

Living with Alzheimer's disease: an exploratory case study

By

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Abstract

Living with Alzheimer's disease: an exploratory case study

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This case study of an elderly man undertook to explore the lived experience of a person in the early stages of Alzheimer's disease (AD) using interpretative phenomenological analysis. It was undertaken to gain a deeper understanding of the lived experience of the disease.

Within the literature reviewed, an overview is given of the symptomology, diagnosis and aetiology of AD, as well as a brief discussion of AD in the South African context. Discourses surrounding AD- regarding insight and awareness, definitions of selfhood, and views on the mind body relationship- are critically discussed, as these discourses have contributed to the lack of research on the subjective experience of AD. Looking at the available literature disputing these discourses, it becomes clear that awareness, insight and the self is not completely or inevitably lost in AD, and that those with AD are able to respond consistently and reliably. Research that has taken into account the subjective experience is thus discussed. It is argued that it is not only viable, but essential, to include the experience of the person with AD in research on AD. A better understanding of how the person with AD experiences living in the world, and how AD impacts on them, is of importance in being able to better assist them and their caregivers.

The themes derived using interpretative phenomenological analysis are first reported and then discussed, embedded within relevant literature. Taken together, this case study found that awareness of the difficulty associated with changes accompanying AD resulted in the person experiencing

affective changes, wrestling with the self and undergoing a spiritual crisis. It was seen that the changes and challenges of the disease occur in the context of a psychological self, and that the self engaged in responses aimed at either maintaining his sense of self, or adjusting his sense of self. There are multiple factors which contributed to either of these responses. It was seen that responses aimed at maintaining the self resulted in apparent unawares or lack of insight, while responses aimed at adjusting the self resulted in expressed awareness.

This study adds to the growing body of literature attesting to the importance of including the person with AD in research. It also highlights the potential benefit of therapeutic assistance within the early stages of the disease to help the person deal with the distressing changes.

Furthermore, it is suggested that a protocol surrounding diagnosis be considered which can aid the person and family in better understanding and dealing with the disease. Psychoeducation could be an important facet; especially regarding preparing the family for the variety of psychological responses the person with AD may have to the difficulties and challenges. Such an understanding may help them better cope with the changes.

Keywords:

Alzheimer's disease; subjective experience; lived experience; interpretative phenomenological analysis; insight; awareness; anosognosia; selfhood; embodiment; coping

Chapter 1

Introduction

A very good day

*Fighting our battles with confusion each day,
Routines are established to keep befuddlement at bay.
We watch for stress and avoid mental fatigue,
harmonious striving to make mind and body agree.*

*We can still make decisions and want to interact
with those called normal; but it's a balancing act.
Simple is much better and less is okay -
Our motto for having a very, good day.*

Tim Brennan

1.1 Overview

By starting this mini-dissertation with the voice of Tim Brennan (1997), diagnosed with Alzheimer's disease (AD), the researcher invites the reader to enter the experiential world of a person diagnosed with AD.

In this chapter, the research that has allowed the researcher, and will allow the reader, to enter this world is introduced. The research is first contextualised and the research problem posed. The aims of the research are discussed, and lastly an outline of the structure of the Chapters is given.

1.2 Context

The research is contextualised through looking at the broader context in which this study takes place.

1.2.1 Lack of research on the subjective experience of AD

Although a lot of research has been done on AD, comparatively few research studies have particularly focused on the subjective experience of person's with AD. Recently various authors within the field of AD research have placed emphasis on the importance thereof (Aminzadeh, Byszewski, Molar, & Eisner, 2007; Clare, 2003; Cohen, 1991; Snyder, 2001; Whitlatch, 2001).

1.2.2 Reasons for the lack of research on the subjective experience of AD

While reasons for the lack of such research will be further explored within Chapter 3, these are briefly mentioned.

- The notion that those with AD have a lack of insight or awareness renders research with them as participants questionable regarding validity and reliability. However, authors such as Snyder (2001), Ready, Ott and Grace (2006) and Clare (2004a, 2004b) have argued that matters of awareness are not as simple as presumed, and that those with AD do retain awareness.
- Another contributing factor is the ethos of modern biomedicine and the Western dichotomous view between the mind and body (Beard, 2004). A disease model focuses on the pathological processes, emphasizing physiological aspects of the disease instead of the emotional and psychological aspects of the illness. The reduction of people to their physical parts does not contribute to optimal care of people with a disease. Thus various authors argue against such a view and advocate for a more holistic understanding of the person which is more helpful in assisting the 'diseased' person (Kitwood, 1998; Sabat, 2001).

- The idea that the self is lost in AD also contributes to the lack of research, and authors such as Basting (2003), Kitwood (1990, 1997), Post (1998) and Sabat (2001, 2005) argue against such a presumed inevitable loss.

1.2.3 Including the person with AD

It is important to include the person with AD in research as one will not be able to deliver adequate care for people with AD if one does not get acquainted with their experience of the disease. Developing an understanding of the person's experience of the disease holds importance for effectively assisting them and their family through therapeutic interventions as the disease progresses (Cohen, 1991). This understanding cannot be gained without including the person with AD in the research. Beard (2004) reiterates this by saying that if we try to understand how people think about impending loss while their cognitive functioning and confidence are still relatively intact, we will be able to give better care and provide support in the later stages of the disease.

Including the person with AD in research is also becoming more plausible, as Aminzadeh et al. (2007) emphasises. With the recent advances in the diagnosis of AD, it is being detected earlier. This creates an opportunity for recruiting people with AD early on, while they are able to reflect on and verbalise their subjective experience and needs. It also creates an opportunity for clinical practice to support the person with AD through implementing interventions aimed at maximising adaptive coping responses and quality of life, in the presence of a progressive illness.

1.2.4 The South African Context

Various authors, in light of the paucity thereof, have recently begun doing research in which the person with AD is included (Beard, 2004; Clare, 2003, 2004; Clare, Roth & Pratt, 2005; Gilmour & Huntington, 2005; Harman & Clare, 2006; MacQuarrie, 2005; Pearce, Clare & Pistrang, 2002).

While internationally research is being done to address this, the researcher could find no studies done in the South African context.

1.3 Research Question

In light of the lack of research on the subjective experience of AD, the research question posed is as follows: What is the lived experience of a person with Alzheimer's disease?

1.4 Aims of the research

This research aims to explore how a person with Alzheimer's disease experiences living with an organic brain disease from a phenomenological perspective. This is in order to gain a deeper understanding of the manifestation of the disease in the lives of individuals and consequently be able to better assist both the individual and caregiver. It is therefore hoped that the study can contribute to more effective therapeutic interventions.

1.5 Structure

In Chapter 2, the relevant literature regarding AD is discussed to further contextualise the current research for the reader. Chapter 3 outlines the methodology used for this study, which is qualitative in nature. Chapter 4 finally introduces the reader to the participant and his caregiver, and the reader is invited into the lived experience of AD through the results given. Chapter 5 discusses the results in light of current available literature, the limitations of this study and provides conclusions and recommendations.

Chapter 2

Literature Review

2.1 Introduction

In Chapter 2, relevant literature as background for this study is discussed. Firstly, an overview of what AD is and how it is diagnosed is given. The increase in the incidence of AD in the South African context is briefly looked at, together with the anticipated impact thereof. Various discourses regarding awareness and insight; views on the mind-body relationship; and definitions of selfhood are discussed as factors contributing to the lack of research focussing on the subjective experience of AD. Research that has started addressing this paucity is then discussed, as well as research on caregiving. The chapter ends with a discussion of studies that has included both the person with AD and their caregiver.

2.2 Alzheimer's Disease: symptoms, diagnosis and aetiology

AD is an irreversible cortical dementia causing inevitable cognitive decline. Although dementia is characterised by numerous cognitive deficits, the Diagnostic and Statistical Manual of Mental disorders, fourth edition, text revised (DSM-IV-TR) emphasises that the levels of consciousness remain unaffected. Those cognitive functions that deteriorate include general intelligence, learning and memory, language, executive functioning, problem solving, orientation, perception, attention, concentration, judgment and social abilities (American Psychiatric Association, 2000).

The DSM-IV-TR states that the associated features of AD may include spatial disorientation, poor judgment, suicidal behaviour, motor disturbances of gait, disinhibition, neglecting personal hygiene,

exhibiting undue familiarity with strangers or disregarding rules for conventional social conduct (American Psychiatric Association, 2000). What are also important to take into account are the non-cognitive neuropsychiatric and neurobehavioural symptoms in AD which may include agitation, irritability, fatigue, apathy, anxiety, sadness, psychomotor difficulties and psychosis (Cassimjee, 2008; Cassimjee, Stuart & Marchetti-Mercer, 2005).

The diagnosis of dementia of the Alzheimer's type is based on a clinical examination, which includes a mental status examination, as well as on collateral information from family, friends and colleagues. Memory impairment is a prominent feature, usually for recent events. Orientation to person, time and place may be affected due to memory deficits, and worsens as the disease progresses. To be diagnosed with AD according to the DSM-IV-TR, memory impairment and at least one other symptom of cognitive decline, such as aphasia, agnosia, apraxia or abnormal executive functioning, needs to be present. In addition, there needs to be a gradual decline in functioning and impairment in social or occupational functioning. The diagnosis of AD is one of exclusion, and is diagnosed once other causes for dementia, such as central nervous system conditions and systemic conditions have been ruled out (American Psychiatric Association, 2000).

The classification of severity of AD into mild, moderate and severe is most commonly used in clinical practice. Generally speaking, those in the mild stages have obvious cognitive difficulties, but are able to reasonably communicate and perform self care tasks. The person can still accomplish complex functions like utilising a telephone or household appliances. The moderate stage is characterised by an increase in cognitive difficulties, the person needing help with self care, and there being deficits in voluntary control of bodily functions. When the disease is in the severe stages, the person is no longer able to function independently and nursing home placement is usually considered. Due to the atrophy of brain cells in large portions of the brain, there is gross

deterioration cognitively and also physically Various assessment measures, such as the Mini Mental Status Examination (MMSE), Clinical Dementia Rating Scale (CDR) and Global Deterioration Scale (GDS) is useful in assisting the clinician in establishing the severity (Dash & Villemarett-Pittman, 2005).

Although the aetiology of AD is unknown, it is linked to increased age. The onset is specified as early when the disease is present at or before age 65, and late if the onset is after age 65. Genetic factors play a role in some cases, where Alzheimer's seems to be inherited as an autosomal dominant trait linked to chromosomes 1, 14 and 21. Also, those individuals who carry one or both alleles coding for apolipoprotein E-4 on chromosome 19 bear an elevated risk for later onset AD. Neuropathology associated with AD include diffuse atrophy, flattened cortical sulci, enlarged cerebral ventricles, senile (amyloid) plaques, neurofibrillary tangles as well as neural and synaptic loss (Sadock & Sadock, 2003).

2.3 Alzheimer's disease in the South Africa context

Currently in South Africa, there is an estimated 3.5 million people over the age of 60 years (7% of the population) (Statistics South Africa, 2008). It is estimated that with an increasing lifespan this figure will increase by 2025 to 10% (Kinsella & Ferreira, 1997). As the incidence of Alzheimer's disease increases exponentially with age, Cassimjee (2007, 2008) contends that this increase in lifespan- with the resultant increase in cases of AD- will further burden the already economically strained health care system of South Africa. Proper diagnosis and education of both caregivers and health care personnel is consequently of immense importance, as is addressing the lack of research into the sociocultural nuances of AD. Such research will contribute to studying *how* the disease manifests, and not just *why* (Cassimjee et al., 2005). Flaskerud (2000) emphasises that

consideration should be given in such studies to the following: insight of the patient and caregiver, experience of difficulty by the patient and caregiver and expression of the problem by the patient.

Few research studies have specifically focused on the subjective experience of person's with AD and recently various authors have highlighted the importance thereof (Aminzadeh et al., 2007; Clare, 2003; Cohen, 1991; Snyder, 2001; Whitlatch, 2001). Following is a discussion of a variety of factors and theoretical discourses, which contributed to the paucity of such research.

2.4 Embedded discourses on Alzheimer's disease

2.4.1 Awareness and insight in Alzheimer's disease

Snyder (2001) links the lack of exploring the subjective experience of AD to conceptions of insight in people with AD. Anosagnosia, i.e. the inability to recognise one's own disease (Kashiwa, Kitabayashi, Narumoto, Nakamura, Ueda, & Fukui, 2005), implies a lack of insight into or awareness of the nature and extent of the disease (Sabat, 2002a). Anosagnosia has been found to increase as the severity of AD, and thus dementia, increases (Kashiwa et al., 2005). If anosognosia is present, the person may underestimate their condition, impacting on the reliability and validity of self report data. The resultant view that such data is not reliable or valid has contributed to the limited research done on the subjective experience of AD.

However, matters of insight and awareness in AD appear to be more complex than presumed and have been commented on by various authors in the field. Snyder (2001) argues that all people, and not just those with AD, have varying degrees of insight into their mental, physical and emotional states. While, depending on the path of AD through the brain, some persons with AD are unable to comprehend their symptoms, others do have insight or variable insight into their disease. Ready et al., (2006) conducted a study in which they found that better insight into AD on behalf of the patient

did not necessarily result in better agreement between patient and caregiver reports on quality of life. Discrepancies were found between caregivers and persons with both high and low levels of insight into their disease. This study demonstrates firstly that discrepancies between caregiver and patient reports do not automatically evidence a lack of insight on the behalf of the patient. This is significant as patient-caregiver discrepancies has been one of the ways lack of insight has been measured. It further highlights the fact that caregiver reports cannot stand as a replacement for the experience of the person with AD.

Further complicating the matter of awareness is the fact that awareness has different conceptualisations dependent on the domain from which it is viewed. Thus neurological, neuropsychological, psychiatric, psychoanalytic, relational and psychosocial perspectives all differ with regard to how awareness and unawareness are defined (Clare, 2004a; Markova, Clare, Wang, Romero & Kenny, 2005). In addition to this, the methods used to assess awareness vary, with each assessment having its own limitations and being based on differing conceptualisations of awareness. A review of studies on insight and awareness shows that assessment includes clinician ratings of awareness; questionnaire based methods in which patient-caregiver discrepancy scores are determined; prediction-performance discrepancies; or a combination of these. This has led to many discrepancies in the research results regarding awareness in AD. Researchers have consequently argued that a broad conceptualisation and clearer theoretical framework regarding awareness is needed, as well as improved assessment measures (Aalten, Van Valen, Clare, Kenny, & Verhey, 2005; Clare, 2004b; Clare, Markova, Verhey & Kenny, 2005).

2.4.1.1 Psychological concomitants of awareness and insight

Although disturbances of awareness are generally given biological explanations and viewed as a facet of neuropsychological deterioration (Agnew & Morris, 1998), Seiffer, Clare and Harvey

(2005) contend that certain psychological factors, such as denial, may impact on the expression of awareness. Aminzadeh et al., (2007) confirmed this in a study which found that although individuals exhibit a broad range of emotions reactions, the immediate response in the majority of people to being diagnosed with AD was shock and distress. Their resultant responses to this distress could suggest an active denial, perceived as lack of insight, in order to minimise the emotional impact of being diagnosed with AD.

Denial is not only restricted to a reaction on diagnosis. If people have had high expectations of themselves throughout their lives and view illness as a sign of weakness, they are more likely to deny impairments when they develop AD (Clare, 2003). Such denial can be mistaken for neurologically based unawareness. Weinstein Friedland and Wagner (1994) concluded that people most likely to use denial are those who are highly conscientious as well as reserved in emotional expression. Seiffer et al. (2005) however, did not find this to be the case after controlling for disease severity, duration, depression and anxiety. They found an individual relationship only between conscientiousness and awareness. Higher self-ratings of conscientiousness correlated with reduced awareness of level of functioning. It appears as if those who are work orientated, conscientious, efficient and organised -the prototypical denial personality- may experience dementia as particularly distressing and as a result may employ denial as a defence, showing reduced awareness.

2.4.1.2 Psychosocial concomitants of awareness and insight

Awareness seems to be impacted not only by psychological factors, such as denial, but also by social factors. Persons with AD may appear to be unaware in certain contexts, while demonstrating clear awareness in another. This may reflect a fluctuating level of awareness, but it may also be explained by the person adapting what they choose to express. The choice regarding expression of awareness is based on three things: on the context; on the person's perception of how their

expressed awareness will be received; and on their perception of the impact it will have (Clare, 2003). The concepts of malignant social positioning and malignant social psychology, to be discussed in more detail shortly, provide a conceptual framework for how the social context impacts on behavioural manifestations of the person with AD (Kitwood, 1990, 1997; Sabat & Harré, 1992).

As the assessment situation is social in nature, it can be argued that how people react in the assessment of insight is not only determined by the organic effects of the disease. In a social situation, what people do or do not do is influenced just as much by their reaction to the disease; the behaviour and reactions of others; and their reaction to such behaviours. Thus reports of self awareness during assessment can thus be influenced by psychosocial factors such as anger about, frustration by, and embarrassment of their cognitive losses. Not reporting the effects of these losses may thus show a paradoxical heightened awareness about and insight into their problem (Sabat, 2002a).

2.4.1.3 Integrated biopsychosocial model of awareness

From the literature discussed, it is clear that awareness is thus impacted by not only neurological factors, but also by psychological and social factors. Clare (2004a) has formulated an integrated biopsychosocial conceptual model regarding awareness that takes into account key contributions of cognitive neuropsychological models, as well as psychological and social factors. This is summarised in figure 1 on the following page.

