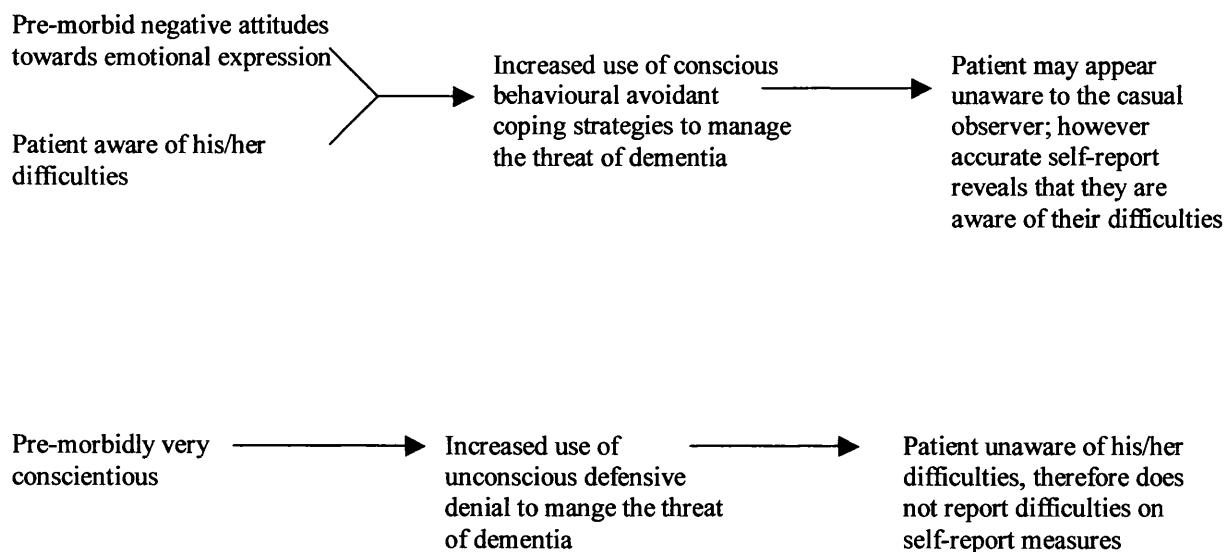
Although the contribution of organic factors to unawareness always needs to be kept in mind, it seems likely that aspects of unawareness in this group of patients are the outcome of unconscious defensive denial. If this preconscious defence is effective then the patient is unaware of their difficulties and does not perceive a problem, therefore there is possibly less of a need to employ conscious behavioural avoidant coping strategies.

The proposed pattern of relationships in these two processes is represented diagrammatically in Figure 4.1.

These two distinct processes have important implications for the assessment of unawareness. It seems possible that studies which assess awareness through clinical observation and judgement may incorrectly classify some people who cope through avoidance as being unaware. If we consider some of the avoidant coping strategies

included on the Ways of Coping checklist (e.g. *went on as if nothing had happened; kept my feelings to myself; kept others from knowing how bad things were*), it seems possible that an observer might interpret these signs as an indication of unawareness. This highlights the importance of including self-report measures which consider patients' perception of their current situation when assessing awareness. These two different processes also have implications for clinicians working with people with dementia which will be discussed later in detail.

Figure 4.1: Proposal of a revised model regarding the relationship of psychological factors and unawareness.



Further research into this proposed model may need to be based on more than clinical observations or self-report questionnaires. For example, it may be possible to uncover a deeper understanding of these processes through an in-depth

interview. Alternatively, an indirect implicit task paradigm may be better equipped to assess covert unconscious processes such as defensive denial.

Overall, it appears that there may be a small effect of psychological variables, in particular self-rated conscientiousness, on level of awareness which was not detectable in the regression analysis once control variables had been included in the model. Indeed, the number of participants in the study meant that there was sufficient power to detect a large effect size but not a small effect. It could be argued that if a study with relatively lower power detects a significant result then there is a good possibility that it is robust. Therefore, the small effect of psychological variables on level of awareness, which was detected in this study, can be regarded as relevant and clinically significant.

4.2.3. Part 3: Does patient's level of awareness contribute to carer burden?

A subsidiary aim of the study was to consider unawareness in dementia from the perspective of the caregiver, and to examine the impact of patients' unawareness on the spouse in terms of its contribution to carer burden.

Psychological well-being of the spouse was assessed using the Hospital Anxiety and Depression Scale. The proportion of carers reaching the criterion for 'caseness' was 35% on the anxiety scale and 12.2% on the depression scale, which although a significant proportion is in keeping with the prevalence found in other studies (e.g. Clare, 2000; Harvey, 1998).

The study's results indicated that patients' level of awareness predicted carer burden (as measured by the Burden Interview). This result was consistent with the studies of Seltzer et al. (1997) who found that unawareness of memory deficit was associated with increased carer burden and DeBettignies et al. (1990) who found that unawareness for independent living skills was significantly related to degree of carer burden. However, when the present study controlled for a wider number of variables such as dementia severity, quality of the pre-morbid marital relationship and symptoms of depression and anxiety in the partner, unawareness did not predict carer burden independently of partners' level of anxiety and depression. Disease severity and quality of the pre-morbid marital relationship also did not independently predict carer burden.

This result could be due to a number of possibilities.

