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Narratives of a spouse regarding his experiences with Dementia of the Alzheimer's Type (DAT)

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Submitted in partial fulfillment of the requirements for the degree:

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SUMMARY

TITLE	Narratives of a spouse regarding his experiences with Dementia of the Alzheimer's Type (DAT)
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The aim of this research study was to determine the perceptions and experiences of the spouse of an individual with Dementia of the Alzheimer's Type (DAT) regarding the impact of DAT on communication interaction. A qualitative research design was implemented as this allowed the researcher to collect, organise and interpret textual information gained from conversation and observation and to comprehend specific issues within their natural contexts. Four informal interviews were conducted with the spouse of an individual with DAT. These interviews were then transcribed and subjected to both a holistic form analysis and a holistic content analysis. The participant's narrative was found to be regressive in nature. The themes that emerged from the holistic content analysis were those of: Change, Verbal Communication, Paranoia, Love and Loyalty, Coping Strategies and Professional Support Provided. The information pertaining to Change that the participant highlighted with regard to his spouse's communication and personality correlates with the literature on DAT. Information extracted from the content analysis considered to be of clinical value to SLTs is that of the strategies that the spouse developed in order to deal with these changes and to facilitate communication. Throughout the narrative it became clear that the participant felt that professional support to the individual with DAT and his/her family is of utmost importance. The participation of all team members, including family, in the treatment of an individual with DAT can lead to each team member benefiting from the other members' knowledge and experiences. It is conclusive that professionals can benefit by including the spouse of an individual with DAT, as they can provide useful and valuable background information and possible coping strategies that can benefit the treatment programme that is compiled for the individual with DAT. Thus the use of interviews in assessment of an individual with DAT can be implemented in order to ensure that we as professionals provide the best possible services to improve and maintain the quality of living for an individual with

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DAT and his/her spouse and/or family. The results of this study further portrayed the importance that a narrative analysis can have in the ongoing research of DAT.

KEYWORDS

Dementia of the Alzheimer's Type (DAT), Speech-Language Therapist (SLT), narrative, communication, Quality of Life (QOL), Activities of Daily Living (ADL), holistic form analysis, holistic content analysis, professional support, spouse, family.

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CHAPTER 1

PROBLEM STATEMENT

1.1 INTRODUCTION

Traditionally, dementia has not been viewed as a field of practice for speech-language therapists (SLT). Over the past few years, however, speech-language therapy has increasingly become involved in the treatment of neurogenic patients, including individuals afflicted by dementia (Dajee, 2002). In such individuals, the interaction between complex linguistic and cognitive skills has been affected, creating problems with communication and thereby necessitating the involvement of speech-language therapy (Waterer, 2002).

Dementia, a chronic, progressive deterioration of intellect, memory and communicative functioning resulting from organic brain disease (Bayles, 1987), typically presents itself in three stages: early/mild, middle/moderate and final/severe (Kempler, 1995). As the afflicted individual progresses through the three different stages, a variety of symptoms may prevail.

During the onset of the disease, the behavioural, cognitive and communicative difficulties exhibited may be so subtle that only family members or close acquaintances notice them (Goldsmith, 1997). These difficulties include subtle memory impairments that result in increased anxiety, paranoia and apathy. The individual may display poor judgement and appear disorientated (Dajee, 2002; Doehring, 1988). Initial signs of language distress include word-finding, lexical and conversational difficulties. Expressive language may be characterised by semantically empty words and circumlocutions (Dajee, 2002; Kempler, 1995). At the same time, the individual with dementia may struggle with receptive language, in particular with the comprehension of abstract language (Hart, 1990; Herman, 1999).

As the disease progresses through the middle/moderate stage, memory impairment becomes more evident and disorientation in time, place and individual, more severe (Doehring, 1988; Herman, 1999). The apathy initially exhibited changes to restlessness, characterised by frequent pacing (Dajee, 2002; Heston & White, 1983). Discourse becomes empty as the individual increasingly experiences persisting difficulty in comprehending and producing language (Kempler, 1995).

The final stage of dementia is characterised by impairment of all intellectual capacities and, in some cases, motor abilities. The afflicted individual may experience difficulty with walking, balancing and fine-motor skills and is often bed-ridden and dependent on caregivers for provision of basic needs. Owing to severe disorientation and impairment of the ability to

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recognize unsafe situations, those who remain independently mobile are a danger to themselves (Dajee, 2002; Kitwood, 1997). Communication is reduced to the production of unrecognisable sounds, echolalia, palilalia or mutism (Kempler, 1995). The afflicted individual is eventually unable to function socially or occupationally and becomes totally reliant on others for basic care (Goldsmith, 1997). The individual often requires feeding due to a lack of interest in food, or because the ability to co-ordinate the complex process of swallowing has been lost (Gillick, 2001), resulting in weight loss and aspiration pneumonia (Post, 2001). It becomes necessary for caregivers to assist with safe oral feeding or, in extreme cases, to implement non-oral feeding such as Percutaneous Endoscopic Gastronomy (PEG) or assisted oral feeding (Post 2001).

Modern medical technology has brought about an increased life expectancy for elderly people. In 1990, life expectancy for males and females was 69 years of age. Current estimates stand at 76,9 years (US Library of Medicine and the National Institute of Health, May 2004). Increased life expectancy, however, has associated risks of illness, disease or death of a spouse due to pathological aging, brought about by age-related diseases such as cancer and dementia (Worrall & Hickson, 2003).

Together with the increase in life expectancy, there has been an increase in the prevalence of dementia. The worldwide incidence of dementia in *elderly* people, defined as people above the age of 65 years (Kitwood, 1997; Molloy & Lubinski, 1995), is estimated at over 30 million (Gillick, 2001). The prevalence of the most common form, Dementia of the Alzheimer's Type (DAT), ranges from 4 to 8% (Barbas & Foster, 2001). South African statistics reflected that by 2005 an estimated number of 110,000 South Africans (i.e. 4,09%) would suffer from Alzheimer's Dementia (Potocnik, 2002). As the population of elderly people in South Africa increases, it is likely that there will be a concomitant increase of individuals with dementia.

It is clear from the multiple difficulties mentioned previously, that a team approach to the care and treatment of an individual with dementia is needed. Owing to the many cognitive, communicative and feeding difficulties associated with dementia, the SLT has a valuable role to play in a team of this nature. Sadly, the role of the SLT is often overlooked (Molloy & Lubinski, 1995).

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The role of the SLT in treating dementia is challenging and difficult due to the complexity of the disease, compounded by the fact that individuals are differently affected by it (Chapman & Marshall, 1993). It is therefore essential for the SLT to be knowledgeable about the condition, and to remain fully conversant in respect of management options.

ASHA (2003) clarifies the role of the SLT into the following functions:

1. Identifies individuals in need of SLT services and evaluates strengths, deficits and needs associated with all processes of communication
2. Plans and provides treatment for deficits involving processing and production of oral, gestured and written language, including articulation, voice, fluency, swallowing, hearing and cognitive-based communication
3. Refers patients to medical and allied health professionals and/or alternative community resources
4. Counsels clients, family, caregivers and associated individuals regarding the status, needs and emotional adjustment of the patient
5. Maintains appropriate documentation of each case
6. Implements research concerning the nature and management of specific communication disorders and the influence of normal development processes
7. Administers service programmes, maintains standards (quality assurance) and serves as an advocate for individuals with communication disorders

As mentioned previously, the role of speech-language therapy is often overlooked, not only by other professionals, but also by SLTs themselves. A study by De Waal (2003) indicated that SLTs felt they had a role to play in the management of dementia but were uncertain about the nature of that role. This uncertainty may stem from the fact that individuals with dementia are seldom referred for speech-language therapy (Goldsmith, 1997). A study by Molloy and Lubinski (1995) reveals that SLTs regard their role in management of dementia as limited to evaluation of auditory comprehension, and expression.

In other studies, SLTs have indicated the role they can play in reminiscence and cognitive-oriented treatment (Goldsmith, 1997); also in combating hindrance in communication, swallowing and other upper digestive disorders (Connell & Francis, 2002; Herman, 1999). Quality of life is enhanced by habilitation, rehabilitation and enhancement of functional areas that enable the patient to participate in Activities of Daily Living (ADLs) (Herman, 1999; Dajee, 2002). Other important contributions that can be made by SLTs when treating dementia include: counselling, educating, problem-solving, long-term planning and

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addressing emotional needs with patients, families and caregivers (Bowling, Gabriel, Dykes, Dowding, Evans, Fleissig, Banister, & Sutton, 2003; Herman, 1999).

In recent years, speech-language therapy has shifted its focus in management of dementia to include the caregiver (Burns, Nicholis, Graney, Martindale-Adams & Lummus, 2006). This has been an important development since the caregiver, who spends a large amount of time with the patient, is usually more knowledgeable about the needs of the patient and can discern when, or if, decisions need to be made (Burns, et al., 2006). Thus therapy should be directed through the caregiver who will report changes and focus on behaviours and limitations that are most important. This will provide useful information to the SLT who will then be able to define more clearly, the role he/she should play in the management of the patient.

In order to improve the service provided, the SLT must take cognisance of the fact that as dementia progresses and communicative and cognitive difficulties become more severe, people with DAT are increasingly unable to make incisive decisions (Jacques, 1997). When this happens, these people need the assistance of someone else, a spouse, family member or friend, to make decisions on their behalf. It has been noted, however, that often patients and family members are not consulted when decisions are made (Jacques, 1997). This may be due to the fact that family members are not involved at all, or because some medical practitioners still approach treatment purely from a medical point of view, whereby neither patients, nor family members, are consulted (Ross & Deverell, 2004) and only clinical solutions, offered.

Research has shown that the number of studies regarding the experiences of individuals suffering from dementia, is limited. Similarly, only a few studies have investigated the experiences of *family members* who live with, and care for, such individuals (Bam, 2003). Dementia is a relatively new field of study for the SLT and thus far, most research by SLTs, merely investigates memory dysfunction, language and speech aspects of dementia (Ardila & Ostrosky-Solis,1989). It has been noted in the studies, however, that dementia is stressful, not only for the individual who has the disease, but also for an older spouse burdened by his/her own health problems and age-related concerns that may prevent him/her from providing adequate care (Worrall & Hickson, 2003).

Spouses and families may be better able than strangers to provide important information to members of the professional team involved in the care of the patient. Increased participation by the client as well as the family in the management of disability brought about by

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dementia, is therefore receiving more prominence and is reflected in a recent shift from the Medical Model, to a Social Model (Ross & Deverell, 2004). The Social Model, unlike the Medical Model that is disease-centred and requires the "patient" to be passive, allows the patient to share the decision-making process, also focusing on the family members and the roles they play in the social environment of the individual who is ill. This improves that individual's participation in his/her own immediate society (Worrall & Hickson, 2003).

A method of obtaining information from family members that has gained increasing popularity in the field of speech-language therapy, both for clinical and research purposes, is that of narrative analysis. Narratives are, in essence, dialogues (Nason-Clark & Neits, 2001) that take place between professionals and immediate family members concerning dementia and the treatment of individuals who suffer from the disease. They are helpful in that they can provide in-depth understanding of context. This frame of reference about the individual with DAT is critical in determining the scope of medical care and clinical work required (Borkan, Reis & Medalie, 2001). In a study conducted by Borkan et al. (2001), the researchers found that narratives can document breakthroughs and transformations in individual and professional development. This allows professionals such as SLTs, to adapt and improve their services to individuals with dementia, as well as to their spouses (often seen as the "hidden patient", according to Borkan et al., 2001). It must be cautioned, however, that although narratives provide great truths about dementia, they are no "magical elixir" (Stein, 2001, p. 144) since interpretation of narratives can be misleading. It is a method that should be used circumspectly, with great care to take everything into account. SLTs who strive to conduct accountable and evidence-based practice are increasingly taking note of research findings regarding narratives, and looking for ways to incorporate the potential value of narratives into service delivery.

This study aims to investigate the experiences recorded by the spouse of an individual affected by dementia, using narrative analysis. It is envisaged that, by gathering information about the experiences and perceptions of the spouse regarding the impact of dementia on communication, the role of the SLT will be more clearly defined.

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1.2 OUTLINE OF CHAPTERS

This research project consists of six chapters namely:

Chapter 1: Problem Statement

Chapter 2: Literature Study

Chapter 3: Method

Chapter 4: Results and Discussion

Chapter 5: Conclusions and Recommendations

The content and motivation for each chapter is presented in Table 1.1

1.3 ABBREVIATIONS

SLT: Speech-Language Therapist

DAT: Dementia of the Alzheimer's Type

QOL: Quality of Life

ADL: Activities of Daily Living

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1.4 DEFINITIONS OF TERMINOLOGY

1.4.1 Dementia

The term *dementia* refers to multiple cognitive deficits and a decline in previously attained intellectual levels. These deficits can include memory impairment and at least one of the following: aphasia, apraxia or agnosia. Impairment of the ability to carry out ADLs, such as occupational or social functions, also occurs (Halpern, 2000).

1.4.2 Dementia of the Alzheimer's Type (DAT)

DAT is the most common form of *irreversible dementia*, constituting more than 8% of all dementias diagnosed (Barbas & Foster, 2001). Individuals with DAT progressively lose their cognitive competence as the disease takes its course. The most common symptoms are: severe memory deficits, impairment of communication, confusion, limited ability to concentrate and plan and consequently, a loss of independence in ADLs (Romero & Wenz, 2001). As it is a chronic, progressive disease, it inevitably leads to death within seven years of symptom onset (Whalley, 1997).

1.4.3 Quality of Life (QOL)

"*Quality of Life* is a multi-level, formless concept that reflects both macro societal and socio-demographic influences, as well as micro concerns, such as individuals' experiences, circumstances, health, social well-being, values, perceptions and psychology." (Bowling et al., 2003, p. 271)

1.4.4 Narrative

The word is derived from the Latin root, *narre,* meaning, "*to make known*". *Narratives* are frequently used to convey information in a connected sequence of events, each event flowing from a previous one and at the same time, giving rise to a subsequent one (Lacey, 2000, pp 13-14).

1.4.5 Activities of Daily Living (ADL)

ADL refers to the ability to perform *tasks of daily life*, for example, the ability to dress and feed oneself and "miscellaneous common skills, such as communication" (Trombly & Quintana, 1992, p 386). ADL is also seen as "*Independent Living Movement*" that by definition includes the ability to perform activities of self-care, and to operate within a home-community as a individual who is emotionally, physically, mentally, socially and economically capable (Trombly & Versluys, 1992).

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1.4.6 Communication

Communication is a form of social action between people, during which people assess, interpret and influence each other on multiple levels (Ensink & Sauer, 2003, p.1). Efficient communication relies on the interaction between complex linguistic and cognitive skills (Waterer, 2002).

1.4.7 Disease

The term *disease* refers to pathology that affects an individual negatively in terms of physical and emotional wellness (Hodgson & Cutler, 2003). It also refers to objective conditions, caused by bacteria or viruses that impair the normal internal functioning of the body (Ross & Deverell, 2004).

1.4.8 Illness

The term *illness* denotes the subjective experience of disease by humans, in which they perceive themselves as not feeling well (Ross & Deverell, 2004).

1.5 DIVISION OF CHAPTERS

Refer to Table 1.1

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CHAPTER 2

LITERATURE STUDY

2.1 INTRODUCTION

This chapter provides an overview of existing theoretical knowledge about communication difficulties associated with dementia. It also examines current and previous research and seeks to highlight the value of narrative analysis as a means of obtaining information. In addition, it examines the value of including the spouse in the assessment and management of dementia.

2.2 DEMENTIA

Dementia is an irreversible condition that leads to a decline in intellectual and cognitive functioning (Molloy & Lubinski, 1995). Dementia is associated with numerous diseases, of which Dementia of the Alzheimer's Type (DAT) is the most common (Bayles, 1987). In the case of DAT, individuals who have the disease exhibit lesions in the temporoparietal-occipital junctions, as well as in the inferior lobes and hippocampus (Halpern, 2000). As a result of these lesions, they suffer from memory difficulties, including difficulties with declarative memory. Declarative memory enables individuals to recall information about the world, events of their lives, words and rules of syntax (Bayles, 1987). Individuals who experience loss of declarative memory (as seen in DAT) are therefore likely to experience communication difficulties.

2.3 COMMUNICATION IN DEMENTIA OF THE ALZHEIMER'S TYPE

Communication can be defined as: meaningful interaction that conveys information from one individual to another (Bayles & Kaszniak, 1987). The speaker's intention is to convey the ideas that he/she is processing cognitively. The individual suffering from DAT may lack the capacity to form and convey ideas meaningfully (Bayles & Kaszniak, 1987), affecting QOL since an individual who is unable to communicate is likely to withdraw from social interaction. Such an individual finds it difficult to adapt to change, struggles to participate in activities, is unable to establish and maintain friendships and struggles to make decisions (Worrall & Hickson, 2003). An additional characteristic is the tendency to become egocentric. When this happens, the individual increasingly displays a disregard for, and unawareness of, the effect the disease may be having on others. Owing to impaired pragmatic skills, the individual appears to lack sensitivity during conversations. Social withdrawal may follow.

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Owing to the fact that it is difficult to follow the verbal output offered by an individual who has DAT, people tend to avoid conversations with them (Worrall & Hickson, 2003). Lack of capacity in terms of meaningful communication skills underlies the afflicted individual's withdrawal from the act of communication. Together with difficulties relating to speech production, sentence formulation and rules of conversation (Connell, Mc Connell & Francis, 2002), communication with an individual suffering from DAT becomes difficult and laborious. These communication difficulties impact negatively on a spouse and all other family members, as well as the professional team involved in the management and care of the individual.

Difficulties communicating with the individual with DAT, may lead to many complications. The individual with DAT tends towards a decreased ability to form ideas with the purpose of producing and comprehending language, due to the loss of semantic memory (Bayles & Kasniak, 1987). Semantic memory is active "where concepts are represented and inferential processing takes place" (Bayles & Kasniak, 1987, p. 57) in order to store conceptual knowledge about the world. Semantic memory is a higher cognitive function that integrates non-verbal and verbal strands of communication and language (Bayles & Kasniak, 1987). In other words, semantic memory is the system in which ideas and processing takes place. DAT prevents an individual from producing accurate and coherent language by the inability to form relevant ideas. It also prevents the individual from monitoring ideas as they are produced (Bayleas & Kasniak, 1987), thereby producing empty phrases and restricted levels of comprehension (Dijkstra, Bourgeois, Burgio & Allen, 2002). Once the comprehension of the message is affected, potentially negative and/or inappropriate responses may lower the desire of both interlocutors to engage with each other (Cooke, De Vita, Gee, Alsop, Detre, Chen & Grossman, 2002). The communication partner may be unable to decode a message and thus be unable to understand it. Increased effort may be required to decode a message that has not been formulated accurately. In addition to this, abnormal memory loss, disorientation as well as lack of insight and judgement, compound the difficulty experienced with communication (Lubinski, 1995; MacDonald, Almor, Henderson, Kempler & Andersen, 2001; Worrall & Hickson, 2003).

An increasing inability to communicate does not necessarily imply a decrease in the need or desire to do so. On the contrary, communication becomes increasingly necessary in order to maintain some level of social interaction and dignity (Scott, Caird & Williams, 1985). Research has found that an individual who suffers from dementia tends to withdraw socially and experiences feelings of isolation and depression (Worrall & Hickson, 2003). Withdrawal behaviours occur because emotionally, the individual remains human and aware of the

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negative attitudes of others (Kitwood, 1997). Kitwood (1997) also notes that often the individual is treated as if there is no hope for him/her and because of this, provision is made only for the basic physical needs of the individual. This reduces that individual to a mere physical presence (Cowley, 2001). Kitwood (1997) argues that an individual suffering from DAT should be treated normally. It must be remembered that the individual still has "emotions, feelings and relational capability" (Hunter, 1997, p.13). Hence he/she should be encouraged to participate in the activities of daily living (ADL), including the exercise of communicating.

People are often daunted by the prospect of communicating with someone who has DAT. Negative reactions towards this section of the population are characterised by fear and anxiety (Netten, 1993; Wilson, 2000), usually brought about by lack of knowledge and skills concerning how best to interact with an individual who suffers from DAT (Lubinski, 1995). In addition to this, communication between a DAT sufferer and another individual will be influenced by the latter's attitude towards old age, as well as the condition itself (Scott, et al., 1985). In addition, the prominence of modern medicine in curing illnesses contributes to the expectation by people, that cure is of greater value than care (Nolan, Davies & Grant, 2001). Since no cure for DAT exists, sufferers are provided with basic physical care, but little importance is attached to the emotional, social or psychosocial needs of the individual (Dilworth-Anderson, 2001). The various professions involved in the treatment and care of DAT patients typically diverge in terms of emphasis and care, compounding the tendency to provide only basic physical and medical care.

2.4 APPROACHES TO CARE OF PEOPLE WITH DEMENTIA

Improvement in technology has resulted in decreased disability rates and subsequent increased life expectancy (Jacques, 1997). Not only has increased life expectancy led to an increase in the population of elderly people, it has also led to an increase in the number of individuals suffering from age-related diseases, including dementia. Individuals with age-related illnesses require the services of a variety of health-care professionals, including the SLT (Worrall & Hickson, 2003). It has been found that the relationship between the health care professional and the patient/client has a powerful influence on the outcome of treatment in terms of health (Ross & Deverell, 2004).

During the nineteen-eighties, individuals suffering from dementia were deemed to be "patients", nothing more, and incapable of participating in decision-making regarding treatment. Since professionals followed a medical approach (Medical Model), treatment provided for the physical needs of the patients while neurological deterioration took place

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(Kitwood 1997). This clinical approach involved the provision of basic care: a safe place to live, assistance during feeding and treatment during illness (Worrall & Hickson, 2003). The individual's disabilities and impairments also received attention (Worrall & Hickson, 2003).

Also known as the Biomedical Model (Ross & Deverell, 2004), this approach is still followed today, focusing on the treatment of the body rather than the individual as a whole. The Medical Model designates people seeking care, as "patients", and does not require them to be active in decision-making during their treatment (Ross & Deverell, 2004). Medical professionals consider it their role to make decisions that, in their view, will best serve the needs of the "patient" (Worrall & Hickson, 2003). An advantage of this approach is its efficiency in terms of time (Worrall & Hickson, 2003). In addition, it promotes improved standards of basic care for individuals afflicted by dementia, including hospital and residential care. This includes: better accommodation, access to recreational activities and communication partners (Lubinski, 1995).

Many institutions focus on physical rather than holistic care (Dimond, 2003). The principles of the Medical Model are reflected in the opinions of many professionals who believe that "it is not possible or practicable to consult with people who have dementia" (Goldsmith, 1997, p.107). These professionals continue to make decisions without necessarily consulting the affected individual, or the spouse or other family members, concerning the provision of care and possible alternatives (Dilworth-Anderson, 2001).

In addition to the Medical Model, two other models, namely the Rehabilitation Model and the Social Model, have gained increasing attention in recent years.

The Rehabilitation Model focuses on the impaired individual and, by examining activity limitations, determines how this impairment impacts on the individual's ability to function in everyday life (Worrall & Hickson, 2003). The individual is provided with information and solution options recommended by the professional, and thereby becomes part of the decision-making process.

The other contemporary model, the Social Model, focuses on the promotion and maintenance of health through socio-environmental and behavioural changes (Ross & Deverell, 2004). The Social Model allows active participation in treatment-decisions, focusing not only on the individual requiring treatment, but also on the family and other significant people in the life of that individual (Ross & Deverell, 2004).

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A shift in focus towards the Social Model has seen increasing attention being paid to the individual with dementia as a whole, as well as to his/her family. This has allowed such individuals to participate actively in the decision-making surrounding treatment. To the professional, the inclusion of the individual with DAT in decision-making may not seem important, but to the individual involved, all decisions, both minor and major, are important (Jacques, 1997). The Social Model acknowledges the uniqueness of that individual by giving credence to his/her life history and by not making decisions without his/her consent (Ross & Deverell, 2004).

The view that DAT is incurable and that only hospice or palliative care (Wu, 1998) should be provided can lead to a situation where the affected individual's spouse and family members are precluded from playing a role in respect of care-management. Decision-making and contributions by family members are often not accommodated (Jacques, 1997). This lack of participation by the patient has arisen from the use of the Medical Model when managing dementia (Kitwood, 1997). In other words, the afflicted individual is not treated holistically as an individual with needs, wants and emotions. Only the physical needs and disabilities are considered in order to preclude discomfort and pain. This focus on physical care to the exclusion of psychosocial care means that neither the individual, nor the spouse or family, is actively involved in the treatment.

The Social Model examines the context within which the client lives (Worrall & Hickson, 2003) holding the tenet that communication is a social interaction and hence has social dimensions. For this reason, the Social Model aims to ensure that the client becomes active in society once again, potentially improving quality of life. This is only possible, however, when responsibility for the client is shared between the professionals, the client and the family to which the client belongs (Wu, 1998). Several recent studies (see, for example, the research conducted by Dijkstra et al., 2002) show that tenets of the Social Model are increasingly being applied to the management of individuals affected by dementia, allowing a more holistic approach to treatment of DAT, a disease that presents many difficulties. One of these difficulties, for example, includes problems with feeding.

Once the final stage of dementia is reached, the ability to communicate and make decisions will have diminished considerably. Literature reports that a individual suffering from DAT often develops feeding difficulties (Logemann, 1990). Alternative feeding is often required because the individual is unable to perceive what food is, or the necessity to eat (Worrall & Hickson, 2003). Consequently, the professional may instruct that alternative methods of feeding be implemented, such as insertion of a naso-gastric tube (NGT), without explaining

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the procedure to either the affected individual or family members. This may lead to confusion, alarm or other negative responses. It is possible for the affected individual to start eating again after a period of Reality Orientation (Kitwood, 1997). During this process, the affected individual is re-orientated to the concept of food and what he/she would like to eat. At this stage of DAT, the affected individual has become unable to operate independently. He/she may not be able to communicate coherently but may still be able to express, in some manner, emotions regarding feeding. The manner in which this emotion is expressed will naturally differ from individual to individual (Chapman & Marshall, 1993). It is therefore the professional's responsibility to ensure an accurate interpretation of such an emotion, since the management of feeding can present ethical issues. One way of facilitating interpretation of an individual's likes and dislikes, is to know that individual's background (Miller, 2000), including the intimate family culture. This background information can be obtained by means of listening to life stories presented by a spouse or other family members. Family members can then also assist in the setting of goals with regard to treatment and therapy.

2.5 THE ROLE OF THE CAREGIVER

Caring for an individual suffering from dementia can be challenging and difficult (Burns et al., 2006) A professional, such as a nurse, can fulfil the role of caregiver. Alternatively, the best caregiver may be the spouse or another family member (Burns et al., 2006). An individual with DAT is an individual who is part of society, with relationships and experiences that place him/her within a unique, individual context. Caregivers should be able to relate to the individual, and someone related to or a family friend would be more inclined to consider the emotional needs of the individual, as well as basic physical care. It stands to reason that a spouse or other family member is better able to comment on the impact of the illness on communication and family relationships, and to offer solutions within a family context.