In this integrated model, the role of information, as well as knowledge about illness and the ability to understand it, is acknowledged. At a biological level, factors include the type of unawareness as defined by cognitive neuropsychology models, along with the considerations of possible mechanisms involved. Psychological factors taken into account include: denial, coping style,

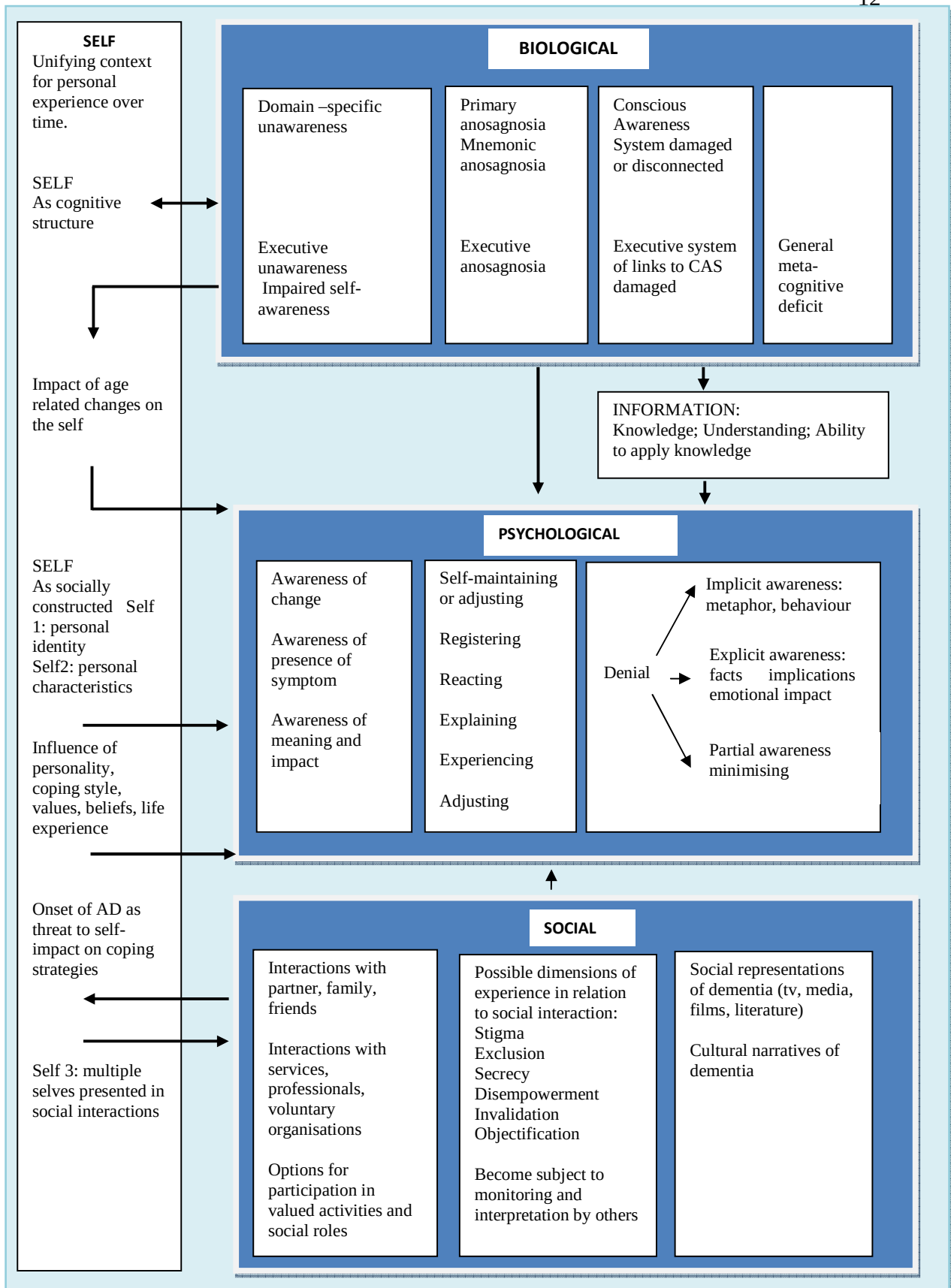


Figure 1: A biopsychosocial framework for considering awareness in early-stage Alzheimer's disease (Clare, 2004a).

behavioural indications of implicit awareness where explicit awareness is not present, the meaning attributed to awareness, and the emotional aspect of experience. Social factors include: interactions with family, friends and health professionals; experiences such as stigma and exclusion; and the cultural representations of dementia. There is dynamic interaction between these biological, psychological and social factors, which influence, and is influenced by, the subjective experience of the self (Clare, 2004a; Ownsworth, Clare & Morris, 2006).

2.4.2 Selfhood in Alzheimer's disease

The Western view of the self, and the resultant belief that those in the later stages of AD experience a loss of the self, is a further contributing factor to the lack of research into the subjective experience of AD. Not all authors accept an inevitable loss of self in AD, and the allegation that a cognitive disease alone results in a loss of self is disputed by various authors in the field. These views will be discussed in this section.

2.4.2.1 Malignant Social Psychology

Persons with AD are exposed to what Kitwood (Basting, 2003; Kitwood 1990; Kitwood & Bredin, 1992) calls *malignant social psychology*. This has an impact on the person's sense of self and can result in a perceived loss of self. According to Kitwood (1990) there are various ways in which a person can be exposed to a malignant social psychology:

1. *Treachery*: In order to ensure compliance from the person with AD, others may use trickery or dishonesty.
2. *Disempowerment*: The person may become disempowered when others do things for them that they are able to do for themselves, but just more clumsily or slowly.
3. *Infantilisation*: The person becomes infantilised when others see their mentality or capacity as equivalent to that of a young child and they are treated accordingly.

4. *Intimidation:* The person may feel intimidated when medical procedures or psychological assessments are performed in impersonal ways by the professional who is in a position of power.
5. *Labelling:* Often times the label of a diagnosis such as AD brings with it the expectation of progressive decline and derangement, which in turn sets up a self fulfilling prophecy as the person is treated in subtly different ways.
6. *Stigmatisation:* Stigmatisation carries with it connotations of exclusion and the person becomes treated as an outcast or diseased object.
7. *Outpacing:* Others may often times outpace the person with AD, in that he or she now functions mentally on a slower rate, while those around him or her continue on their normal pace and consequently fail to establish good contact.
8. *Invalidation:* Invalidation takes place when the subjectivity of the person with AD is ignored or overlooked, consequently they do not have the sense that others understand their emotions or feelings.
9. *Banishment:* The person with AD may become intolerable to others in some ways, leading to him or her being banished from the social milieu, either physically or psychologically. This results in the deprivation of human contact. They are no longer treated as a person but become objectified.

The person is without malicious intent, depersonalised, invalidated and treated dysfunctionally by other people. Being treated as if they are not there- as it is assumed that they do not know what is happening or are bound to forget- is linked to the Western view in which memory and cognition have become equated with identity (Basting, 2003).

Sabat and Harré (1992) and Poveda (2003), much like Kitwood (1990, Kitwood & Bredin, 1992),

locate the 'loss of self' in the ways others view the person with AD. This relates to how others position the person with AD. In a social situation and through conversation, individuals can be positioned by others or they can position themselves into various roles. Such parts or roles can include being powerful or powerless, adequate or inadequate, helpless or self reliant. Those who are categorised as being elderly with a probable diagnosis of AD are in a predicament, in that when their behaviour is briefly examined, it often results in interpretations of their behaviours emphasising deficits and them being positioned in advance as being incapacitated (Sabat, 2001, 2005).

A woman living with AD describes the impact of malignant social psychology on the self in the following manner:

... this condition does more than rob one of short-term memory, inconvenient and aggravating as that is; much worse, it robs one of dignity and the respect of others... For this person is now transformed, with the label, from the former role as a spouse, parent, or lover, into a 'caregiven' and one is never looked at in the same way again (Sterin, 2002, p 8).

In her essay, Sterin expresses her experience of the reactions of people toward someone with AD, which she calls "the process of becoming invisible, the gesture of dismissal and the act of smothering" (2002, p. 8). She reminds us that all people have varying strengths and limitations, not just the person with AD.

2.4.2.2 Preservation of self

Sabat (2005) argues that selfhood may remain intact even though certain cognitive abilities of the person with AD are no longer intact. This is illustrated in a study by Usita, Hyman and Herman

(1998) in which participants- despite cognitive impairment and consequent narrative difficulties- had a preserved sense of self. They were able to share information about themselves with the interviewer and included current events in their life stories, indicating that recent events were included into their self schema. These authors conclude that memory losses, although influential, are not enough to erase a sense of self or the ability to revise self schema. Basting (2003) highlights that there are more ways to express the self than merely through one's control of memory. Those with AD are able to empathise with others, express longings and fears and have a wide range of feelings despite deficits in cognition.

2.4.2.3 *'Sense of self'*

It may appear as if the self is lost when focussing only on the deficits of the individual. However, the self can be described as consisting of two aspects: the personal self (or mind) and public selves or social identity, consisting of the multiple personas projected to the public arena (Poveda, 2003; Sabat, 2002b; Sabat, 2005; Sabat & Harré, 1992). The personal self carries the sense of personal identity, that is, of being a singularity and having the same point of view from time to time. The personal self is expressed through the use of indexical pronouns, such as 'I', 'me' 'myself' etc. The use of such pronouns "locates in psychological space the source of promises, obligations, responsibilities and the ownership of experiences" (Sabat, 2005, p. 1034). The personal self also consists of mental and physical attributes, both past and present. Aspects such as ones height, hair colour, qualifications, health, sense of humour, beliefs, and beliefs about ones attributes are part thereof. The anger, sadness or embarrassment related to the diagnoses of AD is also associated with the personal self. The personal self (mind) remains largely intact, even despite severe deterioration in cognitive and motor function. It is the public selves or social identity of a person that can become lost when the person with AD is positioned as inadequate, confused and helpless through stigma (or malignant social psychology previously discussed). One cannot construct this self without the

cooperation of at least one other person. Often times other people focus on attributes that have been lost as a result of the disease, such as memory, and do not seek out nor honour those remaining self attributes in which the person can take pride. As a result, the needed cooperation of others to socially construct the negotiated public self is lost. The person with AD becomes less able to manifest mental and behavioural abilities that are still intact. It is thus dysfunctional treatment that can lead to losses beyond organic pathology alone (Poveda, 2003; Sabat, 2002b; Sabat 2005).

2.4.2.4 *'Meaning of self'*

Sabat (2005) furthermore argues that those with AD maintain their selfhood by acting in accordance with the meaning a situation has for them. This implies being a semiotic subject, in that one's behaviour is driven by meaning. Meaning in this sense is understood as comprising of three parts: acting out of intention, interpreting events and situations and evaluating events. The meaning of a situation therefore entails all the possible interpretations or inferences about the situation, as the same situation can be understood to have entirely different meanings given the conceptual schemes (overarching way of thinking) of the observers. Given their specific interpretation, the person acts intentionally and evaluates their own behaviour as well as the behaviour of others according to socially agreed standards. Often times the behaviours of those with AD do not appear to make sense to others and seem strange or odd. It is erroneously inferred that they are not semiotic subjects (acting according to meaning). This may be so because the person evaluating them has a differing conceptual scheme or overarching way of thinking. Even though their behaviour may not appear to have meaning, it may indeed have for the person with AD.

The following quote emphasises the impact of the sense of self on resultant behaviour:

The extent to which the afflicted person's independence and well-being can be maintained will have profound effects upon the extent and types of resources that society will have to

bring to bear in the process of caregiving. How we view the sufferer- as a human being whose sense of self, whose dignity, dispositions, pride, and whose ability to understand the meanings of situations and to act meaningfully, remain intact to a degree of the one hand, or as a “demented”, defective, helpless and confused patient lacking a self, on the other- will affect the ways in which we treat the person, which, in turn, will affect how that person behaves (Sabat, 2001, p. viii).

2.4.3 Views on the mind-body relationship

Further contributing to the lack of research on the subjective experience of AD is the ethos of modern biomedicine. Beard (2004) argues that the biomedical model assumes a linear causal relationship between neuropathy and dementia and has a dichotomous view of the mind and body. He furthermore comments that this model has had an influence on societal perceptions of ageing and disease, and as a result the physical, psychological and cultural dimensions of AD have been separated, with a focus predominantly on the physical. It thus ignores personal meaning and social constructions, preventing a systematic examination of the socio-cultural and emotional components of AD.

Sabat (2001) traces the origin of the western view of biomedicine to a science that is reductionistic in nature. He describes how from this perspective the behavioural and psychological dysfunctions associated with AD are primarily ascribed to the presence of the disease, and how it is believed that an objective understanding can be gained through the use of standard tests. The person is defined primarily in terms of his or her catalogued dysfunctions. He emphasises that although this approach is helpful in creating categories, one never comes to understand the person in his or her totality. Rather, one knows the scores on certain standardised tests of abstract cognitive functions, and the dysfunctions revealed by these scores. While one gets a picture of how the disease affects a series of

functions, how the disease affects the person living in the world is left unexplained.

The biomedical model further views pathological changes in AD as leading to a disruption of personal biography, accompanied by alteration or loss of 'personhood'. This is as a result of mainly three contributing factors. Firstly, Crisp (1999) argues that when the self is seen as an inner essence- as a given set of qualities and characteristics which make up a 'true identity'- the self is at risk of being lost or eroded through the dementing process. An inner self seen as a personal endowment which one can develop fully and keep throughout one's life can be lost in adverse circumstances accompanying the dementing process. Thus within the biomedical model- where the 'self' is seen as an intrinsic property of individual consciousness- the self is seen to be lost through AD (Hill, 1999). Secondly, personhood has become measured by autonomy and rationality (Kitwood, 1997), and when people with AD no longer rate high on memory, autonomy and rationality they are at risk of being depersonalised and being seen as falling out of the category of whole people (Post, 1998). Lastly, a sense of self has become linked to one's usefulness in society and usefulness in turn is often associated with cognitive abilities. Loss of memory thus compromises one's usefulness in society, placing one's sense of self in jeopardy (Basting, 2003).

The reductionistic view of the biomedical model is related to Descartes' Cartesian mind-body dualism pervading Western culture, in which human subjectivity is divided into mind and body. The 'self' is equated with mind, will or spirit. This longstanding tradition privileges the mind over the body. While the body is seen as inextricably attached to the mind, it is seen as separate from the mind or self (Tomaselli, 1984).

The biomedical model has resulted in AD being understood in what Kitwood (1998) describes as technical terms. This view of AD includes only neuropathological and neurophysiological

understandings about the immediate cause of AD and its symptoms. Kitwood (1990) has however argued that AD is not fully explained by only neurological changes, as there is dialectical process in which dementia is compounded by the effects of neurological impairment and psychological factors. Dementia is thus not solely attributable to a malfunction of hardware (neurology), but to software as well (psychology). Personal (psychological) factors may affect not only psychological wellbeing, but also physical well-being. Such factors include: loss of a loved one and other important social connections; disempowerment through for example retirement; loss of one's role as a worker-producer; reduction of income and mobility; and the inability to adapt to life's changes. Such psychological factors can exacerbate the deterioration of affected abilities (Kitwood, 1998).

Including these personal aspects in the pathology of AD is an alternative approach to the manner the medical model investigates and explains. Such inclusion does not aim to reduce, but rather to preserve the "wealth of living material" and retain richness (Sabat, 2001 p. 14).

2.4.3.1 Embodied self

Although Kontos (2003) acknowledges the great contributions made by authors such as Kitwood and Sabat in challenging the inevitable degradation of personhood by emphasising the dialectical interplay between neurological factors and psychosocial factors, critique is made on the absence of the body as a potential source of agency. Kontos argues that it is due to the presumed dichotomy between the body and the self (which is precisely what these authors argue against, but in a sense become trapped in). The self, seen as residing in the structural configuration of the brain, is treated as being separate from the body. This is attributed to the Western tendency to separate the mind, where meaning and intelligence reside, from the body, which is reduced to matter. Kontos emphasises that a perspective on embodiment is in contrast to the mind/body dualism and acknowledges that the capacities, senses and experiences of the body lie central to the exercise of

human agency. The body is a source of a sense of self. Agency resides in the body and not just in the mind and can have creative and intentional capacity. This in itself challenges the presumed loss of agency or loss of self in AD. Phinney (2002) too has commented on the fact that even when awareness is fluctuating in AD, or the person has difficulty conveying their experience due to the breakdown of language, the body's actions may tell a clearer story as self-understanding also resides in the inarticulate body. Even when words fail, the lived body continues to be involved in the world.

2.4.3.2 Existential Phenomenology and Alzheimer's disease

Kontos (2003) uses both Merleau-Ponty's existential phenomenology and Bourdieu's practical logic concerning social and cultural practices with regard to human behaviour in arguing to include embodiment in AD. Kontos explains how Merleau-Ponty goes beyond the distinction of the physiological and psychological through grounding perception in the experienced and experiencing body. The idea that the mind is separate from the body is challenged by claiming that the world is perceived through our bodies. The body has a coordinating power in relation to itself that precedes any explicit act of intellection. It has both intention and the capacity to perceive and experience.

Together with this, Kontos (2003) describes how Bourdieu's concept of 'habitus' connects the body to culture and social structure. 'Habitus' refers to the structure of the practical logic responsible for social and cultural practices. These structures are formed by the conditionings linked with membership in a particular social class. These conditionings become the basis of perception and appreciation of all experience. Thus the process of socialisation and being exposed to certain social conditions repeatedly instil in individuals a way of being and perceiving. The power of habitus is derived from the nonconsciousness of habituation and not from consciously learned principles or rules. "The dispositions and generative schemes, which are the essence of the habitus, are embodied

in real human beings, converted into motor schemes, but are placed beyond the grasp of consciousness, below the level of calculation” (Kontos, 2003, p. 162). The actions are the product of the habitus, but the person, for the most part, does not have conscious control thereof. Thus conscious thoughts do not cause behaviour, rather it is the embodiment of the objective structure of relations between social conditions, which are converted into motor schemes, and materialise as postures, gestures and movements. Therefore, in AD, despite the absence of a coherent mind, agency still persists through the body and a sense of self is retained as it is tied to the body. The body is thus a vital source of personhood and remains present in those with AD.

2.4.4 Summary

In summary, it can be said that discourses surrounding insight and awareness- which presume the absence thereof in those with AD as inevitable, without taking into account the psychological and social factors contributing to the expression of awareness- have greatly contributed to the lack of research including the person with AD. This section has thus looked at how insight and awareness is a complex construct impacted on by both psychological and social factors. Furthermore, discourses viewing the loss of self as inevitable trajectory of the disease have been challenged through looking at the various aspects of the self, and how social interaction constructs parts of the self. Malignant social interaction has been described as part of what contributes to the perceived loss of self. Views on the mind-body relationship, particularly of modern biomedicine where mind and body is viewed as dichotomous, have been discussed as further contributing to this perceived loss. When the self is equated to the mind, it can be seen as lost through the dementing process. The importance of the embodied self as disputing this loss has been argued through highlighting how the body can remain an important source of agency and aid in retaining selfhood even when memory and cognitive functions fail.

It has been argued that to gain a deeper understanding of the disease, a more holistic, inclusive view- in which the mind and body are not seen as separate but interrelated- is necessary. Such a view will contribute to research which includes personal, social and psychological contributions to the disease.

2.5 ‘In their own voices’

In viewing those with AD as able to retain insight, awareness and a sense of self, it becomes viable to research the subjective experience of persons with AD. Following is a discussion of research that has focused on the subjective experience of persons with AD.

2.5.1 Coping responses and its relation to the self

Beard (2004) found that coping strategies are implemented by the person with AD to manage their interactions and make sense of the changes in their lives and identities. They engage in a process to preserve their public and private self.

The association between coping and the self has been found by other researchers also. Based on a phenomenological study, Clare (2002, 2003) conceptualises coping responses as falling on a continuum ranging from self-maintaining responses to self-adjusting responses. In self-maintaining responses, people aim at preserving the pre-existing self concept, while in self-adjusting responses, the aim is to integrate new experiences into a changing self concept. These responses are as a result of the awareness of the changes associated with the symptoms of AD. Clare (2003) suggested that five interrelated psychological processes interact in an ongoing reiterative cycle of developing awareness of these changes. These processes include *registering*, *reacting*, *explaining*, *experiencing*, and *adjusting*. It is important to remember that there is a central tension in relation to all five of these processes between attempts to protect the self from the perceived threat of change,

and attempts to integrate the experience into the self. This is summarised in table 1 (adapted from Clare, 2003) and then explained.

Table 1			
<i>Psychological processes in maintaining and adapting the self and influences thereon</i>			
Psychological Process	Self-maintaining themes	Self-adjusting themes	Influenced by
<i>Registering</i>	Uncertainty	Acknowledging	
<i>Reacting</i>	Minimising	Disintegrating	Age, representations of dementia, response of partners
<i>Explaining</i>	Normalising	Switching the wires	Beliefs about memory and aging, response of spouse, interaction with professionals
<i>Experiencing</i>	Putting on a protective cap	Spending time in the depths	Preferred ways of dealing with emotions, need for maintenance of self-esteem and personal control, attitude to death and dying, representations of dementia, response of others
<i>Adjusting</i>	Holding on; compensating	Fighting; accepting	Preferred ways of coping, support from partner and others, positive elements of the present situation, availability of valued roles, level of social engagement and support, provision of medication.