- i. It may be that anxious or depressed carers/partners over-rate patients' difficulties. This rater bias would lead to greater awareness discrepancy scores on the Memory Insight Questionnaire being associated with increased levels of depression and anxiety in the partner. Although this is a possibility, it is difficult to draw firm conclusions without some objective measure of patients' level of functioning to compare with carers' ratings. DeBettignies et al. (1990) concluded in their study that discrepancies in ratings of independent living skills between patients and carers was due to underestimation by the patient as well as overestimation by carers. However, it is difficult to see how this conclusion can be made without objective measures of patients' level of functioning. A new assessment measure of level of awareness in dementia patients, which is currently being developed, the Memory Awareness

Rating Scale (MARS; Clare, 2000), may address some of these concerns in future research studies. The measure assesses awareness by calculating discrepancy scores between patient and informant ratings of patients' memory function as well as comparing patients' self-report of performance and actual performance on the Rivermead Behavioural Memory Test, an objective measure of memory functioning.

- ii. It is also possible that reduced awareness on the part of the patient is causally related to partners' level of depression and anxiety. For example, it could be that reduced patient awareness affects the marital relationship which could affect partners' emotional state. Indeed, a number of partners in the study said that they found the patient's unawareness particularly difficult to cope with as it meant that they could not discuss the situation and the future with their partner, which they felt would have provided them with emotional support. Future research could test this hypothesis by investigating the quality of the current marital relationship and levels of carers' depression and anxiety in patients with varying levels of awareness.
- iii. This result could also be due to carer burden and partners' level of anxiety and depression being overlapping constructs. Indeed, it is unclear from models of caregivers' stress whether depression, anxiety and 'carer burden' can be considered as separate constructs. Pearlin et al. (1990) view anxiety and depression as an outcome or manifestation of stress. Vitaliano et al.'s (1991) model considers the wider construct of 'distress in response to caregiver experiences' which is assessed with measures of anxiety, depression and a measure of appraised distress in response to caregiving.

- iv. It is also feasible that there is a third variable which affects both patients' awareness and levels of depression and anxiety in the partner. Alternatively, it may be that linear explanations cannot adequately capture the relationships between carer burden, carer depression and patient awareness. A circular, systemic process may provide a better framework within which to consider these relationships.

4.3. Methodological considerations & implications for future research

The method of defining unawareness as the discrepancy between carer and patient ratings of patients' level of functioning is generally accepted; however, it is based on the assumption that carers are accurate in their assessment of patient functioning. There is empirical evidence supporting the validity of this approach, as previous studies have shown that caregiver questionnaire ratings correlate with objective measures of patients' cognitive functioning (Feher et al., 1991; Koss et al., 1993). In the current study checks were made to assess the carers' awareness of patients' difficulties. In 73% of cases it was the partner who first noticed difficulties, thus providing some support for the assumption that the sample's spouses were generally sensitive to the patients' difficulties. As was suggested earlier, future research could also address the issue of whether some partners are hyperaware and over-estimate patients' difficulties by using an additional objective psychometric measure of patient functioning as well as the carers' assessment in order to cross-check the validity of partners' ratings (e.g. the recently developed Memory Awareness Rating Scale; Clare, 2000).

A structured, quantitative approach to assessing unawareness has advantages in terms of objectivity. However, questionnaire measures of awareness demand a certain level of cognitive functioning which means that only dementia patients in the relatively earlier stages of the disease can be included in a study. It might be that a more flexible, less structured qualitative approach is needed to evaluate the role of psychological factors in unawareness in patients who are more severely affected. Patients with more significant cognitive difficulties, who are unable to cope with the demands of a formal questionnaire, may benefit from having more freedom to express themselves in a qualitative interview, rather than having to be constrained by quantitative data-collection procedures. A qualitative approach to studying awareness in dementia has other advantages. Unawareness in dementia is undoubtedly a complex phenomenon with a number of different factors possibly having a contributory role (e.g. organic, psychological and social factors). The heterogeneity of the dementia population is such that the relative contribution of these factors may vary from individual to individual; thus a qualitative approach would allow awareness to be studied in more depth and detail in individual cases than a quantitative approach allows.

There are a number of unavoidable design issues associated with the current study which need to be kept in mind as they may affect the power of the study. All questionnaire measures have a certain degree of error associated with them which may arise from incorrect responses, misunderstandings etc. This source of error is possibly increased when the respondent has reduced cognitive resources. Efforts were made to address this by the researcher going through each question with the patient to check out understanding

and to guide them through the possible responses. Occasionally, the researcher needed to take the patient's answer and help tailor it to the possible questionnaire answers. On a few occasions patients were quite rigid in their responses and were only able to give their own answer rather than match it to a possible multiple-choice response. In these rare cases the researcher had to extract an answer from the patient's statement and map it on to one of the possible responses. This approach may have introduced some subtle variations and increased the error associated with the measures. On balance, however, this methodological approach was probably a source of strength in the study as checking out comprehension of questions was vital for some participants to be able to complete the questionnaire measures accurately. Most previous studies which use self-report questionnaires to assess awareness do not indicate whether comprehension was checked and clarification given if necessary or whether patients were left to complete the measures on their own (e.g. DeBettignies et al., 1990; Migliorelli et al., 1995). If the latter scenario is the case it brings the validity of the measure into question. Of course, when considering how able dementia patients are in reflecting on their personality and level of functioning, there is always the question of how 'self-aware' they were before the onset of dementia. It may be that someone who is reserved in their emotional expression and quite rigid in their personality may have difficulty in introspecting and reflecting flexibly on issues such as personality.