As DAT is a relatively new field of study, research and studies involving individuals with DAT and their families, are limited. However, recent studies have illustrated how caregivers can provide information regarding individuals being treated, enabling them to suggest or make appropriate changes where needed. In a study conducted by Burns et al. (2006), caregivers of individuals with DAT were approached to provide cognitive assessments of their patients. These caregivers provided doctors with information regarding the cognitive abilities of their patients, in terms of their own perceptions. The study made use of questionnaires. As the caregivers were not related to their patients, their perceptions in respect of the patient's true abilities were not always accurate. In another study conducted by Goldsmith (1997), family members were questioned about their perceptions regarding the

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problems of every day living faced by themselves and the individual with DAT. Family members completed questionnaires in order to determine which ADLs were more problematic. This study provided information that was more accurate than the previous study, strengthening the view that family members have better insight into the problems of the individual with DAT, more so than strangers employed as caregivers. Knowing the background of an individual also assists in the sense that, when a problem with ADL arises, the caregiver may have better insight into how the individual would have handled the situation before the onset of DAT.

Although the use of questionnaires provides relevant information, it often lacks in providing individual information. This is due to the fact that respondents only provide the information asked for on the questionnaire. The use of questionnaires is therefore rather limiting. An alternative approach is to interview respondents, since this allows for more flexibility by the parties involved. The use of narratives provides a respondent with the opportunity to provide relevant information that can be used to expand the particular field of study under investigation.

In a study conducted by Barker, Lavender and Morant (2001), family members of people suffering from Schizophrenia, as well as the patients themselves, were requested to tell their life stories. This study employed a qualitative approach in the form of narrative analysis. The narrative focused on the patient's sense of self as well as social relationships over time. The use of these narratives assisted doctors in making sense of the disease and its progression. It was found that through narrative analysis, a professional is able to gain access to the patient's life, perceptions, opinions and decisions. In certain cases (such as Schizophrenia) patients are able to add their own narratives to supplement those provided by family members. In the case of DAT, however, the individual is often unable to relate his/her own narrative, or to make decisions alone (Barker et al., 2001). That is why a professional needs to work closely with the spouse and family so that all parties concerned have a clear understanding of their current situation, and where it is heading (Goldsmith, 1997).

2.6 NARRATIVE ANALYSIS

Recent years have seen an increase in the use of narratives as a means of collecting research data (Lieblich, Yuval-Mashiach & Zilber, 1998). Narrative research analysis discourse defined as "*a sequence of connected sentences*" (Ulatowska & Chapman, 1995, p.115). The purpose of a narrative study is to obtain an in-depth understanding of a specific topic with regard to a small group of individuals (Lieblich et al., 1998).

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Narratives have frequently been used to represent the life history of social groups marginalized by discrimination, and to "speak out" on behalf of such groups (Lieblich et al., 1998). Studies on racism and gender have also been done by means of narrative research (Mumby, 1993). The narratives have been used to gain understanding of the current financial, emotional and social status of a group or individual, by examining what has gone before, and establishing a holistic view of the individual (Lieblich et al., 1998). Narrative research allows the professional to gain as much information as possible and at the same time, allows the subject under investigation to determine how much to share. Shared information carries great significance for the researcher since the individual who provides the information, does so with the intention of raising issues important to him/her. It places the professional concerned under an obligation to pass on the information responsibly to those who need to hear it (Darlington & Scott, 2002).

It stands to reason, therefore, that when investigating DAT and its victims, life stories can provide a background against which attitudes, behaviours, actions and inactions can be examined. When treating an individual with DAT, it is important to have a basic knowledge of that individual's background (Dudley & Pringle, 2004) as this affords the professional an increased understanding of that individual's reactions, style of communication and manner towards events and people (Miller, 2000).

The views and experiences of spouses and families in respect of treatment and care have not been fully reported in the past. This is a pity, since life stories provided by such individuals could enhance understanding of the individual who is ill, within his/her own life-context, and thereby create new management possibilities. A spouse and family members can make a valuable contribution if included in the treatment team (Mumby, 1993). This approach is based primarily on a social model where the context of the sick individual (which includes the spouse and family) underlies decisions made (Miller, 2000). This background knowledge is also helpful in facilitating communication with the patient in his/her current state (Gibson, 1993; Goldsmith, 1997).

2.7 SUMMARY AND PROBLEM STATEMENT

This study will explore the experiences of the spouse of an individual affected by DAT. It will seek to document the view of the spouse, concerning the inclusion, or exclusion, of both him/herself and the sick partner in decisions that affect their life and dignity. This information may provide valuable insight into how spouses perceive themselves and others within the context of their situation. As well as the role that the SLT will play in treating the individual with DAT and their communication difficulties. The study will serve to assist the

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SLT in making decisions with the spouse about the communication difficulties of the individual with DAT. Life stories can also give credence to the right of these individuals to the following: autonomy (right of choice), just service provision, non-maleficence and beneficence (the affected individual can be harmed if decisions are made against his/her will) and the right to be treated by professionals who employ virtue by getting to know all they can about the individual, in order to provide high-quality care. The study will also further explore the role of the SLT when treating an individual with DAT and their spouse in a multidisciplinary team.

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CHAPTER 3

METHOD

This chapter will provide a detailed explanation of the method implemented during the research project, which was undertaken to explore the experiences of a spouse indirectly affected by the condition, Dementia of the Alzheimer's Type (DAT).

3.1 AIM OF STUDY

The study was undertaken to determine the perceptions and experiences of a person living with a spouse afflicted by DAT, specifically regarding the impact of DAT on communication interaction.

3.2 RESEARCH DESIGN

This study required a design that would enable the researcher to access and explore a participant's report of personal experiences. Qualitative research considers a participant's own account of social matters (Neuman, 1997) and therefore makes it a suitable tool for this study, which aims to describe the impact of DAT on communication interaction. A qualitative research design allows the researcher to collect, organise and interpret textual information gained from conversation and observation (Malterud, 2001) and to comprehend specific issues within their natural contexts (Boudah & Lenz, 2000; Doehring, 1988). The qualitative approach known as "naturalistic enquiry" (Malterud, 2001, p 400), was deemed appropriate for this study.

Qualitative studies make use of data expressed in words (as in this study), pictures and/or objects (Neuman, 1997). A single case study design within the context of qualitative research was selected for the purpose of this study. This depth and detail allows the researcher to become intimately familiar with the case, including the individual him/herself (Neuman, 1997). The detailed data was collected by means of interviews. The information obtained was subjected to narrative analysis.

A narrative study is a social study conducted through the observations and interpretations (Lieblich et al., 1998) that an individual attaches to his/her life experiences (Barker et al., 2001). Narrative analysis requires researchers to use their own judgement when reflecting on the information gathered from individuals within their natural contexts. It is imperative, however, for researchers to remain objective and to "suspend their own ideas and describe the situation from a number of different perspectives, including the point of view of the person or persons being observed" (Doehring, 1988, p 81).

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Narrative analysis was deemed to be more appropriate than discourse analysis as the latter "does not describe and explain the world" (Zeeman, Poggenpoel, Myburgh & Van der Linden, 2002, p.23). Discourse analysis is a reflexive process that focuses on changes and progress. It is mainly used for linguistics, literary studies and anthropology.

Since the aim of this study was to determine the perceptions and experiences of the spouse of an individual affected by DAT, specifically regarding the impact of DAT on communication interaction, it was felt that narrative analysis, as opposed to discourse analysis, would better facilitate understanding of the case within its context (Higgs, 2004). A narrative analysis also informs professionals in respect of actions that need to be taken "within the story that is being told" (Higgs, 2004, p. 308).

The results obtained from the narrative analysis were used to examine and clarify the impact of DAT on communication interaction and the role of the SLT in this regard.

3.3 PARTICIPANT

The participant and his experiences to be studied was required to be the spouse of an individual with DAT. For the purpose of this study, "spouse" will be defined as "person who fulfils the role of life partner, sharing certain roles and responsibilities (Crosby, 1987).

Only one case study was undertaken owing to the in-depth nature of the data analysis and the need for the researcher to interact closely with the spouse in order to gain insight into the life story of both the participant and the partner with DAT.

3.3.1 Criteria for the selection of the individual with DAT

The individual with DAT was required to:

- Be in the final stage of DAT as determined by a medical practitioner. This selection criterion was specified since the spouse of someone in the final stages of DAT would be better able to provide a valid, experience-based description of "living with dementia", having lived through each stage of the illness and the incumbent changes, than someone still coping with the early stages of the illness.
- Be living either at home with his/her spouse, or in a home situated close to the family home. This would ensure regular contact between the individual with DAT and his/her spouse, thereby increasing the likelihood that the participant would be able to provide an accurate description of how communication interaction was affected by the illness.
- No criteria in terms of age, gender, language or level of education were set, since both males and females from all levels of society can be affected by DAT.

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3.3.2 Criteria for the selection of the participant

The participant (spouse of the person affected by DAT) was required to be:

- In regular contact (approximately once a week) with the individual with DAT. For the purposes of the study, the participant would need to be familiar with the individual with DAT's physical and mental status, and able to provide a valid account of the impact of DAT on social interaction.
- Proficient in both English and Afrikaans as these are the languages employed by the researcher.

No criteria in terms of age, gender or level of education were set.

3.3.3 Procedures for the selection of participants

Once ethical clearance had been obtained, the researcher proceeded to identify a participant. A couple were identified with the assistance of medical practitioners and retirement villages within the urban areas of Gauteng. Medical practitioners and retirement villages were contacted by telephone and the nature and purpose of the study was explained to them. They were requested to assist in identifying a participant who would meet the selection requirements.

The matron of a retirement village identified a potential male participant and obtained permission from him to supply the researcher with contact details. The researcher thereupon contacted the individual telephonically. The nature and purpose of the study was explained both verbally and in writing (Appendix B). His participation in the study was requested. The participant was required to sign a letter of informed consent indicating his willingness to participate in the study (Appendix B).

3.3.4 Description of Participant

The person selected to participate in this study is the spouse of an individual suffering from DAT. The participant is referred to as *Mr R*. A description of *Mr R* follows in Table 3.1.

Table 3.1: Description of Participant (*Mr R*)

Age	Gender	Primary language	Level of education	Residence
74 years	Male	Afrikaans	Tertiary (University)	*Mr R* and his wife were living in the same room in the wing for residents with DAT, at a Residential Village

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3.3.5 Description of the Individual with DAT

The individual with DAT is referred to as *Mrs R*. She is the wife of the participant, *Mr R*. A description of *Mrs R* follows in Table 3.2.

Table 3.2: Description of Individual with DAT (*Mrs R*)

Age	Gender	Primary language	Level of education	Stage of DAT	Number of years since diagnosis	Residence
73 years	Female	Afrikaans	Matric	Final	8 years	*Mrs R* was living in the wing for residents with DAT, at a Retirement Village.

3.4 ETHICAL CONSIDERATIONS

Ethical principles must guide the entire process where people form the core of a social research project. Ethical standards ensure that any concerns, dilemmas and conflicts that arise during the course of research are resolved (Neuman, 1997). Adherence to ethical principles also ensures the trustworthiness of the study (Barbour, 2001; Yardley, 2000). Ethical clearance was obtained from the Faculty of Humanities Research Proposal and Ethics Committee of the University of Pretoria (Appendix A) prior to any data collection.

This research project is underpinned by the following principles (Leedy, 1985 & Neuman, 1997):

- Informed consent of participant and participant autonomy
- Beneficence and non-maleficence (protection from harm)
- Fidelity (anonymity and confidentiality)
- Justice

3.3.6 Informed consent and autonomy

Autonomy implies that the subject of the study has the right to participate in decision-making regarding matters that affect him/her (Beauchamp & Childress, 1983). Thus, once the participant had been selected, the purpose of the study as well as procedures for data collection were explained to him in detail, so that he could make an informed decision regarding participation. Throughout the research, any decision he made was respected. For example, if he decided not to disclose any personal information or names, the researcher did not pursue the topic any further.

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3.3.7 Beneficence and non-maleficence (protection from harm)

Since narratives are a natural human activity, this method of collecting data has been viewed as not being stressful or harmful (Murray, 2000). However, it is up to the researcher to ensure that the form of data collection does not become stressful or harmful, by keeping the ethical principles in mind.

The questions posed to facilitate the semi-structured interviews were non-invasive. They did not question the participant's background, religion or culture. The participant was also assured, both verbally and in writing, that participation in this study would not place him or his wife at any risk or harm. They were also informed that they could withdraw from the study at any point with no negative consequences (Appendix B).

3.3.8 Fidelity (anonymity and confidentiality)

Since this study necessitated the collection of personal information from the subject, it was crucial to ensure that confidentiality was maintained throughout the entire process. The subject of the study and his wife are thus referred to as *Mr R* and *Mrs R* respectively, throughout the study, in order to uphold the principles of anonymity and confidentiality. No names or contact details appear in the Appendices. Once again the participant was assured of this both verbally and in writing (Appendix B).

3.3.9 Justice

An individual with DAT and his/her spouse are entitled to a wide variety of services and professional help. During the research project, the participant was informed about different services available to him and his wife. Once research had been completed, and data analysed, the particular services required by this couple were discussed in detail with the participant, during a final interview.

The Course Followed:

- Ethical clearance was obtained from the Faculty of Humanities: Research Proposal and Ethics Committee, of the University of Pretoria (Appendix A) prior to data collection.
- Once ethical clearance had been granted, general practitioners and directors of retirement villages were approached. The nature and purpose of this study was explained telephonically and they were requested to identify individuals with DAT who met the criteria for selection.
- Once potential candidates had been identified by these instances, those who had given permission for the release of contact details were approached telephonically so that the nature and purpose of the study could be explained to them.

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- Telephone calls were followed up by personal interviews, during which a written explanation of the study was discussed with potential candidates (Appendix B). A letter detailing the goals and procedures of the research project was given to the candidates (Appendix B). They were also informed of the right to withdraw from the study at any time and were assured of confidentiality. Those who agreed to participate were requested to sign a letter of informed consent (Appendix B), stating that they had been informed of all details pertaining to the research and were willing to participate (Leedy, 1985).
- During selection procedures, it became apparent that only one of the potential candidates fully met the criterion of *regular* contact with the affected spouse. He was therefore selected for the study.
- Informed consent (Appendix B) was obtained to allow the researcher to analyse, process, interpret and present any information gathered during the research project (Miller, 2000).
- Interview times had to be reasonable and an estimate of the length of each interview was provided to the participant prior to commencement of interviews. This was essential to avoid misconceptions about the research project and its duration.
- Prior to commencement, the participant was asked for permission to record interviews in order to facilitate data analysis.
- Client confidentiality was assured.

This study adhered to all the above-mentioned ethical principles and procedures, thereby preserving the privacy and dignity of the couple involved in the investigation. These ethical considerations also provide theoretical justification for this project, since it has the potential to promote more effective and individualised services to individuals affected, directly or indirectly, by DAT.

3.5 APPARATUS AND MATERIALS USED FOR DATA COLLECTION

The following apparatus/material was used for this research project:

a) Audio cassette-recorder with built-in microphone. A built-in microphone was needed since both the researcher and participant were present during the recording of narratives, requiring that both voices be heard. A detachable microphone would have necessitated the handing over of the microphone, disrupting the flow of conversation and precluding the addition of insightful comments during conversation.

b) A set of questions, designed to elicit conversation. Data was obtained by guiding the participant through a semi-structured interview. The questions guided the interview and were used to elaborate on the participant's comments. The questions were asked to elicit further information from the candidate with ease and comfort, in such a manner that he would only reveal that which he wished to reveal (Lieblich et al., 1998)

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The questions used, and the rationale for each one, are presented in Tables 5.1 – 5.4

Table 5.1: First Interview

Questions asked	Translation	Rationale
1. Wanneer is Alzheimer se siekte vir die eerste keer by u vrou gediagnoseer?	*When was your wife first diagnosed with Alzheimer's Disease?*	To establish: • time frames in respect of the progress of the disease; • the stage of dementia at commencement of research.
2. Wat was u reaksie daarop?	*How did you react to the diagnosis?*	To establish the experiences of the participant, as positive or negative.
3. Wat was u vrou se reaksie daarop dat sy met Alzheimer se siekte gediagnoseer is?	*What was your wife's reaction to the diagnosis of Alzheimer's Disease?*	To determine how the individual with DAT reacted to the diagnosis, and whether or not such reaction was influenced in any way by the condition itself, at whatever stage presented, at time of diagnosis.
4. Hoe is Alzheimer se siekte vir u gedefinieer en deur wie is dit gedefinieer?	*How and by whom, was Alzheimer's Disease defined and explained to you, and by whom?*	To establish: • which professional made the diagnosis; • how the condition was defined and explained; • whether or not the participant feels that he was provided with sufficient information.
5. Voel u goed ingelig oor Alzheimer se siekte en wat om te verwag? (Hinton & Levkoff, 1999).	*Do you feel properly informed about the disease and what to expect?* (Hinton & Levkoff, 1999).	If the participant were to answer "no", the rationale would be to determine the extent of the information received and whether or not the participant required more.
6. Vertel vir my van u lewe saam met u vrou voordat Alzheimer se siekte by haar gediagnoseer is.	*Tell me about life with your wife before she was diagnosed with Alzheimer's Disease.*	To establish the nature of the communication interaction between the couple prior to the onset of the disease and how the condition has impacted on communication.

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Table 5.2: Second Interview

Questions asked	Translation	Rationale
1. Ons het verlede keer gepraat oor u lewe voordat u vrou met Alzheimer se siekte gediagnoseer is. Kan ons vandag praat oor die verloop van die siekte en hoe haar toestand (d.w.s. die Alzheimer's) verander het sedert die diagnose?	*At the last interview we spoke about your life before your wife was diagnosed with Alzheimer's Disease. Can we speak about how the disease has progressed since the diagnosis, and the changes that have occurred?*	To obtain permission to talk about how the disease has progressed.
2. Hoe, sou u sê, het die siektetoestand verander met verloop van tyd?	*In your view, how has the disease changed over the course of time?*	To establish the life history of the couple and their experience of Alzheimer's Disease throughout its different stages. This rationale also applies to the next question.
3. Het u vrou verander sedert sy gediagnoseer is?	*Has your wife changed since the diagnosis was made?*	
4. Hoe het sy verander?	*How has she changed?*	This question would be asked if the participant's response to question 3 was "yes". If the answer was "yes", then to establish how she has changed and which symptoms of DAT she has experienced.
5. Watter uitwerking het hierdie veranderinge op u lewens gehad?	*What effect have these changes had on your life?*	To establish his experiences with DAT.
6. Hoe reageer u kinders en kleinkinders op die feit dat hulle ma en ouma nie meer dieselfde as voorheen is nie? Weet u kleinkinders wat fout is met haar, en verstaan hulle dit? (Furlini, 2001).	*How do your children and grandchildren react to the fact that their mother/grandmother is not what she used to be? Do your grandchildren know what is wrong with their grandmother?* (Furlini, 2001).	If the answer to Q3 was "yes", then this question would also be asked to establish how the rest of the family has experienced the changes.
7. Hoe verduidelik u die situasie met u vrou aan ander mense?	*How do you explain the situation with your wife to other people?*	To determine the extent of the participant's knowledge regarding DAT, and how it had been explained to him.
8. Volgens u mening, gee u verduideliking 'n goeie beskrywing van die situasie soos dit is, en wat die toekoms nog mag inhou?	*In your opinion, does your explanation give an accurate description of the current state of the illness, and what the future may still hold?*	To establish whether or not he feels that he has obtained enough information from doctors and specialists, so that he can inform family and friends.

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Table 5.3: Third Interview

Questions asked	Translation	Rationale
1. Ons gesprek het verlede keer afgesluit by die beskrywing van Alzheimer se siekte wat u vir ander mense sou gee. Ek wil nou vir u vra: Watter inligting benodig u nog oor Alzheimer se siekte? (Chadwick, Jolliffe & Goldbart, 2002).	*Last time we spoke, we ended with your description of how you explain Alzheimer's Disease to others. I would now like to ask: What other information do you require regarding the disease?* (Chadwick, Jolliffe & Goldbart, 2002).	The 13 questions asked during this interview were designed to establish the participant's experiences in respect of the type and quality of care provided to his spouse suffering from Alzheimer's disease. The questions will determine whether the participant's experiences have been positive or negative, and to highlight the consequences of these experiences.
2. Dink u dat u genoeg inligting van u vrou se dokters gekry het?	*Do you feel that you received enough information from your wife's doctors?*	
3. Indien die antwoord negatief was: Watter mense, voel u, moet meer inligting verskaf aan gesinne wat met Alzheimer se siekte lewe, en waarom? Indien die antwoord positief was: Watter mense het genoeg inligting verskaf, en hoekom?	*If the answer is negative: Which professionals, do you feel, should have provided you with more information?* *If the answer is positive: Which professionals, do you feel, provided you with sufficient, accurate information, and why?*	
4. Wat is die grootste probleem wat u met u vrou se siekte ondervind?	*What is the greatest problem you experience with your wife's disease?*	
5. Dink u dit sou beter gaan as u meer inligting of ondersteuning van professionele mense sou kry?	*Do you think you would cope more easily if you had received more information and support from professionals?*	
6. Voel u dat u 'n rol speel in die versorging van u vrou, en besluite wat geneem word? Met ander woorde, voel u dat u 'n aktiewe deelnemer in die versorging en besluitneming is?	*Do you feel that you play an active role in the decision-making processes that surrounds your wife's treatment and care?*	
7. Neem die professionele mense u gedagtes en besluite in ag?	*Do you feel that the professionals take your opinions and decisions into consideration?*	
8. Hoe aktief is u vrou ten opsigte van haar eie versorging en besluite wat geneem word? Speel sy 'n aktiewe rol of word daar namens haar besluit?	*How active is your wife with regard to her treatment and decisions that need to be made? Does she play an active role or are decisions made for her?*	

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9. As besluite geneem word, neem u in ag hoe sy dit sou wou gehad het as sy self nog kon besluit, en hoe sy in die verlede sekere goed gedoen het?	*If decisions need to be made on her behalf, do you take into consideration how your wife was before the disease, what she would have wanted and how she would have reacted*	
10. Voel u dit is belangrik om haar gevoelens, gedagtes en voorkeure in gedagte te hou wanneer besluite geneem word? Hoekom/Hoekom nie?	*Do you feel it important to take her feelings and opinions into consideration when making decisions? Why/Why not?*	
11. Wat verwag u van die toekoms?	*How do you foresee the future?*	
12. Hoe berei u uself voor vir die toekoms?	*How are you preparing yourself for the future?*	
13.Is daar enige vrae wat u wil vra, of iets wat u graag nog wil vertel?	*Is there anything you would like to ask or share?*	

Table 5.4: Final Interview

Introduction	Translation	Rationale
Vandag gaan ons net gesels oor my bevindings, om seker te maak dat daar geen waninterpretasie van my kant af was nie.	*Today we are going to discuss my findings, in order to ensure that there were no misunderstandings or incorrect interpretations.*	This final conversation was held in order to finalise the narrative and conclude the life history.
Questions asked	**Translation**	
2. Het u enige ander vrae?	*Do you have any other questions?*	

The use of semi-structured interviews facilitates the expression of research participants subjective experiences and beliefs in narrative form (Barker et al., 2001). The emotions of the interviewee were therefore taken into account and questions structured to ensure that each interview progressed in a sensitive manner. Time was allowed for reflection on the answers provided by the spouse. The researcher offered no judgement and did not impose her opinion on the participant. The researcher followed the participant's lead (Kotzè & Kotzè, 2001). A steady flow of dialogue was maintained by means of open-ended questions (Lieblich et al., 1998) that were formulated in Afrikaans, the vernacular of the participant.

The questions asked during the conversation relate to:

- Mr R's perception of his spouse prior to the onset of dementia (e.g. "Tell me about *Mrs R* before she became ill. Has she changed since the diagnosis?")
- Mr R's experiences since the onset of dementia (e.g. "Since the diagnosis, how have the changes in your wife affected your life, and that of your family?")

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- The difficulties that have been experienced by Mr R since the onset of dementia.
- Mr R's perceptions regarding the quality of care provided by the general practitioner, and nurses if the patient is in a retirement village.
- Mr R's needs regarding the care of the individual with DAT.

As a narrative is based upon the experiences and perceptions of the individuals being interviewed, these questions were presented in an informal way. The questions asked were based on studies such as:

- "Constructing Alzheimer's: Narratives of lost identities, confusion and loneliness in old age" (Hinton & Levkoff, 1999)
- "The parent they knew and the 'new' parent: Daughters' perceptions of Dementia of the Alzheimer's Type" (Furlini, 2001)
- "Carer knowledge of dysphagia management strategies" (Chadwick, Jolliffe & Goldbart, 2002).

These studies were used to provide a frame of reference for the type of questions and remarks that could be used to elicit information by means of conversation. However, they were not used to formulate actual questions.

3.6 PROCEDURES

3.6.1 Data Collection Procedures

The following procedures were followed:

1) Once permission had been obtained from all relevant participants, three appointment dates and times were arranged to suit all parties involved. Appointments were made a month apart in order to obtain a progressive narrative, in which the participant would be able to report any changes in his wife's condition during that period of time (three months). It would also give the participant time to contemplate what he would like to disclose during a following conversation.
2) The appointments took place at the retirement village where the couple live, to ensure that the participant was comfortable in a context that is both natural and familiar. The appointments each lasted approximately one hour in duration.
3) Once the conversations had been completed, a final (fourth) date was set. During this final appointment, the interpretations made by the researcher were discussed with the participant to ensure that the information collected was correct and that no misinterpretations had taken place. This has been the practice of other researchers conducting research by means of narratives, including Lieblich et al. (1998) and Barker et al. (2001).

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3.6.2 Data Analysis

The narratives collected over the three consecutive months were handled carefully and sensitively to ensure that the participant's "beliefs and experiences as expressed in the interviews" (Barker et al., 2001, p201) were revealed in a valid manner.

In qualitative research analysis, the researcher must carefully lift out the most important information and investigate it more closely, within the context of its collection. In this research project, the narratives were analysed in a qualitative manner, using an "intuitive analysis style" (Malterud, 2001, p.483). This allowed the researcher to organise the data by examining it in detail, and identifying aspects that were mentioned most frequently by the participant.

According to Lieblich et al. (1998) narratives may be analysed in a variety of ways. In the study at hand, two forms of analysis were used, namely *Holistic-Content* and *Holistic Form Analysis*. Both forms of analysis focus on the narrative as a whole as well as the content presented by the participants (Lieblich et al., 1998). They were deemed appropriate for this research by virtue of the fact that they allowed a holistic focus, thereby facilitating investigation of the participant's beliefs and experiences in context.

Holistic-Form Analysis makes use of the plots and structures of a complete life story. This approach allowed the researcher to determine the progression, form and shape of the narrative (Lieblich et al., 1998). It also facilitated three stages of analysis, namely a detailed description of the phenomena studied, the interpretation of data in respect of the purpose of the study and finally, the correlation of interpretations to data from other studies, allowing integration of these aspects to culminate in a theoretical explanation (Doehring, 1988, p.153).