According to Clare's (2003) model, when memory problems begin, the process of registering begins. On the self maintaining side of the continuum is a response of uncertainty about the change, while the self-adjusting response is one of acknowledging. Once the presence of significant change in memory is registered, the interrelated four other processes are activated, namely reacting,

explaining, experiencing and adjusting. These are not a series of stages, but interact in an ongoing cyclical process with the awareness of change, and will briefly be explained:

- Immediate reactions to the change in memory fall on the continuum between minimising the nature and extent of the change (self-maintaining) and focusing on a sense of disintegration of memory (self-adjusting).
- The explanation for the changes range between normalising explanations often associated with aging (self-maintaining) and explanations of the brain as being causal (self-adjusting and termed 'switching the wires').
- Experiencing the emotional impact associated with the changes range from the need to protect oneself from the emotional pain (self-maintaining and termed 'putting on a protective cap') to 'spending time in the depths' (self-adjusting).
- Adjusting to the change ranges from responses of 'holding on' and 'compensating' (self maintaining) to 'fighting' and 'accepting' (self-adjusting). Holding on involves trying harder to overcome problems, utilising a routine to function, using medication and hoping for a cure. Compensating involves consciously making changes in order to appear to be carrying on, relying on one's partner, and developing coping 'devices' and 'strategies' to function socially and compensate for memory failure.

The interaction between coping and the self is supported by Pearce et al. (2002), who found that men in the early stages of AD make appraisals that impact on their coping strategies to manage their sense of self in relationships and social identities. When they appraise the disease as having limited impact or being reflective of normal memory loss and ageing, the strategies employed to cope are usually: to try a bit harder; take a break; make the most of things; and rely on one's partner and medication. Through these strategies they are able to maintain a sense of self. When these strategies

however no longer work and there is an awareness of difficulties, there is reappraisal and reconstructing of a sense of self rather than maintenance of the self. Appraisal, experience of loss and coping strategies are all intertwined in an ongoing, cyclical process to help manage the sense of self. In addition, the partner's coping processes and the broader socio-cultural setting also have an influence on moving between maintaining and reconstructing a sense of self.

The research of Pearce et al. (2002) thus demonstrates that even in the presence of a debilitating "cognitive" disease, person's with AD employ psychological mechanisms in order to adapt and cope. Furthermore, it shows how awareness sets coping strategies in a wider context where the sense of self is influenced by physical and cognitive changes, the social context of interactions and relationships, as well as by the person's own beliefs experiences and resources. Clare et al. (2005) demonstrated that people with early stage dementia may adapt their strategies for coping as time goes on. Thus while at one point in time mainly self-maintaining strategies may be used, later it may be self-adjusting. This points to the potential for therapeutic interventions with those in the early stages of AD and possibly beyond.

2.5.2 Illness representation, coping and the self

Harman and Clare (2006) found two main themes in the illness representations of persons in the early stages of AD, namely "it will get worse" and "I want to be me." This is reflective of the tension between acknowledgement of the nature and prognosis of AD while at the same time wanting to maintain a sense of identity. Illness representations in turn impact on the development of strategies to manage the threat of dementia. Such strategies are based on existing coping styles and previous experience of managing threats to one's well-being and sense of self. Initially, illness representations are drawn on to make sense of the experience of the disease, but the actual

experience then leads to either an adaptation or maintenance of the representation. This in turn impacts on the maintenance or adaptation of goals for coping with the disease. Illness representations and lived experience together influence the sense of self as the person tries to maintain a sense of self while adapting to changes and consequences of dementia.

Another dialectical tension, namely between agency and objectification, is present in how people with AD organise their understanding of the disease. The paradox is expressed in themes of both resistance and acknowledgment being present simultaneously. It illustrates the challenge in AD of preservation of the self to be able to act in a world (agency) while at the same time experiencing the symptoms with the implication for objectification (MacQuarrie, 2005).

2.5.3 Coping, personality and previous experiences

How people cope with the onset of AD is influenced by their personality as well as by past experiences. The person has, through previous experiences, built up preferences in terms of dealing with difficulties. Thus, while some respond by overtly trying to normalise or explain away difficulty, others may covertly avoid thinking about the difficulty or unconsciously deny the difficulty (Clare et al., 2005).

2.5.4 Experiences associated with the disease

Gilmour and Huntington (2005) investigated the experience of the person with dementia and found three main themes: coming to terms with memory loss, maintaining control and negotiating relationships. Coming to terms with memory loss includes the process of accepting the diagnosis and coming to terms with what that may entail for the future. The tensions between maintaining a sense of independence and needing support, together with the employment of strategies to maximise the abilities that are present are part of maintaining control. Finally, the inevitable change in

relationships, with family, friends and health care workers and various aspects thereof is part of negotiating relationships.

2.6 Caregiving in the context of Alzheimer's disease

AD does not only have a tremendous impact on the individuals living with it, but also on their family members and particularly the primary caregiver. Caregivers may mourn the loss of their previous relationships with the person with AD, as well as the loss of their previous roles in the family (Vellone, Sansori & Cohen, 2002). Caring may not only place strain on family relationships, (Szinovacz, 2003) but also impact on the well-being of the caregiver due to the unrelenting psychosocial, physical and financial demands (Vitaliano, Young & Zhang, 2004). It is not surprising then that caregivers may have feelings of resentment (Chang, Brecht & Carter, 2001). Russel (2001) found that elderly men caring for their wives may experience isolation and have feelings of doing invisible care work. It is however important to remember that it is the caregiver's perception of events occurring in caregiving, rather than the events themselves that contribute to caregiver burden, as different caregivers may find different aspects burdensome (Wuest, Ericson, Stern & Irwin, 2001).

Although caregiving can be a source of much stress, caregivers engage on a daily basis in a process of preserving the comprehensibility, manageability and meaningfulness they ascribe to their lives (Potgieter & Heyns, 2006). In addition to this, they show adaptability and resilience (Russel, 2001).

Looking at the above literature, it can be argued that how the caregiver experiences AD will have an impact on the person with AD. This is because the caregiver's experience will impact on how they treat and react to the person with AD, which in turn will impact on the sense of self of the person with AD as constructed through interaction with their caregivers.

As discussed earlier, the subjective experience of the person with AD has been neglected. This is true also in research regarding giving care to the person with AD, in that the focus has been on the caregiver and not the care-receiver. Whitlatch (2001) outlines how research in family caregiving has changed over the past three decades. Research in the 80's and 90's predominantly excluded care-receivers and focused on the subjective account of the caregiver. Those with AD were rarely asked about their condition or their experience. An example of such research is a study by Vernooij-Dassen, Wester, Auf Den Kamp and Huygen (1998) in which the response of the person with AD, the caregiver and the social network during the process of dementia was investigated through only analysing the diary of the caregiver. New research attests to a more holistic approach within the investigation of experiences of AD. The following section looks at research which includes both the caregiver and person with AD.

2.7 Integrated experiences

2.7.1 Caregiving in context of Alzheimer's disease

A study (Aggarwal, Vass, Minardi, Ward, Garfield & Cybyk, 2003) was conducted in which both the person with AD and their relatives were included to explore how they experience dementia as well as how they perceive and receive care provision. The results of this study are discussed first in terms of the experience of dementia by the patient and caregiver respectively. The experience of care is then similarly described.

Regarding the experience of dementia, the theme of loss was prominent among those with dementia. This included multiple losses as the disease progressed: loss of continence with a loss of dignity; loss of friends and relatives who no longer understood how to relate to the person or found the deterioration too painful; loss of memory; loss of self confidence and loss of communication ability. These losses resulted in depression, aggression or withdrawal. Other experiences of the

person with AD include confusion, bewilderment, fear, obsessive behaviour and a constant need for attention (Aggarwal et al., 2003).

Relatives of those with dementia emphasised the immense psychological and physical burden they had to endure. Support and information was experienced to be insufficient and difficult to access. This impacts on the person with AD, as when their caregivers don't have adequate support or information, the quality of care provided is compromised. The onset of dementia was extremely upsetting, as well as the uncertainty of what was to come and the knowledge that it would only get worse and that there was no cure. Relatives often experienced the loss of being able to communicate with the person with dementia particularly difficult, feeling lonely, isolated and depressed. Caregiving was referred to as a full time, 24 hour job, and as the disease progresses relatives feel more unable to cope with caregiving and fear for the safety of their loved one. This is then what often times precipitates institutionalisation (Aggarwal et al., 2003).

Regarding residential care, those with AD found levels of privacy and the physical environment to be satisfactory, while they experienced limited social stimulation, choice and independence. Issues of power between staff and patients were evident as some patients were reluctant to complain for fear of the repercussions. Those with AD attending day care centres were more positive about this environment than those in residential care. However, special day care centres were perceived better than general centres catering for anybody of pension-age. This is as activities at general centres were sometimes unsuitable with patients feeling lost and the staff were less likely to relate well to people with dementia. The relatives of those in residential homes indicated that they were much happier in the homes than the residents indicated. The relatives were also more positive about services than the residents. It is thus evident that relatives do not always know how the person with dementia feels about different aspects of their care. Video and observational data tended to support

the view of the residents and not the relatives (Aggarwal et al., 2003).

This study thus highlight the fact that relying on caregiver's and relatives reports regarding the experience of those with AD could result in conclusions not representative of the actual experience. It too confirms that including the person with AD is important in research if a more holistic and accurate portrayal is to be obtained.

2.7.2 Multiple Perspectives

Although caregiver's often believe that they know the preferences of the person with AD, Feinberg and Whitlatch (2001) found when including both patient and caregiver in their research that caregivers were often inaccurate regarding their perceptions of the person with AD's values and preferences for care. Furthermore, they found that persons with mild to moderate cognitive impairment were able to respond consistently to the questions asked regarding preferences, choices and their own involvement in decisions about daily living. They were also able to give accurate and reliable responses to questions regarding demographics. Clark, Tucke and Whitlatch (2008) recently did a study with a large sample (215 participants) in which they too found that those with mild to moderate dementia are able to provide consistent and accurate information. This highlights the importance of including the person with AD in research, and how doing so may enhance both their quality of live and sense of autonomy.

Whitlatch (cited in Whitlatch, 2001) found that the person with AD's level of involvement in decision making is linked to their own and their caregiver's quality of life and depression. When there is increased involvement in decision making, the person with AD's depression decreased, while their reported quality of life increased. However, surprisingly the caregiver's depression increased while their quality of life decreased. This emphasises the inter-relationship between the

caregiver and person with AD and the need for further research regarding this inter-relationship.

2.8 Conclusion

From the literature discussed, it can be deduced that the meanings attached to disease are malleable and many psychological factors contribute to this malleability. The meaning of AD appears to emerge from an interplay between the patient, family and culture, perceived threat of suffering, individual responses to the disease, personality factors, previous experience, illness representations, appraisals and coping strategies. AD is more than a cognitive disease; it is a lived experience for those who are diagnosed with it and those who are caregivers.

Furthermore, taking the arguments from the literature, that awareness, insight and the self is not completely or inevitably lost in AD, and that those with AD are able to respond consistently and reliably, it follows that it is not only viable, but very important, to include the experience of the person with AD in studies on AD. Getting a better understanding of how the person with AD experiences living in the world, and how AD impacts on them, will be important in being able to better assist those with the disease and their caregivers.

Chapter 3

Methodology

3.1 Introduction

Chapter three focuses on how the researcher gained access into the lived experience of AD, i.e., the methodology of this study. It begins by looking at the nature of qualitative research and then describes the research design, sampling and data collection of this study. An overview of Interpretative Phenomenological Analysis (IPA) is given and the procedure as used in this study explained. Finally, issues of reliability, validity and ethics are addressed.

3.2 Qualitative Research

This study is qualitative in nature. Qualitative data are not simply the lack of numbers. It entails analysis with an ear for what informants are saying instead of an eye on predetermined categories and hypotheses (Kidder & Fine, 1997).

As described by Kidder and Fine (1997), there are four features of qualitative inquiry that facilitate critical analysis. Firstly, an open-ended stance is assumed. Thus hypotheses are tentatively formed, reformed and revisited. “This way of working requires being willing to give up control, going along for the ride, not always having hold of the steering wheel – and still taking good notes” (p. 37). Secondly, subjectivity and bias are reflected on. The researcher’s own subjectivity is not seen as an obstacle, but it becomes datum. The researchers’ and the respondents’ subjectivity, biases and personal position are examined to see how it affects data collection as well as analysis. Thirdly,

relationships are worried about. Even after ethical approval, researchers continue to worry about their relationships with respondents and communities. Lastly, open-ended questions are analysed and kaleidoscopic interpretations are written. The point of departure is open-ended questions and analyses that yield multiple, open-ended, partial and kaleidoscopic interpretations. Thus multiple patterns from shifting viewpoints are created.

In relation to research on AD, standardised tests can only provide a snapshot of the individual and focus mainly on the deficits of the person. This leads to an understanding of the person mainly in terms of what he or she is unable to do. More than this is needed if one is to understand the extent to which the affected person still has intact mental and behavioural functions. One can approach the person as an individual who is engaged in a courageous, ongoing attempt to navigate through his or her social world as best as able, and take note of successful attempts as well as failures. Present behaviour can be understood in the context of the persons own history and relationships (Sabat, 2001).

Regarding the theories Kitwood proposed based on qualitative data, he says they

are not based on mere common sense or ignorant prejudice – to be corrected by findings of rigorous research ...they have a rich grounding in the data of real life: the minutiae of caregiving, the close involvement with dementia sufferers as they vary in mood and competence from day to day. The data, the facts of lived experience, are of a very different kind from those obtained from, say, psychometric testing, brain scanning and histopathology. They are less highly systematised, but no less valid (Kitwood, 1990, p. 180).

3.3 Research Design

3.3.1 Case Study Research

This study takes the form of a single case study. The case study method is an idiographic approach, with the aim of investigating aspects of behaviour that get lost when looking at group averages, thus enhancing the depth of understanding (Whitely, 2002).

Generalization, by means of which theories evolve, fails in trying to understand man. For in dealing with a particular man, I do not come upon a generality but an individuality, a person. It is precisely the exclusive application of generalities to human situations that accounts for many of our failures. ... No man is an average man. The ordinary, typical man... is the homunculus of statistics. In real life there is no ordinary, undistinguishable man, unless man resigns himself to be drowned in indifference and commonness (Heschel, 1965).

In this study, the researcher looks at the experience of the person with AD and also brings in the voice of his caregiver, as this allows for a more holistic and realistic sense and is more useful for exploring effective interventions (Whitlatch, 2001).

3.3.1.1 Limitations of case studies

The limitations of using a single case study have been said to be not being able to: a) generalise the findings as it is context specific, b) determine whether the findings are unique or typical, c) determine causality due to the high degree of naturalism and d) quantify the results. Furthermore, this approach is vulnerable to research bias (Whitely, 2002). Flyvbjerg (2004, p. 421) argues that these commonly stated limitations are not necessarily limitations, and are based on misunderstandings regarding case studies. Flyvbjerg has revised these misconceptions, as summarised in table 2 below:

Table 2	
<i>Misconceptions and revisions about case study research</i>	
Misconception about case studies	Revision of the misconception
General, theoretical (context-independent) knowledge is more valuable than concrete, practical (context-dependent) knowledge.	Predictive theories and universals cannot be found when studying human affairs. Context dependent knowledge becomes more valuable than the vain search for predictive theories and universals.
Generalisations cannot be made on the basis of an individual case and therefore the case study cannot contribute to scientific development.	
The case study is used in the first stages of research to generate hypotheses, while other methods are more suitable for hypotheses testing and theory building.	
Case study research contains a tendency to confirm the researcher's preconceived ideas, that is, a bias towards verification.	The case study does not contain more bias towards verification than other research methods. On the contrary, the case study contains a greater bias falsification of preconceived ideas than towards verification.
It is difficult to summarise and develop general propositions and theories on specific case studies.	Although it is often difficult to summarise case studies regarding case process, it is less true regarding the outcomes of the study. Problems in summarising are often due to properties of reality being studied than to the case study as research method. Often times it is also not desirable to summarise and generalise case studies, and good studies should be read as narratives.

3.3.1.2 Advantages of case studies

The advantages of the case study method, and the reason for its use in this research, is that a great amount is learnt about the particular person and their lived experience of the phenomenon that is investigated, in this case AD. It is possible to focus on connections between various aspects of the person's account. Through the idiographic approach, a better understanding of the investigated phenomena can be reached as the holistic nature thereof allows the lifeworld of the individual to become visible, portraying the person's ways-of-being-in-the-world (Eatough & Smith, 2008). Furthermore, Eatough and Smith (2008) emphasise that gaining knowledge through focusing on the particular or universal does not need to be mutually exclusive, as the intensive investigation of the individual can be the route to universal laws. By probing deeper into the particular, we are taken nearer to the universal. The researcher is brought closer to significant aspects of the general through connecting the individual unique life with a common humanity.

3.4 Procedure

3.4.1 Sampling

Neurologists working at the Brain and Spinal Cord Unit at a private hospital in Pretoria were asked to refer to the researcher people with AD who were identified during routine visits to the unit.

For the purpose of this qualitative study, the referred person with AD and their caregiver had to fulfil the following clinical criteria:

- The person has a medical diagnosis of AD.
- The person has a Mini Mental Status Examination (MMSE) score of 18 and above, indicating mild or moderate AD.
- The person does not have a co-morbid psychiatric or medical condition that can influence levels of consciousness and impair language or speech abilities.

- The primary caregiver must live with the patient.

Furthermore, the person with AD and caregiver identified for the qualitative study had to live in Pretoria and be available for interviews during the year. Hence, they were also recruited on the basis of convenience and accessibility.

The referred participants were informed by the neurologist about the study and the voluntary nature of their participation before being referred.

3.4.2. Data Collection

3.4.2.1 Interviews

Kvale (1996) uses the metaphor of the qualitative interviewer as a traveller on a journey rather than a miner. The miner sees knowledge as a buried metal that can be unearthed – the knowledge is waiting to be discovered. In contrast, the traveller wanders through the landscape, entering into conversation with those encountered. The interviewer asks questions that lead the subjects to tell their own stories of their lived world. What the traveller sees and hears is described qualitatively – the multiple potential meanings in the original stories are differentiated and unfolded through the traveller's interpretations.

Two in-depth interviews were conducted with the participant and caregiver separately. The second interview allowed for a follow up in order to attain more detail on responses in the first interview. This process of triangulation not only serves as a credibility check and gives additional collateral information from the caregiver's perspective, but also enhances the robustness of the qualitative data obtained from the participant (Clare, 2003). It should however be noted that in this study the

perspective of the person with AD is given primary importance. The caregiver's perspective is thus included only where it sheds light on the experience of the participant.

3.4.2.1.1 The Participant

The interviews were tape-recorded and transcribed. Due to the nature of the disease in relation to memory impairment, the participant was given a card briefly summarising the details of the interviewer as well as the purpose of the interview both times. Terms such as Alzheimer's disease and memory problems were not used in the interview until the participant mentioned it first in order to elicit unique interpretations and representations.