Dementia is a diagnosis of exclusion, and as such the differential diagnosis of the different dementia subtypes can be difficult, and cannot usually be positively confirmed without post-mortem. Therefore, a general problem for research in this area is the

possibility that participants' diagnoses will change over time as the rate and pattern of disease progression becomes clearer. However, the rigorous clinical assessment procedures conducted with the participants attending the specialist clinic in this study mean that this is possibly less of an issue compared to other research studies in the area.

The recruitment difficulties described in the method chapter meant that the study only had sufficient power to detect a large effect size (as estimated by Cohen, 1992). Recruitment was particularly hampered by there being a relatively brief window of time when patients fulfilled the study's inclusion criteria. Patients needed to have experienced symptoms for a sufficient length of time for a diagnosis to be clinically established. However, if the dementia had progressed too far, the patient struggled to cope with the cognitive demands of the assessment. This meant that a significant number of potential participants had to be excluded who were possibly in the very early stages of dementia but who did not yet have an established diagnosis, and patients in the later stages who were too severely affected to complete the research protocol also had to be excluded. The current study had an additional criterion of only including participants who had a partner. This meant that a significant number of potential participants who fulfilled the diagnostic criteria had to be excluded because they were single, widowed or divorced. Future research may be able to increase the number of participants (and hence statistical power) by relaxing this criterion to include other types of informants. However, there is possibly a trade-off in doing this in a study looking at personality variables, as informants who are children or friends may have different observational contexts and be less

accurate in their ratings of patients' personality traits such as conscientiousness, which has been hypothesised to be particularly sensitive to such effects.

In terms of external validity, there are some issues to be considered when thinking about the generalisability of the results beyond the immediate context of the study. It could be speculated that patients with greater awareness are more likely to seek a referral to a specialist clinic. It could also be hypothesised that the assessment process itself increases the awareness of the patient. Indeed, communication with professionals seems likely to affect awareness. Research has shown that professionals often avoid communicating diagnosis and prognosis to people with dementia, and that cognitive problems may often be normalised within the context of 'old age' (Clarfferty et al., 1998). However, the clinic where the research was conducted has a positive policy of discussing diagnosis with patients which is likely to impact on developing awareness. These scenarios could lead to a selection bias in the current study towards participants with a higher level of awareness. This may mean that the level of awareness documented in the current sample of dementia patients is greater than in the general population of people with dementia. Attempts were made to address this potential selection bias by recruiting from a more local, non-specialist memory clinic. However, the majority of patients from this clinic were too severely affected to take part in the study, and their diagnoses were often less clear. This issue is generally a potential problem in any study on awareness in dementia, as patients need to have accessed by a clinic and gone through diagnostic procedures in order to fulfil inclusion/exclusion criteria. O'Connor (1994) found that only 3% of people with mild dementia as identified in a community survey had been referred to

specialist services; therefore, the population of individuals with mild dementia who are referred to a specialist clinic may not be representative of the much larger general population of individuals with mild dementia who are not in receipt of psychogeriatric services.

As well as the diagnostic assessment process having a potential influence on developing awareness, there is the related variable of time and its influence on awareness. Patients who have undergone clinical investigation may have experienced symptoms for a relatively longer duration of time compared to individuals who are not referred to specialist services. The study found that there was a trend for unawareness to be associated with longer duration of symptoms. However, during the research interviews, a number of individuals said that before the decision was made to come to the clinic they refused to admit to difficulties. This study can only speculate on the question of how awareness changes over time and during the period of clinical assessment, as this was not the subject of the specific research hypotheses and as such data was not specifically collected to address these points. A cross-sectional, quantitative design as in the present study does not fully capture the changing nature of awareness. Future research could explore this in more detail using a qualitative approach which could also retrospectively consider level of awareness before a referral to clinic was made. Alternatively, a longitudinal design could look at the changing nature of awareness in dementia patients as they are followed up in the clinic at successive time points.

There was some cultural diversity in the sample which increases the generalisability of the results. However, it should be noted that not all the questionnaire items were relevant to some cultural groups. For example, a few items on the Memory Insight Questionnaire regarding level of functioning on different daily tasks needed to be altered so that they were meaningful for someone from a non-western culture. Development of future measures may benefit from being less culturally specific.

Previous studies of personality in dementia have only used informant ratings of pre-morbid personality (e.g. Strauss et al., 1993; Meins & Dammast, 2000). The dementia patient's perspective is not usually included in studies as it is deemed to have reduced reliability and validity. However, the patients in this study were able to complete personality measures to describe their pre-morbid personality. Indeed there was a significant correlation between patients' self-ratings of pre-morbid personality on the NEO-FFI and partners' ratings on the NEO PI-R, which supports the validity of the current study's methodology. It is important to note that it was only patients' self-ratings of pre-morbid personality which correlated significantly with unawareness discrepancy scores, thus highlighting the importance of triangulating data sources and including the patients' perspective. This is also in line with the growing move towards person-centred approaches to dementia (Woods, 2001).

An important strength of the study is its strong theoretical basis. The proposed model of unawareness in dementia which was investigated in this study is based on a social psychological framework of dementia; however, it also integrates conceptual constructs

and research findings from the fields of psychodynamic defence mechanisms, stress and coping research and personality research. An associated strength of incorporating well-defined and researched constructs is the availability of valid and reliable measures to capture the construct under investigation. The study drew on the different areas of research into dementia, coping and personality in order to use well-researched measures.

