EMOTION PROCESSING IN ALZHEIMER'S DISEASE: THE CLINICAL IMPLICATIONS

By

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ABSTRACT

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The purpose of this study is to extend the literature on recognition and identification of non-verbal communicative signals of emotion in those suffering from Alzheimer's disease. To date, there have been few studies in this area, yet emotion processing deficits may have an important effect on the quality of life of Alzheimer's patients and their families.

The experimental condition consisted of a set of tasks involving face and prosody discrimination problems in which participants were asked to choose between a number of stimuli presented on cards (facial cues) or on audio-tape (prosody cues). In addition, a measure of general cognitive ability was taken. Firstly, it was found that, relative to a group of healthy older adults, performance on cognitive tasks was depressed, while performance on emotion processing tasks was not depressed to the same extent. Thus, the ability to recognise and identify non-verbal affect cues in emotional facial expression and emotional prosody was relatively preserved in patients with Alzheimer's disease.

Secondly, no relationship was found in the Alzheimer disease group between performance on face recognition and prosody tasks. This evidence is consistent with the notion that the mechanisms responsible for discriminating emotional facial expression are dissociated from those involved in discriminating emotional prosody. However, these findings need to be interpreted with caution in view of the small sample size and low statistical power.

Lastly, a number of post-study hypotheses were generated in relation to the Alzheimer disease group. These related to the number and type of errors made on tasks of face and prosody discrimination and suggestions were made regarding further investigation in this area.

Finally, limitations of the study, implications for clinical practice, such as assessment and intervention focussing on preserved emotion processing ability and suggestions for future research are considered.

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AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Clinical Psychology has the author been registered for any other University award.

The contents of this volume are identical to the volume submitted for examination in temporary binding except for the amendments requested at the examination.

This study was conducted while the author was a Trainee Clinical Psychologist in the South West Region in Frenchay Healthcare Trust. The research was conducted in collaboration with Frenchay Healthcare Trust.

Signed.....

CHAPTER 1. INTRODUCTION

1.1 Overview

The main purpose of this introduction is to review a wide range of research, and to delineate some of the key ideas which underpin the theoretical and clinical literature concerning emotion processing in general, and how these might be utilised to aid our understanding and produce testable predictions about the effect of such processes in those suffering from Alzheimer's disease (AD).

A number of theories of emotion processing are considered and studies of emotion processing in neurologically impaired individuals are discussed, to provide a context in which to compare emotion processing in those suffering from AD. This is followed by a review of the small number of clinical studies to date. Together these provide the rationale for the present study and the resultant experimental hypotheses.

1.2 Brief background and history of Alzheimer's disease.

In 1906, Alois Alzheimer described a set of clinical and neuropathological findings seen in a fifty-one year old female patient, which were to become known as Alzheimer's Disease (AD). The modern definition stems from this early case study, and as Alzheimer reported, the most distinctive characteristic of this disease is a progressive loss of memory function, with accompanying changes in behaviour, emotion and autonomic functions.

Alzheimer's Disease began to receive greater attention in both the literature and media during the past twenty years or so, when prevalence rates were estimated at 5 per cent in

those aged 65 years and over. It became increasingly clear that this would have significant implications for the older adult population in terms of both treatment intervention and allocation of Health Service resources.

Interestingly, much of the research into AD and related dementing illnesses concentrated almost exclusively on the cognitive and functional symptoms associated with this disease, with little attention given to the emotional aspects of the illness, despite growing evidence of its influence on both individuals and wider social networks. Nadeau (1990), for example, maintains that loss of ability to express feelings and to comprehend expression of emotion in others is potentially one of the key factors leading to degradation of quality of life in those with dementia, contributing to a sense of alienation from family members and producing caregiver stress. In addition, Kumar, Koss, Metzler, Moore & Friedland (1988), report that caregivers rate behavioural difficulties such as explosive emotional reactions and other changes in emotional reactivity as some of the most distressing and stressful aspects of caregiving

It has been argued, (Magai, Cohen, Gomberg, Malatesta & Culver 1996) that this inattention to affective processes in AD is a consequence of the dramatic expansion in dementia research in the 1970's, when the behavioural sciences were in the midst of a cognitive revolution, leading to a preoccupation with cognition at the expense of other issues.

More recently, however, various models of emotion and emotion-cognition interaction have been elaborated in the literature. For example, 'discrete emotions theory' (Izard 1991, Izard & Malatesta, 1987; Magai & McFadden, 1995) has proposed that the emotion system is separate from other psychological subsystems such as cognition and it

has become increasingly clear that there is indeed a close connection between affect, cognition and behavioural adaptation (Labouvie-Vief, DeVoe & Bulka 1989; Izard 1991; Magai & McFadden 1995).

This has opened up the field of dementia research to question the ways in which emotion processing and other cognitive processes relate to one another during the course of AD, particularly with respect to patient care. It has become increasingly obvious that the care and treatment of those suffering from AD must involve attention to emotion as well as functional need. A greater understanding of the nature and course of emotion processing will have implications for treatment interventions that are sensitive to patient feelings, not just their routine care. It is this question that has provided the impetus for further consideration here.

1.3. A simple definition of emotional functioning

To begin, therefore, we need a simple definition of the term "emotional functioning" as a foundation from which to move forward. Cadieux & Greve (1997) describe it as:

a) "The cognitive process involved in the ability to comprehend the emotional state of others using cues provided by facial expression or the intonation of speech".

and

b) "The ability to communicate one's own emotional state via facial expression and/or vocal prosody".

This definition makes the distinction between concepts of emotion recognition and emotional expression, a division that will be returned to later, with reference to the clinical literature.

1.4. Theoretical explanations of emotion processing.

Contemporary accounts of emotional behaviour view emotion as multidimensional in nature, consisting of at least three components (Lang 1988):

a) physiological arousal and activation, both autonomic and central;

b) overt behaviours, ranging from social displays (e.g. facial expressions and tone of voice), to more broadly based behaviours such as avoidance, withdrawal and attack;

c) verbal reports and cognitions about one's own emotional experience.

One implicit assumption is that these three components should closely correspond, particularly if they are reflecting the same underlying phenomenon, namely, emotional experience. However, these components may be widely divergent, reinforcing the view that these so-called emotion processing components are mediated by different sub-systems within the central nervous system, with each component reflecting the output of different neural processors. This is important because while humans typically have a unified experience of emotion, it is, in fact, composed of multiple systems that can be fractionated (Bowers, Bauer, & Heilman 1993).

In support of Lang's proposal of a "multidimensional" emotion processing model, one of

the main themes arising from the neuropsychology literature on neurologically impaired populations has been the notion of "modularity". This idea was originally proposed by Fodor (1983), who argued that the brain is not simply a huge and uniform set of units with everything connected to everything else, but is made up from a number of subsystems or modules, each of which performs an essential but somewhat different task. Each component is viewed as conceptually separate and can itself, be broken down into smaller modules (e.g. emotion processing module).

Indeed, the neuropsychological evidence gathered from the "normal" population indicates that there is a good degree of modularity in the brain, e.g. in memory systems there is evidence of "sensory", "working" and "long-term" memory. (Baddeley 1991)

In addition, Fodor maintained that the central executive, in the frontal area of the brain, appears to accomplish the co-ordination of information from different modules rather than the storage and retrieval of information within a single unitary system. Furthermore, as the modules in the brain are relatively independent of each other in their functioning, damage to one module does not directly affect the functioning of other modules. Modules are anatomically distinct, so that brain damage will often affect some modules while leaving others intact.

Fodor went on to try to identify the main distinguishing features of modules, one of which was the notion of "domain specificity", i.e. each module can process only one kind of input (e.g. words, faces).

This notion of modularity was further explored by Schacter (1990), who proposed two theoretical explanations to account for the ways in which discrete modality specific

mechanisms might be operating within the central nervous system.

Using the first account in relation to emotion processing, Schacter's model suggests that a disturbance in the ability to process emotion would involve a deficit at the level of a hypothetical awareness system, or the disconnection of such a system from other perceptual or cognitive systems. The second order account, more specifically, refers to an inability to gain access to a certain kind of domain-specific information that would normally be associated with, or provide the basis for, an experience of awareness within a particular domain (e.g. emotion). This idea is not at odds with the idea of a cross-domain awareness mechanism, it merely indicates that such a mechanism need not be disrupted each time an awareness deficit is seen.

These theoretical accounts led Schacter to consider the possibility of a selective disconnection both within and between modules operating in the central nervous system. These ideas are important to the present discussion as they underpin much of the current research into aspects of domain specificity in emotion processing. This, in turn, impacts on the notion of a possible dissociation of the "emotion processing module" from the rest of the cognitive modules in those suffering from AD.

1.5. Emotion expression versus emotion recognition.

So far, this discussion has focused on general theory and experimental evidence regarding the nature of emotion processing in those suffering from neurological deficits. Following on from these ideas, researchers in the field have looked more specifically at the distinction between emotion recognition and expression in those with AD and other neurological disorders.

In a study of patients with Huntingdon's disease, Speedic, Brake, Folstein & Bowers (1990) found that subjects were impaired on tasks of recognition of emotional prosody when compared to controls, but did not differ from unilateral stroke patients, and Blonder, Raquel & Ruben (1989) looked at patients with Parkinson's disease and found impairments on recognition and expression of emotional prosody. Interestingly, Borod, St.Clair, Koff & Alpert (1990) compared patients with Parkinson's disease, right hemisphere focal lesions, Schizophrenia and unipolar depression, and found a correlation for all groups between facial and vocal processing, but no correlation between tasks of recognition and expression of emotion. Finally, Heilman, Watson and Bowers (1983) hypothesised that the emotion recognition deficits seen in a group of unilateral stroke patients were related to depression and indifference seen on clinical observation.

So, converging data from cognitive neuropsychology and the cognitive neurosciences has begun to provide clues as to the organisation of subsystems that are dedicated to the evaluation of domain-specific information processing. In addition, current evidence suggests that these systems may be modular in organisation.

More recently, Bowers, Bauer & Heilman (1993) have taken these ideas one step further, proposing the notion of the existence of two independent non-verbal affect lexicons: one for faces and one for prosody. This is based on experimental evidence demonstrating that some patients with right hemisphere lesions were able to perform normally on receptive emotional prosody tasks, but were impaired on receptive emotional face tasks, whereas others demonstrated the opposite effect. Double dissociations between ability to interpret non-verbal affective signals and express these same signals has also been reported in those with right hemisphere damage, both for faces and voices (Borod, Koff, Perlman-Lorch & Nicholas 1986; Richardson, Bowers, Eyeler & Heilman 1992). These findings

suggest that systems supporting the perception of affect are distinct from those that support production of affective signals.

In an attempt to consolidate and test their hypotheses, Bowers, Blonder & Heilman (1991) developed a standardised test battery- The Florida Affect Battery- (FAB) as a research tool to investigate disturbances at the level of recognition and identification of non-verbal communicative signals of emotion (i.e. facial expressions and prosody) that accompany neurologic dysfunction of the brain.

Selection and use of the specific sub-tests in FAB were theoretically driven, underpinned by much of the preceding literature, and based on a cognitive neuropsychological model of emotion processing described in several publications (Bowers et.al. 1993, 1991, 1985) which argued, that specific neural networks exist in the brain that are particularly concerned with deciphering the affective meaning of perceptual signals.

Bowers et.al. maintain that the brain contains a "vocabulary" or neural representation of non-verbal affect signals (i.e. "a non-verbal affect lexicon") which is "modular" in organisation and has independent lexicons for faces and prosody. Broadly speaking, these "affect" representations are just one component of a cortically-based emotion processing network that is dedicated to reading the non-verbal social displays of other members of the species.

The key aspects of their model propose that distinct sub-types of affective processing disturbances are predicted to accompany dysfunction of neural systems within the hemispheres, producing modality specific affect disturbances from facial affect agnosia, and facial affect anomia, to more global emotion recognition difficulties. Bowers et.al.

devised a battery of affect recognition sub-tests (in conjunction with several output/production tasks) to identify these behavioural sub-types.

Like Ekman (1982) and others, Bowers et.al. maintain that the emotion system is underpinned by an evolutionary substrate that enables us to decipher non-verbal social displays of other members of the species, it is present very early in life and remains relatively constant throughout the adult life-span. They suggest that it represents one of the elemental building blocks of "social cognition" and their evidence to date supports this notion, finding that "normals" have little difficulty "reading" facial expressions and prosody - as reflected in the performance of normal adults and children on the FAB sub-tests.

Based on studies of neurologically impaired patients, Bowers et. al. (1991) found that the ability to identify the meaning of non-verbal affect signals is dissociable from general perceptual abilities and a dissociation exists between recognition of facial affect versus recognition of emotional prosody. Furthermore, a dissociation also exists between recognition of affect signals and expression of these signals. Bowers et.al. are currently in the process of collating evidence from those suffering from Parkinson's Disease.

1.6. Review of the clinical literature on emotion processing.

In addition to theory driven accounts of emotion processing in neurologically impaired individuals, the impetus for much of the clinical study of emotion processing in these populations has been related to patient care, that is, the idea that we should attend to the emotional impact of the disease as well as functional attention to need. In trying to attain a greater understanding of the nature and course of emotion processing, we might then

find it possible to target treatment interventions e.g. behaviour management that is sensitive to the feelings of the patient and not just his/her routine care. In addition, it may be possible to generate advances in the delivery of more effective psychopharmacological interventions e.g. for depression in late stage dementia.

There has been little systematic study of emotion processing in AD to date, although there are some scattered references to changes in "emotionality" over the course of the disease which largely reflect research into expression of emotion, rather than recognition of emotion. For example, Burns, Folstein, Brandt, & Folstein (1990) report increases in anger and paranoia and decreases in interest over the course of the illness and Reisberg, Franssen, Sclan, Kluger & Ferris (1989) report more specific changes as assessed by the Global Deterioration Scale (GDS). Their findings indicate that early on, anxiety is prominent; in the middle stages, a decrease in affectivity is described, and tearfulness and shame predominate. Later, an increase in overt agitation is often seen, with accompanying paranoia and separation anxiety, and by the end stages of the illness, non-verbal agitation becomes more apparent. In a further study, Cohen-Mansfield (1990) saw increases in non-verbal expressions of anger as verbal expressions of anger decreased. Finally two small-group studies of facial expressions of end-stage AD patients undertaken by Jansson, Norberg, Sandman, Athlin & Asplund (1992,1993) discovered that while patterned facial activity may degrade, expressions could be interpreted as reflecting emotional responses to caregiving routines.

Following on from these studies, Magai et.al. (1996) looked at emotional aspects of behaviour in patients with AD. They had two questions in mind: firstly, what is the quality of emotional responsivity in dementia patients? Do they retain the ability to express basic emotions? Secondly, how does emotional expression change from mid-late

stage? Magai et.al., were looking for stage-linked changes in emotion expression that parallel those found in cognitive and functional status.

In accordance with evidence from Izard (1991) they suggested that emotion is subserved by a phylogenetically older brain system than that which serves cognition and as a result, they did not expect a 1:1 correspondence between declines in affect and cognition during the dementing process, and this hypothesis was supported.

They used observational methods of testing and found that despite the low frequency of expressive behaviour in late-stage dementia patients, some of the more basic human emotions were preserved and meaningfully expressed. In addition, emotional expressions bore a functional relation to patient likes and dislikes, with patient's retaining a good deal of ability to signal their wants, needs goals and fears. Although there is no way of establishing whether facial expressions actually index underlying feeling states in patients who are unable to provide a self-report, they felt that the convergence across measures of affectivity, as well as the coherent association between particular expressions and particular environmental contingencies, strengthened their position.

1.7. Summary and introduction to the present study.

In reviewing the theoretical and clinical literature regarding emotion processing, it has become clear that there is growing evidence to support notions of modularity and dissociation within this system. What is needed now is further systematic study to test this hypothesis and bring together the theoretical and experimental evidence regarding emotion processing in those suffering from AD.

With this in mind, the aim of this study was to examine the ability of those suffering from "moderate" AD (classified according to the NINCDS-ADRDA criteria for Alzheimer's Disease; McKhann, Drachman, Folstein, Katzman, Price & Stadlan 1984). to identify the meaning of non-verbal communicative signals of emotion.

The study used the Florida Affect Battery (Bowers et.al. 1991) in conjunction with comprehensive tests of cognitive ability, general medical health and neurological examination, in an attempt to investigate whether individuals with different levels of cognitive impairment in AD can recognise and comprehend the emotional state of others, using cues provided by facial expression or intonation of speech.

1.7.1. Methodological considerations

When studying a population subject to the progressive cognitive decline associated with AD, the researcher has available either (or both) of two strategies: (1) *cross-sectional*, whereby all measurements of any individual are taken at one point in time; (2) *longitudinal*, in which the same individuals are measured, on the same variables, at several points during the course of the study.

In seeking to achieve the aims of this study, both designs, with their relative merits and difficulties, were considered and have impacted on the final decision that was made.

Initially a longitudinal design, with cognitive and affect measures taken over time, was considered, but there were a number of difficulties with this. In terms of practicality, the time boundaries within which the study had to be carried out made it difficult to use a longitudinal approach.

All AD patients were recruited through a memory disorders clinic whose procedure and protocol guidelines regarding sampling of patients suffering from AD suggest an optimum interval of six months between each test procedure. In view of the length of time taken to research the FAB as an appropriate tool, and the difficulties in obtaining a well-defined AD sample, it became increasingly unrealistic to consider a longitudinal design. In addition, this design suffers from the problem of attrition rates, practice or familiarity with the tasks and issues regarding the time at which measures are taken. These difficulties, taken in combination may progressively affect results.

Following consideration and subsequent rejection of a longitudinal design, a cohort study, using 'time since diagnosis' was investigated. The difficulty with this approach was that the insidious onset of AD, and the differences in subjective reporting of initial symptoms by sufferers and carers, made it impractical to use 'time' as a baseline measure.

Although a cross-sectional design has the disadvantage that differences between the groups may be produced by sample differences in variables other than the independent variable, and potential risks of floor and ceiling effects, it was used in this study. The design was, however, generated with an awareness of the imposed time limitations and recognising the relative strengths and weaknesses of both longitudinal and cross-sectional approaches.

1.7.2. Ethical Considerations

In addition to general methodological issues raised in researching the AD population, a number of broad ethical considerations underpin this study.

One of the key factors dominating the design of this study, related to maximising participant numbers. Sabat (1994) has criticised researchers for an insensitive approach to the assessment of participants with dementia. He suggests that little account has been taken of the social-psychological environment in which people are tested, and maintains that the method of study and the environment can have profound effects upon the performance of the person being observed. He goes on to say that the emotional consequences of ignoring these factors can lead to high levels of anxiety, thus producing decrements in performance.

Of particular relevance to this study, Sabat, Wiggs and Pinzizotto (1984) observed intact cognitive and social abilities; particularly memory, language and emotional expression in demented patients' own homes, when these were not observed in the laboratory or clinic. Sabat (1994) argues, therefore, that the way in which a study is designed, the way behaviour is recorded and the environment in which the assessment is carried out, may all contribute to the deficits seen in dementia. He criticises researchers for assuming that all behaviour from dementia sufferers is the product of neuropathology rather than the effect of social circumstances and test situation. This labelling of behaviour has also been strongly criticised by Kitwood (1990).

So, designing studies that are acceptable to participants is an important responsibility for the researcher, particularly in relation to those suffering from dementia. Table 1. outlines some of the factors considered in relation to the design for this thesis.

Factor	Details
1. Consent	Does the individual have the capacity to consent to the research and/or is proxy consent acceptable?
2. Distress	What effect is the assessment likely to have on levels of anxiety, fear, embarrassment, frustration, or anger?
3. Face validity	Does the experiment 'make sense' to the participants?
4. Failure	How obvious is it when an individual fails?
5. Familiarity with surroundings	Will the assessment be conducted at the participant's own home or in the department?
6. Familiarity with testing	Will the participant be familiar with the methods or equipment being used?
7. Fatigue effects	How repetitive is the assessment? How much time will assessment take?
8. Physical comfort	Are the room temperature, lighting, and sound level comfortable?
9. Physical factors	Has vision, hearing, limb weakness been accounted for?
10. Time of day	At what time of day will the participant be seen? Who chooses?

Table 1. Factors to consider in designing and conducting studies for vulnerable individuals.

Given that participants agree, there are a number of ways to make the experience as positive as possible. Table 2. details some experimenter variables, which might influence the results of studies. Ultimately, the needs of the individual come before the research programme. However, only by maximising the individual's performance can meaningful conclusions be drawn from any findings. Thus the needs of the individual and the needs of the research are not in conflict.

Variable	Details
1. Appearance	Participants are expecting to meet someone who looks professional
2. Confidentiality	The participant may disclose sensitive information; the researcher must have some means of dealing with this
3. Explanations	Researchers should explain how the research will help our understanding of the disorder
4. Feedback	Once the assessment is over it can be helpful if the researcher asks for participants' views on the experiment. The researcher should always answer any questions about the research, even if the answer is to say "I don't know".
5. Instructions	Avoid complex language, keep instructions short, repeat them as often as necessary, summarise, write key instructions on 'crib cards'
6. Introductions	Researchers should always wear an identity card, write clear information sheets, send a personalised letter, and follow up with a telephone call a specified number of days later
7. Sensitivity	Be aware of the potential for distress, anger, embarrassment, stop if necessary, debrief.

Table .2. Experimenter variables which may influence results of studies

Finally, cognitive psychologists have historically paid little attention to individual difference variables in experimental research. One particularly important variable is that of circadian arousal. There are age differences in periods of peak arousal, with most older adults performing optimally in the morning, whereas many younger adults (especially students) have their peak times in the evening (May and Hasher, 1998; May,

Hasher, and Stoltzfus, 1993). All participants in this study were seen between 9 am and 12 midday at their own request.

1.7.3. Statement of hypotheses .

The following hypotheses were tested:

1. There will be a difference in scores on cognitive tests, as measured by Mini-Mental State Examination (MMSE Folstein 1975) and the Florida Affect Battery (FAB, Bowers et.al. 1991) between a Comparison Group of healthy older adults (1) and an Alzheimer Disease group (2) when controls are in place on variables of age, gender, 'handedness' and years in education.

2a. Scores on cognitive tests and FAB in group 1, will reflect those seen in the normal population.

2b. In group 2, scores on cognitive tests will be depressed relative to group 1, but scores on the FAB will not be depressed to the same extent. This will be assessed by looking at the analysis of variance (ANOVA) in terms of the interaction of "group" (between subject factor" and "score type" on the FAB and cognitive measures (within subject factor).

3. There will be no relationship between the scores on face recognition and those on prosody tasks in the AD group. This will be evaluated by using a test of correlation.

CHAPTER 2. METHOD

2.1 Introduction

As well as describing the recruitment criteria and assessment methods employed in this thesis, this chapter will highlight some of the equally important 'process' issues considered in designing and conducting this piece of research. The 'process' (i.e. how the research is conducted) can be distinguished from the 'content' (i.e. 'what is done'). Process includes such issues as how tests are conducted, how the studies are designed, how recruitment can be maximised and how performance can be optimised.

2.2 Design

The study is cross-sectional in design. It involves two groups of participants in a repeated measures format, using within and between subject comparisons analysed via Analysis of Variance (ANOVA) interaction. While a longitudinal approach was considered, a pragmatic approach was taken in recognition of the time limits imposed on this piece of work, and in response to many of the difficulties posed in relation to re-testing this population over time.

2.3 Participants

Data from 24 individuals are reported in this thesis. Two groups of participants took part in the study, with twelve individuals in each group. Attempts were made to match participants for age, sex, 'handedness' and years in full-time education.

2.3.1 Alzheimer disease group

The Alzheimer disease group consisted of eight females and four males meeting the diagnostic criteria of 'Probable Alzheimer's Disease' developed by NINCDS/ADRDA (McKhann et.al.1984). The mean age of the group was 75.5 years (SD=7.5), range 60-89 years. The mean number of years in full time education were 10.5 (SD=.99) range 9-12 years. All participants were right-handed. Each AD patient involved in this study attended a memory disorders clinic, where they underwent thorough medical, psychiatric and psychological screening, in an effort to rule out any other treatable pathology that could explain the dementia.

2.3.2 Comparison group

The healthy older adult (HOA) comparison group contained five females and seven males. The mean age of the group was 74.4 years (SD=7.1) range 62-85 years. The mean number of years in full time education were 10.2 (SD=1.0), range 9-12 years. All participants were right handed, had no previous history of physiological or psychological difficulties of note and were taking no medications likely to affect cognition (e.g. newly prescribed anti-depressants).

2.3.3 Exclusion Criteria for AD and HOA groups

For each individual with dementia who was recruited successfully (N= 12), at least five other individuals were considered or contacted but found to be unsuitable or unwilling to help. The inclusion criteria for the AD group in this study were:

- Older adults, aged between 60 –85 years.
- Diagnosis of 'probable' AD (based on NINCDS/ADRDA criteria, McKhann et.al.1984)
- MMSE between 10-22.
- No evidence of depression, or use of medications likely to affect cognition (cholinesterase inhibitors, newly prescribed antidepressants).
- No evidence of concomitant vascular problems at a level likely to increase the risk of including 'mixed' or vascular dementias.
- No significant visual or hearing deficits.

Thus, the sample of individuals with dementia is highly selected. In addition, they were selected through recruitment via a memory disorders clinic. While this increases the likelihood that the diagnosis will be correct, this sample may not reflect the population of individuals with dementia living in the community. Individuals are referred to memory clinics for a number of reasons e.g. they or their relatives are 'demanding' and the General Practitioner decides to refer as a way of dealing with this. Alternatively, it may be that they are premorbidly high functioning and their difficulties are therefore more likely to be noticed or more readily regarded as worthy of investigation. Commonly the referring agent has found it difficult to make a clear diagnosis and is seeking another professional opinion. Finally, these individuals were selected by their willingness to participate in research despite having to cope with a disorder such as dementia.

With regard to the HOA group, nine of those who agreed to participate were the spouses of those individuals recruited to the AD group. The remaining three were recruited from family and friends of the experimenter. Again, there are similar sampling problems

inherent in the recruitment of this group, and they may be no more representative of the general population of healthy older adults than are the participants with dementia representative of the general population of individuals with dementia. Where possible, however, every effort has been made to recruit individuals of equivalent age, gender, 'handedness' and years in full-time education despite the difficulties in recruitment.

2.3.4 Financial incentives

Given that the research may highlight an individual's difficulties it is surprising that many agreed to take part. There was no financial incentive involved in recruitment of participants for this study and it appears that some individuals volunteer because they have a general wish to be helpful, and some probably do not feel that they can say 'no' or 'refuse' (despite carefully worded consent procedures). Fortunately, many agree because they wish to help others who may have similar problems in the future. It is as if taking part in the research, even when they know it will not benefit them, is a way of making sense of their difficulties.

2.4 Selection of Assessment Materials

The tasks making up the core of this thesis have been chosen in light of the central theoretical questions being posed, but have also attempted to take account of factors such as design, conduct, and recruitment. This has significantly impacted on both the study design and materials used.

2.5 Measures and assessments

2.5.1 Medical and psychiatric assessment of AD group

AD patients were referred either by their GP, a hospital consultant or other member of the community mental health team. All patients were assessed by a physician and a psychologist. The physician took a history both from the patient and an informant (usually a family member or friend). Particular attention was paid to presenting symptoms, onset (sudden or insidious), progression (static, stepwise, or gradual), and presence of memory and other cognitive problems, as well as affective or behavioural difficulties.

Past medical history was also evaluated, emphasising conditions that might be associated with cognitive impairment, medications, and substance abuse (especially alcohol). Family history of depression and organic or neurological disease was also noted. A depression rating scale was used (Cornell Scale for Depression in Dementia, Alexopolous, Abrams, Young, and Shomoian, 1988), and patients were referred for assessment by a psychiatrist if there was any clinical suspicion of affective or psychotic illness or if they scored above the cut-off on the depression rating scale. The psychiatrist interviewed the patient and their relative or carer separately in order to assess for depression and/or other psychiatric conditions which might mimic or exacerbate cognitive impairment. Behavioural and functional deficits were measured in interview with the carer using one of two scales: the shortened Stockton Rating Scale (Gilleard and Pattie, 1977), and the Bristol Activities of Daily Living Scale (BADLS; Bucks, Ashworth, Wilcock, and Siegfried, 1996). The Stockton was not designed specifically for use in dementia. The BADLS was designed and validated for use with carer informants

of dementia sufferers living in the community, and has been shown to be sensitive to change (Byrne, Bucks, Hughes, and Wilcock, 1998). The BADLS was adopted in the Bristol Memory Disorders Clinic (BMDC) in 1996. The Hachinski Ischemic Scale was also administered (Hachinski, Iliff, Zilhka, Du Boulay, McAllister, Marshall, et al., 1975) using a modified form designed to improve reliability (O'Neill, Gerrard, Surmon, and Wilcock, 1995).

A comprehensive physical examination was undertaken including neurological examination assessing for signs of apraxia, aphasia, agnosia, extra-pyramidal signs, and primitive reflexes. Laboratory blood testing and Computerised Tomography (CT) scans of the brain were also carried out. CT brain scans were assessed in a monthly multi-disciplinary conference where they were rated blind by the consultant neuroradiologist before being discussed. Where clinically indicated, some patients were also referred for single photon emission computed tomography (SPECT) or magnetic resonance imaging (MRI).

2.5.2 Neuropsychological Assessment of AD group

The neuropsychological assessment used in the BMDC was designed specifically for the clinic and validated in a sample of healthy older individuals and samples with probable Alzheimer's disease and vascular dementia (Bucks and Loewenstein, 1999). The assessment takes about one hour to administer and every patient undertook and completed the assessment at each clinic visit, allowing comparison of change in performance over time. Details of the tests used can be found in Table 3.

Test	Source	Description
Mini-Mental-State Examination	MMSE: Folstein et al., 1975	A test of general cognitive function; measures orientation, calculation, naming, memory, writing and praxis
National Adult Reading Test	NART: Nelson and Willison, 1990	Gives estimate of premorbid IQ due to the correlation between the ability to read 50 irregular English nouns and Wechsler Adult Intelligence Scale – Revised (WAIS-R, Wechsler, 1981)
Similarities	WAIS-R subtest, Wechsler, 1981	Assesses the ability to abstract logical relationships
Picture Completion	WAIS-R subtest, Wechsler, 1981	A test of general non-verbal problem solving
Digit Span	WAIS-R subtest, Wechsler, 1981	Assesses short term memory or attention span, both simple and complex
Story Recall – Immediate and Delayed	Adult Memory and Information Processing Battery, AMPIB: Coughlan and Hollows, 1985	A test of verbal recall for a prose passage, both immediately and after a delay
Visual Recognition	Middlesex Elderly Assessment of Mental State, MEAMS: Golding, 1989	A test of visual recognition
Hopkins Verbal Learning Test	HVLT: Brandt, 1991	A test of verbal learning for 12 semantically related words over three trials. Has a verbal recognition component
Frenchay Aphasia Screening Test	FAST: Enderby, Wood, and Wade, 1975	A test of expression, reading and aural comprehension
Benton Verbal Fluency	FAS: Lezak, 1995	Assesses the ability to generate words beginning with one of three letters (F, A, and S) in one minute. Thought to tap into both semantic memory and executive function
Weigl's Colour Form Sorting Test	Modified CFST: Byrne, Bucks, and Cuerden, 1998	Assesses the ability to shift logical set from colour to shape or vice versa
Cube Analysis	Visual Object Space Perception Battery, VOSP: Warrington and James, 1991	Assesses visuo-spatial function
Digit Copying	Kendrick, 1985	A measure of psychomotor speed

Table 3. The Bristol Memory Disorders Clinic neuropsychological assessment battery

2.5.3 The Mini-Mental State Examination

The MMSE (Folstein, Folstein, and McHugh, 1975) is a test of general cognitive function used extensively in clinical and research settings. It has been used in this thesis as a selection criterion and general measure of cognitive function; therefore its scoring is critical. The MMSE offers two alternative forms of measuring attention (serial subtraction; S7, and backward spelling; WB). Previous research has shown that these two tasks are not equivalent (Olin and Zelinski, 1991; Ganguli, Ratcliff, Huff, Belle, Kancel, Fischer, et al., 1990). Although most investigators have recommended the use of serial subtraction (Ganguli et al., 1990: Molloy, Alemayehu, and Roberts, 1991), recent work (Wilson, Byrne, Bucks, and Scott, submitted) has shown that backward spelling is less subject to differences between men and women. Recently, attention has also been drawn to inconsistency in the scoring of backwards spelling (Gallo and Anthony, 1994). The standardised method they suggested was adopted in the Clinic, and used in this study, (see Appendix 1).

2.5.4 Diagnosis

Each patient's assessments were discussed in a multi-disciplinary case conference at the end of each clinic. Diagnostic criteria were applied as described below. Only patients with unequivocal and stable diagnoses were recruited. Longitudinal evidence from the BMDC suggests that 70% of diagnoses made by the clinic are stable 6 months later (O'Neill, Surmon, and Wilcock, 1992), rising to 90% at one-year follow-up. Participants were followed longitudinally for between 6 months and 2 or more years and any individuals whose diagnosis was subsequently changed were excluded from selection. None of those assessed has come to autopsy. However, autopsy confirmation of other BMDC patients over the last 5 years suggests a hit rate of between 90 and 95% (personal

communication, Professor Gordon Wilcock). Where errors are made, it is usually because autopsy reveals two pathological processes (e.g. AD and vascular pathology). Whilst autopsy confirmation of these diagnoses would be preferable, the stability in diagnosis increases the likelihood that these are 'true' cases of each disease. Individuals with depression or taking medications likely to affect cognition (cholinesterase inhibitors, and newly prescribed antidepressants) were excluded from the studies as were any individuals found to be suffering from prosopagnosia and/or Capgras syndrome. Participants were recruited if they were suffering from early to moderate impairment, as measured on the MMSE (Folstein et al., 1975). MMSE scores ranged from 10 to 22.

2.5.5 Diagnosis of probable Alzheimer's disease

A diagnosis of probable Alzheimer's disease was made according to the NINCDS-ADRDA criteria and DSM-IV (McKhann et al., 1984, APA, 1994). Patients with a score of 5 or greater on the Hachinski scale (Hachinski et al., 1975) were excluded to reduce the possibility of including vascular dementias.

2.5.6 Measures used in sampling AD and HOA groups

Data from the MMSE (Folstein 1975) were obtained on all participants. This is the most widely used and studied measure of cognitive impairment. It has the advantage of brevity, ease of administration, and high inter-rater reliability. MMSE and Bristol Memory Disorders Clinic (BMDC) scores for the AD group were taken retrospectively from tests recorded in the memory clinic within the preceding four months, while MMSE scores for the HOA group were gained as part of the research interview.

The Florida Affect Battery (FAB: Bowers et.al. 1991) was used to measure emotion processing. It is designed to assess the perception of facial and prosodic affect under a variety of task demands. The battery includes 10 different subtests (5 facial, 3 prosodic, and 2 cross-modal) described below. Five different emotions (happiness, sadness, anger, fear, neutral) are used across these subtests and scores are expressed as percentage correct response.

Facial Affect Tasks: The stimuli used in constructing the facial affect tasks include four different women, each displaying one of five different emotions. Black and white photographs of these faces were made and rated by 50 college students and 20 normal elderly. All the face stimuli used in the battery were rated in the same way and exceeded greater than .80 reliability to be included as stimuli. Depending on the subtest (see below) these facial stimuli are presented either individually or in vertical arrays. Twenty trials are given in each of the facial subtests.

- *Subtest1: Facial Identity Discrimination.* Participants are shown pairs of unfamiliar faces and have to determine whether the faces are the same or a different person. The stimuli are photographs of women, each with a neutral facial expression. The hair is covered to reduce nonfacial cues for identification. Half the trials consist of two photographs of the same person, and the remaining trials are photographs of different people. This identity discrimination task can serve as a perceptual 'control' for the facial affect tasks.

- *Subtest 2: Facial Affect Discrimination.* In this task, participants are shown pairs of faces and have to determine whether the faces depict the same or different emotional expressions. Each trial consists of two photographs of two different women. On half

the trials, the two women display the same facial affect (i.e. 10 'same' trials) and on the remaining trials the women display different affects (i.e. 10 'different' trials).

- *Subtest 3: Facial Affect Naming.* This task requires participants to verbally label facial expressions. The participants are shown individual faces and asked to name the emotion depicted by each (i.e. happy, sad, angry, frightened, neutral).

- *Subtest 4: Facial Affect Selection.* This task assesses the ability to select target facial expressions named by the examiner. On each trial, participants are shown five pictures of different women, each expressing a different facial emotion. They are asked to point to the picture of the face that corresponds to the emotion named by the examiner (i.e. 'point to the angry face').

- *Subtest5: Facial Affect Matching.* Participants are asked to match the photograph of an emotional face to another face with the same emotional expression. They are shown a target emotional face on one card. On the facing card are five women, each having a different emotional expression. The task is to match the target expression with its counterpart on the multiple response page.

Prosody Tasks: These are designed to complement the facial perception tasks. The first three prosodic subtests (6, 7, & 8A) consist of a set of semantically neutral simple sentences (e.g. the shoes are in the closet) spoken in various nonemotional or emotional tones of voice. The fourth prosody subtest (8b) involves affectively intoned sentences whose semantic content either conflicts with (i.e. 'I won the lottery' said in a sad tone of voice) or is congruent with, the prosodic message (i.e. 'I won the lottery' said in a happy tone of voice).

- *Subtest 6: Nonemotional Prosody Discrimination.* This task assesses the ability to process propositional prosody and serves as a control for the affective prosody tasks. Participants listen to 16 pairs of sentences, spoken in either an interrogative (fish jump out of water?) or declarative (fish jump out of water) tone of voice. On half the trials, two sentences convey the same propositional prosody (i.e. both are statements or both are questions). For the remaining trials, the two sentences differ in their propositional prosody (i.e. one a statement and one a question). The participant indicates whether the sentence pairs are the same or different in terms of prosody.

- *Subtest 7: Emotional Prosody Discrimination.* Participants are presented semantically neutral sentences that are spoken in the same or different emotional tone of voice. They judge whether the affective prosody is the same or different in both sentences. Half the items are 'same' (10 trials) and half are 'different' (10 trials).

- *Subtest 8A: Name the Emotional Prosody.* This task assesses the ability to verbally label affective prosody. Participants listen to semantically neutral sentences spoken in one of five affective tones of voice (happy, sad, angry, frightened, neutral).They are asked to name the emotional prosody of each item. Twenty trials are given, with four repetitions of each of five affects.

- *Subtest 8b: Conflicting Emotional Prosody.* Participants listen to affectively intoned sentences whose semantic content may differ (i.e. conflict) or parallel the prosodic message. Thirty-six sentences are given and participants judge the affective tone of the speaker in each. In half the trials, the semantic content and prosody conflict (i.e. 'all the puppies are dead' said in a happy tone of voice), such that the participant must disregard 'what the message says'. In the remaining sentences, the semantic

content and prosody are congruent (i.e. 'all the puppies are dead' said in a sad tone of voice).

Crossmodal Tasks: In these tasks participants are required to match the affect conveyed by facial expression with a corresponding prosodic stimulus, or vice versa. Each task consists of 20 trials.

- *Subtest 9: Match Emotional Prosody to an Emotional Face.* Participants are shown a card with three photographs of the same woman, who is expressing three different facial emotions. At the same time, the participant listens to an audiotaped sentence spoken in an emotional tone of voice by a female speaker. They are asked to point to the emotional face that corresponds to the emotional tone of voice of the speaker.

- *Subtest 10: Match Emotional Face to the Emotional Prosody.* Participants are shown a photograph of an emotional face. At the same time, they listen to three pre-recorded sentences, each spoken in a different emotional tone of voice. They are asked to indicate which sentence best corresponds to the facial expression.

Finally, a number of additions were included in using the FAB. These were prompted by the work of Cadieux and Greve (1997) who felt that memory load had a significant impact on the results demonstrated by the AD group in their own study. For each subtest memory load was decreased by providing the participants with a cue sheet explaining the task (e.g. 'match face to voice') or a sheet of the target emotions from which to select (i.e. happy, sad, angry, frightened, neutral.) In addition, on subtest 10, each set of three sentences was presented twice, as recommended by Bowers et.al. (1991) in the test manual.

These additions were made in an attempt to explore under what conditions a person with dementia could actually complete a task accurately. It is easy to find a deficit in dementia. It is more difficult, and more interesting, to find out under what conditions that deficit is not found.

2.5.7 Phenomenological approach

This research has also gathered information on performance in the AD group from an additional and much neglected source - the participants themselves. In this study, any observations or comments made during and following testing were noted by the examiner. Psychologists working with individuals with dementia have routinely assumed that they are incapable of commenting veridically on their own performance. Indeed, in dementia, lack of insight was once thought to be a cardinal feature.

> "A history of memory impairment is particularly characteristic of Alzheimer's disease, but it is usually described by secondary informants. In fact, it is so unusual for the demented patient to complain spontaneously of this that, when he does, it suggests a diagnosis of pseudodementia " (Roberts, 1984).

Whilst insight may be impaired in some dementias very early on (e.g. frontal lobe disorders), researchers have begun to show that patients with dementia, including AD, can comment on their cognitive abilities (Emmerson and Bucks, 1997).

More specifically, clinical experience of testing shows that during or immediately after a task, many patients can and do comment voluntarily on their performance and the cognitive processes underlying it. This research has attempted to take advantage of this phenomenon. Often, this phenomenological information can help to shed light on the

processes underlying performance. Clearly, the downside of exploring a participant's thinking processes during a task is that it may interfere with that task in a number of ways. Participants may become more aware of, and distressed by, their failure to perform the task. They may interrupt task performance to comment and so affect critical timing or other such measures. They may become distracted from the task. Finally, the researcher may find themselves in uncomfortable territory with which they are not equipped to deal. For example, when a patient with dementia asks the experimenter to explain what is wrong with them or asks about treatment options.

2.6 Procedure

Wherever possible, assessment was kept to 1 hour. If longer was required, participants were given the choice to divide the assessment over two sessions. They were also offered a choice of location for testing (at their home or at the Clinic) and a choice of time of day. They all chose to be assessed at home in the morning. The advantage of this is that they were generally more comfortable and confident. The disadvantage is that it was more difficult for the assessor to control distractions such as unscheduled visitors and the telephone. During the recruitment process, individuals were not included if they were known to be anxious or distressed by assessment in clinic, or had previously contributed to a research study and had found the experience particularly difficult.

2.7 Consent

There are a number of broad issues of consent which underpin recruitment and sampling of participants suffering from Alzheimer's disease and other dementias. These are outlined in Appendix 2.

In the research reported in this thesis, consent was obtained in all prospective studies along the following lines:

1. A letter of recruitment was sent to the participant briefly explaining the study and introducing the researcher. All letters were signed by Professor Wilcock, Consultant in Care of the Elderly. (Appendix 3)
2. The letter was followed by a telephone call a few days after its arrival, again explaining the study and what would be required of the participant
3. Verbal consent and a date to visit the participant was obtained over the telephone.
4. At the assessment interview participants again read and kept a copy of the recruitment letter in the presence of their spouse/carer which stated:

   The name of the researcher

   The purpose of the research

   What participants would be asked to do

   How long the assessment would take

   Assured participants of confidentiality .

   Assured them that their decision would not affect any future treatment

   Reminded them of their right to change their minds if they agreed
5. Written consent was obtained (Appendix 4).
6. During the assessment the researcher watched for signs of agitation, distress, fatigue, or anxiety. If the participant appeared to be suffering any of these a pause would be taken, and they would be asked if they wished to continue. Even if they said yes, if it was considered that they were only doing so because they felt unable to refuse, the interview was terminated.

7. At intervals during assessment, the investigator would ask participants for feedback on how they were feeling.

Finally, the prospective research study was approved by Frenchay NHS Trust Research Ethics Committee (Appendix 5).

CHAPTER 3. RESULTS

3.1. Description of methods of data analysis

Statistical analyses were calculated using SPSS for Windows (Norusis, 1997) and graphs were plotted using MS-Exel for Windows (Microsoft, 1983). Descriptive data of each variable were analysed for measures of central tendency and displayed as frequency distributions. In general, it was considered that the use of parametric statistics (ANOVA, T-Test and Pearson Product Moment Correlation) was justified. Where assumptions of normality and homogeneity of variance were at risk of being violated within ANOVA, the Geisser-Greenhouse (1958) conservative F-test was used, without substantially affecting conclusions.

Repeated measures ANOVA'S were used to evaluate within and between group interaction. Pearson product moment correlation, partial correlation and independent sample T-Tests were utilised to test predictions made before the study. In addition, paired sample T-Tests were used to test for significance of differences between FAB error scores, which were identified after the study.

FAB score and MMSE scores were expressed as 'percentage correct scores' and an alpha level of .05 was employed throughout.

3.2. Comparison of groups

Independent samples T-Test showed no significant differences between groups for age (t=.361, df=22 , p=.721) and years of education (t=.796, df=22 , p=.435).

Analysis of gender in the sample using the chi-square test demonstrated that there was no significant difference between groups on this variable (X^2 =1.51, df=1, p=.219). All participants were right handed.

3.3 Hypothesis 1

Hypothesis 1 stated that there would be a difference in scores on cognitive tests (as measured by MMSE) and the FAB between the AD group and HOA group. Means (standard deviation) and ranges of scores on MMSE and FAB are given in Table 4.

Group	AD n=12	HOA n=12
MMSE		
Mean	62.5	93.3
(Standard deviation)	9.60	3.20
Range	40-73	90-97
FAB		
Mean	79.2	87.3
(Standard deviation)	4.70	2.60
Range	72.5-88	82.5-91

Table 4. Means (standard deviations) and ranges of FAB and MMSE scores

Independent samples T-Test showed that there was a significant difference between groups on FAB scores (t=-5.213, df=22, p=<.001) and on MMSE scores (t=-10.51, df=13.3 equal variances not assumed, p=<.001).

3.4 Hypotheses 2a and 2b

Hypothesis 2a stated that scores on cognitive tests (as measured by MMSE) and FAB in the HOA group, would reflect those seen in the normal population.

This was assessed by calculating the value of the 't' statistic, using the means and standard deviations of MMSE and FAB from the HOA group and normative data on MMSE and FAB (Crum, Anthony, Bassett, Folstein 1993 ; Bowers et.al. 1991) respectively. Data was analysed using weighted averages rather than taking the simple arithmetic mean, thus providing a pooled variance estimate, in recognition of the differences in observations between groups, as recommended in Howell (1992).

There was no significant difference demonstrated between the groups on either MMSE ($t=1.11$,df 576, $p=>.05$) or FAB ($t=1.29$,df 23, $p=>.05$). Hypothesis 2a was, therefore, supported.

Hypothesis 2b stated that, in the AD group, scores on cognitive tests would be depressed relative to the HOA group but scores on the FAB would not be depressed to the same extent.

This was assessed by looking at the interaction of 'group' (between subject factor) and 'score type' on the FAB and MMSE (within subject factor) using a repeated measures ANOVA. Results of analysis are shown in Figure 1.

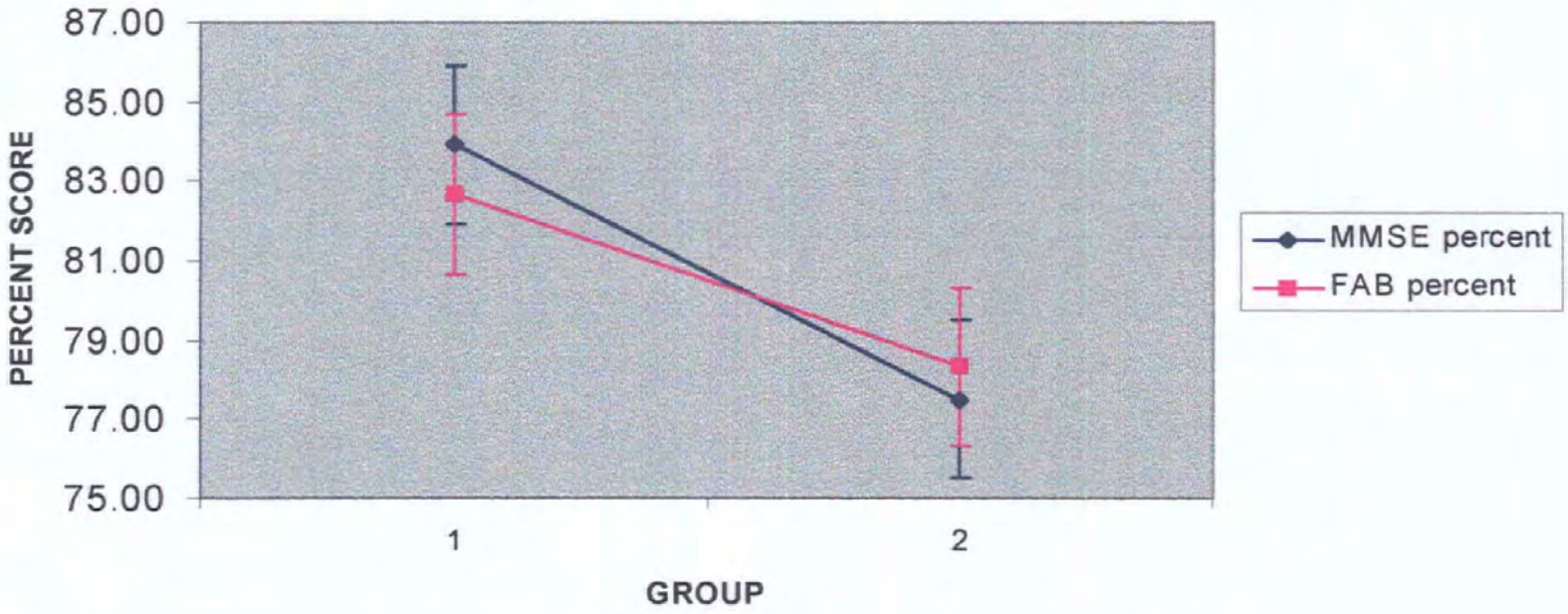

Figure 1. Interaction between HOA (Group1) and AD (Group2) on FAB and MMSE

Repeated measures ANOVA demonstrated a significant interaction of Group x Score ($F(1,22)=67.9$, $p=<.001$). To determine whether the assumption for homogeneity of variance was met in using ANOVA, an 'Fmax' analysis was undertaken to investigate whether the variances were significantly different between the groups ('Fmax' $(2,11)=9.21$, $p<.001$ therefore, we need to be cautious in interpretation of the ANOVA and conservative in attributing effects seen.

With this in mind, the Geisser-Greenhouse (1958) conservative F-Test was applied to the data set, ($F(1,11)=67.9$, $p<.001$) and results were still highly significant, with FAB scores holding up well relative to MMSE scores in the AD group.

Another way of looking at the interaction was to take the 'difference' scores between the groups (i.e. FAB% -MMSE%). The logical basis for this is if scores on the two tests in one group are closer together than scores on the two tests in the other group, there will be a significant difference between the two sets of 'difference' scores. This then permitted the use of the distribution free version of the T-Test, or other nonparametric tests on the data if required. Means (standard deviation) and ranges for 'difference' scores are displayed in Table 5.

Group	AD n=12	HOA n=12
Mean	16.7	-6.00
(Standard deviation)	8.4	4.54
Range	7-32	-12-1.9

Table 5. Mean (standard deviation) and range between AD and HOA groups on 'difference' scores.

Independent samples T-Test, with equal variances not assumed, again demonstrated a significant difference between the groups (t=8.24, df,17, p=<.001).

Returning to the assumption of homogeneity of variance in ANOVA and the degree of variance in FAB mean scores in the AD group, it was decided that correlational analysis of specified BRACE subtest scores would be useful to calculate the amount of variance explained by:

- Concentration and working memory (via scores on 'digit span' subtest from BRACE battery).
- Memory load (via scores on 'immediate recall' subtest from BRACE battery).
- Visuo-spatial perception (via scores on 'cube analysis' from BRACE battery).
- General, non-verbal, problem-solving skills (via scores on 'picture completion' from BRACE battery).

Pearson correlation on these specific subtests demonstrated that:

- 11% of the variance in FAB scores for the AD group was explained by concentration and working memory (r=.329, p=.525).
- 15% of the variance in FAB scores for the AD group was explained by memory load (r=.392, p=.442).
- 9% of the variance in FAB scores for the AD group was explained by visuo-spatial perception (r=.302, p=.340).
- 9% of the variance in FAB scores for the AD group was explained by general non-verbal problem-solving skills (r=.295, p=.570)

3.5 Hypothesis 3

Hypothesis 3 stated that there would be no relationship between scores on 'facial' and 'prosody' tasks in the AD group, as predicted by the 'domain specificity' theory of Bowers et.al. (1993). Tests of correlation, partialling out the effect of MMSE, demonstrated that there was indeed no relationship between the two task types, although this should be interpreted with caution as results show the correlation lies close to the range of significance ($r=.51$, $df=9$, $p=.054$).

Further correlational analysis that did not partial out the effect of MMSE also showed no significant relationship between the two task types, ($r=.48$, $df=10$, $p=.054$) but again, a correlation of .48, though not quite reaching significance, accounts for approximately 25% of the variance. While this may potentially prove clinically important, it should be treated with caution.

In addition to the difficulties associated with attributing effects with levels of significance demonstrated in the correlational analyses, an important consideration in rejecting the null hypothesis is that these correlations are based on small sample size ($n=12$) and low power. Using the power calculation for Pearson's r described in Howell (1992), and assuming that a conservative estimate of the correlation coefficient in the population is approximately .30, the power in this study is .20 at an alpha level of .05. To obtain a power of .80, data on at least 88 participants would be required. The 'domain specificity' hypothesis is, therefore, not defensible under these conditions.

3.6. Post-study analysis.

In addition to the predictions made before the study, a number of questions arose during the execution of this study related to the way in which the AD group, in particular, was performing across the FAB subtests. As a result, some post-study hypotheses were generated in order to look at the FAB 'error' scores in greater detail.

3.6.1. Hypothesis 1

The AD group will be better at recognising differences in faces and vocal prosody than similarities (as measured by error scores on subtests one and six of the FAB). Means (standard deviation) and ranges are displayed in Table 6.

Subtests	Face	Prosody
Same		
Mean	1.25	2.16
(Standard deviation)	0.96	0.93
Range	0-3	0-3
Different		
Mean	0.42	0.33
(Standard deviation)	0.96	0.89
Range	0-1	0-3

Table 6. Means (standard deviation) and range of same/different error scores in AD group for face and prosody judgements.

Paired sample T-Test showed a significant difference between 'same/different' error scores in the AD group for face recognition (t=-2.419, df=11, p=.034) and for prosody recognition (t=-3.743, df=11, p=.003) with fewer errors made on recognising differences than similarities.

3.6.2 Hypothesis 2

The AD group will be better at recognising differences in emotional expression in faces and prosody than similarities (as measured by error scores on subtests two and seven of the FAB). Means (standard deviations) and ranges are displayed in Table 7.

Subtests	Face	Prosody
Same		
Mean	0.83	2.25
(Standard deviation)	0.72	1.86
Range	0-2	0-5
Different		
Mean	1.41	0.25
(Standard deviation)	1.01	0.45
Range	0-3	0-1

Table 7. Means (standard deviations) and ranges of same/different error scores in the AD group on subtests of face/prosody emotional expression judgements

Paired sample t-tests showed no significant difference on recognition of 'same/ different' facial expression of emotion in the AD group (t=1.61, df,11, p=.239). There was, however, a significant difference on recognition of expression of emotion in the AD group on prosody tasks (t=-3.25, df11, p=.008) with fewer errors made on recognising differences in emotion expression than similarities.

3.6.3 Hypothesis 3

The AD group will be significantly better at identifying the target emotions 'happy' and 'sad' when taken together across the facial and prosody FAB subtests, than identifying the target emotions 'angry', 'frightened' and 'neutral' when taken together across the facial and prosody FAB subtests (as measured by error scores on these tasks).

Each subtest presented participants with the same number of trial items in each category, therefore any differences seen were not due to scale effects. Means (standard deviations) and ranges of error scores in the AD group for each variable are demonstrated in Table 8.

AD Group	Happy/Sad	Angry/Frightened/Neutral
Mean	3.50	4.90
(Standard deviation)	1.50	0.75
Range	1.5-6.5	3.3-6.3

Table 8. Means (standard deviation) and ranges of error scores in the AD group on 'happy/sad' and 'angry/frightened/neutral'.

Paired samples T-Test showed a significant difference in recognition of 'happy/sad' and 'angry/frightened/neutral' within the AD group (t=2.838, df=11, p=.016). They made significantly fewer errors in recognising 'happy/sad' emotional expression in faces and voices than in recognising 'angry/frightened/neutral' items.

3.7 Qualitative data

All comments made by the AD group during and immediately following the test session were noted. Overall, the AD group made eight comments regarding the test materials themselves, and a further ten comments in relation to their perceived performance across particular tasks. A number of these will be addressed in the discussion.

CHAPTER 4. DISCUSSION

4.1 Summary of results

This study investigated the ability to recognise and comprehend the emotional state of others, using cues provided by facial expression and/or intonation of speech, in people suffering from Alzheimer's disease and in a volunteer comparison group of healthy older adults. The experimental condition consisted of a set of tasks involving face and voice affect discrimination problems in which participants had to choose between a number of stimuli presented on cards (facial cues) or on audio-tape (prosody cues). In addition, a measure of general level of cognitive ability was taken in both groups.

The results obtained from pre-study hypotheses give some specific support to the theory that the ability to recognise non-verbal affect cues in faces and/or voices is relatively preserved in AD sufferers when compared to global cognitive ability as measured by MMSE. In addition, some evidence consistent with the prediction that there would be a dissociation between facial and prosody tasks in the AD group was found, although this should be viewed within the context of small sample size and low power.

Post-study analyses demonstrated that the AD group made less errors in identifying 'differences' in faces and voices than 'similarities' on visual and auditory forced choice discrimination tasks. While this held up on tasks requiring identification of emotion in voices, there was no significant difference on discrimination of emotional expression in faces in the AD group. In tasks requiring the identification of a range of emotions (happy, sad, angry, frightened, neutral) demonstrated in faces and voices, the AD group made less errors in identifying 'happy/sad' than 'angry, frightened, neutral'.

4.2 Pre-study hypotheses and implications for theory

Having established that there was a difference in the FAB and MMSE scores between the AD and HOA groups, and that the performance of the HOA group was congruent with that of the older adult population in general, it was discovered that, relative to the HOA group, measures of general cognitive ability were depressed in the AD group, while scores on the FAB were not depressed to the same extent. This finding lends some support to both general and more specific accounts of the way in which the central nervous system is organised.

Firstly, the findings concur with the 'modularity' theory of Fodor (1983) who proposed the notion of distinct neural subsystems within the central nervous system. He maintained that these were relatively independent from one another, and supervised by the central executive. Secondly, the findings support Schacter's (1990) view that it is not only possible to find domain-specific neural units, but selective disconnection or 'dissociation' between these units or modules operating in the central nervous system. Evidence from this study suggests that while those suffering from mild-moderate AD may be impaired on tasks of general cognitive ability, they retain much of their ability to recognise non-verbal emotional cues represented in faces and voices.

More specifically, evidence gained in this study is congruent with the theories of emotion processing described by Bowers et.al. (1985, 1991) which argue that specific neural networks exist that are particularly concerned with deciphering the affective meaning of perceptual signals. Furthermore, the evidence found in this study adds some weight to the proposed notion of the existence of two independent non-verbal affect lexicons: one for faces and one for prosody (Bowers et.al. 1993). The findings

demonstrate that the face/prosody lexicons may function independently of one another, although these results need to be interpreted with greater caution.

Interestingly, these findings also lend support to the theory that the neural subsystem serving emotion may be located in a phylogenetically older part of the central nervous system than that serving cognition (Izard 1987) and so, would not be expected to decline at the same rate or in the same way as cognitive ability. This expectation has been supported here in relation to 'recognition' of emotion, just as it has been previously in relation to 'expression' of emotion in those with AD (Magai et.al. 1996).

4.3 Post-study analysis of FAB error scores and implications for theory

During the execution of this study, a number of intriguing issues arose with respect to the particular number and type of errors seen across FAB subtests in the AD group. At the outset, it is important to remember that few errors were made overall and we need to be circumspect in attributing any findings discovered. Nevertheless, the results of the study raise interesting questions in relation to some of the theories already discussed and may provide the impetus for future research in this area.

With regard to identification of 'same/different' categories on identification of faces and prosody, the AD group made fewer errors on discrimination of differences than similarities. This effect may reflect issues of 'task demand', rather than face or prosody recognition per se. For example, the clinical notion of 'alertness' has been translated into the cognitive concept of 'vigilance' (Allport 1989) and is viewed as the ability to detect a stimulus and readily respond to it. In AD, there is some evidence for gross preservation of vigilance (Lines, Dawson, Preston, Reich, Foster, & Traub 1991) and although

reaction time is generally longer in AD, 'readiness to respond' shows no striking deficit in early to moderate AD (Nebes & Brady 1993). These skills are thought to be related to the ability to mobilise cognitive resources in the direction of a stimulus and in stimulus change.

It may be possible that the lower number of errors seen on 'different' items across facial and prosody tasks in this study reflect a greater stimulus change on 'differences' and so are more readily identifiable. This might be further investigated using recognition tasks that vary the 'intensity' of the 'difference' stimuli in order to gauge the discrimination threshold needed to detect 'differences'. It might also be interesting to look at the ability of those with dementia to make same/different judgements on various stimulus sets. For example, sets of 'facial' stimuli versus sets of 'common object' stimuli in the visual modality.

Moving on to identification of emotion in faces and voices, the AD group in this study again made more errors on recognition of similarities than differences on prosody tasks, but demonstrated no significant differences on facial tasks. It is not clear however, whether the results on facial affect discrimination may have been confounded by the quality of the stimulus photographs used. Further investigation using more ecologically valid stimuli such as standardised video images, for example, might help to clarify and extend existing concepts on emotional facial recognition.

Finally, when asked to discriminate between a number of emotions (happy, sad, angry, frightened, neutral) the AD group made less errors in identification of 'happy/sad' than 'angry/frightened/neutral' across facial and prosody subtests of the FAB. In this instance, the evidence supports Ekman's (1982) view that although certain facial expressions

appear to have universal meaning regardless of the culture in which the individual is raised, some appear more readily accessed than others. Ekman found that generally 'fear' and 'surprise' were confused across cultures and like Ekman's healthy 'normal' adults, the AD group in this study had the same difficulty. This was reflected in some of the comments made by the AD group:

- 'She looks surprised, but I don't have that on my list'
- 'I want to say surprised, but it is not here'
- 'This woman looks surprised but if I had to make a choice from the ones I have, I would say she was frightened'

In addition, on facial emotion recognition stimuli, AD participants often confused 'neutral' photographs with 'sad'. Again, this may be more an artefact of 'task' rather than a clear emotion processing difficulty. In common with some of the earlier findings in this study, future studies may need to consider more fully the quality and 'intensity' of stimulus items used in facial recognition tasks.

4.4 General considerations relating to the study

A number of factors need to be discussed in considering the findings of this study. A basic issue is whether participants fully understood the experimental tasks. The practice task preceding each subtest of the FAB ensured that all participants had a certain level of understanding of what was required of them, and following the advice of Cadieux and Greve (1997), cue sheets of target emotions and instructions were provided in order to decrease memory load across subtests. In addition, no pressure to start was put on participants until they expressed confidence in knowing what was required of them and

care was taken to ensure all participants had the same level of understanding of the tasks. The high levels of correctly solved stimulus items across subtests supports the contention that participants did understand task demands.

A second basic issue that applies to all research in this area is whether any decrement seen in AD sufferers regarding performance on emotion processing tasks can be directly attributed to cognitive deficits or whether they can equally well be explained by other factors. One of the key issues to date relates to the contribution that memory load makes to observed outcomes. For example, in terms of recognition of facial emotions, Ekman, Friesen & Ellsworth (1972) have indicated that there are no more than seven basic emotions and these are categorical in nature. The cognitive requirements associated with processing facial emotion are therefore different from those involved in recognition of facial identity. Indeed, Roudier, Marcie, Grancher, Tzortzis, Starkstein & Boller (1998) maintain that recognising facial identity requires complex visual processing, episodic (and in the case of famous faces), semantic (biographical) memory; whereas memory load is not as high in recognising facial emotions. They suggest that here, visual processing is likely to be less complex, as the necessary information is more salient and more readily accessible.

In addition to the issues associated with face stimuli presented in emotion processing tasks, Cadieux & Greve (1997) discovered that performance on such tasks (in the FAB) was significantly affected by memory load in terms of holding task instructions in working memory whilst performing the varying subtests. Interestingly, attempts to decrease memory load in this study by provision of cued information on subtests brought performance of dementia sufferers on the FAB up to levels approaching those seen in the normal older adult population. These findings would suggest that some of the decrements

in performance seen in previous studies of emotion processing in AD may have had more to do with task demand, in terms of memory load, than deficits in emotion processing per se. Future studies accommodating these findings may help to clarify these issues.

Lastly, motivational influences have been given little consideration in the literature but may provide a powerful source of explanation regarding performance on emotion processing tests such as the FAB. For example, in this study, the HOA group appeared to find the tasks relatively simple, with their performance reflecting that seen in the normal population of older adults on the FAB (Bowers et.al. 1991). The apparent low level of challenge may, however, have led to a lack of attention and concentration which subsequently affected the number and type of errors seen in this group. The AD group, however, may have been more influenced by concerns about 'failing' on the tasks. Further research, therefore, investigating the extent of motivational influences on task performance and the degree to which this affects cognitive judgement may provide greater insight into the decrements demonstrated within and across participants in studies of this kind.

4.5 Reliability and validity of findings

The results found in this study need to be interpreted with caution. Great care was taken in recruitment of all participants and every effort was made to maximise performance. None-the-less, individuals with other diagnoses may still have been included in the groups. More problematic still, because of recruitment difficulties, sample sizes were small. Experimental confirmation of findings with further samples would therefore be appropriate. In order to be completely confident about diagnosis, individuals in the AD

group should only be included for whom autopsy diagnosis is available. This is clearly not possible, particularly when individuals have been recruited early in the disease course. However, the patients with dementia recruited for this thesis were all diagnosed by the same experienced memory disorders team and were, therefore, as well characterised as any pre-mortem individuals are likely to be. The diagnostic rigour used by the team makes it more likely, therefore, that these findings will be confirmed.

4.6 Limitations of the study

This study can be criticised in a number of ways.

In common with all other published studies in this subject area, the use of cross-sectional design does not permit any causal inference to be drawn between emotion processing and cognitive ability in those suffering from Alzheimer's disease. Optimally, a longitudinal study would be required to investigate the course of cognitive decline and correlates of non-verbal affect recognition. As previously mentioned, small sample size of the study also limits the representativeness and generalisability of results.

In order to standardise the administration of the experiment and to optimise a similar level of understanding between participants, the facial affect recognition tasks always preceded the prosody tasks, which in turn always preceded the cross-modal tasks. This was carried out in accordance with the way in which Bowers et.al. (1991) developed the test battery, as randomisation of conditions would jeopardise logical transition from one task to another within the facial and prosody subtests. A penalty for this was that it is possible that learning and fatigue effects confounded the outcome. However, it could be

argued, that the relatively small number of trials in each condition meant that the demands made on participants were not sufficient for this to be a significant factor.

A number of studies have established the MMSE (Folstein et.al. 1975) as a good test of general level of cognitive ability, with adequate inter-rater reliability and good test, re-test reliability (Nelson, Fogel & Faust 1986). It is well known, however, that those satisfying the NINCDS-ADRDA criteria for AD (McKhann et.al. 1984) constitute a clinically heterogeneous population. For example, some people may be characterised by significant memory impairment, others by prominent attentional deficit or visuo-spatial dysfunction. As we have seen in this study, much of the variance in the AD group can be attributed to such factors. Given the degree of variance in the clinical expression of AD, perhaps the MMSE is too crude a measure of cognitive ability?

In this study, the AD and HOA groups were matched on 'years in education' in an attempt to control for intelligence level between groups. It is possible that group differences are purely the result of individuals in one group being more intelligent and therefore better problem-solvers. While the BMDC battery data provided NART scores for the AD group, this measure was not taken on the HOA group, and in retrospect, this may have offered a more accurate assessment of intelligence on which to match groups.

Finally, the nature of the tasks themselves needs to be considered. In order to infer individual differences in processing of emotional cues provided by facial and/or prosodic cues, tasks must be comparable. However, the face and prosody tasks used in this study differ in an important way. The facial stimuli were still photographs, and thus presented emotions as static visual patterns so as to achieve standardisation. In the natural environment, however, facial expressions evolve, they are dynamic events (Gibson &

Spelke 1983). In contrast, and by necessity, the prosodic stimuli were audiotaped utterances, in which the emotional expression was dynamic and the task was much more similar to the kind of emotion prosody task an individual would encounter in the natural environment. Thus, face and prosody tasks were qualitatively different. It is possible that, because of their static nature, the facial photographs lacked essential information that would allow the AD sufferer to more accurately interpret the portrayed emotion. In addition, all face stimuli presented across subtests were female in composition and this may have had an effect on the data obtained.

4.7 Implications for clinical interventions

From the outset, this study has sought to extend current thinking with respect to emotion processing in those suffering from Alzheimer's disease. The evidence to date lends some support to the view that while dementia may have a direct impact on cognitive functions such as memory, language and attention, there appears to be a more complex interdependency between cognitive ability, emotion and behaviour which could be used to inform clinical interventions.

Psychological approaches to these difficulties have an extensive history based on 'management', with the aim of ameliorating certain aspects of the disorder, decreasing disability in certain areas and decreasing the frequency of behavioural difficulties (Woods & Britton 1977). For example, memory dysfunction has often been described as an early and virtually universal cognitive feature of dementia and interventions have historically targeted this aspect of the disease to the exclusion of other concomitant difficulties.

More recently, however, links have been made between cognition and emotion. Kitwood (1990) argues that anxiety or depression in a person with dementia will further increase decrements in performance levels associated with cognitive decline, and suggests that under-functioning is commonplace in dementia, in that the person functions at a level below the limits set by the actual degree of neurological impairment. He attributes this disparity to the person withdrawing, in reaction to a general devaluing of the emotional and behavioural aspects of their social environment.

In this study, evidence has been gained in support of the view that ability to recognise non-verbal emotional cues in faces and prosody is spared relative to cognitive function in those with AD. How does this help us to plan effective interventions?

In looking at interactions between people with dementia, Sabat (1994) reported that at a purely verbal level, some interactions that occur are intelligible and appear to make little sense in terms of accepted linguistic conventions. He suggests that in this situation it is likely that much of the message is being conveyed non-verbally and in some instances the words are more of an accompaniment or adornment to the main vehicle for communicating content. He goes on to say that many non-European languages depend far less on grammar and vocabulary than on tone and gesture, it would, therefore, be unwise to discuss interactions with those suffering from AD as meaningless or nonsensical. Furthermore, the relative sparing of non-verbal skills on facial and prosody tasks demonstrated in this study may lead to creation of effective forms of communication that are not reliant on cognitive ability.

If, as Ekman et.al. (1972) and others argue, semantic memory is not relied upon in facial/prosodic recognition, then cognitive load is minimal in these tasks. This provides

an opportunity to invest in target interventions utilising procedural memory and certain aspects of implicit memory with appropriate retrieval cues such as those provided by facial expression of emotion or tone of voice.

In order to operationalise ideas, comprehensive assessments need to take account of both cognitive and emotion processing strengths and deficits in order to accurately gauge individual strengths and weaknesses. Pairing intact areas of function with damaged areas may help weaker ones to improve or be maintained.

Interventions based on such evidence may then be used to inform and develop high quality interactions, carried out within stable secure relationship contexts. For example, carers might be trained in utilising retained emotion processing abilities: using facial expression of emotion and tone of voice, in addition to behavioural interactions and reactions. This could perhaps underpin programmes seeking to provide individualised care based on feedback, thus reinforcing and sustaining positive reactions and interactions, ultimately enhancing quality of life .

4.7.1 Expanding existing theories on intervention.

Findings from this study may support the development of new approaches to intervention arising from existing theoretical foundations. For example, theoretically, Williams (1994) proposes that the Interacting Cognitive Subsystems Model developed by Teasdale & Barnard (1993) may be helpful in understanding and underpinning future interventions.

Teasdale & Barnard suggest the notion of two meaning subsystems, 'propositional' and 'implicational' reflecting cognitive and emotional representations respectively. William maintains that if the implicational subsystem is relatively intact, the propositional subsystem may not be able to make sense of its output in relation to recent events, as propositional event memory is impaired in dementia. Instead, it will use material relating to events maybe many years previously to complete the fragmented description emerging from the implicational subsystem. What may then emerge when a person with dementia is feeling lonely or abandoned (generated in implicational subsystem) may only be interpretable propositionally as 'where is mother?' the task of the caregiver is to respond at a level that connects with the implicational content. It may, therefore, be possible to use facial expression of emotion and prosody to enhance non-verbal cues that connect with implicational content, thus directing interactions at an appropriate level. For example, professionals and carers might be encouraged to utilise and reflect upon both verbal and non-verbal cues from the AD sufferer, in terms of individual levels of implicational content. Communication systems based on channelling information back via the implicational system through facial expression of emotion and tone of voice could then be developed in order to support and enrich existing interactions.

4.8 Future research

The few systematic investigations of facial and prosodic emotion discrimination in dementia have yielded different results and interpretations and many aspects remain that could be fruitfully investigated.

Further investigation is generally needed to clarify the extent of dissociation in emotion processing modules in those suffering from AD, and the experimental conditions under

which this can be demonstrated. Furthermore, a longitudinal study investigating emotion processing in AD would be valuable in overcoming the methodological weaknesses of present studies.

Lastly, it would be interesting to add an extra dimension to future studies of this kind by including an AD group who are taking cholinesterase inhibitors, in order to assess the effect of such medication on emotion processing ability relative to a 'no medication' group of AD sufferers.

4.9 Conclusions

The experimental results support the theory that non-verbal emotion processing ability (as present in facial and prosodic cues) is retained in those suffering from AD relative to cognitive function. In addition, tentative evidence has been gained in support of the notion of dissociation between facial and prosodic elements of a non-verbal affect lexicon.

A number of observations were also made in relation to post-study analyses of FAB error scores which may provide the impetus for further research in this area.

The need for caution in interpreting the results and the generalisations that are valid about the emotion processing skills of individuals with AD were made. For increased reliability, these need further investigation, using different research methodologies and using different tasks prior to attributing any specific abilities to this population.

APPENDIX 1

Standardised scoring systems for serial subtraction and backwards spelling from the Mini-Mental-State Examination

Serial 7s

"Starting with 100 take away 7. What do you get?"
"Now take 7 away from that number." "Now take 7 from that number" and so on...if the person is doing well, you may only need to say "Keep going" until they reach 65.

Scoring

Forgetting the number
if the person forgets the number they have just calculated remind them, but do not score the result.

Instruction	*Response*	*Score*
"Starting with 100 take away 7. What do you get?"	'93'	✔
"Now take 7 away from that number"	'What number?	
"From 93"	'86'	x
"Now take 7 away from that number"	'79'	✔
"And again"	'72'	✔
"Once more"	'65'	✔

Miscalculation

If the person gets the subtraction wrong, but gets the next subtraction correct from that wrong number then score this next sum correctly.

Instruction	*Response*	*Score*
"Starting with 100 take away 7. What do you get?"	'93'	✔
"Now take 7 away from that number"	'87'	x
"Now take 7 away from that number"	'80'	✔
"And again"	'73'	✔
"Once more"	'66'	✔

World backwards

Scoring is based on a "chess-like" strategy. The score is derived from the answer to the question "what is the minimum number of "moves" or "changes" required to make the reverse spelling accurate?" The number correct is then 5 minus the number of errors.

E.g. DLOOW = 1 error, scores 4
E.g. D= 4 errors, scores 1
E.g. DR = 3 errors, scores 2

APPENDIX 2

Broad issues of consent to consider when recruiting participants with dementia.

The declaration of Helsinki (1964, cited in Kennedy and Grub, 1994) and the Nuremberg Code (1947; cited in Kennedy and Grub, 1994) both state that it is necessary to obtain an individual's consent to research procedures. In the early stages of a dementing disorder individuals may have the capacity to consent but may not be able to remember their decision. As the dementia progresses, establishing true consent becomes more difficult and researchers often involve the carer in determining whether consent has been obtained. However, carer or proxy consent has no status in law. Although individuals can take out an enduring power of attorney which enables a named person to make decisions on their behalf (Powers of Attorney Act, 1971), this applies only to decisions over material goods. It does not apply to decisions about treatment or involvement in research.

Non-therapeutic research is particularly problematic. Firstly, there is the potential for conflict of interest. In therapeutic research the individual is at least offered the possibility of benefiting from the therapy. In non-therapeutic research the study will be of no direct benefit to the participant (though it may benefit the researcher) and may even be distressing. A doctor's (or psychologist's) obligations to patients include beneficence, non-maleficence, and respect for autonomy. Non-therapeutic research does not uphold the obligation for beneficence. If the research is potentially harmful, or if the patient would not have consented to the research if s/he had been able, then the second two obligations may also be violated. However, if the patient is excluded from the research solely because they are incapable of consenting but they would have chosen to take part, had they been well, then this too violates the principle of respect for autonomy.

This area is further complicated by a conflict between societal good and protection of the patient (Berghmans and Ter Meulen, 1995; Kitwood, 1995). The Committee of Ministers of the Council of Europe has stated that:

> "National law may authorise research involving a legally incapacitated person which is of no direct benefit to his health when that person offers no objection provided that the research is to benefit persons in the same category and that the same scientific results cannot be obtained by persons who do not belong to this category" (Working Party on Research on the Mentally Incapacitated, 1991).

In addition, the Royal College of Psychiatrists has proposed that it may be unethical not to undertake research as this deprives future and present patients of better treatment and the prospect of prevention (Working Party on Research on the Mentally Incapacitated, 1991). Finally, Procter (1995) argues that it is unethical not to undertake research with people with dementia because this is a breach of trust with those who have already contributed.

Where does this leave the non-therapeutic researcher? Most research in dementia is carried out with individuals who are only mildly to moderately affected. This is usually because many research studies are not viable in more severely impaired individuals, and because research into possible diagnostic, preventative or therapeutic measures is more likely to be of benefit in early stages. Even cognitive psychological research, which recruits participants in order to further understanding of normal cognitive processes, is likely to involve only very mildly impaired individuals in order to limit the degree of neuropathology. Given that mildly impaired individuals are likely to retain capacity to consent, establishing consent should be possible. However, due to the memory difficulties of dementia it will often be insufficient to obtain consent for research once only. Consent must also be reaffirmed if time has elapsed between consent and assessment. As Agarwal, Ferran, Ost, and Wilson (1996) reported, many individuals in research trials forget that they are involved in a trial. This is relevant even to one off

cognitive psychological studies because individuals may consent to an interview but have forgotten doing so when the investigator turns up to assess them a few days later.

Despite the lack of legal imperative, researchers should also usually obtain proxy consent to the research process. Even if consent is obtained from either a participant and/or a carer, the participant should be seen to be consenting during the research. If there are any verbal or non-verbal indications that the participant is not consenting then the research should be discontinued – even if proxy consent has been obtained (Procter, 1995).

APPENDIX 3 - PARTICIPANT INFORMATION SHEET

UNIVERSITY OF BRISTOL
DEPARTMENT OF CARE OF THE ELDERLY
Clinical Research Centre & Memory Disorders Clinic
The BRACE Centre
Blackberry Hill Hospital
Manor Road
Bristol BS16 2EW
Telephone:(0117) 965 6061 Ext. 4655
Fax:(0117) 965 6061 Ext. 4709

Dear

You will be contacted shortly by Shirley Radford about a study she is carrying out in collaboration with The BRACE Centre, Blackberry Hill Hospital.

This project is studying the ways in which we can identify and name emotions in the faces and voices of others. We hope it will tell us something about why people have difficulties with these tasks. We need people who are over the age of 60 and would be very grateful if you would consider helping us.

If you agree to take part you will be asked to look at a series of photographs of faces and to listen to a tape recording of someone speaking, then you will be asked some questions about them.

The whole session takes approximately one hour and can be divided into two visits. If you decide that you no longer wish to continue, then you can stop at any time.

We will add your results to those of all the other people who agree to help us with this study. This means that all information will be confidential and no individual will be identified by his or her results.

We recognise that the findings will not directly affect you, but we believe that what we learn will be of benefit to people who experience difficulties in recognising emotion in others in later life. If you are a patient in my care, your decision to help us or not will not affect your treatment.

If you are willing to take part, or have any queries about this project please call Shirley Radford, at The BRACE Centre on 0117 *965* 6061 ext. 4448.

Many thanks for considering this project.
Yours Sincerely,

Professor Gordon. K. Wilcock Consultant in Care of the Elderly

APPENDIX 4

CONSENT FORM

Please cross out as necessary

Have you read the information sheet? Yes / No

Have you had the opportunity to ask questions? Yes / No

Have you received satisfactory answers to all your questions? Yes / No

Do you understand that you are free to change your mind:

- At any time?
- Without having to give a reason?
- And without affecting your or your relative's future medical care? Yes / No

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

Name (in block letters) .....

Counter signed ..... Date .....

Name (in block letters).....

Signed (Researcher).....Date.....

APPENDIX 5

APPROVAL FROM FRENCHAY HEALTHCARE TRUST ETHICS COMMITTEE

Frenchay Healthcare Trust

Headquarters, Beckspool Road, Frenchay, Bristol BS16 1JE
Telephone: (0117) 970 1070 Fax (0117) 975 3806

20 July 1998

Our ref: rtapp 98.15

Tel DDI (0117) 9186517

Ms S Radford
BRACE Centre
Cedar House
Psychology Dept
Blackberry Hill Hospital

Dear Ms Radford

Project 98/15 Emotion processing in Alzheimer's disease: the clinical implications

Further to our telephone conversation on 2nd July 1998, I am writing to confirm that your response of 19 June 1998 to my letter of 8 June 1998, which incorporated the comments made by Members of the Avon Health Authority, Frenchay Healthcare NHS Trust Research Ethics Committee in respect of the above project, was considered by the Committee at its meeting held on 26 June 1998 and approval, in as far as ethics matters are concerned, was ratified. However, the Committee requests a copy of the "procedures for recruiting subjects for research" which you advised was produced by the BRACE Centre Manager.

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

I have forwarded to the Trust's insurance broker the copy of the Trust's insurers questionnaire that you completed.

Whenever contacting the Committee about this project, and/or any amendments or extensions which should be submitted for approval before initiating, it will be appreciated if you always quote **'Project 98/15'** as this will enable the project to be identified.

I look forward to receiving a copy of the 'procedures for recruiting subjects for research' document.

Yours Sincerely

Mrs K M Matthews
Research Ethics Administrator

cc Dr D Rogers, Chairman REC

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