During the interview with the participant, open ended statements and reflection were used to facilitate the conversation. Areas of possible exploration included:

- Biographical and historical data, general personality traits, coping styles and idea of premorbid self.
- Perceptions, representations, interpretation and evaluation of AD in general.
- Reaction to diagnosis, knowledge of symptoms, insight into own illness.
- Understanding and acknowledging change from premorbid functioning.
- Insight into the nature and context of changes.
- The impact of the disease on a variety of contexts (physical, mental and social consequences of the disease).
- Compensatory strategies used in these contexts.
- Anticipation of the future.

Interviews with the participant were thus aimed at gaining knowledge of the individual's background and strengths, and well as allowing him to establish his own account of his current situation.

3.4.2.1.2 The caregiver

In the interviews with the caregiver, she was asked to give a description of her experiences of the disease, the observed changes in the participant in terms of personality, self and insight and the impact of these on the family and interpersonal relations.

3.4.2.2 Tests and Inventories

The Mini Mental Status Examination (MMSE), Neuropsychiatric Inventory (NPI) Alzheimer's Disease Cooperative Study- Activities of Daily Living Inventory (ADCS-ADLI), Alzheimer's Disease Assessment Scale – Cognitive Subtest (ADAS-Cog) and Clinical Dementia Rating Scale (CDR) were done at the time of both interviews. It should be noted that these assessments were used to serve as collateral information on the status of the patient's activities of daily living, the severity of the disease and the neuropsychiatric profile of the patient.

3.4.2.2.1 Mini Mental Status Examination

The MMSE is a formalised mental status examination and is used widely as a brief screening instrument for dementia. It is a 30 point scale, consisting of several orientation questions, registration and recall tasks, attentions tasks, a multistep command, two naming tasks, a repetition task, a reading comprehension task, a written task and a visual construction task. It assesses the domains important to the diagnosis of dementia, namely orientation, language, memory, attention and construction abilities. The standardised administration takes approximately five to ten minutes. A total score of 30 is possible, with a total score of less than 24 being the criterion for cognitive

impairment (Camicioli & Wild, 2006). Lezak, Howieson and Loring (2004) reports on the reliability in Folstein's original sample to standardise the test. The test-retest reliability over 24 hours in the original standardisation sample of non-demented patients was high, whether the examiner was the same ($r = .89$) or different ($r = .83$). Test-retest reliability over four weeks for dementia patients was almost perfect ($r = .99$). Camicioli and Wild (2006) report the internal consistency of the MMSE to be good, with Cronbach's alpha ranging from 0.54 to 0.96. There is however a practice effect with repeated administration.

3.4.2.2.2 Neuropsychiatric Inventory

The NPI has been standardised for use in the Alzheimer's population (Cummings, Mega, Gray, Rosenberg-Thompson, Carusi & Gornbein, 1994) and was developed to assess the behavioural disturbances common in dementia patients. There are ten domains which are assessed: delusions, hallucinations, agitation or aggression, depression or dysphoria, anxiety, elation or euphoria, disinhibition, irritability or lability or aberrant motor control (Lezak et al., 2004). The primary caregiver is asked scripted questions about the person with AD's behaviour over the previous month. Each section has screening questions. If the behaviour has occurred, more in depth questions are asked, resulting in a frequency score on a four point scale and a severity score on a three point scale. The test can be administered in 10 minutes, although certain caregivers tend to elaborate on their answers, making administration longer (Camicioli & Wild, 2006). Camicioli and Wild (2006) report the inter-rater agreement to range from 89% for apathy to 100% or several other subscales. Overall test-retest correlations were 0.79 for frequency and 0.86 for severity. All subscale test-retest reliabilities showed significant correlations. The NPI has good internal consistency, with a Cronbach's coefficient alpha of 0.88.

3.4.2.2.3 Alzheimer's Disease Cooperative Study- Activities of Daily Living Inventory

The ADCS-ADLI was specifically developed for functional assessment of the elderly with AD. An interview is done with the caregiver, lasting between 30 and 45 minutes, in which 30 items assess abilities in the person with AD. Yes or no answers are provided by the caregiver to specific questions, with the questions describing the functional tasks the person may or may not do. It also addresses the need for supervision during the performance of these tasks (Camicioli & Wild, 2006). Camicioli and Wild (2006) report the ADCS-ADLI to have high face validity as well as convergent validity with other psychometric and clinical measures, such as the Global Deterioration Scale. Kappa values assessing reliability on individual questions ranged from low (0.41) for "makes conversation" to a high of 0.73 for "bathing".

3.4.2.2.4 Extended Alzheimer's Disease Assessment Scale – Cognitive Subtest

Items from the Alzheimer's Disease Assessment Scale (ADAS) were selected for the ADAS-Cog which were thought to be that most salient features of cognitive dysfunction in AD (Lezak et al., 2004). It is directly administered to the person with AD. The items in the ADAS-Cog cover language ability, memory, praxis and orientation. Administration takes 30 to 35 minutes. The total score of the ADAS-Cog ranges from 0-70, with higher scores indicative of greater impairment, as scores are based on errors (Camicioli & Wild, 2006). Lezak et al. (2004) reports the inter-rater reliability to be high (.82 - .89), as well as test-retest reliability over six weeks (.91).

3.4.2.2.5 Clinical Dementia Rating Scale

The CDR is frequently used in AD research, and rates severity on a 5 point scale, with a score of 0 reflecting no evidence of dementia. Ratings are based on memory, temporal orientation, judgment, problem solving, community activities, home activities and hobbies. A score of 0 refers to no impairment, 0.5 to questionable dementia, 1 to mild dementia, 2 to moderate dementia and three to

severe dementia. The final score is worked out using an algorithm (Camicioli & Wild, 2006). Questionable dementia reflects mild consistent forgetfulness or slight problems with two or more cognitive areas. Mild dementia reflects either moderate difficulty in recent recall which interferes with daily activities, or mild forgetfulness with mild to moderate impairment in three or more other cognitive areas. These may also include having to be prompted for personal hygiene. Moderate dementia reflects severe memory loss, or moderate memory loss with severe impairment in three or more other cognitive areas. These may include assistance with personal hygiene or dressing. Finally, severe dementia reflects severe memory loss, with there only being memory fragments, orientation to person only, the inability to make judgments or solve problems, there being no independent functioning inside or outside the home, the inability to perform personal care and oftentimes incontinence (Lezak et al., 2004). Camicioli and Wild (2006) report the face validity of the CDR to follow from the fact that it was developed directly from established criteria for diagnosing dementia. Furthermore, the scale has been validated against verified cases of AD. The scale has a high inter-rater reliability (weighted kappa = 0.87).

3.5. Data Analysis

3.5.1 Interpretative Phenomenological Analysis: An overview

Interpretative Phenomenological Analysis (IPA) is used in this study to analyse the data collected from the interviews. It complements the aims of the study, as IPA aims to explore how participants make sense of their worlds and what the meanings of certain experiences, events and states hold for participants. It highlights the subjective lived experience of the person- their personal perception- as opposed to objective statements. It further aims to explore experience in a flexible and detailed manner (Smith, Jarman, & Osborn, 1999; Smith & Osborn, 2003).

3.5.1.1 Theoretical underpinnings of Interpretative Phenomenological Analysis

According to Eatough and Smith (2008), IPA has joint theoretical underpinnings in both phenomenology and hermeneutics. The approach only became articulated as a specific research approach in the mid 1990's, drawing on both phenomenology and hermeneutics, and taking into account the neglected concern in psychology with subjective experience and personal accounts. Part of the development of IPA was the establishment of a qualitative approach to psychology that was also grounded in psychology. The two theoretical underpinnings of IPA will now briefly be looked at.

3.5.1.1.1 Contributions from Phenomenology

It is important to realise that phenomenology is not a unified system of propositions and practices. As a philosophical framework it has undergone multiple changes since its inception, and its application as a research method has taken on many different forms (Willig, 2001).

Eatough and Smith (2008) explain that broadly speaking, phenomenology concerns itself with how things are experienced, as reality from this stance is viewed as an experiential one. Reality is experienced through practical engagements with others and things and seen to have inherent meaning. Phenomenology thus avoids reductionism, and rather aims at describing the world in the way it is experienced by humans.

Dahlberg, Drew and Nyström (2001) discuss the important contributions to phenomenology by philosophers such as Heidegger and Husserl. According to these authors, Heidegger defines 'phenomenon' as meaning *that which shows itself in itself*. A phenomenon is thus a *thing* as it presents itself to- or as it is experienced by- a person. They further explain that a slogan in phenomenological philosophy *-to go to the things themselves-* would be defined by Husserl as doing

justice to the everyday experience, the *lived experience*. The aim is to approach the world as it is experienced. The *things* do not exist entirely in themselves, as is the main idea of realism. Neither are they mere aspects of a person's conceptual world, as in the idea of idealism. Rather, they are things of experience. Phenomenology turns to the world as it is experienced. The authors point out that as a researcher, one takes a position where things can reveal themselves, and thus the *thing* becomes understood as a phenomenon.

According to Eatough and Smith (2008) an important concept in phenomenology influencing IPA is Heidegger's proposal that a human being is a *Dasein*, meaning *being there*, and is often times referred to as *Being-in-the-world*. This *Being-in-the-world* dissolves the Cartesian dualism of person/world or mind/body, as individuals are seen as *Being-in-the-world* with others and with things. The authors argue that this is also emphasised by Merleau-Ponty's statement that "man is in the world, and only in the world does he know himself" (p. 180). They regard Merleau-Ponty as an important philosopher who gave the body a central role, as the body is seen to be inextricably caught up with one's sense of self, one's lifeworld, as well as one's relations with others. It is through your body that a particular world unfolds, a world that differs from the one disclosed through the body of another person.

Dahlberg et al. (2001) argues that from a phenomenological viewpoint, human beings and their existence cannot be fully understood without being considered as a living whole. Thus while objective findings, such as brain scans, test results and diagnoses are important tools in healthcare, they only have limited value. Understanding is incomplete without the subjective experience, the lived viewpoint of body and health, knowledge and existence.

3.5.1.1.2 Contributions from Hermeneutics

Studying a ‘*Dasein*,’ a human existence, is however difficult as it cannot be studied directly. When attempting to reflect on that which is, the phenomenon is distorted (Dahlberg et al., 2001). Eatough and Smith (2008) continue to describe how the study of an individual life is done through a lens of already existing cultural and socio-historical meanings. They emphasise that all that can be studied is what Heidegger calls the *factical existence*, meaning “experiences which appear to the individual in her/his own way” (p. 180). *Hermeneutics of factical life* can only be examined through a method which claims that understanding is reached by investigating how events or objects are experienced and given meaning by the individual.

Hermeneutics, the theory of interpretation, is a strong influence in IPA. As a method, hermeneutics aims at understanding lived experience. In hermeneutics, the text is seen as the objectification of the lived experience, and understanding happens when life understands itself (Eatough & Smith, 2008). Smith (2007) describes how Heidegger was influenced by these ideas, and proceeded to describe the very nature of *Being-in-the-world* as hermeneutic. The person’s relationship with the world is hermeneutic, operating in a ‘hermeneutic circle’. Understanding is always mediated by already existing knowledge, stemming from experience, and access to knowledge mediating understanding is often complicated.

3.5.1.2 Summary of Interpretative Phenomenological Analysis

In IPA then, what is fundamental is experience, and uncovering, expressing or illuminating individual subjective experience. Experience is seen as subjective, because what is experienced is a phenomena and not a direct reality. We connect with “events, objects and people in the context of how they appear to us” (Eatough and Smith, 2008, p. 181). The *lived experience* becomes a term used to encompass the “embodied, socio-culturally and historically situated person who inhabits an

intentionally interpreted and meaningfully lived world.” (p. 181). Whatever the phenomenon is under study, what is emphasised is what it is like, for the particular person, to be experiencing whatever is being studied. This necessitates studying the phenomenon from the personal perspective, “taking the standpoint of the conscious, thinking, unreflecting/reflective, feeling person” (p.181). IPA thus has its starting point in the unique intersubjective experience of the individual, and also gives attention to the body as it is lived and experienced. It looks at the lived body and how its felt meaning is communicated to others.

IPA draws on a range of phenomenological positions, being influenced as much by Heidegger’s hermeneutic phenomenology as Husserl’s emphasis on description and the essence of a phenomenon. It emphasises the interpretative features of analysis, with the type of interpretation following from close attendance to the presented phenomenon. It has an idiographic commitment, believing that the manner through which psychological meaning are constituted can be usefully explored through examining, in a detailed manner, unique individual lives. It thus focuses on the particular, rather than the universal. Inherent in the approach is a shift from focusing on establishing causal laws to a concern with understanding meaning in individual lives. This is often done by the use of single person case studies (Eatough & Smith, 2008).

In summary, it can be said that IPA is phenomenological as it aims to explore the participants’ view of what is being investigated. What makes it interpretative, is that it acknowledges that the perception of the participants are elicited through a dynamic, interactive process where the researcher’s beliefs and understandings play a part. This is because the researcher engages in a process of interpretative activity to make sense of the participants’ subjective world (Clare, 2003).

3.5.2 Procedures

IPA recognises that the process of data analysis is dynamic in nature. The researcher engages in an interpretative relationship with the transcript in order to understand the content and complexity of the meanings as these meanings are not transparently available. Access to these meanings is thus dependant on the researcher's own conception, as these are required to make sense of the participant's personal world through interpretation. This process is explained in Smith et al., (1999) and Smith and Osborn (2003) and is applied to this study. It should be however noted that IPA does not have a prescriptive methodology, and the described outline below indicating how it was used in this study is merely one way to do IPA. IPA consists of a basic process of moving from description to interpretation and does not have a detailed formula. Furthermore, it is important, as mentioned earlier, that the interpretative role of the researcher in IPA must be acknowledged (Brocki & Wearden, 2006).

3.5.2.1 Interpreting the Participant's Transcript

3.5.2.1.1 Looking for themes

The participant's transcript was read a number of times to look for themes. The researcher went about this process in the following manner. The left hand margin of the interview transcript was used to annotate what is interesting or significant about the text. Comments included summaries, paraphrases, associations and connections that come to mind and preliminary interpretations. Language use, similarities, differences, echoes, amplifications and contradictions were commented on.

Once the whole transcript had been worked through in this manner, the right hand margin of the interview transcript was used to document emerging theme titles. The initial notes were transformed into concise phrases to capture the essential quality. This working through of the transcript involved

more psychological terminology, and is at a slightly higher level of abstraction. The themes that emerged were however grounded in what was said by the participant.

3.5.2.1.2 Connecting the themes

The themes that emerged were listed sequentially. The researcher then tried to make sense of the connections between the themes that were emerging. This level involved analytical or theoretical ordering. Some themes clustered together, while other themes were superordinate concepts. The clustering of themes was checked to make sure that connections were still in relation to the primary source material. The researcher thus drew on her interpretative resources to make sense of what is said, while at the same time checking her own sense-making against what the person actually said.

A table was then drawn up, with the superordinate themes and clustered themes, and was ordered coherently.

3.5.2.1.3 Use of a metaphor

Once the themes were clustered and ordered, it became evident that they could be grouped under the unifying metaphor of a tennis game, with different aspects of the game accounting for different themes and subthemes. This metaphor was spontaneously introduced by the participant, and elaborated on by the researcher. This manner of ‘data ordering’ respected the essence of an interpretative phenomenological approach.

The final themes under the various aspects of the metaphor were written up, outlining the inherent meanings in the participant’s experience. The themes were translated into a narrative account, and each theme is explained, illustrated and nuanced.

3.5.2.2 Caregiver's transcripts

The caregiver's transcripts were read in relation to the thematic list generated from the participant transcript, with both similarities and differences taken note of. Thus it was determined which central themes were emphasised, reinforced or contradicted. The spouse's transcripts also provide clarification on factual data which the participant could not remember.

3.6 Reliability

3.6.1 Inter-rater reliability

An independent researcher analysed the transcript and followed the same stages of analyses, finally deriving the themes. These were compared to the researchers themes and any differences were discussed and consensus reached as to the final list of themes.

3.6.2 Decreasing researcher bias

Krefting (1991) proposes the application of the criteria of credibility, transferability, dependability and conformability to lessen the possible bias of the researcher.

- Credibility can be attained through member validation and peer evaluation. In this study, as already discussed, an independent researcher also analysed the data and the themes were compared and discussed.
- Transferability enables others to transfer the research findings to other areas in the field. This is achieved by describing all aspects of participants and well as the research context. In this study, the participants and caregiver were described in as much detail possible within ethical constraints.

- Dependability is enhanced by giving a thorough description of the methodology used. How this research was carried out is described in a step by step manner earlier in this chapter.
- Conformability is enhanced by researcher reflexivity. It is acknowledged that the researcher is not merely an objective bystander but a contributor to the process of research. Inputs and discussions with the researcher's supervisor was thus of immense importance.

3.7 Ethical Considerations

3.7.1 Informed Consent

Written consent was obtained from both the participant and the caregiver. They were informed regarding the voluntary nature of their participation, and made aware that at any point during the research they could withdraw their consent without giving a reason and without any negative consequences.

3.7.2 Confidentiality

Confidentiality was assured as no identifying names are used on the transcripts or in the mini-dissertation. Participants were informed that the interview would be tape recorded, but assured that only the researcher would have access to these tapes.

3.7.3 Consequences

It was undertaken that should the person with AD or the caregiver experience any distress as consequence of the interviews, they would be offered psychological assistance.

3.7.4 Ethical approval

Ethical approval for the study was obtained from the Faculty of Humanities' ethics committee of the University of Pretoria.

Chapter 4

Results

4.1 Introduction

Finally, after the chapters that have contextualised the research and described how and why it done, this chapter takes the reader into the lived experience of AD. It starts by firstly giving an overview of the background information of the participant, Martin, and Sarah, his wife and caregiver. Please note that these pseudonyms have been used in order maintain the anonymity of the participant and caregiver. Results from the neuropsychological tests administered to Martin at the time of the first and second interview are given and the significance thereof discussed. The themes derived from the analysis of the two interviews with Martin are discussed, as well as the contradictions and confirmations as given by Sarah.

4.2 Overview of participant and caregiver

Martin is a 65 year old male who is married to Sarah. She is also his primary caregiver. His highest level of education is a University degree. Martin was diagnosed with AD five years ago in 2003. Significant clinical history includes the onset of depression and aggression in 2007. Martin received treatment and these symptoms no longer persist at the present time.

4.3 Neuropsychological test results

At the time of the first and second interview, the following tests were administered as discussed in the Chapter 3: MMSE, NPI, ADCS-ADLI, ADAS-Cog and CDR.

4.3.1 Results at the time of the first interview

4.3.1.1 Mini Mental Status Examination

Martin had a MMSE score of 25. According to Lezak et al., (2004) this indicates mild or moderate cognitive impairment in a person with AD.

4.3.1.2 Neuropsychiatric Inventory

Table 3						
Neuropsychiatric Inventory: Positive domain						
Domain	N/A	Absent	Frequency	Severity	FxS	Caregiver distress
Apathy/ Indifference			1 2 3 4	1 2 3	04	1 2 3 4 5

The NPI indicates that at the time of the first interview Martin displayed the symptom of apathy. It was of mild severity and was mildly distressing to Sarah. The NPI further indicates that Martin displayed none of the following symptoms: delusions, hallucinations, agitation or aggression, depression or dysphoria, anxiety, elation or euphoria, disinhibition, irritability or lability or aberrant motor control.

