

**PERSONALITY CHANGES
IN
ALZHEIMER'S DISEASE**

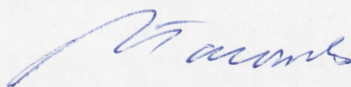
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Except where otherwise acknowledged in the text,
the data and analyses in this thesis represent my
original research.

A handwritten signature in blue ink, appearing to read 'Patricia Jacomb', with a stylized, flowing script.

Patricia Jacomb

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Abstract

Although cognitive impairment is seen as the predominant feature of dementia, personality changes are also frequently reported. Such changes can be very distressing to carers. Despite this, there has been little quantitative research into the nature of these changes. This study aimed to describe the occurrence of personality change in Alzheimer's disease, the most commonly occurring cause of dementia. In an attempt to cover the complete domain of personality, an informant-based instrument was developed based on a personality inventory designed by Lewis Goldberg for measuring personality in the normal population. Goldberg's questionnaire was based on the five-factor model of personality. This inventory contained 339 trait adjectives and was considered too long to be completed by carers or relatives of dementia patients. A preliminary questionnaire was developed using all of these adjectives in which respondents were asked to rate each trait adjective as to how often this trait is seen in people suffering from Alzheimer's disease compared to normal, healthy elderly. This was completed by 28 clinicians who were working with dementia patients. Based on the differences which they reported, a questionnaire containing 124 trait adjectives was developed. These 124 adjectives could be grouped into 46 synonym clusters. This questionnaire was completed by 50 informants of clinically diagnosed DAT sufferers and also by 167 carers of dementia sufferers who attended NSW Alzheimer's Association support groups. This latter group was included to provide a large enough sample to allow psychometric analysis. Fifty non-cognitively impaired, community residents, approximately matched for age and sex provided the control group.

Both the clinically diagnosed group and the Alzheimer's Association group were found to show a decrease in Extroversion, Agreeableness, Conscientiousness and Openness and an increase in Neuroticism. The control group showed very little change. Principal components analysis of the combined sample revealed a large factor which accounted for 33% of the variance. This suggests that there is a global change in personality across the five factors. A scree plot of the principal components analysis revealed three meaningful factors. Varimax rotation was then undertaken on these three factors. Traits from the positive poles of each of the five factors of personality loaded on the first factor, which was found to be highly

correlated to cognitive decline as assessed by the IQCODE. The second contained disagreeable and neurotic traits. This factor was found to be only moderately correlated to cognitive decline. One interesting feature of this factor was that while the majority of subjects all changed in the same direction a small number were reported to change in the opposite direction i.e to become less disagreeable and less neurotic. While methodological limitations may have accounted for this difference, it is possible that there is a subgroup of dementia sufferers who show different patterns of personality change. The third factor contained traits from the negative poles of Extroversion, Conscientiousness and Openness. These three factors were not correlated to any of the demographic characteristics of the subject or informant.

Finally, a shorter inventory of traits was derived from the 124 adjective questionnaire. This included the disagreeable and neurotic traits which may be problematic for carers and may be useful for exploring carer stress or examining further the possibility of a group of dementia sufferers who change in a different way to the majority.

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Chapter 1

Introduction

Dementia is characterised by a range of cognitive and behavioural changes. While impairment of both short and long term memory are seen as central to the diagnosis of dementia (American Psychiatric Association, 1987), personality changes are also considered to be frequently occurring features of the syndrome (Roth and Myers, 1969). Both the Tenth Revision of the International Classification of Diseases (WHO, 1993) and the Diagnostic and Statistical Manual, DSM-III-R (American Psychiatric Association, 1987) include personality changes as part of the diagnostic criteria for dementia.

Many disorders can cause dementia in the elderly, the most common being dementia of the Alzheimer's type (DAT). With the percentage of elderly in the population of Australia and many other countries increasing, dementia, and in particular DAT has become a significant public health problem. Personality change has been reported as often occurring quite early in the course of the disease (Rubin and Kinscherf, 1989) and may even be the main presenting symptom to doctors (Lishman, 1987). It has also been found that such changes can be very distressing for carers and disabling for sufferers (Greene et al., 1982; Gilleard et al., 1982).

Until quite recently, however, there has been little systematic or quantitative study of personality changes in dementia. Research has concentrated almost solely on cognitive changes, such as short and long term memory loss, aphasia, agnosia and apraxia. Many instruments have been developed to measure these cognitive changes and are often used in the diagnosis of dementia.

It is uncertain why personality change has been a neglected area of research. One possible reason may be the difficult methodological problems encountered in assessing personality change. Cognitive change can be measured directly by testing the patient to determine responses which are outside the normal range. Although current personality can be assessed by observation over time, this is a time consuming procedure and is not very meaningful without information about

premorbid personality characteristics. Such information could not be reliably obtained from people whose memory and judgement is impaired.

Although there are difficulties in this area of research, the study of the personality changes that occur in dementia is important for a number of reasons:

- Development of an instrument which quantitatively measures another dimension of dementia could be useful in the diagnostic process. As different patterns of personality change have been reported in different diseases which produce dementia, studies which look at personality changes in such diseases may help not only in the diagnosis of dementia but also in discriminating between different causes of dementia. Such research may lead to a better understanding of the disease process, including the relationship between personality and the regional distribution of brain pathology.
- Knowledge of specific personality changes that may occur in dementing diseases may enable development and testing of drugs which could modify these distressing changes.
- If certain personality changes are anticipated, coping strategies may be developed for carers.

Recently, a number of researchers have been investigating personality change using informant questionnaires to overcome the problem of self-report mentioned above. The informant questionnaire involves asking someone who has known the patient well over a number of years to answer questions about changes in this person's personality since developing dementia. One advantage of this type of instrument is that it can be used by a non-clinician.

1.1 The Aims of This Study

The aims of the present study were two-fold:

The first was to systematically describe the personality changes which occur in DAT. To do this, an informant questionnaire containing a comprehensive range of personality change items would be developed. This instrument would be completed by informants of people suffering from the mild to moderate stages of DAT and by informants of elderly people who were not cognitively impaired. From these data, it would be possible to describe quantitatively the personality changes which informants observe in people suffering from DAT.

The intention has been to look specifically at people in the mild to moderate stages of DAT, because those in the severe stages are so cognitively impaired that they

barely react to their environment and it would be impossible to determine their current personality attributes. In that situation, personality becomes a meaningless construct.

The second aim of this study was to derive from the comprehensive personality questionnaire a shorter questionnaire which discriminates between people suffering from DAT and cognitively unimpaired people. This questionnaire should be easy to complete by informants without expert supervision.

Chapter 2

Literature Review

In attempting to review the available literature on personality change in dementia many difficulties were encountered. These included the interpretation of the concept of 'personality' as well as the range of methods and instruments chosen to study this phenomenon. These problems will be discussed in more detail below. To clarify, and hopefully, aid interpretation of this field of study, this review will begin by discussing both the definition of personality and ways of measuring personality in the normal population. This is an area which has been extensively studied for many years. A model of personality used in the normal population will then be used as a guide in selecting and categorising variables which have been examined in the dementia literature.

2.1 Clinical Descriptions of Personality Changes

Personality changes have been frequently mentioned as early symptoms in clinical reports of dementia (Adams and Victor, 1977; Joynt and Shoulton, 1985; Katzman, 1986). In fact, Alois Alzheimer wrote of his first recognised case, "One of the first disease symptoms of a 51-year-old woman was a strong feeling of jealousy toward her husband" (Alzheimer, 1907). Apathy and lack of initiative have also been reported as occurring early in the course of dementia (Joynt and Shoulton, 1985; Jolles, 1986). Other changes which have been described as occurring in dementia include irritability, anger, mood swings, fearfulness, anxiety and suspicion. The two cases described in this study (Appendix 2.1) illustrate a number of such changes. Roth and Myers (1969) have described a 'coarsening of personality'. This included a 'deterioration in social conduct and personal appearance.' They also stated that 'emotions become labile and blunted'. Katzman and Karasu (1975) have described a 'disorganisation of personality'.

Personality changes in dementia are often regarded as an accentuation of previous personality traits (Joynt and Shoulton, 1985; Jolles, 1986). Roth and Myers (1969) go so far as to say that 'personality may become a caricature of its worst features', with 'traits such as meanness, tactlessness, impulsiveness, laziness and overconcern

with health' emerging. Some clinicians reporting on personality changes consider that these changes are emotional reactions to the dementing process (Roth and Myers, 1969; Katzman and Karasu, 1975; Katzman, 1986).

2.2 Problems in Studying Personality Changes in Dementia

Studies specifically designed to investigate the personality changes which occur in dementia are few. Those which have attempted this have used different terms to describe personality and are difficult to compare. No attempt has been made in these studies or in the clinical reports of personality change to define what is meant by *personality*, while only a few studies have defined the characteristics which they have examined. Also, the terms *personality* and *behaviour* are sometimes used interchangeably. To add to the confusion, a number of investigations of specific behaviours in dementia include behaviours which may be seen as reflections of personality. In these, there is the implicit assumption that these behaviours are abnormal and reflect changes from the subject's premorbid state. Therefore, before reviewing the literature on personality change in dementia, it may be helpful to define what is meant by *personality* in the psychological literature and to consider how it can be measured in normal individuals.

2.3 Measuring Normal Personality

2.3.1 A Definition of Personality

There have been many theories about the nature of personality but only one of these, trait theory, will be discussed here. This theory has been increasingly studied in recent years and has been used in developmental psychology, industrial/organisational psychology and counselling psychology (Costa and McCrae, 1993). In this approach, personality is defined as a collection of traits. Traits may be defined as 'consistencies in the characteristic modes of behaviour exhibited by an individual in diverse settings' (Brody, 1972). This theory assumes that everyone exhibits all traits to a greater or lesser degree and that these traits can be quantified i.e. given a rating on a scale measuring any trait. This definition does not imply that an individual will always exhibit a trait to the same degree in all situations. Rather, they will tend to exhibit a trait more often or more strongly than someone who does not rate as highly on that trait. An individual's personality can then be described by how they score on a collection of traits.

2.3.2 Development of the Five-Factor Model of Personality

To develop an adequate theory of personality based on traits, it was necessary to discover the appropriate set of traits necessary to fully describe an individual's

personality. To achieve this end, many psychologists have used the technique of factor analysis to look for correlations between a large range of personality measures. These personality measures have included data from life records, objective tests and questionnaires which may be self-reports or peer ratings. Many studies using factor analysis of personality measures have been undertaken in the last forty years and many different factor solutions have been proposed. One of these, the five-factor model, has received much attention in recent years. In 1949, Fiske analysed Cattell's 21 bipolar scales and found evidence for a five factor solution (Fiske, 1949). A similar result was obtained by Tupes and Christal in 1961 (Tupes and Christal, 1961) which was later replicated by Norman (1963). However, it was not until the 1980's that interest re-emerged in the five factor model of personality. During this decade many researchers, using a range of different personality measures, came to conclude that these factors were fundamental dimensions of personality. The names given to these factors have varied somewhat but they are usually called as follows:

- Factor 1. Extroversion or Surgency
- Factor 2. Agreeableness
- Factor 3. Conscientiousness, Will or Dependability
- Factor 4. Emotional Stability or Neuroticism
- Factor 5. Openness to Experience or Intellect

Norman (1967) elaborated on these five factors by proposing a hierarchical system of personality descriptors. At the top are the five factors or traits. Each factor is made up of more specific traits which can be measured by single scales. Each of these specific traits is made up of habits or behaviour frequencies which may be measured by specific items on a single scale. Finally, each habit can be divided into specific responses to specific situations. This is shown diagrammatically in Figure 2.1

2.3.3 Personality Inventories Based on the Five-Factor Model

The five-factor model actually originated in studies of trait terms found in natural language. In this approach, researchers extracted all such terms from dictionaries and developed rating scales for either self or observer ratings. Analysis of the results from such studies led to the five-factor model. Lewis Goldberg has done much of the work in this area and in 1990 published a paper in which he demonstrated the generality of this model (Goldberg, 1990). In the first of three studies, Goldberg had college students rate themselves on 1431 trait adjectives which were grouped into 75 synonym clusters. Ten different factor analytic procedures were applied to these ratings resulting in virtually identical structures emerging. A second study comparing peer and self ratings resulted in the same structure for both methods of rating. In the third study, Goldberg developed a personality inventory of 339 adjectives which were

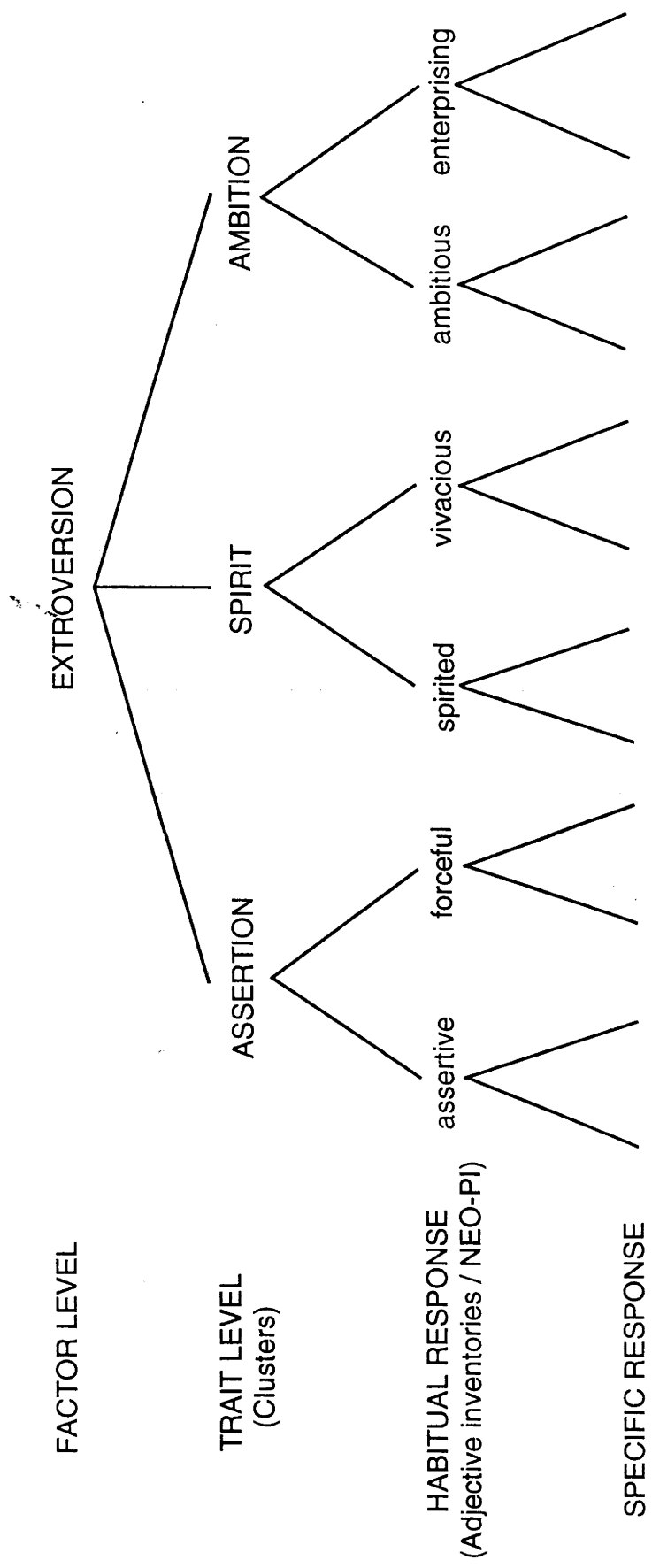


FIGURE 2.1: Norman's hierarchical system of personality descriptors (adapted from Eysenck, 1953) with examples from the Extroversion factor.

arranged into 100 clusters. This inventory is shown in Appendix 2.2. As can be seen in this inventory, clusters have been further divided into positive and negative poles within each factor. The clusters were made up of adjectives which were judged by lexicographers as being synonyms. Also, the mean social desirability rating of each adjective had to fall within a reasonably narrow range. Analysis of ratings based on this much smaller inventory gave the same factor structure as the other larger inventories and has the advantage of being shorter and much quicker to complete.

Another approach to the measurement of personality based on the five-factor model has been the use of theoretically-based questionnaires. Eysenck originally identified Extroversion and Neuroticism as major components of psychological tests. (Eysenck, 1970). Costa and McCrae (1976) then added to these two factors, the dimension of Openness to Experience. Some years later, these workers, along with others working in the field, added two more dimensions; Agreeableness and Conscientiousness (McCrae & Costa, 1985). McCrae and Costa developed a five factor questionnaire known as the NEO-PI and this has now been used in many areas of personality research. This inventory has been used by McCrae and Costa (1987) in a number of studies to show the ubiquity of this model. While the adjective inventory by Goldberg requires people to evaluate themselves or others in terms of trait adjectives, the NEO-PI contains questions which ask about attitudes, belief systems and behaviours in specific situations. Both the adjective inventory by Goldberg and the NEO-PI by McCrae and Costa relate to the habitual response level of the hierarchical system shown in Figure 2.1.

2.4 Applying Normal Personality Research to Dementia

2.4.1 Use of the Goldberg Inventory to Categorise Personality Change

Having now given a brief overview of the trait theory of personality, the development of the five-factor model of personality and inventories with which it can be measured, the relevance of this work to dementia can be considered. A major difficulty with the literature on personality and behaviour changes in dementia is to determine which changes may validly be considered to be changes in personality traits. Secondly, it is necessary to simplify the terminology used in different studies so that comparisons can be made. In an attempt to overcome these problems, the Goldberg 339 adjective inventory was used as a guide for selecting appropriate behaviours from the literature to be included in the study of personality, grouping these behaviours into the five factors. How this was done will be explained in a later section. In the study to be described here, the Goldberg inventory was used as the basis for a questionnaire on personality change in dementia. By also using the same inventory as a basis for

review of the literature, it will enable comparison of the current study with other studies in the field.

2.4.2 Application of Personality Definition to Studies on Dementia

Another issue that needs resolution is that the definition of personality requires some consistency of behaviours over situations and time. Obviously, as this area refers to personality *change*, we are assuming that it has not been consistent over time and may well still be changing as the disease progresses. To study personality in dementia, it is necessary to consider relatively short periods of time e.g. since the onset of dementia. In looking at consistency over situations, studies tend to fall into two groups. Some studies try to get an overview of change by asking informants to determine whether certain personality or behaviour characteristics have changed in the subject since developing dementia. All but one of these studies either include a control group or use an instrument which has been standardised for a normal population. The second group of studies looks at the occurrence of specific behaviours either by asking a relative how often they occur or recording the occurrence at clinical interview. Such an approach assumes that the behaviours have changed since developing dementia. These studies have usually not been trying to assess personality in dementia, but rather to look at the occurrence of a range of problem behaviours which have been reported as occurring clinically. Such studies have not used control groups. It would be inappropriate to infer personality change from these occurrence ratings. However, many of the behaviours measured in these studies could be seen as reflections of personality, and are very similar to those characteristics looked at in the first group of studies. If they were ignored in this review, much information of possible relevance to personality in dementia would be lost. Therefore, studies which have looked at the occurrence of personality-related behaviours will be included in this review as providing a possible indication of personality in dementia, although not how personality has changed since the onset of dementia.

2.5 Selection of Variables and Studies to be Included in This Review

2.5.1 Selection of Personality Variables and Behaviours

No studies using self reports have been included in this review. All reports of personality change or behaviours are from either relatives or clinicians. The behaviours selected came from studies which covered personality, problem behaviours and psychiatric symptoms. Some of the studies were looking at a wide range of behaviours including behaviours related to cognition. Selection of appropriate items was based on whether they could be viewed as expressions of

personality as defined by Goldberg's inventory. While items assessing irritability and anger have been included, more physical behaviours such as agitation, pacing and physical aggression have been excluded. It was considered that these latter were extreme behaviours which did not fit easily into the Goldberg inventory. Other extreme behaviours which have been excluded are 'constantly talking', refusing to talk and hyperactivity. Such behaviours were considered to be outside the range of normal personality. Some studies included items which had vague or ambiguous meanings and these were omitted from the review.

After selecting personality variables and behaviours to be included in this review, four raters (three psychologists and myself) classified the items into one of the five factors. The items were placed into factors when three out of the four raters agreed. When there was not such agreement, three of the four raters met to reach a consensus.

Table 2.1 shows the list of items which were considered to fit into the definition of personality traits. These items were segregated into the five factors but only the factors of Extroversion, Agreeableness and Neuroticism are shown in Table 2.1. Very few personality-related items covering the two remaining factors were found in the literature. These will be discussed briefly in the text. Within each factor these items have been further grouped into approximate synonyms. Where authors have defined the behaviour items they have used, these have been put into the factor which fits their definition. This does not always agree with the category applied by the raters. These specific items have the author's name after them in the table. Also, it should be noted that there are differences between the five factors as extracted by Goldberg and the NEO-PI. *Positive emotions* fit into the Extroversion factor in Goldberg's analysis and into the Neuroticism factor in the NEO-PI. *Hostility* also falls into different factors in the two inventories, as does *warmth*.

The inclusion of *depressive mood* as a personality trait creates a dilemma in the study of dementia. Although depressive mood can be viewed as a personality trait, it differs from many of the other behaviours discussed above as it often occurs as a more transitory state and is a symptom of depressive disorder. This is particularly relevant when looking at a sample of dementia sufferers. Depressive symptoms are frequently reported as occurring in the early stages of dementia (Pearson et al., 1989; Burns et al., 1990a; Fischer et al., 1990) and have been found to occur more frequently in patients with DAT than in non-demented elderly people (Lazarus et al., 1987; Rovner et al., 1989). As people in the early stages of dementia often have insight into their condition, it is quite possible that such depression may be a natural reaction to the diagnosis. It has also been suggested that depression may be one of

Table 2.1: Personality trait items selected from the literature. These have been classified into one of the five factors and further grouped into approximate synonyms. Only the factors Extroversion, Agreeableness and Neuroticism are shown here. # indicates those traits mentioned in ICD-10 while * indicates those traits mentioned in DSM-III-R.

EXTROVERSION FACTOR	AGREEABLENESS FACTOR	NEUROTICISM FACTOR
Lack of interest in people * emotional withdrawal (Sultzer) dislikes company doesn't socialise loss of interest in people gregarious (NEO-PI) not socialising Apathy # * diminished initiative (Blessed) apathy listless/enthusiastic withdrawal Positive emotion optimistic positive emotions (NEO-PI) excitement (Sultzer) cheerful elated mood Lack of Positive Emotion less cheerful pessimistic Underactivity # activity (NEO-PI) lassitude fatiguability underactive lifeless/energetic Quiet / talkative Warmth (NEO-PI) Assertive (NEO-PI) Excitement (NEO-PI)	Stubbornness stubborn rigid obstinate Self-centredness # self-centred egocentric wants things their own way loss of concern for others Crude behaviour # * coarsening of affect/crude behaviour inappropriate humour embarrassing behaviour disinhibition (Sultzer) affective bluntness (Gustafson) sexual misdemeanour lack of social restraint Irritability / Volatility # * drop in emotional control quick tempered explosivity anger verbally aggressive irritable easily annoyed quarrelsome argues belligerent Suspicion Callousness cold cruel insensitive Mean/generous Unreasonableness Childishness Hostility hostile hostile irritability Agreeableness (NEO-PI)	Emotional Shallowness affective shallowness less emotionally responsive blunted affect (Sultzer) Emotional Lability * emotional lability affective lability mood fluctuations changeable Anxiety * anxious anxious/agitated tense fearful nervous anxiety (NEO-PI) Depressive mood # * depressive mood sad unhappy unusually sad & depressed depression (NEO-PI) tearful feeling worthless feeling hopeless depressive thoughts Excitable / calm Reliant on others Self-conscious (NEO-PI) Impulsive (NEO-PI) Vulnerable (NEO-PI) Hostility (NEO-PI)

the prodromata of dementia (Burns, 1990). Despite this, in an effort to provide a comprehensive review of possible personality changes in dementia, depressive mood will be discussed here. The Goldberg inventory includes the clusters, *optimism* and *pessimism* in the Extroversion factor. However, this trait is usually associated with the factor of Neuroticism and for this review depressive symptoms have been included in the Neuroticism factor.

Table 2.1 also shows those personality traits which are referred to in ICD-10 and DSM-III-R. As can be seen, both diagnostic criteria cover traits in the three factors of Extroversion, Agreeableness and Neuroticism.

2.5.2 Studies Included in This Review

Table 2.2 summarises the studies which look at personality change or the occurrence of behaviours in dementia or DAT. Only the factors of Extroversion, Agreeableness and Neuroticism are shown here as in Table 2.1. Other personality traits will be discussed in the text. Table 2.3 lists studies which have been included in a review of the relationship between personality change or behaviour occurrence and cognitive decline.

All the studies have used clinical samples i.e. those patients who have been specifically referred to specialist services such as memory clinics. It is possible that the people who are brought to the attention of clinicians have more distressing behavioural problems than other dementia sufferers. This possible bias makes it difficult to generalise the results to the total population of dementia sufferers. The current study used a clinical sample and so suffers from a similar limitation. This issue will be discussed more thoroughly in the final chapter. As far as it is possible to ascertain from subject descriptions, Rubin et al. (1987a) and Petry et al. (1988) are the only groups to have excluded dementia sufferers who are also suffering from major depressive disorder.

The majority of studies have used subjects who have been diagnosed as suffering from DAT. One study has looked at a sample with a mixture of specific diagnoses and two have used samples which have been diagnosed only as suffering from dementia. Other studies which have looked at personality and behaviour in multi-infarct dementia (MID) specifically will be discussed briefly later in the review and compared to those studies investigating DAT. These are shown in Table 2.4. Most studies used subjects who had various degrees of severity, from mild to severe.

Table 2.2: Studies included in this review. These have been divided into 2 parts. Part A lists studies which have investigated personality changes while part B lists studies which have investigated the occurrence of behaviours related to personality in dementia. A key to all abbreviations is given at the end of Table 2.4.

Part A: Personality Changes in Dementia

AUTHORS	DEMENTIA DIAGNOSIS	SEVERITY	METHOD	FACTOR 1- / EXTROVERSION	FACTOR 2 - AGREEABLENESS	FACTOR 4 - NEUROTICISM
Rubin et al. (1987a) n=44	SDAT	mild CDR 0.5 - 1.0	Blessed Dementia Scale plus open-ended questions	apathy lack of positive emotion	stubbornness self-centredness crude behaviour irritability / volatility suspicion	emotional shallowness anxiety
Bozzola et al. (1992) n=80	DAT (DSM-III-R)	mild to severe MMSE 0 - 30	Blessed Dementia Scale	apathy	stubbornness self-centredness crude behaviour irritability / volatility	emotional shallowness
Petry et al. (1988) n=30	DAT (DSM-III & NINCDS)	mild to severe MMSE 0 - 28 mean=11	Brooks & Mckinlay inventory of bipolar opposites	lack of interest in people apathy quiet / talkative underactivity	irritability / volatility callousness unreasonableness childishness mean / generous	emotional lability excitable / calm reliant on others depressive mood
Siegler et al. (1991) n=35	memory problems -mostly dementia	mild to moderate MMSE 8 - 30	NEO-PI	lack of interest in people positive emotion underactivity warmth (NEO-PI) assertive (NEO-PI) excitement (NEO-PI)	agreeableness (NEO-PI)	anxiety hostility (NEO-PI) self-conscious (NEO-PI) impulsive (NEO-PI) vulnerable (NEO-PI) depressive mood
Chatterjee et al. (1992) n=38	DAT (DSM-III-R & NINCDS)	mild to severe MMSE 3 - 26	NEO-PI	lack of interest in people positive emotion underactivity warmth (NEO-PI) assertive (NEO-PI) excitement (NEO-PI)	agreeableness (NEO-PI)	anxiety hostility self-conscious (NEO-PI) impulsive (NEO-PI) vulnerable (NEO-PI) depressive mood

Part B: Occurrence of behaviours in dementia

AUTHORS	DEMENTIA DIAGNOSIS	SEVERITY	METHOD	FACTOR 1- EXTROVERSION ²	FACTOR 2 - AGREEABLENESS	FACTOR 4 - NEUROTICISM
Gustafson (1975) n=57	presenile dementia clinical evaluation	unstable	behaviours shown at interview	/	stubbornness irritability / volatility suspicion 4% / 11% crude behaviour 35% / 58%	emotional shallowness emotional lability anxiety depressive mood
Bucht & Adolfsson (1983) n=18	AD/SDAT (DSM-III)	mild to moderate clinical evaluation	CPRS behaviours shown at interview	positive emotion		emotional lability depressive mood
Schwartz (1983) n=45	PDD (DSM-III)	2 to 7 on Global Deterioration Scale (GDS)	GERRI frequency of occurrence	lack of interest in people positive emotion	stubbornness self-centredness crude behaviour irritability / volatility childishness	emotionally labile depressive mood
Reisberg et al. (1987) n=23	AD	GDS of 4 or greater	behavioural symptoms noted in the records	apathy	suspicion	emotional lability anxiety depressive mood
Haley et al. (1987) n=44	dementia	moderate to severe mean MMSE=10	MBPC occurrence in past month		crude behaviour suspicion	
Teri et al (1988) n=127	PDD - (DSM-III)	mild to severe MMSE mean=17	behaviour items reported by clinician or family		suspicion	
Teri et al (1989) n=56	DAT (DSM-III)	varied MMSE mean=23	Behaviour Problems Checklist (BPC) more than twice a week	apathy lack of interest in people underactivity	irritability / volatility	anxiety

Part B (continued)

AUTHORS	DEMENTIA DIAGNOSIS	SEVERITY	METHOD	FACTOR 1- EXTROVERSION	FACTOR 2 - AGREEABLENESS	FACTOR 4 - NEUROTICISM
Burns et al. (1990c) n=178	AD (NINCDS)	mild to severe CDR	Geriatric Mental State - observed behaviours		irritability / volatility	depressive mood
Burns et al. (1990b) n=31	AD (DSM-III)	mild to severe MMSE mean=14	scales for apathy & irritability	apathy	irritability / volatility	
Lachs et al. (1992) n=114	SDAT, MID or mixed	varied MMSE mean=19	behaviours extracted from clinical notes	apathy	irritability / volatility	emotional lability
Sultzer et al. (1992) n=83	AD (DSM-III)	mild to severe MMSE 0 - 28 mean=10	Neurobehavioural Rating Scale level of severity	lack of interest on people positive emotion underactivity	crude behaviour hostility suspicion	emotional shallowness emotional lability anxiety depressive mood
Lukovits & McDaniel (1992) n=33	AD (NINCDS)	severe CDR	behaviours items - presence or absence			anxiety depressed mood
Cohan et al. (1993) n=514	AD (DSM-III-R & NINCDS)	unstated	behaviours recorded at interview	apathy		emotional lability depressed mood
Ballinger et al. (1982) n=100	senile dementia or arteriosclerotic dementia	unstated	various interview schedules plus medical records	lack of interest in people positive emotion underactivity	crude behaviour suspicion hostility	anxiety depressive mood

Table 2.3: Studies used only to review relationship between personality change and cognitive decline.

AUTHORS	DEMENTIA DIAGNOSIS	SEVERITY	METHOD	FACTOR 1- EXTROVERSION	FACTOR 2 - AGREEABLENESS	FACTOR 4 - NEUROTICISM
Rubin et al. 1987b n=24	SDAT	mild to severe CDR 1 - 3	Blessed Dementia Scale	passive behaviours	self-centred behaviours agitated behaviours	
Petry et al. 1989 n=19	DAT (DSM-III & NINCDS)	mild to severe MMSE 0 - 21 mean=3		lack of interest in people apathy quiet /talkative underactivity	irritability / volatility callousness unreasonableness childishness mean / generous	emotional lability excitable / calm reliant on others depressive mood
Cooper et al. 1990 n=680	AD (NINCDS)	mild to severe MMSE	clinical records	apathy	irritability/volatility	depressive mood
Stern et al. 1990 n=187	AD (NINCDS)	not stated	Blessed Dementia Scale	apathy	Agreeableness	
Gilley et al. 1991 n=146	AD (NINCDS)	MMSE 0 - 27 mean=12	Rush Patient Behaviour Checklist	apathy	crude behaviour irritability/volatility	
Forsell et al. 1993 n=142	dementia (DSM-III-R)	CDR 0.5 - 3				anxiety depressive mood

Table 2.4: Studies examining personality changes and behaviours in multi-infarct dementia

AUTHORS	DEMENTIA DIAGNOSIS	SEVERITY	METHOD	FACTOR 1- EXTROVERSION	FACTOR 2 - AGREEABLENESS	FACTOR 4 - NEUROTICISM
Bucht & Adolfsson (1983) n=20	MID (DSM-III)	mild to moderate	CPRS - behaviours shown at interview	lack of positive emotion positive emotion	hostility	emotional lability
Cummings et al (1990) n=20	MID DSM-III-R NINCDS)	mild to severe MMSE 0 - 29 mean=21	Brooks & McKinlay inventory	lack of interest in people underactivity quiet / talkative	irritability / volatility callousness unreasonableness childishness	emotional lability excitable reliant on others depressive mood
Sultzer et al. (1992) n=22	MID (DSM-III)	mild to moderate MMSE 8-28 mean=20	Neurobehavioural Rating Scale level of severity	lack of interest in people positive emotion underactivity	crude behaviour hostility suspicion	emotional shallowness emotionally lability anxiety depressive mood

Key to Abbreviations:

- AD Alzheimer's Disease
- CDR Clinical Dementia Rating Scale (Hughes et al., 1982)
- CPRS Comprehensive Psychopathological Rating Scale (Asberg et al., 1978)
- DAT Dementia of the Alzheimer Type
- GERRI Geriatric Evaluation by Relatives Rating Instrument (Schwartz, 1983)
- MBPC Memory and Behaviour Problems Checklist (Zarit & Zarit, 1982).
- MID Multi-infarct dementia
- MMSE Mini Mental State Examination (Folstein et al., 1975)
- NEO-PI NEO Personality Inventory (Costa & McCrae, 1985)
- NINCDS National Institute of Neurological and Communicative Disorders Association criteria
- PDD Primary Degenerative Dementia

The studies reviewed here used dementia subjects who were living in the community, with the exception of Lukovits and McDaniel (1992).

2.5.3 Difficulties in Comparing Studies on Personality in Dementia

Although grouping of a large number of behaviours into approximate synonyms and further into one of the five factors enables easier comparison of studies, some difficulties are still evident. While some studies express results in terms of the percentage of relatives who report either the occurrence of, or change in a behaviour, other studies express results in terms of the average score on a scale. In those studies which look at occurrence of behaviours, these may be either the *number* of occurrences varying from once a month to at least twice a week or the rated *severity* of the occurrences.

The way in which information is gathered may also affect the extent to which personality changes or behaviour occurrence is reported. In some studies, behaviour occurrence is extracted from clinical notes. In such cases, only some of the behaviours observed may have been recorded. Also, behaviours or personality changes reported by relatives may only be those which cause distress. Such methods of gathering data will probably provide less information or more biased information than the use of an inventory which specifies the behaviours to be looked for or asked about. Another possible problem with using data gathered from clinicians' observations is that a clinician usually sees the patient only for a short time and in a single environment. The behaviour of the patient in this situation may be atypical.

Apart from the numerous differences between studies there are methodological problems in individual studies. Some studies have used small numbers of subjects (for example, Bucht and Adolfsson, 1983; Reisberg et al., 1987). This is particularly relevant for those studies where factor analysis has been used in the analysis (for example, Rubin et al., 1987). Many of the studies have not defined the personality variables used or have only defined them in very general terms. Also, few of the studies examined in this review have included any attempt to look at the reliability or validity of the instruments used.

Despite all these problems, an attempt will be made to provide an integrated account of present knowledge about personality changes in dementia.

2.6 Personality Change and Behaviour Occurrence in Dementia

2.6.1 Extroversion

2.6.1.1 Apathy

This characteristic has frequently been reported in the clinical literature as being a commonly occurring feature of dementia. While Rubin et al. (1987a) found that apathy had increased in 23% and 39% of their subjects depending on the specific question, Bozzola et al. (1992) reported increased apathy in 61% of their sample. Petry et al. (1988), using the inventory developed by Brooks and McKinlay (1983) to assess personality change following head injury, found a significant increase in apathy in their sample. Teri et al. (1989) found that 21% showed apathetic behaviour at least twice a week, while Burns et al. (1990b), using a scale of five items to assess apathy, found that 48% of relatives reported three or more of these items present. Studies which have looked at behaviours recorded in clinical notes show an occurrence in 3% (Reisberg et al., 1987), 45% (Lachs et al., 1992) and 22% (Cohen et al., 1993) of dementia patients. It is difficult to find a reason for the very low occurrence in the Reisberg study.