Holistic-Content Analysis looks at the complete life story of an individual and studies the content of the narrative. This approach enabled the researcher to identify the major themes that ran throughout the course of the narrative (Lieblich et al., 1998). It was decided to make use of both Holistic-Form and Holistic-Content Analysis, to allow the researcher a more in-depth look at the participant's life story. In order to perform this task adequately, the researcher made notes throughout the transcription of narratives, with regard to process, themes and sub-narratives. Owing to the large amount of information provided by Mr R, the researcher decided that during the analysis of the narrative, to focus only on the information pertaining to the impact of DAT on social interaction, as well as the role of the SLT in the management of DAT.

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To ensure correct interpretation of the narratives, both the researcher and the participant did crosschecking. During crosschecking the researcher provided the information that had been transcribed and interpreted. Mr R was then asked to go through this information and verify that all the data collected and interpreted was accurate and that the researcher had not misinterpreted any information. Data collected during this type of qualitative research must reflect the perception of the participant (Boudah & Lenz, 2000). This session of crosschecking verified that the data was correct and that interpretation of data could continue.

Holistic-Form Analysis, also known as Structure Analysis, sketches a prototypical life course. This method requires the researcher to read the narrative carefully, keeping in mind the outline given by the participant. The following phases, according to Lieblich et al. (1998, pp.89-91) apply:

1. The researcher must identify the axis of each stage, in other words, the thematic focus for the development of the plot. During this phase, the researcher is interested in the specific form and direction that the content is taking, enabling comparisons between plots and themes within the structure, as they develop and become organised.
2. The researcher must identify the dynamics of the plot. These may be inferred from particular forms of speech, including reflections on specific phases in the participant's life, responses to a query about why the participant chose to stop talking about a theme at a given point in time, or the use of terms that may express the structural component of the narrative.

According to Lieblich et al. (1998, pp. 62-63) there are five steps to reading for content in a holistic manner, while conducting Holistic-Content Analysis. These five steps are summarised as follows:

1. The researcher must read through the material several times until a pattern emerges, usually in the form of foci found throughout the entire narrative. While reading, the researcher must remain open-minded since significant aspects can only be clearly identified as such by their relevance within the context of the entire story.
2. The researcher must put the initial, global impression of the case into writing, noting exceptions to the general impression as well as unusual features of the narrative, such as contradictions.

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3. The researcher must select special foci of content, or themes, to follow in the narrative as it evolves from beginning to end. A special focus can be identified by several factors, including the amount of space devoted to it, its repetitive nature and the number of details provided by the participant. Focal significance can also be implied by omission of, or only a brief reference to, a particular aspect.
4. Using coloured pens, the researcher should mark various themes in the narrative, reading separately and repeatedly for each theme.
5. The researcher must keep track of the results in several ways and follow each theme throughout the narrative, noting the conclusions. The researcher must be aware of where each theme begins and ends, the transitions between themes, the context of each one and the relative salience of each within the context of the narrative.

In this research project, the following steps were followed in the transcription and analysis of the narrative:

- The narrative was transcribed with the aid of an audio cassette-recorder (Appendix C). Each utterance and comment, whether a single word, sentence, paragraph or sigh, was noted in order to ensure accurate transcription.
- The utterances of the researcher and the participant were isolated from each other and marked *R* for the researcher and *P* for the participant.
- Once the narrative had been transcribed, the phases of the narrative were identified (as suggested by Lieblich et al., (1998) to determine the development and shape of the narrative (Lieblich et al., 1998). To begin with, the narrative was first thoroughly read. Then identification of phases began at the beginning of the narrative, moving to new ones when the narrative changed in terms of decline or incline.
- After the different phases had been identified, the sub-narratives and themes were considered. Once again, the narrative was thoroughly read. Themes that repeatedly appeared throughout the entire narrative were highlighted. Sub-narratives are themes that occur frequently throughout a narrative, signifying importance to the participant.
- From the sub-narratives it was possible to identify narrative themes representing factors that have impacted on the participant's experience. The themes consist of words, phrases or sentences that are repeated throughout the narrative. By doing this, it was possible to identify the main "story" in the narrative, which could then be discussed (Lieblich et al., 1998). Once identified, the main stories could be discussed in detail by referring to them in the discussion of the data results.

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3.7 TRUSTWORTHINESS

Trustworthiness has been defined as “the extent to which the researcher can trust the research” and is based on the descriptiveness of the method and analysis employed, as well as the quality of such descriptiveness (Boudah & Lenz, 2000, p. 153). It also refers to the ability to collect data that would remain constant in a replicated study (Neuman, 1997). Generally a researcher conducts a study in more than one setting and with more than one participant, to ensure that a replicated study can produce the same results. Another way to ensure trustworthiness is for the participant to crosscheck the information obtained and analysed (Boudah & Lenz, 2000). However, no study, irrespective of the method or analysis employed, can provide results that are universally trustworthy (Mangen, 1999).

This study did not make use of various settings or participants. Detailed information regarding the influence of dementia on communication was gathered from one participant. During the interview, the participant and the researcher did crosscheck the information gathered and analysed and could confirm the validity of the interpretation. The transcriptions were also analysed by a second person familiar with narrative analysis.

3.8 SUMMARY

This chapter provides a detailed description of how the research was conducted, the materials used and how the information was analysed.

The research was conducted in an ethical manner, adhering to all the principles mentioned earlier in the chapter (cf. 3.4)

Once the data had been analysed, it was interpreted. During this process, the researcher focussed on extracting important information from the narrative. These important factors will be discussed in the following chapter.

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CHAPTER 4

RESULTS

The purpose of this study was to determine the perceptions and experiences of the spouse of an individual with Dementia of the Alzheimer's Type (DAT) regarding the impact of DAT on ***communication interaction***. This was achieved by conducting a series of interviews with the participant in the study, Mr R, focusing on his perceptions and experiences in this regard. The data collected by means of this narrative analysis was then interpreted, using holistic form analysis as well as holistic content analysis.

Holistic ***form*** analysis involves a plot analysis to determine whether a narrative as a whole, is *progressive*, *regressive* or *steady*. In order to determine the nature of Mr R's narrative, significant events in the life of Mr and Mrs R as a couple were plotted onto a graph. Significant events that were experienced as positive are represented as peaks on the graph, whereas events that were experienced as negative are represented as dips.

A narrative is regarded as *progressive* when the graph ascends and *regressive* when it descends. A *steady* narrative does not have major progressions or regressions, indicating few significant positive or negative events within the narrative. A narrative is thus analysed in terms of its *specific form* so that the phases perceived as significant in a person's life can be identified. These phases, both positive and negative, help to determine the development and shape of the narrative. Once the form of the narrative has been established, it is necessary to establish the sub-narratives within the plot. Sub-narratives are stories or events that appear repeatedly in the narrative.

Holistic ***content*** analysis, on the other hand, focuses on the *entire* narrative produced and reveals major themes that run throughout. These themes emerge prominently and gain stature by virtue of the fact that they appear repeatedly during the narrative, in the form of detailed discussions. Holistic content analysis helps the researcher to establish exactly how important these issues are to the participant, thereby adding relevance and value to the interpretation of the narrative.

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In this chapter, the findings of the holistic form analysis will be presented by means of a graph depicting the flow of the narrative. This will be followed by a discussion of the different phases of the narrative

The progression of the narrative depicted on the graph below, was plotted by meticulously reading the transcriptions of Mr R's narrative. During the reading significant phases/events, that appear to have had a positive or negative impact on Mr R's life, were identified. These phases will be discussed as sub-narratives since they represent the lows and highs in the narrative, thereby highlighting important information.

Once the holistic *form analysis* of Mr R's narrative has been presented, the findings of the holistic *content analysis* will be introduced into the discussion. The holistic form of the narrative needs to be established before the holistic content is analysed since the information thus obtained will provide a background to the narrative as a whole, thereby facilitating the determination of main, recurring themes in the narrative. However, unlike the phases identified in the form analysis, the themes that emerge from the content analysis may not be chronological in nature. Instead they emerge randomly throughout the narrative. Themes that occur most frequently will be discussed first, followed by those that are less prominent.

4.1 Holistic form analysis

Holistic form analysis is a plot analysis of the narrative delivered by the participant during the interviews and establishes whether the narrative was progressive, regressive or steady in nature.

4.1.1 Graphical representation of the narrative

When interpreting a narrative in a holistic manner, the narrative is initially scrutinized as a whole and then broken down into the various time periods that occur throughout (Lieblich et al., 1998). The graph representing the breakdown of Mr R's narrative is presented on the following page (Figure 1). The graph shows one peak and then gradually declines. In general it can be observed that the narrative is *regressive* due to the deteriorating effects of DAT on communication interaction and quality of life

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(QOL) for Mr and Mrs R. The graph also shows that there are four phases within Mr R's narrative, each phase representing different sub-narratives.

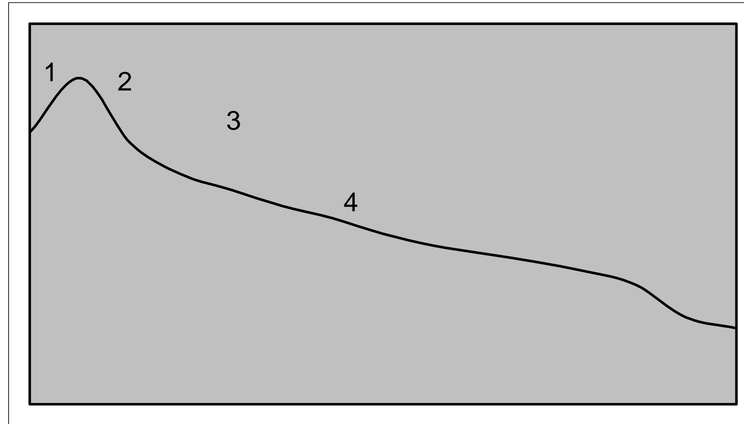

Figure 1: Graphic representation of the regressive nature of Mr R's narrative

Phase 1: Initially, the narrative progresses positively (represented by the first peak of the graph). Phase 1 on the graph represents the period during which Mr R met his wife and the years of their marriage, prior to the diagnosis of DAT. Mr and Mrs R met each other in 1951 and were married in 1953. In due course, Mrs R gave birth to twins. The birth of the twins was traumatic since they were born prematurely in a town without a hospital. However, despite the trauma associated with this event, the early years of Mr and Mrs R's life together were experienced as positive by Mr R, since they were building a family (hence the incline in the narrative). Mr R commented that the birth of their twins was an eventful, but special, experience that had had no negative effects on Mrs R. During this phase their other children were also born. They moved around a lot but finally settled down (approximately 1995).

Phase 2: Phase 2 represents the time during which Mr R began to notice subtle changes in his wife's behaviour, finally culminating in a diagnosis of DAT. The graph (Figure 1) indicates a visible decline in the narrative between Phases 1 and 2. This decline represents the difficult time during which Mrs R began to display symptoms of DAT and Mr R noticed certain changes in her behaviour and communication interaction. One of the first changes in behaviour was paranoia about certain aspects in her daily life. She locked cupboards and hid the keys away. Soon after first noticing these subtle changes in his wife's behaviour, Mr R was offered another job and they moved to a different city. The diagnosis of DAT was made after 46 years of marriage, in approximately 1999.

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Phase 3: During this phase there is, once again, visible regression in the narrative. Phase 3 begins with the diagnosis and ends just before the interviews for this study took place. After the diagnosis, Mr R attempted to take care of his wife on his own but as time passed, this became increasingly difficult. He eventually realized that he had to make a decision about their future and, in consultation with his children, decided to move to a residential home. Mr R's children felt that he needed help in caring for Mrs R and that a residential home was ideal since she would not be able to wander too far away, or hurt herself.

Initially Mr R, his children and family members found it difficult to accept Mrs R's illness. During this phase, it was explained to them that DAT is a progressive disease and that there is no cure. Mr R tells how their children, at times, feel that their mother should have been spared this suffering. Mr R has since come to terms with the fact that his wife is unable to do all the things that she used to do and that her condition will gradually deteriorate. Mr R also mentions that their marriage is no longer what it was. Communication, and therefore companionship, has gradually become increasingly limited. Mrs R has limited moments of clarity where she recognizes Mr R, their children and her surroundings. Mr R has experienced this phase as difficult and negative, hence the decline in the narrative.

Phase 4: In the fourth phase, the narrative continues to decline but gradually stabilizes, despite the negative information and connotations contained in Mr R's descriptions. Mr R reports that there are only a few days on which Mrs R attempts to communicate in any manner but he explains that he has come to terms with the diagnosis and must now consider the future. He therefore copes with one day at a time and tries not to brood about what the future holds since it could take a long time for the disease to run its course. This acceptance of the situation has allowed him to not only help his wife, but also to lead a life of his own. When they first moved to the retirement home, Mr R coped by participating as much as he could in his wife's treatment and everyday living. Lately, however, he has allowed the nurses to take over more and is keeping himself busy. This has helped him to cope with the changes in his wife. However, he says that he will never leave her. He wants to remain a part of her life and wants to know what happens to her every day.

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The four phases that were represented in the graph will now be described in more detail, by discussing the sub-narratives.

4.1.2 <u>Discussion of sub-narratives</u>

The use of the prefix "sub" indicates that the researcher distinguishes between the different phases and "stories" *within a narrative*. In this study the term *sub-narrative* is used, as the sub-narratives are secondary to the main narrative.

4.1.2.1 <u>Sub-Narrative 1:</u> Love and Marriage

Narratives typically begin with themes common to most people, such as love and success (Kotzé & Kotzé, 2001). The story of Mr and Mrs R begins in 1951 when they met. Mr R does not provide details about his earlier life, nor about Mrs R's, but briefly describes their courtship. There appears to have been a mutual attraction between them as Mrs R resigned from a job to follow Mr R to a new job and did so on two separate occasions. They met in S (an independent country within South Africa), where both were working, albeit for different companies. Soon after this, Mr R was transferred to P (a capital city in South Africa) and although they were not yet married, Mrs R resigned from her work to follow him. Mr and Mrs R were again employed at different companies in P. Mr R was then transferred to B (small town in Mpumalanga). Mrs R once again followed him and in 1953 they were married. Mr R appears to have had much respect for his wife and the work that she did, for he spoke highly of her and her various occupations on several occasions during the interviews. Mrs R was trained as a nurse and she worked as a librarian. According to Mr R, she loved to read and enjoyed writing as well. Mr R describes his wife as a perfectionist, someone who was always precise and punctual.

In addition to meeting, getting married and moving home on numerous occasions, the first phase includes the time during which Mr and Mrs R's children were born. The birth of their eldest children, twins, is described as "eventful" due to the fact that they were born two months prematurely in a town without a hospital, after Mrs R had been in labour for approximately two days. A doctor had to be called from E (town in Mpumalanga). Their third child followed. Mr R transferred again, this time to V (town in the Free State). The family lived in V for five years after which Mr R resigned from his work and they moved to E (town in Mpumalanga). Once they had settled in E, their

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youngest child was born, rather late in their marriage. At this stage Mrs R no longer worked and Mr R depicts her as a home creator ("huisvrou"). It was at this point that Mr R began to notice certain changes in his wife.

Extracts from the transcription are provided to support the researcher's interpretations. Please note that certain extracts may appear incomplete and grammatically incorrect. However, these extracts are accurate and reflect the speaker's style and exact utterances.

Participant's utterances are numbered in bold while the researcher's utterances are marked as ***R.*** The translations are included in italics under each utterance.

R: As ons kan begin, as Oom net vir my kan vertel van u vrou, hoe u ontmoet het en hoe lank Oom-hulle al saam is?
If we could start, if you could tell me about your wife, how you met and how long you have been together?

1. Ja, ek het haar in S ontmoet in 1951.
Yes, I met her in S in 1951.

R: O.K.
Okay.

3. Ons het mekaar daar ontmoet en toe is ek verplaas na P toe en toe het sy haar werk ook daar bedank en toe het sy ook in P by 'n biblioteek gewerk en sy was verpleegster, sy was 'n gekwalifiseerde verpleegster.
We met each other there and I was then transferred to P and she resigned her work there and she then worked in a library in P and she was a nurse, she was a qualified nurse.

5. En toe's ek weer terug verplaas B toe, daar naby E, en toe het sy daar by E gewerk en ons is daar getroud in 1953, is ons daar getroud.
I was then transferred again to B, close to E and she worked there in E and we were married in 1952, there we were married.

8. En ons het 'n tweeling, 'n seun en 'n dogter, wat op sewe maande gebore is
We then had twins, a boy and a girl, who were born at 7 months

9. En sy was van die Vrydag tot die Saterdagaand in kraam.
She was in labour from the Friday until the Saturday evening.

R: Dis nogal lank
That's quite long

11. Ja nee, dit is lank. En toe het ons, daar was nie daai tyd 'n hospitaal op B nie
Yes, it is long. We then, at that time there was no hospital in B

13. Toe het ons 'n spesialis van E af gekry, die het gou die kinders…
We then had to get a specialist from E, he delivered the children quickly

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14. Hulle was brugbabas, toe is hulle gebore.
They were breech babies, then they were born.

15. Hulle het altwee saam ses pond daai tyd geweeg.
At that time the two of them weighed 6 pounds together

R: Sjoe, dis klein.
That's small.

16. Ja, baie klein gewees omdat hulle op sewe maande gebore is.
Yes, very small because they were born at 7months.

18. Twee jaar daarna het ons weer 'n dogter ryker geword en toe is ons V toe.
Two years later we had another daughter and then we went to V.

20. Ek het die bank bedank en toe na die goud myne op V
I resigned at the bank and then went to the gold mines in V.

21. En daar het ek so vyf jaar gewerk
I worked there for approximately 5years.

22. En toe is ons weer terug E toe, na die Paaie Departement
Then we went back to E, to the Roads Department.

23. En toe is ons laatlammetjie gebore, 'n seuntjie, Chris.
And then our youngest son was then born, a boy, Chris.

24. Sy't toe nie weer gewerk, sy't as huisvrou al die jare gewees en so.
After that she didn't work anymore, she was a housewife all those years.

25. En ons is nou gewees, 52 jaar getroud.
We have been married for 52 years

68. Ons het 'n lang pad saam gekom
We have come a long way together

69. 'n Verlede van 55 jaar.
A past of 55 years

70. Dis nie maklik nie.
It's not easy.

The first sub-narrative provides useful background information about Mr R's wife.

It is important for professionals to obtain background information when managing individuals with DAT. For this reason, a spouse or close family member should be included in an interview (Borkan, Reis & Medalie, 2001). Unfortunately, professionals often prefer to use questionnaires to obtain history, but these are limited by nature while interviews can elicit a broader scope of details. A spouse or close family member can provide background information that can be extremely helpful in the diagnosis and treatment of an individual with DAT. A caregiver who is not familiar with the history of the person is less likely to provide accurate information (Burns, Nichols, Graney,

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Martindale-Adams & Lummus, 2006). Therefore, professionals should ask a spouse, or willing family member, to provide relevant background information so that decisions regarding treatment and provision of services can be made in an informed manner. For example, if the individual with DAT had not been an aggressive person before the onset of DAT, then the professional would be able to provide the spouse with advice on how to handle the onset of aggression, or perhaps prescribe medication. Professionals can also make use of Reminiscence Therapy (Kitwood, 1997) whereby they make use of past memories during treatment. However, as individuals in the advanced stages of DAT may be unable to provide this background information themselves, a spouse or family member would be helpful. In Mrs R's case, a professional may not have understood to whom Mrs R was referring when she spoke of "Chris", had the information gathered from Mr R not provided the context. (**174.** En dan's ek weer haar jongste seun, Chris. *And then I'm her youngest son, Chris*). Understanding the context enables a professional to create opportunities for conversation (communication) with the person who has DAT.

4.1.2.2 <u>Sub-Narrative 2:</u> Changed Behaviour

In most cases DAT manifests in subtle changes in an individual's behaviour and personality (Bayles & Kaszniak, 1987). This was the case with Mrs R. Mr R began to notice certain changes in his wife after their second move to E, which was in approximately 1995. He noted that she was beginning to forget things. Not only was she absentminded, but also inclined to lock keys away, convinced that other people were trying to steal her things. At this point in time, Mr R realised that Mrs R had become mistrustful of others.

Many individuals with DAT exhibit paranoia and impaired judgement (Lubinski, 1995). The spouse of an individual with DAT is likely to be the first person to notice this increasing inability to accurately judge situations or individuals. Those who do not know the individual well may not recognize these initial symptoms of DAT. The early identification of DAT thus rests with the family of the affected individual. By raising public awareness of initial symptoms, it is hoped that professional assistance will be sought sooner rather than later, thereby facilitating early diagnosis and commencement of treatment.

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At this stage Mr and Mrs R and their family moved to D (another town in Mpumalanga). It is possible that this move (which took place when Mrs R was already becoming forgetful and no longer trusted people) may have caused her some trauma and exacerbated her symptoms (Rau, 1993). Mrs R now frequently requested to "go home", even though she *was* at home with Mr R.

The tendency for individuals with DAT to want to "go home" is thought to occur due to a desire to go back to the time in their lives when they were happiest (Chapman & Marshall, 1993 & Lubinski, 1995). As Mrs R relied on her past for a frame of reference, her requests to "go home" were bound up with the positive associations she had with a previous home. This could also explain why she was "looking" for her parents, hoping to find a sense of familiarity and security. Often an individual with DAT may recognize a smell, sight or familiar face and then associate it with their "home". However, this "home" may be a home from their past since they tend to forget that they are now living elsewhere (Lubinski, 1995).

In order to deal with the many changes in his wife's behaviour, Mr R developed coping strategies. For example, he would drive down the road with her, turn around, and drive back to their home. Once at home, he would tell her that she was now at home. Due to the fact that Mrs R sometimes wandered off by herself, Mr R would lock her in the house if he had to go to town, so that she couldn't get lost or injured.

It has been found that a spouse of an individual with DAT increasingly experiences stress when it comes to Activities of Daily Living (ADLs). The spouse has to assume a double role – his/her own, as well as that of the partner (Perry, 2005). The increasing burden experienced by Mr R is reflected in his description of how he had to keep a watchful eye on Mrs R at all times. He also had to take over all the household tasks, such as cooking and cleaning, since Mrs R could either no longer remember how to complete these tasks, or would injure herself while doing them.

It was eventually decided, in consultation with the children, that Mr R should no longer take care of his wife on his own, even though he would have preferred to do so. Although he had looked after her for a long time, the children felt that it would be safer if there were others to help. Mr R spoke about the fact that, at that stage, he did not

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want to accept that his wife needed professional assistance. However, in the end, they moved back to P (capital city in South Africa) to a retirement home. Once they had moved to P, the diagnosis of DAT was formally made.

Extracts from the transcription to support the reseacher's interpretation:

R: Wanneer het Oom agtergekom?
When did you first realize?

26. Ek het agtergekom dat sy besig is om dinge te vergeet, agterdogtig te raak
I realized that she was forgetting things, forgetful.

27. Dit is 18 jaar terug.
That was 18years ago.

28. Hier by 1995 rond.
In about 1995.

29. En sy het sleutels toegesluit
And she locked keys away

30. Sy was bang hulle steel haar goed
She was scared they would steal her things.

31. En sedertdien het sy sleutels begin wegsteek.
And since then she began hiding keys away.

32. As gevolg moes ek baie kaste oopbreek
As a result I had to break open many cupboards.

33. En naderhand duplikaat sleutels vir al die kaste gemaak sodat as sy die kaste toesluit, die sleutel weggooi, dan weet ek om dit weg te bêre, dan hoef ek nie te soek nie.
And after a while I made copies of the keys for all the cupboards, so that, if she locked the cupboards and threw the key away, then I knew to put the keys away and then I didn't have to look for them

34. Dan sluit ek dit maar oop.
Then I opened them again.

35. En dit het so agteruitgegaan
And it deteriorated in this manner.

36. En sy het begin om ook niemand eintlik vertrou of so nie
And she began to lose her trust in others.

37. Wantrouig geword
Became distrustful

39. En toe het ons natuurlik verhuis na D toe.
And then of course we moved to D.

40. En dis waar ek agtergekom het.
And that's when I realized.

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41. En sy wil huis toe gaan

And she wanted to go home

42. En sy soek haar pa en ma.

And she wanted her dad and mom.

43. Sy wil net huis toe gaan

She just wanted to go home

44. En al die tyd is sy in haar huis.

And all the time she was at home.

45. Dan het ek haar maar gevat en ry ek 'n draai met haar in die kar en dan kom ek terug en sê ek "jy's weer by die huis."

I would then take her and drive around with her and then we'd go home and I would say "you're at home again."

48. Loop en loop

Walk and walk

49. En toe besluit ek, nee ons kom maar hierna.

That's when I decided we are coming here.

R. Wanneer het Oom-hulle hiernatoe gekom?

When did you come here?

50. Dis drie jaar terug, 2001.

It was 3years ago, 2001.

R. En u kinders, was hulle nog in die huis?

And your children, were they still at home?

51. Nee, hulle was almal uit die huis uit gewees.

No they were all out of the house.

R. Het Oom heeltyd alleen na haar gekyk.

Had you always taken care of her on your own?

54. Hulle het saam, hulle het eintlik besluit ek kan nie meer na haar kyk nie

They also did, they had actually decided that I couldn't care for her anymore.

55. Want ek wou dit nie glo nie.

Because I wouldn't believe it.

57. Ek het heeltyd alleen na haar gekyk.

I had always taken care of her on my own

58. Toe het ons hiernatoe gekom

Then we came here.

59. Nadat sy eendag die pad gevat en sy het geloop en ek het haar gelos en met die kar agter haar aan.

One day, after she had taken to the road, I left her to do so and followed her in the car

60. Besig om te kyk waar is haar nuwe huis.

I wanted to see where her new home was.

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61. Sy't geloop en toe het ek haar opgelaai, teruggebring.

She walked and I then picked her up and brought her back.

62. Daarna altyd as ek moes dorp toe gaan, ek het haar in die huis gesluit, dat sy maar daar binne bly.

After that, whenever I had to go to town, I would lock her in the house so that she could stay in there.

63. Op daai stadium het ek haar heeltemal uit die kombuis uit weggevat, want ek was bang sy brand.

At that stage I took her out of the kitchen, as I was scared she would burn herself.

610. Haar probleem is hier, begin '98, '94.

Her problem started in '98, '94.

The changes that occurred in Mrs R's behaviour, as described by Mr R, correlate with the symptoms associated with DAT as discussed in the literature (Heston & White, 1983). These behavioural changes at the onset of DAT are difficult to accept for any individual/spouse. Often individuals with DAT are not diagnosed until the disease has progressed to such an extent that they are a danger to themselves. By this time, their partners and family members are usually unable to cope any longer.