4.3.1.3 Extended Alzheimer's Disease Assessment Scale – Cognitive Subtest

Table 4		
Extended Alzheimer's Disease Assessment Scale – Cognitive Subtest: First Interview		
Domain	Total	Patient Scores
1. Word Recall	0 – 10	Trial 1: 03 Trial 2: 04 Trial 3: 04 Average: 04

2. Commands	0 – 5	00
3. Constructional Praxis	0 – 5	01
4. Delayed word recall	0 – 10	05
5. Naming objects and fingers	0 – 5	00
6. Ideational praxis	0 – 5	00
7. Orientation	0 – 8	03
8. Word recognition task (one trial)	0 – 12	02
9. Remembering test instructions	0 – 5	00
10. Spoken language ability	0 – 5	00
11. Word finding difficulties	0 – 5	00
12. Comprehensions of spoken language	0 – 5	00
13. Concentration/ Distractibility	0 – 5	02

The extended ADAS-Cog indicates that Martin had difficulty with word recall, delayed word recall, orientation, word recognition and concentration or distractibility. It is however important to note that Martin's spoken language ability and comprehension of spoken language remained intact. This is necessary considering an interview with him requires these abilities to be intact.

4.3.1.4 Clinical Dementia Rating Scale

Martin's overall score on the CDR equals one, which is indicative of mild dementia. The CDR indicated that in terms of memory Martin had severe memory loss, with him only retaining highly learned material and losing newly learnt material rapidly. Regarding orientation, he had moderate difficulty with time relationships and was oriented to the place of examination, although he had geographic disorientation elsewhere. In terms of judgment and problem solving ability, he displayed moderate difficulty in handling problems, similarities and differences, while his social judgment was usually maintained. Martin was unable to function in community activities independently, although he was still engaged in some and he appeared normal to casual inspection. He had mild but

definite impairment at home and abandoned more difficult tasks and more complicated hobbies and interests. He also needed prompting in his personal care.

4.3.1.5 Alzheimer's Disease Cooperative Study- Activities of Daily Living Inventory

On the ADCS-ADLI Martin scored 21/ 30, which is indicative of mild impairment in activities of daily living.

4.3.2 Results at the time of the second interview, eight months later.

4.3.2.1 Mini Mental Status Examination

Martin, at the time of the second interview, had an MMSE score of 27/30. This is indicative of mild dementia.

4.3.2.2 Neuropsychiatric Inventory

The NPI evidences that Martin no longer displayed apathy and no additional behavioural symptomology were present at the point in time of the second interview. There was thus no evidence of delusions, hallucinations, agitation or aggression, depression or dysphoria, anxiety, elation or euphoria, apathy, disinhibition, irritability or lability or aberrant motor control.

4.3.2.3 Extended Alzheimer's Disease Assessment Scale – Cognitive Subtest

Table 5
Extended Alzheimer's Disease Assessment Scale – Cognitive Subtest: Second Interview

Domain	Total	Patient Scores
1. Word Recall	0 – 10	Trial 1: 04 Trial 2: 04

		Trial 3: 03
		Average: 04
2. Commands	0 – 5	00
3. Constructional Praxis	0 – 5	00
4. Delayed word recall	0 – 10	06
5. Naming objects and fingers	0 – 5	00
6. Ideational praxis	0 – 5	00
7. Orientation	0 – 8	02
8. Word recognition task (one trial)	0 – 12	01
9. Remembering test instructions	0 – 5	00
10. Spoken language ability	0 – 5	00
11. Word finding difficulties	0 – 5	00
12. Comprehensions of spoken language	0 – 5	00
13. Concentration/ Distractibility	0 – 5	00

At the time of the second interview, Martin again had difficulty in word recall, delayed word recall, orientation, and word recognition. He however no longer had difficulty in concentration or distractibility, and showed no new areas of cognitive difficulty. It is again important to note that his spoken language and language comprehension abilities were still intact, which is important for the purposes of doing an interview with him.

4.3.2.4 Clinical Dementia Rating Scale

Martin had an overall score of one on the CDR, which is indicative of mild dementia. The CDR indicated an improvement in memory, as he had moderate memory loss, which was more marked for recent events and which interfered in his daily living. His moderate difficulty with orientation, community activities and functioning at home remained the same. He showed an improvement in

both judgment and problem solving and personal care, as he only showed a slight impairment in solving problems, similarities and differences and no longer needed prompting in terms of self care.

4.3.2.5 Alzheimer's Disease Cooperative Study- Activities of Daily Living Inventory

The ADCS-ADLI has an overall score of 23/ 30, indicating mild impairment in activities of daily living.

4.3.3 Overview of the test results

An overview of the test results at the first and second interview are given in summary.

Table 6 <i>Overview of test results</i>		
Test	First interview	Second interview
Mini Mental Status Examination	25/30	27/30
Neuropsychiatric Inventory	Mild apathy present	No behavioural symptoms present.
Extended ADAS-Cog	Difficulty in word recall, delayed word recall, orientation, word recognition and concentration/ distractibility.	Difficulty in word recall, delayed word recall, orientation, and word recognition.
Clinical Dementia Rating Scale	Overall score of 1 (mild dementia)	Overall score of 1 (mild dementia)
Alzheimer's Disease Cooperative Study- Activities of Daily Living Inventory	21/30 (mild dementia)	23/30 (mild dementia)

The findings of an MRI Scan done during Martin's diagnosis were consistent with AD. The assessments done during this study confirm this diagnosis, as both the CDR and ADCS-ADLI at both points in testing are indicative of Martin having mild dementia. Martin at the time of the first interview had the behavioural symptom of apathy, as measured by the NPI. This was longer present at the time of the second interview. Additionally, there was an improvement in his cognitive functioning at the time of the second interview, with the MMSE score being two points higher, and the ADAS-COG being four points lower than at the time of the first interview. This improvement could be due to the effect of medication, time of day when testing, and multiple other confounding variables. However, when taken in totality, Martin's diagnosis still indicated mild dementia of the Alzheimer's type. The results also indicated that Martin's cognitive abilities were intact for the purposes of an interview at both sessions.

4.4 Themes derived from the analysis of the two interviews.

The themes derived from analysis of the two interviews were clustered together in groups. The metaphor of a tennis game is used to describe these themes. This stems from Martin's account, as he spontaneously used tennis as metaphor at times to describe his experience of AD. Where applicable, comments from Sarah are included, relating to her account that either confirms or disputes his. The researcher would like to remind the reader, that as discussed in Chapter 3, qualitative studies can be read as narratives. This section can thus be read as a narrative of Martin's life and journey with AD, rather than just keeping an eye out for what themes have been established. It is also important to note that this is merely one possible way in which the narrative can be told.

A) FIRST SET

Two main themes are grouped under the metaphor of a first set. In taking a tennis match as being representative of Martin's life, the first set is here equated to how he used to see both himself and his life before the onset of AD.

A1. Reflections on a premorbid self:

Throughout the interview, Martin reflected on the type of person he used to be before the onset of AD. He described himself as a doer who was achievement driven, competent, adaptable, perseverant, able to overcome obstacles, independent, resourceful and someone who had a good self worth.

Being a doer has been important in many facets of his life. His doing was instrumental in him achieving what he did despite being raised in poverty. Working himself out of poverty had a direct impact on him viewing himself as someone who had learnt how to be resourceful and independent and also as someone who persevered until he overcame the obstacles in his path. This in turn impacted on him developing a good self worth. He felt that these positive qualities had become ingrained in him and that he was able to apply them to all new situations and challenges. He valued going through hardship, saying "*growing up there was many obstacles. But you see it is because of the way that I grew up that I am.*" He felt that he was able to work himself out of it, saying:

Being raised in poverty and working yourself out of it, one develops resourcefulness, one develops independence, one develops a value for one's own worth. Nothing is impossible. But that essentially is what I was and carried to all new situations.

He further saw himself as someone who was competent and independent with *“the ability to do things on my own... I was an effective, functional individual.”*

A2. Reflections on a premorbid life

Martin reflected throughout the interview on where he grew up, places he lived and the work he used to do. He grew up in an area populated by various cultural groups which seems to have developed in him an appreciation for integration of diversity. *“People eventually crossed over and lived everywhere... It was a mixed suburb. So, it was a very very good place to be raised.”*

It is thus not surprising that he described how most of his life was spent working to oppose discrimination and inequality as well as working to educate and uplift the community, which he saw as dependent on him. He worked as a teacher and later a principal. After being sponsored to study theatre abroad, he came back and implemented what he had learnt in the community through theatre. *“I was doing... working with or through Child Welfare, and my input eventually involved theatre and using this to encourage good manners, good ethics and the desire to achieve.”... “My protest theatre revolved around the equality of all people.”... “I opposed the fact that the Tricameral government accepted everybody but blacks.”*

“In (suburb) if anything needed to be done, Martin was called to do it. I could raise money for welfare, I could stage plays, you name it I could do it... I was good at what I did.” Being a figure that he felt the community depended on is thus something that Martin prides himself in. This role, of being depended on, also seems to lie central to how he defined himself and contributed to his sense of belonging in the community.

After resigning from teaching he worked for a government department and he reflects on his travels and work in different countries. It was during one of these travels where his difficulty with AD started. He feels specifically that having grown up in a culturally diverse neighbourhood helped him with the transition of working abroad, as well as the positive characteristics of being independent and resourceful already discussed.

B) DOUBLE FAULT, AGAIN AND AGAIN

Going back to the metaphor of a tennis match, there came a time in the match where Martin started making double faults, over and over again. This describes him not being able to serve on his turn and results in the effective loss of points. Under this metaphor the following themes are grouped: the subjectively experienced symptoms of AD, the onset of the symptoms, his affective response to the symptoms and the spiritual crises he went through.

B1. Subjectively experienced symptoms of AD

The subjective changes experienced due to the disease are described by Martin in the interview.

Memory loss

He describes becoming forgetful, “...*I started suffering memory loss... I would forget what day is it; I didn't know what it is, if you told me I would not remember five minutes later.*”

Disorientation

He also describes being disoriented and getting lost at times. “...*while I was studying at (university)... and drove back home I couldn't find my way back home. I was totally disoriented.*”

Non-functional

He furthermore has an overwhelming experience of himself as not being as functional as he used to be; *“I couldn’t be me... I felt I was becoming useless... I was not functioning at my best.”*

Loss of previous abilities

His symptoms all implicate the loss of something he was able to previously do, he used to be able to remember well, he used to be able to find his way and he was a highly functional individual. In terms of the metaphor, not being able to serve over the net due to his memory and disorientation resulted in him experiencing the loss of functionality, of what he was very able to do in the first set. This loss is exemplified in the loss of points when a double fault is made.

Playing doubles: contributions from his partner

His wife objectively reports his symptoms as initially having been disorientation. The first, as Martin reported, was when driving back from University. Later, when working abroad, he got lost on the roads and was unable to successfully navigate to the required destination. There his son took over driving. The memory problems came at his last overseas job, together with confusion, disorientation, agitation and a decrease in performance at work. Sarah reports that currently, he does not plan or initiate anything.

B2. Onset of symptoms

There are two seemingly discrepant subthemes regarding the onset of the illness. The onset is described as being insidious, with Martin saying how it *“crept up on me”* and reporting how many years previously he had already gotten lost driving home. The onset is also however described as sudden, with the symptoms taking him by surprise and him being *“bowled over for a six”*.

Although these two subthemes may seem to be discrepant, it may also be interpreted in the following way. In looking back, he may realize that the development was insidious, but his experience of finally coming to the realization that there was something wrong, hit him with great surprise. It can through the metaphor be likened to him having had increasing difficulty with his serves and then feeling totally surprised when he suddenly realised he can no longer get the ball over the net and has been struggling for a while. In hindsight it seems insidious, but the impact of the realisation is sudden.

B3. Affective response to symptoms

Martin's response to his memory loss, disorientation and decreased functionality and loss of previous abilities is described according to him primarily as an affective one. *"...emotionally, I was set back terribly... by what was happening to me."*

He described feeling depressed, suicidal, despondent, helpless, distressed and mournful. He gives this period of his life the name "moedverlore vlakke" (fields of despondency). *"I felt I was becoming useless... and I entertained thoughts of suicide"... "I felt 'moedeloos', helpless that I could commit suicide because I was not functioning at my best also because I couldn't be me."... "I was mournful during that time. The phrase that I use for that dark time is 'moedverlore vlakke'. That is where I was. I went through that plane of depression."*

Playing doubles: contributions from his partner:

His wife additionally reports an emotional state that included anxiety, agitation and fear in response to the difficulties he was having at work due to the illness.

B4: Spiritual Crisis

Although Martin sees his faith as a source of support, as will later be discussed, he admits to experiencing a spiritual crisis, which left him feeling let down and rejected by God.

... a feeling during that time that God had let me down... it was as if God had rejected me and relegated me to the scrapheap or something like that. Notwithstanding I could not stop praying or going to church even though there was mixed feelings"

C) TO QUIT, OR NOT TO QUIT THE MATCH

Martin went through a phase where he had an intense struggle with himself, which is in the metaphor likened to him wrestling with whether he should quit the match or keep playing. Under this metaphor the following two themes are grouped: wrestling with an unfamiliar self, and emerging with a familiar self.

C1. Wrestling with an unfamiliar self

"During the dark phase it was Martin wrestling with myself and looking in." There was a period of time when Martin describes turning inward and wrestling with himself. Looking into himself, feeling useless and less functional than he had been throughout his life left him with feelings of not being himself... *"I couldn't be me."* Using the metaphor, the wrestle takes place between who he used to be, Martin who used to be good at his game, and who all of a sudden found himself to be, Martin who couldn't get the ball over the net. It was during this time that he not only wrestled with who he was, but also wrestled with whether he felt like he could carry on playing.

C2. Emerging with a familiar self

“At the end of the journey a very similar Martin emerged that was pulled into the dark planes.” Martin emerges from this wrestling match with himself, feeling more similar to who he used to be. How he works to maintain this emerging sense of self felt to be familiar will be discussed in greater detail later on.

D) UMPIRE’S CALL

The umpire’s call is the part of the metaphor that has to do with Martin’s interaction with medical professionals who are able to make decisions and verdicts about him. It also has to do with the meaning he attributes to the verdict. The following five themes are thus grouped here: dismissing medical professional, supportive medical professional, evaluation reception of the diagnosis and the meaning attached to an AD diagnosis.

D1. A dismissing medical professional.

Martin had an initial interaction which in his words was *“hell”*.

I had a memory problem but I was aware of what she was saying. You know I was almost not compos mentos after the doctor went on about me in front of me like I was not there. But I think I was protecting myself by being non compos mentos.

The professional who had diagnosed him with AD did not acknowledge his awareness or presence. He was treated as invisible whilst a worst case scenario was painted for his family predicting his imminent institutionalisation. This was an extremely traumatic experience for him, and he describes protecting himself by becoming “non compos mentos”.

In an experience with a professional where his awareness was not acknowledged and where he was treated as invisible he felt his self as being attacked and had the need to protect the self by distancing himself from the situation by becoming unaware.

Playing doubles: contributions from his partner:

Sarah too emphasises that this was a traumatic experience for Martin, saying *“When she was saying these things you could see he didn’t feel good. I knew that he understood.”* According to Sarah’s description, one of the ways that Martin protected himself from this experience was saying afterwards that he did not believe the lady. Although his verbal response may be taken as one of denial of the diagnosis, his behavioural reaction the days following this experience shows that he was aware of what was happening as *“we would often find him alone, sitting and staring out. He was aware of everything. He wanted to be alone. When the children came, he would leave the room and sit by himself”*. He also had an intense emotional response with him *“just crying for the first few weeks.”*

It is important to note that this evidences that while there was a lack of explicit awareness, with him saying he did not believe the doctor, his behavioural and affective response shows an implicit awareness.

D2. A supportive medical professional

His subsequent experience with a different health professional was *“heaven”*. This professional was understanding and supportive. Rather than feeling the need to distance himself or protect the self, he saw the supportive professional as *“a peg on which I could hang my hat”*... *“Whenever I went in to have an interview his way of doing it is so spot on and he is encouraging.”*

In this context, where the self felt understood and supported rather than treated as invisible, he felt he could relate to and draw support from the professional rather than distance and protect himself.

D3. Evaluation

Undergoing evaluation is something Martin disliked and does not talk about fondly. “*I detested the fact that I was sent back for more evaluations.*” This is most probably because he, as already stated, saw himself premorbidly as someone who was competent and achievement driven. Undergoing these tests probably frustrated and upset him greatly, because through it his difficulties were highlighted, and he was faced with not being able to function as effectively as he could in the past. In terms of the metaphor, going for evaluation may have felt like having to watch his double faults in a replay loop on the screen in front of an audience.

D4. Reception of the diagnosis

The actual receiving of the diagnosis of AD was traumatic for Martin, “*it was bad, the way it was told especially because at the time I did not know what it actually means, just that it was terrible.*” It is evident that when the diagnosis was given to him, the meaning thereof was not clear to him. He was left feeling uncertain what it really meant and was only aware of the fact that whatever it was, was terrible.

D5. The meaning attached to an AD diagnosis

The diagnosis later takes on various meanings for Martin. These include it being an explanation for his memory loss and emotional turmoil, and he defines it as something he both has to accept and fight against.

Explanation for memory loss

The first meaning of AD is as an explanation for the memory difficulties he has. “...at least now I know why I don’t remember the score.”

Explanation for emotional turmoil

He also views the diagnosis as explanation for the emotional disruption he experienced because of the symptoms of the illness.

By the time I heard the diagnosis I had gone through the emotional disruption in my life. For me the diagnosis meant that I could get treatment and that was okay for me. I could connect with something and I could work with it in keeping with who I am as a doer.

Acceptance and fighting

Martin sees the diagnosis of AD as something he has to accept, but something that once he has accepted he can fight against. “Having accepted that I have Alzheimer’s my only commitment to myself was to fight it. Not question what it is.”

Having a diagnosis to fight against ties in with his premorbid view of himself, in which he was perseverant in fighting until he overcame obstacles. The diagnosis of AD thus for Martin becomes a challenge which he can fight against, in keeping with who he was before the disease. He is not so much interested in questioning exactly what it is or maybe even why he has it (which he may initially have done on his journey), but focuses on fighting it.

Playing doubles: contributions from his partner:

After receiving his diagnoses, there was however an extended period of time before he accepted and fought the disease. As Sarah describes *“In five years time since it started I saw he was calmer and more accepting of the disease, it started to sink in”*.

E) STRAPPING UP AND CHANGING RACKETS

In order to carry on playing the match, Martin uses various coping mechanisms. These can be likened to him changing his racket and strapping up his wrists or knees for additional support. The various ways Martin copes can be divided into coping aimed at protecting his self and coping aimed at integrating the changes of AD into the self.

E1. Self Maintaining Coping Mechanisms

Self maintaining strategies can be likened to “strapping up”- it aims to reinforce and strengthen a self that has become compromised through the symptoms of the disease. Through self maintaining coping mechanisms, Martin deals with the disease in a way that maintains normality and the self he knows. Self maintaining strategies Martin use includes: reliance, cuing, psychological defences, compensation by doing and selective disclosure.

Reliance

Martin relies on his wife’s memory in compensation for his forgetfulness. Such reliance is aimed at maintaining normality and his sense of self. Thus when he is asked about certain things he cannot remember, he will often times ask her for help in answering.

Cuing

Cuing is used much in the same manner as reliance. Sometimes when he has he has asked his wife to respond and she does so, her answer triggers his memory and he finishes answering.

Psychological defences

It is evident that he uses certain psychological defences to protect himself from experiencing painful affect. These defences include avoidance, derailment, denial and deflected insight.

- Avoidance and derailment

When Martin was asked about the family meeting with the doctor, he started saying how painful it was for him and then derailed to talking about how he in the past had been competent and performed well. Thus when he was asked about a painful experience related to the disease, he avoided talking about this and derailed to talking about the past when he was competent and overcame obstacles. He thus used avoidance and derailment as a means of protecting himself from the painful affect aroused by the memory.

- Denial

Another psychological defence Martin may use is defensive denial. This defence could be mistaken for a lack of awareness of insight. Such defensive denial can possibly be seen when he attributes the cause of memory impairments to stress with the boss. *“I did not think of the cause when I was there, but when I came back I realised that it was because of the work stress that this happened to me because of the stress.* The denial is psychologically defensive as it protects him from ascribing the cause of his memory impairment to something being wrong with him that he can do nothing about. Such a

realisation would go against what he has always believed about himself: that he overcomes obstacles placed in his way. He thus denies in attempt to maintain his views of himself.

Playing doubles: contributions from his partner:

While he attributes the cause of his memory problems to his work situation and the stress with the boss, Sarah is aware that his memory problems would have occurred regardless thereof.

- Deflected insight

He furthermore oscillates between having insight into his illness and at times deflecting this insight. Such deflected insight may also be interpreted as a lack of insight or awareness or as denial, but it can on the other hand be argued that he deflects the insight he has as a protective defensive mechanism. This may be seen when he attributes the cause of difficulties at work to racial discrimination rather than memory problems or a decrease in his functionality, both of which he has acknowledged to be present.

I could do things, but I was not given any work because when I came back, I had racial discrimination from all sides. I could do all the things still. The head of the desk took all my responsibilities and gave it to the other person"

Playing doubles: contributions from his partner

His wife reports that he initially went to the doctor and asked for a letter to say he isn't competent at work anymore. He was thus at the time very aware of his decrease in competency at work, but yet seems to rather attribute the cause to racial discrimination.

A second example of deflected insight is where he explains no longer working because of his own choice. “...*the lady who medically boarded me... well we know the reason. I did not want to work there anymore.*”

Playing doubles: contributions from his partner:

He was not dismissed from his work, and he indeed did initiate being medically boarded. He then said to the doctor that he is no longer competent, and now he saying he did not want to work there.

A final example is where Martin had been talking about the difficulties he had with his memory while working abroad, saying “*I decided to come home not because of my memory loss but because of that situation with the boss.*” It is easier for him to attribute him coming back to his own choice in relation to the stress with the boss than to memory problems, even though he has insight into the fact that he was having memory problems. This is related to how he saw himself before getting AD. If he attributes coming home to memory problems, it reflects on him not being functional and competent, something he values highly. If he attributes it to the boss, this is an external factor which keeps his sense of self intact.

Compensation by doing

Martin compensates for a forgetful memory and painful affect by staying busy and doing things. His motto has become “*why worry, live and do*”. When he experiences painful affect, he reverts to doing something. “*When I feel off, I get busy with things I like and then it's okay again*”. He describes how gardening allowed him to come out of his “*dark emotional phase*”. He found meaning in doing what he could do, rather than being bothered about his memory. This strategy takes the focus off what he

cannot do, and maintains a competent self. The difficulty faced with in terms of memory or affect thus do not become integrated into his view of himself, but is avoided.

My gardening allowed me to come out of it (dark emotional phase), and I loved working in the community. I found meaning in doing things that I could do. Fact of the matter I couldn't be bothered about my memory, I just wanted to do things.

Selective disclosure

Selective disclosure is another means through which Martin copes with the disease. He believes only his family knows about his diagnosis. He feels that accepting the disease is something for him to do and others do not need to know about it. For him, not disclosing his illness links to his attempts at wanting to keep his premorbid identity intact. *'It's not that I'm ashamed of my illness, it's just simple... It is not my identity. In (suburb) I walk with the identity that people have of me.'* For him, if others relate to him as who he was before he became ill, he feels as if that identity is kept intact despite the illness.

Playing doubles: contributions from his partner

Selective disclosure is a coping mechanism that his close friends and his wife understand to be important to him. His wife has insight into the function of this coping mechanism, saying that he thinks that his friends don't know about the disease, but they do, and they do not treat him any differently or badly and also don't tell him that they know about his diagnosis.

E2: Self adjusting coping mechanisms

In terms of the metaphor, "changing rackets" where a different racket is taken relates to those coping mechanisms Martin uses through which he faces the threats head on in order to integrate

them into the self. These include acceptance, not questioning, developing a fighting spirit and focusing on positive things.

Acceptance

For Martin, one of the integrating ways he copes with the disease is through acceptance. *“For me, acceptance of my illness is for me to do, not for anyone else.”* Acceptance is however not only limited to the disease, but includes the limitations and losses accompanying the disease.

Not questioning

Martin focuses on not questioning, *“... not harking back to why is this thing happening to me.”* Rather than question why it is happening, he works to accept it as discussed, and also to fight it.

Developing a fighting spirit

Martin developed a spirit of actively fighting the implications of the disease. *“If this is called... uhm... a disease... Alzheimer’s, then that is what it is, the technical term for it. But I have to fight this thing.”* Fighting the disease implies meeting the challenges and changes that accompany the disease.

Focusing on the positive

Martin focuses on the positive and what he still has left after acknowledgement of what he has lost. After having given AD the metaphor of playing tennis with a wooden leg, he says *“At least I am doing it. I don’t have two wooden legs (laughs).”*

F) CHEERS OF SUPPORT

In a tennis match, the support of the crowd and the player's coach is immensely important for the player. Cheers of support thus signify the important sources of support that Martin gets from his faith, family and a supportive doctor.

F1: Faith as support

Martin's faith is of immense importance to him, as

When I asked myself (why), I turned to Him (God) to ask Him to please help me. Get me out of this. Spirituality was strengthened and I regularly in my bench at church prayed daily and nightly and did not deviate in my belief at all.

The other thing which was very very very important to me and got me going was my faith. Uhm, I, I, I, have an absolute firm belief in God and trust Him. He comes through for me, for all of us. If you hang on to Him, you are safe.

It is thus evident that Martin turned to his faith in God as a source of support, asking Him to help him. He used prayer and attending church as an important source of support

F2: Family as support

Martin relies heavily on his family as a source of support, saying

You see, fortunate thing for me is that we have a very good family life, between the two of us and our children. Uhm, and our extended family. The family set up was a very good buffer against this thing.

Playing doubles: contributions from his partner

It is interesting to note that Martin sees his entire family as being very supportive of him, while Sarah did not have the support of the rest of her family initially. They questioned her and were in disbelief when she told them about “this other person” – because they were not there to see for themselves.

F3: Supportive doctor

Finally, Martin draws support from an understanding, supportive doctor. *“I have wonderful support through which I can fight it, in the sense of my doctor.”*

G) TIE BREAK

In tennis, a player wins a set by winning six games, but the player must win by two games. Thus when both players have won six games, a tie breaker needs to be played. The player who gets to 7 games must continue to win the next game too, in order to win by two games and win the set. Thus if the opponent wins the next game and both are at seven games, another tie breaker needs to be played, until one wins by two games. This tie break may be a metaphor for the constant tension between adjusting and maintaining the self, two themes evident from the interview. Also discussed is how he keeps AD defined as non-central to the self, which is part of maintaining the self.

G1. Maintaining the self

“...I believe that we go through different phases in our lives but remain the same person.”

It is evident that Martin tries to maintain who he was before he got AD. While certain of the self maintaining coping strategies already mentioned contribute to this, he further does this by focusing on familiar characteristics, engaging in a life review where he reminisces about his past achievements and defining himself as being a better man. This allows him to see *“the person who*

was always there, the same person. When I go to play tennis I see that Martin is playing there... This is who I am, this is who I was, and this is who I am now."

Familiar characteristics

He focuses on certain characteristics he has, and defines himself as being a people's person and someone who is loving, committed and respectful. *"I am a people's person. I feed off them. One cannot help but feel good about this. This I keep at my core."... "I am a person who respects other people and who would appreciate being respected by them."... "If I were to do it (write a book) it would be a very positive book about myself and my love and commitment to people."*

These characteristics, namely being a people's person, loving, committed and respectful can be seen as being underlying of important premorbid characteristics and the work he used to do for the benefit of the community and to oppose inequality and injustice. Because he is still able to identify these driving factors, he feels as if he is still the same person he was before he got AD.

Life-review

Another self maintaining strategy is that Martin reviews his life, and reminisces about his past achievements and identity.

I have retired on the cushion of what I have done and what I have achieved and I hold that dear.

He thus largely defines himself by thinking about and holding onto his past contributions as having been valuable.

A better man

Martin defines himself as being a better man because of AD. “*I think I am better than what I was. When I was thinking of the Martin that I was I was thinking of before this thing happened to me. But I am a better man for it.*” This is a self maintaining strategy as it is how he used to define difficulty premorbidly. He valued fighting and persevering until he overcame obstacles, whether it be poverty, injustice or discrimination. Because he has been fighting against AD, he feels that he is better off for it, just as he has defined previous obstacles in his life. He thus continues to define himself in the manner he did before he got AD.

G2: AD as non-central to the self

Martin further does not define AD as being central to his identity. He talks about having a disease and not being the disease:

I hold on to myself inside. When I go to (suburb) I am (title). The person who was always there, the same person. When I go to play tennis, I see that Martin is playing there... This is who I am, this is who I was, and this is who I am now.

An important part of keeping AD non-central to himself is the fact that his illness is not visible. “*I don't walk with it (Alzheimer's) as a badge. My face is my badge and there is nothing wrong with my face, it is still Martin.*”... “*I don't see this disease...*”

Because the illness he has is not visible, being an ‘invisible wooden leg’, and he has chosen not to disclose to others but only to his family, he feels that others still relate to him as they did before the illness, which maintains his sense of self.

Playing doubles: contributions from his partner

It seems to be almost the reverse for his wife. It would have been easier for her if his illness had been visible. Had it been visible, it would be easier for her to cope with the changes in her husband. It would also have been easier for her if those in public could see his illness to explain the behavioural problems that often occur in public. Because his disease is invisible, it makes it harder to explain his behaviour to others.

... you can't see outward signs that they are ill and need help like the cancer patient... that's why I forget and ask him to fix something and expect him to do it. It takes very long to do it and sometimes it cannot get done, and then I remember that he is ill and I have to adapt and remember. And people tell me there is nothing wrong with him because he looks well. And it makes it difficult for me to tell them this and what really happens... Maybe it would be easier if I could see this disease, and not experience it only when I realize my husband is no longer there when we are together.

G3. Adjusting the self

Given the disease context, it is however not possible to only be in process in which the self is maintained. As the disease progresses and Martin is faced with new challenges and losses, he is faced with having to adjust the view he has of himself.

Part of this adjustment is that he has come to recognise himself as “*totally reliant on my wife*”. This is an important change in how he views himself, as he used to view himself as someone who was totally independent and self-reliant and now defines himself as someone who is reliant and dependent.

He has also come to accept his limitations, saying that “*I accepted it. I... you see it is like I play tennis and I have a wooden leg ... Uhm, I don't do it as well as I could, should or want to but I am doing it. This still makes me Martin, but a Martin with a wooden leg...*” He has thus adjusted the view he has of himself in order to include his limitations.

H) UNDERSTANDING THE GAME AND TRACKING THE SCORE

The metaphor of Martin being able to understand the game of tennis and keep track of the score is representative the amount of insight or awareness Martin has. Insight is not a unitary concept and is here divided into various domains: insight into the self, relationships his environment and the disease. Each domain is discussed in terms of either the insight he has or does not have regarding that domain.

H1. Insight into the self

Insight into the self is compromised of insight into his identity, the cognitive changes, the emotional changes, his limited capabilities, increased dependence, and behavioural and personality changes.

Identity

Insight into his identity, in terms of what type of person he is, is evidenced by various aspects of his account: autobiographical details, self characteristics and his religious faith.

- Autobiographical details

Martin gives account of autobiographical details, such as where he grew up, his family, his studies and his work. He further reflects on various memories he has from his childhood.

- Self characteristics

Martin is able to talk about what type of person he used to be and the type of person he is now. He thus maintains awareness of important characteristics evidencing the self. There is however certain characteristics that he does not have insight to. These are discussed under changes in his personality.

- Religious faith

Part of the awareness he maintains regarding his identity is the awareness of his faith. He talks about his Christian faith and the importance thereof for him.

Cognitive changes

- Memory

Martin shows insight into the changes associated with cognitive symptoms of AD. He has insight into and talks about his memory deficits and his resultant difficulty in remembering dates, telephone messages, words and tennis scores.

- Disorientation

He also shows insight into his disorientation and describes his difficulty in finding his way.

Emotional changes

Martin acknowledges the emotional change and disruption which accompanied the change in his functioning as consequence of the memory loss. He talks about being “set back emotionally” and feeling despondent, helpless and suicidal. Martin however did not report, as his partner did, that he is more agitated, anxious and easily angered.

Capabilities

Martin is aware that he no longer has the same capabilities he has before he got the disease. He talks about becoming less functional, not being able to things as he should, could or would want to and how even his ability to play tennis has changed – he no longer remembers the score.

Dependence

Martin realises that although he used to be a very independent man, he is now very reliant on his wife.

Playing doubles: contributions from his partner:

Sarah confirms this, saying *"His environment and routine has to be managed and he is dependent on me for that."* *"Yesterday we went to our accountant... and I have to explain everything to him, he doesn't understand things and it's a big responsibility on me."*

Behavioural and personality changes

Martin seems to lack insight into certain changes in his personality and behaviour. *"I am still the same person, calm and collected and happy now"*.

Playing doubles: contributions from his partner:

The picture painted by the wife in terms of his behaviour and personality is in sharp contrast to his. She says *"he is not aware that some things have changed... he says he is a happy chappie..."* but his *"personality, it's changed..."*

Easily angered and aggressive

She reports that *"this was not like him to get angry suddenly and lose his temper. He is very temperamental."* *"He is very aggressive with drivers on the road. Wouldn't give way and swore at them. I don't think he remembers and after that he laughs."* *"He sometimes misunderstands, he gets so angry and grabs something."* Before AD, she says he was *"very sweet and soft. Diplomatic, caring and especially for other people."*

This has a big impact on both of their lives, as *“we don’t go out anymore even if people invite us because he may get upset and it’s embarrassing and dangerous.”* He however seems to forget these incidents as *“He wanted to hit the man. People had to hold him back... and the next day he didn’t say anything so I don’t know if he remembers anything.”*

Clingy

Sarah also reports him as being clingy, and that it is getting worse.

Anxious

Martin becomes more easily anxious. *“When he is not driving and we are going somewhere he is a nervous wreck, he is over anxious,”* he *“screams all the time ‘watch out’.”*

Paranoid

“He is very paranoid about criminals...” In the afternoon Martin locks all the doors and draws all the curtains. Sarah feels it is too early and feels trapped, and has to open them up again.

Misinterpretation

Martin oftentimes misinterprets and misunderstands the intentions of others, and responds in a way in which his behaviour is inappropriate, uncontrolled and often aggressive. *“He misinterpreted something in the speech... after the speech... he started screaming at the man... he wanted to hit the man.”*

Initiative and planning

Sarah reports that Martin no longer takes initiative, and that he is not able to plan.

In contrast to him who still sees himself as not having changed much, she describes him as “gone”... *“where are you, Martin... No parts of him are back. He cannot have a conversation like he used to. On a cognitive level it’s there in bits and pieces”*

Sarah also feels that this part, the part he seems to have the least insight into, is the hardest for her to handle. *“To handle the memory problems, I know what to expect, but the outburst and his personality is hard because I don’t know what to expect and it’s not the memory problems that we don’t go out, it’s because of the behaviour.”*

Even his wife realises that insight is not as simple as either there or not. *“He says he is fine. He knows he is not what he was before... Maybe he says that because it makes him feel safe. I don’t think is aware of many things...”*

H2: Insight into relationships

Insight into relationships is divided into insight regarding roles, and also the conversation we had.

Roles

The role Martin used to fulfil in his community- one where he was depended on- is something he remembers with pride. He also has insight into the change in roles that has accompanied the disease, with him no longer able to fulfil that role in the community and so he rather focuses on what he has done.

The roles in his relationship with his wife too changed, and he acknowledges that he now is dependent on her.

Playing doubles: contributions from his partner:

While Martin does acknowledge that he is more dependent on his wife, he does not seem to express awareness of the impact of this on her. Sarah says *"He is unaware about how important it is for me to still live a active life... I have to sacrifice, but again he is unaware of these sacrifices I make."*

Furthermore, Martin is aware of the role of his family relationships as a great source of support.

Playing doubles: contributions from his partner:

Again, while he acknowledges the relationship with his family as supportive, he seems to be unaware or does not express the impact of his disease on them. *"After one incident where he was violent towards his grandson (who pointed a toy gun at him), our daughter went into a panic attack. The family can't forget it. They say that is not their father, he was like a lion..."*

Conversation

Martin was aware of our conversation and the general etiquette surrounding interaction with another.

H3: Insight into the environmental context

Surroundings

Martin maintains awareness of his surroundings. He is able to talk about the different places he travelled to abroad and the changes in South Africa pre-and post-apartheid. He is also aware that he lives at home.

H4: Insight into the nature of the disease

It also seems as if he lacks insight into the nature of the disease, saying *"Maybe if they put me somewhere else I would have worked better and happier and these memory problems would have gone away."* This is in relation to him having attributed the cause of the disease to work-related stress.

I) FUTURE SETS

Martin expects and anticipates the future sets he still has left to play to be certain way. The expectation of what future sets will be like thus acts as a metaphor for what Martin expects the rest of his life to be like.

11. Framing the future

Martin puts his focus on what it is that he can still do, rather than focusing on what he cannot do. His focus is to carry on playing, despite his limitations. *"...it doesn't stop me from moving so I will still do what I can."... "I go to play tennis totally confident in myself. I admit to sometimes forgetting what the score is but have no problem with it."... "I play tennis and I have a wooden leg and I play beyond that. It is like a metaphor I use for myself. I play on; I do what needs to be done."*

Playing doubles: contributions from his partner:

His wife, carrying all the responsibility and being depended on seems to be more fearful of the future, saying *"My daughter and I have put a few things on paper because what if one day I have memory loss and our memories then die."* She thus feels to be the carrier of the memories they have made together and fears this dying if she is not longer able to remember it either. Being held in mind is thus of importance, and something that cannot fail to remember, paper and a pen, is used to compensate for the fear of no longer being able to hold in mind or be held in mind.

Summary of themes

Table 7 summarises the metaphor, themes and subthemes as discussed in this chapter.

Table 7 <i>Summary of themes</i>		
Metaphor	Theme	Subtheme
First Set	Reflection on a premorbid self	a) doer b) achievement driven c) competent d) adaptable e) perseverant f) overcomes obstacles g) independent h) resourceful i) good self worth
	Reflections on a premorbid life	a) growing up and environment raised in b) previous jobs c) opposing discrimination and inequality d) community upliftment and education e) depended on by community
Double fault, again and again	Subjectively experienced symptoms of AD	a) memory loss b) disorientation c) non-functional d) loss of previous abilities
	Onset of symptoms	a) insidious b) sudden
	Affective response to symptoms	a) depressed b) suicidal c) despondent d) helpless e) distressed f) mournful
	Spiritual crises	a) let down b) rejected
To quit, or not to quit the match	Wrestling with an unfamiliar self	

	Emerging with a familiar self	
Umpires call	Dismissing medical professional	a) invisible self b) worst case prediction c) self protection
	Supportive medical professional	a) acknowledged self b) support c) at ease
	Evaluation	a) dislike and frustration
	Reception of diagnosis	a) traumatic reception
	Meaning attached to an AD diagnosis	a) explanation for memory loss b) explanation for emotional turmoil c) acceptance d) fighting
Strapping up and changing rackets	Self maintaining coping mechanisms	a) reliance b) cuing c) psychological defences • avoidance • derailment • denial • deflected insight d) compensation by doing e) selective disclosure
	Self adjusting coping mechanisms	a) acceptance b) not questioning c) fighting spirit d) focusing on the positive
Cheers of support	Faith as support	
	Family as support	
	Supportive doctor	
Tie break	Maintaining the self	a) focussing on familiar characteristics b) life-review c) a better man

	AD as non-central to the self	a) having vs. being the disease b) the invisible disease
	Adjusting the self	a) reliant b) dependent c) accept limitations
Understanding the game and tracking the score	Insight into the self	a) Identity • Autobiographical details • Characteristics • Faith b) Cognitive changes • Memory • Disorientation c) Emotional changes d) Capabilities e) Dependence f) Behavioural and personality changes
	Insight into relationships	a) Roles b) Conversation
	Insight into the environmental context	a) Surroundings
	Insight into the nature of the disease	
Future sets	Anticipating the future	a) focusing on what he can do

Chapter 5

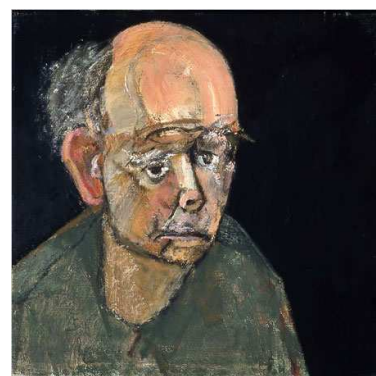
Discussion



Self-portrait 1967



Self-portrait 1996



Self-portrait 1997

5.1 Introduction

In 1995 William Utermohlen, an American artist in London, was diagnosed with AD. In response, he started painting self-portraits to try to understand it (Grady, 2006). Three of these portraits are shown above. Chapter five aims to discuss the results of this study in light of current available literature, and these portraits will be brought into the discussion later in the chapter. The chapter starts with a discussion of the test results, and then discusses the themes derived from the interviews. Limitations of this research are then discussed, and conclusions drawn. Lastly, recommendations are made.

5.2 Discussion of test results

Martin had a MMSE score of 25 at the first interview, and a score of 27 at the second interview eight months later. The conventional cut off point on the MMSE indicating impairment is a score of 24. This cut off point does not have good sensitivity when screening for AD (Feher & Martin, 1992; Kukull, Larson, Teri, Bowen, McCormick & Pfanschmidt., 1994). The ideal screening test should emphasise sensitivity, in contrast to diagnostic tests that should emphasise specificity. Kukull and colleagues recommended raising the cut-off point to 26 or 27. When applying this criteria, together with the CDR score of 1 at both interviews, and an ADCS/ADLI score of 21/30 and 23/30 at interview one and two respectively, it is evident that Martin falls into the category of having mild dementia.

The NPI indicated that at the time of the first interview, Martin was mildly apathetic, and this was no longer the case at the time of the second interview.

An interesting pattern emerged, in that his scores indicated less severe cognitive symptoms at the time of the second interview, eight months later. A general decline is to be expected. This improvement in cognitive functioning can be as a result of time of day of testing, adjustment in medication or numerous other confounding variables. Taken in totality, what the test scores also indicate is that Martin has mild dementia and had intact cognitive abilities for him to understand the nature of the interview, and also respond in a manner whereby he could express his thoughts and feelings.

5.3 Discussion of themes

The themes derived from the two interviews are discussed in this section in light of current available research. The themes have been grouped together, into three main sections. The discussion

starts with matters of awareness and unawareness. In this section, awareness is linked with self-adjusting responses and factors supporting such responses are discussed. Unawareness is linked to self-maintaining responses, and factors supporting such responses are also discussed. Secondly, how the self is seen to be retained is discussed. Lastly, the discussion focuses on experiences of the disease prior to diagnosis.

5.3.1 Awareness and Apparent unawareness

As discussed extensively in the literature review, one of the main reasons for the lack of research that includes the person with AD is the view that this population lacks awareness or insight, impacting negatively on the reliability and validity of the research (Snyder, 2001). Furthermore, many studies refer to awareness in relation to the disease as a whole. Awareness can however best be understood as expressed in relation to something specific, such as behaviour, cognition, mood, personality, mobility, word finding, activities of daily routine etc. It thus has a specific focus. This is because dementia is characterised by diverse symptoms and signs as a result of various organic, psychiatric, psychological and functional changes (Aalten et al., 2005; Clare, Rowlands, Bruce, Surr & Downs, 2008; Markova et al., 2005).

From the current research study, it is clear that Martin retains awareness in various domains and also displays instances of apparent unawareness. This is because as Martin develops awareness of the changes to the self associated with AD, there is a constant tension between attempts to protect the self from threatening changes on the one hand and on the other attempts to engage with the threat and integrate the result into the self. As new changes associated with AD occur, the person enters a process, either self maintaining or self-adjusting, of registering these changes and reacting, explaining, experiencing the emotional effects and trying to adjust. Processes aimed at protecting the self contributes to apparent unawareness while adjusting and integrating the change into the self

aids in expressed awareness (Clare, 2003; Clare et al., 2005). This is not a static process, but cyclical as there are constant changes as the disease progresses (Steeman, de Caterlé, Godderis, & Grypdonck, 2006). Due to this, awareness in AD is not fixed (Clare, 2003). MacQuarrie (2005) too found that those in the early stages of AD people simultaneously acknowledged and also resisted aspects of their disease. This is in order to maintain a sense of agency when facing cognitive loss that pushes them towards objectification.

In this part of the discussion, instances of expressed awareness will first be discussed, followed by those self-adjusting responses which aid expression of awareness. Factors which support self-adjusting responses will then be discussed. The discussion then shifts focus to, similarly, first discuss instances of unawareness, followed by the self-maintaining responses contributing to this and the factors that support such responses.

5.3.1.1 Instances of awareness

The focus of awareness in Martin's case relates to awareness of the self, awareness of relationships and the environment. Clare et al. (2008) also found retained awareness in these three domains in a population of moderate to severe AD patients.

- In the domain of the self, Martin remains aware of his past identity (who he was) regarding autobiographical details, characteristics of the self and his religious orientation. He shows awareness of cognitive changes, namely his memory problems and disorientation. Emotional changes are acknowledged to a certain degree. He is aware of his limited capabilities and his increased dependence on others.

- He has maintained awareness regarding relationships. He is aware of changes in roles in his relationship with the community, his family and his wife. He was also aware of our conversation and the general etiquette around interaction.
- Martin is also aware of his environment and surroundings.

5.3.1.2 Self-adjusting Responses contributing to expression of awareness

Self-adjusting responses contributes to the expression of awareness, as they attempt to openly confront the threats of dementia in order to deal with them (Steeman et al., 2006).

Acceptance of AD and limitations

It is known that accepting the loss associated with AD contributes to relieving pressure and also allows the person to focus on enjoying what is left of life (Werezak & Stewart, 2002). Accepting the disease and his limitations is an important part of Martin's adjustment. Acceptance however entails a constant renegotiation and is not fixed (Clare, 2003).

Fighting Spirit

Developing a fighting spirit, like Martin has done, after being in emotional turmoil is aimed at incorporating the awareness of changes into the self. This process of adjustment is further facilitated by focusing on the good things in life (Clare, 2003).

Focusing on the positive

While Martin acknowledges his difficulties, he focuses on carrying on and continuing doing what he is able to do. MacRae (2008) found that those with AD are more likely to focus on what they are still able to do, than on what they cannot do. This is especially so if they have accepted the disease

(Werezak & Stewart, 2002). Focusing on the abilities they still have left is another means of normalising the disease, as well as constructing meaning in life. Sabat (2001) describes that oftentimes those with AD are viewed by outsiders in exactly the opposite manner: they become defined by what it is they cannot do.

Realising reliance and dependence

Although reliance on his wife is a self maintaining coping strategy, he has adjusted his identity by no longer defining himself as independent and self-reliant but rather as dependent and reliant on his wife. The assimilation of AD into ones identity is a cyclical as well as ongoing process (Pearce et al., 2002).

AD defined as explanation for symptoms and emotional disruption

Another self-adjusting response is how Martin defines the diagnosis. While Langdon, Eagle and Warner (2007) found that their participants had a strong aversion to the terms ‘dementia’ and ‘Alzheimer’s disease,’ this was not so in Martin’s case. After coming to terms with the diagnoses, he views it as an explanation for his memory loss and the emotional disruption he had gone through. He sees the diagnoses as something to both accept and then fight against. It thus becomes a challenge for him.

5.3.1.3 Factors contributing to self-adjusting responses

There are various factors contributing to the Martin’s self adjusting responses. These include his premorbid personality, an understanding medical professional, a supportive family and his faith.

Premorbid personality

Martin defining AD as something to fight against is in keeping with his premorbid personality, as someone who fought to overcome difficulty. Clare et al. (2005) found that the ways in which people deal with AD are influenced by their personality. Coping responses are consistent with pre-existing personality traits or attributes in an attempt to maintain self esteem. These responses are shaped by pre-existing psychological factors, like coping styles, and social factors (Clare, 2003). His determination to fight the disease is congruent with previous research which showed the diagnosis as validating for the person, because it provides an explanation for their experiences and also legitimizes their need to feel supported (MacRae, 2008; Robinson, Ekman & Wahlund, 1998).

Understanding medical professional

How professionals interact with people with dementia and their families can either help or hinder efforts to deal with dementia. This has been an area which has only been superficially touched on (Steeman et al., 2006). A professional who provided encouragement seemed to be of assistance in helping him fight the disease. Interaction with such a supportive, encouraging doctor, in which Martin felt acknowledged, resulted in him feeling he could relate to and draw support from the doctor. He thus did not have to become defensive and deny his difficulties, which would be a self-maintaining response.

Supportive family

Martin saw his family as being an important source of support for him, especially in helping him through the time in which he was depressed and suicidal. This is in contrast to his wife who initially did not experience the rest of her family as supportive when his symptoms started. There is however a paucity of research regarding the impact on the person with AD regarding whether their family is perceived as supportive or not. Sorensen, Waldorff and Waldemar (2008) in a study on coping with

AD did however find that the relationship with the spouse is the most important relationship. It is thus not surprising that family support was very important to Martin in coming to terms with and accepting the disease.

Faith

It is evident that Martin uses his faith as a source of support in coping with AD. Connection to the transcendent through faith in God provides strength, guidance and comfort to those trying to cope with AD (Beuscher and Beck, 2008). According to Folkman and Greer (2000), existential causes and meanings for suffering are often turned to in stressful times of disconnection caused by illness. Beuscher and Beck (2008) argue that in the early stages of AD, the effects of AD cause disconnections for the person with AD from their self-identity and from others. This was the case for Martin, where he felt useless, and had lost his normal roles, resulting in a disruption in his self-identity. Spirituality then served as a means through which he could make sense of these disconnections (thus, self-adjusting) and also served as a way through which meaning could be added to his life. Prayer is an important way of coping for Martin and this is confirmed by Beuscher and Beck (2008) who found prayer to be an important means of facilitating a connection.

Martin did not blame God for the disease, but rather turned to God to rely on Him. Snyder (2003) and Katsuno (2003) describe this as a surrender style of coping, where an active decision is made to hand control of a problem to God, trusting that God will both protect and guide. Snyder (2003) found this positive response in people who saw God as loving and helpful. This is in contrast to some people with AD who blamed themselves for not living according to God's teachings and saw God as judgmental (Stuckey, Post, Ollerton, FallCreek & Whitehouse, 2002) or who attributed to the cause of their AD to God testing them and doubted God's existence (Katsuno, 2003).

Snyder (2003) found that AD often leads to personal growth, and Martin speaks of his spirituality being strengthened. The fact that Martin uses his spirituality as a means of coping is positive, as Katsuno (2003) found that those who use spirituality as a means of coping in AD have a higher perceived quality of life. MacRae (2008) also found that continued participation in religious routine furthermore gives life continuity.

What is highlighted by this current research is that although faith and spirituality may be used as a means of support, the process is not a simple or uncomplicated one. Martin describes going through a spiritual conflict in which he first did feel that God had rejected him. Thus although he ultimately relies on his faith as a source of support, there was a time in which he was in a conflict.

5.3.1.4 Instances of unawareness

Martin also displays instances of unawareness in various domains.

- Aspects of unawareness regarding the domain of the self relate to the changes in his personality described by his wife. He describes himself as still the same person and appears to be unaware of being easily angered and aggressive, clingy, anxious, more paranoid, misinterpreting others and no longer initiating activities or plans as he used to.
- In the domain of relationships, Martin does not seem to be aware of the impact of his dependence and personality changes on his wife and family.
- When it comes to insight into the nature of the disease, Martins seems to have limited insight. While he attributes memory loss to the disease, he thinks that if he didn't experience stress at work he may not have gotten AD.

5.3.1.5 Instances of unawareness explained

The awareness Martin seems to lack in these various domains cannot merely be ascribed to being a symptom of AD as awareness is a multidimensional construct in which cognitive factors needs to be viewed in light of psychological and social factors (Clare, 2004b, 2005; Sabat, 2002a). Psychological, social and biological aspects of the self and identity as well as the psychological self is central in determining the way awareness is expressed (Clare, 2003). Sense of self is in turn interlinked with biological, psychological and social underpinnings of unawareness (Clare, 2004a).

The onset of AD can be viewed as a threat to the self, with significant implications for coping responses (Clare, 2004a). Engaging in self maintaining responses to the threat of AD is one explanation for instances of unawareness. It has been found that these responses aim to protect ones identity and provide one with a sense of continuity in line with ones identity before the onset of dementia (Steeman et al., 2006).

Reliance and cuing

Martin's reliance on his wife has been defined as a strategy used to maintain a sense of self (Pearce et al., 2002) and his use of cuing serves the same purpose (Snyder, 2007). When he relies on his wife to act as an external memory, he does not need to face the consequences of not being able to remember.

Psychological defences

Psychological defences Martin use, such as denial and avoidance can account for certain instances of his apparent lack of awareness (Clare 2003; Seiffer et al., 2005).

- *Defensive denial*

As described by Markova et al. (2005), generally denial might refer to refusal by an individual to admit an overt dysfunction of experience. When, as in this specific context, denial is used as a defence it is referred to as defensive denial. Defensive denial is a psychological coping response which aims to protect Martin from the consequences of having awareness of knowledge of his difficulties. It is an underlying unconscious protective process preventing overt acknowledgement of the dysfunction, leaving the threat outside of awareness (Markova et al., 2005; Seiffer et al., 2005).

Denial may provide Martin with time to gradually accept the truth, which is currently too painful. Snyder (2001) linked using denial to the difficulty the person has with reconciling their self-image with the image of dementia, and hypothesised that it may result from a fear of acknowledging that the disease will result in a loss of autonomy. This may explain Martin's use of denial.

- *Avoidance and derailment*

In this case study it is also evident that Martin uses avoidance and derailment as defence in order to escape the painful affect associated with painful experiences regarding AD. This differs from denial discussed above, as he started talking about the painful experience and then avoided it by derailing.

It should also be noted that it is extremely difficult to de-tangle manifestations of his unawareness based on neurological impairments versus unawareness based on psychological responses of denial and avoidant coping (Clare et al., 2005). There is however enough evidence to hypothesise that instances of unawareness may be attempts at maintaining his sense of self, thus reflecting a motivated attempt at adaptive coping and not neurological impairment (Clare, 2003).

- *Deflected insight*

Martin also at times deflects the insight he has as a defence, appearing to be unaware. This can be seen in his wife reporting that he had gone to the doctor and asked to be medically boarded due to the difficulties he was having at work as a result of his symptoms, and him ascribing the difficulties at work to racial discrimination. Given that efficiency was something he valued, it is less painful to attribute his difficulties to racial discrimination than to a decline in his competency due to the disease. This deflected insight may in fact show a paradoxical heightened awareness, as Sabat (2002a) found that psychosocial factors such as frustration and embarrassment regarding cognitive losses may very well result in the person not reporting this.

Compensation

Martin compensates for a forgetful memory by staying busy and doing things, such as gardening. It can be said that these activities with which he keeps himself busy provides him with a sense of meaning, as well as continuity in light of him defining himself as a 'doer' premorbidly. Activities such as gardening do not draw on his compromised memory, and it may thus provide him with a sense of competency, maintaining his sense of self.

Selective disclosure

Martin further copes with AD through selective disclosure, only telling his family. He is not comfortable to tell his friends. This is unusual, as Langdon et al. (2007) found that, as a rule, people were comfortable disclosing their diagnosis to family and close friends, valuing their support and care. However, outside of this familiar circle, they were cautious about whom to tell and more reluctant. This caution is usually present due to concern about how other would react, with the expectation being one of prejudice and stereotyping. This does not seem to be the case for Martin. He anticipates that others will accept him. For him, not disclosing his diagnosis seems to rather be

related to an attempt at keeping his premorbid identity, namely his public self, intact. As the public self is constructed in cooperation with others (Poveda, 2003; Sabat, 2002b; Sabat, 2005), he is indirectly protecting this public self through non-disclosure. As long as others relate to him as he was, and not as someone with AD, this part of him feels to be intact. The fact that he only feels comfortable to tell his family can thus be seen as his attempt to maintain his sense of self.

Focusing on familiar characteristics

Martin focuses on familiar characteristics that can be seen to underlie a lot of what he did and how he saw himself premorbidly. Focusing on these characteristics maintains his sense of self.

Life review

In maintaining his sense of self, Martin values his past achievements and “retires on the cushion of past success”. MacRae (2008) found such life review to be present in her study. This is a process where a person looks back at his or her life in an attempt to legitimate and make sense of it. Parker (1995) sees the life review as a means through which individuals can adapt to significant changes. MacRae (2008) emphasises that successful completion of the life review is both comforting and allows a person to focus on the present. Through the life review, identities formed and confirmed in the past are drawn upon in order to create and also sustain a positive sense of self. Thus, such reminiscence about the past is seen as a self-maintaining strategy, as it seeks to maintain the identity of the person before getting AD.

Defining himself as a better off

Further maintaining his sense of self is that Martin defines himself as a better man for having gotten AD. His premorbid personality has an impact on this, as he used to see himself as better off for going through difficulty from early on.

Defining AD as non-central to the self

Martin accepts having AD but defines it in such a manner that it is non-central to his identity, comprising only a part thereof. This is confirmed by MacRae (2008) who found that those with AD acknowledged AD but in such a way that it is not allowed to take over their lives. Often times from the perspective of others, they have acquired a new dimension of identity, but for those with AD, the disease itself does not appear to be a salient dimension of the self. Such a sense of personal continuity is achieved if the relationships they have with others have not been significantly changed, and others continue to provide validation. This seems to be the case with Martin, as his wife and friends all try to treat him the same.

5.3.1.6 Factors contributing to self-maintaining responses

There are various factors that contribute to the self-maintaining responses Martin has. These include his premorbid personality, a dismissing medical professional, negative evaluative experiences and an invisible disease.

Premorbid Personality

The person with AD had a style of personality long before the onset of the disease, which may persist into the severe stages of the disease and continue to have an effect on their reactions (Sabat, 2002a).

Martin's prior personality too contributes to the use of denial as a coping mechanism, as it has been established that highly conscientious people are more likely to respond with unconscious defensive denial, as well as those who had high expectations of themselves throughout their lives, were work orientated, efficient and organised (Clare, 2003; Seiffer et al., 2005).

Dismissing medical professional

When Martin interacted with a dismissing medical professional who did not acknowledge his awareness of what was going on and treated him as invisible, he responded by becoming “non compos mentos”. Interaction with professionals where a blunt presentation of the diagnosis is given without adequate information results in self maintaining strategies and apparent unawareness (Clare, 2003). Langdon et al. (2007) furthermore found that responses to individuals with AD that fail to take into account their awareness hinders their adjustment to AD and also reinforces their attempts to conceal or deny the impact of their condition to avoid being marginalised or infantilised. This can be seen in Martin’s case with him afterwards saying that he did not believe the doctor.

Traumatic diagnosis

The diagnosis of AD may at first be devastating, then become more of a challenge than a threat (Steeman et al., 2006), as in Martin’s case. The receiving of the diagnoses was traumatic for Martin. This is in congruence with MacRae (2008) who found that receiving the diagnoses, even if previously suspected, is traumatic. The diagnosis may cause shock, anger, fear, horror, depression and disbelief and it takes time to come to terms with and interpret the personal meaning of the diagnoses. This may be explanatory for wife’s account of him initially withdrawing and isolating himself after the diagnosis. His isolation may further have been an initial self-protective strategy.

Negative evaluative experiences

Evaluation was something Martin detested. This may be because he saw himself premorbidly as being someone who was competent, and his difficulty in the evaluations highlighted his shortcomings. Burgener and Dickerson-Putman (1999) found that neuropsychological evaluation may trigger or heighten feelings of threat, uncertainty and anxiety, which may also explain his

aversion to being evaluated. It was not an experience where he could integrate the difficulty he was having with the assessments as something relating to the disease, he rather tried to avoid it.

Invisible disease

An important part of keeping AD non-central to himself is the fact that his illness is not visible. Because the illness he has is not visible, it gives him a certain amount of control. He can choose not to disclose to others but only to his family. Through not disclosing others don't know he is ill and still relate to him as they did before the illness. This in itself maintains his sense of self, as one's sense of self is also constructed in relationship (Poveda, 2003; Sabat, 2002b; Sabat, 2005; Sabat & Harré, 1992). This will be elaborated on shortly. Furthermore, the fact that there are no major changes in his bodily processes, other than normal aging, may also contribute to him experiencing a sense of continuity with regard to his embodied sense of self. The embodied self has been largely overlooked as a means of maintaining a sense of self, and the importance thereof has been highlighted by Kontos (2003).

The invisible aspect of AD, and consequence thereof, is quite different when compared to Parkinson's disease, which is also common in the elderly. Because Parkinson's is a neuromuscular disease and the symptoms include difficulty in carrying out smooth and coordinated muscular activity with resultant tremor, rigidity, akinesia and bradykinesia, the disease is visible to the observer (Uitti, Baba, Wszolek & Putzke, 2005). These symptoms are both distressing and socially embarrassing. In a study where the perceptions of Parkinson's symptoms were studied, the psychosocial symptom that was reported to be third severe but reported the most (68% of participants) was problems related to social interaction (Abudi, Bar-Tal, Ziv & Fish, 1997). The authors argue that this can be related to the fact that their appearances tend to make strangers feel

that they have some mental impairment and they are treated accordingly. This is a great source of stress for them, as the visible aspects of their disease evoke wide ranging inferences about it. They are treated as though they are affectively and intellectually crippled, when this is not the case. Harshaw (2002), giving a personal account, describes “how grotesque and freak-like I was in appearance. Parkinson’s had really disfigured me. The contortions of my face and body were more like a person with cerebral palsy... My face had become a reptilian mask” (p. 730). He then describes becoming enraged at those who would treat him in a condescending manner. Being treated in such a way when there was nothing wrong with his mind and he was fully cognisant of what was happening was very hard for him. A study by Birgersson and Edberg (2004) showed that when person with Parkinson’s are on the contrary treated with respect despite their bodily impairments, they feel supported.

Thus, where in Parkinson’s the disease can be said to be embodied, in AD it can be said to be invisible. While this has advantages in the sense that the person with AD can choose in the initial stages whether to disclose and feel a sense of control regarding their social interactions, the fact that it is not an embodied disease but one of the mind has its own complications. One of the most prominent is the belief that the self is lost in AD as it is a disease of the mind.

5.3.2 The self as retained in the disease

It has been said that with AD, there is a loss of self, with a book titled *The loss of self: a family resource for the care of Alzheimer’s disease and related disorders* (Cohen & Eisdorfer, 1986) and a chapter in a book called *The deselfing of Alzheimer’s disease* (Tobin, 1999). Basting (2003) has argued that this view stems from the Western equation of identity with memory and cognition. Kontos (2003) reiterates this by saying that the self is seen to reside in the brain, where according to Western belief meaning and intelligence resides. Because AD causes a progressive decline and

ultimate loss in these faculties, the self is believed to have the same fate. Basting (2003) further argues that views of the disease being a “funeral before death” (p.88) results in the fear within the population of losing the self as a result of the disease. Post (1998) also emphasised that as soon as people are no longer autonomous, have intact memory and are rational, they are often no longer seen as whole people.

From the current research, it is evident that a lost self is not inevitable, and Martin has not lost his sense of self. This can be seen in him expressing both aspects of his personal and public identity. Available research, (Poveda, 2003; Sabat, 2002b; Sabat, 2005; Sabat & Harré, 1992) defines the personal self as expressed through the use of pronouns and consisting of mental and physical attributes, as well as affective responses. The fact that Martin reflects about what he used to be like (his attributes) before he got AD evidences memory of his personal self, carrying his personal identity before he got AD. His affective responses to the disease also serve as evidence.

The public self is constructed in cooperation with another person. It is those personas that are projected into the public arena (Poveda, 2003; Sabat, 2002b; Sabat 2005). Martin was very involved with his community. His life was largely dedicated to opposing discrimination and inequality, and working to educate and uplift the community, which depended on him. His public self is linked closely to all the work he used to do in the community. It is his public self that can then be seen to be under threat when he is no longer able to perform the activities in the community he used to do. His interaction with the community will either maintain his sense of self, or in interaction with them it will be lost.

Given this, his focus on the invisibility of the disease becomes understood more clearly. He feels that because the disease is not a badge that can be seen, it is not his identity. Those he chooses not to disclose to still interact with him like they did before the onset of AD when he is in contact with them, maintaining his sense of self. As the disease progresses however, this may become more difficult, as people may start asking him questions when memory impairment becomes more evident to them.

Further evidencing the fact that the self is not lost in the disease is that, as described, Martin engages in many strategies to either maintain his sense of self or adapt his sense of self. While it may be erroneously assumed that self-adjusting strategies result in a loss of self, it is the opinion of the researcher that this is indeed not so. The view that an adjusted self equates a lost self may result from a positivist view where, as noted by Gergen (1995), it is normal for a person to develop a stable sense of identity. Traditionally, psychologists maintained that once the sense of self is fixed, it remains a stable feature of the personality, and enables one to predict certain behaviors. Those who did not have a stable sense of self or identity were seen to be abnormal and unhealthy. Various authors (Anderson, 1995; Gergen, 1991, 1995, 2001; Lifton, 1995) have argued that, on the contrary, the self is ever changing as we move through a world of different relationships and contexts, each evoking a different potential self. Being able to adapt the self is according to these authors a strength and not pathological. Thus while the self may need to be adjusted or altered as new challenges arise and abilities are lost as a result of the disease, this task is not unique to the context of AD. All people, through the various phases of their lives, need to integrate and adjust their sense of self in response to varying contextual and relational changes. The self-adjustment can thus be defined in light of rather growth or change of the self than loss of the self.

It is here that the researcher would like to refer back to the three self-portraits in the beginning of the chapter to illustrate what has just been explained. The first self portrait was painted before the onset of AD, and the other two thereafter. The self portraits, exemplifying the expression of a sense of self, are seen to change over time as the disease progresses. The later versions do not necessarily evidence a loss of self, but a change as has just been described. Indeed, it is the opinion of the researcher that these portraits have a greater emotional impact on the viewer, even though they are not as “reality based” as the first self-portrait and more abstract. This might evidence the emotional process the artist was going through in response to the disease. Would one say that he is losing himself? I would hope not, as the portraits show that the self is changing as the disease progresses.

5.3.3 Experiences of the disease prior to diagnoses

For those with AD, the experience of the disease starts long before a diagnosis is made by a professional. In this part of the discussion, the subjective experiences of the disease prior to diagnosis are looked at.

5.3.3.1 Subjectively experienced symptoms

Martin subjectively experienced problems with getting lost and forgetting. His experience of these symptoms all represent a loss of something he was previously able to do. Memory loss and disorientation ultimately result in him experiencing himself as being less functional as a result. According to research, the loss associated with the symptoms in AD often leads to feelings of incompetency (Clare 2003; Pearce et al., 2002), which was evident, as in his case.

5.3.3.2 The experienced onset

In reviewing literature, Steeman et al. (2006) found that during the prediagnostic phase, people with AD may gradually become aware of problems, initially ascribing it to stress. As problems intensify

in severity, they come to suspect that something is seriously wrong. On the other hand, they may experience a dramatic wake-up when critical events happen. It is interesting that in Martin's account, he describes the onset of his symptoms as both insidious and sudden. In looking back, he may realize that the development was insidious, but his experience of finally coming to the realization that there was something wrong, hit him with great surprise and feels to be sudden.

5.3.3.3 Affective changes

MacRae's (2008) research suggests that the early stage of AD can be a gradual progression from an initial emotional response to a point of acceptance and realization that one is still able to live a meaningful life. This too is the case with Martin, as his initial emotional response was one in which he became suicidal, despondent, helpless, distressed and mournful. His wife further describes that he displayed symptoms of anxiety, agitation and fear in response to the difficulties he was having at work due to the symptoms. Recognition of changes in memory and the resultant impact on self-concept result in patients spending time in 'emotional depths' (Clare, 2003).

His response further correlates with research that has shown that mood and anxiety symptoms are common in the evolution of AD (Cassimjee, 2007). It is interesting to note that an association between depression and higher levels of awareness has been established. It appears as if mild depression and depressive symptoms rated by patients are correlated with increased awareness rather than major depressive disorder (Aalten et al., 2005; Kashiwa et al., 2005). There is also a correlation between anxiety and increased awareness. The correlation between both depression and anxiety with increased awareness can be explained by a psychological reaction to noticing the cognitive decline (Aalten et al., 2005) or the anticipation of memory loss which is accompanied by fear (Kashiwa et al., 2005). It is thus the awareness of something being wrong that produces

frustration, uncertainty, fear and stress in interpersonal relationships which in turn may contribute to anxiety and depression.

5.3.3.4 Wrestling with the self

Before Martin was able to move beyond his initial emotional response, he had had intense time of wrestling with himself. The wrestle takes place between who he used to be and who he all of a sudden found himself to be. He also wrestled with whether he felt like he could carry on. Martin however emerged from this wrestling match with himself, feeling more similar to who he used to be. This tension between feeling the self to be familiar and unfamiliar reflects the constant tension between engaging in self-maintaining and self-adjusting responses, as feelings of unfamiliarity will necessitate one of these responses. Although he describes this as a once off wrestle, the wrestle will continue as new symptoms emerge and he again feels himself to be ‘unfamiliar’.

5.3.3.5 Spiritual Crises

What is clear from Martin’s experience is that apart from his emotional response to his symptoms, he underwent a spiritual crisis. He felt as if God had rejected him. Being a Christian he struggled with these feelings and turned even more to his faith. While faith as a source of support has been discussed (Beuscher & Beck, 2008; Folkman & Greer, 2000; Katsuno, 2003; Snyder, 2003) in literature, an initial response of a spiritual crisis is not often discussed.

5.4 Conclusion

This research firstly adds to literature illustrating that people in the early stages of AD can present meaningful, coherent and insightful accounts of their experiences with AD (Clare, 2003, Langdon et al., 2007).

As summarised in figure 2 on the following page, it also illustrates that a person in the early stages of AD, who was aware of changes associated with the symptoms of AD, responded affectively to these changes, and also underwent a spiritual crisis. He furthermore wrestled with himself, the wrestle between who he was and was becoming and whether he could carry on.

Changes associated with the disease develop in the context of a psychological self, and how the self deals with the threat of the changes of the disease fall into two categories: self maintaining and self adjusting responses. Self maintaining responses result in apparent unawareness, while self-adjusting responses contribute to awareness.

The premorbid view of the self plays an important contributing role to which type of response is given. Also contributing is interaction with others, where a dismissing medical professional results in self-maintaining response, where supportive interaction with family and his doctor results in self-adjusting responses. Furthermore, his faith contributes to self-adjusting responses, while negative evaluative experiences and the fact that the disease is invisible contributes to self- maintaining responses.

It is further significant in that the experiences of a South African man has so many similarities to the experience of others globally as shown by research that has been done on the subjective experience of AD.

From this study, it has become apparent that even during the pre-diagnostic phase the person with AD can find the symptoms and resultant impact thereof on their lives distressing. It can be a time as immense uncertainty and result in affective disturbances such as anxiety or depression. It could be

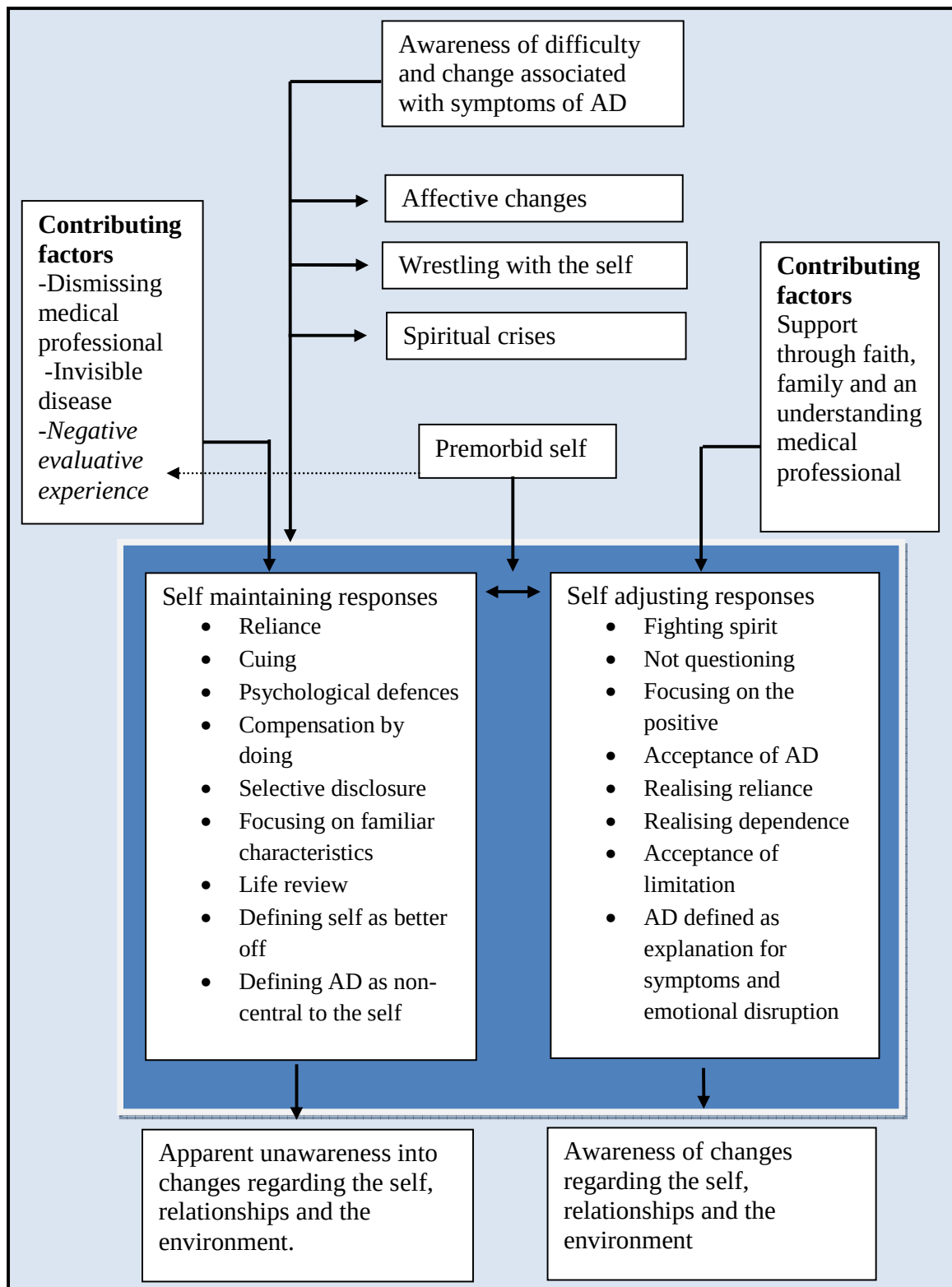


Figure 2: Processes resulting from the changes associated with AD

greatly beneficial to after diagnosis help the person make sense of what has been happening to them up until that point, especially since they may be more aware of the changes than thought.

While the time of diagnosis could be an opportunity to establish a trusting relationship with the person through showing an understanding of what they have gone through up until that point, it is often a traumatic experience. It can be taken for granted by professionals that people understand words like dementia and consequently do not adequately explain the diagnosis. People may not always ask for an explanation, and will leave the consulting room feeling confused and emotionally overwhelmed. A protocol around disclosing diagnosis to the person and family in understandable terms and referring the person and their family to a mental health professional who can be of assistance in processing and understanding the diagnosis should be considered. Therapeutic intervention and support and psychoeducation after a diagnosis is made can greatly benefit the person and family.

It may also be useful if the person's coping strategies which result in apparent unawareness can be explained to the family and loved ones to help them understand the person better. A better understanding will result in the family being better able to support the person. Furthermore, support for the caregiver is important.

When it becomes apparent that the person's coping strategies are no longer adaptive, mental health professionals can assist the person in finding more adaptive ways of coping.

This research lastly evidences that the person in early stages of AD maintains enough awareness to necessitate their inclusion regarding research on AD.

5.5 Limitations

The limitations of this study include that it is a single case study, with the participant being of a specific race and gender and representing a specific socio-economic class.

While this study has allowed greater scope for the individual to express his views, including emotional responses and the perceived impact of difficulties, the account is still subject to the researcher's interpretation. The themes that have emerged have thus been shaped by some degree by the researcher's expectations (Clare et al., 2005).

Furthermore, the researcher only had access to what the participant said, not what he does. It would be useful to observe for example how he copes with difficulty.

5.6 Recommendations

Given the limitations of this study, it should be expanded to a sample that is larger in number, multiracial, includes both men and women and represents a diverse socio-economic population. It should also be expanded to other stages of the disease, namely persons with moderate and severe dementia.

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