4.4. Implications for clinical practice

The results of the current study have important implications for clinical psychologists working with individuals with dementia and their partners in terms of making clinical decisions about disclosure of diagnosis and what type of intervention might be useful.

Disclosure of diagnosis to patients carries important ethical considerations. Clinicians need to balance patients' 'right to know' with decisions as to whether withholding information will prevent harm. A patient's level of awareness is an important factor to consider when making decisions about whether to share diagnostic information. If aspects of a patient's unawareness are the outcome of defensive denial, then confrontation with information regarding diagnosis may be a particularly threatening experience. Alternatively if the defence is particularly strong then the individual may not be able to assimilate the information. Cheston's (1998) and Woods (2001) assertion that ideally people with suspected dementia should receive pre-assessment counselling, so that results of the assessment can be fed back in such a way as to meet the emotional needs of the patient and carer, seems particularly relevant for the people identified in this study who cope with their condition by using avoidant coping strategies.

The opportunity for psychological therapy or counselling for individuals facing the threat of dementia has until relatively recently been virtually non-existent (Cheston, 1998). Husband (1999) points out that people with dementia have traditionally been considered unsuitable for therapy because it is thought that their cognitive impairment presents too severe an obstacle to their understanding and engagement with the therapeutic process. However, there has been a gradual shift in emphasis within dementia care to a more person-centred approach. The recognition of the emotional and psychological impact of dementia has led to a growing clinical interest in developing therapeutic interventions for this group of individuals (Cheston, 1998). In the current study it was noted that the research interviews had a significant effect on some participants willingness to admit to difficulties, with some individuals admitting to more difficulties towards the end of the assessment. It was speculated that one reason for this could be that as a rapport was established and patients' perspectives were listened to and valued, they felt safe enough to disclose some of their fears and admit to difficulties. This observation has not been empirically proven, but it does point to the role of therapy for individuals who are facing the threat of dementia and the value of exploring thoughts and feelings within a safe, therapeutic environment. There has been little research looking at the effectiveness of therapy with people with dementia, and therefore at this time there is little in the way of an evidence-base to guide clinicians in terms of 'what works for whom' (Woods & Roth, 1996). The current study, however, has important implications in terms of what type of intervention might be useful for different individuals with dementia. The study has identified two potentially different groups of individuals with dementia who differ in

terms of their level of awareness. There appears to be a group of individuals who are consciously aware of their difficulties but who manage their illness by using avoidant coping strategies, and this seems to be influenced by pre-morbid characteristics such as negative attitudes towards emotional expression. In contrast, there seems to be another group of people who are less aware of their condition and this reduced awareness seems to be possibly related to the pre-morbid psychological factor of conscientiousness and the use of defensive denial. Of course, there are also individuals who fall into neither of these categories. For example, people who are consciously aware of their problems but who do not have an avoidant coping style, and individuals with dementia who are less aware of their condition but for whom psychological factors are not a contributory factor (in this group organic variables may play a greater role).

The first group of patients who are consciously aware of their illness but who find it threatening to discuss their feelings and who cope using avoidant coping strategies may benefit from a more behavioural, problem-focused approach to therapy. A psychological intervention might include work to improve the patient's range of coping skills, and to help them achieve a sense of control and agency so that they are able to make their own choices and solve their own problems. Such patients may also be candidates for cognitive rehabilitation in order to assist with adaptation to memory difficulties (Clare et al., 2000). Thus, the focus of therapy is on aspects of the situation which are changeable, rather than emotions associated with the losses involved which may be too threatening for these individuals to consider initially. As the therapeutic relationship strengthens, a number of these individuals may feel supported and safe enough with time to begin to

explore their feelings of grief regarding the losses involved in dementia. This could be done on an individual basis or through a group setting. Indeed, a support group may be particularly beneficial as it would provide an opportunity to share feelings, experiences and support, and to meet other people who are facing the prospect of similar losses (see Yale, 1995 for a further review of the issues involved in group work for people with early-stage dementia).

In the second group of individuals who are unaware of their condition and who do not perceive a problem, the focus of therapy may be more on working with the carer. Indeed, the study found a relationship between unawareness and carer burden and spouses' level of depression. Although the specific nature of this relationship is unclear, it does suggest that partners who are caring for patients with decreased awareness may be more at risk of increased levels of carer stress and emotional difficulties, which may require therapeutic intervention. Therefore, therapy might include providing emotional support to carers as well as possibly helping the carer to implement behavioural strategies which might benefit the patient and his/her level of functioning. Patients with low awareness of their condition have also been found to make poorer treatment gains in cognitive rehabilitation programmes (Clare, 2000). The possibility that in some of these patients low awareness may reflect the use of defensive denial indicates that unawareness should not be considered to be a simple obstacle to rehabilitation. Indeed, Lazarus (1983) argues that if direct action is irrelevant to the outcome of the difficult situation (as is the case in dementia) then denial may be of value as it reduces distress and allows the person to 'get on with things'. Therefore, these patients should probably not be considered as

candidates for cognitive retraining programmes. However, the observation that level of awareness can change over time indicates that these patients should be carefully monitored, as they may admit to difficulties in the future, which could become a focus of intervention.