It is important for the public to become aware of the early symptoms of DAT, so that individuals can seek professional help more quickly. Professionals also need to have a raised awareness of the early symptoms so that they can facilitate appropriate management as soon as possible, and include the caregiver in the management of the symptoms. Knowledge of the individual's background, as well as information about changes in that person's personality and communication-interaction, can aid the professional in the treatment and decision making process (Hinton & Levkoff, 1999). This information could speed up the process of deciding, together with the spouse or family members, on treatment that would best suit the individual. For example, if the individual with DAT was interested in photography, the photos could facilitate communication or provide a context to facilitate communication. Along with the support from professionals, it would also be helpful if spouses and family members living with DAT received support in the form of workshops or training by professionals, regarding what to expect and how to cope with these changes. In Mr R's case, he received little support from professionals in the initial stages of dealing with DAT, due to the fact that he had no knowledge of the early symptoms prior to the formal diagnosis. As a result he had to develop his own coping strategies. Had he been

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aware of the initial symptoms, he could have sought professional assistance sooner and treatment could have begun earlier (De Waal, 2003). Training the spouse and family members would not only equip them to cope more easily with the symptoms, but would also enhance their understanding of the disease, enable them to explain it coherently, and empower them to provide support to others in the same situation.

4.1.2.3 Sub-Narrative 3: Diagnosis of DAT

Mrs R was diagnosed with DAT, at the age of 63, at a private hospital in P. Dr G, a psychiatrist, made the diagnosis. Thereafter, Mr R took his wife to a neurologist for a second opinion. The neurologist confirmed the diagnosis. Initially, Mr R had difficulty accepting the diagnosis but gradually came to terms with it, realizing that his wife needed his help. DAT was explained to Mr R as a disease that is irreversible. In order to educate himself about the disease, Mr R read any information that he could find on DAT and spoke to professionals about the disease. His children also supported him. It was difficult for them to accept that their mother would never again be the same. They were also concerned about the potentially hereditary nature of DAT.

The specialists described DAT as a disease for which there is no cure and indicated that Mrs R would need medication for the rest of her life. Mr R stated in the interview that the specialists had pinpointed the "kleinbrein" (cerebellum) as the area of the brain that was deteriorating. It can be assumed that the area the specialists were referring to was actually the cerebral cortex, in particular the hippocampus, as this is the area that is affected in DAT (not the cerebellum) (Sherwood, 2001). The belief that the cerebral cortex is the affected area is based on the fact that the symptoms are characteristic of a loss of function in this part of the brain. For example, the hippocampus plays an important role in memory (Sherwood, 2001). If, however, Mr R misinterpreted the information provided by the specialists, this could indicate that the manner in which the information was conveyed, and the terminology that was used, did not facilitate his understanding of the illness. Specialists need to be aware of this so that they can convey information in a manner that is understandable to the lay person.

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It was explained to Mr R that due to the deterioration of the brain function, a close eye would need to be kept on Mrs R's medication (*Aricept*). If the dosage was too high it could make her excessively passive (hypo-alert and "zombie"-like.) However, when they moved to the retirement village, the specialist decided to discontinue the use of *Aricept.* He felt that it only retarded the process of DAT and since they were now in a retirement village, there were professionals who could monitor Mrs R. Mrs R was also prescribed *Risperdal* and vitamins to increase her appetite. Mr R was concerned about Mrs R at this stage as she often shivered. However, the shivering was a negative side-effect of *Risperdal*.

This uncertainty must have caused Mr R concern, and serves as an indication that professionals should remember to inform patients and their caregivers of any possible side-effects of medication. Mr R reported during the interview that he has decided to keep Mrs R on medication that would be beneficial to her in terms of QOL, for example, vitamins to increase her appetite. However, he has decided against the use of medication to delay the progression of the disease, as he does not wish to prolong her suffering. Thus, with regard to Mrs R's medication, Mr R has been involved in the decision-making process (**494.** So ek het 'n deel daar gehad. *So I played a role there*). This has been a helpful approach to both Mr and Mrs R, since Mr R knows that this is what his wife would prefer.

Much of Mr R's knowledge about DAT comes from what he has read and researched himself, as well as from his own experience with Mrs R over the years. Another great resource for Mr R has been the home at which they reside, since it caters for individuals with DAT. This has provided Mr R with the opportunity to prepare for what the future holds, as he is able to see how other patients with DAT deteriorate as the disease progresses. Furthermore, the retirement village also provides training to nurses on how to manage individuals with DAT. Thus, the professionals at the residential home have helped Mr R a great deal by giving him access to information, such as videos, on DAT. This information has helped Mr R to understand many aspects of the disease. Despite this, however, during the interviews he expressed the need for additional information to further prepare for what is still to come.

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Extracts from the transcription to support the researcher's interpretations:

***R*:** Het iemand al ooit die tannie gediagnoseer met Alzheimer's?

Did anyone ever diagnose your wife with Alzheimer's?

86. Ja, al twee keer.

Yes, twice before.

R: Wanneer was dit?

When was this?

87. Die eerste maal was dit hier in die W Hospitaal

The first time was here at the W Hospital

88. Toe ons nog op D was

When we were still living in D

89. Dit was ongeveer hier in 1998, 1999.

It was approximately in 1998, 1999.

90. Toe het ek haar na 'n ander dokter, ek kan nie sy naam onthou nie, ook 'n neuroloog, hier by EM.

I then took her to another doctor; I can't remember his name, a neurologist at EM.

91. En hy het haar ook gediagnoseer.

He also diagnosed her.

96. Toe was sy op Aricept

She was then on Aricept

97. En toe ons hiernatoe gekom het, het hy die Aricept weggevat

When we came here, he took the Aricept away

98. Hulle sê dit vertraag dit net.

They say that it only retards it.

99. Aricept kan jou nie genees nie.

Aricept can't cure you.

R: Wat was Oom se reaksie toe hulle vir haar, die tannie, gediagnoseer het met Alzheimer's?

What was your reaction when they diagnosed your wife with Alzheimer's?

118. Ek het dit nie eers geglo nie.

At first I didn't belive it.

R: En het Oom enige vrae gehad oor of, ek bedoel natuurlik wil jy weet wat gaan gebeur.

And did you have any questions about?, of course one wants to know what is going to happen.

119. Ja, ja ek het gevra wat gebeur of daar nie 'n genesing is nie of so.

Yes, yes I asked what is going to happen and if there isn't a cure.

R: Hoe het die neuroloog vir Oom Alzheimer's gedefinieer? Wat het hy gesê is Alzheimer's? Kan Oom onthou?

How did the neurologist define Alzheimer's. What did he say about Alzheimer's? Can you remember?

135. Hy't maar gesê die kleinbrein

He said the small brain

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136. Die geheue-brein

The memory brain

137. Is besig om te krimp.

Is busy shrinking.

140. En dat daar geen medikasie is wat haar kan help nie.

And that there is no medication that can help her.

141. Die kinders wou dit nie eers aanvaar nie,

At first the children didn't want to accept it,

142. Maar hulle het dit gouer aanvaar as wat ek dit aanvaar het.

But they accepted it sooner than I did.

143. Tot 'n sekere mate glo ek dit is oorerflik.

To a certain extent I do believe that it is hereditary.

144. Nou die dag met die psigiater, uh, Dr. G gepraat

The other day I spoke to the psychiatrist, uh, Dr G

145. Hy't gesê dit is geglo dat dit oorerflik is.

He said that it's believed to be hereditary.

R: Ek wil graag weet hoe oud was Oom se vrou toe sy gediagnoseer is met Alzheimer's.

I would like to know how old your wife was when she was diagnosed with Alzheimer's

249. Dink 63, toe sy gediagnoseer is.

I think 63, when she was diagnosed.

250. Ja, ongeveer 63. Dis nou 10 jaar wat sy so is en….

Yes, I think approximately 63. It's been 10 years that she's been like this and…

366. So, uh, die meeste wat ek weet van Alzheimer's is maar deur ondervinding.

So the most that I know about Alzheimer's is through experience

R: Voel Oom dat die dokters genoeg inligting vir Oom gegee het?

Do you feel that the doctors gave you enough information?

366. Nie eintlik nie.

Not really.

R: En die neuroloog?

And the neurologist?

367. Nee ook nie.

No also not.

R: En die psigiater?

And the psychiatrist?

368. Die psigiater het maar gevra hoe, soos jy nou maar vra en so.

The psychiatrist asked how, like you are asking questions now.

370. Eintlik wou hy net gesê het dat, uh, die bewerigheid

Actually he had just wanted to say that, uh, the shivering

371. As sy begin bewe dan dink ek sy kry koud

If she begins to shiver then I think that she's cold

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372. Sê hy dis nie dat sy koudkry nie, dis 'n newe-effek van die Risperdal.

He said that it's not that she's cold, but it's a negative side effect of the Risperdal.

374. Toe het hy gesê hy wil nie vir haar 'n sterker pil gee nie

He then said that he doesn't want to give her a stronger pill

375. Want hy wil nie van haar 'n zombie maak nie.

Because he doesn't want to make her a zombie.

376. Ek stem heeltemal saam.

I agree completely.

377. Dis maar al wat hy gesê het.

That's all he said.

R: Sou oom dit graag wou gehad het?

Would you have liked to have it? (***"it"*** *refers to* ***more information***).

383. Ag, ja, tot 'n sekere mate dat ek gereed was.

Yes, that I would be prepared to a certain extent.

R: Dink Oom dat daar spesifieke inligting is wat dokters of neuroloë vir 'n persoon moet gee wie se gesinslid Alzheimer's het?

Do you think that a doctor or neurologist should give a person whose family member has Alzheimer's, specific information?

482. Maar hulle het nie eintlik baie vir my gesê oor Alzheimer's nie

But they didn't actually tell me a lot about Alzheimer's

R: Sou Oom sê dat in die vervolg moet dokters stukke inligting vir die familie verskaf?

Would you say that doctors should provide information pamphlets to family members in the future?

486. Ja-nee, ek sou dit regtig as 'n

Yes, I would really

487. As dit 'n ordentlike dokter is sal hy dit doen

If it is a decent doctor then he will do it

488. Sal hy vir jou sê wat om te verwag en al daai dinge.

He will tell you what to expect and all those things.

R: Voel Oom, Oom deel is van daai besluit neming?

Do you feel that you are part of the decision making process?

489. Ja-nee, kyk, dit is soos ek gesê het, ek was by Dr. G. Hy's 'n psigiater.

Yes. Look, it's like I said, I was at the psychiatrist, Dr. G

490. Hy't gevra watse medikasie

He asked about the medication

491. Hoe werk die medikasie en

How it works and

492. Ek moes hom toe maar gesê en goed.

I then had to tell him and so on.

493. En daarby het ons toe die medikasie aangepas.

And in that manner we adapted the medication.

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494. So ek het 'n deel daar gehad.
So I played a role there.

R: So hy het vir oom vrae gevra oor die tannie?
So he asked you questions about your wife?

495. Ja, Dr. G het, maar nie die neuroloog nie.
Yes, Dr. G did, but not the neurologist.

500. Kyk hulle evalueer die geskiedenis.
They evaluate the history.

693. Hy't my niks gesê van wat ek moet verwag of wat of wat.
He didn't tell me anything about what to expect or any of that.

694. Hy moes sê wat hulle moet verwag.
He should have said what to expect.

695. Ek het maar gelees en als.
I had to read myself.

Mr R stated that he is grateful for the opportunity to have witnessed the progression of DAT in other patients at the residential home as this prepared him for what to expect. However, he still feels that the professionals who diagnose DAT should explain the disease in more detail, specifically in terms of what family members can expect and how to handle the changes. If these professionals are unable to provide patients and their families with information, they should refer them to other professionals who can.

From this sub-narrative it is apparent that professionals should attempt to convey the diagnosis of DAT in a "user-friendly" manner and also, by providing information, empower family members to become effective partners in the decision-making process. Time frames should be identified for follow-up visits so that updated information can be imparted. Properly structured follow-up visits will also allow the professional to establish the progression of the disease and the stage it has reached at that point. As DAT is a progressive disease, the individual with DAT is continually changing, with concomitant implications for the spouse. The spouse requires information that will enable him/her to develop coping strategies for the constant changes that the individual with DAT will experience, including changes in communication interaction. It would be advisable for the spouse to receive information on how to cope with the changing communication needs and demands brought about by the disease. For example, professionals can inform the spouse or family members about Reminiscence Therapy, where the spouse uses photographs to discuss family and memories from the

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individual's past (Kitwood, 1997). This is useful as it relies on long term memory that is firmly established. Professionals need to inform the spouse of all possibilities.

4.1.2.4 Sub-Narrative 4: Progression of DAT

DAT is an irreversible, progressive neurological disease, in which there is cortical atrophy and enlargement of the brain ventricles (Hart & Semple, 1990). An individual with DAT initially displays symptoms of memory disturbance of recent events. However, as the disease progresses, the individual's memory of past events also becomes muddled (Hart & Semple, 1990). In addition to this, the individual with DAT displays impaired orientation, judgement, reasoning and abstract thinking together with communication difficulties such as apraxia, aphasia and agnosia (Hart & Semple, 1990).

However, knowing this does not make it any easier for the individual living with the disease, or for the individual's spouse who has to watch his/her partner decline and suffer. Although Mr R has read up about the disease and the progressive course it takes, he still finds it difficult to see his wife suffer. He and his wife had been married for 53 years at the time of the interview. Even though Mrs R is going through this life changing disease, Mr R is supporting his wife. Mr R has seen how other spouses have brought their partners with DAT to the residential home and then left, never to return. He realizes that he could never do this to his wife.

Living with his wife during the advanced stages of DAT has not been easy for Mr R. He has had to stand by and watch how the neat, precise and educated woman he met and married has changed in many ways. He commented during the interviews that he now has to think for two people, which is not easy. Mr R portrayed her as a person who was once active, enjoying life and everything around her. She is now no longer able to participate in any of the activities that she used to enjoy. He stated during the interviews that she no longer shows an interest in any event or activity around her. He described how she now not only forgets recent events, but also fails to recognize people, including him and their children. She mistakes Mr R either for her father or their youngest son. He reports that she forgets basic necessities, such as going to the toilet or eating. Mr R feels that her QOL has deteriorated but acknowledges that she has

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become calmer. This calmness can be ascribed to her lack of interest in the acitivities around her, thus there is nothing that upsets her.

Mr R has noted that not only has Mrs R's QOL deteriorated over the years, but also her ability to communicate. At times she may communicate with Mr R, but these interactions are unclear and incoherent. Mr R is therefore unable to understand what she wants or needs and relies on instinct to try to please her. He also relies on her facial expressions and body language to aid him in identifying how she feels or is reacting towards a specific activity. For example, he has learnt to take her to the toilet when she becomes restless. As they have a long history and he knows her well, he is able to understand her better than others do. Mr R stated that Mrs R's ability to communicate has deteriorated to such an extent that she does not speak and has almost become mute. However, she does communicate non-verbally. This non-verbal communication does not appear to be intentional, though, as she will grimace if she is in pain or smile when she hears music that she enjoys. She will also try to write, but the end product is a few scribbled lines. This makes it difficult for someone who does not know her, to help her. With all this said, it can be seen how important it is to include the spouse and family in the management of an individual with DAT. The spouse and family know the person best and are more likely to "read" and interpret the non-verbal behaviour correctly. This underscores the necessity for including the spouse, as well as other family members, in the decision-making process (Burns et al., 2006).

Extracts from the transcription to support the researcher's interpretations:

72. Maar ons kommunikeer glad nie meer nie.
But we don't communicate at all anymore.

R: Glad nie? Sy praat nie meer nie? En as sy praat, hoe is haar spraak?
Not at all? She doesn't speak anymore? And if she does speak, how is her speech?

73. Ja, haar spraak was alright. Toe sy nog
Yes, her speech was alright. When she still

R: En hoe hanteer Oom dit dan?
And how do you handle it then?

107. Wel, dis moelik.
Well, it's difficult.

108. Ek hanteer dit maar
I handle it

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109. En partymaal raas ek maar 'n bietjie

And at times I might scold her a little

110. Maar dit help niks nie.

But it doesn't help.

125. Maar deur die genade van die Here moes ek dit maar aanvaar.

Through the grace of the Lord I accepted it

127. Ek versorg haar en dat sy versorg is.

I care for her and make sure that she is cared for.

173. Sy't my haar pa genoem

She called me her father

174. En dan's ek weer haar jongste seun, Chris.

And then I'm her youngest son, Chris.

175. Maar partydae herken sy dit nie.

But other days she doesn't recognize it.

191. Sy's geneig ook om te vergeet dat sy moet eet

She tends to forget to eat

192. Sy vergeet ook om toilet toe te gaan.

She also forgets to go to the toilet.

193. Hel, jy moet vir twee mense dink.

Hell, you have to think for two people.

194. Jy leer haar naderhand so ken

After a while you get to know her like that

195. En as sy rusteloos raak dan weet jy daar's iets wat hinder

If she is restless then you know that there is something bothering her

196. Vat jy haar toilet toe

Then you take her to the toilet

197. Of vra vir haar of daar pyn is of so.

Or ask her if there is pain.

198. Sy voel nog pyn, hoor.

Listen, she still feels pain.

199. As jy haar hare kam en jy trek die hare, dan sal sy vir jou sê "Eina!"

If you brush her hair and you pull it, then she'll say "Ouch!"

R: En die res van die mense in Oom hulle se gang, het hulle ook mense wat saam met hulle bly of is baie van hulle alleen?

And the rest of the people in your passage, do they also have people living with them or are a lot of them alone?

212. Nee, hulle is meeste. Ek is enigste een.

No most of them are. I'm the only one.

213. Ek is die enigste een wat saam bly.

I'm the only one that lives with someone.

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214. Daar is van hulle wie se kinders nie eers meer kom of iets nie.

There are those whose children don't even come to visit anymore.

R: Hoe is dit nou, deesdae, hoe is dit nadat sy gediagnoseer is?

How is it nowadays, now that she has been diagnosed?

254. Kyk, dit het met tye verswak, so ek al gesê het….

At times it has worsened, as I've said…

255. Want, uh, ek kyk maar na haar omdat ek, weet, uh ek voel, uh, nie dat ek verplig is nie, maar omdat ek darem 'n hele pad saam haar kom.

I take care of her, uh, not because I feel obliged to, but I have come a long way with her.

256. En sy's die moeder van my kinders en ja.

And she is the mother of my children.

304. Sy stel glad nie belang in enigiets nie.

She's not interested in anything.

305. Sy was 'n baie presiese 'n vrou

She was a very precise woman

306. Netjiese vrou

Neat woman

307. En sy was baie lief vir lees.

And she loved to read.

310. Sy het nou die dag probeer skryf

The other day she tried to write

311. Sy't die pen so gevat en 'n paar lyntjies getrek.

She took the pen and drew a few lines.

389. Sy antwoord my nie eers meer nie.

She doesn't answer me anymore.

R: Het sy enige gesiguitdrukkings nog of…

Does she still have any facial expressions or…

390. Ja, sodra daar meer as twee by haar kom, die verpleegsters, dan kan jy sien sy…

Yes, as soon as there are more than two people, the nurses, then you can see…

391. Angs.

Anxiety.

392. Partymaal lag sy nog.

At times she still laughs.

413. Byvoorbeeld, sy sal 'n toilet herken en dan sê ek partymaal vir haar "gaan pie-pie nou"

For example, she'll recognize a toilet and then I say "go pee-pee now"

414. En dan sal sy haar broekie aftrek

Then she'll pull down her pants

415. En dan vergeet sy om die pantie af te trek.

But she'll forget to pull down her panties.

416. Dan wil ek net die pantie aftrek.

Then I just want to pull down her panties.

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417. Kyk, ek het dit hier ondervind.
Look, I've experienced it here.

R: Wat sou Oom sê , is die grootste probleem met die tannie? Wat Oom ervaar?
What would you say is the biggest problem with your wife? What do you experience?

453. Ag, ek glo nie sy ervaar enigiets nie, hoor.
I don't believe she experiences anything.

454. Maar wat ek ervaar is dat 'n mens vir twee mense moet dink.
But what I experience is that you have to think for two people.

455. Weet ek moet vir myself en vir haar ook dink.
You know I have to think for myself and for her.

457. Maar mens leer dit naderhand so aan
But after a while you learn to

R: Hoe sou Oom sê, vandat ek en Oom begin praat het, hoe het die tannie se, bly sy dieselfde of het sy al afgeneem in hierdie afgelope drie maande? Het sy baie agteruit gegaan?
How would you say your wife has, since we began talking, has your wife remained the same? Has she deteriorated these past three months?

536. Nee, sy het eintlik agteruit gegaan. Sy's meer rustig.
No, she has actually deteriorated. She's more calm.

R: Rustiger?
Calmer ?

551. Ja, maar sy praat nie meer nie.
Yes, but she doesn't talk anymore.

552. Vir my is sy so te sê dood.
To me she is dead, so to speak.

R: Maar daar is tog tye wat sy dalk 'n "peak" het?
But there are times where she has a peak?

553. So nou en dan.
Now and then.

554. Dit gebeur maar selde deesdae.
It seldom happens nowadays.

558. Sy praat so deurmekaar
Her speech is very muddled.

559. Jy kan dit eintlik nie mooi verstaan wat sy sê nie.
You can't really understand what she is saying.

This sub-narrative summarises the difficulties and challenges that Mr R has experienced with regard to Mrs R's changing behaviour, brought about by the progression of the disease and concomitant deterioration. As described in literature, it is clear that the disease has not only had a negative impact on Mrs R's life, but also on the lives of her husband and children (Hunter, 1997 & Rau, 1993). The progression of DAT

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has led to Mrs R becoming dependent on Mr R and others for most of her ADLs. For example, she needs someone to remind her to eat and to go to the toilet. However, this is not easy as she no longer communicates verbally and is unable to tell someone when she is hungry, or that she would rather have something else to eat. The progression of DAT has transformed a neat, precise woman, who once enjoyed certain activities such as reading and writing, into someone who no longer has an interest in life. She now has nothing to communicate about to anyone. Her world has been narrowed down to the "here and now", which she no longer understands.

As a professional it is important to remember that individuals with DAT have not only lost the ability to function and communicate, but at times also lose their dignity. It is the responsibility of the professional to restore that dignity as far as possible (Lloyd, 2000). In order to restore dignity and a sense of identity to these individuals, professionals must ensure that they work closely with them as well as their loved ones. One way of doing this is by establishing a treatment plan that suits the needs of the entire family and addresses their difficulties, including communication difficulties (Moran, 2001).

4.1.3 Summary of Form Analysis

The Holistic Form Analysis clearly indicates the unfolding of Mr R's narrative, which is of a regressive nature. The regression in the narrative is concomitant with the degenerative nature of DAT and the associated deterioration that has occurred in Mrs R's behaviour and ability to communicate. Although Mr R has experienced the onset and progression of DAT as largely negative, he has taken positive action by becoming involved in her care. By doing this, he is ensuring that not only *her* QOL, but also *his*, does not deteriorate further than it should.

The most significant conclusion from this section relates to the depth of impact that DAT has on the lives of spouses and family members. This is evident from the form of the narrative. Professionals who are involved with people suffering from DAT need to reflect on their responsibilities in this regard. The various sub-narratives were discussed at length to demonstrate how important it is for professionals to become involved with the families of individuals with DAT. The help offered to family members should include support in the form of information about the disease and what to expect, the

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gathering of information about the person from family members and finally, well considered treatment options that include and involve the family at all levels.

4.2 Holistic Content Analysis

The holistic content analysis focused on the entire narrative produced by the participant and brought to light the major themes that run throughout the narrative. These themes emerged as especially significant by virtue of the fact that the participant devoted space and time to discussing them.

4.2.1 Themes of Narrative

It has been stated that a narrative can be seen as a life story, as the history of an individual's life (Kotzé & Kotzé, 2001). Therefore, the stories or themes in this narrative must be discussed in greater detail in order to obtain a clear picture of what the participant's experiences of DAT have been, and which experiences hold greater significance.

Extracting the main themes allows the researcher to focus on what was important to the participant. By examining the information that the participant portrays frequently, the researcher is able to extract the most important themes in the narrative. These themes are ones that run throughout the narrative and it is therefore possible that one theme may have different levels of significance in the various sub-narratives. In order to understand the relevance of the different themes, it is essential to discuss each one on its own. These themes appear at various intervals within each sub-narrative. In this narrative the following themes were identified:

1. Change
2. Verbal Communication
3. Paranoia
4. Love and Loyalty
5. Coping Strategies
6. Professional Support Provided

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4.2.2 Theme 1: Change

A theme that emerged strongly from the analysis of Mr R's narrative was that of change. Not only did his wife change as the disease ran its course, but he also had to make changes to his own life in order to adapt to living with someone with DAT. The changes that have occurred are discussed under the following headings: Changes experienced before the onset of DAT, Changes associated with DAT and Changes in Mr R's responsibilities, necessitated by the impact of DAT.

Changes experienced before the onset of DAT

The changes experienced before the onset of DAT pertain mainly to the number of times that Mr R changed jobs and moved house. Initially Mr and Mrs R moved twice before they were married in 1953. Mr R transferred due to job offers and Mrs R followed him to new locations. She resigned and pursued another career path in order to be with Mr R. After the initial move to an independent country, they then moved to different cities on four separate occasions. Mr R changed jobs on three separate occasions and Mrs R changed jobs on two separate occasions. Once they were married their lives began to change in terms of caring for one another and their children, who were born prior to the onset of DAT.

Sub-Narrative 1

26. Ek het agter gekom dat sy besig is om dinge te vergeet, agterdogtig te raak.
I noticed that she began to forget things, became forgetful.

Changes associated with DAT

Mr R began to notice subtle changes in his wife after 37years of marriage. He noticed that her personality was changing, that she was becoming paranoid and that she would lock cupboards and hide keys away so that people could not take her belongings. He also noted that although she was at home, she frequently requested that she wanted to "go home". She asked for her father and mother, even though they had been dead for several years. Mr R was aware that something was wrong with Mrs R and sought medical help.

Sub-Narrative 1

26. Ek het agter gekom dat sy besig is om dinge te vergeet, agterdogtig te raak.
I noticed that she was forgetting things, becoming suspicious.

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Sub-Narrative 2

29. En sy het sleutels toegesluit

And she locked keys away

30. Sy was bang hulle steel haar goed

She was scared that they would steal her things

37. Sy was nog nie daai tyd aggressief nie

She wasn't aggressive at that time

Sub-Narrative 3

227. Die een kleindogter het sy nou die dag het sy so geraas.

She shouted at the one granddaughter the other day.

228. Sê sy "maar Ouma, ek kan mos nou nie, Ouma." "Ja, maar my kind jy't dit en dit en dit gedoen." Sy't dit nie gesê nie, maar sy sê los my en daai dinge, weet.

She said "but Granny, I can't do it." "Yes, my child but you did this and this and this." She didn't say it, but she says leave me alone and all those sort of things.

232. Hulle het nie hulle ouma so geken nie.

They didn't know their granny like that.