2.6.1.2 Lack of Interest in People

It would seem possible that a lack of interest in people may occur in people who have become apathetic. However, Petry et al. (1988) found no significant difference in this characteristic compared to a significant increase in apathy. Using the NEO-PI both Siegler et al. (1991) and Chatterjee et al. (1992) also found that their subjects had not significantly changed in this characteristic. Of those studies looking at the occurrence of behaviours, Teri et al. (1989) found that 18% showed this behaviour more than twice a week while Sultzer et al. (1992) found that 35% exhibited it to a mild extent and 15% to a moderate extent. These figures are quite similar to some of those found for the occurrence of apathy. In a study of 100 Alzheimer's disease (AD) patients by Ballinger et al. (1982), 85% were reported as not socialising. Schwartz et al. (1983) found that the mean score for their measure of *does not socialise with friends* on the GERRI scale was between 'often' and 'most of the time'.

2.6.1.3 Positive Emotions and Lack of Positive Emotions

Positive emotion as assessed by the two studies using the NEO-PI (Siegler et al., 1991 and Chatterjee et al., 1992) was found to decrease significantly after the onset of dementia. Rubin et al. (1987a) reported a decrease in cheerfulness for only 9% of subjects. Schwartz (1983) found that, while on average his sample was reported to be optimistic only 'sometimes', they were reported to 'often' appear cheerful. Sultzer et al. (1992) found that 32% of patients showed an excited, elated behaviour to a mild extent and 13% to a moderate extent at interview, while Ballinger et al. (1982) reported only 8% exhibiting such behaviour. Bucht and Adolfsson (1983) found that

17% of patients suffering from DAT showed what they termed, an 'expansive hilarity with exaggerated self-confidence and mirth'. It is possible that these expressions of elation may be related more to emotional lability which will be discussed under the Neuroticism factor.

These results suggest that while positive emotions do decrease in dementia, some dementia sufferers still show positive emotions at least some of the time.

2.6.1.4 Underactivity

Petry et al. (1988), Siegler et al. (1991) and Chatterjee et al. (1992) all found a significant decrease in energy and physical activity. Teri et al. (1989) found that 43% were underactive, moving very slowly more than twice a week. Compared to this quite high occurrence, Sultzer et al. (1992) reported that only 7% of their sample showed even a mild level of fatigue and Ballinger et al. (1982) recorded fatigue in only 8% of patients.

2.6.1.5 Other Areas of Extroversion Covered by the NEO-PI

The NEO-PI also covers *excitement-seeking*, *assertiveness* and *warmth* within the factor of Extroversion. In both studies using the NEO-PI (Siegler et al., 1991 and Chatterjee et al., 1992) it was found that these three traits had decreased significantly. Petry et al. (1988) reported no significant change in the characteristic of *quietness*.

2.6.1.6 General Comments on Extroversion

Studies which have looked at personality changes all found a decreased level of Extroversion. Subjects were generally less active and more apathetic but were not seen as being any less interested in mixing with people. Those studies which looked at the occurrence of behaviours did find a proportion of dementia sufferers who showed a lack of interest in people and who appeared apathetic. Underactivity was observed in a number of studies. Positive emotions are reported to decrease, but some studies found that a proportion of their subjects showed elated mood some of the time.

2.6.2 Agreeableness

2.6.2.1 Stubbornness

While Rubin et al. (1987a) using the Blessed Dementia Scale (Blessed et al., 1968) found that 21% of their subjects had become more stubborn, Bozzola et al. (1992) found an increase in 41% using the same scale. Gustafson (1975) found that 26% of his sample of presenile dementia patients showed stubborn behaviour to a significant

extent, while 58% showed at least some evidence of it. Schwartz (1983) found that, on average, subjects showed stubborn behaviour most of the time.

2.6.2.2 Self-centredness

Increases in self-centred behaviours were reported by both Rubin et al. (1987a) and Bozzola et al. (1992). Rubin had three measures of this trait with frequencies of change of 5%, 18% and 20%. The item which was reported in only 5% of cases was from the open-ended questions, raising the possibility that a structured questionnaire could elicit a higher acknowledgment of behaviours than just relying on informants to recall changes.

Bozzola found that 26% reported increases in egocentricity and 39% showed loss of concern for feelings of others. In the study by Schwartz, (1983) the average occurrence of such behaviours was between 'often' and 'most of the time'.

2.6.2.3 Crude Behaviour

While Rubin et al. (1987a) found that crude behaviour occurred in 11% of their subjects, Bozzola et al. (1992) reported it in 36% of their sample. In the more specific behaviour of *increase in inappropriate hilarity* both studies found similar frequencies of 11% and 13%. It is possible that the Bucht and Adolfsson (1983) item of *expansive hilarity*, found in 17% of patients is very similar to *inappropriate hilarity*. Sexual misdemeanours were very rare, occurring in only one subject (2%) in the Rubin study and in three subjects (4%) in Bozzola's study.

Gustafson (1975) found that socially crude behaviour was manifestly present in 35% of patients and that there was at least some evidence of this behaviour in 58%, while Sultzer et al. (1992) also using behaviours noted during clinical interviews found that 34% showed a mild level of crude behaviour and 8% a moderate level. Using a number of rating scales, Ballinger et al. (1982) reported that 57% of their subjects exhibited what they termed, a *lack of social restraint*. Schwartz (1983) found that the average occurrence of embarrassing behaviour was between 'most of the time' and 'almost all the time'. Haley et al. (1987) found that crude behaviour occurred at least once a month in 39% of subjects. One difficulty with measuring crude or embarrassing behaviour is that it is a very subjective measure and may depend somewhat on the attitude of the informant. Reports of crude behaviour may, therefore, be rather unreliable unless specific behaviours are targeted. These results suggest that approximately one third or more of dementia patients show crude, inappropriate behaviour.

2.6.2.4 Irritability / Volatility

This trait has often been reported in the clinical literature. In this review it covers a large range of behaviours. Rubin et al. (1987a) found similar reports of increase in irritability for the structured interview (21%) and for the open-ended reports (23%). Bozzola et al. (1992) reported almost the same occurrence of change (19%). In the study by Petry et al. (1988), irritability was found to increase significantly, but there was no significant increase in quick-temper.

There was at least some evidence of irritability in 25% of Gustafson's patients (Gustafson, 1975) but only 9% showed any sign of explosive temper. Observed belligerence as assessed by the Geriatric Mental State was seen in 21% of patients studied by Burns et al. (1990c). Angry outbursts were reported by clinicians in 11% of patients in the study by Lachs et al. (1992) while verbal aggression occurring more than twice a week was reported by Teri et al. (1989) in only 11% of subjects. Burns et al. (1990b), using a different sample to that used in the Burns et al. (1990c) study, assessed irritability using a five item scale and found that 58% of relatives reported some degree of irritability.

Schwartz (1983) found that for the items, *appears to be easily annoyed or angered*, and *when asked questions, seems quarrelsome and irritable* the average response was between 'most of the time' and 'almost all the time'.

These results are remarkably consistent with about 25% showing increases in irritability since developing dementia and about the same proportion showing the occurrence of irritable behaviour. However, more extreme expressions of anger were rarer, occurring to some extent in about 10% of patients.

2.6.2.5 Hostility

While Bucht & Adolfsson (1983) found a very low occurrence of hostility in Alzheimer's disease (AD) patients, Sultzer et al. (1992) found that at clinical interview, 27% showed a mild level of hostility. Compared to these, Ballinger et al. (1982) found that 67% demonstrated hostile irritability.

2.6.2.6 Suspicion

Only Rubin et al. (1987a) have looked at changes in suspicion. They found that this trait was reported in the open-ended questions for only 5% of subjects. Reports of occurrence of suspicion are quite variable. Gustafson (1975), reporting behaviours shown at interview, found that 11% showed at least some degree of suspicion, while Reisberg et al. (1987) found that suspicion had been noted in the records for 50% of

patients. In this latter study the information was based on information gathered from carers as well as from clinical interview. In the study by Teri et al. (1988) where behaviours were also reported by family or clinicians, 24% of the subjects were said to show suspicion, while Ballinger et al. (1982), using rating scales and clinical notes, reported 39% showing this behaviour. Sultzer et al. (1992), using the Neurobehavioural Rating Scale, reported a mild level of suspicion in about 30% of their sample, while only 15% showed suspicion to a more extreme extent. In Haley's study (Haley et al., 1987), suspicion had been shown in the past month by 50% of subjects. Where rating scales have been used to gather information, between 25% and 50% of dementia sufferers were found to show some level of suspicion.

2.6.2.7 Other Personality Traits Related to Agreeableness

Petry et al. (1988) investigated a number of other traits which fell into this factor. Subjects were found to be somewhat more callous, showing a small but significant increase in coldness and cruelty, but no significant decrease in sensitivity. Subjects were found to have, on average, a small but significant decrease in generosity. Greater increases were seen in unreasonable and childish behaviour. In the study by Schwartz (1983), subjects were found, on average, to show childish behaviour between 'most of the time' and 'almost all the time'. In those studies using the NEO-PI (Siegler et al., 1991; Chatterjee et al., 1992), there is one general measure of Agreeableness. The Siegler study found an insignificant change in this trait, while Chatterjee and colleagues found a significant but small decrease in agreeableness. However, *warmth* is included under the Extroversion factor in the NEO-PI, rather than the Agreeableness factor where it is found in Goldberg's inventory.. Both studies using the NEO-PI found quite a large and significant decrease in *warmth*.

2.6.2.8 General Comments on Agreeableness

Although the frequencies of the different behaviours looked at here are very variable, it seems that people suffering from dementia, in most cases DAT, show a moderately high level of disagreeable behaviours, with some studies showing that these have increased since developing dementia. One point of interest is the differences between the studies by Rubin et al. (1987a) and Bozzola et al. (1992), as both have used the personality component of the Dementia Rating Scale. Bozzola et al. show a higher incidence of change for most characteristics in both the Extroversion and Agreeableness factor. A possible reason is that Rubin et al. were using only DAT subjects in the mild stage of cognitive decline while Bozzola and colleagues have used subjects showing a range of cognitive decline.

Another factor which may effect the results found in the factor of Agreeableness may be the influence of a clinical interview. It seems quite possible that some of these behaviours such as irritability and suspicion may be exacerbated by the process of clinical interview.

In contrast to the changes seen in the above studies are the small changes seen using the NEO-PI. A possible reason for this is the way the questions are phrased in the NEO-PI. Many of the questions assume an ability to make rational decisions, to evaluate their situation and respond appropriately. It may be difficult for informants of dementia sufferers to relate such questions to people who may be unable to do this.

2.6.3 Neuroticism

2.6.3.1 Emotional Shallowness

Gustafson (1975) defined *affective shallowness* as 'emotional reactions to events and topics which would ordinarily be expected to deeply affect the patient either can not be observed or seem to be superficial or volatile' while Sultzer et al. (1992) described *blunted affect* as 'reduced emotional tone; reduced range or intensity of affect'. This variable was included in this discussion as it is similar to some of the adjectives in the positive pole of Neuroticism, such as *unexcitable* and *unemotional*. It is possible, however, that this variable is outside the range of normal personality. Despite this, it will be included here.

Using the Dementia Rating Scale, both Rubin et al. (1987a) and Bozzola et al. (1992) found quite small numbers of informants reporting this behaviour: 7% and 14% respectively. However, Sultzer et al. (1992) found that this behaviour was recognised by clinicians as being present to a mild extent in 42% of patients and to a moderate extent in 16%, while Gustafson reported it as being manifestly present in 58% and there being at least some evidence of it in 95% in patients with presenile dementia. It is possible that this type of behaviour is more easily recognised by clinicians or perhaps that informants had difficulty understanding the concept of *less emotionally responsive* as used in the Blessed Dementia Scale.

2.6.3.2 Emotional Lability

Petry et al. (1988) found a large significant increase in what they termed *changeability* since developing DAT. Gustafson (1975) found this behaviour to be manifestly present in 26% of patients and at least some evidence of it in 65%. Bucht & Adolfsson (1983), using the Comprehensive Psychopathological Rating Scale

(CPRS), found that 22% of AD patients showed this behaviour frequently at interview, while Sultzer et al. (1992) reported it as occurring at a mild level of severity in approximately 37% of patients, but only to a moderate level of severity in 8% of patients. Compared to this, Reisberg et al. (1987) found that only 3% of patients had mood fluctuations mentioned in their notes, Lachs et al. (1992) reported a 6% occurrence based on clinical notes and Cohen et al. (1993) found that only 6% had this behaviour reported at interview. It is possible that this difference is due to the method of collecting information about behaviours. The studies which reported high levels of emotional lability were those in which clinicians were completing a schedule of behaviours while the studies showing low frequencies involved behaviours reported by clinicians at interview.

Schwartz (1983) found that, on average, informants reported that mood changes occurred between 'most of the time' and 'all the time'.

2.6.3.3 Anxiety

In the open-ended questions asked by Rubin et al. (1987a), only 7% of informants mentioned an increase in anxiety in their relatives. Both Siegler et al. (1991) and Chatterjee et al. (1992), using the NEO-PI, found a large increase in anxiety. Studies looking at the occurrence of behaviours have also found a high incidence of this trait. Gustafson (1975) reported that 58% of his subjects showed some evidence of anxiety at interview, while in 26% it was manifestly present. Sultzer et al. (1992) reported a mild level of anxiety in about 25% of patients, but only 5% showed a moderate level, while Ballinger et al. (1982) reported a 54% occurrence of anxious/agitated behaviour. Anxiety was reported as occurring more than twice a week in 34% of subjects in the study by Teri et al. (1989). In a study of institutionalised patients with quite severe AD, Lukovits and McDaniel (1992) compared the ratings of family members and nursing staff. Both raters reported about 35% of patients as showing anxiety and close to 30% expressing fears. As has been seen in other behaviours, the Reisberg study (Reisberg et al., 1987) gave rather different results with clinicians recording anxiety in the notes of only 12% of patients and fearfulness in only 6% of patients. These results suggest that anxiety is frequently seen in dementia patients and most studies of personality change indicate that anxiety has significantly increased.

2.6.3.4 Other Neurotic Behaviours Assessed by the NEO-PI

Both Siegler et al. (1991) and Chatterjee et al. (1992) found small but significant increases in self-consciousness, no significant change in impulsiveness and a large increase in vulnerability. Hostility as assessed by the NEO-PI was found not to

change significantly in Siegler's study and to have increased to a small but significant extent in Chatterjee's study.

2.6.3.5 Depressive Mood

Of the studies looking at personality change, Petry et al. (1988) found quite a large significant increase in unhappiness while both Siegler et al. (1991) and Chatterjee et al. (1992) reported large increases in depressive mood. High levels of depressive mood are also seen in those studies which have looked at the occurrence of behaviours at interview. Gustafson (1975) found that at least 44% showed some evidence of depressive mood but it was only fully manifest in 14%, Reisberg et al. (1987) reported 24%, Cohen et al. (1993) reported 25%, while Sultzer et al. (1992) found that 26% showed depressive mood at a mild level of severity and only 2% at more severe levels. Bucht and Adolfsson (1983), using the CPRS, found that only 11% *appeared sad most of the time*. Ballinger et al. (1982) reported 42% as being depressed but only 11% as having depressed thoughts.

Burns et al. (1990c) found that while clinicians rated only 24% of patients as having depressive symptoms using the Geriatric Mental State schedule, caregivers reported such symptoms in 43% of patients. A similar result was found in the study by Lukovits and McDaniel (1992) in which nurses reported depressive mood in approximately 18% of patients while caregivers reported the same symptom in 40% of patients. Schwartz (1983) included 4 measures of depressive mood in the GERRI and all of these occurred on average between 'most of the time' and 'almost all the time'.

A number of studies have examined the co-occurrence of depression with dementia. Those studies looking specifically at AD have been reviewed by Teri and Wagner (1992) who found that the majority of studies report between 17% and 29% occurrence of depressive disorder in people suffering from AD. As the majority of studies reviewed here have not excluded dementia sufferers who were also suffering from a depressive disorder, it is quite possible that the depressive mood found in these studies may in many cases be indicative of depression. Some of the other traits discussed in this review may also be symptoms of depression. These include apathy, underactivity, lack of positive emotions, irritability and anxiety. However, these behaviours were also found to increase in the studies by Rubin et al. (1987a) and Petry et al. (1988) where AD subjects with major depression were excluded. Therefore, it would appear from these studies that depressive mood can occur in dementia independently of such co-morbidity.

2.6.3.6 General Comments on Neuroticism

It would appear that emotional shallowness is recognised more often by clinicians than by family, while the reported occurrence of emotional lability may be dependent on the way in which the data are gathered. Quite high levels of anxiety have been found, with most studies finding frequencies of between 20% and 40%, while studies of personality change have found a significant increase in anxiety. Depressive symptoms are also often seen with frequencies of around 25% being common, but reports were influenced by the role of the informant. Studies looking at personality change have also found a significant increase in depressive symptoms in dementia patients.

2.6.4 Conscientiousness

Petry et al. (1988) found that there was no increase in rash behaviours, but that the subjects in this study were much more *out of touch* as opposed to *down to earth*. This latter trait is very general and probably would have been seen as covering many aspects of life including areas of cognition. Teri et al. (1989) reported that 20% carried out strict rituals of behaviour more than twice a week and that 14% showed unpredictable behaviour more than twice a week. The former behaviour has sometimes been viewed as a reaction to memory loss (DSM-III-R). Sultzer et al. (1992) found that *diminished initiative/motivation*, defined here as 'fails to initiate or persist in tasks; reluctant to accept new challenges', occurred to a moderate extent in about 14% of subjects but to a mild extent in about 50% of subjects.

Both studies which assessed personality change using the NEO-PI (Siegler et al., 1991 and Chatterjee et al., 1992) found large decreases in Conscientiousness.

2.6.5 Openness to Experience

Lukovits and McDaniel (1992) found that over 60% of family members reported that their relative had lost interest in activities or people, while nursing staff reported this in about 50%. Loss of interest in activities was reported as occurring more than twice a week in 32% of the subjects in the study by Teri et al. (1989). In the study by Rubin et al. (1987a), hobbies had been relinquished by 32% of the subjects, while in Bozzola's study (Bozzola et al, 1992) 55% had relinquished hobbies. All of the behaviours mentioned here could be cognitively related.

2.6.6 Overall Comment on Personality Change and Behaviour Occurrence

Looking first at those studies which have measured personality change in dementia, it is possible to make some generalisations. The studies by Rubin et al. (1987a) and Bozzola et al. (1992) have both used the Blessed Dementia Scale to assess

personality change. Although Bozzola found higher frequencies of change than Rubin, the order of frequency with which most of the items occur is the same. Apathy is the most frequently occurring characteristic in both studies, followed by stubborn, self-centred, crude, and emotionally shallow. The only exception to this is the occurrence of irritability which was reported nearly as frequently as the occurrence of apathy in Rubin's work, but relatively less frequently in Bozzola's study. Petry et al. (1988) also found that measures of apathy showed more change than many of the other characteristics measured.

Both Siegler et al. (1991) and Chatterjee et al. (1992) used the NEO-PI to assess personality change and found remarkable agreement. Rank ordering of the change scores for each trait assessed found that both studies had almost the same rank order.

Comparing the studies which have looked at the occurrence of behaviours did not reveal any pattern of change. Considerable variability was also found in those studies assessing frequency of change in personality.

Many of the behaviours examined above are also behaviours which may be considered symptomatic of depression. These include loss of energy, lack of positive emotions, irritability, emotional lability and anxiety. It is possible that these behaviours, when found in dementia sufferers, are actually part of a co-morbid depressive disorder. Of the studies reviewed here, only the study by Rubin et al. (1987a) has excluded AD sufferers with the co-occurrence of major depression from their sample. It is interesting to note that the levels of apathy and anxiety were much lower in this study than it was in Bozzola's study using the same scale. It is also possible, however, that these results were influenced by Rubin and colleagues' use of a sample of only mildly cognitively impaired dementia sufferers.

2.7 Correlation Between Personality Change and Cognitive Status

It is of interest to know whether the expression of certain personality traits changes with decline in cognitive status. If such a relationship is found, it is possible that these changes are simply a secondary effect of cognitive decline. The dementia sufferer may be reacting to their loss of memory or their ability to express certain personality traits may be limited. Another possible reason for such an association may be that the same areas of the brain are involved in cognitive decline and change in certain personality traits. If there does not appear to be any correlation between cognitive decline and personality changes, it is possible that different biological processes are involved.

The best way to look at such a relationship is longitudinally which allows researchers to measure the relationship between expression of personality and cognitive status in the same individuals over time. Only two studies have followed a demented sample longitudinally to examine changes in personality over the course of the disease. Rubin et al. (1987b) followed up 24 of their original sample of 44, 50 months after the original study (Rubin et al., 1987a). Petry et al. (1989), three years after the initial interviews (Petry et al., 1988) were able to follow up 19 of the original sample of 30 AD sufferers. All other studies to be reviewed here have looked at differences cross-sectionally. As with the above section, the relationship between personality change and cognitive decline will be discussed in the context of the five-factor model.

2.7.1 Extroversion

Rubin and his co-workers originally used the Blessed Dementia Scale plus open-ended questions to assess personality change in AD subjects (Rubin et al., 1987a). However, after analysis they grouped the items into three clinically meaningful groups which they labelled *Passive*, *Self-centred* and *Agitated*. The passivity factor contains items which mostly fall within the Extroversion factor and hence will be looked at here. In this follow-up study (Rubin et al., 1987b), they found that the frequency of passivity symptoms increased from 66% for mild AD through to 88% in those who had reached the severe stage of dementia. This increase, however, was found to be statistically insignificant. In a study by Rubin and Kinscherf (1989) using the same methods, 71% were reported to show passive behaviours in mild dementia while 41% with questionable dementia, as defined by the Clinical Dementia Rating Scale (Hughes et al., 1982) demonstrated such behaviours. These studies suggest that such personality-related behaviours occur very early in the course of dementia but may not increase greatly with further cognitive deterioration. Stern et al. (1990) also used the Blessed Dementia Scale to study 187 patients with AD. Principal components analysis revealed two personality factors; one for apathy/withdrawal and one which fell into the Agreeableness factor. They found that the apathy/withdrawal factor was significantly, negatively correlated to MMSE scores.

In the initial study by Petry et al. (1988) no correlation was found between MMSE score and interest in people, apathy, quiet behaviour or activity. In their follow-up study (Petry et al., 1989), they found no correlation between the serial ratings of all items of personality change and the MMSE scores. The authors, however, made the point that there were large changes between onset and the initial interview and that a floor effect may have made the instrument insensitive to further change. This would not have applied to *quiet* and *interest in people* however, as these were not seen to

have changed significantly at the initial interview. Activity level was found to decrease continuously over the course of the disease.

In the study by Chatterjee et al. (1992) using the NEO-PI they found that patients with higher MMSE scores were seen as having decreased more in the general Extroversion factor. However, the authors considered this finding to be hard to explain and in need of replication. Gilley et al. (1991) using the Rush Patient Behaviour Checklist to examine 143 patients with AD found that apathy was significantly, negatively correlated to the MMSE score. In a study of 680 AD patients, Cooper et al. (1990) found a significant, negative correlation between MMSE scores and a general factor labelled *personality change / apathy*. However, the correlation was quite low.

As was the case with the frequency of behaviour and personality change, there is no general agreement here. It seems likely that apathy occurs early in the course and increases somewhat as cognitive performance declines.

2.7.2 Agreeableness

In looking at the combined factor of *Self-centred behaviour* at follow-up, Rubin et al. (1987b) found that the reported occurrence increased significantly from 34% in the original, mildly impaired subjects to 58% when moderately impaired but to only 63% when severely impaired. This suggests that such behaviours may increase until a moderate level of impairment is reached and then level off. In both the study by Rubin et al. (1987b) and the study by Rubin and Kinscherf (1989), the level of *Self-centred behaviour* in the mild stage was about 30%, while Rubin and Kinscherf found that only 14% of their group with questionable dementia showed these characteristics. These results suggest that such personality changes are not as frequent in the early stages of dementia, but occur quite often as cognitive impairment increases to a moderate level.

Rubin et al. (1987b) also examined, at follow-up, a group of items which they called *Agitated behaviour*. This factor included the trait of irritability. *Agitated behaviour* was found to increase throughout the entire course, with 30% showing these behaviours in the mild stages, increasing gradually to 67% at the severe stage. Rubin and Kinscherf found that only 14% showed such behaviours in the very mild or questionable stage and 21% at the mild stage.

Petry et al. (1988) found no correlation between MMSE and any of the measures of Agreeableness. At follow-up (Petry et al., 1989), there was also no correlation with

serial ratings and MMSE scores, however, differences over time were found. The traits of unreasonableness, cruelty and meanness changed significantly between onset and the first evaluation, but showed little change between first and second evaluations. Coldness and insensitivity were found to increase continuously over time with significant differences between the three scores. While irritability showed a trend toward a decrease in scores between the first and second evaluations, this was not significant.

A number of the studies which have looked at changes in behaviour have looked at the relationship between irritable/volatile behaviours and cognitive decline with mixed results. Gustafson (1975), using a sample of 57 with presenile dementia, found that a factor called *explosive temper*, which included the behaviours of irritability and obstinacy, was significantly positively correlated to measures of memory loss and confusion. Using the Clinical Dementia Rating Scale to assess cognitive impairment, Burns et al. (1990a) found that *observed belligerence* increased from zero occurrence in the mild stage to 25% in the moderate stage then levelled off to 20% in the severe stage although these changes were not significant. Both Cooper et al. (1990) and Gilley et al. (1991) found that there was a negative correlation between the MMSE score and the occurrence of irritable/volatile behaviours and that these correlations were significant although in the case of Gilley's study, quite small. The results from these studies suggest that the frequency of irritable/volatile behaviours increase with cognitive decline although it may only be to a small extent.

The occurrence of suspicion at different stages of dementia has been examined in three studies. Gustafson (1975) found that a factor which included suspicion was not correlated to measures of memory loss and confusion. Teri et al. (1988) found no correlation between suspicion and MMSE scores while Sultzer et al. (1992) dichotomised their subjects at MMSE scores of 10 or more and less than 10 and found no significant difference between the groups in the occurrence of suspicion. These results suggest that although suspicion is known to occur in dementia, it may not be related to cognitive decline.

Sultzer et al. (1992) also looked at the differences between these two groups in measures of hostility and crude behaviour, dichotomised on the basis of MMSE score, and found that there was no significant difference. Gilley et al. (1991) found a significant, negative correlation between MMSE scores and disinhibition.

Chatterjee et al. (1992) found no correlation between the general factor of Agreeableness in the NEO-PI and the MMSE scores. However, relatives did

perceive a greater decrease in Agreeableness, the longer the patient had the illness. As this study involved having the relative complete an inventory about the patient's personality before developing dementia and another based on their current personality, this result may have been due to how the informant remembered the patient over time.

Using the Blessed Dementia Scale, Stern et al. (1990) extracted a general factor covering many of the items in the Agreeableness factor. They found that there was a significant increase in this factor as MMSE scores declined although the correlation was small.

2.7.3 Neuroticism

A number of studies have looked at the occurrence of depressive mood at different stages of dementia. Petry et al. (1988) found no correlation between MMSE scores and unhappiness in their initial evaluation. At follow-up, however, they found that, after an increase in unhappiness at the beginning of the study, this characteristic was reported as decreasing to a significant extent (Petry et al., 1989). In the study by Burns et al. (1990a) of 178 AD subjects, depressive mood was reported by relatives as occurring in 58% of the mild cases, dropping to 36% and 41% in moderate and severe cases respectively. Although clinical raters observed depressive symptoms less frequently than relatives, the pattern of change was similar, ranging from 41% in the mild cases to 23% and 24%. However, only 12 cases were rated as mildly impaired and these changes were not statistically significant. Cooper et al. (1990), using a sample of 680 AD subjects, found that as MMSE scores decreased, depressive mood was reported less frequently and this change was statistically significant. In a study by Ballard et al. (1993) looking at 58 people with dementia, they found that those with minimal dementia according to the CAMDEX (Roth et al., 1986) were significantly more depressed than those with mild to moderate dementia severity. There was no significant difference in level of depression between those with mild and moderate dementia. Gustafson (1975) found a factor which included items measuring depression, anxiety and *less* affective shallowness. The occurrence of this factor was found to decrease as memory and confusion problems increased. This study found little association with other features often associated with depression. Gustafson considered this finding and the finding that increased anxiety and low mood were associated with better preserved emotions (i.e. less emotional shallowness) to be an indication that such behaviours may be a patient's reasonable reaction to her condition.

However, not all studies find that depressive mood tends to decrease with greater cognitive impairment. Burns et al. (1990c) found that depression observed by clinicians or relatives was not related to cognitive function, while Forsell et al. (1993), studying 142 people with dementia found no significant difference in the reporting of depression at different levels of cognitive impairment. Sultzer et al. (1992) found that there was no significant difference in the occurrence of depressive mood between those with MMSE score of 10 or higher and those with scores of less than 10. It is possible that if there is a drop in the occurrence of depressive mood after the mild stage of the disease as reported by some of the studies above, then the low MMSE score at which this group was split may not have allowed the detection of early changes.

Forsell et al. (1993) found that while informants reported an increase in anxiety with increased severity of dementia, clinicians examining the same group actually reported a small decline as severity increased. A significant positive correlation was found between anxiety and dementia severity rating in the study by Burns et al. (1990a).

Gustafson (1975) found that emotional shallowness increased as memory problems and confusion increased, while Sultzer et al. (1992) found no significant difference in this trait between those subjects with MMSE scores of 10 or more and those with scores of less than 10.

Petry et al. (1988) found that there was a positive correlation between an increase in excitability and a decline in MMSE scores. Chatterjee et al. (1992) found that there was no correlation between the total change score for Neuroticism and the MMSE scores of their subjects. There was also no correlation with duration of illness.

2.7.4 Conscientiousness and Openness

Change scores for both Conscientiousness and Openness were found to be uncorrelated to MMSE scores in the study by Chatterjee et al. (1992). These factors were also unrelated to duration of illness. This finding is rather surprising given that these factors contain traits such as punctuality, organisation and analytical ability which would to be influenced by cognitive ability. Petry et al. (1988) found no correlation between an increase in being out-of-touch and MMSE score and at follow-up (Petry et al., 1989) there was also no correlation between serial ratings of this change and MMSE score.

2.8 General Comment

Although the results are very mixed in this area, it does appear likely that the expression of personality traits varies to some extent with different levels of cognitive impairment. Only two studies examined personality change longitudinally. While Rubin et al. (1987b) found that the occurrence of certain traits did change with cognitive decline, Petry et al. (1989) found no such association. Petry and colleagues, however, made the point that their instrument may have had floor effects.

It seems likely that a decrease in Extroversion occurs in many dementia sufferers in the early stages of the disease and that introverted behaviour such as apathy or withdrawal may increase slightly as cognitive impairment increases. Irritability and self-centredness appear to increase with cognitive decline while suspicion does not seem to be related to cognitive function. The relationship between cognitive decline and depressive mood is a complex one (Henderson, 1990). Although depressive mood can often occur early in the course of dementia, some studies found that it decreases with cognitive decline and others find no relationship.

2.9 Comparison of Personality Changes in DAT and MID

So far only studies looking at DAT or dementia in general have been discussed. There is some evidence of different types of personality changes occurring in dementias of different aetiologies. Such differences may be able to play a role in diagnosis of specific diseases. After DAT, MID is the most commonly occurring cause of dementia. Although MID has not been investigated in the current study, the differences in personality change occurring in DAT and MID will be briefly reviewed here.

Clinical reports of MID state that personality may be well preserved until quite late in the disease (Lishman, 1987). Many people suffering from MID retain the capacity for judgement for quite a long time as well as insight into their condition, and will often react to their decline with severe anxiety and depression (Rothschild, 1941). People suffering from MID have been found to show emotional lability and sometimes, explosive emotional outbursts.

Bucht and Adolfsson (1983) looked at behaviour changes in 20 MID patients as well as the 18 AD patients previously discussed. Both groups were mild to moderately impaired. The patients with MID were found to show apparent sadness, elated mood and a labile emotional response less frequently than the AD group but the difference was not significant. Hostility was found to occur infrequently in both groups.

Using the same personality inventory as Petry et al. (1988), Cummings et al. (1990) examined personality changes in a sample of 20 patients with MID. They then compared the results with those obtained by Petry and her colleagues on 30 patients with DAT. The DAT patients were significantly more cognitively impaired than the MID group and had been ill for longer. MID subjects had a similar pattern of change to DAT subjects but some differences emerged. Patients with DAT were seen as having become more irritable and less affectionate than those with MID, while MID patients were less sensitive, less talkative and less energetic. These last two features suggest that the MID group showed greater decreases in Extroversion. Some of the differences seen here may have been due to the different degree of cognitive impairment in the two groups.

Sultzer et al. (1992) studied behaviour changes in 22 MID patients as well as the 61 AD patients discussed earlier. As was the case in the study by Cummings et al. (1990), the AD group were more cognitively impaired than the MID group. There was little difference between the two group in the factor of Extroversion, with lack of interest in people and underactivity being reported with similar frequency. However, less than half the number of MID patients were reported to show elated or euphoric mood. In the factor of Agreeableness, crude behaviour was reported about half as often in the MID group, while reports of hostility and suspicion were quite similar. However, suspicion was reported as occurring to an 'severe to extreme' extent in 5% of the MID patients while none of the AD patients showed this behaviour to this extent. The MID group were less often reported as being emotionally labile but more often found to be emotionally shallow. Anxiety was seen more often in the MID group but depressive mood was reported in approximately the same proportion. To summarise, the results from this study suggest that while some expressions of personality occur at similar frequencies in these two disorders, people with MID are less likely to show crude behaviour, or emotional lability, but to be more often emotionally shallow and anxious.

Both the studies by Bucht and Adolfsson (1983) and Sultzer et al. (1992) found similar levels of depressive mood in the MID and AD groups but lower levels of emotional lability in the MID. These results do not substantiate the clinical reports of increased emotional lability but Sultzer's study did find higher levels of anxiety as reported clinically.

Chapter 3

Development of the Personality Questionnaire

The majority of researchers investigating personality changes in dementia have based their selection of personality traits on clinical reports of the changes that occur. Others have used inventories designed for looking at other types of brain disorders. Exceptions are those studies using the NEO-PI (Siegler et al., 1991 and Chatterjee et al., 1992). The possible problem with using clinical reports for inventories is that these may well concentrate on those personality characteristics which are troublesome to carers and not cover other, more subtle changes which do not become a problem.

3.1 Development of the Preliminary Questionnaire

This study has aimed to cover a broader range of personality traits, as was done by Chatterjee et al. and Siegler et al.. To achieve this, the Goldberg 339 adjective inventory was used as a basis for the development of an informant questionnaire looking at personality changes in dementia. By using a comprehensive personality inventory, changes which are not necessarily troublesome or bizarre but are none the less a significant part of the changes that occur in dementia may be detected. It was considered that the NEO-PI may not be a suitable inventory for use in a demented sample as it is designed for assessing personality in a normal population. By using a list of trait adjectives to evaluate someone's personality, however, no assumptions are made about that person's cognitive abilities.

The complete list of adjectives included in this inventory is shown in Appendix 2.2. It was considered unreasonable to expect a relative or carer of a demented person to rate 339 trait adjectives. Therefore, the first step in developing a questionnaire suitable for informants was to reduce the number of adjectives to be included in such an instrument.

Firstly, a questionnaire was developed using all of the 339 adjectives in which respondents were asked to rate each trait adjective as to how often this trait is seen in people suffering from mild to moderate DAT compared to normal, non-cognitively

impaired elderly. Clinicians and other people who worked regularly with dementia sufferers were recruited to complete this questionnaire. An example of the format of this questionnaire is shown in Figure 3.1.

Figure 3.1: An example of the format of the questionnaire completed by clinicians. Below is a list of 339 adjectives describing different aspects of personality. We wish to know the frequency with which you have observed such characteristics in patients with mild to moderate Alzheimer's disease compared to healthy elderly people. Please circle the appropriate response. You may circle more than one response.

Greedy	much	a bit	about	a bit	much	don't
	less	less	the same	more	more	know

As it was considered possible that some DAT sufferers may show a trait to a greater extent and some to a lesser extent (e.g. some may be more passive and others less passive than seen in the normal elderly population,) people completing the questionnaire were given the option of circling more than one answer. From the results obtained from this group, personality traits which were not seen as changing in DAT could be excluded from the inventory.

The 339 adjective questionnaire was completed by 28 people familiar with the behaviour of DAT sufferers. These included

- 3 psychogeriatricians
- 14 geriatricians
- 3 social workers
- 3 occupational therapists
- 5 others (nurses, physiotherapists)

These people were associated with various hospitals in Sydney and Canberra.

3.2 Analysis of the Results

The SPSS-X computer package was used for analysis of these data (SPSS Inc, 1988). For each adjective a mean score was calculated based on the absolute difference score. As the reason for this small survey of clinicians was to select those personality traits which were seen to be different in DAT compared to the normal population, the direction of change was not considered to be important to the analysis.

These adjectives were then grouped into their synonym clusters according to Goldberg's inventory (see Appendix 2.2) and mean difference scores were calculated for each cluster. 'Don't know' answers were treated as missing data. The possible score ranged from zero, (indicating 'about the same' for all of the adjectives in the cluster,) to two (meaning that all adjectives were scored as either 'much more' or 'much less'). Table 3.1 shows the clusters arranged in quartiles according to their mean change score, while Figure 3.2 shows the distribution of scores diagrammatically.

Table 3.1: Mean absolute change score of clusters. Clusters prefixed by an asterisk indicate those clusters with means of 0.80 or higher.

First Quartile	Second Quartile	Third Quartile	Fourth Quartile
Extroversion Assertion Animation Courage Shyness Pessimism Agreeableness Amiability Generosity Modesty Morality Warmth Earthiness Overcriticalness Rudeness Cruelty Pomposity Selfishness Surliness Cunning Prejudice Unfriendliness Deceit Conscientiousness Dignity Conventionality Nonconformity Neuroticism Envy	Extroversion Playfulness Talkativeness Candour Optimism Silence Reserve Passivity Unaggressiveness Agreeableness Cooperation Courtesy Naturalness Belligerence Bossiness Irritability Conceit Distrust Callousness Stinginess Conscientiousness Thrift Sloth Neuroticism Placidity Gullibility Intrusiveness Openness Sophistication Stupidity	Extroversion *Spirit *Gregariousness *Spontaneity *Energy Level Self-esteem *Humour *Inhibition *Lethargy Agreeableness Empathy Leniency *Stubbornness Volatility *Thoughtlessness Conscientiousness *Persistence *Caution *Recklessness Frivolity Neuroticism *Insecurity *Fear Instability *Emotionality Openness *Intellectuality *Depth *Curiosity *Shallowness	Extroversion *Expressiveness *Unrestraint *Ambition *Aloofness Agreeableness *Flexibility Conscientiousness *Organisation *Efficiency *Dependability *Precision *Punctuality *Decisiveness *Predictability *Logic *Disorganisation *Negligence *Inconsistency *Forgetfulness *Aimlessness *Indecisiveness Neuroticism *Independence Openness *Insight *Intelligence *Creativity *Unimaginativeness *Imperceptiveness

FIGURE 3.2: Mean absolute change scores for clusters shown separately for each factor.

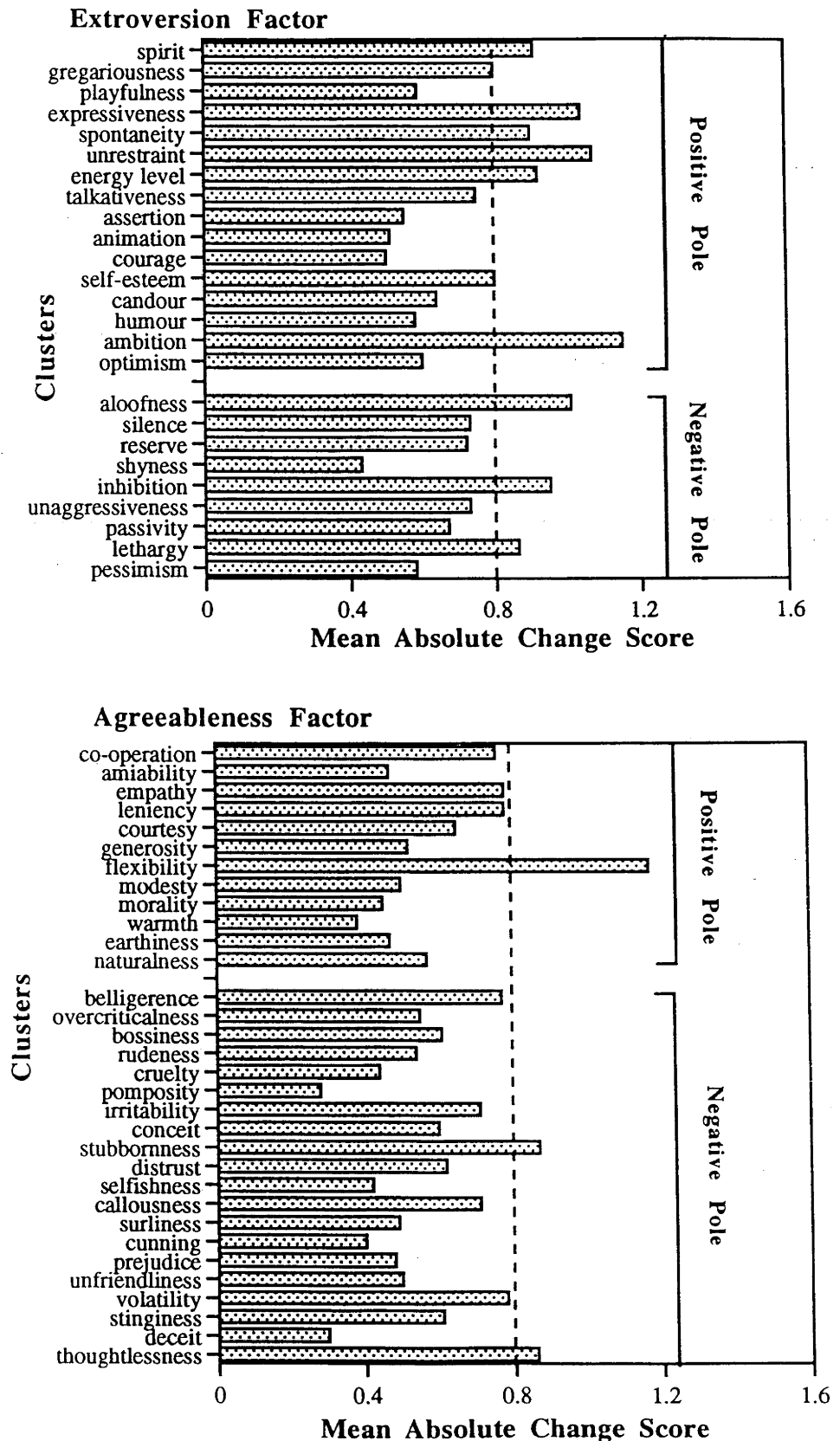
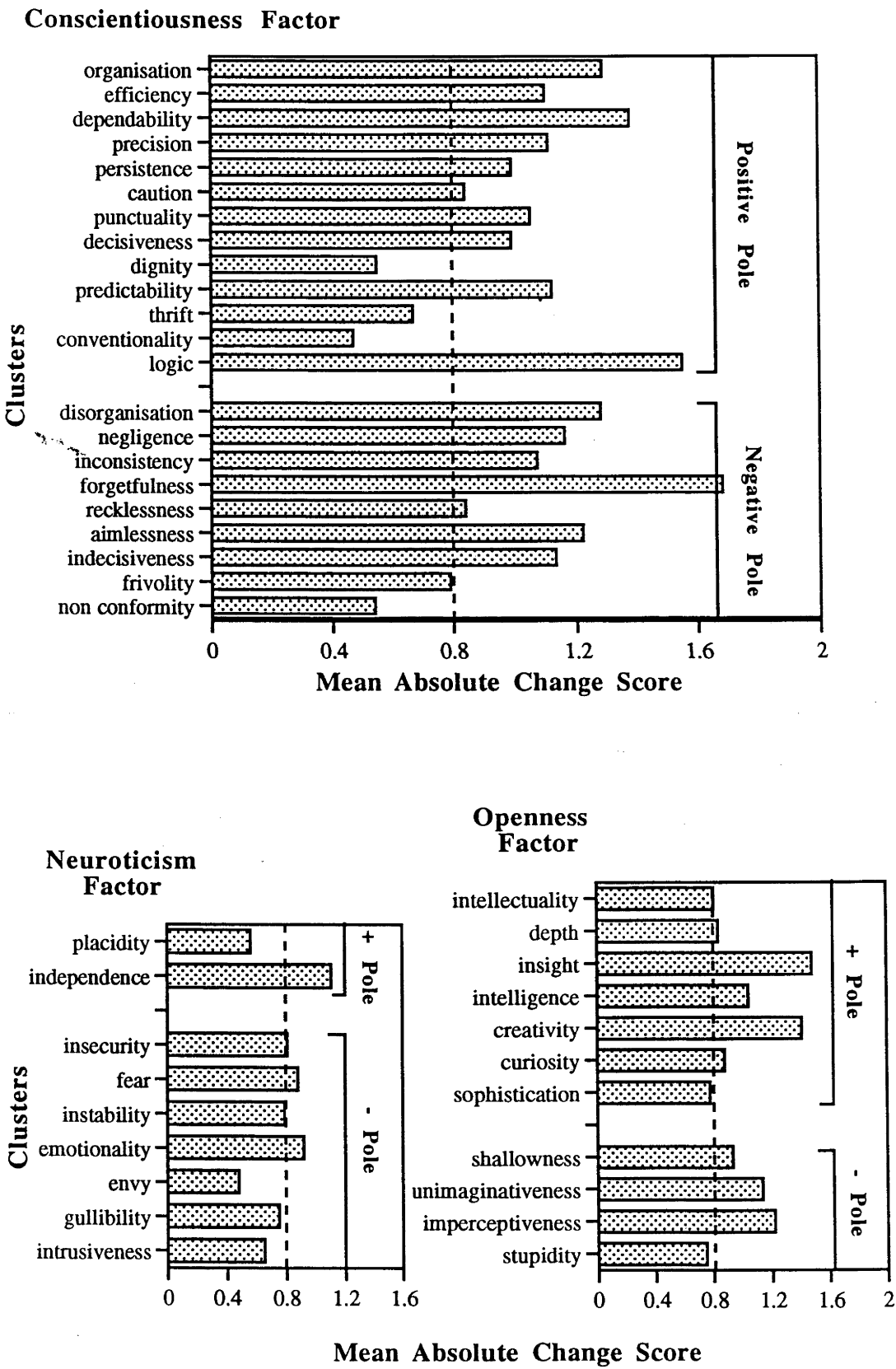


Figure 3.2 (continued).



As has been done in Goldberg's inventory, clusters within factors have been further divided into positive poles and negative poles. Clinicians reported changes in all of the five factors, although there was considerable variability within factors. Table 3.2 shows the mean absolute change score for each factor.

Table 3.2: Mean absolute change score for each factor of personality.

Personality Factor	Mean absolute change score
Extroversion	0.77
Agreeableness	0.61
Conscientiousness	1.03
Neuroticism	0.77
Openness	1.02

The greatest differences were reported as occurring in the Conscientiousness and Openness factors which had almost the same change score. As previously discussed, the personality traits covered in Conscientiousness would certainly be influenced by cognitive decline as would Openness which contains traits of intelligence and insight. The factors of Extroversion and Neuroticism showed the same amount of change with Agreeableness showing the least change.

3.3 Selection of Adjective Clusters for the Final Questionnaire

It was decided that clusters of adjectives rather than individual adjectives would be selected for the smaller questionnaire. By using a number of adjectives to measure an individual trait it was hoped that higher reliability would be achieved for each trait. Goldberg treated each cluster as a scale and found the internal reliability of each cluster to be quite high for the size of the scales. Mean item intercorrelations for the final clusters chosen here varied from 0.21 to 0.76 with most around 0.40. These are shown in Appendix 2.2.

The mean absolute difference score was used as the first step in deciding which clusters to include in the final questionnaire. Clusters which were found to have a mean difference score of 0.80 or greater were included. These clusters are prefixed by an asterisk in Table 3.1.

Following this, personality-related terms found in the clinical literature were listed. The adjective clusters were then compared to the personality changes which had been recorded by clinicians to ensure that these had been adequately covered by the clusters. Some personality changes previously reported by clinicians were not

covered by clusters with means of 0.80 or greater so appropriate clusters were chosen to include these clinically observed changes. Table 3.3 shows the clinically observed personality traits and the equivalent clusters. These include, in some cases, polar opposites.

Table 3.3: List of personality traits noted in the clinical literature with equivalent clusters. Those clusters prefixed by an asterisk had means of less than 0.80.

Personality traits from clinical literature	Clusters from positive pole of Goldberg's inventory	Clusters from negative pole of Goldberg's inventory
apathy / withdrawal	unrestraint	*passivity aloofness inhibition
lack of spontaneity	spontaneity	
lack of motivation/drive	ambition	aimlessness
irritability		*irritability
coarsened/crude/inappropriate behaviour	*courtesy *empathy	thoughtlessness
mood swings		emotionality
suspicion		*distrust
anxiety/fearfulness		fear
underactive/listless	energy level	lethargy

To further reduce the number of adjectives, it was decided that no more than three adjectives would be used for each cluster. Rejection of adjectives was based on the number of 'don't knows' that had been recorded, the word frequency of each adjective (Johansson, S. & Hofland, K., 1989) and finally some adjectives were rejected on the basis of possible ambiguity. For example, *crabby* was not included in the *irritable* cluster as it was considered to an American term and not used commonly in Australia. *Bull-headed*, in the *stubborn* cluster, was replaced by *pig-headed* as it was considered to be a more commonly used term in this country. The final clusters were made up of two or three adjectives. Four clusters with means of greater than 0.80 were accidentally left out of the final inventory. These were *candour* from the Extroversion factor and *organisation*, *logic* and *indecisiveness* from the Conscientiousness factor. These two factors contain a large range of clusters which should adequately cover these domains of personality, so it was considered unlikely that the omission of the four clusters would seriously influence the final outcome. The final inventory contained 46 clusters with a total of 124 adjectives and can be seen in Table 3.4.

Table 3.4: Final list of clusters with component adjectives.

Clusters	Adjectives
Factor I: Extroversion	
<u>Positive pole</u>	
Spirit	enthusiastic, spirited, vivacious
Expressiveness	communicative, expressive, verbal
Spontaneity	carefree, happy-go-lucky, spontaneous
Unrestraint	impetuous, uninhibited, unrestrained
Energy level	active, energetic, vigorous
Ambition	ambitious, enterprising, opportunistic
<u>Negative pole</u>	
Aloofness	seclusive, unsociable, withdrawn
Inhibition	inhibited, restrained
Passivity	docile, passive, submissive
Lethargy	lethargic, sluggish
Factor II: Agreeableness	
<u>Positive pole</u>	
Empathy	considerate, kind, sympathetic
Courtesy	courteous, polite, tactful
Flexibility	adaptable, flexible, obliging
<u>Negative pole</u>	
Irritability	cranky, irritable, grumpy
Stubbornness	pig-headed, obstinate, stubborn
Distrust	distrustful, sceptical, suspicious
Callousness	cold, impersonal, insensitive
thoughtlessness	inconsiderate, tactless, thoughtless
Factor III: Conscientiousness	
<u>Positive pole</u>	
Efficiency	exacting, efficient, fastidious
Dependability	dependable, reliable, responsible
Precision	meticulous, perfectionistic, precise
Persistence	industrious, persistent, thorough
Caution	careful, cautious
Punctuality	prompt, punctual
Decisiveness	decisive, deliberate, purposeful
Predictability	consistent, predictable, steady
<u>Negative pole</u>	
Disorganisation	disorganised, inefficient, scatterbrained
Negligence	careless, negligent, unreliable
Inconsistency	erratic, inconsistent, unpredictable
Forgetfulness	forgetful, absent-minded
Recklessness	foolhardy, rash, reckless
Aimlessness	aimless, unambitious
Sloth	lazy
Factor IV: Neuroticism	
<u>Positive pole</u>	
Independence	autonomous, independent, individualistic
<u>Negative pole</u>	
Insecurity	defensive, fretful, insecure
Fear	anxious, fearful, nervous
Emotionality	emotional, excitable
Factor V: Openness	
<u>Positive pole</u>	
Intellectuality	contemplative, intellectual, meditative
Depth	complex, profound
Insight	foresighted, insightful
Intelligence	bright, intelligent, smart
Creativity	artistic, creative, imaginative
Curiosity	curious, inquisitive
<u>Negative pole</u>	
Shallowness	shallow, unintelligent, unreflective
Unimaginativeness	uncreative, unimaginative
Imperceptiveness	imperceptive, unobservant

3.4 Piloting of the 124 Adjective Questionnaire

The smaller questionnaire was set out in the same way as the larger questionnaire. However, the instructions were changed to read:

"This questionnaire contains a list of words which describe different aspects of personality. We would like you to show us how you think your friend or relative has changed in the last ten years. Ten years ago was 1981. Please show the changes you have observed by circling the appropriate answer."

The period of 10 years was chosen because this would almost certainly be before the subject developed symptoms of dementia. Other studies have asked about changes since developing dementia. As this period will vary between subjects, it requires informants to think back to different periods of time which may influence the way in which they perceive the change in their relative or friend.

Relatives of people suffering from dementia, not specifically DAT, were recruited for the pilot by approaching various community services within Canberra. These organisations then asked clients who were relatives of dementia sufferers if they would be willing to complete a questionnaire on personality change in dementia. In the majority of cases, I was present while the relative completed the questionnaire. In a few cases, questionnaires were sent to people who later returned them by mail. Thirteen pilot questionnaires were completed.

Some problems were encountered by the informants completing this questionnaire. A number stated that their relative had very changeable behaviour, and in consequence they were unable to choose an appropriate answer. Some were concerned that they had never shown this trait and so were not able to record any change. Others felt that their relative was so severely demented that it was not possible to assess some of the traits. In an attempt to make the questionnaire easier to understand, more detailed instructions were prepared telling informants how to deal with these difficulties. These new instructions are shown in Appendix 3.1 along with the final 124 adjective questionnaire.

Apart from the more detailed instructions, no further changes were made to the questionnaire.

Chapter 4

Method

4.1 Ethics Clearance

Before work on this study began, ethics clearance was obtained from the Australian National University Ethics in Human Experimentation Committee. Ethics approval was also obtained from the Alfred Group of Hospitals Ethics Review Committee to recruit DAT subjects from the Caulfield General Medical Centre Memory Clinic.

4.2 The Sample

4.2.1 The DAT Patients

These subjects were recruited from five different sources. These were as follows:

- Woden Valley Hospital Aged Care Assessment Team, Canberra, A.C.T.
- Department of Geriatric Medicine, Aged and Extended Care Department, Repatriation General Hospital, Sydney, N.S.W.
- Academic Department of Psychogeriatrics, Prince Henry Hospital, Sydney, N.S.W.
- Memory Clinic, Caulfield General Medical Centre, Melbourne, Victoria.
- Psychogeriatric outpatient clinic, James Fletcher Hospital, Newcastle, N.S.W.

The majority of the subjects had been referred from general practitioners or assessment teams. However, most of the subjects recruited from the Repatriation General Hospital were recruited through advertisements in newspapers or letters sent to general practitioners asking for people who were having memory problems. These people were originally recruited to take part in a trial of tetrahydroaminoacridine (THA). This trial found that THA produced no clinically relevant difference on a range of assessments including mood states (Maltby et al., 1994). From this data it seems unlikely that this drug would have any effect on personality.

The five sources used for recruitment can be viewed as falling into one of two categories. Those people consulting clinicians at Woden Valley Hospital and the Repatriation General Hospital were assessed by geriatricians in a general aged care

setting, while those people consulting the other hospitals were assessed at specific memory clinics by psychogeriatricians. While both types of assessment centres may get referrals from general practitioners, the latter group is probably more likely to see dementia patients with psychiatric problems which may fall into the category of personality change. This possibility will be explored in the analysis.

Assessment of patients varied somewhat between hospitals. All hospitals used blood tests and other physical testing to exclude other causes of dementia and full histories were taken. Some level of neuropsychological testing was carried out at all hospitals. In an attempt to achieve a homogeneous sample of DAT patients, all clinicians referring subjects to this study were asked to complete a checklist based on the DSM-III-R criteria for Primary Degenerative Dementia of the Alzheimer Type (see Appendix 4.1). Only those patients who fulfilled these criteria and had a friend or relative who was willing to provide information about them, were referred to this study. The clinicians were also asked to indicate the level of severity of the dementia using the same criteria and to refer only those who were not severely impaired. When a clinician found that a patient fulfilled the criteria for this study, they then approached the relative or carer who had accompanied the patient, to ask if they would be willing to participate. If they were willing, they were given a letter assuring them of confidentiality (Appendix 4.2), followed by the questionnaires for self-completion. No requirement was made that the informant be able to read English. The majority of informants completed the questionnaires while still at the doctor's office. The completed questionnaires were then returned by the doctor. In the case of those informants recruited through the Caulfield General Medical Centre, the Alfred Group of Hospitals Ethics Review Committee required the informants and the patients to be given more complete details about the project and to sign consent forms (Appendix 4.3a to 4.3d). The number of patients recruited from each source and the level of severity of the DAT patients are shown in Table 4.1.

Checklists indicating the diagnosis and level of severity were not received for seven of the DAT patients. Although the aim was to recruit patients who were still in the mild to moderate stages of dementia, only eight (16%) were rated as being in the mild stage and 20 (40%) in the moderate stage. Thirty percent of this sample were rated as suffering from the severe stage of dementia, while the remaining 14% were unknown. Recruiting clinically diagnosed DAT patients who are only mildly cognitively impaired is very difficult as these people are rarely referred to specialist clinics until they have reached a more advanced stage of the disease. While the majority of DAT patients were living in the community, three were living in nursing homes and 4 were in hospital at the time of assessment.

Table 4.1: Sources of DAT patients by level of severity as rated by clinicians using DSM-III-R criteria.

Hospital Source	Severity				
	Mild	Moderate	Severe	Unknown	Total
Woden Valley Hospital	0	0	0	4	4
Repatriation General Hospital	5	3	12	1	21
Prince Henry Hospital	0	1	1	2	4
Caulfield General Medical Centre	0	3	1	0	4
James Fletcher Hospital	3	13	1	0	17
Total	8	20	15	7	50

4.2.2 The Controls

Initially, controls were selected from a sample of over 70 year olds from the electoral rolls of Canberra and the nearby town of Queanbeyan. The controls were chosen to match the subjects by age and sex. As the Canberra population has, on average, a higher level of socio-economic status than many of the areas from which the DAT patients were drawn, an attempt was made to select controls from fairly low socio-economic areas of Canberra. Letters were sent to the selected people asking them if they would be willing to participate in a study on the health of the elderly (see Appendix 4.4). This letter mentioned that we would also like to interview someone who had known them well for at least 10 years. A few days later, they were telephoned to ask if they would take part. At the same time they were asked if they would be willing to provide the name of someone else who could provide information about them.

Although most of the controls were obtained through this source, problems were encountered in recruiting sufficient controls this way and finally, friends and colleagues of the author volunteered to provide information about their aged parents. As shown in Table 4.2, the final response rate for the sample taken from the Electoral roll was very poor with only 28% of the letters sent out resulting in completed interviews. Forty four percent refused to participate, no telephone contact was possible with 22%, while 6% were unsuitable for various reasons. Of those contacted by telephone, 57% refused to be interviewed, with 36% completing interviews. Only two did not have a suitable informant and four did not complete the interview. Thirty six percent of the controls were recruited from volunteer informants. One reason which was often given for refusing to take part was ill-health

of person contacted. All of the controls were living in the community and it is possible that they were physically healthier than the DAT patients. Given the high percentage of refusals and non-contacts, the final group interviewed here may not have been typical of the elderly population as a whole. Perhaps a more appropriate source of a control group would have been to recruit patients from a clinical source unrelated to dementia. This method of recruitment would have had the advantage of providing controls who were also a clinically referred group like the DAT subjects.

Table 4.2: Response from community residents contacted for controls.

Outcome	Number (Percentage)
Total contacted from electoral roll	113 (100)
No contact (moved or dead)	25 (22)
No informant available	2 (2)
Incomplete data	4 (2)
Completed interviews	32 (28)
Refusals	50 (44)
Volunteer informants	18

One control was found to have an IQCODE score within the range of scores found for the DAT patients. However, the MMSE score for this person was 26 out of 30 and so they were retained as a control.

4.3 Content of the Interview

This consisted of the following:

1. Demographic data (Appendix 4.5a to 4.5e).

A variable, level of education, was derived by coding primary level of education as '1', secondary level of education as '2' and tertiary level of education as '3'.

Occupational status is based on a scale ranging from '1' (unskilled) to '6' (upper professional).

2. The final 124 adjective personality inventory (Appendix 3.1).

3. Mini-Mental State Examination (MMSE). This test, developed by Folstein et al. (1975) provides a means of grading a person's cognitive state. Only the controls themselves were asked to do this test.

4. The Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) (Appendix 4.6). This 26-item informant questionnaire was developed by Jorm and

Korten (1988) to measure changes in memory and intelligence which have taken place in the previous 10 years. It has been found to correlate highly with the MMSE and also to be uninfluenced by pre-morbid ability as estimated by the National Adult Reading Test (Jorm et al., 1991). The IQCODE has also been found to have high internal reliability in a general population sample ($\alpha = 0.95$), and reasonably high test-retest reliability over one year in a dementing sample ($r = 0.75$) (Jorm and Jacomb, 1989). The questions of the IQCODE are answered on a five-point scale from 'much better' to 'much worse' with 'no change' scoring three. The higher the score, the greater the decline in cognitive ability.

4.4 Method

4.4.1 The DAT Patients

Prior to the commencement of the interview, the informant of each patient was asked if they could provide the name and address of another person who knew the patient well and may be willing to complete the same questionnaires by mail. This would allow estimation of inter-rater reliability of the personality inventory. The informants were then asked to complete the demographic data, the personality inventory and the IQCODE. If this informant had been able to provide the name of a second informant, this person was then contacted by mail and asked if they would be willing to take part in the study (Appendix 4.7). This letter also assured the person of confidentiality. The personality inventory, the IQCODE and demographic questions were sent at the same time along with a reply-paid envelope.

Of the 50 informants recruited to provide information about DAT patients, only 29 were able to provide the name of someone else who knew the patient well enough to complete these questionnaires. Of these, only 17 returned the questionnaires that were posted to them. This was not considered enough to examine inter-rater reliability and analysis of these data was not pursued.

4.4.2 The Controls

As it was necessary to contact the controls to get the name of an informant who could provide information about this person, it was considered advisable to gather some information from the control themselves. At the commencement of the interview, the controls were given a letter assuring them of confidentiality (Appendix 4.8) and asking them to provide the name and a contact telephone number or address for someone who had known them well for at least 10 years and would be willing to answer questions about them. After answering a few demographic questions, the MMSE was administered to the controls who were then asked to complete the

personality inventory about themselves. Although the IQCODE would be completed by the informant of the controls, the MMSE would provide further evidence that the controls were not cognitively impaired. After this interview, the person whose name had been provided, was contacted and an interview time was arranged. In a few cases, questionnaires were posted to these informants who then mailed them back on completion. These informants were asked to complete some demographic questions about themselves and their relationship to the control and then asked to complete the personality inventory about the control and the IQCODE.

4.4.3 The NSW Alzheimer's Association Sample

As well as gathering data on personality change from informants of a clinically diagnosed sample of DAT patients, members of the NSW Alzheimer's association were also asked to provide information about their demented relative. This group provided a large, convenient sample for psychometric analysis although not as well diagnosed as the clinical sample.

Approval was granted by the Association's Research Policy Committee and the names and contact addresses for each of the support group leaders throughout NSW were provided. Each group leader was sent 12 sets of questionnaires with a covering letter asking that they be given to carers whose relative or friend was still living at home. (Appendix 4.9a) This was done in an attempt to gather information on dementia sufferers who were not in a very severe stage of the disease. They were also asked to indicate how many questionnaires they had distributed (Appendix 4.9b). Each carer was given a covering letter assuring them of confidentiality (Appendix 4.9c) and asked to complete some demographic questions, the personality inventory and the IQCODE. A reply-paid envelope was included.

Bundles of questionnaires were sent to 117 support group leaders, of which 31 distributed questionnaires to their group members. Two hundred questionnaires were given to carers of which 186 were completed and returned. Some of these were rejected due to previous death of the demented person or no diagnosis of dementia. This left a final sample of 167, all of whom had been diagnosed as suffering from some form of dementia. The distribution of diagnoses is shown in Table 4.3.

As can be seen from this table, the majority had been diagnosed as suffering from Alzheimer's disease. Eighty two percent of this sample had been diagnosed by a specialist or an assessment clinic. Although group leaders were asked to give the questionnaires to carers whose relative was still living in the community, 16% of this sample was actually living in hostels, nursing homes or hospitals.

Table 4.3: Breakdown of diagnoses for NSW Alzheimer's Association sample.

Diagnosis	Number (Percentage)
Alzheimer's Disease	97 (58)
Dementia	43 (26)
Multi-Infarct Dementia	13 (8)
Mixed / Other	10 (6)
Unknown	4 (2)
Total	167 (100)

Three subjects from this sample were found to have IQCODE scores indicating that they had *improved* considerably in most of the areas assessed. This is highly unlikely and probably resulted from the informants' misinterpreting the scoring instructions. These 3 subjects were omitted from any further analysis involving the IQCODE.

4.5 Demographic Characteristics of the Three Groups

The demographic characteristics of these three groups are summarised in Table 4.4. While there were almost equal numbers of males and females in the DAT patients, there were slightly more females to males in both the control group and the NSW Alzheimer's Association sample. Both the mean age of the groups and the range of ages were almost the same for the three groups. There was no significant difference between the DAT patients and the NSW Alzheimer's Association sample in the level of education or in occupational status. However, the control group had a significantly higher mean level of education and occupational status than the DAT patients, the majority of controls coming from the white collar and lower professional groups. Although an attempt was made to select controls from the lower socio-economic areas of Canberra, this was not achieved, partly because of the high refusal rate obtained in these suburbs. The reason for this is unknown.

The DAT patients and the NSW Alzheimer's Association sample showed very similar levels of cognitive decline according to the IQCODE, with answers averaging between *a bit worse* and *a lot worse*. The control group, as would be expected, showed very little cognitive decline.

There were more female informants than male, particularly for the two demented samples. This is hardly surprising given that females are more likely to take on a caring role than males.

Table 4.4: Demographic characteristics of the three groups of subjects and informants.

	DAT Patients	Controls	NSW Alzheimer's Association Subjects
Subject			
Sex (%) - Male	24 (48)	21 (42)	75 (45)
- Female	26 (52)	29 (58)	92 (55)
Mean Age (Range)	75.9 (59 - 90)	75.8 (58 - 88)	74.9 (51 - 92)
Level of Education	2.1	2.4*	2.1
Occupational Status	3.3	4.1**	3.7
Mean IQCODE (range)	4.4 (3.4 - 5.0)	3.1 (2.7 - 3.7)** #	4.6 (3.3 - 5.0) @
Informant			
Sex (%) - Male	14 (28)	18 (36)	46 (28)
- Female	36 (72)	32 (64)	121 (72)
Level of Education	2.2	2.2	2.1
Relationship to subject (%)			
- spouse	23 (46)	18 (36)	103 (62)
- son/daughter	19 (38)	23 (46)	52 (31)
- other	8 (16)	9 (18)	9 (7)
Living with subject (%)			
- yes	25 (50)	20 (40)	122 (73)
- no	22 (44)	30 (60)	45 (26)
- unknown	3 (6)		

** $P < 0.001$ between DAT patients and controls.

* $P = 0.024$ between DAT patients and controls.

Only one control had an IQCODE score in the same range as DAT patients.

@ Those with IQCODE scores indicating improvement have been omitted.

The level of education of the informants for these three groups was the same. The informants were almost all either a spouse or son or daughter (usually daughter) for each of the three groups. Approximately one half of the DAT patients and the controls were living with the informants, while 73% of the NSW Alzheimer's Association subjects lived with the informants.

Chapter 5

Results

5.1 Selection of the Final Clusters for Analysis

The personality questionnaire used in this study contained many trait adjectives which may have been difficult for the respondents to interpret. Therefore, prior to examining reported personality change, an attempt was made to identify those adjectives which may have presented a problem in interpretation and so not be valid measures of personality change.

5.1.1 Missing Data in the Personality Questionnaire

Missing data arose from the informant either indicating the *don't know* category or by omitting to answer the question at all. Informants were encouraged to use the *don't know* category if they did not understand the meaning of the word or if they found it difficult to evaluate this trait in their relative. Therefore, the use of this category should provide information about the ease of interpretation of the adjectives. It is also possible to examine whether certain characteristics of the subject or informant influenced the extent to which the informant selected this category. In analysing these data, the use of this category was looked at in the total sample i.e. combining the 50 DAT patients, the 50 controls and the 167 NSW Alzheimer's Association sample.

While a few informants omitted answering some of the questions, a much larger number of respondents used the *don't know* category for some adjectives. It was considered that such information would be important if a smaller questionnaire was later developed for clinical use. For this analysis, the *don't know* category was combined with the actual missing data. A score was computed for each respondent indicating the number of missing answers. Only 20% of the total respondents had answered all 124 questions without using the *don't know* category or omitting an answer, while the highest number of missing answers was 85. However, the distribution of missing data was highly skewed, with 58% of respondents having 10 or fewer missing answers. The median number of missing answers was seven.

5.1.2 Possible Reasons for Missing Data

This missing data score was then correlated to characteristics of the subject and informant. Because of the skewed distribution of this score, non-parametric methods were used. The Spearman rank correlations for those characteristics which were found to be significantly correlated to the missing data score are shown in Table 5.1. These included the IQCODE score, the occupational status and qualifications of the subject and the years of schooling of the informant.

Table 5.1: Spearman rank correlations between the missing data score for the total sample and demographic characteristics of the subjects and the informants.

Characteristic	Spearman rank correlation
Mean IQCODE	0.34 **
Occupational Status	-0.19 *
Years of Schooling of the Informant	-0.38 **
Qualifications of the Subject	-0.23 **

** $P < .001$.

* $P = 0.002$.

Using a Mann-Whitney U test, the spouses were found to provide significantly more missing data than the children. To determine the relationship of each of these variables to the missing data score, logistic regression was performed on the dichotomised missing data score. As these data were so skewed, they would have been unsuitable for linear regression. Missing data scores were dichotomised at a score of 10/11. The results are shown in Table 5.2. Only the IQCODE score and years of schooling of the informant were significant predictors. This analysis was repeated using missing data scores dichotomised at a score of 0/1. This gave the same result.

Table 5.2: Logistic regression analysis predicting missing data.

Predictor Variable	Beta	S.E.
IQCODE	0.55 *	0.21
Occupational Status of Subject	-0.09	0.11
Qualifications of Subject	-0.16	0.09
Relationship of Informant to Subject	-0.10	0.07
Years of Schooling of Informant	-0.36 *	0.11

* $P < 0.01$

The correlation of the missing data score to the mean IQCODE score suggests that it may be more difficult to rate personality changes in people who are more cognitively impaired. The negative correlation between the missing data score and years of schooling of the informant suggests that those with less schooling found it more difficult to answer the questions, probably due to lack of understanding of the adjectives. It is also possible that the the number of missing items may have been influenced by whether the informant had English as their first language. Unfortunately, this information was not collected.

5.1.3 Removal of Adjectives with a High Percentage of Missing Data

It was considered that those adjectives which many of the informants had not been able to answer were either poorly understood words or difficult to evaluate in the context of dementia. Therefore, prior to further analysis, all adjectives for which 20% or more of the respondents had been unable to answer were removed. Those adjectives to be dropped from further analysis were *unrestrained*, *uninhibited*, *impetuous*, *opportunistic*, *inhibited*, *sceptical*, *impersonal*, *rash*, *foolhardy*, *individualistic*, *autonomous*, *meditative*, *contemplative*, *profound*, *insightful*, *shallow*, *unreflective* and *imperceptive*. This resulted in the removal of the whole cluster of *unrestraint*, leaving 45 clusters and 101 adjectives. Also, a number of the clusters were now represented by only one adjective.

5.1.4 Correlation of Adjectives Within Clusters

Goldberg (1990) found that the adjectives within clusters showed moderately high inter-item correlations. (Appendix 2.2). To test whether this was still the case when asking about change in a person, correlations were calculated between adjectives within clusters for those clusters which still retained more than one adjective. (Appendix 5.1). The adjectives within clusters are meant to be measuring the same trait so it is important to show that they are significantly correlated. Lack of correlation would suggest that they were not measuring the same trait. The majority of adjectives were significantly correlated ($P < 0.001$) to the other adjectives in the same cluster. Those adjectives which were not significantly correlated (at least $P > 0.01$) were removed from further analysis. These adjectives were *unsociable*, *thoughtless*, *persistent* and *unreliable*. There were no cases in which there were only two adjectives in a cluster and these were not significantly correlated.

5.1.5 Treatment of Adjectives with Opposite Meanings

One difficulty which became apparent when respondents completed the personality questionnaire is that the presence of negative adjectives e.g. *unsociable*, *unreliable*, *tactless* tended to create a double negative in the question. For example, for the

adjective, *unintelligent*, the question reads: 'Is your relative more / less unintelligent?'. Such questions were likely to be confusing for the respondents to answer. One way of examining whether respondents were able to interpret such adjectives correctly is to look at whether direct opposites were negatively correlated as would be expected. Only 12 such pairs were identified. For those which were not negatively correlated, the negative adjective was removed from further analysis, if not already removed by previous criteria. This led to the removal of *tactless*, all other such adjectives already having been removed. It can be seen that many of the adjectives which were removed due to the high percentage of missing data or lack of correlation within a cluster, are negative adjectives.

5.1.6 Final Clusters for Further Analysis

The final list of adjectives and clusters which were used for subsequent analysis is shown in Table 5.3. The remaining adjectives should have provided little difficulty in understanding. Also, there is a significant correlation between the adjectives within the same cluster suggesting that it is valid to use these adjectives to assess a specific trait. Although an attempt was made to reject any negative adjectives which were not interpreted correctly, a number of negative adjectives remain. There is no way of knowing whether these were correctly interpreted.

In the above steps, a number of adjectives, as well as one cluster have been removed from further analysis. Despite this, the majority of clusters still contain at least two adjectives and all five factors are represented by a range of clusters. The remaining clusters contain adjectives which were able to be interpreted by the majority of respondents.

5.2 Personality Change in DAT

5.2.1 Measurement of Change

A change score was calculated for the clusters by taking the average change score for the adjectives within each cluster. Table 5.4 shows the percent of informants for each of the three samples who, for each cluster, indicated at least *a bit less* or *a bit more*. One feature of these data is that respondents have not all indicated change in the same direction. For some clusters, the percent of respondents indicating *a bit less* is similar to the percent indicating *a bit more*. One possible reason for this could be that the remaining negative adjectives have confused respondents. Those clusters containing negative adjectives are indicated with an asterisk in Table 5.4 and it can be seen that some of these show a bimodal distribution. However, other clusters showing such a distribution do not contain negative adjectives. It is possible that this is a real effect whereby some demented people may show a decrease in a trait, while

others may demonstrate an increase. The percentage reporting change in the NSW Alzheimer's Association sample is very similar to those reporting change in the DAT patient's group.

Table 5.3: The final clusters and adjectives to be used for analysis.

Clusters	Adjectives within Clusters
Factor I - Extroversion	
Spirit	enthusiastic, vivacious, spirited
Expressiveness	communicative, verbal, expressive
Spontaneity	spontaneous, carefree, happy-go-lucky
Energy Level	active, vigorous, energetic
Ambition	ambitious, enterprising
Aloofness	withdrawn, seclusive
Inhibition	restrained
Passivity	passive, docile, submissive
Lethargy	sluggish, lethargic
Factor II - Agreeableness	
Empathy	considerate, kind, sympathetic
Courtesy	courteous, tactful, polite
Flexibility	adaptable, obliging, flexible
Irritability	cranky, grumpy, irritable
Stubbornness	obstinate, pig-headed, stubborn
Distrust	distrustful, suspicious
Callousness	cold, insensitive
Thoughtlessness	inconsiderate
Factor III - Conscientiousness	
Efficiency	exacting, fastidious, efficient
Dependability	responsible, dependable, reliability
Precision	perfectionistic, meticulous, precise
Persistence	industrious, thorough
Caution	cautious, careful
Punctuality	punctual, prompt
Decisiveness	decisive, purposeful, deliberate
Predictability	steady, predictable, consistent
Disorganisation	scatterbrained, disorganised, inefficient
Negligence	careless, negligent
Inconsistency	erratic, inconsistent, unpredictable
Forgetfulness	absent-minded, forgetful
Recklessness	reckless
Aimlessness	aimless, unambitious
Sloth	lazy
Factor IV - Neuroticism	
Independence	independent
Insecurity	insecure, fretful, defensive
Fear	fearful, nervous, anxious
Emotionality	emotional, excitable
Factor V - Openness	
Intellectuality	intellectual
Depth	complex
Insight	foresighted
Intelligence	bright, intelligent, smart
Creativity	imaginative, creative, artistic
Curiosity	inquisitive, curious
Shallowness	unintellectual
Unimaginativeness	uncreative, unimaginative
Imperceptiveness	unobservant

Table 5.4: Percent of informants with a mean rating of at least 'a bit more' or 'a bit less' for adjectives in clusters. Clusters containing negative adjectives are indicated by an asterisk.

Cluster		DAT Patients		Controls		NSW Alzheimer's Association Sample	
		'a bit less'	'a bit more'	'a bit less'	'a bit more'	'a bit less'	'a bit more'
Factor I - Extroversion							
+ve pole	Spirit	74	0	12	0	79	1
	Expressiveness	58	2	2	8	79	2
	Spontaneity	56	2	14	2	70	2
	Energy Level	72	4	41	8	86	4
	Ambition	74	2	14	4	91	1
-ve pole	Aloofness	2	50	8	12	7	66
	Inhibition	35	25	20	14	46	35
	Passivity	12	43	4	4	22	36
	Lethargy	4	67	8	16	4	80
Factor II - Agreeableness							
+ve pole	Empathy	27	4	2	20	48	6
	Courtesy	24	0	6	4	37	4
	Flexibility	46	6	10	10	66	2
-ve pole	Irritability	10	44	8	20	6	53
	Stubbornness	6	50	4	18	4	62
	Distrust	8	58	2	12	7	64
	Callousness *	8	22	10	6	10	45
	Thoughtlessness *	26	23	20	14	23	47
Factor III - Conscientiousness							
+ve pole	Efficiency	57	0	6	6	72	3
	Dependability	72	0	0	4	86	1
	Precision	49	2	8	0	78	2
	Persistence	74	0	6	0	94	1
	Caution	34	26	2	20	32	11
	Punctuality	60	2	2	10	70	3
	Decisiveness	68	2	0	4	77	2
	Predictability	48	0	4	6	78	2
-ve pole	Disorganisation *	2	64	6	4	10	55
	Negligence	2	51	4	8	8	63
	Inconsistency *	0	50	2	0	2	64
	Forgetfulness	10	74	6	29	8	73
	Recklessness	28	17	29	6	31	33
	Aimlessness *	6	61	6	4	12	65
	Sloth	9	19	8	0	11	62
Factor IV - Neuroticism							
+ve pole	Independence	90	6	22	36	86	7
-ve pole	Insecurity	6	61	2	8	2	70
	Fear	2	63	0	18	2	67
	Emotionality	10	30	6	14	18	34
Factor V - Openness							
+ve pole	Intellectuality	73	0	6	8	92	1
	Depth	20	47	17	8	27	49
	Insight	86	0	11	14	90	1
	Intelligence	64	2	0	2	91	1
	Creativity	54	0	6	2	71	3
	Curiosity	48	20	6	6	66	10
-ve pole	Shallowness *	19	47	11	4	32	57
	Unimaginativeness *	13	48	8	6	19	54
	Imperceptiveness *	30	60	12	18	29	57

The distribution of change was also examined in those from the Alzheimer's Association sample who had been given a specific diagnosis of Alzheimer's disease. The results were almost identical to the total Alzheimer's Association sample.

It is apparent from Table 5.4 that a high percentage of the informants of the demented samples indicated personality change toward the negative pole in all five factors. One cluster, *depth*, gave somewhat anomalous results, with a higher percentage indicating an increase in this trait, than those indicating a decrease. This is the opposite trend to the other clusters in the positive pole of the factor, Openness. This cluster contains the single adjective, *complex*, and although this is meant to be interpreted in the sense of being more or less intellectually complex, it may have been interpreted by the informants of the demented sample as 'more difficult to understand'.

A much smaller percentage of the informants of the controls indicated personality change. For some traits, however, a quite high percentage of informants have indicated a change. Energy level is reported as having decreased in 41%. This trait may well relate to physical ageing rather than personality. In the factor of Agreeableness, 20% of controls were reported as being more empathic, while 20% and 18% respectively were seen as being more irritable and stubborn. Thirty four percent reported change in *thoughtlessness* although some were considered to be more thoughtless and others, less. *Imperceptiveness*, in which 30% indicated change, showed a similar distribution. Twenty percent were viewed as being more cautious and 29% as less reckless while 29% were reported as being more forgetful. Table 5.4 shows the percent of people showing at least 'a bit more' or 'a bit less' of each trait. To see if the inclusion of only extremes of personality would alter the results, the distribution of personality change was also examined for those who showed greater extremes of change. In this analysis, where there were one or two adjectives per cluster, one had to be scored as 'much more' or 'much less'. Where there were three adjectives per cluster at least two of the adjectives had to be scored as 'much more' or 'much less'. While a lower percentage of people fell into these categories, the pattern of change was very similar. Almost no controls showed this level of change, while more of the NSW Alzheimer Association group showed this level of change than the clinically diagnosed DAT group.

The change reported in each cluster has been expressed in a different way in Figure 5.1 which compares the DAT patients with the controls. Here, the mean change has been calculated for each cluster in two ways. One mean change score was computed using the original scoring from one to five. This is called the *mean directional*

FIGURE 5.1: Personality change for each cluster expressed as both directional change and absolute change. DAT patients and controls are compared.

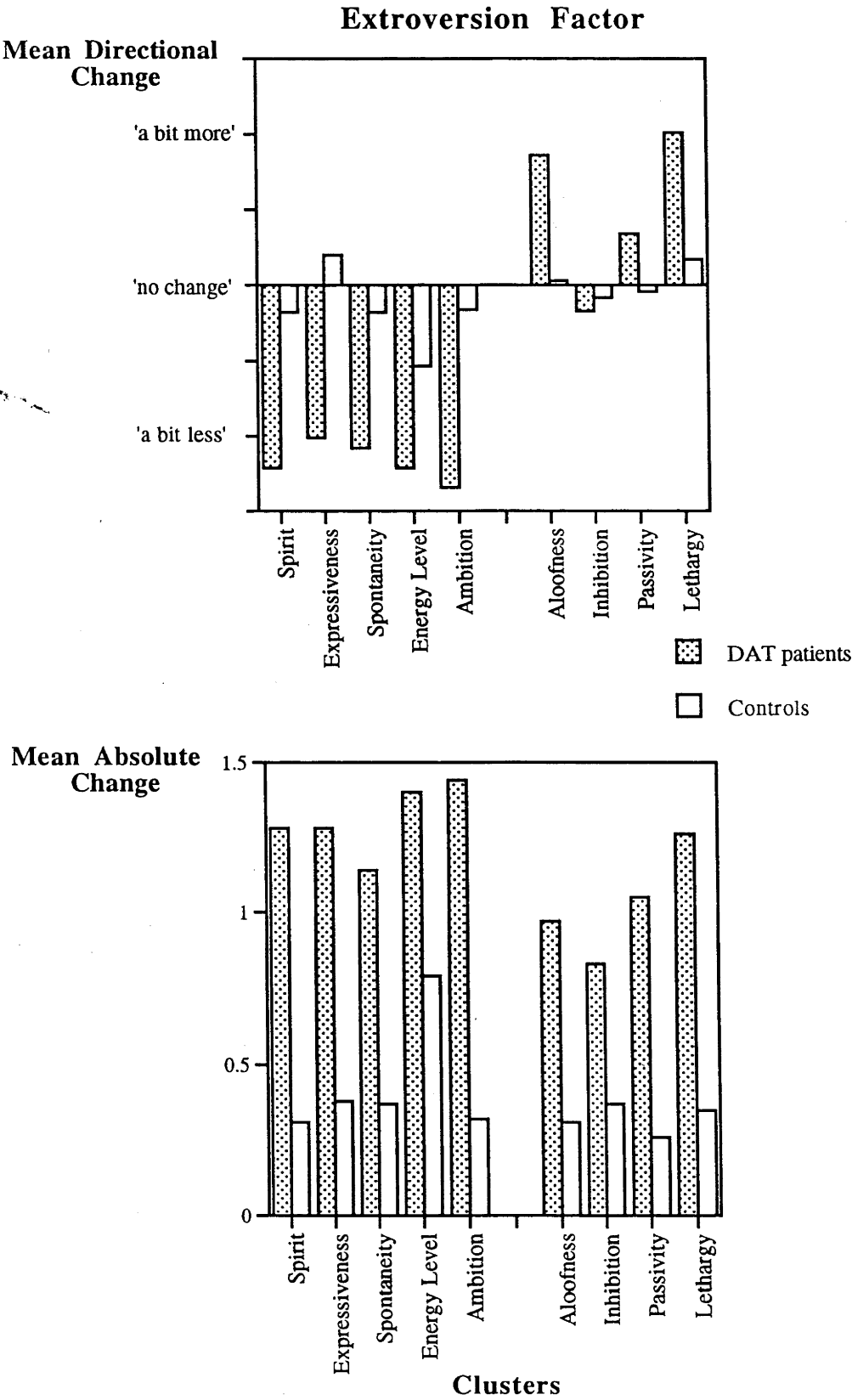


Figure 5.1 (continued).

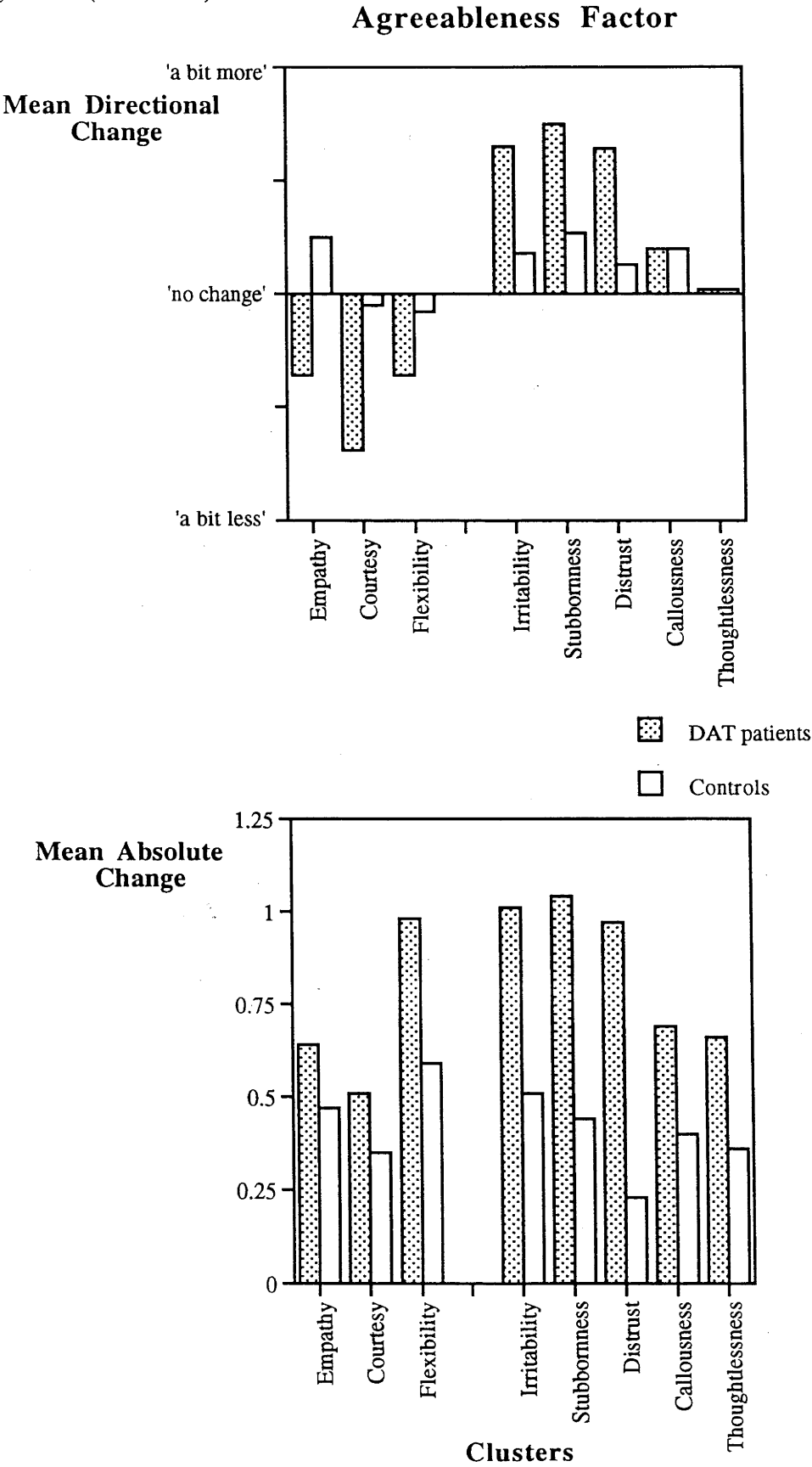


Figure 5.1 (continued)

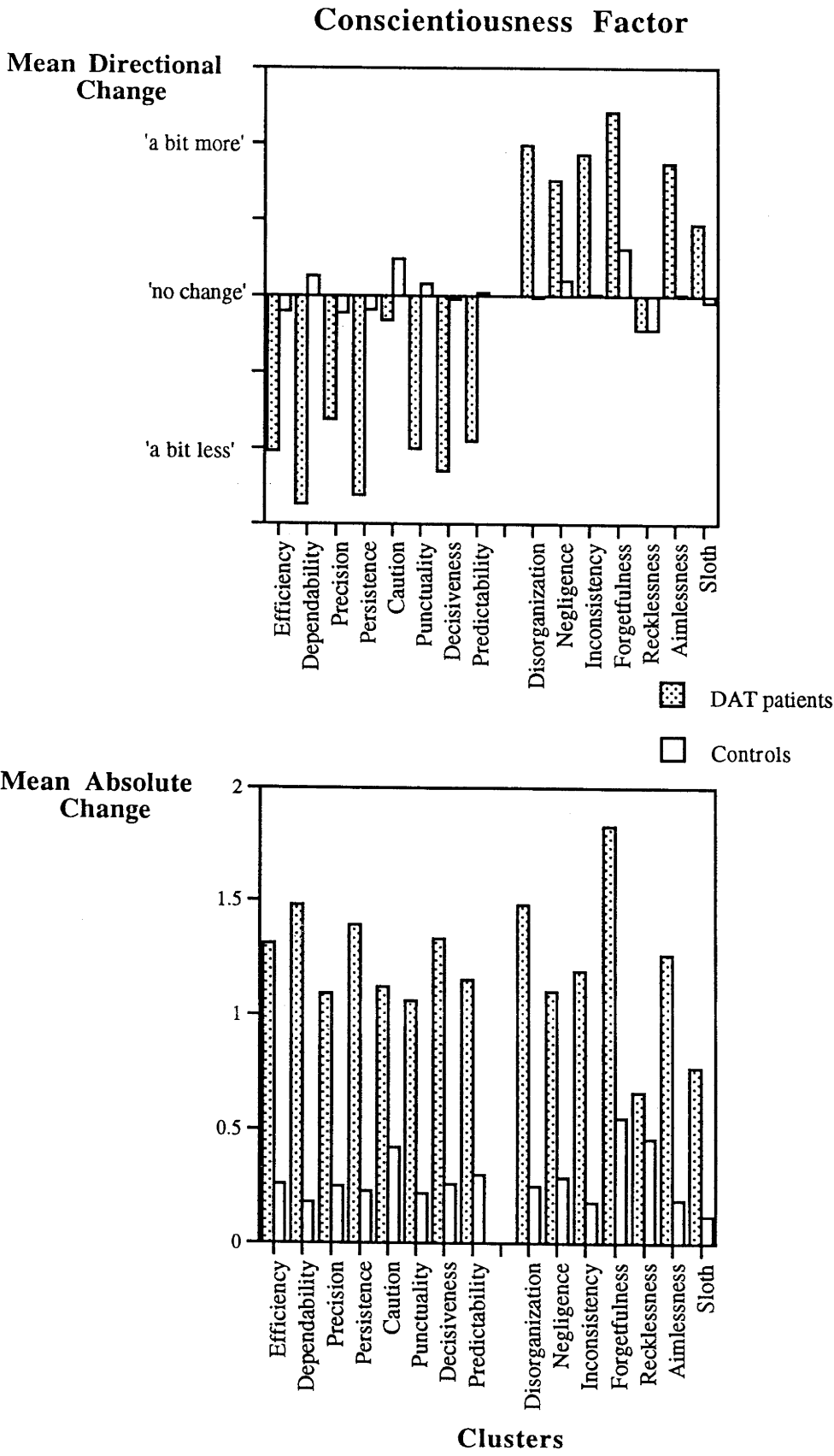


Figure 5.1 (continued)

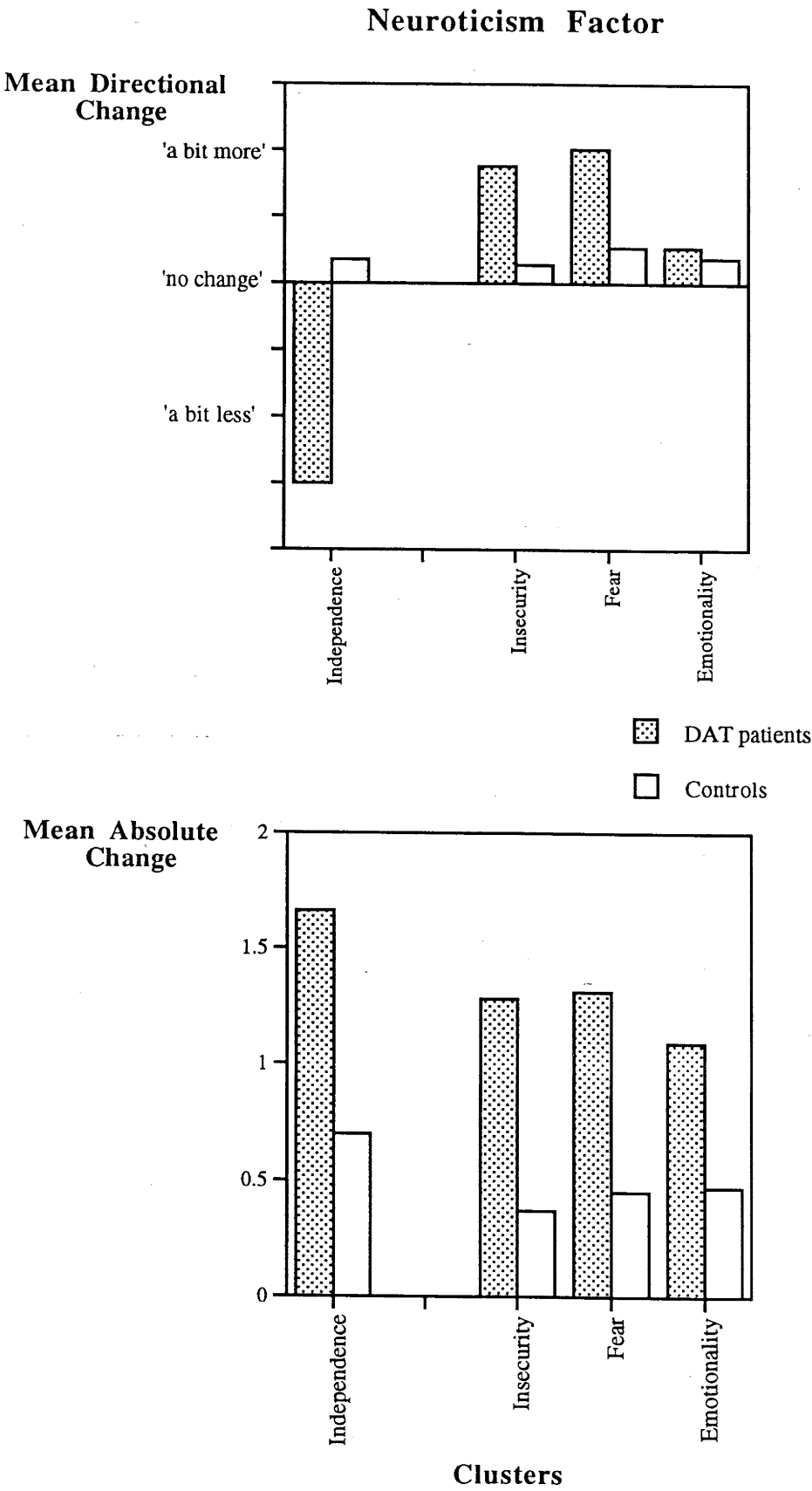
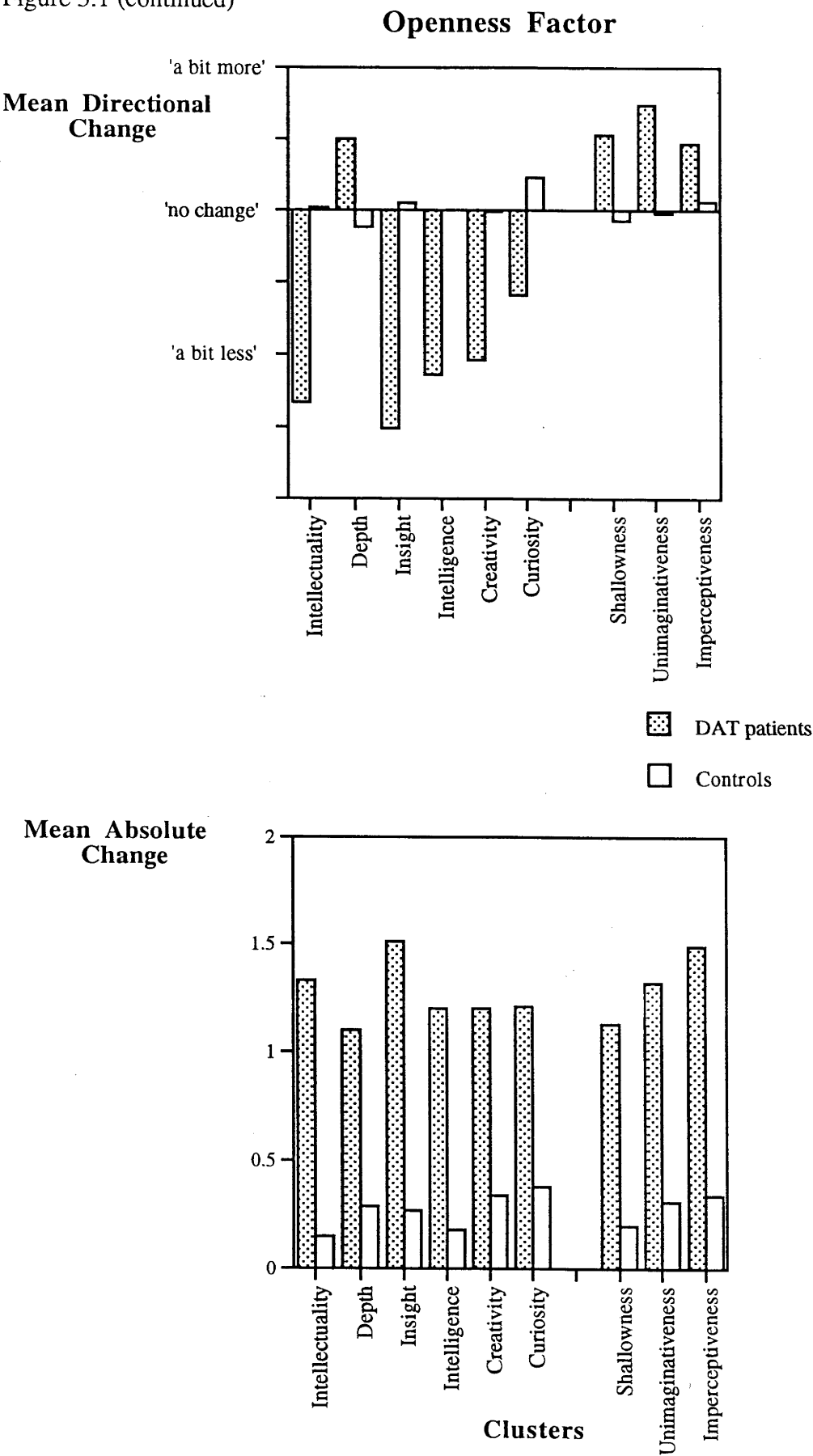


Figure 5.1 (continued)



change score. One difficulty with such a score is that for clusters showing change in both directions, the change score tends to cancel out, giving the impression that little change has occurred. To try to overcome this, another mean score has been computed based on absolute change in which *no change* has been coded as zero, *a bit less* and *a bit more* have been scored as one and *much less* and *much more* have been coded as two. This has been called the *mean absolute change score*. A difficulty with this score is that for some clusters the mean change for controls was in the opposite direction to the mean change for DAT patients. The absolute change score does not reflect this difference. This has occurred most noticeably in the clusters *expressiveness*, *empathy*, *caution* and *curiosity*.

5.2.2 Comparison Between DAT Patients and Controls

5.2.2.1 By cluster: Independent sample t-tests were carried out to compare the DAT patients with the control group. This was done using both the mean directional change and the mean absolute change. T-tests on the mean directional change showed that there was a significant difference between all clusters except *callousness*, *thoughtlessness*, *recklessness*, *emotionality* and *imperceptiveness*. When the mean absolute change was used, the only clusters for which there was no significant difference between DAT patients and controls were *empathy*, *courtesy* and *recklessness*. As *recklessness* was the only cluster for which there was no significant difference between the two groups for both measures, this was now omitted from further analysis.

DAT patients who were assessed by geriatricians were compared to those who were assessed by psychogeriatricians using independent sample t-tests. There was no difference in cognitive decline but those who had been referred to a psychogeriatrician were significantly less dependable, independent, punctual and restrained ($P < 0.05$). The lower levels of restraint could be indicative of more difficult behaviour. However, there was no difference on the remaining clusters suggesting there is not much difference in behaviour between these groups.

5.2.2.2 By the Five Factors of Personality: The mean absolute change scores for the five factors of personality were compared for the DAT sample and the controls using independent sample t-tests. The mean differences as well as the DAT patients mean change scores for the five factors are shown in Table 5.5. The two samples were significantly different ($P=0.000$) for all five factors. It is interesting to note that the rank order of the mean difference scores was the same as that found when the 28 clinicians rated the total 339 adjectives.

Table 5.5: Mean absolute change score for DAT patients and mean differences between the DAT sample and the controls for the five factors of personality.

Personality Factor	Mean Change Score for DAT Patients	Mean Difference Score
Extroversion	1.19	0.81
Agreeableness	0.77	0.37
Conscientiousness	1.00	1.00
Neuroticism	0.84	0.84
Openness	0.93	0.93

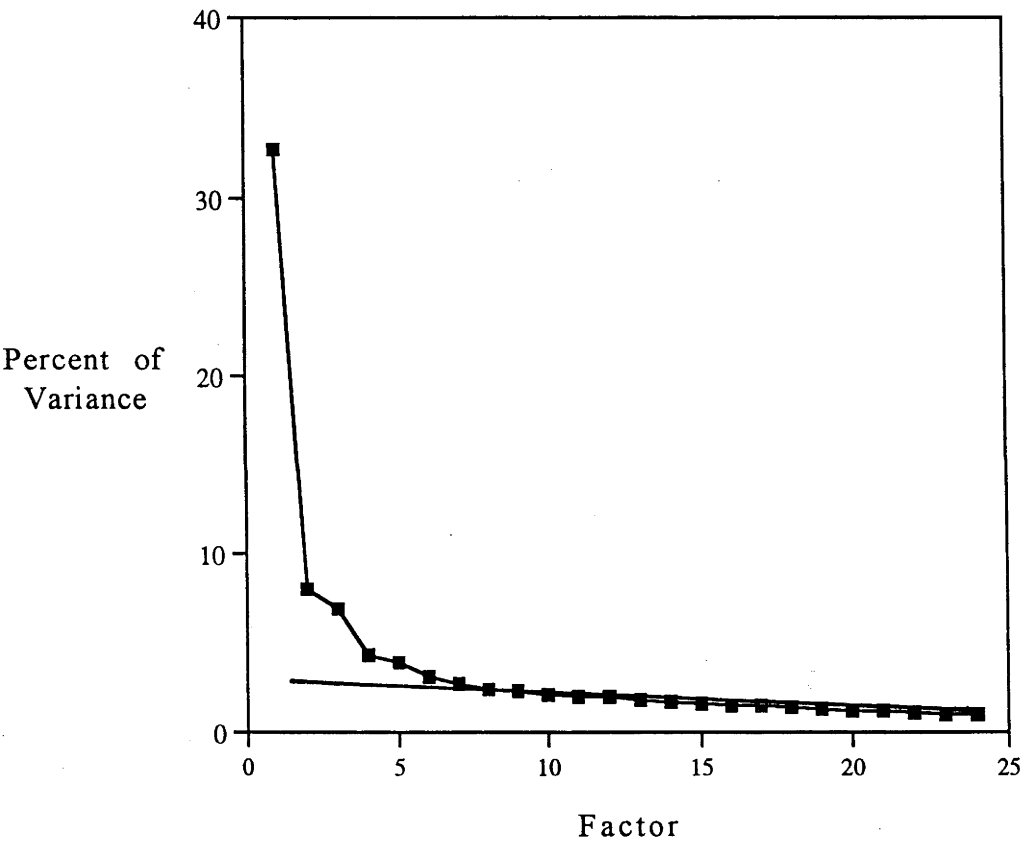
5.3 Factor Analysis of the 44 Clusters

Principal components analysis using varimax rotation was carried out on the remaining 44 clusters (those listed in Table 5.3 minus *recklessness*) using the total sample of 267. Pairwise deletion was used to handle missing values. This involves computing a 'correlation coefficient using cases with complete data on the pair of variables correlated regardless of whether the cases have missing values on any other variables' (SPSS Inc., 1988). The total sample was used for factor analysis to give a higher ratio of clusters to cases and hence increase the stability and replicability of the results. The average number of cases was 256, giving a ratio of clusters to cases of 1:5.8. One major factor emerged, accounting for 32.7% of the variance, the next factor accounting for 8.0%. A scree plot of this analysis (Figure 5.2) indicated that either three factors or six factors could be meaningfully retained for rotation.

5.3.1 The Stability of the Factors

To investigate the stability of these factors, the principal components analysis was repeated, this time replacing missing values by the variable mean. Using this method there was a ratio of clusters to cases of 1:4.4. This analysis revealed similar results for the first three factors, but the next three were quite different. The instability of the six-factor rotation led to the decision to rotate only the first three factors. The results of the three factor rotation are shown in Appendix 5.2. Looking again at the scree plot (Figure 5.2), it can be seen that there is a definite drop in percent of variance after three factors. This reinforced the decision to rotate only three factors. To examine whether the inclusion of the control group in the factor analysis had affected the extracted factors, factor analysis was carried out using only the clinically diagnosed DAT sample the NSW Alzheimer's Association sample. This gave a ratio of clusters to cases of 1:4.6. The loadings on the three factors were compared by the coefficient of congruence (Reynolds, 1982) to see if they were the same. The

FIGURE 5.2: Scree plot showing the percent of variance accounted for by the extracted factors following principal components analysis of the personality trait clusters.



coefficients for each of the factors, respectively were .98, .96 and .99 indicating that the factor structure was almost identical for the two groups.

To test whether there was any difference between those in the NSW Alzheimer's Association sample who had received a specific diagnosis of Alzheimer's disease and those who had only received a diagnosis of dementia, factor analysis was carried out on the DAT sample plus only those in the NSW Alzheimer's Association sample who had received a diagnosis of AD. Comparing the three factors from this analysis with those obtained from the DAT sample and the total NSW Alzheimer's Association gave coefficients of congruence of 1.00, 0.96 and 0.97.

5.3.2 Description of the Three Factors

Those clusters with factor loadings of 0.5 or greater for the three rotated factors are shown in Table 5.6.

Table 5.6: Clusters with factor loadings of 0.5 or greater in the first three factors. The clusters, *courtesy* and *flexibility* were negatively loaded on the second factor.

Factor 1	Factor 2	Factor 3
Spirit Expressiveness Spontaneity Energy Level Ambition Empathy Flexibility Efficiency Dependability Precision Persistence Punctuality Decisiveness Predictability Independence Intellectuality Insight Intelligence Creativity Curiosity	Courtesy Flexibility Irritability Stubbornness Distrust Callousness Insecurity Emotionality	Aloofness Inhibition Passivity Lethargy Disorganisation Forgetfulness Aimlessness Shallowness Unimaginativeness

The first extracted factor contains only clusters from the positive poles of Goldberg's inventory. This includes all of the positive clusters from the Extroversion factor, all the positive clusters except *caution* from the Conscientiousness factor, the only positive cluster representing the Neuroticism factor and, with the exception of *depth*, all of the positive clusters from the Openness factor. For the Agreeableness factor, only the clusters of *flexibility* and *empathy* loaded on this first factor. The second extracted factor appears to describe an increase in disagreeable and neurotic personality traits while the third extracted factor describes an increase in the negative traits in Extroversion, Conscientiousness and Openness.

5.4 Scales Based on the Three Factors

5.4.1 Composition of the Scales

Three scales were computed for each of these extracted factors by calculating the mean of the directional change scores of the component adjectives of the clusters with factor loadings of 0.5 (or -0.5) or more. These will be referred to as Scale 1, Scale 2 and Scale 3. Internal consistency was evaluated by calculating Cronbach's coefficient α for each of these scales. Scale 1 had an α of 0.98, Scale 2 had an α of 0.91 and Scale 3 had an α of 0.89. Table 5.7 shows the correlations between these three scales as well as the correlations between the three extracted factors when an oblique rotation was used instead of varimax. Scale 1 is significantly negatively correlated to Scales 2 and 3, which show a small but significant positive correlation.

Table 5.7: Correlations between the three extracted factors and between the three scales for the total sample.

Factor Correlation Matrix		Correlation between scales using total sample (n)	
Factor 1 with Factor 2	-0.21	Scale 1 with Scale 2	-0.57 * (227)
Factor 1 with Factor 3	-0.34	Scale 1 with Scale 3	-0.46 * (213)
Factor 2 with Factor 3	0.11	Scale 2 with Scale 3	0.27 * (218)

* P = 0.000

Table 5.8 shows the means and standard deviations of the three scale scores for the three groups. Independent sample t-tests showed the scores on all three scales for the DAT patients to be significantly different (P=0.000) to the scores for the controls. There was also a significant difference between the DAT sample and the NSW Alzheimer's Association sample for Scale 1 (P=0.000) and Scale 2 (P=0.005) but not for Scale 3.

Table 5.8: Means and standard deviations (SD) of the three scales for the three groups.

Scale	DAT patients (SD)	Controls (SD)	NSW Alzheimer's Association (SD)
Scale 1	1.99 (0.48)	2.97 (0.29)	1.65 (0.44)
Scale 2	3.58 (0.60)	3.13 (0.38)	3.85 (0.57)
Scale 3	3.79 (0.68)	3.04 (0.26)	3.82 (0.67)

5.4.2 Relationship of the Scales to the IQCODE Score

5.4.2.1 Scale 1: The correlations between the scales and the IQCODE score for the three groups of subjects is shown in Table 5.9. There is a significant, negative correlation between Scale 1 and the IQCODE score for the three groups. This indicates that as cognitive impairment increases, there is a decrease in the occurrence of the positive personality traits included in Scale 1.

Table 5.9: Correlations between IQCODE score and the three scale scores for the three groups of subjects.

Scale	DAT Patients: r (n)	Controls: r (n)	NSW Alzheimer's Association: r (n)
Scale 1	-0.64** (45)	-0.38* (47)	-0.28** (135)
Scale 2	0.13 (46)	0.27 (49)	0.10 (138)
Scale 3	0.40* (44)	-0.05 (47)	-0.06 (130)

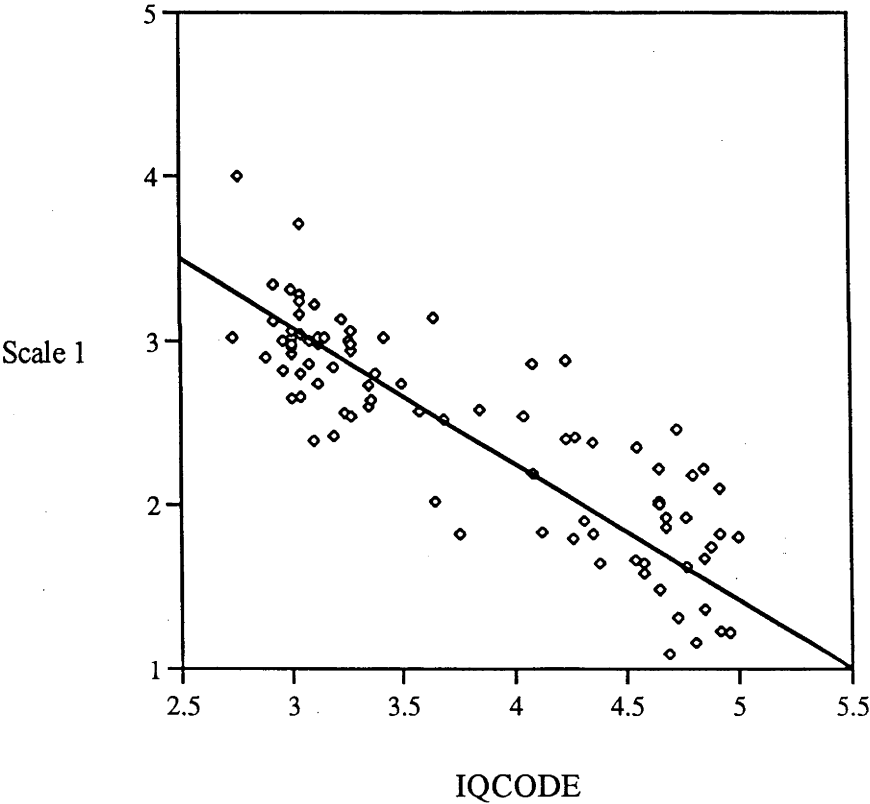
** $P < 0.001$

* $P < 0.01$

There appears to be a stronger relationship between the IQCODE score and Scale 1 for the DAT patients than for the NSW Alzheimer's Association subjects. To investigate this difference further, this relationship was examined in the 97 subjects in the NSW group who had been diagnosed as suffering specifically from Alzheimer's disease. The correlation coefficient was the same as that found for the total NSW Alzheimer's Association group.

As both the control group and the DAT patients showed a significant correlation between Scale 1 and the IQCODE score, these two groups were combined and a regression analysis performed on the resulting 100 subjects to examine the relationship over the full range of cognitive decline. This is shown diagrammatically in Figure 5.3. It can be seen that a strong relationship exists between the two

FIGURE 5.3: Plot of Scale 1 against IQCODE score for both DAT patients and controls.



R squared = 0.74

measures, with an R squared of 0.74. It may, therefore, be reasonable to conclude that the IQCODE and Scale 1 are measuring the same thing: cognitive decline.

5.4.2.2 Scale 2: Scale 2 was found to be uncorrelated to reported cognitive decline for each of the three groups (Table 5.9). However, when a scale was constructed using the absolute change score for the same adjectives, this scale was found to be significantly correlated to cognitive decline for both the DAT patients (0.47, P=0.000) and the NSW Alzheimer’s Association sample (0.19, P=0.025), but not for the control group. The only negative adjectives in this scale were *insensitive* and *insecure*, the remaining 19 being frequently used adjectives which should not have presented a difficulty in understanding. This suggests that as cognitive impairment increases, the personality traits measured by this scale change, but the direction of change may involve either an increase or a decrease in their expression. While most dementia sufferers may become more disagreeable and neurotic, a small proportion may become less so. Two examples of clusters showing change in both directions against IQCODE score are shown in Figure 5.4.

The lack of correlation between the IQCODE score and Scale 2 based on directional scoring of adjectives for each of the groups was considered surprising given that there was a strong negative correlation between Scale 1 and 2 for the total sample and Scale 1 appears to be measuring the same as the IQCODE as discussed above. A stronger, positive correlation may have been expected between Scale 2 and the IQCODE score. To explore this further, the relationship was examined in both the total sample and the DAT patients and controls combined. This is shown in Table 5.10.

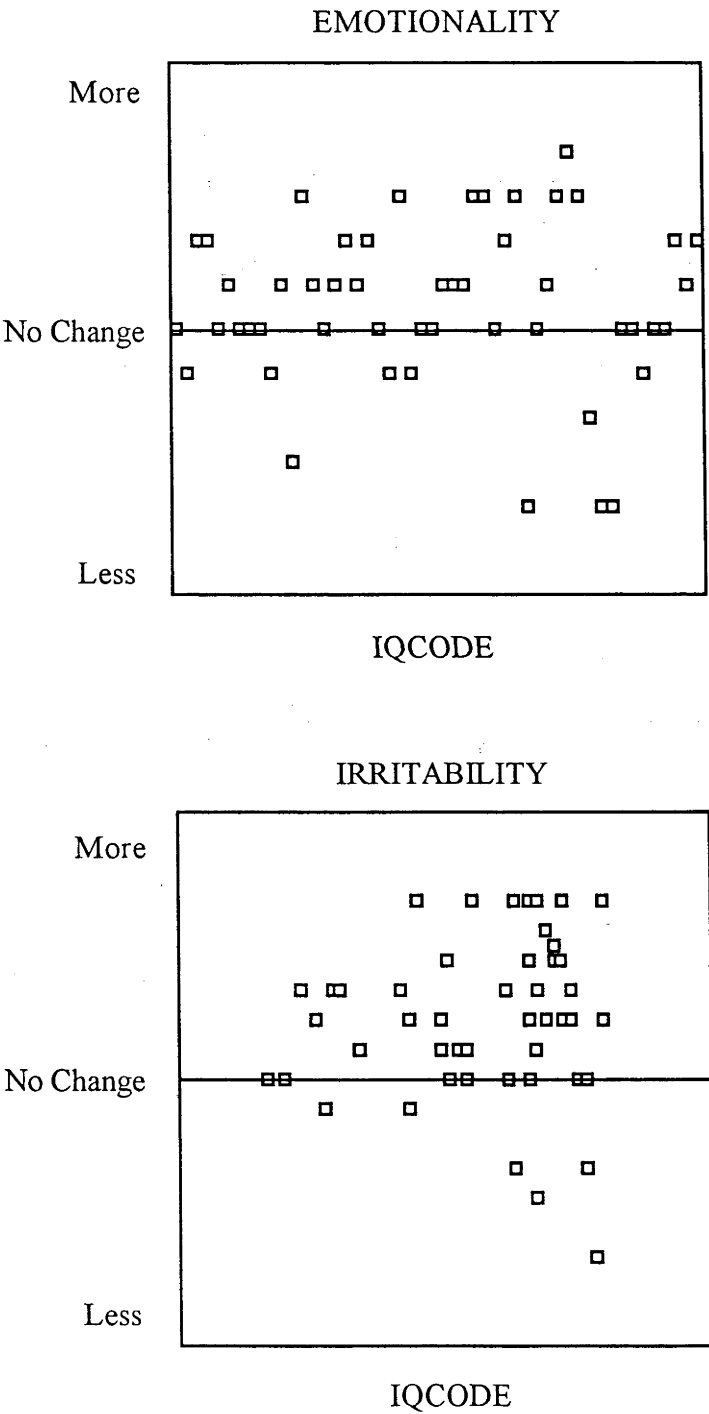
Table 5.10: Correlations between the three scales and the IQCODE score for the total sample and for the DAT patients and controls combined.

Scale	Total sample (n)	DAT patients plus controls (n)
Scale 1	-0.79 * (227)	-0.86 * (92)
Scale 2	0.46 * (233)	0.43 * (95)
Scale 3	0.45 * (221)	0.66 * (91)

* P=0.000

As can be seen, a significant positive correlation was found for both of these groups. The reason for the lack of correlation in the individual groups may be due to the limited range of IQCODE scores for these groups combined with the tendency for some subjects to change in the opposite direction.

FIGURE 5.4: Examples of clusters in which change was found in both directions using DAT patient data.



5.4.2.3 Scale 3: Scale 3 was found to be positively correlated to the IQCODE score but this was only significant for the DAT patients (Table 5.9). This scale is measuring the negative poles of the factors, Extroversion, Conscientiousness and Openness. As Scale 1 is measuring the positive poles of these factors, a positive rather than a negative correlation to the IQCODE score would have been anticipated for each of the three groups of subjects. That this was found only for the DAT patients may have been because of the presence of many negative adjectives in this scale, making interpretation difficult. (The component adjectives of all of the clusters can be seen in Table 5.3). As with Scale 2, however, Scale 3 also showed a significant positive correlation to IQCODE for the total sample and for the DAT patients and controls combined (Table 5.10).

5.4.3 Relationship of the Scales to Demographic Variables

No correlation was found between either Scale 1 or Scale 2 and the demographic characteristics of the subject or informant for the three subject groups. The score on Scale 3 was not correlated to any of the demographic characteristics of the subjects or informants in either the DAT patients or the NSW Alzheimer's Association sample. However, there was some effect of demographic variables on the Scale 3 score in the control group. Independent sample t-tests followed by regression analysis of the control sample showed that both the sex of the control and whether the informant lived with the control or not contributed significantly to the variance of the score of this scale. Females were seen as showing less of the traits measured by this scale than previously, while males were reported to be showing more. Those informants who lived with the controls thought that they showed these characteristics less than previously, while those not living with the informant considered that they showed them more.

5.4.5 One Factor or Three

As the first factor from the principal components analysis of the personality data accounted for 33% of the variance, it would have been a reasonable decision to accept a single factor solution rather than a three factor solution. To briefly explore this option, a mean score was computed using the clusters which had factor loadings of 0.5 (or -0.5) or greater on the first, unrotated factor. Those clusters with negative loadings were reverse scored. This scale was very similar to the scale derived from the first rotated factor and the correlation to the IQCODE score was almost the same.

5.5 Relationship Between Cognitive Decline and Specific Clusters

Table 5.11 shows the correlation for the DAT sample between the IQCODE score and those clusters representing personality traits which have been examined in other studies looking at personality change in dementia. *Aloofness* and *empathy* were significantly correlated to the IQCODE score for both the directional and absolute scores while *inhibition* was not correlated for either score. For the remaining clusters, only the absolute scores were correlated to the measure of cognitive decline. For the NSW Alzheimer's Association sample, *empathy* was significantly correlated to the IQCODE for both the directional and absolute score, while *passivity* and *thoughtlessness* were significantly correlated only when scored on absolute change score.

Table 5.11: Correlation between the IQCODE score of the DAT patient sample and those clusters describing personality traits which have been examined in other studies on dementia. Correlations are given using clusters based on directional scores and absolute scores.

Cluster	Equivalent Synonym Groups in Table 2.1	Directional	Absolute
Energy Level	Underactivity	-0.21	0.51 ***
Aloofness	Apathy	0.36 *	0.33 *
Inhibition	Apathy	0.24	0.19
Passivity	Apathy	0.07	0.53 ***
Lethargy	Underactivity	0.21	0.51 **
Empathy	Crude Behaviour	-0.34 *	0.39 **
Courtesy	Crude Behaviour	-0.22	0.34 *
Irritability	Irritability/Volatility	0.03	0.36 *
Stubbornness	Stubbornness	0.14	0.33 *
Distrust	Suspicion	-0.10	0.45 ***
Callousness	Callousness	0.07	0.36 *
Thoughtlessness	Self-centredness	0.02	0.57 ***
Fear	Anxiety	0.18	0.42 **
Emotionality	Emotional Lability	-0.03	0.29 *

* $P < 0.05$

** $P < 0.01$

*** $P = 0.000$

When directional cluster scores for the DAT sample were plotted against the IQCODE score, it was apparent that there was an increase in change score with cognitive decline, but that this could be either an increase or a decrease in the trait described. These results suggest that there is a change in the traits occurring with cognitive decline which is in the same direction for most but not all of the sample.

5.6 Reliability of Personality Change

As discussed in Chapter 4, an attempt was made to get information from two informants for each DAT subject. Unfortunately, data from a second informant was only achieved for 17 of the subjects which was not considered enough to estimate interrater reliability. No attempt was made to contact the informants at a later date and so it was not possible to estimate test-retest reliability.

5.7 Conclusions

Prior to analysis of personality change, any adjectives which were difficult to understand or did not correlate with other adjectives within the cluster were removed. The remaining 45 clusters were used to examine change in personality in DAT compared to controls and the relationship of this change to cognitive decline. All but one of the clusters (*recklessness*) showed significantly greater change in the DAT patients than controls. DAT sufferers were seen to be less extroverted, less agreeable, less conscientious, more neurotic and less open. Three factors were extracted and were all found to be correlated to different extents to the IQCODE score. One interesting feature of this data was that while the majority changed in the same direction, a few subjects were seen to have changed in the opposite direction.

Chapter 6

Discussion

6.1 A Comment on the Sample

The aim of this study was to examine personality changes in DAT. Data on a sample of 50 clinically diagnosed DAT patients were collected and compared to data collected on 50 community-dwelling controls. These controls were not significantly different to the DAT patients in age and sex. They had not received a diagnosis of dementia and showed little, if any cognitive impairment according to the IQCODE. Information on personality change was also gathered on 167 demented people whose relatives attended support groups run by the NSW Alzheimer's Association. As well as being used to enhance the reliability of psychometric analysis, the data gathered from this group were used to provide further information on personality change. Although the NSW Alzheimer's Association sample includes a range of diagnoses, 58% had been diagnosed as suffering from Alzheimer's disease, most having been diagnosed by a specialist. Of those given a non-specific diagnosis of dementia, approximately 70% may be expected to be suffering from DAT (Jorm and Henderson, 1993). This would mean that nearly 80% of the NSW Alzheimer's Association sample could be expected to be suffering from DAT. It would, therefore, seem reasonable to use the data gathered from this sample to support data reporting on personality change in DAT.

6.2 Occurrence of Personality Change in DAT

The major finding of this study is that there are large changes in the five factors of personality in people suffering from DAT. Very few changes were reported in older people who were not cognitively impaired. A high percentage of the informants of both the clinically diagnosed DAT sample and NSW Alzheimer's Association sample reported at least some change in most of the traits examined. The changes involved decreases in most positive traits and an increase in most negative traits. The DAT patients were found to be significantly less extroverted, less agreeable, less conscientious, more neurotic and less open than the control group. Although the informants of the two demented samples reported very similar patterns of change, a

consistently higher percentage of the Alzheimer's Association informants reported some change.

There was found to be a significant difference between the clinical sample and the control group based on either the absolute change score or the mean change score for all the clusters except *recklessness*. However, as was discussed in Chapter 4, the controls used in this study may not be representative of the elderly population. A number of other studies have looked at personality change with normal ageing and the results from these tend to be similar to that found with the controls. This control group showed little change in the last 10 years for most traits. Longitudinal studies of personality over time have found that personality tends to be stable over time, even into old age (Field, 1991). However, some studies have reported decreases in Extroversion with age (Eysenck, 1987; Field & Millsap, 1991) which was also found in the current control group. Some studies have detected decreases in Neuroticism with ageing (Eysenck, 1987) others have reported an increase (Nilsson, 1983). In the current study, the control group tended to show some increase in the negative pole of Neuroticism with changes in either direction in the positive pole of this factor. Therefore, the small amount of personality change shown by the controls used in this study is similar to that found in other studies.

6.3 Comparison with Other Studies

The instrument used in this study to examine personality change allows respondents to record either an increase or a decrease in a range of traits. This is unlike the majority of studies discussed in the literature review, where most instruments only record either an increase in, or the occurrence of, specific personality characteristics. Three studies, however, did use instruments which allow the informant to report either an increase or a decrease in personality traits. Each of these studies asked informants to complete a personality questionnaire about their relative before they developed dementia and again, as they are currently. Petry et al. (1988) found that for each characteristic, all their informants reported change in the same direction. Both Siegler et al. (1991) and Chatterjee et al. (1992), using the NEO-PI, found that the rank order of their subjects' personality characteristics were usually the same before and after developing dementia. In the current study, some characteristics were reported as changing in either direction. While for most of the clusters almost all informants have reported change in the same direction, some clusters show a more 2-sided distribution. These include *inhibition*, *passivity*, *thoughtlessness*, *caution*, *emotionality* and *imperceptiveness*. While every effort was made to remove any ambiguous clusters, *thoughtlessness* and *imperceptiveness* still contain negative adjectives which may have made interpretation difficult and would explain the 2-sided

distribution. The remaining clusters may, however, genuinely indicate that some informants are reporting an increase in these traits while others are reporting a decrease.

6.3.1 Apathy

The clusters of *aloofness*, *inhibition* and *passivity* would most closely equate with the characteristic of apathy. *Aloofness* was reported to increase in 50% of the DAT patients and 66% of the NSW Alzheimer's Association sample. For the clusters, *inhibition* and *passivity*, about 40% of informants reported increases, while a similar percent reported decreases. These clusters contain the adjectives *restrained*, *docile*, *submissive* and *passive* and it would seem possible that those who show a decrease in these characteristics are showing increased restlessness, agitation and possibly aggression. These behavioural characteristics were not assessed in this study as they were considered to fall outside the range of normal personality traits. Only two other studies have looked at change in these characteristics. Rubin et al. (1987a) found a lower occurrence of passive behaviours than the current study, while Bozzola et al. (1992) found that 61% of informants reported an increase in apathy. This latter figure was similar to that found in the current study. Other studies looking at the occurrence of behaviours found that apathy was reported in between 20% and nearly 50% of cases (Teri et al., 1989; Burns et al., 1990b; Lachs et al., 1992; Cohan et al., 1993).

6.3.2 Underactivity

The clusters, *energy level* and *lethargy* fall into this category. This study found that around 70% of the DAT sample and 80% of the NSW Alzheimer's Association sample showed at least some decrease in energy and increase in lethargy. Other studies looking at personality change, while not reporting the percentage showing change, have all found a significant decrease in energy and physical activity. Studies reporting the occurrence of underactivity vary from 7% to 43% (Teri et al., 1989; Sultzer et al., 1992; Ballinger et al., 1982), which is considerably less than this study. In the current study, 41% of the control group were thought to have decreased energy level, suggesting that this may be, not unexpectedly, a normal part of ageing.

6.3.3 Stubbornness

In this study, 50% of the DAT patients and 62% of the NSW Alzheimer's Association sample were reported to have shown some increase in stubbornness. This is more than that reported by either Rubin et al. (1987a) for whom 21% were reported to show an increase in this trait, or Bozzola et al. (1992) who reported that 41%

showed an increase. However, Gustafson (1975) found that 58% showed some evidence of stubbornness which is very close to that reported in the current study.

6.3.4 Self-centredness

In the current study, the cluster *thoughtlessness* contains the single adjective, *inconsiderate*. This negative adjective may account for the 2-sided distribution of this cluster, with an almost equal number reporting a decrease as reported an increase. About 25% reported an increase in thoughtlessness for both the DAT and the NSW Alzheimer's Association samples, which is similar to the number reporting such changes in the studies by Rubin et al. (1987a) and Bozzola et al. (1992). It is possible that informants misunderstood the negative adjectives in this cluster and most if not all, intended to report an increase in this trait. This would have resulted in about 50% reporting an increase which is high compared to other studies.

6.3.5 Coarse / Crude Behaviour

The clusters, *empathy* and *courtesy* have been included under this section as it was considered likely that decreases in such traits could be reflected in coarse, crude or socially inappropriate behaviour. This study found that around 30% of the DAT patients were reported to show some decrease in empathy, although the NSW Alzheimer's Association sample reported some decrease in this trait in nearly 50% of cases. This level of occurrence is similar to a number of the studies discussed earlier, with Bozzola et al. (1992) reporting this characteristic in 36% of subjects and Sultzer et al. (1992) noting a mild level in 34% during clinical interviews. Ballinger et al. (1982) and Gustafson (1975), however, reported higher levels of over 50%.

6.3.6 Irritability / Volatility

Forty four percent of the DAT sample and 53% of the NSW Alzheimer's Association sample reported some increase in irritability. This is a much higher percentage than most other studies that have looked at irritability in dementia. It is, however, in close agreement with the study by Burns et al. (1990b) in which they used a five item scale and found that 58% reported some degree of irritability.

6.3.7 Suspicion

A higher percentage of informants reported suspicion in the current study (approximately 60%) than has been reported by other studies. Rubin et al. (1987a) found that only 5% of their sample were reported as showing a change in suspicion. Rating scales measuring the occurrence of suspicion yielded levels of between 25% and 50%. Suspicion is often studied in association with psychiatric symptoms in dementia, extreme suspicion being viewed as a paranoid state (Mendez et al., 1990).

It is likely, however, that many demented people show greater levels of suspicion than previously without being classed as paranoid.

6.3.8 Callousness

Only Petry et al. (1988) have also looked at this trait. They found that the mean change in this trait was significantly greater in their DAT patients than in their controls, as was found in this study. The current study found that 22% of the DAT sample and 45% of the NSW Alzheimer's Association sample reported some change.

6.3.9 Emotional Lability

Emotionality was reported as increasing in about 30% of both DAT patients and the NSW Alzheimer's Association sample. About a half of this number were reported to show a decrease in this trait. The 30% increase is similar to the levels reported by those studies where clinicians have completed checklists of current behaviour (Gustafson, 1975; Bucht and Adolfsson, 1983; Sultzer et al., 1992).

6.3.10 Anxiety

In the current study, fear (which included the adjective, *anxiety*) was reported as having increased in approximately 65% of the subjects in both the demented samples. This is higher than that reported by most other studies. Gustafson (1975), however, reported some evidence of anxiety in 58% of demented subjects and Ballinger et al. (1982) the occurrence of anxious behaviour in 58% of their subjects.

6.3.11 General Comment on Comparison with Other Studies

For many of the traits investigated in the current study, the percent of informants reporting change is higher than found in many other studies. This may have occurred partly because this study has reported *some* change rather than *much* change. Also, information has been gathered from informants, usually carers, who know the subject well and who have ample opportunity to observe changes. Many of the studies looking at the occurrence of behaviours used clinician reports or extract behaviours mentioned by relatives at interview. The major difference in this study compared to others is the observation that changes may occur in the opposite direction to that usually encountered. Many researchers studying behaviour or personality change in dementia are interested in those changes which are distressing to carers and, as a result, the instruments used may only include such changes, neglecting other changes which may not cause distress.

6.4 Comparing Changes in the Factors of the Five-Factor Model of Personality

In the preliminary study 28 clinicians, using the total Goldberg inventory covering the five factors of personality, rated the difference between DAT patients and cognitively unimpaired elderly people. Conscientiousness and Openness were reported to display the most difference, followed by Extroversion and Neuroticism showing almost the same difference, with Agreeableness showing the least difference. When the changes reported by the controls were subtracted from the changes reported by DAT patients, the same rank order of change was found. The main difference which is apparent when comparing this with the studies by Chatterjee et al. (1992) and Siegler et al. (1991) using the NEO-PI is in the factor of Openness. In both of these studies Conscientiousness showed the greatest change followed by changes in Extroversion and Neuroticism which were almost the same, with the least change being shown in the factors of Agreeableness and Openness. This difference may have occurred for two reasons. Firstly, in the studies using the NEO-PI, subjects were seen to be showing increases in imaginativeness while showing decreases in the other traits within this factor. In the current study, the adjective, *imaginativeness* was clustered with the adjective, *creativity* and these were both reported to decrease in the majority of cases. Also, the NEO-PI contains questions covering values and feelings which were rated as showing little change in dementia while the Goldberg inventory does not cover such traits.

6.5 Principal Components Analysis and the Three Scales

According to the five factor model of personality, analysis of inventories covering the full range of personality traits will result in five different factors. It would be reasonable to expect DAT to produce changes specific to these five factors. However, this was not the case. In the current study, a three factor solution was chosen as appropriate after examining the scree plot and testing the stability of the factors. As the first factor accounted for 33% of the variance it would also have been valid to choose a single factor solution. Such a large first factor is indicative of a global personality change across the five factors. In a recent study by myself and colleagues, personality changes in an elderly community sample were examined using the personality changes included in the DSM-III-R and ICD-10 criteria for dementia (Jacomb et. al., 1994, see Appendix 6.1). Factor analysis of this data showed that the first factor accounted for 26% of the variance with the next factor dropping to 9%. The sample used in this study included a large majority of normal, elderly people for whom no personality changes were reported. Of those who were reported to show some personality change, most only showed change in a few items. There was not considered to be enough variability within this group to be able to identify different patterns of change and so a single factor solution was considered appropriate. In the

current study the majority of the sample were demented and informants reported considerable personality change. It was therefore considered that there was enough variability in this sample to be able to determine different patterns of change.

Three scales were constructed from the three rotated factors. Scale 1 contains clusters from the positive poles of each of the five factors described in the five-factor model of personality. The second scale, Scale 2, is composed of clusters from the Agreeableness factor of personality as well as the negative pole of Neuroticism. Scale 3 is composed of clusters from the negative poles of Extroversion, Conscientiousness and Openness. It would be expected that the clusters from the negative poles would have loaded negatively on the first factor. This was in fact the case, but the degree of factor loading was relatively low and so these clusters were not included in Scale 1. Scale 3 was, however, significantly negatively correlated to Scale 1.

Some other studies have carried out factor analyses on instruments assessing personality or behaviour changes in dementia. It is very difficult to compare such studies as the different factors which are obtained will depend to a great extent on the range of items entered into the analysis. One of the strengths of the current study was the use as a sampling frame, of a personality inventory covering the full range of personality traits found in the normal population. Following the rating of a scale based on Goldberg's complete inventory by clinicians, the instrument was reduced to a more manageable size while still containing all those personality traits seen as changing in DAT. A weakness of many other studies is that they have used instruments which are based on clinical reports of change or carer reports of problem behaviours. Obviously, such scales can only detect relationships between a small range of variables. Factor analysis of the data collected in this study enables us to examine the relationship between traits across the full spectrum of personality.

Despite the difficulties in making such comparisons, these studies will be briefly compared to the current study. Sultzer et al. (1992) carried out a principal components analysis on the results obtained from the completion of the Neurobehavioural Rating Scale on 83 patients with dementia. This gave a six factor solution with cognition loading on a separate factor to those characteristics which were similar to those in Scale 2. No measures of extroversion or apathy were included in Sultzer's study. In a study by Greene et al. (1982), factor analysis was carried out on a scale designed to measure behavioural and mood disturbance and three factors emerged. The first factor was similar to Scale 3 and included passive behaviours plus some memory items, the second factor included agitated, restless

behaviour and some memory items while the third factor contained items measuring irritability and moodiness. This last factor, which is similar to Scale 2, was not associated with the memory items. The results found in Greene et al.'s study for the first and third factors are similar to that found in the current study. The study by Greene et al., however, had 34 variables and only 38 subjects, so the results may not be stable or reliable.

Gustafson (1975) carried out a factor analysis on a large range of items including memory, behaviour and psychiatric problems, which he had assessed in 57 patients with pre-senile dementia. Again, the ratio of variables to cases was only about 1:1. Fourteen factors were reported, with most of the items which are comparable to the current study loading on different factors. Irritability and obstinacy did, however, load on the same factor.

Recently, Jorm et al. (1993) carried out a principal components analysis on a range of clinical variables from a community sample of elderly people in Sweden. The first factor, which included a range of cognitive items, also included apathy and quietness, while the second factor included many of the traits covered in the current study. This second factor did include some measures of memory loss. Overall and Beller (1984) factor analysed the Brief Psychiatric Rating Scale and found separate factors for anxiety/depressed mood as well as another factor measuring hostility, suspiciousness and uncooperativeness.

Two studies have performed factor analysis on results obtained from demented subjects using the Blessed Dementia Scale. Stern et al. (1990) found four factors, two of which contained personality items. One factor included items similar to those found in Scale 2, while the other factor contained items assessing apathy or withdrawal. Rubin et al. (1987a) analysed 17 items based on 44 subjects and isolated seven factors. However, they then grouped these factors into 'four clinically meaningful groups'. These were passive behaviours, agitated behaviours, including irritable, self-centred behaviours and suspiciousness. As with the study by Stern et al., passive behaviours including apathy fell into a separate factor from the more 'disagreeable' characteristics.

In all of the studies discussed here, items measuring the negative pole of Extroversion (apathy, withdrawal, lack of initiative), load in different factors to items which fall into the Agreeableness factor of personality such as irritability, obstinacy. This is what was found in the current study.

6.6 Relationship of Personality Change to Cognitive Decline

Using the total sample, the first unrotated factor was significantly, negatively correlated to the IQCODE score indicating that, as cognitive impairment increases, the majority of positive aspects of personality are seen to decrease. This suggests that there is a global change in personality with cognitive decline. After rotation, the first factor was found to be very similar to the first unrotated factor. The first rotated factor was found to be significantly negatively correlated to the IQCODE score for the three subject groups. Regression analysis using the combined DAT patients and controls to examine further the relationship between Scale 1 and the IQCODE showed a strong relationship. One of the major components of Scale 1 is Conscientiousness. Examination of the clusters in this factor of personality reveals that they are measuring those traits which would be strongly influenced by cognitive decline e.g. *dependability, efficiency, punctuality, predictability* (Table 5.3). The factor of Openness, which is a component of Scale 1, also contains clusters which would obviously be influenced by cognitive decline e.g. *intellectuality, insight, intelligence*. In fact, these factors could be seen as direct indicators of cognitive decline.

Scale 3 assesses the changes in the negative poles of Extroversion, Conscientiousness and Openness. This scale had a significant, positive correlation to the IQCODE for the DAT sample but not for the control group or the NSW Alzheimer's Association group. This lack of correlation is surprising if this scale is measuring the opposite of Scale 1. The controls and the Alzheimer's Association groups also had lower correlations between the IQCODE and Scale 1 than the DAT sample. In the case of the controls, this may be because there was very little variability. In the NSW Alzheimer's Association group the mean IQCODE score was higher than in the DAT sample and also higher levels of personality change were reported, so it is possible that there may be a ceiling effect operating with this group.

In the studies using factor analysis discussed above, items assessing a lack of, or a decrease in Extroversion (apathy, withdrawal) were found to load with memory and cognition items, indicating a correlation with cognitive decline. This association was found with a number of other studies which used factor analysis as discussed above.

Looking at the individual clusters that are part of the Extroversion factor and are comparable to characteristics examined in other studies, it was found that, for the DAT sample, *Energy level, lethargy* and *passivity* were only significantly correlated to the IQCODE score when the absolute score was used (see Table 5.15). *Inhibition* was not correlated at all, while *aloofness* was correlated for both directional and

absolute scores. Scatter plots of the directional scores of these clusters against the IQCODE score revealed that while the majority were showing a change in the same direction (toward Introversion), a small number were reported to show changes in the opposite direction (toward Extroversion). These few cases were enough to result in the lack of correlation when using the directional score. As mentioned earlier, those few people who are reported to show decreases in introversion may well be that group of demented people who become agitated and restless and these changes may be more extreme at high levels of cognitive impairment. Other studies which have looked at characteristics of extroversion have given mixed results. Both Stern et al. (1990) and Gilley et al. (1991) found a significant, negative correlation between measures of apathy and MMSE scores in AD samples. Rubin et al. (1987b) found that symptoms of passivity increased with cognitive impairment but that this was not statistically significant while Petry et al. (1989) also found no significant correlation between measures of apathy, activity or interest in people and MMSE scores. Contrary to the finding in the current study, Chatterjee et al. (1992) found that there was a greater decrease in Extroversion for those subjects with higher MMSE score.

Scale 2 is composed of most of the personality characteristics which are usually studied in dementia, covering the personality factors of Agreeableness and Neuroticism. This scale was not correlated to the IQCODE score for any of the three groups of subjects when using directionally scored adjectives, but when the scale was computed using absolute scored clusters, there was a significant positive correlation for the DAT sample and the NSW Alzheimer's Association sample. Many of the component clusters in this scale were significantly correlated to the IQCODE score only when scored for absolute change (Table 5.11) and scatter plots revealed similar patterns to that found for the clusters in Extroversion. This suggests that while the majority of dementia sufferers become more disagreeable and neurotic as cognitive impairment increases, a small minority are being viewed as becoming more agreeable. This latter group may be those who are so cognitively impaired that they are unable to respond to their environment. It is also possible that some of the negative adjectives in this scale were misunderstood and answered incorrectly. It is, however, possible that people with Alzheimer's disease may become more agreeable. Perhaps as a person with dementia becomes more dependent, particularly if she or he retains insight, they may become more considerate of their carer.

Most other studies that have assessed changes which fall within the factor of Agreeableness, have found a positive correlation between disagreeable behaviours and cognitive decline. A number of studies have found an increase in the reporting of irritable behaviour with increased cognitive impairment (Gustafson, 1975; Rubin et

al., 1987b; Cooper et al., 1990; Gilley et al., 1991), although in some cases the increase was small. In the current study a significant, positive correlation was found between the absolute irritability cluster score and the IQCODE score, but this association was not as strong as for some of the other clusters (Table 5.11). Petry et al. (1989) found no correlation between reported irritability and MMSE scores.

Three studies besides the current one have looked at the association between suspicion and cognitive decline and have found no association (Gustafson, 1975; Teri et al., 1988; Sultzer et al., 1992). This study, however, found that the cluster, *distrust*, which contains the adjective *suspicion*, was significantly correlated to the IQCODE score when the absolute score was used. It is possible that as suspicion increases, paranoid behaviour becomes more obvious.

Rubin et al. (1987b) found that self-centred behaviours increased significantly from mild to moderate cognitive impairment. The current study found a high correlation between the absolute score of *thoughtlessness* and the IQCODE score. This study also found a relatively small but significant correlation between the absolute score of *callousness* and cognitive decline. In the study by Petry et al. (1989), the items, *cold* and *insensitive* were not correlated to MMSE scores but did increase over time.

Empathy, the lack of which was considered to be a possible measure of crude behaviour, was found to be negatively correlated to the IQCODE score even when scored directionally, while both *empathy* and *courtesy* were correlated with the IQCODE score when scored as an absolute change score. In the majority of cases, these characteristics decreased as cognitive impairment increased. Gilley et al. (1991) found a significant, negative correlation between MMSE scores and disinhibition, while Sultzer et al. (1992) found no difference in the reported occurrence of crude behaviour between subjects with high MMSE scores and those with low scores. Looking at Agreeableness in total, Chatterjee et al. (1992) found no correlation with MMSE scores.

In the personality factor of Neuroticism, both the cluster, *fear*, which contains the adjective *anxiety*, and the cluster *emotionality*, were significantly correlated to the IQCODE score but only when using the absolute change score. The correlation was quite low for *emotionality* which showed a definite bi-modal distribution (see Figure 5.4). Burns et al. (1990) found a significant positive correlation between the reported occurrence of anxiety and dementia severity, while Forsell et al. (1993) found that informants reported an increase in anxiety with disease severity but

clinicians reported a decrease. Petry et al. (1988) that their subjects became significantly more excitable as MMSE scores decreased.

The current study also looked at the trait of *insecurity* and found that this had quite a high correlation with IQCODE when using the absolute change score (0.57, $P=0.000$). This trait has not been investigated in other studies of personality change in dementia.

In the study by Chatterjee et al. (1992) using the NEO-PI, there was found to be no correlation between Neuroticism and MMSE scores.

To summarise, the three factors isolated in the current study were all significantly correlated with cognitive change. There was a particularly strong association between the first factor and the IQCODE score. For clusters measuring passive, disagreeable and neurotic behaviours, there is some indication that while these characteristics increase in one direction for the majority of demented subjects, there may be a small number of demented people who change in the opposite direction.

6.7 Relationship of Personality Change to Demographic Variables

Assessment of personality changes in dementia in this study has been based on information obtained from someone, usually a spouse, son or daughter who knows the subject well. The use of informant ratings introduces the possibility that the information provided by these people may be contaminated by such factors as their relationship to the subject, whether they live with the subject or the informant's gender. For Scale 1 and Scale 2 no relationship was found between the score on each scale and any of these variables for any of the three groups studied. There was also no relationship found between these scales and any of the demographic characteristics of the subject. The score for Scale 3 was found to be related, in the control group only, to the sex of the control and whether the informant lived with the control. It is possible that, while such variables may influence the reporting of personality change in a group where there is little actual change such as the control group, the much greater changes which are reported in dementia cases outweigh any effect of demographic variables of the subject or informant. Gilley and Wilson (1991) found no association between reports of apathy, agitation and irritability and either the gender of the informant or the informant's relationship to the subject while Thompson and Orvaschel (1982) found that reports of psychiatric symptomatology varied with the informant's relationship to the subject. In the study by Jacomb et al. (1994, see Appendix 6.1), no relationship was found between reports of personality change and relationship of informant to subject, gender of the informant, or whether

the informant lived with the subject. However, neurotic symptoms in the informant were found to be a predictor of reported personality change in the Jacomb study although no conclusion could be made about the direction of this relationship. Information on neurotic symptoms in the informant were not assessed in the current study.

6.8 Limitations of the Study

There were a number of limitations of this study which should be considered in interpreting these results. Two of these limitations may be the selection of the demented sample and the diagnosis of DAT.

Although every attempt was made to recruit only subjects who were suffering from DAT, this is very difficult to do without post mortem results and it is possible that some diagnoses were incorrect. For example, some of the clinical subjects may have had the fairly recently recognised disorder of Frontal Lobe Dementia (Gustafson, 1987; Brun, 1987), which is characterised by personality change.

It is possible that the personality changes reported in the DAT sample and the NSW Alzheimer's Association sample are not representative of all people in the population who suffer from dementia. Those patients who are referred to specialised clinics, as in the DAT sample used here, may be a subsample of people displaying more distressing and disruptive behaviours. Some studies have found a relationship between behaviour and personality changes and carer stress (Greene et al., 1982; Gilleard et al., 1982, 1984). It is possible that those carers who attend support groups, as did the informants in the NSW Alzheimer's Association sample, may be caring for dementia sufferers who are displaying personality or behaviour changes which the carer is finding stressful. This may have resulted in their seeking help from such groups. In an attempt to examine possible sample bias in this study, personality change in those patients referred to geriatricians was compared to change in those who had been referred to psychogeriatricians. It was considered likely that psychogeriatricians would see those with more severe or disruptive behaviours, but there was found to be little difference in the two groups. To investigate sample bias properly, it would be necessary to compare the changes found in this study with those seen in a general population study. Very few population studies which have investigated dementia have included a measure of personality change. In a study of 1000 elderly people in 1990/91 by this Unit, personality variables taken from the DSM-III-R and ICD-10 criteria for dementia were assessed. As these questions were included in the algorithm for diagnosing dementia, it was not possible to make a comparison between personality change and dementia diagnosis. However, 29% of

the total sample were reported to show personality change, while very few of these people had previously been clinically assessed for dementia (Jacomb et al., 1994, Appendix 6.1). In a study by O'Connor et al. (1990), 120 people suffering from dementia were identified in a general population sample. These investigators looked at the occurrence of a range of disturbed behaviours in this group, including demanding behaviour, crude behaviour, temper outbursts and aggression. Demanding behaviour was shown by 20% of those with mild dementia and 60% of those with severe dementia, 40% (mild) and 70% (severe) displayed temper outbursts, while up to 60% were reported to show disruptive behaviour. Despite this, less than 10% had previously been referred to a psychogeriatrician (personal communication). This study found that the reasons given for referral included disruptive behaviour as well as other factors such as the carer's expectation of the outcome (personal communication). These studies suggest that personality change does occur in the general population of dementia sufferers. However, it is possible that there is a difference in degree.

In any study of this kind there are inevitable limits to the amount of possibly relevant information that can be collected. Almost all information gathered in this study came from informants. As the final personality questionnaire was still quite long (124 questions), the decision was made not to ask for too much other information from the informants, many of whom may have been under considerable stress in caring for their demented relative. In consequence, information was not obtained which may have aided the interpretation of the data on personality change.

No information was obtained on whether the dementia subjects studied here were using psychotropic medication. Such medication is often prescribed for dementia patients who display difficult behaviours. If this was the case, certain behaviours may have been modified, which may account for the small group of dementia sufferers who were seen as showing a decrease in traits such as irritability, stubbornness and emotionality. An example of this is Mrs K described in Appendix 2.1. This woman showed quite violent behaviour until placed on major tranquillisers and now is relatively calm.

As discussed earlier, Teri and Wagner (1992) reviewed studies of AD patients and found that the majority reported between 17% and 29% occurrence of depressive disorders. No attempt was made to exclude such people from the sample. Although the current study did not include questions on depressive mood, some of the trait adjectives could also be symptoms of depression. These include increased

withdrawal, irritability or anxiety. It seems highly probable that there was comorbidity of dementia and depression in some of the DAT subjects used in this study.

No data were obtained on the physical health of the subjects and it is possible that some of the changes mentioned above could have been related to this variable. Studies of general population samples of the elderly have found that physical ill health is a predictor of subsequent depressive symptoms (Harlow et al., 1991; Wallace and O'Hara, 1992).

Recent studies have found that informant's reports of personality change (Jacomb et al., 1994) and cognitive decline (Jorm et al., 1994) were correlated to the informant's own anxiety and depression symptoms. It would have been interesting to assess this in this study.

It was also not possible to assess inter-rater reliability for the DAT patients as had been hoped. The primary informants often found it difficult to nominate someone else that they felt knew the dementia patient well enough to complete the questionnaires.

Another possible limitation of this study may relate to the questionnaire design. The questionnaire used in this study was derived from an inventory designed to assess personality in a normal population. This inventory was able to be successfully completed by college students when assessing current personality of peers. The questionnaire used here asked about change in personality rather than current personality and, in using negative adjectives, awkward questions occurred that were difficult to understand. Also, the people completing this questionnaire were, in most cases, not as well educated as the college students. A high level of missing data was found for most of the negative adjectives indicating that such adjectives are either inappropriate for such a questionnaire or that the questionnaire should have been worded more carefully. The occurrence of missing data was higher in those informants who were more poorly educated, suggesting that many of the adjectives may have been difficult to understand. Although adjectives with more than 20% missing were removed prior to analyses, it is still possible that many of the remaining adjectives proved difficult for some informants. Missing data were also found to increase with increased cognitive impairment. It is possible that the descriptors of personality used in this study were very difficult to interpret in people who had reached the more severe stages of cognitive decline. Such an assessment may, therefore, be inappropriate for this group.

This study has attempted to examine the relationship between personality change and cognitive decline. However, the design was cross sectional and it is therefore, difficult to make accurate statements about the changes in personality which occur with cognitive decline. To do this, a longitudinal study is required, preferably one in which personality is assessed in a cognitively normal sample prior to the development of any symptoms of dementia. A planned follow-up of the community sample described by Jacomb et al., (1994, see Appendix 6.1) will allow such a comparison to be made. The personality items used in this longitudinal study are, however, less comprehensive than those used in the current study.

This study attempted to assess personality change by asking informants to give a direct rating of change for each characteristic. While this is not necessarily a limitation of the study, other ways of obtaining a measure of personality change could have been used and should be mentioned. Another method, as used in a number of the studies discussed in Chapter 2, would have been to ask informants to rate their relative's personality as it was before they became demented and as it is currently. Having a measure of premorbid personality would have allowed testing of the clinical observation that dementia sufferers show an accentuation of premorbid traits. Alternatively, it is possible that someone with an exaggerated trait, premorbidly, may show less change with dementia than someone who had previously hardly shown this trait. Using a direct rating of change did not allow testing of this possibility. However, it should not be assumed that this alternative method is preferable to a direct rating of change. Two disadvantages of this alternative assessment of change are that recollections of past personality may be contaminated by current personality and the reliability of difference scores is often much poorer than the reliability of the two score being subtracted (Cohen and Cohen, 1975). The possibility of using two measures of personality was considered prior to starting this study but it was felt that it would be too time consuming for the informants.

6.9 Theoretical Implications

A number of theories have been put forward to explain the reasons for personality change in dementia. One theory is that perceived personality change is actually the demented person's reasonable reaction to their condition. For example, they may become anxious and depressed at their decrease in cognitive ability, or they may become irritable and angry when unable to remember where they have put things. If this were the case then considerable variability of change could be expected between demented people depending on their situation and possibly their premorbid personality. In this study large changes in personality were found with most dementia sufferers showing changes in the same direction. The large, global change found here

suggests that the personality changes are unlikely to be solely due to the person's reaction to the disease. Studies which have looked at premorbid personality have found that this has little effect on changes seen in dementia (Petry et al., 1988; Siegler et al., 1991; Chatterjee et al., 1992). Such findings would argue against this theory.

The relationship between personality change and cognitive decline found in different studies has often been used to support different theories of personality change. The lack of correlation between personality and cognitive decline found in some studies has been used as evidence to support the theory that personality change may be a direct result of damage to particular neurotransmitter systems or specific areas of the brain, independent of those changes causing cognitive decline. In the current study those clusters covering disagreeable and neurotic traits (Scale 2) and those covering passive traits (Scale 3) showed, a significant but moderate correlation to cognitive decline suggesting that these personality changes may be caused, at least in part, by processes independent of those involved in cognitive change.

Studies which have examined personality change due to brain injury have shown that specific personality changes may occur following damage to particular areas of the brain. Bilateral temporal lobe lesions can result in placidity and hypersexuality, while damage to the nondominant parietal lobes may affect insight and disturb emotional processing (Lilly et al., 1983). Injury to the frontal lobes may result in apathy, a lack of impulse control, irritability and mood changes (Lishman, 1987). Such changes are often seen without accompanying cognitive change suggesting that different areas of the brain or neurotransmitter systems may be involved. As was mentioned previously, Frontal Lobe dementia is characterised specifically by personality changes including either apathy and underactivity or disinhibition and overactivity (Neary, 1990). Involvement of the frontal lobes has been shown in such cases using single photon emission tomography (Neary et al., 1987). Recent studies on neurotransmitter systems suggest that levels of different neurotransmitters can influence personality traits (Mulder, 1992). For example, low levels of a metabolite of serotonin have been linked with violent, disinhibited and impulsive behaviour. Levels of this neurotransmitter have also been associated with behavioural disturbance in DAT (Chui, 1989). Certain neuropsychological tests have been found to be sensitive to frontal lobe pathology. Future studies including such tests would allow correlations between

Another possibility is that the same pathological or neurochemical changes which cause cognitive change are also responsible for personality change. This theory

would be supported by finding a strong correlation between cognitive decline and personality change.

These last two theories are proposing that personality change is a direct result of changes to areas of the brain. Another possibility is that personality change may be a direct result of cognitive decline. The finding of a strong correlation between personality change and cognitive decline may also be used to support this theory. The decrease seen in the Conscientiousness and Openness factors is probably largely a direct result of cognitive decline. Katzman and Karasu (1975) have suggested that there may be a decline in 'moral standards'. They considered that this could occur due to a 'loss of adaptive mechanisms dependent on memory, including the memory of the social consequences of these actions'. Many personality related behaviours are learned, particularly those related to social acceptability. It is possible that loss of memory could result in an increase in disagreeable traits. In the current study, disagreeable traits showed some association with cognitive decline which may support the idea that memory plays a part in socially appropriate behaviours. An explanation for the relationship between passive behaviours and cognitive decline proves more difficult to hypothesise. Perhaps passivity increases as the demented person becomes less able to interpret her or his environment and to know how to respond to it. It is also possible that the neurological changes which cause cognitive decline also affect this aspect of personality.

One final possibility is that personality changes may arise as a combination of the above possible causes: both biological and psychological. Given the complex nature of personality this explanation may be the most likely.

Unlike other reports, this study found that some demented people change in the opposite direction to the majority, becoming less passive or less disagreeable and emotional. While this finding may be attributable to methodological factors, it is more likely to be a real phenomenon. In dementia changes to the brain typically occur in the frontal and temporal lobes, with neuronal degeneration occurring in the limbic areas, and hippocampi and amygdaloid nuclei (Lishman, 1987). However, variants of the typical picture are sometimes seen and this may explain those subjects whose personalities appear to change in a different way to the majority. These individuals may be examples of a sub-type of DAT.

6.10 Future Directions

One of the aims of this study was to develop a short questionnaire which could be completed by informants and which would discriminate between people suffering

from DAT and non-cognitively impaired people. However, as there was quite a strong correlation between the personality traits studied here and cognitive decline, such a questionnaire would contribute little to the diagnostic procedure. It may be of more interest to investigate further those personality traits for which a small group of DAT sufferers appear to change in the opposite direction to the majority. A questionnaire containing adjectives from Scale 2 has been constructed and is shown in Appendix 6.2. The traits covered in this scale include those which are often seen as problem behaviours in dementia.

The relationship between personality change and cognitive decline is still unclear. This study found quite strong correlations between most of the personality traits assessed. However, other studies have not found such an association. Further research is necessary to clarify this relationship.

The most effective way to investigate both of these issues would be to follow DAT sufferers from the early stages of the disease process through to the advanced stage while collecting more comprehensive data about medication, physical illness and mood state. One of the problems that may be encountered in such a study may be finding enough subjects who are diagnosed as suffering from DAT in the mild stages. The majority of such people would not be clinically diagnosed until reaching a moderate stage of dementia, while many dementia sufferers may never receive a clinical diagnosis at all. This problem could be overcome by starting with a sample of non-cognitively impaired elderly people and measuring cognitive decline and personality change over time. A follow-up of the study described in Jacomb et al. (1994) will be doing this. The difficulty with such a study, however, is that the number of people who ultimately become demented may be quite small.

Consideration of the possible mechanism of personality change in DAT is at this stage largely theoretical. The use of modern neuroimaging techniques in association with the type of study described here could lead to concrete information on the association between brain changes and personality change in dementia. Certain neuropsychological tests have been found to be sensitive to frontal lobe pathology. Future studies including such tests would provide the opportunity to look at the relationship between personality change and frontal lobe functioning. Also, biochemical studies of changes in levels of neurotransmitters may provide information on specific biochemical pathways which may be involved in personality change in dementia. Such studies may provide leads for the development of drugs which may be used to moderate some of the distressing behavioural changes which occur.

6.11 Conclusion

The principal conclusions of this study are:

1. There is a global change in personality in DAT covering all five factors of personality: Extroversion, Agreeableness, Conscientiousness, Neuroticism and Openness to Experience. This change is highly correlated to cognitive decline. One major factor influencing the relationship between cognitive decline and personality change that was found in this study is the inclusion of traits likely to be strongly affected by cognitive decline. These traits are included in the Conscientiousness and Openness factors.
2. There are some personality traits which show a somewhat different pattern of change to the majority of those traits assessed in this study. These include 'disagreeable' and 'neurotic' traits and include many of the behaviours which are often seen as a problem to carers of dementia sufferers. The correlation with cognitive decline was significant but only to a moderate degree suggesting the involvement of independent neurobiological processes.
3. While the majority of DAT patients were reported to have become more disagreeable and neurotic, there was a small group who were reported to have changed in the opposite direction, becoming more agreeable and less neurotic. Methodological limitations may account for this difference, but it is possible that there is a subgroup of patients who experience a different pattern of change.

One of the aims of this study was to derive from the long questionnaire used here, a shorter instrument which would discriminate between DAT sufferers and non-cognitively impaired people. Given the strong correlation that was found between cognitive decline and personality change, such a questionnaire would contribute little to the existing body of diagnostic instruments. However, an instrument including only the 'disagreeable' and 'neurotic' traits has been developed. This could serve two purposes:

1. Changes in such characteristics may be particularly stressful for carers and this instrument could be used in investigating the relationship between personality change and carer stress.
2. This questionnaire could also be used to explore further the different patterns of change which were found in the current study.

Overall, it is hoped that this study will be a contribution towards the systematic description of the personality changes which occur in Alzheimer's disease.

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Appendix 2.1: Two case studies of people suffering from dementia.

Case 1

Mrs K is 81 years old and lives in the community with her husband. About 12 years ago she began to have some memory problems. Mrs K was very aware of the difficulties she was having and approached her doctor. She was given a series of tests including a brain scan. The doctors concluded that while some memory problems existed, she did not have dementia.

Over the next few years, Mrs K's memory gradually deteriorated until about five years ago when her family felt that she started to deteriorate more rapidly. Since this time, her memory has become considerably worse, she is having great difficulty with speech and is unable to say what she wants to say. Her speech has become slow and monotonous. She is inclined to wander. Sometimes she will leave the house to go somewhere and on arrival forget where she is, how she got there and how to get home. She forgets things that have happened within five minutes of the event. At this stage, she is still able to recognise those around her although the only people she sees are her family and she has no problems recognising objects. Mrs K is still aware of her problems. She appears depressed, is unsure of herself and has become clinging. Despite this, she has been unwilling to see a doctor again regarding her condition.

Until a few years ago, Mrs K was involved in a range of social activities including bowling and playing cards. Now, she is unwilling to see the people she used to associate with. Her grand daughter felt that this was because of her inability to speak and the feeling that her friends would just feel sorry for her.

Mrs K has become more demanding and impatient, frequently nagging people to do things. She tends to handle money foolishly, having been found carrying many thousands of dollars in her purse on one occasion. Her eating habits have changed considerably. Often she is willing to eat only certain foods such as cream cakes which she now stuffs into her mouth. She has become obsessive about some things, particularly hair nets of which she may wear about 14, both on her hair and sometimes over her face.

The major and most disruptive changes which her family have reported are suspicion and violence. Mrs K has had an unusual attitude to her husband for many years. For 50 years, she has insisted that he eat outside on newspaper because she thinks he is dirty, while she eats inside. Also, they have had separate bedrooms throughout these years. Mrs K is always hiding things and consequently losing them. She has now become extremely suspicious of her husband, repeatedly blaming him for stealing things that she has lost. This has led to violent behaviour on a number of occasions. A year ago she attacked her husband with a knife and although he was able to take the

knife from her, she hit him repeatedly, resulting in extensive bruising. Shortly after this, Mrs K had to consult a doctor regarding a physical problem. The family took this opportunity to discuss her mental deterioration. This resulted in admission to hospital for a full evaluation. At this time she was diagnosed as suffering from DAT and was put on major tranquillisers to control the violent behaviour. According to the family, her behaviour has become much more acceptable since this time.

Case 2

Mrs W is a 77 year old widow living alone in the community. About five or six years ago her family started to notice that she was having memory problems. For example, on a number of occasions she forgot where she had parked her car. Since then her memory has slowly deteriorated. Despite this, she has been unwilling to consult a doctor about these problems. Mrs W denies that she has any problems. Although she has never been clinically assessed, she attends a day care centre where the staff consider her to be suffering from dementia.

Mrs W no longer recognises her nieces and nephews and is having problems recognising words. Although she still is able to do some shopping locally, she gets confused handling money and can no longer pay her bills. She has had hallucinations and has been hearing things through the walls when she is alone in her house. Also, she has become suspicious and has taken to hiding her handbag when people visit and now develops 'hates' for certain people.

Although Mrs W was not seen as apathetic or withdrawn, she is less inclined to join in conversations than previously and does not take part in activities which she once enjoyed. She also complains of being lonely and her daughter believes that she is feeling sad. While she used to like doing things for other people, she is now much more self-centred and less flexible. She has also become a little more forthright and more inclined to tell people what she thinks of them. Her family have found this behaviour to be rather embarrassing on occasions. In comparison to Mrs K, this woman has shown no increase in irritability or hostility. Mrs W's daughter considers that her mother has retained basically the same personality and describes her as 'still a nice lady'. Mrs W attends a day care centre five days a week currently and is still able to manage at home alone, but her daughter does not feel that she will be able to do this for much longer.

Appendix 2.2: Goldberg's 100 synonym clusters with the component adjectives and the mean inter-item correlation for each cluster. (From Goldberg, 1990).

Factor pole/cluster	Adjectives included	Mean inter-item correlation
Extroversion +		
Spirit	Enthusiastic, spirited, vivacious, zestful	.45
Gregariousness	Extroverted, gregarious, sociable	.35
Playfulness	Adventurous, mischievous, playful, rambunctious	.25
Expressiveness	Communicative, expressive, verbal	.45
Spontaneity	Carefree, happy-go-lucky, spontaneous	.37
Unrestraint	Impetuous, uninhibited, unrestrained	.26
Energy level	Active, energetic, vigorous	.50
Talkativeness	Talkative, verbose, wordy	.42
Assertion	Assertive, dominant, forceful	.34
Animation	Demonstrative, exhibitionistic, flamboyant	.29
Courage	Brave, courageous, daring	.46
Self-esteem	Assured, confident, proud	.41
Candour	Direct, frank, straightforward	.49
Humour	Humorous, witty	.45
Ambition	Ambitious, enterprising, opportunistic	.36
Optimism	Cheerful, jovial, merry, optimistic	.38
Extroversion -		
Aloofness	Seclusive, unsociable, withdrawn	.48
Silence	Quiet, silent, untalkative	.57
Reserve	Detached, reserved, secretive	.35
Shyness	Bashful, shy, timid	.55
Inhibition	Inhibited, restrained	.42
Unaggressiveness	Unadventurous, unaggressive, uncompetitive	.29
Passivity	Docile, passive, submissive	.34
Lethargy	Lethargic, sluggish	.48
Pessimism	Bitter, joyless, melancholic, moody, morose, pessimistic, sombre	.35
Agreeableness +		
Cooperation	Accommodating, agreeable, cooperative, helpful, patient, peaceful, reasonable	.23
Amiability	Amiable, cordial, friendly, genial, pleasant	.30
Empathy	Considerate, kind, sympathetic, trustful, understanding	.36
Leniency	Lenient, uncritical, undemanding	.24
Courtesy	Courteous, diplomatic, polite, respectful, tactful	.39
Generosity	Benevolent, charitable, generous	.33
Flexibility	Adaptable, flexible, obliging	.21
Modesty	Humble, modest, selfless, unassuming	.17
Morality	Ethical, honest, moral, principled, sincere, truthful	.38
Warmth	Affectionate, compassionate, sentimental, warm	.38
Earthiness	Down-to-earth, earthy, folksy, homespun, simple	.16
Naturalness	Casual, easygoing, informal, natural, relaxed	.21
Agreeableness -		
Belligerence	Antagonistic, argumentative, combative, quarrelsome	.47
Overcriticalness	Faultfinding, harsh, unforgiving, unsympathetic	.33
Bossiness	Bossy, demanding, domineering, manipulative	.41
Rudeness	Abusive, disrespectful, impolite, impudent, rude, scornful	.34
Cruelty	Cruel, ruthless, vindictive	.48
Pomposity	Condescending, pompous, smug, snobbish	.39

Factor pole/cluster	Adjectives included	Mean inter-item correlation
Irritability	Crabby, cranky, irritable, grumpy	.62
Conceit	Boastful, conceited, egocentric, egotistical, vain	.50
Stubbornness	obstinate, stubborn	.38
Distrust	Cynical, distrustful, sceptical, suspicious	.36
Selfishness	Greedy, selfish, self-indulgent	.39
Callousness	Cold, impersonal, insensitive	.47
Surliness	Caustic, curt, flippant, gruff, surly	.44
Cunning	Crafty, cunning, devious, sly	.45
Prejudice	Bigoted, prejudiced	.51
Unfriendliness	Unfriendly, ungracious, unkind	.52
Volatility	Explosive, tempestuous, volatile	.42
Stinginess	Miserly, stingy	.51
Deceit	Deceitful, dishonest, underhanded, unscrupulous	.35
Thoughtlessness	Inconsiderate, tactless, thoughtless	.45
Conscientiousness +		
Organisation	Orderly, organised, systematic	.63
Efficiency	Concise, exacting, efficient, fastidious, self-disciplined	.24
Dependability	Dependable, reliable, responsible	.66
Precision	Meticulous, perfectionistic, precise	.46
Persistence	Industrious, persistent, tenacious, thorough	.26
Decisiveness	Decisive, deliberate, firm, purposeful	.22
Dignity	Dignified, formal, mannerly	.27
Predictability	Consistent, predictable, steady	.34
Thrift	Economical, thrifty	.51
Conventionality	Conventional, traditional	.40
Logic	Analytical, logical	.30
Conscientiousness -		
Disorganisation	Disorganised, haphazard, inefficient, scatterbrained, sloppy, unsystematic	.32
Negligence	Careless, negligent, undependable, unconscientious, unreliable	.43
Inconsistency	Erratic, inconsistent, unpredictable	.25
Forgetfulness	Forgetful, absent-minded	.67
Recklessness	Foolhardy, rash, reckless	.44
Aimlessness	Aimless, unambitious	.39
Sloth	Lazy, slothful	.36
Indecisiveness	Indecisive, wishy-washy	.33
Frivolity	Extravagant, frivolous, impractical	.34
Nonconformity	Nonconforming, rebellious, unconventional	.22
Neuroticism +		
Placidity	Passionless, unexcitable, unemotional	.36
Independence	Autonomous, independent, individualistic	.27
Neuroticism -		
Insecurity	Defensive, fretful, insecure, negativistic, self-critical, self-pitying.	.36
Fear	Anxious, fearful, nervous	.34
Instability	Temperamental, touchy, unstable	.40
Emotionality	Emotional, excitable	.40
Envy	Envious, jealous	.57
Gullibility	Gullible, naive, suggestible	.31
Intrusiveness	Intrusive, meddlesome, nosey	.46
Openness +		
Intellectuality	Contemplative, intellectual, introspective, meditative, philosophical	.36

Factor pole/cluster	Adjectives included	Mean inter-item correlation
Depth	Complex, deep	.46
Insight	Foresighted, insightful, perceptive	.35
Intelligence	Bright, intelligent, perceptive	.60
Creativity	Artistic, creative, imaginative, innovative, inventive	.53
Curiosity	Curious, inquisitive	.46
Sophistication	Cosmopolitan, cultured, refined, sophisticated, worldly	.37
Openness -		
Shallowness	Shallow, unintellectual, unreflective	.36
Unimaginativeness	Uncreative, unimaginative	.74
Imperceptiveness	Imperceptive, unobservant	.35
Stupidity	Dull, ignorant, unintelligent	.33

Appendix 3.1: Final 124 adjective personality questionnaire.

Personality and Behaviour Changes in the Elderly

This questionnaire contains a list of words which describe different aspects of personality and behaviour. We would like you to show us how you think your relative has changed in the last 10 years.

You will notice as you go through this questionnaire that there are a number of words which have similar meanings and also words with opposite meanings. We are aware of this, and need to have it designed this way.

You may feel that you have no way of knowing whether your relative has changed in regards to a particular characteristic. In this case, please circle **"don't know"**.

You may find that your relative's behaviour is very changeable. If you feel that it is impossible to decide whether a particular characteristic is now shown to a greater or lesser degree than previously, then circle **"don't know"**.

You may feel that some of the characteristics are ones which your relative has never shown and still does not show. In this case circle **"about the same"**.

Some of the words are unusual and you may not understand some of them. Many people don't. If you find a word you don't understand, please circle **"don't know"**. Please do not hesitate to use this category if you have difficulty with a word, as it is important for us to know which words are a problem.

***Finally, don't spend too long on any one word. Sometimes, first impressions are best.

1.	responsible	much less	a bit less	about the same	a bit more	much more	don't know
2.	thoughtless	much less	a bit less	about the same	a bit more	much more	don't know
3.	imaginative	much less	a bit less	about the same	a bit more	much more	don't know
4.	courteous	much less	a bit less	about the same	a bit more	much more	don't know
5.	steady	much less	a bit less	about the same	a bit more	much more	don't know
6.	sceptical	much less	a bit less	about the same	a bit more	much more	don't know
7.	unrestrained	much less	a bit less	about the same	a bit more	much more	don't know
8.	profound	much less	a bit less	about the same	a bit more	much more	don't know
9.	unsociable	much less	a bit less	about the same	a bit more	much more	don't know
10.	emotional	much less	a bit less	about the same	a bit more	much more	don't know
11.	decisive	much less	a bit less	about the same	a bit more	much more	don't know
12.	scatterbrained	much less	a bit less	about the same	a bit more	much more	don't know
13.	adaptable	much less	a bit less	about the same	a bit more	much more	don't know
14.	unreliable	much less	a bit less	about the same	a bit more	much more	don't know
15.	opportunistic	much less	a bit less	about the same	a bit more	much more	don't know
16.	obliging	much less	a bit less	about the same	a bit more	much more	don't know
17.	imperceptive	much less	a bit less	about the same	a bit more	much more	don't know
18.	cold	much less	a bit less	about the same	a bit more	much more	don't know
19.	complex	much less	a bit less	about the same	a bit more	much more	don't know

20.	independent	much less	a bit less	about the same	a bit more	much more	don't know
21.	reckless	much less	a bit less	about the same	a bit more	much more	don't know
22.	aimless	much less	a bit less	about the same	a bit more	much more	don't know
23.	unintellectual	much less	a bit less	about the same	a bit more	much more	don't know
24.	considerate	much less	a bit less	about the same	a bit more	much more	don't know
25.	obstinate	much less	a bit less	about the same	a bit more	much more	don't know
26.	creative	much less	a bit less	about the same	a bit more	much more	don't know
27.	rash	much less	a bit less	about the same	a bit more	much more	don't know
28.	communicative	much less	a bit less	about the same	a bit more	much more	don't know
29.	absent-minded	much less	a bit less	about the same	a bit more	much more	don't know
30.	disorganised	much less	a bit less	about the same	a bit more	much more	don't know
31.	meditative	much less	a bit less	about the same	a bit more	much more	don't know
32.	bright	much less	a bit less	about the same	a bit more	much more	don't know
33.	withdrawn	much less	a bit less	about the same	a bit more	much more	don't know
34.	ambitious	much less	a bit less	about the same	a bit more	much more	don't know
35.	fearful	much less	a bit less	about the same	a bit more	much more	don't know
36.	uncreative	much less	a bit less	about the same	a bit more	much more	don't know
37.	cranky	much less	a bit less	about the same	a bit more	much more	don't know
38.	unimaginative	much less	a bit less	about the same	a bit more	much more	don't know

39.	impersonal	much less	a bit less	about the same	a bit more	much more	don't know
40.	uninhibited	much less	a bit less	about the same	a bit more	much more	don't know
41.	active	much less	a bit less	about the same	a bit more	much more	don't know
42.	punctual	much less	a bit less	about the same	a bit more	much more	don't know
43.	consistent	much less	a bit less	about the same	a bit more	much more	don't know
44.	restrained	much less	a bit less	about the same	a bit more	much more	don't know
45.	grumpy	much less	a bit less	about the same	a bit more	much more	don't know
46.	spontaneous	much less	a bit less	about the same	a bit more	much more	don't know
47.	vigorous	much less	a bit less	about the same	a bit more	much more	don't know
48.	nervous	much less	a bit less	about the same	a bit more	much more	don't know
49.	industrious	much less	a bit less	about the same	a bit more	much more	don't know
50.	tactless	much less	a bit less	about the same	a bit more	much more	don't know
51.	reliable	much less	a bit less	about the same	a bit more	much more	don't know
52.	intelligent	much less	a bit less	about the same	a bit more	much more	don't know
53.	foolhardy	much less	a bit less	about the same	a bit more	much more	don't know
54.	perfectionistic	much less	a bit less	about the same	a bit more	much more	don't know
55.	inefficient	much less	a bit less	about the same	a bit more	much more	don't know
56.	forgetful	much less	a bit less	about the same	a bit more	much more	don't know
57.	persistent	much less	a bit less	about the same	a bit more	much more	don't know

58.	erratic	much less	a bit less	about the same	a bit more	much more	don't know
59.	seclusive	much less	a bit less	about the same	a bit more	much more	don't know
60.	meticulous	much less	a bit less	about the same	a bit more	much more	don't know
61.	careless	much less	a bit less	about the same	a bit more	much more	don't know
62.	insensitive	much less	a bit less	about the same	a bit more	much more	don't know
63.	tactful	much less	a bit less	about the same	a bit more	much more	don't know
64.	inhibited	much less	a bit less	about the same	a bit more	much more	don't know
65.	cautious	much less	a bit less	about the same	a bit more	much more	don't know
66.	insecure	much less	a bit less	about the same	a bit more	much more	don't know
67.	enthusiastic	much less	a bit less	about the same	a bit more	much more	don't know
68.	exacting	much less	a bit less	about the same	a bit more	much more	don't know
69.	sluggish	much less	a bit less	about the same	a bit more	much more	don't know
70.	pig-headed	much less	a bit less	about the same	a bit more	much more	don't know
71.	smart	much less	a bit less	about the same	a bit more	much more	don't know
72.	carefree	much less	a bit less	about the same	a bit more	much more	don't know
73.	negligent	much less	a bit less	about the same	a bit more	much more	don't know
74.	lazy	much less	a bit less	about the same	a bit more	much more	don't know
75.	unambitious	much less	a bit less	about the same	a bit more	much more	don't know
76.	individualistic	much less	a bit less	about the same	a bit more	much more	don't know

77.	kind	much less	a bit less	about the same	a bit more	much more	don't know
78.	vivacious	much less	a bit less	about the same	a bit more	much more	don't know
79.	lethargic	much less	a bit less	about the same	a bit more	much more	don't know
80.	irritable	much less	a bit less	about the same	a bit more	much more	don't know
81.	impetuous	much less	a bit less	about the same	a bit more	much more	don't know
82.	insightful	much less	a bit less	about the same	a bit more	much more	don't know
83.	verbal	much less	a bit less	about the same	a bit more	much more	don't know
84.	predictable	much less	a bit less	about the same	a bit more	much more	don't know
85.	dependable	much less	a bit less	about the same	a bit more	much more	don't know
86.	fretful	much less	a bit less	about the same	a bit more	much more	don't know
87.	purposeful	much less	a bit less	about the same	a bit more	much more	don't know
88.	happy-go-lucky	much less	a bit less	about the same	a bit more	much more	don't know
89.	flexible	much less	a bit less	about the same	a bit more	much more	don't know
90.	inconsistent	much less	a bit less	about the same	a bit more	much more	don't know
91.	prompt	much less	a bit less	about the same	a bit more	much more	don't know
92.	expressive	much less	a bit less	about the same	a bit more	much more	don't know
93.	inquisitive	much less	a bit less	about the same	a bit more	much more	don't know
94.	spirited	much less	a bit less	about the same	a bit more	much more	don't know
95.	fastidious	much less	a bit less	about the same	a bit more	much more	don't know

96. unpredicatable	much less	a bit less	about the same	a bit more	much more	don't know
97. contemplative	much less	a bit less	about the same	a bit more	much more	don't know
98. energetic	much less	a bit less	about the same	a bit more	much more	don't know
99. artistic	much less	a bit less	about the same	a bit more	much more	don't know
100. enterprising	much less	a bit less	about the same	a bit more	much more	don't know
101. precise	much less	a bit less	about the same	a bit more	much more	don't know
102. curious	much less	a bit less	about the same	a bit more	much more	don't know
103. passive	much less	a bit less	about the same	a bit more	much more	don't know
104. defensive	much less	a bit less	about the same	a bit more	much more	don't know
105. shallow	much less	a bit less	about the same	a bit more	much more	don't know
106. foresighted	much less	a bit less	about the same	a bit more	much more	don't know
107. stubborn	much less	a bit less	about the same	a bit more	much more	don't know
108. autonomous	much less	a bit less	about the same	a bit more	much more	don't know
109. docile	much less	a bit less	about the same	a bit more	much more	don't know
110. distrustful	much less	a bit less	about the same	a bit more	much more	don't know
111. polite	much less	a bit less	about the same	a bit more	much more	don't know
112. efficient	much less	a bit less	about the same	a bit more	much more	don't know
113. unobservant	much less	a bit less	about the same	a bit more	much more	don't know
114. suspicious	much less	a bit less	about the same	a bit more	much more	don't know

115. unreflective	much less	a bit less	about the same	a bit more	much more	don't know
116. careful	much less	a bit less	about the same	a bit more	much more	don't know
117. intellectual	much less	a bit less	about the same	a bit more	much more	don't know
118. inconsiderate	much less	a bit less	about the same	a bit more	much more	don't know
119. thorough	much less	a bit less	about the same	a bit more	much more	don't know
120. submissive	much less	a bit less	about the same	a bit more	much more	don't know
121. deliberate	much less	a bit less	about the same	a bit more	much more	don't know
122. excitable	much less	a bit less	about the same	a bit more	much more	don't know
123. sympathetic	much less	a bit less	about the same	a bit more	much more	don't know
124. anxious	much less	a bit less	about the same	a bit more	much more	don't know

Appendix 4.1: Diagnostic checklist based on DSM-III-R criteria for primary degenerative dementia of the Alzheimer type.

Checklist for Diagnosis of Dementia of the Alzheimer Type.

DSM-III-R dementia

	yes	no	don't know
A. Impairment of short-term memory and of long term memory.....	☐	☐	☐
B. The following symptoms present?			
1) Impaired abstract thinking.....	☐	☐	☐
2) Impaired judgement.....	☐	☐	☐
3) Impairment of higher cortical function.....	☐	☐	☐
4) Personality change.....	☐	☐	☐
One or more symptoms checked in B?.....			
C. Disturbance in A. & B. significantly interferes with work or usual social activities, or relationship with others?.....	☐	☐	☐
D. Patient delirious?.....	☐	☐	☐
E. Evidence of a specific organic factor judged to be aetiologically related to the above; any non-organic factor, such as major depression, accounting for the cognitive impairment?.....	☐	☐	☐
Criteria satisfied for DSM-III-R dementia?..... (Patient scored 'yes' to A., B. & C. and 'no' to D. & E.)	☐	☐	☐

Diagnostic Criteria for Primary Degenerative dementia of the Alzheimer Type

	yes	no
A. Dementia.....	☐	☐
B. Insidious onset with a generally progressive deteriorating course.....	☐	☐
C. Exclusion of all other specific causes of dementia by history, physical examination and laboratory tests.....	☐	☐

Severity Rating

Mild: Cognitive impairment sufficient to interfere with everyday activities, but independent living still possible.....	☐	☐
Moderate: Cognitive impairment which is a serious handicap to independent living.....	☐	☐
Severe: Cognitive impairment severe, not able to function in the community without close supervision.....	☐	☐

Appendix 4.2: Letter to first informant of DAT patient .



The Australian National University

NH&MRC Social Psychiatry Research Unit

Canberra ACT 0200
Australia

Telephone (06) 249 2741
International +61 6 249 2741
Fax (06) 249 0733

Dear Carer,

Thank you for helping me with my study on personality changes in elderly people.

As part of this study, I would also like to ask a second person if they would be willing to complete these questionnaires about your relative. If there is someone besides yourself who has known your relative well for 10 years or more and you believe would be willing to complete these questionnaires, could you please write their name and address on the front sheet of the questionnaire.

I give my assurance that anything you have told me about your relative is in the strictest confidence, and that we undertake to honour this. Neither your name or that of your relative will be recorded in the pages containing your answers.

If you would like to ask any questions at a later date please contact me on (06)2492741 or write to me at the above address. Thank you again for your help. It is greatly appreciated.

Yours sincerely

Trish Jacomb

Appendix 4.3a: Explanatory statement to informants of DAT patients recruited from the Caulfield Medical Centre.

Research Project: Personality Changes in People with Memory or Concentration Problems

Chief Investigators: Professor Scott Henderson and Ms Patricia Jacomb, Social Psychiatry Research Unit, The Australian National University

This research is being carried out in collaboration with Dr Kathryn Hall and colleagues from the Memory Clinic, Caulfield General Medical Centre

Personality changes occur frequently in people with memory or concentration problems. Such changes can be disabling to sufferers and very distressing to carers. Despite this, there has been very little research into these changes. The aim of this research is to develop a questionnaire which will enable clinicians and researchers to measure more accurately, the specific personality changes which occur when memory or concentration problems develop.

It is hoped that by having such a measure, more effective coping strategies for carers may be developed. It may also provide a better means of assessing the effectiveness of certain drugs in alleviating distressing changes.

Your relative or friend has been given an Explanatory Statement and has signed a consent form allowing you to provide information about him or her. This involves asking you to complete 3 questionnaires about the following:

1. Some brief information about your relative or friend.
2. Personality changes which you may have observed in this person since developing memory or concentration problems.
3. Changes which you may have observed in their memory and concentration in the last 10 years.

These questionnaires will be given to you to complete while your relative or friend is seen by the doctors.

We would also be asking if you could provide the name of another person who has known the patient for 10 years and may be willing to complete the same questionnaires. We will also be asking the doctor who is seeing your relative or friend to complete a checklist of symptoms. This will indicate to us whether they fall into the diagnostic category necessary for this study.

These questionnaires take about 30 minutes to complete. We will not be asking you to participate in any other way.

If you are willing to participate we will ask you to sign a consent form.

If you want further information before agreeing to participate, you can speak to the doctor who is seeing your relative or friend or you can telephone Trish Jacomb on (06)2492741.

All information you give us will be treated strictly confidentially. The sheet which Appendix 4.3a (continued)

Appendix 4.3a (continued)

you complete with your name and, if possible, the name of another contact, will be

removed from the questionnaires as soon as it is received at this office . This front sheet will then be kept in a safe, away from the questionnaires which have all been given a unique number. The information will not be added to the patient's medical records. The only people who will have access to the information are the chief investigators and Dr Tony Jorm, another investigator on this project.

As these questions ask about changes which you have observed in your relative or friend, there is a possibility that you may find some of the questions disturbing. If you do find the questionnaires disturbing, please discuss this with one of the staff at the clinic.

You are under no obligation to take part in this study. However your help would be greatly appreciated. If you do decide to take part and you would like the results of the study, please indicate this on the front sheet.

Ms P Jacomb

Professor A S Henderson

Dr K Hall

Appendix 4.3b: Explanatory statement for DAT patients recruited from the Caulfield Medical Centre.

**Research Project: Personality Changes in People with Memory
or Concentration Problems**

Chief Investigators: Professor Scott Henderson and Ms Patricia Jacomb, Social Psychiatry Research Unit, The Australian National University.

This research is being carried out in collaboration with Dr Kathryn Hall and colleagues from the Memory Clinic, Caulfield General Medical Centre.

Personality changes occur frequently in people who have developed problems with their memory or concentration. Such changes can be distressing for both the sufferer and the family. Despite this, there has been very little research into these changes. The aim of this research is to develop a questionnaire which will enable clinicians and researchers to measure more accurately, the specific personality changes which occur when memory or concentration problems develop. This may provide a better means of assessing the effectiveness of certain drugs in alleviating distressing changes.

If you are willing to participate in this study, we would be asking the friend or relative who has accompanied you, to complete 3 questionnaires about the following:

1. Some brief information about your education, age and occupation
2. Personality changes which they may have observed in you since developing memory problems
3. Changes which they may have observed in your memory and concentration in the last 10 years.

These questionnaires will be given to them to complete while you are seen by the doctors.

We would also be asking if your relative or friend could provide the name of another person who has known you for 10 years and may be willing to complete the same questionnaires. We will also be asking the doctor who is seeing you to complete a form which asks a few questions about your health.

We will not be asking you to participate in any other way. If you want further information before agreeing to participate, you can speak to your doctor or you can telephone Trish Jacomb on (06)2492741.

All information your friend or relative gives us will be treated strictly confidentially. The sheet which they complete with your name, their name and, if possible, the name of another contact, will be removed from the questionnaires as soon as it is received at this office. This front sheet will then be kept in a safe, away from the questionnaires which have all been given a unique number. The information will not be added to your medical records. The only people who will have access to the information are the chief investigators and Dr Tony Jorm, another investigator on this project.

You are under no obligation to take part in this study. However your help would be greatly appreciated.

Ms P Jacomb

Professor A.S. Henderson

Dr K Hall

Appendix 4.3c: Consent form to be signed by informant of DAT patient recruited from the Caulfield Medical Centre.

CONSENT FORM

Title of Research Project: Personality Changes in People with Memory or Concentration Problems

1. Investigator

I,.....have fully explained the aims and procedures of the research project to

.....

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

2. Relative or Friend of Patient

I,.....(print name)

of.....

.....

agree to take part in the research project on personality changes in people suffering from memory and concentration problems, being conducted by..... who has given me a copy of the explanatory letter.

I understand that I am free to withdraw from the project at any time.

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

Appendix 4.3d: Consent form to be signed by DAT patients recruited from the
Caulfield Medical Centre

CONSENT FORM

Title of Research Project: Personality Changes in People with Memory
or Concentration Problems

1. Investigator

I.....have fully explained the aims and
procedures of the research project to

.....

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

2. Patient

I.....(print name)

of.....

.....

agree to the following;

1. The person who has accompanied me to complete questionnaires asking about
ways in which I have changed in the last 10 years.

2. A second person who has known me for 10 years to complete the same
questionnaires

3. The doctor who has attended me to complete a form which asks brief questions
about my state of health.

I realise that this research is being conducted by

.....who has fully explained the research to me and given
me a copy of the Explanatory Statement.

I understand that I am free to withdraw from the project at any time.

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

Appendix 4.4: Letter sent to community residents asking them if they would be willing to participate in the study.



The Australian National University
NH&MRC Social Psychiatry Research Unit

Canberra ACT 0200
 Australia

Telephone (06) 249 2741
 International +61 6 249 2741
 Fax (06) 249 0733

date

Dear,

We would like to ask for your help in a medical research study that we are conducting into the health and well-being of older persons in Canberra and Queanbeyan. Its object is to learn more about various changes in behaviour that may occur as people age. You can help us greatly by giving us a little of your time.

We would need to spend about 1 hour with you asking some questions about your memory and concentration and having you fill out a questionnaire which looks at ways in which you may have changed in the last 10 years.

We would also like to speak to a close relative or someone who has known you very well for the last 10 years.

Your name was selected randomly from those people over 60 years on the Electoral Roll. The use of this sample has been approved by the Privacy Commissioner.

We give our assurance that anything you tell us about yourself is in the strictest confidence. We undertake to honour this. Your name will not be recorded in the pages of your research record.

Trish Jacomb will telephone you shortly to explain the study more fully and to ask if you will be kind enough to allow her to interview you. We very much hope that you will help us by agreeing to take part.

Yours sincerely,

Trish Jacomb

Professor A S Henderson

Appendix 4.5a: Demographic questionnaire given to the first informant of the DAT patients.

I.D.....

These questionnaires ask about changes you may have observed in your relative over the past 10 years. But first, we need to know something about him/her.

1. How old is your friend or relative right now?.....
2. How long have you known him/her?.....
3. What was this person's main occupation before he/she retired?
.....
.....
4. What was the main occupation of this person's husband/wife?
.....
.....
5. How old was this person when he/she left school?.....
6. Highest qualification (or degree) obtained:
 1. No schooling
 2. Attended Primary School
 3. Completed Primary School
 4. Attended Secondary School
 5. Intermediate, Junior or School Certificate; School Boards (C Certificate)
 6. Matric, Higher School or Leaving Certificate; School Boards (A and B Certificate)
 7. Attended Tertiary College or University
 8. Completed Tertiary College or University (two years or more)
7. How old were you when you left school?.....
8. What is your relationship to him/her?
 1. Husband or wife
 2. Son or daughter
 3. Brother or sister
 4. Other relative
 5. Friend

Appendix 4.5a (continued)

9. How long has it been since you lived with this person?
1. Never lived with him/her
 2. It has been more than 10 years since I lived with him/her
 3. It has been less than 10 years since I lived with him/her
 4. I am currently living with him/he
10. Where is this person currently living?
1. Nursing home
 2. hostel
 3. Hospital
 4. In the community
11. Has your relative ever been diagnosed as suffering from dementia or Alzheimer's Disease by a medical practitioner?
1. No
 2. Yes (Please specify disease).....
12. If 'Yes', who made the diagnosis?
1. General practitioner
 2. Specialist
 3. Assessment Clinic
 4. Other (Please specify).....
13. Your relative is:
1. Male
 2. Female
14. You are:
1. Male
 2. Female
15. Name /area of support group which you attend:

Appendix 4.5b: Demographic questionnaire given to the second informant of the DAT patients.

I.D.....

Before completing the questionnaires on personality and memory changes which you have observed in your relative or friend, I would like to ask a few general questions.

1. How long have you known your relative or friend?.....

2. How often do you see this person?

- live with them
- daily
- once a week or more
- monthly
- less than once a month

3. What is your relationship to this person?

- husband/wife
- son/daughter
- son/daughter-in-law
- other relative
- friend
- other

Appendix 4.5c: Demographic questions for controls.

I.D.....

Some Preliminary Questions

1. How old are you now?.....

2. What was your main occupation beofer you retired?

.....
.....
.....

3. What was the main occupation of your husband/wife?

.....
.....
.....

4. How old were you when you left school?.....

5. What is the highest qualification you have obtained?

- 1. No schooling.
- 2. Attended primary school
- 3. Completed primary school
- 4. Attended secondary school
- 5. Intermediate, Junior or School certificates; School Boards (C Certificate)
- 6. Matric, Higher School or Leaving Certificate; School Boards (A and B Certificate)
- 7. Attended Tertiary College or University
- 8. Completed Tertiary College or University (two years or more)

Appendix 4.5d: Demographic questionnaire for the informant of the controls.

I.D.....

Some Preliminary Questions

1. What is your relationship to this person?

- husband/wife
- son/daughter
- son/daughter-in-law
- other relative
- friend
- other

2. How long have you known your relative or friend?.....

3. How long is it since you lived with?.....

- 1. Never lived with him/her
- 2. It has been more than 10 years since I lived with him/her
- 3. It has been less than 10 years since I lived with him/her
- 4. I am currently living with him/her

4. Has this person ever been diagnosed as suffering from Alzheimer's disease or dementia?

- 1. Yes
- 2. No

5. You are:

- 1. Male
- 2. Female

6. How old were you when you left school?.....

Appendix 4.5e: Demographic questionnaire given to NSW Alzheimer's Association carers.

These questionnaires ask about changes you may have observed in your relative over the past 10 years. But first, we need to know something about him/her.

1. How old is your friend or relative right now?.....
2. How long have you known him/her?.....
3. What was this person's main occupation before he/she retired?
.....
.....
4. What was the main occupation of this person's husband/wife?
.....
.....
5. How old was this person when he/she left school?.....
6. Highest qualification (or degree) obtained:
 1. No schooling
 2. Attended Primary School
 3. Completed Primary School
 4. Attended Secondary School
 5. Intermediate, Junior or School Certificate; School Boards (C Certificate)
 6. Matric, Higher School or Leaving Certificate; School Boards (A and B Certificate)
 7. Attended Tertiary College or University
 8. Completed Tertiary College or University (two years or more)
7. How old were you when you left school?.....
8. What is your relationship to him/her?
 1. Husband or wife
 2. Son or daughter
 3. Brother or sister
 4. Other relative
 5. Friend

9. How long has it been since you lived with this person?

1. Never lived with him/her
2. It has been more than 10 years since I lived with him/her
3. It has been less than 10 years since I lived with him/her
4. I am currently living with him/he

10. Where is this person currently living?

1. Nursing home
2. hostel
3. Hospital
4. In the community

11. Your relative is:

1. Male
2. Female

12. You are:

1. Male
2. Female

Appendix 4.6: The IQCODE.

Now we want you to remember what your friend or relative was like 10 years ago and to compare it with what he/she is like now. 10 years ago was in 1982. Below are situations where this person has to use his/her memory or intelligence and we want you to indicate whether this has improved, stayed the same, or got worse in that situation over the past 10 years. Note the importance of comparing his/her present performance with 10 years ago. So if 10 years ago this person always forgot where he/she had left things, and he/she still does, then this would be considered "Hasn't changed much". Please indicate the changes you have observed by circling the appropriate answer.

Compared with 10 years ago how is this person at:

	1	2	3	4	5
1. Recognizing the faces of family and friends	Much better	A bit better	Not much change	A bit worse	Much worse
2. Remembering the names of family and friends	Much better	A bit better	Not much change	A bit worse	Much worse
3. Remembering things about family and friends e.g. occupations, birthdays, addresses	Much better	A bit better	Not much change	A bit worse	Much worse
4. Remembering things that have happened recently	Much better	A bit better	Not much change	A bit worse	Much worse
5. Recalling conversations a few days later	Much better	A bit better	Not much change	A bit worse	Much worse
6. Forgetting what s/he wanted to say in the middle of a conversation	Much better	A bit better	Not much change	A bit worse	Much worse

	1	2	3	4	5
7. Remembering her/his address and telephone number	Much better	A bit better	Not much change	A bit worse	Much worse
8. Remembering what day and month it is	Much better	A bit better	Not much change	A bit worse	Much worse
9. Remembering where things are usually kept	Much better	A bit better	Not much change	A bit worse	Much worse
10. Remembering where to find things which have been put in a different place from usual	Much better	A bit better	Not much change	A bit worse	Much worse
11. Adjusting to any change in her/his day-to-day routine	Much better	A bit better	Not much change	A bit worse	Much worse
12. Knowing how to work familiar machines around the house	Much better	A bit better	Not much change	A bit worse	Much worse
13. Learning to use a new gadget or machine around the house	Much better	A bit better	Not much change	A bit worse	Much worse
14. Learning new things in general	Much better	A bit better	Not much change	A bit worse	Much worse
15. Remembering things that happened to her/him when s/he was young	Much better	A bit better	Not much change	A bit worse	Much worse
16. Remembering things s/he learned when s/he was young	Much better	A bit better	Not much change	A bit worse	Much worse

	1	2	3	4	5
17. Understanding the meaning of unusual words	Much better	A bit better	Not much change	A bit worse	Much worse
18. Understanding magazine or newspaper articles	Much better	A bit better	Not much change	A bit worse	Much worse
19. Following a story in a book or on TV	Much better	A bit better	Not much change	A bit worse	Much worse
20. Composing a letter to friends or for business purposes	Much better	A bit better	Not much change	A bit worse	Much worse
21. Knowing about important historical events of the past	Much better	A bit better	Not much change	A bit worse	Much worse
22. Making decisions on everyday matters	Much better	A bit better	Not much change	A bit worse	Much worse
23. Handling money for shopping	Much better	A bit better	Not much change	A bit worse	Much worse
24. Handling financial matters, e.g. the pension, dealing with the bank	Much better	A bit better	Not much change	A bit worse	Much worse
25. Handling other every day arithmetic problems, e.g. knowing how much food to buy, knowing how long between visits from family or friends	Much better	A bit better	Not much change	A bit worse	Much worse
26. Using her/his intelligence to understand what's going on and to reason things through	Much better	A bit better	Not much change	A bit worse	Much worse

Appendix 4.7: Letter sent to second informant of DAT patients.*The Australian National University***NH&MRC Social Psychiatry Research Unit**

Canberra ACT 0200
Australia

Telephone (06) 249 2741
International +61 6 249 2741
Fax (06) 249 0733

date

Dear.....,

I am currently carrying out a study looking at personality and behaviour changes in the elderly, particularly those with memory problems.

I was given your name by (first informant) when she brought her husband for assessment by At that time she completed some questionnaires for me and provided your name as someone who knew her husband well and may be willing to complete the same questionnaires. I have enclosed copies of these questionnaires and would appreciate it if you could complete them regarding changes that you may have noticed in (patient) since he developed memory problems. I have enclosed a Reply Paid envelope for your convenience.

Thank you for giving this your time. Your willingness to help with this research would be greatly appreciated.

Yours sincerely,

Trish Jacomb

Appendix 4.8: Letter given to the controls at the time of the interview assuring them of confidentiality.



The Australian National University

NH&MRC Social Psychiatry Research Unit

Canberra ACT 0200
Australia

Telephone (06) 249 2741
International +61 6 249 2741
Fax (06) 249 0733

date

Dear,

Thank you for helping me with my study on behaviour changes in older people.

I give my assurance that anything you have told me about yourself is in the strictest confidence, and that we undertake to honour this. Your name will not be recorded in the pages containing your answers.

If you would like to ask any questions at a later date, please contact me on 2492741. Thank you again for your help. It is greatly appreciated.

Yours sincerely

Trish Jacomb

Appendix 4.9a: Letter sent to the NSW Alzheimer's Association support group leaders asking for their help in distributing questionnaires to their members.



The Australian National University
NH&MRC Social Psychiatry Research Unit

Canberra ACT 0200
 Australia

Telephone (06) 249 2741
 International +61 6 249 2741
 Fax (06) 249 0733

Dear

I am currently undertaking research into personality changes which occur in dementia.

As you will be aware, such changes can be very distressing to carers and disabling to sufferers. However, despite this very little research has been done in this area. The NSW Alzheimer's Association has agreed to help me with this research by allowing questionnaires to be distributed to members of the support groups. This follows consideration of my research proposal by the association's Research Policy Committee, chaired by Professor Henry Brodaty.

You will have been given a number of sets of questionnaires. Each set contains the following:

1. A covering letter
2. Some general demographic questions
3. A questionnaire designed to look at personality changes which may have occurred since developing dementia.
4. The IQCODE. This is a questionnaire which asks about memory changes in the dementia sufferer in the last 10 years.
5. A Reply-paid envelope

The questionnaires take about 30 to 40 minutes to complete.

I would appreciate it if you would ask those members of your group who are caring for someone with dementia at home if they would be willing to take a set of questionnaires, complete them for me and return them to me in the reply-paid envelope.

I am not asking people to put their names on the questionnaires. However, I would appreciate it if they could tell me the name of the group which they attend.

Attached to this sheet is a form in which I ask you to write down the name of your group and the total number of people to whom you have given these questionnaires. This will enable me, at the completion of the study, to determine the response rate. There is also a reply-paid envelope for you to post this information to me.

Your help with this research project is greatly appreciated.

Yours sincerely

Trish Jacomb

Appendix 4.9b: Questions completed by the NSW Alzheimer's Association support group leaders.

Name (or region) of support group.....

Date (or dates) of handing out questionnaires.....

Number of people who took questionnaires.....

Appendix 4.9c: Letter given to members of the NSW Alzheimer's Association support groups when they completed questionnaires.



The Australian National University

NH&MRC Social Psychiatry Research Unit

Canberra ACT 0200
Australia

Telephone (06) 249 2741
International +61 6 249 2741
Fax (06) 249 0733

Dear Carer,

Thank you for helping me with my study on personality changes in dementia. As you, no doubt, are aware personality changes often occur in dementia and can be very distressing for carers and disabling for sufferers. If more can be learned about the specific personality changes which occur, it may be possible to develop new and better ways for carers to cope with these changes.

Please note when you are completing the questionnaires that there are questions on both sides of the paper.

If you have any queries about this research you can telephone me on (06)2492741 or write to me at the above address.

Thank you again for your help.

Yours sincerely

Trish Jacomb

Appendix 5.1: Correlation between adjectives within the same clusters after removing those adjectives with a high percentage of missing data.

- - Correlation Coefficients - -			
Spirit			
Enthusiastic	1.0000 (245) P= .000	.5247 (208) P= .000	.5907 (228) P= .000
Vivacious	.5247 (208) P= .000	1.0000 (221) P= .000	.5881 (208) P= .000
Spirited	.5907 (228) P= .000	.5881 (208) P= .000	1.0000 (238) P= .000
Expressiveness			
Communicative	1.0000 (260) P= .000	.4913 (252) P= .000	.6121 (241) P= .000
Verbal	.4913 (252) P= .000	1.0000 (258) P= .000	.4738 (238) P= .000
Expressive	.6121 (241) P= .000	.4738 (238) P= .000	1.0000 (245) P= .000
Spontaneity			
Spontaneous	1.0000 (233) P= .000	.5075 (221) P= .000	.3757 (221) P= .000
Carefree	.5075 (221) P= .000	1.0000 (242) P= .000	.5932 (231) P= .000
Happy-go-lucky	.3757 (221) P= .000	.5932 (231) P= .000	1.0000 (248) P= .000
Energy Level			
Active	1.0000 (264) P= .000	.7046 (244) P= .000	.7175 (255) P= .000
Vigorous	.7046 (244) P= .000	1.0000 (245) P= .000	.6931 (241) P= .000
Energetic	.7175 (255) P= .000	.6931 (241) P= .000	1.0000 (256) P= .000
Ambition			
Ambitious	1.0000 (236) P= .000	.6163 (205) P= .000	
Enterprising	.6163 (205) P= .000	1.0000 (221) P= .000	
Aloofness			
Unsociable	1.0000 (263) P= .004	.1818 (254) P= .004	.01 (219) P= .855
Withdrawn	.1818 (254) P= .004	1.0000 (257) P= .000	.3934 (215) P= .000
Seclusive	.0124 (219) P= .855	.3934 (215) P= .000	1.0000 (220) P= .000

Passivity

Passive	1.0000 (226) P= .000	.4002 (220) P= .000	.4591 (199) P= .000
Docile	.4002 (220) P= .000	1.0000 (254) P= .000	.5908 (215) P= .000
Submissive	.4591 (199) P= .000	.5908 (215) P= .000	1.0000 (218) P= .000

Lethargy

Sluggish	1.0000 (242) P= .000	.5747 (229) P= .000	
Lethargic	.5747 (229) P= .000	1.0000 (245) P= .000	

Empathy

Considerate	1.0000 (256) P= .000	.6194 (249) P= .000	.7036 (240) P= .000
Kind	.6194 (249) P= .000	1.0000 (257) P= .000	.5921 (244) P= .000
Sympathetic	.7036 (240) P= .000	.5921 (244) P= .000	1.0000 (248) P= .000

Courtesy

Courteous	1.0000 (258) P= .000	.3362 (232) P= .000	.5614 (251) P= .000
Tactful	.3362 (232) P= .000	1.0000 (238) P= .000	.4271 (233) P= .000
Polite	.5614 (251) P= .000	.4271 (233) P= .000	1.0000 (260) P= .000

Flexibility

Adaptable	1.0000 (252) P= .000	.4084 (247) P= .000	.5443 (232) P= .000
Obliging	.4084 (247) P= .000	1.0000 (259) P= .000	.4077 (236) P= .000
Flexible	.5443 (232) P= .000	.4077 (236) P= .000	1.0000 (241) P= .000

Irritability

Cranky	1.0000 (258) P= .000	.7594 (250) P= .000	.5806 (252) P= .000
Grumpy	.7594 (250) P= .000	1.0000 (252) P= .000	.5678 (248) P= .000
Irritable	.5806 (252) P= .000	.5678 (248) P= .000	1.0000 (256) P= .000

Stubbornness

Obstinate	1.0000 (254) P= .000	.4860 (231) P= .000	.4371 (243) P= .000
Pig-headed	.4860 (231) P= .000	1.0000 (239) P= .000	.6345 (231) P= .000
Stubborn	.4371 (243) P= .000	.6345 (231) P= .000	1.0000 (251) P= .000

Distrust

Distrustful	1.0000 (233) P= .000	.4755 (225) P= .000	
Suspicious	.4755 (225) P= .000	1.0000 (242) P= .000	

Callousness

Cold	1.0000 (241) P= .005	.1856 (223) P= .005	
Insensitive	.1856 (223) P= .005	1.0000 (238) P= .005	

Thoughtlessness

Thoughtless	1.0000 (260) P= .024	.1474 (233) P= .024	.1177 (245) P= .066
Tactless	.1474 (233) P= .024	1.0000 (239) P= .000	.2665 (231) P= .000
Inconsiderate	.1177 (245) P= .066	.2665 (231) P= .000	1.0000 (251) P= .000

Efficiency

Exacting	1.0000 (216) P= .000	.3612 (202) P= .000	.2647 (211) P= .000
Fastidious	.3612 (202) P= .000	1.0000 (230) P= .000	.3803 (228) P= .000
Efficient	.2647 (211) P= .000	.3803 (228) P= .000	1.0000 (254) P= .000

Dependability

Responsible	1.0000 (264) P= .000	.6144 (249) P= .000	.4710 (257) P= .000
Reliable	.6144 (249) P= .000	1.0000 (252) P= .000	.6026 (249) P= .000
Dependable	.4710 (257) P= .000	.6026 (249) P= .000	1.0000 (260) P= .000

Precision

Perfectionistic	1.0000 (237) P= .000	.6009 (211) P= .000	.5210 (218) P= .000
Meticulous	.6009 (211) P= .000	1.0000 (226) P= .000	.5107 (209) P= .000
Precise	.5210 (218) P= .000	.5107 (209) P= .000	1.0000 (235) P= .000

Persistence

Industrious	1.0000 (247) P= .983	-.0014 (225) P= .983	.5887 (234) P= .000
Persistent	-.0014 (225) P= .983	1.0000 (236) P= .691	-.0267 (224) P= .691
Thorough	.5887 (234) P= .000	-.0267 (224) P= .691	1.0000 (243)

Caution

Cautious	1.0000 (245) P= .000	.3152 (238) P= .000	
Careful	.3152 (238) P= .000	1.0000 (256)	

Punctuality

Punctual	1.0000 (232) P= .000	.6435 (224) P= .000	
Prompt	.6435 (224) P= .000	1.0000 (246)	

Decisiveness

Decisive	1.0000 (249) P= .000	.5742 (214) P= .000	.3132 (204) P= .000
Purposeful	.5742 (214) P= .000	1.0000 (224) P= .000	.3933 (198) P= .000
Deliberate	.3132 (204) P= .000	.3933 (198) P= .000	1.0000 (217)

Predictability

Steady	1.0000 (239) P= .000	.4719 (219) P= .000	.4686 (225) P= .000
Consistent	.4719 (219) P= .000	1.0000 (241) P= .000	.3778 (233) P= .000
Predictable	.4686 (225) P= .000	.3778 (233) P= .000	1.0000 (250)

Disorganisation

Scatterbrained	1.0000 (222) P= .000	.3582 (216) P= .000	.2572 (204) P= .000
Disorganised	.3582 (216) P= .000	1.0000 (254) P= .000	.3416 (232) P= .000
Inefficient	.2572 (204) P= .000	.3416 (232) P= .000	1.0000 (240)

Negligence

Unreliable	1.0000 (251) P= .037	.1381 (229) P= .037	.0739 (221) P= .274
Careless	.1381 (229) P= .037	1.0000 (241) P= .000	.3961 (217) P= .000
Negligent	.0739 (221) P= .274	.3961 (217) P= .000	1.0000 (230)

Inconsistency

Erratic	1.0000 (239) P= .000	.3178 (227) P= .000	.2466 (230) P= .000
Inconsistent	.3178 (227) P= .000	1.0000 (245) P= .000	.3779 (235) P= .000
Unpredictable	.2466 (230) P= .000	.3779 (235) P= .000	1.0000 (249) P= .000

Forgetfulness

Absent-minded	1.0000 (257) P= .000	.4757 (253) P= .000	
Forgetful	.4757 (253) P= .000	1.0000 (260) P= .000	

Aimlessness

Aimless	1.0000 (238) P= .000	.3388 (215) P= .000	
Unambitious	.3388 (215) P= .000	1.0000 (232) P= .000	

Insecurity

Insecure	1.0000 (254) P= .000	.3973 (232) P= .000	.2827 (227) P= .000
Fretful	.3973 (232) P= .000	1.0000 (242) P= .000	.3131 (220) P= .000
Defensive	.2827 (227) P= .000	.3131 (220) P= .000	1.0000 (235) P= .000

Fear

Fearful	1.0000 (246) P= .000	.6070 (235) P= .000	.4545 (239) P= .000
Nervous	.6070 (235) P= .000	1.0000 (251) P= .000	.4279 (245) P= .000
Anxious	.4545 (239) P= .000	.4279 (245) P= .000	1.0000 (258) P= .000

Emotionality

Emotional	1.0000 (259) P= .005	.1785 (241) P= .005	
Excitable	.1785 (241) P= .005	1.0000 (247) P= .005	

Intelligence

Bright	1.0000 (257) P= .000	.5626 (246) P= .000	.5479 (243) P= .000
Intelligent	.5626 (246) P= .000	1.0000 (255) P= .000	.7219 (242) P= .000
Smart	.5479 (243) P= .000	.7219 (242) P= .000	1.0000 (250) P= .000

Creativity

Imaginative	1.0000 (246) P= .000	.3356 (230) P= .000	.1845 (215) P= .007
Creative	.3356 (230) P= .000	1.0000 (244) P= .000	.5626 (218) P= .000
Artistic	.1845 (215) P= .007	.5626 (218) P= .000	1.0000 (225)

Curiosity

Inquisitive	1.0000 (244) P= .000	.7937 (238) P= .000	
Curious	.7937 (238) P= .000	1.0000 (246)	

Unimaginativeness

Uncreative	1.0000 (239) P= .000	.3880 (220) P= .000	
Unimaginative	.3880 (220) P= .000	1.0000 (234)	

Appendix 5.2: Correlations between the clusters and the rotated factor matrix using a 3 factor solution.

	SPIRIT	EXPRESSIVENESS	SPONTANEITY	ENERGY LEVEL	AMBITION	ALOOFNESS	INHIBITION
SPIRIT	1.00000						
EXPRESSIVENESS	.64934	1.00000					
SPONTANEITY	.53960	.48784	1.00000				
ENERGY LEVEL	.62710	.45736	.48410	1.00000			
AMBITION	.66187	.66048	-.39155	-.30762	1.00000		
ALOOFNESS	-.43907	-.41716	.05265	.05258	.14932	1.00000	
INHIBITION	.10277	.03693	-.02545	-.08120	-.03746	.09170	1.00000
PASSIVITY	-.11818	-.09458	-.45035	-.56346	-.41526	.47580	.37122
LETHARGY	-.48082	-.41836	-.45590	.41727	.47668	-.32063	.07330
EMPATHY	.51087	.46681	.36232	.33103	.35139	-.34809	.23295
COURTESY	.45263	.31590	.43777	.35628	.59126	-.38479	.22758
FLEXIBILITY	.53918	.50947	-.28457	-.19064	-.21490	.30543	-.25796
IRRITABILITY	-.28019	.22027	.43777	.35628	-.32359	.37790	-.10864
STUBBORNNESS	-.29944	-.25403	-.25436	-.12278	.24721	.37993	.00862
DISTRUST	-.23081	-.19065	-.19544	-.10249	-.28255	.42674	.01648
CALLOUSNESS	-.26453	-.24695	-.24973	-.19936	-.28255	.23735	-.00364
THOUGHTLESSNESS	-.21296	-.14714	-.11758	-.13735	-.14294	.23735	-.00364
EFFICIENCY	.45328	.46409	.44823	.33161	.54804	-.24744	.13999
DEPENDABILITY	.59719	.62181	.46518	.45605	.64158	-.31233	.18396
PRECISION	.51079	.50663	.45081	.37761	.49704	-.24047	.16385
PERSISTENCE	.69877	.63093	.49504	.60693	.69151	-.41354	.13182
CAUTION	.08798	.12898	.05237	.05428	.09350	-.08358	.28827
FUNTUALITY	.40003	.44780	.36502	.26368	.42002	-.16328	.13114
DECISIVENESS	.48710	.57848	.39661	.38834	.56887	-.28649	.11390
PREDICTABILITY	.58330	-.24503	-.15691	-.19617	-.26264	.46304	.06250
AIMLESSNESS	-.25560	-.27012	-.13634	-.15036	-.24330	.43381	.08571
SLOTH	-.50768	-.36412	-.34797	-.49037	-.37369	.39844	-.03561
INDEPENDENCE	.42105	.40018	.37303	.41527	.47271	-.24019	.05734
INSECURITY	-.40414	.04510	.03620	-.03627	-.04325	.06686	-.06987
INTELLECTUALITY	.52942	.62352	.43741	.37906	.67316	-.38243	.11478
DEPTH	-.17359	-.10037	-.15442	-.15801	-.13579	.21661	-.02819
INSIGHT	.58133	.63632	.38898	.39273	.60066	-.30936	.09075
INTELLIGENCE	.64980	.58736	.54999	.46305	.71032	-.34917	.15175
CREATIVITY	.50867	.52546	.44125	.34490	.58362	-.27216	-.01780
CURIOSITY	.45193	.48716	.40748	.28636	.29634	-.25512	-.11779
SHALLOWNESS	-.10545	-.02453	-.02453	-.01584	-.07174	.29797	.18315
UNIMAGINATIVENESS	-.14155	-.22616	-.15676	-.11630	-.14516	.31416	.20457
IMPERCEPTIVENESS	-.13944	-.10535	-.07437	-.19468	-.11083	.13731	.11377

	PASSIVITY	LETHARGY	EMPATHY	COURTESY	FLEXIBILITY	IRRITABILITY	STUBBORNNESS
PASSIVITY	1.00000						
LETHARGY	.18854	1.00000					
EMPATHY	.18100	-.34471	1.00000				
COURTESY	.17318	-.21718	.72680	1.00000	1.00000	1.00000	1.00000
FLEXIBILITY	-.17904	-.35091	.58006	.55378	-.50834	.63629	.45768
IRRITABILITY	-.28281	.24046	-.41087	-.38962	-.51948	.44057	.48886
STUBBORNNESS	-.24257	.23175	-.39788	-.41690	-.35123	.39633	.20156
DISTRUST	-.02617	.27102	-.22147	-.24506	-.37835	.16806	.14806
CALLOUSNESS	-.12504	.35823	-.45953	-.40866	-.20709	-.09887	-.34509
THOUGHTLESSNESS	.10842	.19818	-.38295	-.31829	.38912	-.26874	-.25999
EFFICIENCY	.01209	-.32373	.41121	.33047	.51783	-.15347	-.27524
DEPENDABILITY	.00479	-.38255	.49700	.37620	.43709	-.19045	-.17336
PRECISION	.04472	-.35822	.48977	.38142	.48200	-.11750	-.18585
PERSISTENCE	-.09915	-.51715	.51245	.41485	.11894	-.16149	-.15258
CAUTION	.19329	.02868	.31239	.38973	.38453	-.17168	-.32264
PUNCTUALITY	.01577	-.27061	.33335	.25197	.43222	-.37584	.22266
DECISIVENESS	-.19755	-.37546	.37055	.31821	.54983	-.20180	.29436
PREDICTABILITY	.05022	-.33771	.56918	.45300	-.22911	.25517	.23315
DISORGANIZATION	.03154	.36217	-.09804	-.15287	.32270	-.26230	.43047
NEGLIGENCE	.12028	.53330	-.30395	-.21815	-.42239	.46622	.32643
INCONSISTENCY	.10323	.46527	-.39546	-.39318	.50248	.31875	.27745
INSECURITY	.04488	.46242	-.31394	-.27257	-.34549	.31965	.35119
FEAR	.09921	.41862	-.15048	-.13089	-.17683	-.31092	.23349
EMOTIONALITY	-.11812	.00175	.00584	-.07785	.49022	.18894	-.27035
INTELLECTUALITY	-.01307	-.45097	.41298	.32862	-.21625	-.23253	-.33823
DEPTH	-.15694	.22274	-.11878	-.09407	.44465	.54827	-.18357
INSIGHT	-.17328	-.39711	.38022	.33329	.54827	-.08020	-.08197
INTELLIGENCE	-.03841	-.42019	.51870	.40061	.33491	-.12537	.08935
CREATIVITY	-.07788	-.37671	.36488	.27799	.25362	.00716	.09013
CURIOSITY	-.19044	-.23741	.25247	.20522	-.05664	.03756	-.04482
SHALLOWNESS	.13153	.16175	.03020	.05890	-.12138	.02145	
UNIMAGINATIVENESS	.06379	.28409	-.10343	-.04588	-.05807		
IMPERCEPTIVENESS	.23247	.31224	-.14678	-.14214			

	DISTRUST	CALLOUSNESS	THOUGHTLESSNESS	EFFICIENCY	DEPENDABILITY	PRECISION	PERSISTENCE
DISTRUST	1.00000						
CALLOUSNESS	.32421	1.00000					
THOUGHTLESSNESS	.18280	.38422	1.00000				
EFFICIENCY	-.03532	-.21741	-.10775	1.00000			
DEPENDABILITY	-.24770	-.28688	-.18309	.56515	1.00000		
PRECISION	-.16308	-.16093	-.17773	.64499	.55634	1.00000	
PERSISTENCE	-.28388	-.28827	-.23626	.59963	.73213	.63742	1.00000
CAUTION	.02252	-.10343	-.08977	.33891	.22691	.33326	.22328
PUNTUALITY	-.16132	-.18217	-.13361	.43520	.56331	.43101	.46140
DECISIVENESS	-.20939	-.17516	-.12714	.52163	.54110	.58298	.58298
PREDICTABILITY	-.25030	-.27117	-.16437	.50729	.70561	.50730	.63537
DISORGANISATION	.19010	.32601	-.27532	-.16612	-.32882	-.14911	-.27468
NEGLECTANCE	.32236	.36709	.21027	-.30476	-.39516	-.35179	-.41993
INCONSISTENCY	.38542	.40525	.31657	-.32896	-.51281	-.28704	-.44110
FORGETFULNESS	.20905	.36526	.15457	-.13228	-.24911	-.11656	-.25839
AIMLESSNESS	.21635	.38560	.30066	-.15812	-.30416	.49850	.52106
CURIOSITY	.00174	-.08939	-.01450	.35479	.37477	.37467	.32341
SHALLOWNESS	.10379	.20930	.07352	-.10112	-.16284	-.04505	-.15247
UNIMAGINATIVENESS	.11981	.28429	.11303	-.13975	-.20258	-.05201	-.22225
IMPERCEPTIVENESS	.13201	.10971	.29787	-.05035	-.12272	.00201	-.19092
CAUTION	1.00000						
PUNTUALITY	.27978	1.00000					
DECISIVENESS	.16146	.40074	1.00000				
PREDICTABILITY	.19708	.51378	.57070	1.00000			
DISORGANISATION	-.11832	-.25736	-.27716	-.21084	1.00000		
NEGLECTANCE	-.16502	-.29742	-.37105	-.48907	.40535	1.00000	
INCONSISTENCY	-.12798	-.33970	-.41622	-.18884	.41484	.53790	1.00000
FORGETFULNESS	.02359	-.16893	-.29000	-.22326	.67033	.39890	.33751
AIMLESSNESS	-.02395	-.19655	-.35647	-.22326	.42443	.36536	.36497
SLOTH	-.12482	-.17822	-.30534	-.28549	.26410	.44366	.25896
INDEPENDENCE	.18386	.31423	.45762	.49999	-.29514	-.25866	-.39434
INSECURITY	.13580	.16215	-.35009	-.37280	.24114	.34057	.35382
EMOTIONALITY	.00310	.05738	-.00058	-.03320	.08602	.05331	.14424
INTELLECTUALITY	.15269	.45016	.66953	.57520	-.34290	-.40892	-.47548
DEPTH	-.04096	-.12610	-.02351	-.10175	.14301	.12964	.10706
INSIGHT	.20642	.47516	.66890	.55756	-.33607	-.47180	-.45484
INTELLIGENCE	.16553	.48222	.61890	.63388	-.27715	-.38595	-.46928
CREATIVITY	.08616	.32638	.46021	.40084	-.10670	-.13225	-.17018
CURIOSITY	.07764	.24881	.45062	.28719	-.21840	-.15262	-.24730
SHALLOWNESS	.04033	-.09415	-.22668	-.10095	.34515	.15067	.24723
UNIMAGINATIVENESS	-.01917	-.13467	-.17818	-.17818	.40888	.28661	.24119
IMPERCEPTIVENESS	.01917	-.07097	-.20690	-.15529	.28172	.29648	.34069
CAUTION	1.00000						
PUNTUALITY	.27978	1.00000					
DECISIVENESS	.16146	.40074	1.00000				
PREDICTABILITY	.19708	.51378	.57070	1.00000			
DISORGANISATION	-.11832	-.25736	-.27716	-.21084	1.00000		
NEGLECTANCE	-.16502	-.29742	-.37105	-.48907	.40535	1.00000	
INCONSISTENCY	-.12798	-.33970	-.41622	-.18884	.41484	.53790	1.00000
FORGETFULNESS	.02359	-.16893	-.29000	-.22326	.67033	.39890	.33751
AIMLESSNESS	-.02395	-.19655	-.35647	-.22326	.42443	.36536	.36497
SLOTH	-.12482	-.17822	-.30534	-.28549	.26410	.44366	.25896
INDEPENDENCE	.18386	.31423	.45762	.49999	-.29514	-.25866	-.39434
INSECURITY	.13580	.16215	-.35009	-.37280	.24114	.34057	.35382
EMOTIONALITY	.00310	.05738	-.00058	-.03320	.08602	.05331	.14424
INTELLECTUALITY	.15269	.45016	.66953	.57520	-.34290	-.40892	-.47548
DEPTH	-.04096	-.12610	-.02351	-.10175	.14301	.12964	.10706
INSIGHT	.20642	.47516	.66890	.55756	-.33607	-.47180	-.45484
INTELLIGENCE	.16553	.48222	.61890	.63388	-.27715	-.38595	-.46928
CREATIVITY	.08616	.32638	.46021	.40084	-.10670	-.13225	-.17018
CURIOSITY	.07764	.24881	.45062	.28719	-.21840	-.15262	-.24730
SHALLOWNESS	.04033	-.09415	-.22668	-.10095	.34515	.15067	.24723
UNIMAGINATIVENESS	-.01917	-.13467	-.17818	-.17818	.40888	.28661	.24119
IMPERCEPTIVENESS	.01917	-.07097	-.20690	-.15529	.28172	.29648	.34069

Rotated Factor Matrix:

	Factor 1	Factor 2	Factor 3
SPIRIT	.75444	-.20278	-.15191
EXPRESSIVENESS	.75999	-.09474	-.17721
SPONTANEITY	.63440	-.19965	-.08323
ENERGY LEVEL	.58790	-.13349	-.14975
AMBITION	.76190	-.20115	-.11279
ALOOFNESS	-.28315	.42821	.50275
INHIBITED	.22471	-.23837	.52961
PASSIVITY	-.06895	-.39413	.49794
LETHARGIC	-.42902	.26778	.49991
EMPATHY	.59808	-.46667	.15241
COURTESY	.46822	-.51113	.16733
FLEXIBILITY	.54470	-.56898	.00803
IRRITABILITY	-.16517	.76573	-.04660
STUBBORNNESS	-.20204	.74119	.00497
DISTRUST	-.09036	.61911	.22428
CALLOUSNESS	-.15976	.60217	.26000
THOUGHTLESSNESS	-.13943	.30137	.20267
EFFICIENCY	.74110	-.01496	-.01215
DEPENDABILITY	.79421	-.21100	-.13655
PRECISION	.75400	-.08604	.04857
PERSISTENT	.79828	-.20141	-.19986
CAUTION	.30800	-.13893	.27469
PUNCTUALITY	.58966	-.10565	-.04288
DECISIVENESS	.72189	-.04075	-.26920
PREDICTABILITY	.72394	-.30305	-.01154
DISORGANISATION	-.15949	.27642	.59940
NEGLIGENT	-.32262	.35047	.44230
INCONSISTENCY	-.38316	.47714	.38043
FORGETFULNESS	-.14857	.27933	.58751
AIMLESSNESS	-.17838	.24511	.63293
SLOTH	-.40657	.29717	.26731
INDEPENDENCE	.56198	-.11909	-.18216
INSECURITY	-.29669	.56692	.31912
FEAR	-.21976	.39596	.41357
EMOTIONALITY	.16511	.50028	.00687
INTELLECTUALITY	.73235	-.21297	-.27841
DEPTH	-.04473	.39375	.04429
INSIGHT	.73143	-.11927	-.28853
INTELLIGENCE	.80390	-.21509	-.17949
CREATIVITY	.69072	.06304	-.11107
CURIOSITY	.53280	.13595	-.25349
SHALLOWNESS	-.06013	.00387	.57628
UNIMAGINATIVENESS	-.15624	.05448	.58821
IMPERCEPTIVENESS	-.10083	.04059	.44509

PERSONALITY CHANGES IN NORMAL AND COGNITIVELY IMPAIRED ELDERLY: INFORMANT REPORTS IN A COMMUNITY SAMPLE

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SUMMARY

Personality changes are included in the DSM-III-R and ICD-10 criteria for diagnosis of dementia. However, until quite recently, dementia research has emphasized cognitive decline, with little interest being shown in personality change. Recent studies looking at personality changes in dementia have usually used small clinical samples. In the study reported here, such changes have been assessed in a community sample of persons over 70 years. Information was obtained from a close relative or friend. A single dimension of personality change was found. There was a moderate but significant correlation between personality change and cognitive change. Reports of personality change were also correlated to neurotic symptoms in the informant. Personality change was unrelated to the gender of the informant, the relationship of the informant to their relative or whether they lived with their relative. Also, there was no association between personality change and the elderly subject's age, gender or level of education. Through logistic regression, the neurotic symptom score of the informant was found to be the best predictor of reported personality change. This suggests that caution may be needed in interpreting information about personality change obtained from informants.

KEY WORDS—Personality change, cognitive impairment, dementia, community survey

Dementia is characterized by a range of cognitive and behavioural changes. Although impairment of memory and abstract thinking is central to its diagnosis (Lishman, 1987), personality change is also considered to be a frequently occurring characteristic (Roth and Myers, 1969). Both the Tenth Revision of the *International Classification of Diseases* (WHO, 1990) and the *Diagnostic and Statistical Manual*, DSM-III-R (American Psychiatric Association, 1987) include personality changes as part of the diagnostic criteria for dementia. Until quite recently, personality change has been a neglected area of investigation, with most research looking at cognitive decline in dementia. Knowledge of personality changes was based on clinical reports, but in the last few years there have been

a number of quantitative studies reporting changes in many areas of personality including an increase in apathy, withdrawal, irritability and emotional lability and a decrease in conscientiousness (Rubin *et al.*, 1987; Petry *et al.*, 1988; Siegler *et al.*, 1991; Chatterjee *et al.*, 1992).

All of these studies have been based on persons who have reached hospitals or clinics and have been diagnosed as suffering from dementia or probable dementia. It is possible that the patients referred to such clinics are not representative of all people in the population who suffer from dementia, but rather are a subsample suffering more socially disruptive symptoms. Furthermore, such studies have not always compared the demented sample to a normal group.

Assessment of personality changes in dementia is usually based on information from a spouse or other close relative who is often caring for the demented person. The use of informant ratings introduces the possibility that the information pro-

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vided by these people may be contaminated by such factors as their relationship to the subject, whether they live with the subject, or their own well-being. Gilley and Wilson (1991) found no association between reports of apathy, agitation and irritability and either the gender of the informant or the informant's relationship to the subject. Thompson and Orvaschel (1982), however, found that reports of psychiatric symptomatology varied with the informant's relationship to the subject.

Anxiety or depression in the informant may also influence their reports of personality change. Carers of people suffering from dementia report high levels of psychological distress (Haley *et al.*, 1987; Anderson, 1987; Brodaty and Hadzi-Pavlovic, 1990). Some studies looking at a range of behaviour and personality changes have reported a correlation with carer stress (Gilleard *et al.*, 1982, 1984; Zarit *et al.*, 1986). It is reasonable to expect that changes in the personality of a close relative may cause anxiety or depression in a carer. Another possible explanation is that such symptoms in the carer may cause them to perceive higher levels of personality change. Such an effect is suggested by research on mothers' reports of children's behaviour. Studies by Schaughency and Lahey (1985) and Webster-Stratton and Hammond (1988) have shown that depression in the mother is associated with a negative perception of the child's behaviour.

The aim of this study was to investigate personality changes associated with cognitive impairment and to look at the relationship between characteristics of the informants and their reports of personality change.

METHOD

This study has used data collected as part of an epidemiological study examining dementia and depression in a community sample. This sample covered a range of cognitive levels, from those who were cognitively normal through to those who were significantly cognitively impaired. The strength of a community sample is that it does not have the possible biases found in clinical studies. Although dementia was diagnosed in this sample, it was not possible to examine the relationship between dementia and personality change, as the personality change items had been used in the algorithms for the diagnosis of dementia according to DSM-III-R and ICD-10 criteria. An association would obviously be found between the occurrence of per-

sonality change and the diagnosis of dementia, largely due to the inclusion of personality change in the dementia diagnosis. The present study therefore examined personality change in relation to cognitive impairment rather than dementia.

The sample

The subjects were a sample of elderly, community dwelling persons from the Australian city of Canberra and the nearby town of Queanbeyan. These persons were sampled from the electoral roll, which is a register of eligible voters. Registration on this roll is compulsory for all Australian citizens aged 18 or over, although individuals can be removed from the roll in circumstances such as severe illness or disability. The sample was selected to give equal numbers of males and females. For each sex, there were three age strata (70-74 years, 75-79 years and 80+ years), with each stratum sampled to give an achieved sample which was proportional to the number of individuals in the census population in that age group.

Following the interview, subjects were asked if they would be willing to provide the name of someone who knew them well and might be willing to answer some questions about them. The relative or friend was later contacted and a separate interview was arranged. Only one member of a household was chosen as a subject in this study. Every effort was made to interview the subject alone; however, in some cases the informant was present during the subject's interview. The final informant sample included a total of 745 persons, 361 of whom answered questions about female subjects and 384 answered questions about male subjects. From this sample, 740 persons completed the personality questions, 358 about females and 382 about males. For some analyses, sample size was lower than 740 due to incomplete information from the informant. In the case of 46 of the informant interviews, there was no corresponding subject interview. This was because the subject either was unwilling to be interviewed or was too physically or cognitively impaired to do so.

Content of the interview

The information collected from the subject and informant interviews provided data for the diagnosis of dementia or depression (Social Psychiatry Research Unit, 1992; Mackinnon *et al.*, 1993). Data were also collected on social background, physical

health, personality, social support, mental activity, self-reported cognitive function and use of services. With the exception of the Mini-Mental State Examination (MMSE), all data used in this article came from the informant interview.

Personality change questions. The questions were asked in two steps. First, the informant was asked if the subject showed a specific personality characteristic. If they answered 'yes', they were asked if the subject had changed from earlier in life. Those who indicated 'no change' were classified with those indicating that the subject did not show the characteristic. Personality characteristics included in the scale are shown in Table 1. The questions

(1988) to measure changes in memory and intelligence which have taken place in the previous 10 years. It has been found to correlate highly with the MMSE and also to be uninfluenced by premorbid ability as estimated by the National Adult Reading Test (Jorm *et al.*, 1991). The IQCODE has also been found to have high internal reliability in a general population sample (alpha 0.95) and reasonably high test-retest reliability over 1 year in a dementing sample ($p=0.75$) (Jorm and Jacomb, 1989).

Mini-Mental State Examination (MMSE). This test, developed by Folstein *et al.* (1975), provides a means of grading a person's cognitive state.

Table 1. Per cent of informants reporting change over last 10 years on each personality and judgement item

Items in scale	Per cent
Personality items	
1. Irritable	9.1
2. Demanding and attention seeking	6.4
3. Lacking initiative	6.3
4. Sad or depressed	6.3
5. Doesn't like mixing with others	4.9
6. Overly emotional	4.6
7. Apathetic and withdrawn	4.6
8. Inflexible	4.3
9. Impatient	4.2
10. Suspicious	3.7
11. Cantankerous	2.5
12. Not easy to get on with	2.0
Judgement items	
13. Doesn't keep clean and respectable	3.9
14. Embarrassing behaviour	3.8
15. Doesn't consider others' feelings	3.3
16. Doesn't think through consequences	3.0
17. Handles money foolishly	2.4

were derived from the 'personality change' and the 'impaired judgement and impulse control' components in the DSM-III-R description of dementia and the ICD-10 description of dementia.

Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE). This 26-item informant questionnaire was developed by Jorm and Korten

Global rating of memory decline. Informants were asked: 'In your opinion, does — remember things as well as she used to?'. Those who answered 'no' or 'depends' to this were then asked: 'Does this interfere with her/his day-to-day life?'.

Global rating of intellectual decline. Informants were asked the questions: 'In your opinion, can — think and reason as clearly as earlier in life?' and 'Does this interfere with her/his day-to-day life?'.

Anxiety and depression symptoms. Informants were asked to complete the scale measuring anxiety and depression described by Goldberg *et al.* (1988). These items can be combined to give a scale of neurotic symptoms.

Statistical analysis

The statistical package SPSS-X was used for analysing the data. Principal components analysis with orthogonal rotation was used to develop a personality change scale. The distribution of reported personality changes was found to be quite skewed, with 71% (523) reporting no changes and 29% (217) reporting one to 16 changes. Therefore non-parametric statistics were used in all analyses involving the personality change scale. For comparison of means, the Mann-Whitney U test was used, while Spearman correlation coefficients were computed to examine the correlation between the personality score and a range of continuous variables. Statistical significance was evaluated at the 0.01 level.

RESULTS

Personality change scale

The 17 questions covering personality and judgement change (Table 1) were entered into a principal components analysis. The first factor accounted for 26% of the variance, the next three accounting for 9%, 7% and 7% respectively. This analysis suggests that a single-factor solution is appropriate. Internal consistency was evaluated by calculating Cronbach's coefficient α which was found to be 0.81. Item-total correlations indicated that the α could not be improved by dropping any items. Therefore, all items were retained in the personality change scale and a score was obtained by adding the personality items for which change was reported. Using data from another informant sample of 76 elderly patients attending a hospital clinic (Social Psychiatry Research Unit, 1992), the test-retest reliability of this personality scale was 0.82. Interviews were on average 3.2 days apart.

Relationship between personality change and sociodemographic characteristics of subject

The Spearman correlation coefficient between the reported number of personality changes and the age of the subject was 0.18 ($p < 0.001$). The correlation between the number of reported personality changes and years of education of the subject was not statistically significant. There was also no significant difference between the mean personality changes for males and females. Males had a mean score of 0.78 (SD = 1.75), while females had a mean score of 0.70 (SD = 1.60).

Relationship to MMSE and measures of cognitive decline

The correlations between reported number of personality changes and five measures of cognitive decline as well as a measure of current cognitive function (MMSE) are shown in Table 2. For all measures of cognitive decline, a high score means more decline, whereas a high score on the MMSE indicate good performance. All correlations were found to be significant at the $p < 0.01$ level. The lowest correlation was found with the MMSE. Correlations of personality change with global reports of memory and intellectual decline are higher when this decline was seen as interfering with the sub-

Table 2. Correlations between measures of cognitive decline and reports of personality changes

Measures of cognitive decline (N)	Correlation with personality change score (Spearman coefficients)
MMSE (686)	-0.19*
IQCODE (695)	0.37*
Global report of memory decline (738)	0.28*
Memory decline interferes (412)	0.37*
Global report on intellectual decline (738)	0.35*
Intellectual decline interferes (231)	0.46*

* $p < 0.01$.

ject's day-to-day life. The highest correlation was with the report of intellectual decline interfering with day-to-day life.

Relationship to characteristics of the informant

There was no significant difference in the mean number of reported personality changes between male (0.64, SD = 1.53) and female (0.78, SD = 1.73) informants. There was also no significant differences between the mean number of personality changes reported by those informants who lived with the subject (0.83, SD = 1.82) compared to those who did not (0.66, SD = 1.54). The mean number of personality changes reported by spouses (0.73, SD = 1.76) was not significantly different to the mean number of changes reported by child informants (0.85, SD = 1.56). To further investigate the possible effect of relationship, principal components analysis was carried out on the responses to the personality questions given by the spouses and the children separately. In this sample, 40% of the informants were spouses and 37% were either sons or daughters. This showed that for spouses the first principal component accounted for 32% of the variance while for children the first principal component accounted for only 18%. The loadings on this first component were compared by the coefficient of congruence (Reynolds, 1982) to see if they were the same. The coefficient had a value of 0.89, which suggests that the principal component being measured was very similar in the two groups.

In this study, there were not enough informants who considered themselves 'carers' of dependent elderly to examine anxiety and depression in this specific group. Therefore, we have examined the informants in general, 49% of whom lived with the subject and a further 43% of whom saw the subject at least once a week. Correlations between the

number of reported personality changes and measures of anxiety and depression in the informant were both significant at 0.24 and 0.23 respectively. There was found to be no difference in this correlation between those who lived with the subject and those who did not. To investigate the effect of cognitive impairment in the subject on this relationship, a two by two analysis of variance was performed using the MMSE scores of the subjects dichotomized at a score of 23/24 and the personality change score dichotomized on 'no change' or 'any change' as independent variables and anxiety and depression as dependent variables. There was found to be no interaction effect of cognitive impairment and personality change on either anxiety or depression, indicating that the relationship between stress in the informant and reports of personality change was the same regardless of cognitive impairment.

Multivariate analysis

Of the variables examined in this study, the only ones showing a significant relationship to personality change were age of the subject, neurotic symptoms in the informant and all of the cognitive measures. To determine the relationship of each variable to personality change independently of the other variables, logistic regression was performed on the dichotomized personality change score. The IQCODE was used as an indicator of cognitive change. The results are shown in Table 3. These

Table 3. Logistic regression analysis predicting personality change

Predictor variable	Beta	SE	Interquartile odds ratio
IQCODE	2.11*	0.33	1.63
Age of subject	0.05	0.02	1.38
Neurotic symptoms of informant	0.15*	0.03	2.09

* $p < 0.01$.

include the calculated interquartile odds ratio developed by Mackinnon (1992). Continuously scaled predictors are often dichotomized to allow calculation of an odds ratio but at the expense of the power of the analysis. The interquartile odds ratio is based on the interquartile range of a continuously scaled predictor variable, so full power of this predictor is retained. It can be seen that the interquartile odds

ratio was higher for neurotic symptoms in the informant than for cognitive decline measured by the IQCODE. This suggests that although cognitive decline is a significant predictor of reported personality change, neurotic symptoms in the informant have stronger predictive power. The correlation with age, independent of other predictors, became non-significant.

DISCUSSION

Principal components analysis of the personality items included in this study revealed one single major factor of personality change in the elderly community sample. Studies which have examined similar changes in a diagnosed dementia sample have found that principal components analysis revealed more than one factor. In his study of 60 subjects with questionable or mild senile dementia, Rubin *et al.* (1987a) found seven factors using the personality items on the Blessed Dementia Scale plus open-ended questions. These were then grouped into four clinically meaningful groups: passive, agitated, self-centred and suspicious. In a study by Greene *et al.* (1982) of 38 people diagnosed as suffering from senile dementia, factor analysis of 34 questions covering mood and behaviour revealed three major factors: apathetic-withdrawn, active-disturbed and mood disturbance. It is not unusual to find differing results between general population samples and selected clinical samples. In clinical samples, most of the subjects will show some level of personality change and factor analysis of such change may reveal differences in the types of changes. In the community sample examined here, however, there was a very low occurrence of personality change, 71% of subjects showing no change at all. Analysis of these data reveals one major factor which differentiates between those showing no change and those showing some change. Any differences in types of personality change would have been too small to be detected in this sample. One limitation of this scale is the narrow base for selection of personality items, all having come from either the DSM-III-R or ICD-10 criteria for dementia. The changes assessed here are largely those which are viewed as problem behaviours and do not cover all aspects of personality change which may occur in dementia or in normal ageing. Some of the items are expressed as behaviour changes while some ask more directly about personality. However, all the characteristics

assessed by this scale can be found in personality inventories designed to measure the five-factor model of personality, for example the NEO-PI (Costa and McCrae, 1985).

This study has two advantages over studies based on small, clinical groups. First, we have data from a large sample, making principal components analysis of the personality variables more stable and more representative of the general population. Secondly, our sample would not suffer from the biases which may occur in a sample of people who have presented to physicians for diagnosis.

A number of studies have looked at the relationship of personality changes to cognitive change. The results have not been consistent. Some studies report no association between cognitive change and personality change in dementia samples (Teri *et al.*, 1989; Petry *et al.*, 1989), while others report an increase in a number of personality changes with decrease in cognitive scores (Cooper *et al.*, 1990; Rubin *et al.*, 1987b). All of these studies have used people who have been diagnosed as suffering from dementia or probable dementia. In the present study, there was a significant correlation between reported personality change and each of the measures of cognitive change. Controlling for other predictor variables by logistic regression indicated that cognitive change was a significant predictor of personality change. Possible reasons for this association are:

1. Personality changes may be, in part, a reaction to the disease process itself, particularly in the early stages when the person is more aware of their condition.
2. Damage to areas of the brain concerned with cognitive function may also influence personality.
3. Some of the items in the personality scale used in this study may be indicative of cognitive change, particularly some of the items on judgement. This is a possible weakness of the scale.

The correlation, however, was found only to be moderate. There may therefore be processes involved in personality change that are unrelated to cognitive decline.

Information about behaviour and personality changes in people suffering from dementia is frequently obtained from carers or close relatives. It is possible that the responses to the questions may be influenced by characteristics of the informant. In this study, no correlation was found between reported personality changes and gender of informant,

relationship of subject to informant or whether the informant lived with the subject. Principal components analysis of the responses to the personality items for spouse informants and child informants separately showed that for the spouses' responses the first factor accounted for a greater percentage of the variance than the children's responses. This suggests that the spouses were most likely to see a more global personality change in their partners, while their children were more likely to report specific changes. Calculation of the coefficient of congruence, however, indicated that the principal component being measured was very similar for both groups.

Symptoms of anxiety and depression in the informant, were significantly correlated with the number of reported personality changes. This correlation was about the same for those informants who lived with the subject as it was for those who did not live with the subject. The relationship was also found to be the same for different levels of cognitive impairment. Logistic regression showed neurotic symptoms in the informant to be a better predictor of reported personality change than cognitive change or the age of the subject. In this study it is not possible to draw any conclusions about the direction of the relationship between reported personality change and informant stress. It is interesting that Jorm *et al.* (in press) using the same survey data found a similar relationship between informant stress and informant reports of cognitive change (although not the IQCODE score). A follow-up of this sample is planned during 1994 and it will then be possible to look at this association longitudinally.

As it is possible that information obtained from informants is influenced by their level of stress, then the reliability of such information may be thrown into doubt. Studies using the DSM-III (Spitzer *et al.*, 1979) and the DSM-III-R (Arntz *et al.*, 1992) diagnostic criteria for personality disorders have found interrater reliability to be poor. Other studies which have investigated the interrater reliability of inventories designed to assess personality in healthy individuals have found that items which are easily observable have better reliability than those items which have to be inferred (Funder and Dobroth, 1987; Funder and Colvin, 1988). This needs to be considered in interpreting results based on informant reports.

Personality changes were not found to be correlated with gender or years of education of the subjects. Also, the correlation with age of the subject

disappeared when the effect of other variables was controlled by logistic regression. Cooper *et al.* (1990) also found that personality change was not significantly correlated with age, gender or education. Given that such personality changes are included in the diagnostic criteria for dementia, it is useful to know that they are not influenced by such factors.

Although only a small proportion of the sample were diagnosed as demented, 29% of informants reported that personality changes had occurred in their elderly relatives. These changes were found to be moderately correlated to cognitive change. It has frequently been reported that personality changes occur early in the course of dementia (Rubin and Kinscherf, 1989). The 4-year follow-up of this sample will make it possible to determine the incidence of dementia in currently non-demented subjects in whom personality changes have been reported. It will also be possible to look at further change in personality and whether this varies on an item-by-item level.

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Appendix 6.2: Personality questionnaire containing only those adjectives from Scale 2 covering disagreeable and neurotic traits.

1.	courteous	much less	a bit less	about the same	a bit more	much more	don't know
2.	emotional	much less	a bit less	about the same	a bit more	much more	don't know
3.	adaptable	much less	a bit less	about the same	a bit more	much more	don't know
4.	obliging	much less	a bit less	about the same	a bit more	much more	don't know
5.	cold	much less	a bit less	about the same	a bit more	much more	don't know
6.	obstinate	much less	a bit less	about the same	a bit more	much more	don't know
7.	cranky	much less	a bit less	about the same	a bit more	much more	don't know
8.	insensitive	much less	a bit less	about the same	a bit more	much more	don't know
9.	tactful	much less	a bit less	about the same	a bit more	much more	don't know
10.	insecure	much less	a bit less	about the same	a bit more	much more	don't know
11.	pig-headed	much less	a bit less	about the same	a bit more	much more	don't know
12.	irritable	much less	a bit less	about the same	a bit more	much more	don't know
13.	fretful	much less	a bit less	about the same	a bit more	much more	don't know
14.	flexible	much less	a bit less	about the same	a bit more	much more	don't know
15.	defensive	much less	a bit less	about the same	a bit more	much more	don't know
16.	stubborn	much less	a bit less	about the same	a bit more	much more	don't know
17.	distrustful	much less	a bit less	about the same	a bit more	much more	don't know
18.	polite	much less	a bit less	about the same	a bit more	much more	don't know
19.	suspicious	much less	a bit less	about the same	a bit more	much more	don't know

20.	excitable	much	a bit	about	a bit	much	don't
		less	less	the same	more	more	know
21.	grumpy	much	a bit	about	a bit	much	don't
		less	less	the same	more	more	know