The study also highlighted a link between self-reported symptoms of depression (and to a lesser extent anxiety) with increased patient awareness. This has potentially important clinical implications, as it may be that increased awareness is a risk factor for depressive symptoms (and possibly anxiety symptoms), which may require intervention. Treatment targeted to reduce depression in people with dementia may also have the concomitant effect of improving cognitive and behavioural functioning as this may have been further reduced by emotional factors (Thompson et al., 1990). Studies are beginning to emerge which suggest that cognitive behavioural therapy can be successfully adapted to help individuals with dementia who are experiencing emotional difficulties (Teri & Gallagher-Thompson, 1991). In addition, this group of dementia patients may benefit from the emotional support provided by a group intervention.

To conclude, the current study points to the importance of considering a person's awareness, personality style, use of defence mechanisms and coping strategies when selecting a model of clinical intervention for people facing the threat of dementia. Indeed, this research study raises the issue of what a clinical assessment of a person with suspected dementia should include. As clinical psychologists maybe we should not just be assessing an individual's neuropsychological functioning but also a person's

emotional needs and his/her emotional and cognitive capabilities to engage with a specific approach to clinical intervention. Hopefully, future research will provide further insight as to how clinicians can best help and support people facing this tragic disease.

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Appendix 1

OPCS Occupational Classifications

The study uses the socio-economic classification of occupations detailed by the Office of Population Censuses and Surveys (1995). Socio-economic groups are derived from occupational coding in order to bring together people with jobs of similar social and economic status. The relevant groupings are as follows:

Professional and managerial group

1. **Employers and managers in central and local government, industry, commerce etc. – large establishments**
 - Employers in industry, commerce etc.
 - Managers in central and local government, industry, commerce etc. Persons who generally plan and supervise in non-agricultural enterprises employing 25 or more persons.
2. **Employers and managers in industry, commerce etc. – small establishments.**
 - Employers in industry, commerce etc. – small establishments. As above but in establishments employing fewer than 25 persons.
 - Managers in industry, commerce etc. Persons who generally plan and supervise in non-agricultural enterprises employing fewer than 25 persons.
3. **Professional workers – self employed**
Self-employed persons engaged in work normally requiring qualifications of university degree standard.
4. **Professional workers – employees**
Employees engaged in work normally requiring qualifications of university degree standard.

Skilled and semi-skilled group

5. **Junior non-manual workers**
Employees, not exercising general planning or supervisory powers, engaged in clerical, sales and non-manual communications occupations, excluding those who have additional and formal supervisory functions.
6. **Skilled manual workers**
Employees engaged in manual occupations, which require considerable and specific skills
7. **Semi-skilled manual workers**
Employees engaged in manual occupations which require slight but specific skills.
8. **Own account workers (other than professional)**
Self-employed persons engaged in any trade, personal service or manual occupation not normally requiring training of university degrees standard and having no employees other than family workers.

Classifications cited from Office of Population Censuses and Surveys, 1995

Appendix 2



THE NATIONAL HOSPITAL FOR NEUROLOGY AND NEUROSURGERY

Queen Square, London WC1N 3BG

Telephone: 020 7829 8773

Fax: 020 7209 0182

<http://dementia.ion.ucl.ac.uk/>
enquiries@dementia.ion.ucl.ac.uk

Information Sheet: How do people attending the clinic and their partners cope with memory difficulties?

We would like to invite you to participate in a research project which looks at how different individuals and their partners cope with memory difficulties and the problems that arise in everyday life. We will be talking to a range of people attending the Specialist Cognitive Disorders Clinic. We would be interested in talking to you and your partner, if you have concerns about your memory or if anyone else has concerns about your memory.

The result of this research will be important in furthering understanding of how different people and their families experience and cope with difficulties. This understanding is very valuable in order to improve the support and services provided to individuals and their families.

The research involves filling out a number of questionnaires which look at individual strengths, difficulties and ways of coping. The researcher will be able to help you fill these out. The questionnaires should take approximately 45 minutes to fill out and can be done during waiting times at the clinic. If you would like to talk about anything that arises from completing the questionnaires or if you have any questions, please feel free to ask the researcher. If there are any further queries the researcher may be able to help you by directing them to the appropriate person.

Your participation in this research is entirely voluntary. You are free to decline to participate or to withdraw from the study at any time without having to give a reason. If you choose not to participate in this research, or to withdraw, this will in no way affect your medical care. All information obtained from the questionnaires will be treated as strictly confidential. Once the information is collated it will be stored on a computer in a coded form so that confidentiality is strictly maintained. Participation in this study will in no way affect your legal rights.

This research project has been reviewed by the National Hospital for Neurology & Neurosurgery and the Institute of Neurology Ethics Committee.

Professionals involved in the study:

Anna Seiffer, Clinical Psychologist in training

Linda Clare, Clinical Psychologist

Dr Harvey, Senior Clinical Research Fellow

Professor Rossor, Consultant Neurologist



The University College London Hospitals

University College London Hospitals is an NHS Trust incorporating The Eastman Dental Hospital, The Hospital for Tropical Diseases, The Middlesex Hospital, The National Hospital for Neurology and Neurosurgery, The United Elizabeth Garret Anderson Hospital and Hospital for Women, Soho, and University College Hospital.

Appendix 2



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Telephone: 020 7829 8773
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enquiries@dementia.ion.ucl.ac.uk

CONSENT FORM – Confidential

How do people attending the clinic and their partners cope with memory difficulties?