Changes in Mr R's responsibilities, necessitated by the impact of DAT

After 37years of marriage to a neat, precise woman, Mr R found that he now had to take over household tasks. He also had to learn to cope with the changes that were taking place in his wife. Initially he took over the cleaning and cooking, in order to ensure that Mrs R did not harm herself. He left her at home when he went shopping as she would wander off. At this stage their children decided that their mother needed more intensive care and encouraged Mr R to move to a retirement village. Once Mr and Mrs R had moved to the retirement village, Mr R had to learn how to care for her. He had to make decisions that affected both their lives, on his own. He had to accept that they could no longer visit their children or go on holiday together, since she is a danger to herself and others, and that he would have to leave his wife in the care of the staff at the retirement village if he wanted to go somewhere. In order to cope with all these changes, Mr R has slowly begun to withdraw himself from Mrs R's care. He now tries to keep himself busy in order to cope better, thereby helping himself as well as his wife. (Lubinski, 1995).

Although Mr and Mrs R have experienced many life changing events, Mr R's experiences with her have made it possible for him to recognize and identify her wants and needs. The fact that Mr R was married to her and noticed the changes in her behaviour enabled Mr R to provide the professionals with important information that

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enabled them to design an appropriate approach to treatment. Without an accurate diagnosis and background information, it would have been difficult for a professional to develop a treatment plan that best suited Mrs R. The utterances that highlight this theme are most apparent in Sub-Narrative 2. However, they do come across in all four sub-narratives.

4.2.3 Theme 2: Verbal Communication

Communication is an integral part of all the themes that appear throughout this narrative, but because of its great significance, it has been lifted out as a separate theme. However, this theme should not be regarded as a separate issue. DAT is a neurological disease that affects the higher functioning of the brain, thus communication is often the area where the most changes occur and can be observed (Campbell-Taylor, 1995).

In the early stages of DAT an individual can display difficulties with spontaneous speech and language, which can be associated with anomia and semantically empty words (Kempler, 1995). In the moderate stage of DAT, the individual could have difficulties with production and comprehension of language as well as poor pragmatics, such as topic maintenance (Kempler, 1995). An individual who presents with DAT in the late stages often displays symptoms of aphasia, apraxia and/or agnosia (Molloy & Lubinski, 1995). This makes it difficult for the individual to communicate in a coherent manner or to make sense of what someone else is saying. The deterioration in language skills makes it difficult for the person to understand the complexity of language rules and the uses of language (MacDonald, Almor, Henderson, Kempler & Andersen, 2001). Many times an individual in the latter stages of DAT is no longer able to communicate. However, he/she will be able to recall hymns and say a prayer. This ability to recall familiar utterances is known as “automatisms” (Bayles, 1987).

Mrs R was an individual who loved to communicate, read and write. She had been employed in a library where she had the opportunity to broaden her knowledge. She had also worked as a nurse, which entailed being able to communicate with others. She had many hobbies where reading and writing were required. She belonged to many book clubs and until recently Mr R still received subscriptions for her from her favourite magazines. However, as the DAT progressed, Mrs R’s communication skills began to decline and gradually became less. When they first moved to the retirement

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village, Mr R would often find her in the chapel, singing to herself with lyrics that were understandable. She also recalled certain individuals' names, which may have been due to automatism (Bayles, 1987) as these were words that she had used many times with no language rules or complexities attached to them. However, this does not happen often anymore. She has had episodes of clearer communication, but people who do not know her, do not understand her.

The theme of communication will now be presented in the different sub-narratives that they appeared.

Sub-Narrative 1

4. Sy was 'n gekwalifiseerde verpleegster.
She was a qualified nurse.

565. Ek noem haar Gogga en sy het my Kaffir genoem.
I called her "Gogga" and she she called me "Kaffir".

566. Sy't nou die dag gesê "Hello Kaffir."
The other day she said "Hello Kaffir."

Sub-Narrative 2

68. Ja, haar spraak was 'all right'.
Yes, her speech was all right.

70. Maar dit het geleidelik heeltemal agteruitgegaan.
But gradually it deteriorated completely.

71. Sy was baie lief vir lees
She loved to read

72. En sy lees nou glad nie.
And now she doesn't read at all.

73. Sy was baie lief om te skryf
She loved to write

74. Sy skryf nou glad nie.
She doesn't write at all now.

85. En, uh, daar's nie meer kommunikasie.
And, um, there isn't any more communication.

93. Dan moet sy sê watter volgorde dit was. Of watter onderwerpe.
Then she has to say what order it was. Or which subjects.

94. Sy weet dit glad nie.
She doesn't know it.

183. Snaaks weet, sy was altyd 'n mens wat kerk toe gegaan het en alles. Sy sing hierdie Hallelujaliede wat ons hier sing
Strange you know, she was always a person who went to church and everything. She sings these Halleluja songs that we sing here

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184. Partymaal sing sy uit haar kop uit.

Sometimes she sings them off by heart.

185. Jy kan hoor wat sing sy.

You can hear what she is singing.

186. Dit onthou sy nogal baie goed.

That she remembers rather well.

389. Ja, in die beginstadium het ek baie met haar oor die ou dae gepraat en oor haar pa-hulle.

Yes, in the beginning I spoke to her a lot about the old days and about her parents.

396. Sy antwoord my nie eers meer nie.

She doesn't even answer me anymore.

399. Partymaal lag sy nog.

Sometimes she still laughs.

408. Nee, nie eers hello of niks nie.

No, not even hello or anything.

409. Sy sal miskien net so lag.

She may just laugh.

573. Vra ek haar "wat maak jy, maak jy skoon?"

I ask her "what are you doing, are you cleaning?"

574. Sal sy jou nie antwoord nie

She won't answer

Sub-Narrative 4

176. Maar daar is nie kommunikasie nie.

But there is no communication.

201. As jy haar hare kam en jy trek die hare, dan sal sy vir jou sê "Eina!"

If you brush her hair and you pull it, then she'll say "Ouch!"

308. Ek het al die tydskrifte vir haar gekry

I used to get all the magazines for her

309. Sy het aan 'n boekklub behoort.

She belonged to a book club.

310. Sy het nou die dag probeer skryf

She tried to write the other day

311. Sy't die pen so gevat en 'n paar lyntjies getrek.

She took the pen and drew a few lines.

312. Dit was dit.

That was it.

403. Ja, sy sal sê dit is die tweeling

Yes, she'll say these are the twins

404. Sy sal miskien sê dis Tossie en dis ook al.

She'll perhaps say this is Tossie and that's it.

405. Sy sal nie sê die ander een is Boetie nie.

She won't say the other one is Boetie.

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413. En dan sê ek partymaal vir haar "gaan piepie nou"
And then sometimes I tell her to "go pee now"

414. En dan sal sy haar broekie aftrek
And then she'll pull down her pants

415. En dan vergeet sy om die pantie af te trek.
And then she'll forget to pull down her underwear.

554. Ja, maar sy praat nie meer nie.
Yes, but she doesn't speak anymore.

561. Sy praat dan roep sy "Chris."
She talks and then she calls "Chris."

562. Sy praat so deurmekaar
She speaks incoherently

563. Jy kan dit eintlik nie mooi verstaan wat sy sê nie.
You can't actually understand what she is saying.

4.2.4 Theme 3: Paranoia

Individuals who suffer from DAT often suffer from paranoia (Lubinski, 1995). Therefore, this theme has been lifted out as a separate theme, as was done with the previous theme (Communication). Paranoia can be due to the fact that the individual's thoughts are no longer clear. Because of this, he/she may think that the other person is unknown and shouldn't be trusted (Kitwood, 1997). Individuals with DAT become paranoid about their possessions and suspicious of other people's motives and actions. As a result they do not trust others, whom they may regard as strangers, with their possessions. This paranoia may lead to individuals with DAT becoming aggressive about their possessions and whom they can trust. For example, they may form the impression that a new caregiver is trying to poison them with medication and as a result will refuse to take medication, or become violent and aggressive. Kitwood (1997) suggests that the personality changes that occur, such as an individual becoming paranoid, are not real changes but can be ascribed to the fact that the individuals are no longer able to control their moods, including feelings of fear and mistrust. The paranoia is a psychological defence against these feelings.

Mrs R's paranoia began in the early stages of DAT and has continued throughout the progression of DAT. She became paranoid about her possessions and would lock her cupboards, fearful that others would take her things. She did not trust many individuals and as a result, Mr R had to make duplicates of all the keys, so that he did not have to break cupboards open when she locked them. During the advanced stages of DAT Mrs

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R has also become distrustful of Mr R, and fights with him when he tries to help her dress or undress. Mr R assumes that she thinks he is assaulting her. However, in reality, Mrs R probably does not recognize Mr R and therefore assumes that he is a stranger who is trying to assault her (Cohen-Almagor, 2000).

Paranoia can be identified in the following sub-narratives.

Sub-Narrative 2

29. En sy het sleutels toegesluit
And she locked keys away.

30. Sy was bang hulle steel haar goed
She feared that they might steal her things

31. En sedertdien het sy sleutels begin wegsteek.
And as a result she began to hide keys away.

34. En dit het so agteruitgegaan
And it deteriorated

35. En sy het begin om ook niemand eintlik vertrou of so nie
And she also began to not really trust anyone or so

36. Wantrouerig geword
Became suspicious

37. En sy was nog nie daai tyd aggressief nie
And she wasn't aggressive at that stage

Sub-Narrative 4

104. En as ek haar wil aantrek of so dan, uh
And if I want to dress her or so

105. Ek dink sy dink ek wil haar aanrand
I think that she thinks I want to assault her

106. Dan baklei sy vreeslik.
Then she fights fiercely.

108. Dis nie altyd nie.
It's not always.

109. Maar partymaal veg sy kwaai.
But sometimes she struggles hard.

159. Ja, sy vertrou nie mense.
Yes, she doesn't trust people.

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4.2.5 Theme 4: Love and Loyalty

Love and loyalty are present throughout the whole narrative, which makes it clear that these qualities are important to Mr R. Mr R stated on several occasions that he would not desert his wife at the residential village. He also voiced his opinion about other individuals who do just that - bring their spouses to the residential home, leave them there and never come to visit again. In the past it has been found that caregivers who do not receive enough support may perceive the future as hopeless and desperate (Miner, Winters-Miner, Blass, Richter & Valentine, 1989), and this could be the underlying reason why this desertion happens. Mr R rejects this practice, saying that he would never do it, not only because Mrs R is the mother of his children, but also because they have come a long way together. This presents a man who is not only loyal, but also committed, to his wife. Along with this love, respect for Mrs R is also displayed. This can be seen in the manner in which he describes the birth of the twins, as well as the type of person she was prior to the onset of DAT. Various utterances from the narrative were selected to highlight the importance of this theme. These utterances about Love and Loyalty predominately come from Sub-Narratives 1 (Love and Marriage) and 4 (Progression of DAT).

Sub-Narrative 1

4. En toe is ek verplaas na P toe en sy het haar werk ook daar bedank en toe is sy ook in P
And then I was relocated to P and she resigned from her work and then she was also in P

7. En ons is daar getroud in 1953, is ons daar getroud.
And we were married there in 1953, there we were married.

68. Ons het 'n lang pad saam gekom, 'n verlede van 55 jaar.
We have come a long way together, a past of 55years.

569. Ag, nee ons was baie gelukkig gewees.
Ag, no we were very happy.

580. Sy het baie maal op my bed gaan lê en so.
She often lay down on my bed.

587. Nee, ek het te veel lang pad met haar.
No, I have walked too long a road with her.

684. Ek kan nou darem 'n oog oor haar versorging en als.
At least I can keep an eye on her care and everything.

Sub-Narrative 4

67. Ek kyk nou nog na haar.
I still care for her.

432. Ek het nou-nou baklei met hulle
I argued with them a minute ago

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433. Hulle het haar nog nie eers reggemaak nie.
They haven't dressed her yet.

435. Ek het hulle mooi gesê
I told them clearly

436. Hulle moet kyk 4 uur dat hulle haar kos gee
They must see that they give her food to her at 4 o'clock

629. Toe sê ek "Aikona, ek bly hier by haar."
I then said, " 'Aikona', I'm staying here with her."

4.2.6 Theme 5: Coping Strategies

It has often been found that caregivers of an individual with DAT tend to take care of the physical aspects of the progressive disease, but forget the person inside who is living with this life changing disease (Burns et al., 2006). However, this tends to happen when the caregiver does not have a solid support network and coping strategies (Burns et al., 2006). When caring for an individual with DAT, it is important to remember the person behind the disease and to accept that person and the situation in which he/she finds him/herself.

It is important to Mr R to treat Mrs R as a person and not to just lock her up. He keeps himself busy so that he can retain perspective and support his wife. He has decided that if he allows the disease to get the better of them, he will be unable to care for his wife. To him she is no longer the woman that he married. She no longer has passion for the interests that she had before, such as reading and writing.

Mr R has developed his own coping strategies to ensure that he can support his wife in any way possible, and much of this was gained through experience. For example, initially, Mr R had to learn to cope with Mrs R's paranoia when she hid keys away and wanted to "go home". Then he had to start taking over the household chores. Through personal experience and living in a retirement village where they specialize in Alzheimer's Disease, Mr R has learnt not to agrue with his wife. For example, when he tries to help with her with dressing, instead of arguing with her when she fights him, he rather walks out of the room and gives her time to calm down. By the time he comes back, she has usually forgotten about the incident. He has also learnt to make sure that she receives meals that she enjoyed before the onset of DAT. However, due to her lack of appetite, he has to make sure that she actually eats. To do this, he allows her to take a few mouthsful of food. Then he lets her walk around, because by the time she comes

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back, she has forgotten that she had already eaten, and will not argue with him about eating again. Due to the fact that Mrs R no longer communicates verbally, Mr R has had to learn to read her body language and facial expressions. If he did not have the background knowledge about his wife and the experience of dealing with her, he would not be able to help her to the extent that he does. As she no longer communicates verbally, she is unable to express her wants and needs to Mr R (or anyone else). Mr R is able to differentiate between her facial expressions in order to tell when Mrs R has pain or when she is tired. He can also tell when she is concentrating on something of importance and then talks to her about it. For example, when he sees her wiping surfaces, he recognises that that is how she cleaned before she became ill and then speaks to her about those times. Initially he also coped with her lack of communication by speaking about the past. Now, during the late stages of DAT, Mr R has learnt to communicate with her by playing music to her and touching her.

Mr R's experience is beneficial to professionals. He is able to speak on his wife's behalf and can tell the professionals when a certain treatment, medication or approach works or not since he is able to interpret her reactions and responses. A caregiver who is a stranger, as well as a professional who has had little contact with a particular individual with DAT, would find it difficult or impossible to understand that individual's reactions. Thus it is important when planning treatment, to keep in mind that the person best suited to provide relevant information about the individual, is a spouse and/or family members. Mr R's coping strategies were evident throughout the entire narrative.

Sub-Narrative 2

33. En naderhand, uh, duplikaat sleutels vir al die kaste gemaak sodat as sy die kaste toesluit, die sleutel weggooi, dan weet ek om dit weg te bêre, dan hoef ek nie te soek nie.

And after a while, um, made duplicate keys for all the closets, so that when she locked the cupboards, then I knew to put them away, then I didn't have to search for them.

45. Dan het ek haar maar gevat en ry ek 'n draai met haar in die kar en dan kom ek terug en sê ek "jy's weer by die huis."

I then took her and drove a bit in the car and then I come back and say "you're at home."

50. En toe besluit ek nee ons kom maar hierna.

And then I decided no we are coming here.

58. Toe het ons hiernatoe gekom.

We then came here.

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62. Daarna altyd as ek moes dorp toe gaan het ek maar die huis toegesluit, dat sy maar binne bly.

After that whenever I had to go to town I would lock the house, so that she stayed inside.

63. Op daai stadium het ek haar heeltemal uit die kombuis uit weggevat, want ek was bang sy brand.

At that stage I took her completely out of the kitchen, because I was scared she would burn herself.

64. Ek het maar die koskokery oor geneem ensovoorts.

I took over the cooking and so on.

389. Ja, in die beginstadium het ek baie met haar oor die ou dae gepraat en oor haar pa hulle

Yes, in the beginning I spoke to her a lot about the old days and her parents.

635. Ek besef dit en aanvaar dit en dis hoekom ek my effens onttrek dat hulle bietjie oorvat.

I realize that and accept it and that is why I am withdrawing slightly, so that they can take over a little bit.

Sub-Narrative 3

121. Ek het enige ding probeer.

I tried anything.

Sub-Narrative 4

112. En partymaal raas ek maar ‘n bietjie

And sometimes I scold

113. Maar dit help niks nie.

But it doesn’t help.

114. Ek het al by baie gehoor: “Los haar alleen, los haar.”

I have heard from many “leave her alone, leave her.”

115. “Moenie argumenteer nie.”

“Don’t argue.”

116. Jy los haar en as jy weer 2minute later met haar praat dan het sy skoon vergeet.

You leave her and when you come back after 2minutes she has completely forgotten.

127. Ek versorg haar en dat sy versorg is.

I take care of her and that she is cared for.

130. Dit help nie, ek het toe ek hier gekom het, het ek gaan sit en tokkel. Dit help nie.

It doesn’t help, when we came here, I sat and brooded. It doesn’t help.

134. Ja, ek het ook ‘n lewe wat moet aangaan.

Yes, I too have a life that must go on.

179. Ja, aanraking help ook baie.

Yes, touch also helps a lot.

180. Musiek help ook baie, weet.

Music also helps a lot you know.

197. En as sy rusteloos raak dan weet jy daar’s iets wat hinder

And if she is restless then you know that something is bothering her

198. Vat jy haar toilet toe, of vra vir haar of sy pyn of so voel.

You take her to the toilet or ask her if she has pain.

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223. Dan los ek haar maar hier.

Then I leave her here.

224. En dan gaan ek gou bietjie na hulle toe en dan kom ek weer terug.

Then I quickly go to them and then I come back again.

267. Ek gaan nou op 'n Dinsdag, nee Maandag, as dit die Here se wil is, gaan ek bietjie wegbreek.

I am going away for a while on Tuesday, no Monday if it's the Lord's will.

268. Ek gaan op 'n toer hier af Laeveld toe.

I am going on a tour to the Low Veld.

298. Op die huidige stadium, um, vat ek haar 8uur in die aande toilet toe

At the moment, um, I take her to the toilet at 8 o'clock in the evening

299. En dan het ek opdragte vir die verpleegsters om haar elke 4 ure te vat.

And then I have given instructions that the nurses must take her every 4hours.

324. Ek sit haar kos voor haar neer, dan gee ek haar lepel in haar hand, as sy eet dan sal sy 3 lepels eet dan sal sy opstaan.

I put her food in front of her, then I give her her spoon in her hand, if she eats then she'll eat 3 spoonsful and then stand up.

325. Wel, ek los haar en dan vat ek haar net so rukkie en sê ek weer "eet" dan het sy nou vergeet dat sy wel 3 lepels geëet het.

Well, I leave her and then after a while I take her and then I say "eat", then she has forgotten that she had already eaten 3 spoonsful.

333. Maar ek, ek het uit ondervinding het ek geleer dit help nie om met sulke mense te redeneer nie.

But I, I learnt from experience that it doesn't help to reason with these people.

336. Ek loop maar uit die kamer uit.

I walk out of the room.

337. Want as ek terug kom, dan is sy weer baie lief vir my.

Because when I come back, then she loves me again.

353. Kyk, uit ondervinding leer jy baie beter as wat jy lees.

Look, from experience you learn a lot more than by reading.

354. Ja, ek het, uh, baie gelees

Yes, I have, uh, read a lot

542. Maar ek kyk maar nie vorentoe nie.

But I don't look to the future.

543. Bedoel ek leef van dag tot dag.

I mean I live from day to day.

548. Ek weet wat sy geëet het

I know what she ate

549. Of waarvan sy gehou het en daai dinge, dan kyk ek dat sy daarvan kry.

Or what she liked and all those type of things, then I make sure she gets it.

583. Of gaan lê maar in 'n kamer

Or go and lie down in a room

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615. Kan nie op ‘n hopie sit hier.

Can't sit on a heap here.

679. Ek het vrede daarmee gemaak.

I have made peace with it.

4.2.7 Theme 6: Professional Support Provided

A theme that emerges strongly from Mr R's narrative is his perception of the professional support that they have received since the onset of DAT. These perceptions appear to be both positive and negative. An individual with DAT often receives various forms of professional support, for example, from doctors, neurologists, nurses, speech-language therapists and retirement villages (Lloyd, 2000). In Mr and Mrs R's case, they have received support from all the above-mentioned professionals. However, the quality of professional input has differed.

Initial support provided by professionals

The initial support involved diagnosis of DAT from two separate doctors. The diagnosis was first made by a psychiatrist and then confirmed by a neurologist. After the diagnosis, Mr R was informed that DAT is a progressive disease for which there is no cure. Mr R was told that Mrs R's cerebellum was deteriorating and that certain medication could delay the progression of DAT. However, in the case of DAT, it is not the cerebellum that deteriorates. Mr R acquired much of the initial information about DAT on his own. He did a lot of reading and research as he felt that the professionals had not provided enough information about the exact symptoms of DAT, or what to expect as the disease progressed.

It is suggested that professionals should keep their explanations of the disease understandable by using vocabulary that the ordinary man in the street can follow. They should also ensure that the diagnosed individual as well as immediate family members are properly informed about the disease, by providing essential information that will equip them to deal with the ordeal of this life-altering disease. Initially, information given should be just enough to help the affected individuals come to terms with the diagnosis. Thereafter, a well-planned schedule of regular visits should be set up so that the professional can provide information and guidance relevant to the problems as they arise at different stages of the disease. It is important to provide new and updated information about the disease, as DAT is a progressive disease with symptoms that change as the individual progresses through the various stages (Hart & Semple, 1990).

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Sub-Narrative 3

90. Toe het ek haar na ‘n ander dokter, ek kan nie sy naam onthou nie, ook ‘n neuroloog, hier by EM.

I then took her to another doctor, I can’t remember his name, also a neurologist here at EM.

91. En hy het haar ook gediagnoseer.

And he also diagnosed her.

136. Hy’t maar gesê die klein brein, die geheue brein, is besig om te krimp.

He said that the cerebellum, the memory brain, is shrinking.

137. Dis omtrent al wat hy gesê het.

That is about all that he said.

482. Maar hulle het nie eintlik baie vir my gesê oor Alzheimer’s nie.

But they didn’t actually tell me much about Alzheimer’s.

483. Hulle het maar gesê sy het Alzheimer’s en dit is dit en daar is nie ‘n, ja daar is nie medikasie wat dit, uh, soos ek gesê het, Aroset vertraag dit.

They said that she has Alzheimer’s and that’s that, and that there isn’t medication that, as I said Aroset only delays it.

487. Ja, nee ek sou dit regtig, as dit ‘n ordentlike doktor is sal hy dit doen, sal hy vir jou sê wat om te verwag en al daai dinge.

Yes, I would really, if it was a decent doctor he would do it, he would tell you what to expect and all of those things.

Sub-Narrative 4

314. Ek was by ‘n psigiater, ja, Dr G.

I was at a psychiatrist, yes, Dr G.

315. Hy’t toe gekyk na haar medikasie.

He then looked at her medication.

316. Hy’t nou vir haar ‘n pil voor, ‘n vitamine pil voorgeskryf wat haar eetlus sal gee.

He has given her a tablet, a vitamin tablet to give her an appetite.

Professional support provided since the diagnosis of DAT

Although Mr R feels negative about the initial support from professionals, he has since received substantial support from the staff at the retirement village where they now reside. Mr R has continued to read and learn about DAT since moving to the retirement village where he has been provided with advice and useful information, including videos on DAT. As they are also a training facility for nurses who work with DAT patients, Mr R has been able to discuss his wife’s condition with one of the lecturers. The lecturer advises him, for example, about eating habits and told him to ensure that Mrs R receives food that she used to like. Mr R commented that his most valuable knowledge about the condition has come from his personal experience of living with his wife, as well as observing other individuals who also suffer from DAT. This hands-

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on experience has been valuable. Not only has Mr R received valuable support from the professionals at the retirement village, but has, in turn, become an asset to the retirement village. His experiences have empowered him to offer support to others, especially to those individuals recently diagnosed and their families, who are facing the unknown prospect of where the journey will lead them.

Sub-Narrative 3

368. So die meeste wat ek weet van Alzheimer's is maar deur ondervinding.
So the most that I know about Alzheimer's is through experience.

Sub-Narrative 4

204. Die verpleegsters help baie.
The nurses help a lot.

353. Ag, kyk, uit ondervinding leer jy baie meer as wat jy lees.
Look, through experience you learn a lot more than when you read.

354. Ja, ek het baie gelees, maar nie veel nie.
Yes, I did read a lot, but not much.

440. Ek kry inligting van Alzheimer's.
I get information about Alzheimer's.

441. Ek het die video wat hulle gespeel het, 'n Engelse video, wat ek na kyk en so.
I have the video that they played, an English video, that I watch and so on.

447. Ja, ons het 'n opleidingskool hierso vir verpleegsters.
Yes, we have a training school for the nurses here.

448. En ons het 'n dosent wat dit doen en sy gebruik daai videos "Abuse of the Elderly".
And we have a lecturer that does it and she uses those videos "Abuse of the Elderly".

4.2.8 Summary of Content Analysis

Discussing these themes allows professionals to extract crucial information from the narrative that would help to improve their service to people affected by DAT.

A speech-language therapist, for example, would need to obtain information regarding communication skills, as well as any eating, chewing and swallowing difficulties. Therefore, it would be important to obtain information about the individual's communication profile prior to the onset of DAT, for example, whether there were any speech defects, whether he/she made use of full sentences or whether there ever were any language difficulties. It would also be important to note whether or not the individual with DAT has a family history with regard to communication disorders. That is why it is important to look at the life story in detail, so that all prior information can be used to assess the effect of the diease on communication-interaction.

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4.3 Summary

This chapter has looked at Mr R's narrative in terms of a form as well as a content analysis. The form analysis showed that Mr R's narrative generally is regressive in form, due to the progressive nature of DAT and the concomitant symptoms that occur within the disease. The content analysis revealed various themes that emerged from Mr R's narrative. These themes all provide valuable information for professionals to keep in mind when making a diagnosis and designing a treatment plan. The analysis of the study suggests that professionals should re-assess their approach to individuals with DAT, their spouses and families, since these individuals can provide valuable information about the person. The spouse and other family members should form part of the team that treats an individual with DAT.

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CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The scope of practice for speech-language therapists (SLT) has expanded over the past few years, both in character and terms of responsibility, to include intervention for patients with neurogenic conditions (Dajee, 2001; Wu, 1998). The field has increasingly opened up to speech-language therapists (and other professionals), bringing new challenges and responsibilities to those charged with providing services to individuals (and their families) living with dementia. A significant change has been the manner in which relevant, valid information is obtained and utilized in the diagnosis and treatment of individuals with Dementia of the Alzheimer's Type (DAT).

5.2 AIM OF THE STUDY

Research in the field of DAT has shown an upward trend in recent years. However, the tendency of traditional research has been to focus on symptoms (as observed by professionals), rather than the perceptions and experiences of, for example, a spouse, especially with regard to the impact of DAT on communication (Burns et al., 2006).

For this reason, the study presented here aims to determine the perceptions and experiences of a spouse affected by a partner's DAT, regarding the effect of DAT on communication interaction. This study is grounded within the field of speech-language pathology by virtue of its objective, which is to establish the areas wherein speech-language therapists can improve the services provided to individuals with DAT, and their spouses.

5.3 AIM OF THE CHAPTER

In this chapter the results and conclusions of the study will be discussed. Issuing from these, recommendations for responsible, accountable clinical practice, will be proposed. In addition, an objective evaluation of this venture will determine whether or not the purpose of the study was achieved.

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5.4 RESULTS OF THE STUDY

The role of a SLT is to facilitate communication where there has been a break down in the process.

This study investigates the influence of DAT on communication interaction, by using Narrative Analysis. The spouse of an individual with DAT was interviewed and the narrative thus obtained, analysed.

The understanding of a narrative is a complex process. To understand the narrative presented by the participant, a holistic form analysis, as well as a holistic content analysis was performed. A summary of the results follows.

5.4.1 Holistic Form Analysis

The holistic form analysis looked at the pattern of the narrative and what this disclosed about the narrative itself.

The narrative obtained from the participant, Mr R, was regressive by nature, indicating a decline in the number of positive experiences and sentiments expressed by Mr R. The progressive nature of Mr R's narrative is likely to be typical of most narratives relating to DAT, owing to the chronic and progressive nature of the illness.

According to the form analysis of the narrative, the graph stabilized later in the narrative. This stabilization is viewed as an indication that, at this point, the negative connotations associated with the disease had lessened. Based on this, it is assumed that, had Mr R received professional support and assistance earlier on in his wife's illness, the graph may have stabilized sooner. This underlines the importance of early intervention.

Professionals need to recognize the importance of providing immediate, adequate support for the individual with DAT, as well as the spouse and other family members. The quality of this support can be a deciding factor in how quickly the affected parties come to terms with the illness and learn to cope with the ever-changing behaviours and symptoms of DAT. Professional support that includes participation by affected individuals in the management of DAT facilitates acceptance of the situation and implementation of coping strategies, allowing those individuals to carry on with life (Sherlock & Gardner, 1993).

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5.4.2 Holistic Content Analysis

The holistic content analysis looked at the narrative as a whole and highlighted the major themes that ran throughout. The information contained in these themes is regarded as vital to the success of the study by virtue of its obvious significance to the participant (established as significant due to the repetition encountered in the narrative). The themes highlighted in the narrative were those of: Change, Verbal Communication, Paranoia, Love and Loyalty, Coping Strategies and Professional Support Provided.

The information pertaining to *Change*, highlighted by Mr R with regard to his wife's communication interaction, personality and their marriage, correlates well with the literature on DAT. However, the information of clinical value to a speech-language-therapist can be found in the strategies that he developed to deal with these changes and the manner in which he facilitated communication. These include: talking about family photographs, touching his spouse to gain her attention while talking to her, reading her body language and non-verbal communication, as well as giving her time-out when the external stimulation becomes too much. These strategies can all be useful in the treatment of DAT.

Since a spouse is able to report on the success (or not) of certain strategies, professionals could benefit from including the spouse in the intervention team since this would ultimately improve the quality of intervention. The participation of all individuals involved can lead to a sharing of knowledge and experience that would benefit all members of the team. The results of this study showed that in order for spouses to be of benefit to the intervention team, they need to be supported not only by family and friends, but also by professionals.

In addition to this, the study shows that it is important for professionals to use terminology that is understandable to the average person and to provide information that is sufficient and of the highest quality. In view of the high fees charged for medical consultations, the professional should consider how best to meet the needs of his/her patients in this respect. It is apparent from the study that the participant experienced a lack in this area since he noted that insufficient information had been given to him by professionals. This was viewed in a poor light by Mr R, since the consultation fees were high.

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The participant solved the problem by conducting his own research. He received a great amount of support from the retirement village where he and his wife were residing at the time of the data collection. He developed his own coping strategies, learning through his own experiences and by observing treatment of individuals with DAT at the retirement village. He feels that, all things considered, personal experience has been his greatest "tutor" (even more so than reading about the disease).

Professionals are in a position to establish a network of individuals living with DAT. This would facilitate communication within the group, enabling families to provide mutual support in respect of understanding and coping with the illness.

5.5 CONCLUSIONS

The results obtained from this study have allowed the researcher to come to several valuable conclusions. The conclusions pertain to services rendered in the field of DAT. These conclusions could assist in improving the services provided by a multi-disciplinary team.

Theoretical and clinical implications can assist professionals to make informed decisions about the services that they render to individuals with DAT.

5.5.1 CLINICAL IMPLICATIONS

5.5.1.1 The role of the spouse in the management of DAT:

- From this study it is evident that it would be to the benefit of both professionals and the patient, to use the spouse as a resource for information. Background information about the individual with DAT is useful in making an accurate diagnosis and also facilitates Reminiscence Therapy. In addition to this, background information could assist professionals such as SLTs in the compilation of memory books, which have been found to facilitate communication between professionals and individuals with differing severities of dementia (Andrews-Salvia, Roy & Cameron, 2003). For example, if an individual with DAT were to refer to something that had happened in his/her past, the professional would be able to continue the conversation and interact with the individual. Such information also allows the professional to determine previous medication and its efficacy. In this study, Mr R indicated that he was involved in decisions about medication that would enhance his wife's Quality of Life

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(QOL). Since he is aware of what her wishes would have been, he is able to make a decision on her behalf. A spouse is also valuable in providing information about the current status of the individual with DAT. Due to the fact that DAT is a progressive disease, the individual's needs are constantly changing. Updated information is therefore of paramount importance to the affected individuals. This can only be provided if the professional is aware of the level at which the individual with DAT is functioning and the areas in which they require additional information or assistance. For example, at the time of data collection, Mr R had been asked whether or not he felt that Mrs R needed to use diapers. At the time, however, he felt that it was not necessary as he took her to the toilet himself, and ensured that she was taken in the evenings. Without his input, the professionals could possibly have made an unwise decision regarding the use of diapers, which could have resulted in humiliation for Mrs R with concomitant deterioration in QOL. Mr R has the experience and perception to know what treatment will best suit Mrs R. Often it is the spouse who is the primary caregiver. The spouse needs to be involved in decisions that are made pertaining to the management of the individual with DAT. It is therefore re-iterated, that professionals should make use of spouses and family members when considering treatment and management of individuals with DAT.

- The results of this study highlighted the value of the coping strategies implemented by the spouse in order to facilitate communication interaction. Professionals suggested numerous strategies to the participant regarding the care of his wife. For example, the staff at the retirement village suggested that her meals should consist of foods she had enjoyed prior to onset of DAT. However, the participant also developed his own coping strategies, by drawing on his own experiences with his wife. Professionals who involve spouses and family members in the treatment plan and decision making process are able to gain insight into the coping strategies that spouses employ. They are then able to pass these coping strategies on to others struggling to cope with similar situations. For example, Mr R has learnt to read Mrs R's nonverbal communication (such as facial expressions) in order to determine how Mrs R is feeling, or what her reactions are to certain situations. This has helped him to better understand her reactions. However, this is only possible because he has known her for many years and knows what certain facial expressions mean. This strategy could be passed on, by a professional, to another person struggling to understand a non-verbal partner. It is clear, therefore, that spouses and family

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members of individuals with DAT can provide support and advice to other families living with DAT. Spouses living with DAT also need to be informed of professional support available to them. Since DAT affects the whole family, it is important that professionals develop intervention skills that include and support the family as a unit and not only the individual with DAT (Sherlock & Gardner, 1993).

5.5.1.2 The role of the SLT in the management of DAT:

- In the past, the SLT's role in the diagnosis and treatment of DAT was poorly defined, not only by SLTs themselves, but also by other professionals and affected individuals (Dajee, 2002; De Waal, 2003; Ross & Deverell, 2004). This study has highlighted the areas in which the SLT does play a role, as well as the importance of involving the SLT. It also showed that DAT does have a life altering effect on an individual's communication interaction, as well as associated Activities of Daily Living (such as feeding). This study supports the view that the role of the SLT should be one of advocate, counselor and educator. A SLT should attempt to obtain information from the spouse with regard to the pre-morbid communication style of the individual with DAT. This background information will allow the SLT to understand how the individual communicated and enable the construction of a management plan based on the identified style of the individual. As an educator and informer, the SLT should teach the spouse and other professionals how to communicate with the individual in the best possible manner.
- The SLT should try to work as closely as possible with the spouse to implement management strategies that facilitate communication. The SLT must enquire which strategies work best for the spouse and adjust these so that they work in all contexts. In order to do so, the SLT should be aware of the stresses associated with DAT so that appropriate counseling can be provided to the family. Familiarity with the spouse and family will also assist the SLT in making realistic and practical suggestions for communication management. This will allow the SLT to function more effectively as a member of an inter-disciplinary team (Rau, 1993).
- Individuals affected by DAT may be unaware of the valuable contribution a SLT can make to treatment and management. In this study, Mr R reported that his wife had thus far not been seen by a SLT or any additional specialist such as, for example, a dietician. For this reason, it is suggested that professionals should take note of the benefits that a SLT can provide (Dajee, 2002). SLTs should ensure that *they* promote

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their role in the treatment of DAT, by making other professionals aware of the value they can add to management of DAT, thereby ensuring that affected individuals receive optimum treatment by early referrals. This would allow for comprehensive support and counseling, not only to the individuals concerned, but to their spouses and family members as well (Dajee, 2002; Nolan & Grant, 2001).

- This study showed that SLTs need to increase *public awareness* of the role they play in the treatment of DAT. SLTs can ensure that retirement villages, care centres and other professionals, such as neurologists and dieticians, are aware of the potential role SLTs have in treating certain deficits that can occur in a patient with DAT. This implies that SLTs should educate professionals about such possible deficits so that they are able to refer the individual with DAT to the SLT, if needed, or to another professional for appropriate treatment.
- An important role that a SLT plays is the provision of information regarding communication and dysphagia in DAT. It is the responsibility of a SLT to remain up to date and well-versed in the latest research concerning DAT, especially with regard to the deficits that affected individuals can experience, as well as the possible compensatory techniques that can be implemented to facilitate communication, swallowing and a better quality of living. In this study Mr R was asked whether professionals had informed him about alternative feeding techniques, such as a Percutaneous Endoscopic Gastrostomy (PEG). His reply indicated that no alternative techniques had been discussed with him.

- **The role of the professional team in the management of DAT:**
- The role of professionals is important even before a diagnosis has been made. Professionals in all fields should ensure that the public becomes educated about DAT, the identifying symptoms and the treatment thereof. The participant in this study sought professional assistance only when his wife was already in the fairly advanced stages of DAT. Had he been more aware of the symptoms and sought assistance sooner, he may have been able to deal with her difficulties sooner and coped better himself. Members of the public must be made aware of initial symptoms and which professionals to consult if they recognize any of the identifying symptoms in either themselves, or a loved-one, so that professional assistance can be sought as soon as possible. It is clear that professionals have a responsibility towards the general public

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in respect of DAT. Therefore, it can be stated that the role of a professional commences even before an individual steps into a consulting room for diagnosis.

- Once a professional is confronted by an individual about the possibility of DAT, the professional should establish an open relationship from the start. Professionals should keep in mind that many individuals may be uneducated in the field of dementia and therefore require as much information about the disease as possible. In this study, the participant mentioned on numerous occasions that he would have liked additional information with regard to what would happen to his wife and what to expect from the future. Professionals should provide a variety of information brochures on the various types of dementia and be open to all forms of questions that the individual may present to them. When information is provided, it should be tailored to suit the current stage of dementia being experienced at the time of enquiry. It is not advisable to provide an individual in the early stages, with information on the advanced stages of DAT, as this can be discouraging. However, this information must never be kept from an individual (Heston & White, 1983).
- Professionals should keep in mind that the diagnosis of DAT can be a daunting experience for both the individual concerned and the spouse. Most professionals will explain the diagnosis in a professional manner but need to be cautioned against becoming too clinical. In this study, it became apparent that the professionals who worked with the participant and his wife made use of terminology that neither of the couple understood. For example, the participant was confused about the area of the brain affected by DAT, due to the terminology that had been used during consultations. It is important for the professional to use terminology that is understandable to his patients, and to give explanations with empathy and sympathy for the affected individuals, so that they can become as informed as possible, in as kind a manner as possible.

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5.5.2 THEORETICAL IMPLICATIONS

- The value of interviewing as a method of data collection has come across strongly in this study. Interviews allow participants to provide information they find comfortable to reveal. They also provide opportunity for discussion in an informal setting where the researcher can give feedback on the information provided, and also clarify information, if necessary. From this study it is evident that interviews can provide in-depth information that, for example, rating scales could possibly *not* provide (Zeeman et al., 2002). A rating scale does not allow for the participant to expand on answers and a formal tool has a finite number of answers. Interviews, on the other hand, are less impersonal and allow for reflections that could lead to change and progress in the area under scrutiny. (Zeeman et al., 2002). Although interviews provide information that formal tools do not, it is important to keep in mind that it is often useful to triangulate a study with a rating scale or questionnaire (that would provide quantitative data) since this would allow the researcher to confirm qualitative data with quantitative data.

5.6 CRITICAL EVALUATION OF THE STUDY

Although this study has provided insight into the impact of DAT on communication interaction in an individual with DAT, there are limitations to the study which need to be acknowledged and taken into account in future research in order to improve the possible outcomes of such a research project.

- Only one participant was used for this study. Therefore, the results obtained cannot be generalized to other DAT research projects.
- The method of data collection in this study involved informal interviews conducted at a retirement village and then analysed by means of a narrative analysis. Only one method of data collection was used due to the intensive nature of a narrative analysis. The outcome, however, is that the researcher has been unable to triangulate the data. Although only one method of data collection was used, the researcher ensured trustworthiness by transcribing the interviews and then confirming the transcribed information with the participant. After all four interviews, the participant and researcher cross-examined the interviews to ensure that there was no information that had been incorrectly transcribed or interpreted by the researcher.

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- Another limitation is the possibility that the informal questions used for the interview may have been leading, thus influencing the participant to answer in a certain manner. This limitation could have been eliminated by conducting a subsequent transcription, using an independent rater, before discussing the issues separately.

5.7 RECOMMENDATIONS FOR FUTURE RESEARCH

Several recommendations can be made for future research on this topic.

- A similar research study could be conducted on a larger population of individuals with DAT, their spouses and/or family members, in order to determine similarities or differences amongst the population with regard to their experiences and perceptions. This would facilitate greater generalization of the results obtained. These similarities and differences could be considered in order to improve service delivery to individuals affected by DAT.
- This study has demonstrated the possibility that the process of narrative analysis is more effective than a questionnaire, in eliciting information about the effects of DAT on people and their families. Therefore, this method of research and data collection can be used in respect of other patients with neurogenic conditions and communicative disorders.
- In order to facilitate triangulation of data, it is recommended that researchers make use of checklists or questionnaires to supplement the information collected by means of narrative analysis. The use of a checklist or questionnaire allows the researcher to confirm information. Using both a qualitative as well as a quantitative method of research establishes reliability.
- In the United Kingdom, researchers have been making use of an electronic form of qualitative data analysis known as NUD*IST (Mroz, 2006) since 1993, which works with non-numerical data. This form of data analysis allows researchers to reduce any bias. The data is inserted into the software and the software then explores the data in terms of possible categories, phases, sub-narratives and themes. The software also provides new questions and areas for possible future research (Richard & Richard, 1993). This form of qualitative analysis ensures high levels of inter-coder reliability (Mroz, 2006).
- Compensatory techniques that can be facilitated by a SLT are techniques such as Reminiscence Therapy (Kitwood, 1997), using photographs to help the individual recall individuals, events and places, making use of facial expressions to determine

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the individuals reactions when they are no longer communicating verbally and making use of Augmentative and Alternative Communication (AAC) for the individual who has difficulty formulating sentences and understanding complex sentences (Beukelman & Mirenda, 2000). Although a SLT may have many techniques to facilitate communication, the SLT should keep in mind that the spouse of an individual with DAT is an exceptional source from which to gain insight into techniques that have been learnt through trial and error. A spouse can provide helpful information with regard to which techniques were beneficial to them, or not. If a technique was found to be unsuccessful, a spouse or family member can assist the SLT in improving or altering it to become successful.

5.8 SUMMARY

As a result of this study, the researcher has concluded that narrative analysis can play an important role in ongoing research of DAT. It has been found valuable to do a needs-assessment of a person with DAT by means of informal interviews and narratives. A narrative analysis can be used not only as an assessment tool, but also as a form of treatment as it increases individuality and restores dignity to an individual who may feel lost and disempowered (Herman, 1999).

The researcher has also noted that professionals often tend to take over the role of decision making when dealing with cases of DAT. However, a spouse or family member with relevant background information would be a better judge of what would work and what would not (Jacques, 1997). That is why it is important for professionals to keep in mind that, although they may be more knowledgeable about the disease, the assistance of a spouse or family member is needed in order to implement this knowledge effectively so that the condition can be managed with optimum success.

It should be kept in mind that it is not only the individual with DAT who suffers, but the spouse (and other family members) as well. The condition can become very stressful for a spouse, especially for an older spouse burdened by caring for a partner with DAT while also dealing with his/her own health problems and age-related concerns (Lubinski, 1995). Hence a professional not only caters for the needs of the individual with DAT, but also for those of the spouse, since the spouse will be the one who is mostly aware of difficulties or successes while monitoring the progression of DAT (Burns et al., 2006).

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APPENDICES

APPENDIX A ETHICAL CLEARANCE LETTER
APPENDIX B INFORMATION LETTER TO PARTICIPANT
INFORMED CONSENT FROM PARTICIPANT
APPENDIX C TRANSCRIPTION OF INTERVIEWS

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APPENDIX A
ETHICAL CLEARANCE LETTER

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APPENDIX B

INFORMATION LETTER TO PARTICIPANT
INFORMED CONSENT FROM PARTICIPANT

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APPENDIX C
TRANSCRIPTION OF INTERVIEWS

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Datum:_______________

Ingeligte Toestemmingsvorm

Geagte__________________

Ek is 'n Kommunikasiepatologie Meestersgraad student aan die Universiteit van Pretoria. Ter vervulling van die vereistes vir die graad M Kommunikasiepatologie, word daar van my verwag om 'n navorsingsprojek uit te voer. My studie is daarop gemik om vas te stel wat 'n gesin se ervarings is met dementia (siektetoestande wat onder andere Alzheimer se siekte insluit). Hierdie brief dien om aan u inligting oor die navorsingsprojek te verskaf en om u te versoek om my van hulp te wees..

1. Titel van Studie:
Die titel van die studie is "Narratives of a family regarding their experiences with Dementia of the Alzheimer's Type."
2. Doel van Studie:
Die doel van die studie is om die ervarings en lewensverhale ("life stories") van 'n gesin wat met Alzheimer se siekte te doen het, te ondersoek. Hierdie inligting kan gebruik word om beter te begryp wat die konsekwensies daarvan is om met Alzheimer se siekte/demensie saam te leef, ten einde meer toegespitste intervensie en bystand te kan lewer.
3. Navorsingsprosedure:
Een gesin sal gevra word om deel te neem aan drie gesprekke wat sal fokus op die gesin en die gesindslid met demensie. Elke sessie sal min of meer een uur duur. Ek sal die gesin voor die tyd kontak om 'n tyd te reel wat hulle sal pas vir die gesprekke en die gesprekke sal vir hulle gerief by hulle huis gevoer word. 'n Bandopname sal van ons gesprekke opgeneem word sodat geen inligting verlore raak nie en sodat ontleding van die inligting op 'n betroubare wyse kan geskied. Die gesin sal gevra word om aan een laaste gesprek deel te neem wanneer die gesprekke klaar ontleed is. Hierdie sessie sal gebruik word om die bevindings van die vorige gesprekke te bespreek om seker te maak dat daar geen waninterpretasies van hulle opmerkings was nie.

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4. Geassosieerde risiko's en ongemak:
Daar is geen gesondheidsrisiko's of gevolge geassosieer met deelname aan hierdie studie nie.
5. Voordele:
Daar is geen direkte voordele as 'n gesin aan in die studie sou deelneem nie.
6. Regte van die deelnemer:
Die gesin mag op enige stadium uit die studie onttrek sonder enige nagevolge. Geen inligting sal gebruik word sonder hulle toestemming nie. Alle inligting wat ek van en deur die opnames verkry, sal as vertroulik beskou word en name sal nie in enige verslag verskyn nie. Die resultate van die studie sal na afhandeling van die projek in die vorm van 'n Magistersverhandeling beskikbaar wees in die biblioteek van die Universiteit van Pretoria. Weereens sal toestemming gevra word voordat dit beskikbaar gemaak word. Sou u dit verlang, sal 'n kopie van die finale skripsie aan u en aan die gesin beskikbaar gemaak word.

Ten einde 'n gesin op te spoor wat as vrywillige deelnemers sal optree, wil ek u graag versoek om enige potensiële deelnemende gesinne te identifiseer en hulle te vra of hulle bereid sal wees om aan die navorsing deel te neem. Eers nadat hulle hulleself bereid verklaar het, kan u die naam en kontakbesonderhede aan my bekend maak. Die gesin sal dan dieselfde inligting ontvang wat ek hierbo aan u verstrek het.

7. Navrae:
Indien u enige navrae het, kan u te enige tyd die navorser (083-468-9989) of die stuidieleier (012 420 2357) kontak.

____

Zandrè van Zyl
Departement Kommunikasiepatologie
Universiteit van Pretoria

____

Mev A. Stipinovich
Studieleier

____

Prof Brenda Louw
HOOF: DEPARTEMENT KOMMUNIKASIEPATOLOGIE

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Toestemmingsbrief

Ek verstaan die doel van die navorsing en begryp my regte as deelnemer. Ek stem vrywillig in om aan die studie deel te neem. Ek bevestig dat ek 'n inligtingsbrief ontvang het en verstaan dat ek ook 'n ondertekende kopie´ van hierdie toestemmingsvorm sal ontvang.

Indien ek enige navrae het, kan ek te enige tyd die navorser (083 468 9989) of die studieleier (012 420 2357) kontak.

Naam en Handtekening:

Deelnemer:____________________________ Datum:_____________________

Studentnavorser: _______________________ Datum:_____________________

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Datum:_______________

Ingeligte Toestemmingsvorm

Geagte Deelnemer

Ek is 'n Kommunikasiepatologie Meestersgraad student aan die Universiteit van Pretoria. Ter vervulling van die vereistes vir die graad M Kommunikasiepatologie, word daar van my verwag om 'n navorsingsprojek uit te voer. My studie is daarop gemik om vas te stel wat 'n gesin se ervarings is met dementia (siektetoestande wat onder andere Alzheimer se siekte insluit). Hierdie brief dien om aan u inligting oor die navorsingsprojek te verskaf en om u toestemming te vra om deel te neem.

1. Titel van Studie:
Die titel van die studie is "Narratives of a family regarding their experiences with Dementia of the Alzheimer's Type."
2. Doel van Studie:
Die doel van die studie is om die ervarings en lewensverhale ("life stories") van 'n gesin wat met Alzheimer se siekte te doen het, te ondersoek. Hierdie inligting kan gebruik word om beter te begryp wat die konsekwensies daarvan is om met Alzheimer se siekte/demensie saam te leef, ten einde meer toegespitste intervensie en bystand te kan lewer.
3. Navorsingsprosedure:
U sal gevra word om deel te neem aan drie gesprekke wat sal fokus op die gesin en die gesinslid met demensie. Elke sessie sal min of meer een uur duur. Ek sal u voor die tyd kontak om 'n tyd te reel wat u sal pas vir die gesprekke en die gesprekke sal vir u gerief by u huis gevoer word. 'n Bandopname sal van ons gesprekke opgeneem word sodat geen inligting verlore raak nie en sodat ontleding van die inligting op 'n betroubare wyse kan geskied. U sal gevra word om aan een laaste gesprek deel te neem wanneer die gesprekke klaar ontleed is. Hierdie sessie sal gebruik word om die bevindings van die vorige gesprekke te bespreek om seker te maak dat daar geen waninterpretasies van u opmerkings was nie.

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4. Geassosieerde risiko's en ongemak:
Daar is geen gesondheidsrisiko's of gevolge geassosieer met deelname aan hierdie studie nie.
5. Voordele:
Daar is geen direkte voordele as u aan in die studie sou deelneem nie.
6. Regte van die deelnemer:
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7. Navrae:
Indien u enige navrae het, kan u te enige tyd die navorser (083-468-9989) of die stuidieleier (012 420 2357) kontak.

____

Zandrè van Zyl
Departement Kommunikasiepatologie
Universiteit van Pretoria

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Studieleier

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Toestemmingsbrief

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Indien ek enige navrae het, ka ek enige tyd die navorser (083 468 9989) of die studieleier (012 420 2357) kontak.

Naam en Handtekening:

Deelnemer: __________________________ Datum: ___________________

Studentnavorser: ________________________ Datum: ___________________

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Transcription of three interviews

R: Reseacher
S: Subject

First Interview:

R: As ons kan begin, as oom net vir my vertel van u vrou, hoe u ontmoet het en hoe lank oom hulle al saam is.
S: Ja, ek het haar in S ontmoet in 1951.
R: Ok
S: en ek was by B Bank daai tyd gewees en sy was werksaam by S F, toe het sy…
S: ons het mekaar daar ontmoet en toe is ek verplaas na P toe en toe het sy haar werk ook daar bedank en toe het sy ook in P by 'n biblioteek gewerk en sy was verpleegster, sy was 'n gekwalifiseerde verpleegster.
S: En toe's ek weer terug verplaas B toe, daar naby E en toe het sy daar by E gewerk en ons is daar getroud in 1953, is ons daar getroud.
S: En ons het 'n tweeling, 'n seun en 'n dogter, wat op sewe maande gebore is en sy was van die Vrydag tot die Sondag aand in kraam.
R: Dis nogal lank
S: Ja, nee dit is lank. En toe het ons, daar was nie daai tyd 'n hospitaal op B nie, daar is nou nog nie een nie. Toe het ons 'n spesialis van E af gekry, die het gou die kinders….
S: Hulle was brug babas, toe is hulle gebore. Hulle het al twee saam ses pond daai tyd geweeg.
R: Sjoe, dis klein.
S: Ja, baie klein gewees omdat hulle op sewe maande gebore en ons is op B getroud, twee jaar daarna het ons weer 'n dogter ryker geword en toe is ons V toe. Op die goud myne gaan werk. Ek het die bank bedank en toe na die goud myne toe op V en daar het ek so vyf jaar gewerk en toe is ons weer terug E toe na die Paaie Departement en toe het, is ons laat lammetjie gebore, 'n seuntjie, Chris. En, dit is dit. Sy't toe nie weer gewerk, sy't as huisvrou al die jare gewees en so. En ons is nou gewees, wel, 52jaar getroud. Ek het agter gekom dat sy besig is om dinge te vergeet, agterdogtig te raak.
R: Wanneer het oom dit agter gekom?
S: Dit is 18 jaar terug. Hier by 1995 rond. En sy het sleutels toe gesluit, sy was bang hulle steel haar goed en sedert het sy sleutels begin wegsteek.
S: As gevolg moes ek baie kaste oopbreek en naderhand duplikaat sleutels vir al die kaste gemaak sodat as sy die kaste toesluit, die sleutel weggooi, dan weet ek om dit weg te bêre, dan hoef ek nie te soek nie.
R: Ja?
S: Dan sluit ek dit maar oop.
S: En dit het so agteruit gegaan en sy het begin om ook niemand eintlik vertrou of so nie, wantrouig geword en sy was nog nie daai tyd aggressief nie en…en toe het ons natuurlik verhuis na D toe.
S: En dis daar waar ek agter gekom het.
S: Toe wil sy altyd huis toe en sy wil huis toe gaan en sy soek haar pa en ma. Sy wil net huis toe gaan, en al die tyd is sy in haar huis. Dan het ek haar maar gevat en ry ek 'n draai met haar in die kar en dan kom ek terug en sê ek "jy's weer by die huis."
R: Het iemand al ooit vir oom verduidelik hoekom 'n persoon met Alzheimer's vra dat hulle wil huis toe gaan?
S: Nee, nee.

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R: Wat eintlik gebeur is hulle sê gewoonlik daai tyd waar hulle 'n kind was of waar hulle die gelukkigste was of waar hulle dit die meeste geniet het, is hulle huis, so te sê. So dit kan wees waar sy kind was of dit kan wees waar oom en sy eerste ontmoet het of waar sy haar kinders groot gemaak het. Sy wil heeltyd teruggaan na daai tyd toe wat sy onthou.
S: Is dit wat dit is?
R: Ja, want dis mos lang termyn geheue wat wasgelê is. Al hierdie nuwe plekke kan sy dalk nie onthou nie, dis hoekom sy heeltyd terug wil gaan na dit wat sy onthou, want sy's nie bang oor wat sy onthou nie, sy's bang oor wat sy nie meer kan onthou nie, die wat omlangs gebeur het. Sy's bang oor dit. So sy wil terug gaan na waar sy was.
S: Ja, en dis toe wat sy begin te loop en pad vat. Loop en loop, en toe besluit ek, nee ons kom maar hierna.
R: Wanneer het oom hulle hierna toe gekom?
S: Dis drie jaar terug, 2001.
R: En u kinders, was hulle nog in die huis?
S: Nee, hulle was almal uit die huis uitgewees.
R: Ok. En hoe het hulle dit gevat?
S: Hulle het dit maar moeilik gevat. Hulle het saam, hulle het eintlik besluit ek kan nie meer na haar kyk nie, want ek wou dit nie glo nie.
R: Het oom die heeltyd alleen na haar gekyk?
S: Ek het heeltyd alleen na haar gekyk. Toe het ons hierna toe gekom, nadat sy eendag die pad gevat en sy het geloop en ek het haar gelos en met die kar agter haar aan. Besig om te kyk waar haar nuwe huis is.
S: Sy't geloop en toe het ek haar opgelaai, terug gebring.
S: Daarna altyd as ek moes dorp toe gaan, ek het maar die huis toe gesluit, dat sy maar daar binne bly. Op daai stadium het ek haar heeltemal uit die kombuis uit weg gevat, want ek was bang sy brand. Ek het maar die kos kookery oor geneem ensovoorts. Dit is dit.
S: Nou dat sy hier is gaan dit baie bietjie slegter. Ek kyk nou nog na haar. Ons het 'n lang pad saam gekom, 'n verlede van 55jaar. Dis nie so maklik nie.
S: Maar ek het vrede daarmee gemaak.
S: Kyk, die klein brein krimp mos en ek het haar nou die dag by die psigiater gehad, by Dr. G en hy sê hoe kleiner die brein werk, hoe minder sal die medikasie word. Ons wil haar nou nie 'n zombie maak nie. En ek stem heeltemaal saam daarmee.
R: Oom soek darem nog die geselskap en die persoon wat indaai liggaam is!
S: Dis reg, ja! Definitief. Maar ons kommunikeer glat nie meer nie.
R: Glad nie? Sy praat nie meer nie? En as sy so praat, hoe is haar spraak?
S: Ja, haar spraak was alright. Toe sy nog. Maar dit het geluidelik heeltemal agteruitgegaan. Sy was baie lief vir lees en sy lees nou glad nie. Sy was baie lief om te skryf, sy skryf nou glad nie. Ek het nou die dag gesien sy vat 'n en sy krap so daar 'n paar dingetjies. En, uh, daar's nie meer kommunikasie.
R: Het iemand al ooit die tannie gediagnoseer met Alzheimer's?
S: Ja, al twee keer.
R: Wanneer was dit?
S: Die eerste maal was dit hier in die W Hospitaal, toe ons nog op D was. Dit was ongeveer hier in 1999, 1998. Toe het ek haar na 'n ander dokter, ek kan nie sy naam onthou nie, ook 'n neuroloog, hier by E M. En hy het haar ook gediagnoseer. Hy het haar byvoorbeeld gevra: pen, appel en hy vra haar drie vrae. Dan moet sy sê watter volgorder dit was. Of watter onderwerpe. Sy weet dit glad nie.

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S: Toe het hy haar gediagnoseer met Alzheimer's. Toe was sy op Ariset en toe ons hierna toe gekom het, het hy die Ariset weg gevat, hulle sê dit vertraag dit net. Ariset kan jou nie genees nie.
R: Ongelukkig is daar niks wat Alzheimer's kan genees nie.
S: Daar is nie.
R: Dis maar die liefde en tyd wat dit maak dat die persoon langer lewe.
S: Ja, nee kyk. Sy's baie dwalend en partydae onrustig en uh, as ek vir haar wil aantrek of so dan, uh, ek dink sy dink ek wil haar aanrand, dan baklei sy vreeslik. Byvoorbeeld haar broekie, langbroek wil uittrek of haar pantie of haar pajamas wil aantrek. Dis nie altyd nie. Maar partymaal veg sy kwaai.
R: En hoe hanteer oom dit dan?
S: Wel, dis moeilik. Ek hanteer dit maar en partymaal raas ek maar 'n bietjie, maar dit help niks nie. Ek het al by baie gehoor los haar alleen, los haar. Moenie argumenteer nie. Jy los haar en as jy weer 2 minute later met haar praat dan het sy skoon vergeet. Sy't skoon daarvan vergeet.
R: Wat was oom se reaksie toe hulle vir haar, die tannie, gediagnoseer het met Alzheimer's?
S: Ek het dit nie eers geglo nie.
R: Die dokters, het hulle dit verduidelik vir oom, wat die kondisie is, wat dit behels, wat…
S: Ja. Hulle het dit almal….
R: En het oom enige vrae gehad oor of, ek meen natuurlik wil jy weet wat gaan gebeur.
S: Ja, ja ek het gevra wat gebeur of daar nie 'n geneesing is nie of so. Ek het enige ding probeer.
S: Maar ek het baie kontak gehad met hierdie Alzheimer's mense.
S: En uh, ek het dit toe aanvaar, ek wou eers dit nie aanvaar nie, maar deur die genade van die Here moes ek dit maar aanvaar. Alhoewel, ek hou myself besig. Ek versorg haar en dat sy versorg is. Ek is onder andere nou Ouderling hierso van die ge, van die wyk en ons hou, ek reël die dienste hier elke dag. Ek hou my maar besig, sodat. Dit help nie, ek het toe ek hier gekom het, het ek gaan sit en tokkel. Dit help nie.
R: Nee, dit help nie. Oom se lewe moet ook aangaan.
S: Ja, ek het ook 'n lewe wat moet aangaan.
R: Hoe het die neuroloog vir oom Alzheimer's gedefinieer? Wat het hy gesê is Alzhemier's eintlik? Kan oom onthou?
S: Nee, ek kan nie regtig onthou nie. Hy't maar gesê die klein brein, die geheue brein, is besig om te krimp. Dis omtrent al wat hy gesê het.
R: Ok. En as familie, vriende of vriende van die familie ooit vir oom vra of in die begin daaroor gevra het, wat eintlik aangaan….
S: Kyk, ek het maar verduidelik dat sy Alzheimer's het en soos die neuroloog vir my gesê het dat die klein brein besig is, die geheue brein, besig is om te krimp. En dat daar nie geen medikasie is wat haar kan help nie.
R: En, uh….
S: Die kinders wou dit nie eers aanvaar nie, maar hulle het die gouer aanvaar as wat ek dit aanvaar het. En al wat hulle bevreeste is dit oorerflik. Tot 'n sekere mate glo ek dit is oorerflik. Nou die dag met die psigiater, uh, Dr. G gepraat, hy't gesê dit is geglo dat dit oorerflik is.
R: Ja, daar is partykeer daai moontlikheid…Um, weet u of die tannie se ouers…
S: Ja, haar pa. Maar daai tyd het hulle gesê dis verkalking van die are gewees. Dis snaaks, hy's die enigste een… Hy't 9 kinders gehad en, uh, ek's die enigste een wat hom

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kon kalmeer. Hy was baie aggressief. En hy't, die enigste een wat hy vertrou het was vir my, hy't byvoorbeeld my skoonma gewantrou as sy sop vir hom bring, moes ek eers aan die sop proe, om, uh, dat daar nie gif in is of iets nie. En ek glo dat dit toe al met Alzheimer's te doene gehad het.
R: Ja, as oom daar oor dink, dis dieselfde as met die tannie, daai wantroue.
S: Ja, maar sy is nie so. Ja, sy vertrou nie mense. Hy't beweer dat ons skoonma rond loop, toe sluit hy haar eendag in die buite toilet toe vir die hele nag. En, uh, al een wat hom eintlik kon kalmeer is ek. Hy't volle vertroue gehad in my. Hy't nie eers een van sy dogters of van sy seuns.
R: En die tannie, is sy die enigste een uit die 9 kinders wat Alzheimer's het?
S: Ja.
R: Die enigste een.
S: Ja, kyk haar suster wat ouer as sy is. Maar ek reken dis maar ouderdom. Sy is ook vergeetagtig en steek goed weg en so. Maar ek dink nie dis Alzheimer's nie
R: Ja, daar is mos baie spesifieke goed wat 'n mens na moet kyk voor dit as Alzheimer's gedifinieer word.
S: Ja, nee. Maar ek glo nie sy't Alzheimer's nie. Dit is maar ouderdom en vergeetagtigheid
R: En die tannie ooit, voordat sy nou minder begin kommunikeer het, is daar ooit 'n tyd wat sy gevra het wat met haar gebeur het?
S: Nee, nooit! Nooit dit genoem.
R: Nie.
S: Sy't my haar pa genoem en dan's ek weer haar jongste seun, Chris. Maar partydae herken sy dit nie. Maar daar is nie kommunikasie nie. Dis eintlik, uh, vir haar glo ek leef sy in haar eie wêreld.
R: Ja, hulle sê mos, wat oom nou gesê het as oom partykeer dalk haar wil aantrek, sy veg daarteen. Sy's in haar eie wêreld, so hulle sê 'n mens moet nooit as 'n persoon met Alzheimer's besig is om oor iets te praat en hulle is in hulle eie wêreld, moet jy hulle nie, sê "Nee, man waaroor praat jy? Jy's mos nou nie daar nie." Los hulle. Dis hulle persepsie van die wêreld en van hulle lewe. En dis wat hulle maak om bietjie langer te lewe as wat jy teen hulle gaan veg die heeltyd. Dis daai hulle, ek meen, maar om hulle te aanvaar hoe hulle is op die oomblik. En hulle nog steeds lief te hê.
S: Ja, nee.
R: Dan lewe hulle baie langer, as wat 'n mens….
S: Ja, aanraking help ook baie. Musiek help ook baie, weet. Ek is baie lief vir musiek. Snaaks weet, sy was altyd 'n mens wat kerk toe gegaan het en alles. Sy sing hierdie Halleluja liede wat ons hier sing, partymal sing sy uit haar kop uit. Jy kan hoor wat sing sy. Dit onthou sy nogal baie goed. En al waar sy baie stil en gelukkig is, is hier in die kapel. Jy kom baie maal, dan sit sy hier stoksiel alleen. Daar was eendag, ek het omtrent hier die hele plek plat geloop en gesoek en almal het gesoek na haar, hulle was in die kapel, toe sit sy agter die preekstoel op die stoel. Toe kon 'n mens haar nie sien daar nie. Daar het sy gesit.
S: Sy's geneig ook om te vergeet dat sy moet eet, sy vergeet ook om toilet toe te gaan. Hel, jy moet vir 2 mense dink.
R: Ja, dit is so.
S: Jy leer haar naderhand so ken en as sy rusteloos raak dan weet jy daar's iets wat hinder, vat jy haar toilet toe, of vra vir haar of daar pyn is of so. Sy voel nog pyn hoor. As jy haar hare kam en jy trek die hare, dan sal sy vir jou sê "Eina!"
R: En die mense hier by die Te Huis.

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S: Ja, hulle is baie lief vir haar.
R: Is dit? En hulle help oom ook?
S: Ja, nee.
R: Dit maak die werk ligter.
S: Die verpleegsters help baie. Maar 'n mens is te haastig. Hulle sit baie, byvoorbeeld in die Roos, is daar seker 10 Alzheimer's. So hulle kan nie spesifiek elke, so, hoe sê ek nou, so noukeurig na 'n pasiënt om sien nie, as wat ek doen nie.
R: Ja, hulle het so baie mense om na te kyk.
S: Om na te kyk, ja.
R: En die res van die mense in oom hulle se gang, het hulle ook mense wat saam met hulle bly of is baie van hulle alleen?
S: Nee, hulle is meeste. Ek is die enigste een.
R: Ja, dit maak 'n groot verskil.
S: Ek is die enigste een wat saam bly. Daar is van hulle wie se kinders nie eers meer kom of iets nie.
R: En u kinders, kom hulle nog?
S: Ja, hulle kom.
R: Hulle is in die omgewing?
S: Ek het nou agter gekom, uh, die dogter hier op, uh, Kameeldrif, hier op Callinun pad. Hulle is daar op 'n plot en, uh, daar. Ek vat haar ook nie eintlik meer saam soontoe nie, want jy moet heeltyd agter haar aan hardloop. So, die draad is geelektrifiseerd en al daai dinge en uh
R: Dis gevaarlik.
S: Ja, gevaarlik. As gevolg, as sy terug kom is sy heeltemal "haywire", weet.
R: Sy is gedisoriënteerd.
S: Dan los ek haar maar hier. En dan gaan ek gou bietjie na hulle toe en dan kom ek weer terug.
R: En, kleinkinders. Het hulle, um, hulle ouma geken voordat sy gediagnoseerd is?
S: Ja.
R: En sien hulle die verskil?
S: Ja, definitief. Die een kleindogter het sy nou die dag het sy so geraas. Sê sy "maar ouma ek kan mos nou nie, ouma." "Ja, maar my kind jy't dit en dit en dit gedoen." Sy't dit nie gesê nie, maar, sy sê los my en daai dinge weet. Hulle het nie hulle ouma so geken nie.
R: Nee, dis 'n groot aanpassing vir kleinkinders.
S: Ja, dis al wat hulle dalk, maar soos om bekommerd te wees of om stress te hê, glo ek nie hulle het so iets nie.
R: Nee, ek glo nie. En soos oom sê hulle vergeet om te eet en om badkamer toe te gaan, om klere, ek meen, nuwe, skoon klere aan te trek, hare te borsel. Al daai goedtjies, wat 'n mens. Dis nie meer belangrik nie.
S: Nee, dis nie meer belangrik nie.
R: En dis partykeer hoekom dit so probleem is met die etery, dan verloor hulle baie gewig.
S: O, ja!
R: En dan word hulle vinnig siek. Dis wanneer hulle vinnig agteruit gaan. Dis wanneer hulle al hierdie ander siektes optel. Ek meen, longonsteeking en al daai goed.
S: Nee, ek sukkel met haar om te eet. By die dag verloor sy gewig. Sy wil nie gevoer word nie. Moenie dink jy gaan haar mond oop kry nie.

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R: Was daar al 'n Spraakterapeut hier om met oom te praat oor alternatiewe voedings maniere.
S: Nee.
R: Oom moet dalk vir die verpleegsters vra dat hulle iemand in bring. 'n Verpleegster kan dit doen, 'n dokter ook, of 'n spraakterapeut of 'n dieetkundige ook. Maar dis goed, dat al vier van die mense saam werk. Dat die dieetkundige kan sê wat om vir haar te gee, die spraakterapeut hoe om dit te doen, want die spraak en eet strukture is dieselfde. Maar die dokter en verpleegster om die susters hier…
S: Ja, hulle sê vir my wat om vir haar te gee wat sy lief is voor en so. Maar om haar mond te probeer oop te kry is 'n groot probleem.
R: Het oom al daar aan gedink om 'n, wat ons noem 'n PEG in te sit. Dis 'n buisie wat hulle in haar maag sit.
S: Ja, nee op een of ander stadium sal dit seker gebeur.
R: 'n Mens kan dit nou al doen, dis nie iets wat 'n mens moet doen as sy bedlêend is nie. 'n Mens kan dit nou al begin doen. Dat oom hulle vir haar kan help.
S: Nou goed, maar dankie!
R: Groot plesier!

<u>Second Interview</u>

R: Hierdie gesprek gaan bietjie korter wees as verlede keer want ons het baie van die goed al bespreek.
S: Ja, en ek het nie veel meer te sê nie.
R: Nee, dis reg. Ek wil graag weet hoe oud was oom se vrou toe sy gediagnoseer is met Alzheimer's.
S: Dink 63, toe sy gediagnoseer is.
R: 63?
S: Ja, ongeveer 63. Dis nou 10 jaar wat sy so is en….
R: Sy is nou 73.
S: Ja 73.
R: Ok. Laas het ons gepraat oor hoe u lewe was saam met u vrou.
S: Uh…
R: Voordat sy gediagnoseerd is met Alzheimers. Hoe is dit nou, deesdae, hoe is dit nadat sy gediagnoseer is?
S: Kyk, dit het met tye verswak, so ek al gesê het… Sy het begin om sleutels, jy ken die storie.
R: Ja.
S: En, um, maar wat ons huweliks lewe betref, daar's nie meer so iets nie, soos huweliks lewe, afgelop 8, 9, 10 jaar. Want, uh, ek kyk maar na haar omdat ek, weet, uh, ek voel, uh, nie dat ek verplig is nie, maar omdat ek darem 'n hele pad saam haar kom.
R: Ja, oom is nog lief vir haar.
S: En sy's die moeder van my kinders en ja. Dis so.
R: Ja, ek glo nie dis verpligtend nie, dis maar jou lewe.
S: Ek weet nie, baie mense sal dit's hoe ek dit hier sien, kom hulle laai hulle familielid of eggenoot hier af en dan ry hulle in vrede. Ek kan dit nou maar net nie doen nie.
S: Ek gaan nou op 'n Dinsdag, nee Maandag, as dit die Here se wil is, gaan ek bietjie wegbreek. Ek gaan op 'n toer hier af Laeveld toe.
R: Dis lekker. En die tannie, sy gaan bly?

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S: Nee, sy gaan bly, nee. Daars nie 'n manier wat ek haar saam kan vat nie. Byvoorbeeld as ons hier na die plot toe gaan, hier by my dogter, hier op Kameeldrif. Ek vat haar ook nie meer soon toe saam nie, want, um, jy rus nooit nie. Hulle is mos altyd aan die gang om te loop. En dis maar neiging. En dan loop sy en die draad is geelektrifiseerd en jy moet net 'n oog oor haar hou. Sy loop so stadig, maar hoor hier sy loop.
R: As sy eers begin dan hou sy nie op nie?
S: Ja, en die aande bring ek my tyd deur. Ek het, um, CD speler met alles wat musiek, kyk, eks vreeslik lief vir musiek. Ek kyk nie eintlik meer televisie nie, want daar is maar niks.
R: So oom sê die siekte toestand het baie verander vandat sy eers gediagnoseer is, of…
S: Ja, geleidelik af.
R: Geleidelik afgegaan, nie ewe skielik nie.
S: Nee, nee. Dis 'n storie wat geleidelik gaan. Ek kom nou 'n lang pad daarme saam. Maar, uh, huidige stadium is dit moeilik, soos jy weet sy eet nie, sy vergeet om te eet, sy vergeet om toilet toe te gaan, sy vergeet wanneer sy dit moet doen en dis altyd vir haar sê.
R: Wat se inligting gee die dokters, neuroloog vir oom oor die feit dat sy nie meer eet nie of vergeet om te eet, of toilet toe te gaan…
S: Nee, wat hulle praat maar van doeke en daai dinge, en ek oorweeg dit self om haar op doeke te sit. Maar dis nou weer 'n ekstra uitgawe. Op die huidige stadium, um, vat ek haar 8uur in die aande toilet toe en dan het ek opdragte vir die verpleegsters om haar elke 4 ure te vat.
R: O, dan vat hulle haar?
S: Ja, maar ek is wakker sodra hulle in die kamer inkom.
R: Ja, ek kan dink, 'n mens slaap dan nie lekker nie.
S: En, uh, ja. Huweliks lewe is daar natuurlik nie meer nie.
R: So oom sê sy't enige, is sy nog, stel sy nog belang in enigiets?
S: Niks.
R: Niks.
S: Niks, niks. Sy stel glad nie belang in enigiets nie. Sy was 'n baie presiese vrou, netjiese vrou. En sy was baie lief vir lees. Ek het al die tydskrifte vir haar gekry, sy het aan 'n boekklub behoort. Sy het nou die dag probeer skryf, sy't die pen so gevat en 'n paar lyntjies getrek. Dit was dit. Ja, jy't gevra wat sê die neuroloog, toe het ek jou in die rede geval.
S: Ek was by uh, 'n psigiater, ja, Dr. G. Hy't toe gekyk na haar medikasie. Hy't nou vir haar 'n pil voor, 'n vitamien pil voorgeskryf wat haar eetlus sal gee.
R: O, ok.
S: Maar, ja.
R: Het dit nog nie begin help nie. Hoe lank is sy nou op hierdie vitamien pil?
S: Omtrent 'n maand al.
R: 'n Maand. Partykeer is dit nie jou eetlus nie, jy vergeet om te eet.
S: Ja, jy vergeet om te eet. Jy vergeet jy's honger of dis wat ek vermoed. Kyk ek gee…
R: Ja, sy kan dalk onthou maar as sy by 'n ding uitkom dan dink sy maar hoekom was ek eintlik hierso, is ek eintlik honger en dan wil sy nie weer eet nie.
S: Ja, ek gee haar, ek sit haar kos voor haar neer, dan gee ek haar lepel in haar hand, as sy eet dan sal sy 3 lepels eet dan sal sy opstaan. Wel, ek los haar en dan vat ek haar net so rukkie en sê ek weer "eet" dan het sy nou vergeet dat sy wel 3 lepels geëet het.
R: Ja?

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S: Verstaan? Dis maar soos die mensies is hoor. En, uh, as ek uittrek partymal dan sê sy ek wil haar aanrand of iets, dan is daar hengse argumente, maar ek, ek het uit ondervinding het ek geleer dit help nie om met sulke mense te redeneer nie.
R: As, oom sê uit ondervinding, is dit maar uit ondervinding met die tannie of deur goed wat die dokters vir oom gesê het ?
S: Nee, wat. Die ondervinding met die tannie. Ek het …dit help nie, ek loop maar uit die kamer uit. Want as ek terug kom, dan is sy weer baie lief vir my.
R: Ek dink, ek het laas vir oom gevra oor oom se kinders en kleinkinders, hoe ervaar oom se eie kinders dit nou op die stadium hoe die siekte ontwikkel het. Is hulle, hoe is hulle gevoelens daaroor, hoe reageer hulle?
S: Ag, maar dieselfde as ek. Ag, weet jy dis moeilik eintlik vir.. ek glo nie dis moeilik vir 'n Alzheimer's pasiënt nie, maar, uh, vir die mense na aan haar is dit maar moeilik. Hulle aanvaar dit maar net soos ek dit aanvaar. Dit is eintlik ook moeilik, die een dogter het nou die dag gesê "Pa, ons moet ma maar liewers toegegooi het." Dit sou beter gewees het as wat sy so is. Nou is hulle bekommerd, want hulle sê dis in die gene. Hulle glo nou dis in die gene en ek weet tot 'n sekere mate, ons het nou die dag daaroor gepraat, die oorerflikheid, toe jy gesê het dit is moontlik en so. Maar, uh, dit is dit.
R: Ja, dis maar 'n ding waarme jy moet saam lewe en kyk hoe vorder dit. Glo oom as oom nou vir iemand verduidlik oor Alzheimers dat dit, dat dit goed beskryf. Sou oom ooit enige iets anders daarby wil, ekstra wil weet oor Alzheimers, ekstra inligting.
S: Ag, kyk, uit ondervinding leer jy baie beter as wat jy lees.
R: Ja, nee dit is so. Het oom baie inligting stukke gelees oor Alzheimers of..
S: Ja, ek het, uh, baie gelees, maar nie veel nie. Soos ek jou gesê het, haar pa was daai tyd, ek het jou mos vertel, haar pa het. Daar by het ek bietjie gesien wat is dit en so is hoe dit werk.
R: Het die dokters daai inligting stukke vir oom gegee of het oom dit self gaan soek?
S: Nee, ek het maar, die dokters het maar, jy weet hulle kan ook maar sê alright dis Alzheimer's, die neuroloog sê vir jou alright. Sy vra vir jou 2 vrae, pen, potlood en dit en dan kan sy. Dan identifiseer hulle dit en sê hulle kan niks daaraan doen nie.
R: Ja.
S: Klein brein is besig om te krimp. So, uh, die meeste wat ek weet van Alzheimer's is maar deur ondervinding.
R: Voel oom dat die dokters genoeg inligting vir oom gegee het? Kom ons sê die dokter self…
S: Nie eintlik nie.
R: En die neuroloog?
S: Nee ook nie.
R: En die psigiater?
S: Die psigiater het maar gevra hoe, soos jy nou maar vra en so. En ek het maar daai tyd gesê die, uh, eintlik wou hy net gesê het dat, uh, die bewerigheid, as sy begin bewe dan dink ek sy kry koud, sê hy dis nie dat sy koud kry nie, dis 'n newe effek van die Risperdol.
R: O, ok. Dis interressant.
S: Dis 'n newe effek. Toe het hy net gesê hy wil nie vir haar 'n sterker pil gee nie, want hy wil nie van haar 'n zombie maak nie. Ek stem heeltemal saam. Dis maar al wat hy gesê het.
R: En in die begin, oom het nou deur ervaaring geleer, oom het nie nou op die huidige oomblik inligting nodig nie. Maar in die begin toe hulle haar gediagnoseer het, sou oom

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meer inligting wou gehad het van die dokters af, dat hulle vir oom presies gesê het hoor hier dis presies die simtome, dit is wat kan gebeur, dit kan ook nie gebeur nie maar…
S: Nee.
R: Sou oom dit graag wou gehad het?
S: Ag, ja, tot 'n sekere mate dat ek gereed was. Die feit dat hulle gesê het die klein brein verswak, sy, hoe so ek nou sê…dat netnou sal sy nie onthou wat het gebeur nie, maar wel wat in die verlede was.
R: Ja.
S: En ek sien, sy onthou nie eers meer wat in die verlede gebeur het nie. Ja, in die begin stadium het ek baie met haar oor die ou dae gepraat en oor haar pa hulle, so dan het sy haar pa hulle onthou. Sy't altyd na haar pa gesoek. En dan sê ek vir haar "Pa is oorlede." Stry sy, nou ja. Maar, deesdae voel sy vere daarmee. Dan sê ek vir haar onthou jy vir ma, onthou jy vir pa. Sy antwoord my nie eers meer nie.
R: Het sy enige gesig uitdrukkings nog of…
S: Nee. Ja, so dra daar meer as 2 by haar kom, die verpleegsters, dan kan jy sien sy….
R: Angs?
S: Angs. Partymaal lag sy nog…..
R: En as die kinders kom kuier, lyk dit as of sy hulle herken en onthou wie hulle is?
S: Nee.
R: En met oom?
S: Partymaal.
R: Partymaal. Ok, en as sy fotos van hulle sou sien?
S: Nee, ek het baie fotos en so.
R: Geen reaksie oor wie hulle is nie?
S: Ja, sy sal sê dit is die tweeling, sy sal miskien sê dis Tossie en dis ook al. Sy sal nie sê die ander een is Boetie nie.
R: Ja. Oom het laas gesê sy kommunikeer nie meer nie.
S: Ja.
R: Niks nie?
S: Nee.
R: Nie eers "hello" of iets nie?
S: Nee, nie eers hello of niks nie. Sy sal miskien net so lag. Kyk daar is sekere tye wat ek glo dat hulle bietjie helderder is as ander tye, hoor. Definitief. Partykeer sal sy my herken en ander dae nou weer nie.
S: Byvoorbeeld, sy sal 'n toilet herken en dan sê ek partymaal vir haar "gaan pie-pie nou" en dan sal sy haar broekie aftrek en dan vergeet sy om die pantie af te trek. Dan wil ek net die pantie aftrek.
R: Sê vir my is daar enige inligting wat oom nou aan kan dink wat oom sal verder wil weet oor Alzheimer's? Oor wat met haar op die oomblik gebeur of wat dalk in die toekoms kan gebeur of…
S: Ag, nee wat. Kyk ek het dit hier ondervind. Ek is al 3jaar hier en die 3jaar het ek gesien hoe gaan die mense agteruit en hoe hulle dood gaan en al daai goed.
R: So, dis eintlik goed dat oom hier is.
S: Ja, dis goed dat ek hier by haar is.
R: En dat oom ook kan sien hoe dit met die ander mense gaan wat Alzheimer's het.
S: Nee dis so!
R: Ok, is daar enigiets anders wat oom nog vandag oor wil praat?
S: Nee, wat.

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R: Ok, die volgende gesprek sal ek net graag bietjie oor die tannie se kommunikasie gesels en dan die laaste een sal net wees om seker te maak dat daar nie enigiets anders is nie.
S: Nee maar goed. Wanneer is die volgende een nou weer?
R: Die volgende een is nou weer in Junie. Maar ek sal oom weer skakel. Gaan oom weg in Junie?
S: Maar gedurende die Junie maande is die studente wat ek toesig hou hier, wat eksamen skryf.
R: Wanneer is dit?
S: Ek weet nog nie. Ek het nog nie my rooster van P Universiteit gekry nie.
R: Gaan oom dan P toe?
S: Nee, nee, nee. Dis so 'n sentrum hier.
R: Oom is nogal besig.
S: Nee, ek is besig. Ek glo dit is al wat my aan die gang hou. Ne ek is baie besig, ek is besig om tuin te maak, daarom dis hoe ek lyk.
R: O, ag nee! Maar ek sal oom skakel oor die volgende keer.
S: Nou goed.

Third Interview

R: Ok, ons sal vinnig klaar maak dat oom weer by die tannie kan uitkom.
S: Ja, nee. Ek het nou nou baklei met hulle, hulle het haar nog nie eers reg gemaak nie.
R: Is dit? Het hulle haar vergeet?
S: Ja, nee, sy loop dwaal vanoggend. Ek het hulle mooi gesê, hulle moet kyk 4uur dat hulle haar kos gee, maar hulle sê sy het geëet.
R: O, ok. Ek wil by oom hoor, dit is nou die laaste gesprek. So kan ons sê. Ek gaan net nog een keer kom net om alles afterond. Maar vandag se gesprek gaan net min of meer oor die Alzheimer's siekte self. Wat ek graag wil weet is of oom enige verdere inligting benodig van die dokters af.
S: Van die dokter af?
R: Ja.
S: Ag, nee wat. Ek kry inligting van Alzheimer's, ek het die video wat hulle gespeel het, 'n Engelse video, wat ek na kyk en so.
R: Is dit van die Alzheimer's Association wat oom…
S: Nee, dit is wat, kyk ons het baie Alzheimer's hierso. Hulle lei die verpleegsters daar op hierso. Om, uh…
R: Om hier te kan werk?
S: Om hier te kan werk. Want daai hele gang waar ek in is, is Alzheimer's.
R: O, so dis maar meer van die inligting wat oom hier kry?
S: Ja, ons het 'n opleidings skool hierso vir verpleegsters. En ons het 'n dosent wat dit doen en sy gebruik daai videos "Abuse of the Elderly" en ag daar is verskeie videos wat hulle…..swat.
R: Wie is die dosent wat hierso is?
S: Mev., sy is M. Sy is 'n Hongaar, sy's met 'n Hongaar getroud.
R: Wat sou oom sê is die grootste probleem met die tannie? Wat oom ervaar?
S: Ag, ek glo nie sy ervaar enigiets nie, hoor. Maar, wat ek ervaar is dat 'n mens vir twee mense moet dink. Weet, ek moet vir myself en vir haar ook dink. Dink, wanneer is naasteby, maar mens leer dit naderand so aan, jy kan sommer in haar gesig lees as sy toilet toe wil gaan of…
R: Is dit moeilik vir oom, dan om met oom se lewe ook aan te gaan?

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S: Ja, nee, dit is eintlik maar moeilik, maar ek hou my besig maar hierso. Ek is maar net hier naby. Ek wil nie by die kinders gaan bly nie.
R: Ja, dis oom se vrou.
S: Ja, hulle het, hulle is ‘n generasie op hulle eie. Daar gaan dit eers eensaam wees. So ek hou dit maar uit hierso.
R: Is oom eensaam hierso?
S: Nee, ek is nie eintlik eensaam nie. Ek hou my baie besig, ek is voorsitter van die huis kommitee en ons doen fondsinsameling en ons reik uit en ek ry baie saam uit om aankope te doen, al daai dinge.
R: So..
S: Ek hou my baie besig.
R: So oom sê oom is ‘n goeie persoon om met te praat as iemand oor Alzheimer’s wil weet?
S: Ja, nee, jy behoort te weet.
R: Ja, maar ek bedoel nou soos iemand wat wou inkom, ‘n ander getroude paar wat wou inkom dalk en die man of die vrou het Alzheimer’s, sou oom bereid wees om met hulle te sit en gesels?
S: Ja, weet ek het dit al gedoen, maar die groot probleem is hulle kom en laai hulle vrou of die vrou laai die man af, hulle gaan aan met hulle lewe en ek het net nie daarvoor kans gesien nie, dit is nou maar in my.
R: Ja, dit is so. Dink oom dat daar is spesifieke inligting wat dokters of neuroloë vir ‘n persoon moet gee wat se gesinslid Alzheimer’s het?
S: Ja, kyk. Ek het baie opgelees daaroor, maar hulle het jou gesê dat jy nie met haar kan argumenteer of al daai dinge nie. Maar hulle het nie eintlik baie vir my gesê oor Alzheimer’s nie, hulle het gesê sy het Alzheimer’s en dit is dit en dit en dit en daar is nie ‘n, ja daar is nie ‘n medikasie wat dit, uh, soos ek gesê het Ariset vertraag dit.
R: Sê nou oom ervaar ‘n spesifieke ding met Alzheimer’s die siekte, wat oor en oor gebeur, maar oom het nie daai inligting gekry van die dokters af nie. Sou oom sê dat in die vervolg moet dokters suke inligting vir die familie verskaf?
S: Ja, nee ek sou dit regtig as ‘n, as dit ‘n ordentlike dokter is sal hy dit doen, sal hy vir jou sê wat om te verwag en al daai dinge.
R: Voel oom dat oom ‘n rol speel in die versorging in u vrou, in die besluite wat die dokters dalk sal neem sal hulle vir oom vra “wat is u opinie, sal sy as sy vir haarself kon praat en besluite neem sou sy sit wil doen, sou sy hierdie terapie of hierdie medikasie wou neem?” Voel oom, oom is deel van daai besluit neming?
S: Ja, nee, kyk dit is soos ek gesê het ek was by Dr. G, hy’s ‘n ……psigiater. Hy’t gevra watter medikasie, hoe werk die medikasie en ek moes hom toe maar gesê en goed. En daar by het ons toe die medisyne aangepas. So ek het ‘n deel daar gehad.
R: So hy het vir oom vra gevra oor die tannie?
S: Ja, Dr. G het, maar nie die neuroloë nie.
R: Nie, het hulle nie oom betrek by die behandeling of toetsing of die uitslae nie?
S: Soos ek jou gesê het, hulle het maar net gesê sy het Alzheimer’s, daar is nie ‘n geneesmiddel nie.
R: Ok, en hierso by die Te Huis, is die susters hierso? Toe oom in gekom het, het hulle baie vrae gevra oor die tannie watter tipe goed hou sy van…?
S: Ja, hulle het. Dit het hulle alles. Kyk hulle evalueer die geskiedenis.
R: So oom sê hulle neem oom se gedagtes en besluite in ag as hulle iets moet doen?
S: Byvoorbeeld, hulle het gevra of sy al op doeke moet kom en dan het ek gesê, nee dis nog nie op hierdie stadium nodig nie.

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R: Ek's bly daaroor. As die tannie nou nog kon praat, hoe aktief sou sy gewees het in haar, in die besluit nemings? Was sy 'n baie aktiewe persoon…
S: O, ja, sy was baie. Sy was baie aktief, sy was 'n baie netjiese, sy't haar sê gesê, sy het 'n sterk persoonlikheid gehad, baie sterk persoonlikheid. Jy sou nie sê dis dieselfde vrou wat net 55jaar terug met getroud was nie.
R: Sou oom sê dis moeilik om te sien hoe dinge nou verander het, veral vir oom, om te sien sy het so sterk persoonlikheid gehad en nou ewe skielik kan sy nie meer…
S: Niks, niks. Dit is tragies, traumaties, maar wat jy moet dit maar verwerk, wat kan jy daaraan doen?
R: Is daar ooit mense wat vir oom vra wat hulle vir oom kan doen, watter inligting wil oom hê, hoe kan hulle dit makliker maak vir oom?
S: Ja, wel, uh, die bestuurder, Mev. L. sy is baie opgelei, sy het baie met Alzheimer's, sy spesialiseer in Alzheimer's. Ek en sy gesels baie daaroor.
R: Hoe dink oom sou dinge gewees het as oom, byvoorbeeld by die huis was en..
S: Nee, dit sou nag gewees het.
R: En byvoorbeeld nie hierdie ondersteuning sisteem gehad het by die Te Huis wat soveel ervaring het met Alzheimer's.
S: Nee, dit sou nag gewees het. As ek iewers alleen gegaan het, sou hulle haar moes toesluit. Kyk, dit is veilig hierso, sy kan nie uit nie. Sy's nie toegelsuit nie, sy kan beweeg soos hulle wil. Hierdie mense glo daaraan, baie van hierdie ouetehuise, soos by voorbeeld Huis V en als, hulle het ook Alzheimer's, maar hulle word opgesluit. En in hierdie geval nie. Hulle gee hulle vryheid en om te doen wat hulle wil.
R: So oom sou nie in enige ander opset wou wees nie. Hierdie is die ideale opset vir oom. Neem u kinders nog deel in besluite?
S: Ag, nee wat ek doen. Hulle weet nie wat aangaan nie. Hulle sien net hulle ma en dan is hulle baie treurig en…kyk as jy nie so persoon elke dag sien nie…ek was by voorbeeld 'n week weg, toe ek terug kom toe was dit vir my sy het agteruit gegaan. En hulle ervaar dit elke keer so.
R: Hoe sou oom sê, vandat ek en oom begin praat het, hoe het die tannie se, bly sy die selfde of het sy al af gegaan in hierdie afgelope drie maande, het sy baie agteruit gegaan?
S: Nee, sy het nie eintlik agteruit gegaan. Sy's meer rustig.
R: Rustiger?
S: As gevolg van die aanpassing van die medikasie.
R: Wat verwag oom van die toekoms? Oom weet van al die tipe goed wat aangaan, wat kan gebeur. Wat verwag oom…
S: Ag, ek sal maar wag dat sy agteruit sal gaan, en naderhand bedlêend wees, of in 'n stoel sal vasgemaak word, maar ek kyk maar nie voorentoe nie. Bedoel ek leef van dag tot dag.
R: Veral met sulke tipe mense, dis moeilik.
S: Jy kan nie voorspel nie, kyk daai mense, en ek glo, hulle word nogal oud en dit, want hulle het nie bekommerrnis of iets nie. As sy wil pie-pie dan pie-pie sy.
R: As oom besluite neem, dink oom oor hoe sy was en hoe haar gevoelens sou wees oor iets of hoe sy dit wou hê? Neem oom dit in ag en dan neem oom 'n besluit of neem oom besluit in die oog van wat nou gebeur?
S: Ek weet wat sy geëet het, of waarvan sy gehou het en daai dinge, dan kyk ek dat sy daarvan kry.
R: So oom sê oom berei oom eintlik voor maar vir die toekoms om dit dag vir dag te vat?
R: 'n Mens kan ook nie nou al begin bekommerd raak oor dit nie, jy weet nie hoe lank dit gaan vat nie.

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S: Nee, my kinders het gesê ons moes liewers vir ma toegegooi het, dan was dit beter gewees. Ek sien dit partymaal so, maar……
R: Sy is nog, soos oom sê, sy het nog die vryheid om rond te loop en…
S: Ja, maar sy praat nie meer nie. Vir my is sy so te sê dood.
R: Maar daar is tog tye wat sy dalk 'n "peak" het.
S: So nou en dan. Dit gebeur maar selde deesdae. Sy sien my baie as haar pa of sy sien my as haar jongste seun, dan sal sy sê, sy sal nie hello sê nie, sy sê "Chris kom hier." Of "Pa kom hier."
R: Sal sy nou nog praat?
S: Ja, sy't nou die, sy praat dan roep sy "Chris."
R: So daar sal nou en dan 'n paar uitininge wees wat sy dalk sal sê?
S: Sy praat so deurmekaar, jy kan dit eintlik nie mooi verstaan wat sy sê nie.
R: Hoe hanteer oom dit dan as sy iets sê wat oom nie verstaan nie?
S: Sê maar "Ja, nee dis reg so, Gogga" ek noem haar gogga en sy het my Kaffer genoem. Sy't nou die dag gesê "Hallo Kaffer."
R: Ek dink dit moet 'n ervaring wees om so lang pad met iemand te loop.
S: Ja, nee dit is.
R: Het oom enige vrae?
S: Ag, nee wat nie eintlik nie.
R: En enigiets anders wat oom wil deel oor die tannie oor oom hulle se geskiedenis saam, die pad wat oom hulle al geloop het met Alzheimer's?
S: Ag, nee, ons was baie gelukkig gewees. Soos ek al gesê het, sy was 'n pynlike netjiese vrou, nou nog as sy daar staan, sal sy so vryf, vryf op die kussing. Vra ek haar wat maak jy, maak jy skoon. Sal sy jou nie aantwoord nie, maar ek weet in haar geheue werk sy in die huis.
R: Soos oom sê, oom hulle is al 53jaar saam, oom ken die tannie beter as enige iemand anders.
S: Definitief.
R: So die feit dat oom hierso is saam met haar, sy sou al verlore gewees het as oom nie hier was nie.
S: Ja, nee. Sy erken dit nie meer nie. As ek weg gaan, sy weet dit nie eers nie.
R: Ja, maar die tog…
S: Ja, dis belangraik. Sy het baie maal op my bed gaan lê en so.
R: Ag, ja, sy het oom gemis. Sy sê dalk nie dat dit belangrik is nie, maar, sy sal dit voel as oom nie hier was nie.
S: Ja, maar soos ek sê, daar is nie 'n manier nie, ek hou my eerder besig of gaan lê maar in 'n kamer, maar daar is nie 'n manier wat ek by die kinders. Ek gaan haar nie drop nie…weggaan nie.
R: Ja.
S: Nee, ek het te veel lang pad met haar.
R: Ja, dit is. Ok dis al nou.
S: Is dit al?
R: Dis al vir vandag.

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Closing Interview

R: Dink oom die tannie was bewus van die feit dat haar pa dalk Alzheimer's gehad het en dat sy ook dalk eendag dit kan erf?
S: Nee glad nie.
R: Nie.
S: Nee, kyk daai tyd het hulle dit genoem verkalking van die are, weet. Sy was bewus daarvan dat haar pa, vergeet. Maar hy's nie gedianoseer daai tyd as Alzheimer's nie.
R: Ja, want dis 'n rukkie terug.
S: Nee, dis darem al…..nee ek weet nie.
R: 'n Hele rukkie terug
S: 74 is hy oorlede, so dit was hier 64 gewees.
R: Maar oom was min of meer bewus daarvan dat oom begin leer het oor Alzheimer's, dat dit dalk.
S: Ja, toe het ek besef wat dit was. Maar daar is 'n verskil tussen Alzheimer's en gewone ouderdom.
R: Ja, definitief. Dis gewoonlik, hierdie gesprekke noem ons min of meer soos 'n storie, dis die storie van oom en die tannie se lewe saam, of die tannie se lewe. Waar sou oom sê het oom hulle se storie begin?
S: Toe ons mekaar ontmoet het?
R:Ja, sou oom sê dit is waar oom hulle se storie begin het?
S: Ons was in Swaziland, daar het ek haar ontmoet.
R: Wat sou oom sê is die grootste gebeurtenis van oom hulle se storie?
S: Die grootste?
R: Ja, soos toe oom hulle ontmoet het, toe oom hulle getrou het, soos gedeeltes uit oom hulle se lewe saam.
S: Die grootste storie was toe my tweeling gebore is.
R: Is dit? Hoekom sou oom so sê?
S: Nee, dit was dramaties gewees, hulle's nie in 'n hospitaal gewees, ons kinders is op 7maande gebore en hulle was brug babatjies gewees, hulle was maar saam 6 pound, 3 pound gewees, ja. Daar was nie 'n hospitaal naby nie, dit was daar op B gewees. En dat hulle in 'n broeikas was.
R: Hoe het die tannie dit gevat?
S: Nee, sy was heeltemal gesond.
R: Geen probleme daarmee nie?
S: Nee dit was heeltemaal normaal. Haar probleem is hier, begin 98, 94.
R: 94. Is ek reg as ek sê oom het 'n goeie ondersteunings sisteem hierso by die ouetehuis?
S: Ja.
R: En familie en vriende is…
S: Familie en vriende, hulle is baie lief vir tannie, en als, help my met haar.
R: So oom se ondersteuning sisteem bestaan basies uit familie, vriende, die ouetehuis, die verpleegsters hierso?
S: Ja, ek moet kyk dat ek my besig hou. Kan nie op 'n hopie sit hier.
R: Is daar enigiets waaroor oom ongelukkig is, dalk met die siekte, of by die ouetehuis, iets wat oom dalk anders sou wou gehad het?
S: Nee, nie eintlik nie. Maar ek is nie ongelukkig daaromtrent nie, ek verstaan dit. Hulle kan haar nie so intensief hanteer soos ek nie. Hulle kan nie toe lê op een persoon nie. Ek begin my nou af te skaal, dat hulle maar nou bietjie oorneem, 'n mens kan nie al die aandag gee nie.

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R: Sou oom sê mense wat Alzheimer's het dat dit 'n goeie idee het dat hulle in 'n ouetehuis is?
S: Ja, maar hulle moet net voorsiening maak daarvoor. Hulle moet net nie toegelsuit word nie. Wat ek verstaan, van die ouetehuise wat hulle in 'n kamer sit en toesluit. Hier beweeg hulle rond.
R: So 'n ouetehuis wat voorsiening maak vir mense met Alzheimer's en dat hulle familie dalk meer deel is van hulle ondersteuning as enigiets anders?
S: Kyk die idée van die kinders daai tyd was gewees dat, soos ek vir jou gesê het, dat ek by hulle moet gaan bly en…toe sê ek "ikona" ek bly hier by haar. Hulle het hulle eie lewe wat hulle lei, hulle het hulle eie vriende, hulle gaan werk almal. Wat maak ek daar?
R: Hierso het oom darem mense wat die selfde ouderdom as oom is.
S: En ek hou my besig.
R: Sou oom sê daar is enige ander tipe ondersteuning wat oom dalk verwag oom sal moet hê in die toekoms?
S: Ag, nee nie eintlik nie. Dit, gaan slegter en slegter en ek besef dit en aanvaar dit en dis hoekom ek my effens onttrek dat hulle bietjie oorvat.
R: As oom sê dit gaan slegter en slegter, sou oom sê van die punt waar die, van oom hulle ontmoet het, het dit baie goed gegaan en toe by die diagnose het dit begin afgaan, as 'n mens…
S: Nie die verhouding tussen ons nie, maar wat haar siekte aanbetref.
R: En haar kwaliteit van lewe?
S: Kwaliteit van lewe het af gegaan, definitief.
R: Van die diagnose begin af gaan?
S: Ja.
R: Is daar enige "peaks" wat ooit gebeur het, van dat die diagnose gemaak is?
S: Nee, van tyd tot tyd is sy weer helder, maar nie meer eintlik nie. Dis meer geleidelik so af, soos 'n grafiek. Die grafiek loop so (wys met sy hande hoe die grafiek af loop). Dit het geleidelik begin, nou gaan dit al hoe meer af, die grafiek loop al. Hy't eers so geloop, nou loop dit so (wys weer hoe die grafiek loop).
R: So dis 'n grafiek wat basies geplato het, nou begin dit af gaan? Dink oom dis belangrik dat elke familielid 'n rol speel in die persoon se lewe wat Alzheimer's het.
S: Ja, hulle behoort, maar party, soos bevoorbeeld haar broer. Hy kan dit nie vat dat sy so is nie, en hy kom net hierso dan sal hy omtrent vir 10min hier wees, dan kan jy sien Tollie…
R: Hy kan dit nie hanteer, hy kan dit nie verwerk nie?
S: Hy kan dit nie verwerk nie, dan ry hy.
R: Maar wie nog in dit familie?
S: Dis omtrent al.
R: Verder het almal dit maar aanvaar?
S: Ja, my kinders aanvaar dit.
R:Het sy enige ander boeties en sussies?
S: Die een is Issa, sy is net so vergeetagtig, maar hulle sê sy het ook nou Alzheimer's, sê ek vir haar nee sy het nie, dis ouderdom. En, sy't een suster, sy's in haar 90's, sy's nog helder en alles, en dan is dit Issa, dan is dit sy, ou Brunnie sy is nog reg, Tollie is nog reg. Daar is nog 5 wat lewe van die 9.
R: En dis net die tannie uit die 9 kinders wat oom sou sê…
S: Ja..
R: Ander het ouderdoms….

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S: Ja, die ander een wat ouer, 2 jaar, 4 jaar ouer as sy is. Sy's vergeetagtig en al…Jy kom op daai ouderdom wat vergeet raak, ek self moet mooi dink, maar ek hou my brein maar besig, blokkies raaisels en ek doen dit en dit en dit.
R: Is oom se kinders bewus daar van dat hulle, dat dit kan gebeur?
S: Ja, hulle is bewus daarvan. Maar ek glo daai mense lewe in hulle lewe, hulle, ek glo nie hulle het 'n probleem nie.
R: Hulle lewe waar hulle….
S: Kyk, as ek nou moet vat, hoe 'n puik en netjiese mens sy was, kinders goed opgevoed en alles, dan sal sy hier in die kerk kom en haar kaal uittrek. So hulle weet nie wat hulle doen nie.
R: Nee, hulle is nie bewus van wat hulle doen nie.
S: Ek wonder of sy weet as ek vir haar aangetrek het in die oggend, ek weet nie, hulle sal allen weet, ek weet nie. Ek sal graag net 'n insig in hulle denke wil, dis al. Sy't boeke en boeke gelees. Die Rooi Rose gekry, die Sarie, die Huisgenoot gekry en sy het alles deur gelees. Nou…
R: Niks.
S: Ag, nee. Vir die afgelope 67 jaar. Partymal vat sy 'n pen, dan probeer sy skryf. Sy't 'n netjiese handskrif gehad.
R: Mis oom die tannie hoe sy was?
S: Ek het vrede daarme gemaak.
R: Ek's bly om te weet.
S: Nee, ek aanvaar haar.
R: Jy kry dit nie baie keer nie.
S: Nee, dit is so. Jy's maar dankbaar vir die genade wat van bo af kom. Ek hou my maar besig en so, maar. Ek kan nou darem 'n oog hou oor haar versorging en als.
R: Wat belangrik is vir oom…
S: Nie eintlik nie. Net dankbaar dat ons kon gesels. Ek het nou meer begrip.
R: Dink oom dis nodig.
S: Ja, nee, definitief. Maar soos die Dr. kom sê het hy diagnoseer jou met Alzheimer's en dit is dit.
R: Ja, dit is die julle punt van…
S: Nee, wat, ek is nou miskien lelik, maar, byvoorbeeld ek sal nou nie name noem nie, die neuroloog, die spesialis, nee dit was 'n psigiater wat na haar medikasie gekyk het, hy't nie met my gepraat nie. Hy's net gesê dit en dit en dit. En R380 vir 'n kwartier, hy't my niks gesê van wat ek moet verwag of wat of wat of wat.
R: En oom voel dit moet eintlik anders wees, dat hy moet die tyd vat om met die mense te praat
S: Hy moet sê wat hulle moet verwag. Ek het maar gelees en als, ons het al daaroor gepraat.
R: Ek wil net sê dankie vir oom se tyd.
S: Plesier.
R: Ek het alles nou opgeskryf, soos oom kan sien. Hier begin ons eerste gesprek. So ek gaan nou begin werk aan hierdie. En as oom wil ek kan 'n kopie van die finale een, as dit klaar is, vi room gee.
S: Nee ek sal graag wil sien.
R: Dit is ongelukkig in Engels.
S: Nee, goed! Al is dit in Engels.

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