Professionals involved in the study:

Anna Seiffer, Clinical Psychologist in training, tel: 020 76795699

Linda Clare, Clinical Psychologist, tel: 020 76791844

Dr Harvey, Senior Clinical Research Fellow

Professor Rossor, Consultant Neurologist

- | | | |
|--|-----|----|
| 1. Have you read the information sheet? | Yes | No |
| 2. Have you had an opportunity to ask questions? | Yes | No |
| 3. Have you received satisfactory answers to your questions? | Yes | No |
| 4. Which researcher have you spoken to about this study? _____ | | |
| 5. Do you understand that you are free to withdraw from this study at any time | Yes | No |
| without giving a reason for withdrawing | Yes | No |
| without affecting your future medical care | Yes | No |
| 6. Do you agree to take part in this study? | Yes | No |

Signed _____ Date _____

Name in BLOCK LETTERS _____
Patient/Parent/Guardian – please delete as appropriate

Researcher _____
Signed name in BLOCK LETTERS



The University College London Hospitals

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Appendix 2

Hounslow Information Sheet (on NHS trust headed paper)

Information Sheet: How do people attending the memory clinic and their partners cope with memory difficulties?

We would like to invite you to participate in a research project, which looks at how different individuals and their partners cope with memory difficulties and the problems that arise in everyday life. We would like to talk to a range of people who have attended the Memory Clinic. We would be interested in talking to you and your partner, if you have concerns about your memory or if anyone else has concerns about your memory. The study will involve one appointment lasting approximately one hour. The appointment will be arranged so that it is convenient for you. The appointment can take place at the hospital or if you would prefer we could visit you at home.

Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Different people and different personalities cope with changes in their memory in different ways. This research is, therefore, important in furthering understanding of how different people and their families experience and cope with difficulties. This understanding is very valuable in order to improve the support and services provided to individuals and their families.

What will I have to do?

The research involves filling out a number of questionnaires, which look at individual strengths, difficulties and ways of coping. The researcher will be able to help you fill these out. If you would like to talk about anything that arises from completing the questionnaires or if you have any questions, please feel free to ask the researcher. If there are any further queries the researcher may be able to help you by directing them to the appropriate person.

Do I have to take part?

Your participation in this research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are free to decline to participate or to withdraw from the study at any time without having to give a reason. If you choose not to participate in this research, or to withdraw, this will in no way affect your medical care.

Is it confidential?

All information obtained from the questionnaires will be treated as strictly confidential. Once the information is collated it will be stored on a computer in a coded form so that confidentiality is strictly maintained. Participation in this study will in no way affect your legal rights. This research project has been approved by the Hounslow Research Ethics Committee.

Contact names and telephone numbers for further information:

Anna Seiffer, Clinical Psychologist in training, tel: 020 83216826

Linda Clare, Clinical Psychologist, tel: 020 76791844

Appendix 2

Hounslow Consent Form (on NHS trust headed paper)

CONSENT FORM - Confidential

How do people attending the Memory Clinic and their partners cope with memory difficulties?

Professionals involved in the study:

Anna Seiffer, Clinical Psychologist in training, tel: 020 83216826

Linda Clare, Clinical Psychologist, tel: 020 76791844

- | | | |
|---|-----|----|
| 1. Have you read the information sheet? | Yes | No |
| 2. Have you had an opportunity to ask questions? | Yes | No |
| 3. Have you received satisfactory answers to your questions? | Yes | No |
| 4. Which researcher have you spoken to about this study?
_____ | | |
| 5. Do you understand that you are free to withdraw from this study
at any time | Yes | No |
| without giving a reason for withdrawing | Yes | No |
| without affecting your future medical care? | Yes | No |
| 6. Do you agree to take part in this study? | Yes | No |

Signed _____ Date _____

Name in BLOCK LETTERS _____
Patient/Parent/Guardian-please delete as appropriate

Researcher _____
signed name in BLOCK LETTERS



Appendix 3
THE NATIONAL HOSPITAL FOR NEUROLOGY
AND NEUROSURGERY

Queen Square, London WC1N 3BG
Telephone: 0171 837 3611
Fax: 0171 829 8720

NHNN Research Director:
Professor Alan Thompson

UCLH Trust R&D Director:
Professor Allyson Pollock

Please address all correspondence to:
1st Floor, Vezey Strong Wing
112 Hampstead Road
London NW1 2LT
Department Numbers:
020 7380 9833/9579
Fax. 020 7380 9937

10 April, 2000

Miss Seiffer
Department of Clinical Health Psychology
UCL

Dear Miss Seiffer,

Study ref: 00/N023
Title: How do psychological factors affect the level of awareness of current
functioning in young onset-dementia?

Thank you for registering the above study with the R&D Directorate. I am pleased to give Trust approval for the study to commence. Please ensure you have addressed any outstanding issues raised by the ethics committee.

Yours sincerely

Professor Alan Thompson
Director of Research, NHNN



The University College London Hospitals

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University College London Hospitals is an NHS Trust incorporating The Eastman Dental Hospital, The Hospital for Tropical Diseases, The Middlesex Hospital, The National Hospital for Neurology and Neurosurgery, The United Elizabeth Garret Anderson Hospital and Hospital for Women, Soho, and University College Hospital.



Appendix 3
THE NATIONAL HOSPITAL FOR NEUROLOGY
AND NEUROSURGERY

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The NHNN and the Institute of Neurology
Joint Medical Ethics Committee
Chairman: Dr GD Schott

Please address all correspondence to:
Iwona Nowicka
Research & Development Directorate
1st Floor, Vezey Strong Wing
112 Hampstead Road, LONDON NW1 2LT
Tel. 020 7- 380 9579 Fax: 020 7-380 9937
e-mail: iwona.nowicka@uclh.org

Ms Anne Seiffer
Sub-Department of Clinical Health Psychology
UCL
Gower Street

17-Aug-00

Dear Miss Seiffer

Study ref: 00/N023 (*Please quote in all correspondence*)
Title: How do psychological factors affect the level of awareness of current functioning in young onset-dementia?

Thank you very much for your letter dated 4th August enclosing the amended information. I confirm that the study can go ahead.

Please note that it is important that you notify the Committee of any adverse events or changes (name of investigator etc) relating to this project. You should also notify the Committee on completion of the project, or indeed if the project is abandoned. **Please remember to quote the above number in any correspondence.**

Yours sincerely

Iwona Nowicka
Administrator, UCL/UCLH/NHNN Ethics Review Committees

Hounslow District Research Ethics Committee
C/o Kate Godfrey
Clinical Governance Manager
WMUH NHS Trust
Twickenham Road
Isleworth, Middlesex.
TW7 6AF

10th January 2001

Dear Ms. Seiffer,

Re: 00/581 How do psychological factors effect the level of awareness of current functioning in dementia?

Thank you for submitting the changes recommended by the Committee. I have reviewed them today and am happy to approve your research proposal, which you may commence as soon as you like.

Please note the approval is subject to the following conditions:

- a) Your notifying the committee should a change of researcher take place during the study
- b) Your allowing a member of the Committee access to your records for audit purposes if required
- c) Your submitting a short report on the completion of your study or at 12 monthly intervals from the acceptance date for work in progress. **Please use the local reference number in any future correspondence.**

Yours sincerely



Salim Vohra
Chairman, Hounslow District Research Ethics Committee

Appendix 4

Attitudes towards Emotional Expression Questionnaire

(Participants title: Dealing with Emotions)

Participant's version:

Please fill out this questionnaire so that it best describes how you have been as a person throughout life.

Name:

Sex:

Age:

Date:

For each item please circle the letter (a or b or c etc.) according to how much you agree or disagree with the statement.

1. I think you should always keep your feelings under control
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

2. I think you ought not to burden other people with your problems
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

3. I think getting emotional is a sign of weakness
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

4. I think other people don't understand your feelings
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

5. When I'm upset I bottle up my feelings
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

6. You should always keep your feelings to yourself
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

7. Other people will reject you if you upset them
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

8. My bad feelings will harm other people if I express them
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

9. If I express my feelings I'm vulnerable to attack
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

10. You should always hide your feelings
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

11. When I'm upset I usually try to hide how I feel
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

12. I seldom show how I feel about things
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

13. Turning to someone else for advice or help is an admission of weakness
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

14. It is shameful for a person to display his or her weaknesses
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

15. I should always have complete control over my feelings
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

16. If other people know what you are really like, they will think less of you
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

17. When I get upset I usually show how I feel
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

18. People will reject you if they know your weaknesses
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

19. If a person asks for help it is a sign of weakness
 - a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree

20. I don't feel comfortable showing my emotions
- a. Strongly disagree
 - b. Disagree
 - c. Neutral
 - d. Agree
 - e. Strongly agree
-

Appendix 5

Ways of Coping Checklist (Revised)

(Vitaliano, P.; Russo, J.; Carr, J.; Maiuro, R. & Becker, J. (1985). The Ways of Coping Checklist: Revision and Psychometric Properties. *Multivariate Behavioural Research*, 20, 3-26)

Participant's version

This questionnaire asks about ways of coping with stressful situations. We all face stressful situations, and we have all developed our own preferred ways of coping with them. It is often easiest for people to think about their preferred ways of coping in terms of how they have dealt with a specific stressful situation in the recent past. To start with, we would like you to think of a stressful situation that you have experienced recently, or are currently experiencing - ideally something connected with memory problems. Then we would like you to look at this list of possible ways of coping. For each way of coping, we would like you to say whether or not you tried this in the situation you are thinking about. Circle Yes or No on the sheet to show whether or not you used this way of coping.

Name:

Date:

The stressful situation I have chosen is:

Possible ways of coping	Did you try this?	
1. Talked to someone to find out about the situation	Yes	No
2. Blamed myself	Yes	No
3. Bargained or compromised to get something positive from the situation	Yes	No
4. Hoped a miracle would happen	Yes	No
5. Concentrated on something good that could come out of the whole thing	Yes	No
6. Went on as if nothing had happened	Yes	No
7. Tried not to burn my bridges behind me, but left things open somewhat	Yes	No
8. Felt bad that I couldn't avoid the problem	Yes	No
9. Accepted sympathy and understanding from someone	Yes	No
10. Wished I was stronger person - more optimistic and forceful	Yes	No
11. Changed or grew as a person in a good way	Yes	No
12. Criticised or lectured myself	Yes	No
13. Wished that I could change what had happened	Yes	No
14. Made a plan of action and followed it	Yes	No
15. Kept my feelings to myself	Yes	No
16. Slept more than usual	Yes	No
17. Got professional help and did what they recommended	Yes	No
18. Realised I brought the problem on myself	Yes	No
19. Wished that I could change the way that I felt	Yes	No
20. Got mad at the people or things that caused the problem	Yes	No
21. Accepted the next best thing to what I wanted	Yes	No
22. Came out of the experience better than when I went in	Yes	No

Possible ways of coping	Did you try this?	
23. Daydreamed or imagined a better time or place than the one I was in	Yes	No
24. Tried to forget the whole thing	Yes	No
25. I tried not to act too hastily or follow my own hunch	Yes	No
26. Tried to make myself feel better by eating, drinking, smoking or taking medications	Yes	No
27. Changed something so things would turn out alright	Yes	No
28. Talked to someone who could do something about the problem	Yes	No
29. Had fantasies or wishes about how things might turn out	Yes	No
30. Just took things one step at a time	Yes	No
31. I knew what had to be done, so I doubled my efforts and tried harder to make things work	Yes	No
32. Asked someone I respected for advice and followed it	Yes	No
33. Came up with a couple of different solutions to the problem	Yes	No
34. Avoided being with people in general	Yes	No
35. Accepted my strong feelings, but didn't let them interfere with other things too much	Yes	No
36. Thought about fantastic or unreal things (like perfect revenge or finding a million pounds) that made me feel better	Yes	No
37. Kept others from knowing how bad things were	Yes	No
38. Changed something about myself so I could deal with the situation better	Yes	No
39. Wished the situation would go away or somehow be finished	Yes	No
40. Refused to believe it had happened	Yes	No
41. Stood my ground and fought for what I wanted	Yes	No
42. Talked to someone about how I was feeling	Yes	No

Appendix 6

Dyadic Adjustment Scale - Partner's version

Name: _____

Every relationship has its ups and downs, but please consider how your relationship has generally been in the past, and indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
1. Handling family finances						
2. Matters of recreation						
3. Religious matters						
4. Demonstrations of affection						
5. Friends						
6. Sex relations						
7. Conventionality (correct or proper behaviour)						
8. Philosophy of life						
9. Ways of dealing with parents or in-laws						
10. Aims, goals, and things believed important						
11. Amount of time spent together						
12. Making major decisions						
13. Household tasks						
14. Leisure time interests and activities						
15. Career decisions						

	All the time	Most of the time	More often than not	Occasionally	Rarely	Never
16. How often do you discuss or have you considered divorce, separation, or terminating your relationship?						
17. How often do you or your partner leave the house after a fight?						
18. In general, how often do you think that things between you and your partner are going well?						
19. Do you confide in your partner?						
	All the time	Most of the time	More often than not	Occasionally	Rarely	Never
20. Do you ever regret that you married? (<i>or lived together</i>)						
21. How often do you and your partner quarrel?						
22. How often do you and your partner "get on each other's nerves?"						
	Every Day	Almost Every Day	Occasionally	Rarely	Never	
23. Do you kiss your mate?						
	All of them	Most of them	Some of them	Very few of them	None of them	
24. Do you and your partner engage in outside interests together?						

How often would you say the following events occur between you and your partner?

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
25. Have a stimulating exchange of ideas						
26. Laugh together						
27. Calmly discuss something						
28. Work together on a project						

These are some things about which couples sometimes agree and sometime disagree. Indicate if either item below caused differences of opinions or were problems in your relationship during the past few weeks. (Check yes or no)

	Yes	No
29. Being too tired for sex		
30. Not showing love		

31. The dots on the following line represent different degrees of happiness in your relationship. The middle point, "happy" represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

32. Please tick which of the following statements best describes how you feel about the future of your relationship?

- I want desperately for my relationship to succeed, and *would go to almost any length* to see that it does.
- I want very much for my relationship to succeed, and *will do all I can* to see that it does.
- I want very much for my relationship to succeed, and *will do my fair share* to see that it does.
- It would be nice if my relationship succeeded, but *I can't do much more than I am doing* now to help it succeed.
- It would be nice if my relationship succeeded, but *I refuse to do any more than I am doing* now to keep the relationship going.
- My relationship can never succeed, and *there is no more that I can do* to keep the relationship going

Dyadic Adjustment Scale - Self administered version

(Spanier, G. (1976) Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and the Family*, 38, 15-28.)

Participants version:

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner recently for each item on the following list.

	All the time	Most of the time	More often than not	Occasionally	Rarely	Never
1. Do you confide in your partner?						
2. How often do you and your partner quarrel?						
	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
3. Have a stimulating exchange of ideas						
4. Calmly discuss something						

Appendix 7

Burden Interview (Participants title: Partners' Interview)

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
4. Do you feel embarrassed over your relative's behaviour?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
5. Do you feel angry when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
7. Are you afraid what the future holds for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
8. Do you feel your relative is dependent upon you?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
9. Do you feel strained when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

10. Do you feel your health has suffered because of your involvement with your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

11. Do you feel that you don't have as much privacy as you would like, because of your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

12. Do you feel that your social life has suffered because you are caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

13. Do you feel uncomfortable about having friends over, because of your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

14. Do you feel that your relative seems to expect you to take care of him/her, as if you were then only on he/she could depend on?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

16. Do you feel that you will be unable to take care of your relative much longer?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

17. Do you feel you have lost control of your life since your relative's illness?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

18. Do you wish you could just leave the care of your relative to someone else?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

19. Do you feel uncertain about what to do about your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

20. Do you feel you should be doing more for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

21. Do you feel you could do a better job in caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely