
**An exploration of family members
perceptions of palliative care given to
dementia patients and their families in
old age homes in Cape Town**

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ABSTRACT

The disease trajectory that characterises dementia is one of progressive neuro-psychiatric, physical and cognitive decline. It is family members who often bear the brunt of the suffering that these sequential 'deaths' and losses bring. As they retain strong bonds, placement of loved ones in an institution is often seen as the ultimate act of betrayal resulting in ongoing guilt. How families perceive care given in these homes, the relationships they form with staff and the new roles they take depends on multiple variables. Although this has been the subject of some studies in the USA, UK and Europe, there is at yet no research on this phenomenon in South Africa and Africa as a whole.

This study utilised Interpretative Phenomenological Analysis (IPA) to explore the experience of 10 family members of 8 patients with moderately severe to severe dementia in 5 different old age homes in Cape Town. IPA seeks to give a credible account of the interpretation of the person's experience, by using a deeper analysis whilst remaining firmly anchored in the participants account. The analysis and discussion of this study were conducted by the primary researcher and corroborated by an independent Social Worker experienced in psychoanalysis. The discussion was integrated with the literature review to enhance validity and place this research within the context of broader research on the subject.

Analysis of emergent themes revealed that family members enter old age homes with a prior agenda shaped by their experiences prior to admission. Home placement is an extremely traumatic event and carries with it an ongoing heavy burden of guilt. The unwillingness or inability of medical professionals to provide information significantly increases that burden. Perceptions of how staff and administrators may think or function are often negative and distrustful and may well be misconceived. None the less they are believed to be true and heavily influence the integration of families into the home in either a positive or negative way. Old racial divides entrenched during Apartheid still hold sway and influence reactions towards and from nursing staff. Ultimately families still seek to play an active role in their loved ones lives and to seek purpose in their relationships. The quality of communication between staff and family members is the primary determinant of whether care is perceived to be good or bad. This applies particularly to issues of identity and dignity.

Although the findings were not generalizable they were transferrable and they led to specific recommendations on how to improve information dissemination, communication and team building within old age homes. Better role definition and focus on residents as people and not disease entities would decrease family burden. Further research to elucidate staff perspectives and the experiences of other ethnic groups in old age homes in Cape Town and other areas of South Africa would further clarify the topic within the local context.

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CHAPTER 1 – INTRODUCTION

Dementia is the end result of a number of disease processes which slowly but surely erode the sufferer both physically and intellectually. More than that the course of the disease removes the essence of the person, often leaving what appears to be the shell of the individual that once was. This particular aspect of the illness, above all others, places an enormous and at times intolerable burden on family members and loved ones. Although much recognition is being given to problems faced by an aging population in the Developed World, the Developing World has lagged behind in this regard. In middle and low income countries such as South Africa, as general health improves, so do the proportion of over 65's within the population and thus the incidence of Alzheimer's disease. At the same time, an increase in lifestyle diseases such as hypertension and diabetes, results in a corresponding increase in vascular dementia. As families are put under increasing pressure by the demands of the disease, many are forced to look for old age homes to care for their loved ones in the final stages of their lives. The way these family members experience the care given within these homes, to both their loved ones and themselves, has never been investigated either in South Africa or in Africa as a whole.

1.1. DEMENTIA: A GLOBAL EPIDEMIC

As access to better food, living conditions and health care improve, and previously untreatable illnesses become curable or at least manageable; the Developed World's population is ageing rapidly. The trend towards smaller families means the shift in age demographic is continuing, resulting in a growing aged population. Trends in the UK show there will be a marked rise in the aged population over the next 20years particularly in the group aged 85years and over. Dementia is a disease primarily associated with people aged 65years and above. The incidence of this disease increases from one in 1000 to one in five in those over 85. ⁽¹⁾

The World Health Organisation estimates that 18 million people worldwide suffer from dementia with an anticipated 34 million by 2025, ⁽²⁾ ⁽²⁾ and 81 million by 2040 ⁽³⁾ In the developed world death with or from dementia is now commonplace and increasingly being recognised as a growing problem which is impacting health budgets and policy alike. (The cost of dementia care in England and Wales in 2001 was estimated to be between 9.5 and 13.5 billion pounds.)⁽¹⁾ In Holland one in nine deaths involves dementia and in the US Alzheimer's is listed as the seventh leading cause of death, with an estimated 4.5 million people suffering from Alzheimer's disease.^{(4,5)(5,6)} In the UK about 100,000 people die with dementia each year.⁽¹⁾

Thus without a doubt dementia is increasing exponentially in the Developed world and according to the World Health Organisation worldwide.

1.2. DEMENTIA IN THE DEVELOPING WORLD

In 2000 the 10/66 Dementia research group met to discuss the lack of knowledge surrounding this group of illnesses in the Developing World. Less than one 10th of population studies into dementia were conducted in the Developing World. This despite the fact that since 1990 two-thirds of people with dementia were found to be living in developing countries and by 2020 this number will have risen to three-quarters.⁽⁷⁾ The ageing population is not limited to the Developed World with a large increase in the absolute and proportional numbers of elderly throughout the global population. This is particularly true in emerging economies such as India and China where the prevalence of dementia is expected to increase by as much as 300% within the next three decades.⁽⁸⁾

The few studies that have been done have tended to reveal lower rates of dementia and particularly Alzheimer's dementia than have been found in Western countries. The reasons for this are complex and multiple. They include different survival rates, relatives perhaps hiding those with the disease because of possible stigma, inadequate access to medical care, the belief that seeking medical care would be inappropriate as their family member would be coming to the end of his or her useful life and case finding techniques that may not be applicable in these communities.^(9,10)

Certainly the diagnosis of dementia in the Developing World is largely attributed to vascular dementia rather than Alzheimer's disease, with lifestyle related illnesses such as hypertension and diabetes on the steady increase. The Ibadan study of ageing which took place in the Yoruba-speaking areas of Nigeria (representing 22% of the Nigerian population) found the prevalence of dementia to be 10.1% with more than one in five over the age of 80 having the diagnosis. This was closer to the reported rate amongst African-American and in some studies to that amongst Caucasians.⁽¹¹⁾ To date only one study has been carried out on the incidence of dementia in South Africa. In 1983 Ben-Arie et al. examined a sample of elderly people in a Cape Coloured community. 12% of these were assessed as demented and 3.6% as severely demented, rates which resembled those found in Europe.⁽⁹⁾

1.3. DEMENTIA AS A LIFE LIMITING ILLNESS: BARRIERS TO PALLIATIVE CARE

The World Health Organisation's definition of palliative care is an approach that improves the quality of life of patients and their families, facing problems associated with life threatening illnesses, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain, physical, psychological and spiritual problems. Palliative care is the active total care of patients with life limiting diseases and their families, by a multi professional team, when their disease is no longer responsive to curative or life prolonging treatments.

Dementia is now universally recognised as a progressive, life limiting, terminal disease. Patient prognoses range from two to over 15 years,⁽¹⁾ with survival rates being extremely variable across

studies but showing a median survival from diagnosis or study entry of between five and nine years.⁽⁶⁾ If one looks at advanced dementia there are high mortality rates as shown in the study by Mitchell *et al* which found a six month mortality rate of 25% and a median survival of 1.3 years in patients with advanced dementia. This is not very different from other end-of-life conditions such as stage 4 cardiac failure or metastatic carcinoma. Furthermore they found that these deaths were not caused by other illness but by the dementia itself.⁽¹²⁾ A 2004 study of 521 newly diagnosed Alzheimer's disease patients showed an overall lower survival rate across all ages when compared to the general population. For men at age 70 this was 4.4 years compared to 12.4 for the general population and for woman age 70 the figure was eight years compared to 15.7, again showing little difference to other terminal illness.⁽⁵⁾ Thus, if one followed the WHO guidelines there should be no doubt about the inclusion of those people suffering with dementia under the palliative umbrella.

What then is the reason for the reluctance of medical personnel in this respect? Perhaps one of the major barriers is the lack of recognition by doctors themselves that dementia is the actual cause of death and as such a terminal illness.⁽¹³⁾ A study in the UK of 281 general practitioners looked at the differing attitudes between sharing the diagnosis of terminal cancer and dementia. Although 73% felt confident about making the diagnosis of dementia only 39% felt they would be able to discuss the diagnosis and prognosis with the patient's. In contrast 93% felt they would be able to discuss the diagnosis of terminal cancer with patients.^(3,14) Chang's study used focus groups of specialist palliative teams, hospice doctors and GP's and found little awareness of dementia as a terminal disease or one that anyone other than specialists should deal with.⁽¹⁵⁾ Similarly literature has shown that dementia patients often have symptoms for which no palliation is given and are often given only half the analgesia of their cognitively intact counterparts with the same medical condition.^(1,16)

Another reason cited is the unpredictability of the course of the disease. Dementia has a difficult entry, re-entry trajectory, the end-of-life period may continue for months or years or death may occur suddenly. Often there is no recognition of the terminal period and in a study on end-of-life planning for dementia patients even the hospice delayed the discussion of the end-of-life wishes until death was imminent.⁽¹⁶⁾ The decline in function in the last years or months of life brings an inexorable and steady 'dwindling' which may be hastened by concurrent illnesses. Cox and Cook describe three ways of 'dying with dementia', those who die with dementia but as a result of another identifiable disease, those who die with physical and mental impairments but the mental impairment is not severe and those who die as the result of dementia itself. This difficulty in prognostication remains despite many efforts to develop models which could accurately predict the last six months of life and this makes the implementation of 'terminal care' complex.⁽¹⁵⁾ This focus on providing palliative care in the 'terminal phase' is perhaps the problem itself as this should be provided long before the final days and the term end-of-life care would be preferable and more appropriate. Lack of disease knowledge and poor training further enhances medical

practitioners' reluctance to deal with dementia appropriately. Smythe et al found that GP's in Australia had very little geriatric specific undergraduate training and thus a specific knowledge gap.⁽¹⁷⁾ This lack of knowledge may translate into a reluctance to disclose the diagnosis of dementia let alone discuss its implications.⁽¹⁴⁾ Doctors may feel ill equipped with knowledge or they may be uneasy about facing the inevitable and painful decline with family and patient. Even as the families have expressed feelings of helplessness so it seems have these doctors.

Yet another barrier to effective palliative care is the inability of patients to communicate their needs and articulate their symptoms. Even in the case of impeccable advance care planning having taken place when patients have minimal cognitive impairment, as the disease advances the ability to make current needs understood becomes more and more difficult. In this regard the role of close family or friends becomes indispensable and inclusion of family as key members of the palliative team becomes paramount.

1.4. DEMENTIA – A DISEASE OF FAMILY AND PATIENT

LOSSES

The nature and progression of dementia leads to multiple losses in many spheres. All domains of functioning are ultimately affected: physical, cognitive, behavioural, financial, relationships and personality. It is not only the patient who experiences the gradual losses and 'mini-deaths' of dementia, family members are forced to witness and participate in each of these losses as well. Dementia is likened to a journey that family members take with their loved ones. It is a gruelling journey which people have been forced into, "*a journey in the land of death.*"⁽¹⁸⁾

DECISION MAKING

These are families who are grieving continuously, yet they are forced into making decisions for a family member who is increasingly incapable of making their own decisions. This is particularly true when it comes to institutionalising a loved one and end-of-life decision-making. Study after study has shown that the decision to place one's loved one in a home is the most difficult that families have to make. Caregivers are forced into placements because of lack of alternative. They experience deep guilt, sorrow and apprehension. Family relationships are put under tremendous strain. Often this step heralds the beginning of a breakdown of relationships, a loss of hope and a loss of purpose. Ultimately it would seem from most studies that placement in a care facility does not relieve burden but often increases it.⁽¹⁹⁻²¹⁾

End-of-life decision-making is no less stressful particularly when information and communication is lacking or non-existent. In a study assessing end-of-life care by Greg Sachs *et al.* investigators found that although 70% of families interviewed after the death of the patients believed their family members were terminally ill and dying, two-thirds of them believed that they were dying of something other than dementia.⁽²²⁾ Even thinking about end-of-life decisions can be so

overwhelming that often people focus on daily challenges and tasks where they have an ability to maintain control and thus a level of emotional comfort.

In the study by Forbes *et al* on end-of-life decision-making, questions on end-of-life care needs were answered by focusing on daily needs such as food or personal hygiene.⁽¹⁸⁾ It is unlikely therefore that these family members would broach the subject spontaneously. Yet carers were found to have had profound needs during this time. Hennings *et al.* found family sought out staff needing empathy, guidance, reassurance and understanding. They needed peace of mind that they had done everything they could and had not given up on their relative. They had a strong desire to do what was best.⁽³⁾

The US Institute of Medicine claims that a “*decent or good death is one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards.*” For those with dementia the key tasks in achieving this are often not attainable on their own and thus the responsibility for this falls on the shoulders of carers and family members. This is a complicated and emotionally taxing task for trained medical staff but even more so for those with no previous experience to call on. Poor communication and lack of inclusivity will result in huge stress for family members and ‘bad deaths’ for patients. People generally recognise the inevitability of the death of their loved ones. It is the provision of a ‘good death’ for that person and the peace of mind for those remaining, as they deal with the experience of the dying process, that remains an unresolved issue long after death due to the unrecognised and unmet needs that preceded that death.

STRESSORS

Just as dementia exacts a physical, emotional, psychological and financial toll on the person afflicted so do the family members suffer in these same spheres. As the person moves from one stage of the disease to the next, those close to them experience frustration and anxiety about their parent’s well-being. As they juggle their lives with the increasing needs of their dependant the sense of burden increases. Guilt is often overwhelming with people feeling trapped by the disease and choices they have to make.^(19,21) Many of these family members have experienced abusive behaviour at the hands of their loved ones due to the neuropsychiatric symptoms which are part of this disease. In the CARD (caring for relatives with dementia) study over a third of family members interviewed reported they had experienced abuse for at least some of the time. This is often exacerbated by pre-existing patterns of relating. Regardless, stress levels within the situation are high.⁽²³⁾

Feelings of helplessness and disempowerment often follow placement as people who have been primary carers struggle to find a place in this new environment. Having already changed roles within the relationship with their loved ones they are again forced into a new identity with further loss of companionship as well as the distraction and comfort of providing hands-on care, no matter how hard this has been.⁽²⁴⁾ Similarly financial burden is increased, often at a time when

family's financial needs are at a peak.⁽²⁵⁾ Little wonder then that family carers of those suffering with dementia are found to be at much higher risk for poorer mental health and psychiatric illness, physical stressors, financial strain and increased mortality.^(15,24,26,27)

1.5. PALLIATIVE CARE – FAMILY CARE

Having established that dementia fits the criteria for the provision of palliative care, and that the definition of palliative care includes the care of family, we can now see that the need to examine the provision of this care in the context of dementia is indeed important. In the developing world most people dying from dementia will do so in institutions such as Care Homes or Nursing Home facilities with estimates ranging between 44% in Wales to 92% in the Netherlands.⁽²⁸⁾ When looking at those who have placed loved ones in care facilities, one must consider not only the direct care of family members but perhaps more importantly how they perceive the care that their loved one are receiving. This perception be it true or not has a direct impact on the well-being of the family.

In a Canadian study researchers interviewed family members at intervals before and after placement of their loved one. Carers were emphatic that the relationship with their family member had not changed just because they had moved. They were still deeply bonded and desperate to continue continuity. The move was often out of concern and love and they had constant thoughts regarding the well-being of their loved ones.⁽²¹⁾ Just as those with dementia living in old age homes often find themselves becoming spiritually and structurally invisible, secluded from society by their disease, so by association do their caregivers, particularly the spouses who become ambiguous about the terms of their social identity. They are neither one thing nor another, "*betwixt and between*", a condition referred to as "*quasi-widowhood*".⁽⁸⁾

Hennings, Froggatt and Keady reviewed literature relating to end-of-life and dying with dementia in care homes from accounts of family carers. Of the 544 references found, only twelve papers met the inclusion criteria, all in the Developed World. No studies have been done on this specific subject anywhere in the Developing World.⁽³⁾ It is against this background that one must view the aim of this study, that is, the exploration of the delivery of palliative care to dementia patients and their families in old age homes in Cape Town as perceived by their family members.

1.6. ANALYSIS

This is a qualitative study using interpretative phenomenological analysis (IPA). Pioneered by Jonathan Smith in the mid-1990s, IPA has an ideographic focus, that is, it focuses on a particular event or phenomenon and how a particular person may make sense of this. It emphasises the in-depth analysis of a few subjects from a homogenous group, rather than the superficial analysis of many, with the intensive study making the experience of the participant clearer and more understandable to the reader. In other words it is an analysis of the lived experience.^(29,30) The researcher tries to represent both the individual and the group experience intertwining and merging one with the other.⁽³⁰⁾

IPA uses a two-stage analysis or a 'double hermeneutic' where the subject is trying to make sense of their experience whilst the researcher is making sense of his interpretation of this experience. The researcher is looking for the subjects experience rather than what they consciously know.

⁽³¹⁾ Thus the researcher's bias and knowledge is acknowledged and seen as having an interpretive element and there is no attempt to exclude it.⁽³²⁾ IPA does not seek to find a single or only correct answer, but rather to give a credible account of the interpretation of the person's experience, by using a deeper analysis whilst remaining firmly anchored in the participants account. Thus the use of quotes and metaphors from the actual account are important tools.⁽³³⁾ As the experience that family members will be having is both deeply individual and yet shared by others in this situation, IPA is the ideal vehicle for approaching this subject as unlike other methods such as grounded theory it focuses on the individual rather than using larger numbers to reach a conclusion.

1.7. BEDFORD ALZHEIMER NURSING SEVERITY SCALE (BANS-s)

The BANS-s was developed by Volicer *et al* in 1994 to evaluate both cognitive (speech, eye contact), basic activities of daily living (dressing, eating, ambulating), and pathological symptoms (sleep-wake cycle disturbance, muscle rigidity.) Volicer found the score was useful in advanced stages of dementia where patients were scoring at the floor of other scales. It also provided useful in the prediction of mortality and correlated with the extent of neuro-pathological change in the brain. Whilst Volicer's study was conducted on relatively young, male Alzheimer's patients, the validation study by Bellelli *et al* was done on very old patients with both Alzheimer's disease and vascular dementia. It confirmed that the BANS-s showed reliability and validity for the staging of late stage dementia where most other scales are insensitive.⁽³⁴⁾

Accepting the premise that dementia is a terminal disease for which there is at present no cure, and that palliative care should be applied to chronic non curable illnesses as well as cancer, it follows that one should apply palliative principles which include the spiritual, social and emotional needs of the patient and their family. These cannot be fulfilled without the active participation of those closest to the patient and no-where is this more apparent than in the case of advanced dementia where the afflicted people cannot be the advocates of their own rights and needs and are totally dependent on those who care for them. Similarly few other diseases impact family members in so many ways as is in the case of dementia.

CHAPTER 2 - LITERATURE REVIEW

This review will focus on family member's perceptions of the provision of palliative care to dementia patients (and thus by implication to themselves) in care institutions. The literature collected and analysed was accessed online from Academic Search Premier, Africa Wide Information, CINAHL, Health Source: Nursing/Academic Edition, Medline, PsycARTICLES, PsycINFO and SocINDEX via EBSCO. Only English speaking countries as a whole and all were only indirectly relevant to this research topic. Search words or phrases used were: Alzheimer's/dementia and palliative care, Alzheimer's/dementia and family and care homes/old age homes/institutions, Africa and dementia/Apapers with full text available were used. No studies before 1994 were used and in fact almost all research found was done after 2000. Only eight articles of any potential local relevance were found, most referred to devellzheimer's and family, advanced dementia and staff and family, advanced dementia and conflict and staff and family, dementia/Alzheimer's and long term care and South Africa.

Much research has focused on the clinical side of dementia; less however has focused on dementia as a terminal illness and the impact of this on family members. What has been done is weighted heavily towards carers in the community and conducted almost exclusively in the USA, Australia, the UK as well as a few countries in Europe and the Far East. How families experience palliative care received by loved ones dying of dementia in old age homes has attracted little research and, in the case of Africa and South Africa specifically, none at all.

In order to review this particular aspect of dementia care one must first have a background understanding of the impact of this devastating condition on the family unit as a whole.

2.1. ASSAULT OF THE DISEASE ON THE CARER/FAMILY

Although specific evidence is limited in the wider literature, by inference it seems clear that caring for sufferers of dementia is not the same as caring for people with other long-term illnesses. The very nature of the disease and its trajectory impose a relentless progression of not only physical loss but of destruction of the essence of the person. It is been found that the burden that dementia places on families increases their risk for mental and physical illness, social isolation and financial stress in comparison with those caring for non-dementia patients.^(15,24,27) These family members have actually been referred to as the "*forgotten clients*".⁽³⁵⁾

It is interesting to note that in the Developing World nursing home placement of dementia patients is very uncommon. There are multiple reasons for this including resource availability, finance, awareness of disease and fear of stigma. The main reason however, would seem to be that people in developing countries live in extended family units.^(10,36) It should follow that this would decrease the strain on the principal caregiver but it was found by the 10/66 Dementia Research Group that this effect was small and only seemed to apply if that caregiver was resident

with the patient. For those who were non-resident the primary caregivers strain increased even when the patient lived within an extended family unit. In their research they note that the unmet needs of these caregivers will further feed into the cycle of impoverishment, gender inequality and educational disadvantage.⁽³⁶⁾

GRIEF

Grief and mourning are important stages to master after the death of a loved one. In dementia the series of living death's experienced by patient and family make closure impossible and grief endless. Grief is complicated by the inability of the person with dementia and the carer to grieve together leaving the "*tasks of normal grieving*" as described by Worden⁽³⁷⁾, incomplete. A Systematic review by Chan *et al* looked at grief reactions in dementia carers. They reviewed 31 papers and found that severe, complicated grief start at diagnosis and continue through institutionalisation, gradual physical and mental decline and death.⁽³⁸⁾ There was serial grief at loss of future, freedom, companionship and control.⁽¹⁸⁾

Moyle, Edwards and Clinton conducted a study in Queensland Australia looking at how family members of dementia patients in care deal with loss. Using two focus groups in one unit they identified the next of kin on residents care plans. Although it represented a very small proportion of resident's families, and specifically those who visited their family members, they found participants reactions to be similar to the stages of grief described by Elizabeth Kubler Ross.⁽²⁴⁾ Many other studies endorse this with evidence that these caregivers experience "*pre-death grief*" as a result of the multiple "*non-death*" losses'.^(24,27,38) Bramble's study found that these feelings of grief were compounded when families were not properly orientated to the care facility, resulting in the loss of control, hope and a sense of meaninglessness as the system took over.⁽¹⁹⁾

Those who were less involved in the day-to-day care prior to admission and whose expectations of the nursing home were low experienced a higher burden load.⁽³⁹⁾ After placement carers were constantly preoccupied with concern about their loved ones, particularly when they were not in their presence.^(8,21) This resulted in the need to constantly monitor the staff and care given.^(8,35,40)

GUILT/BURDEN AND PLACEMENT IN A LONG TERM CARE FACILITY

Burden does not decrease after placement in care as one would logically expect. In 2002 Tornatore and Grant looked at family caregiver burden after placement. Both authors have extensive experience with geriatric care. The study was a secondary analysis of data collected to evaluate the effectiveness of Senior Care Units in Minnesota. It was drawn from highly specialised dementia units in one State and therefore may be difficult to apply to other places. Data collection was extensive, and was conducted by means of 30min phone conversations with Likert Scale options. This meant that many responses were limited by the constraints of the method; leaving no room for more nuanced answers. They found the burden of caregiving to be influenced by a mixture of circumstance, experiences pre and post admission, responses from staff and available resources. All these elements affected the burden experienced after nursing home placement.⁽³⁹⁾

In a very practical sense there is the need to balance the increasing demands of the dementing patient with those of their own lives. Bramble *et al* looked at family experiences of care giving following placement of a loved one in a care facility. Rather than finding that burden decreased they found an increasing load as people struggled with work commitments, their own families, financial burden and the duty to the afflicted loved one. This balancing act of time and financial management was added to by huge emotional burden. Often there was guilt and regret as the ability to provide ongoing care became impossible forcing placement.⁽¹⁹⁾ This has been confirmed by other studies, where psychological burden increased even as concern over safety and physical care decreased.^(18,24)

Numerous researchers have found that the decision to institutionalise a loved one is amongst the most difficult that a family member will ever have to make. A study by Caron *et al.* in Québec looked specifically at the difficulties facing this decision. All participants had identified themselves as primary caregivers, were involved in the decision making and had family members admitted during the previous six months. Using grounded theory, saturation was reached after only eight interviews with 14 caregivers. They quickly found consensus that the transition was a significant and traumatic event, involving precipitating events which had forced the realisation that they were no longer able to take care of their loved ones. The decision was highly influenced by family dynamics, often creating family tensions. When caregivers were able to give themselves permission via their health care providers the sense of guilt and betrayal was significantly lessened.⁽⁴¹⁾ Similarly, in a meta-ethnographic study looking at the experiences of families who had placed their loved ones in care, family members felt stressed and isolated. They understood the inevitability of what they had done but still felt forced and unprepared, particularly when the precipitant was an immediate crisis. Again support by family members gave a sense of permission and shared responsibility.⁽⁴²⁾

Hertzberg and Ekman conducted a comprehensive study looking at relationships between family and staff in dementia homes. Three groups met every two weeks over a period of three months. Each group consisted of a professional, experienced group leader, a representative of the Dementia Support Group, three family members and three staff members. Contrary to other studies, they found that staff members assumed that family members felt extremely guilty about moving their loved ones to care homes whilst family members interpreted their feelings as worry, anxiety and concern.⁽⁴³⁾ This is not corroborated by the participants in Hennings and Froggatt's study of spouse caregivers who poignantly speak of their never-ending guilt and feelings of wanting to visit and yet not being able to bear being there.⁽⁸⁾ Guilt becomes an overriding theme after placement.⁽⁴⁴⁾ Family members often compensate for the loss by shifting the blame to the staff and the facility. "*Under their apparent acceptance they were seething.*"^(24,43) This deep sense of guilt and failure seems all pervasive, found in many of the studies reviewed by Diana Chan.⁽³⁸⁾

SHIFTING ROLES AND CHANGED RELATIONSHIP PARAMETERS

The loss of cognitive and physical ability with dementia imposes role and relationship changes more than most other life limiting illnesses. Forbes *et al.* conducted a well-planned, multi-disciplinary study of 28 family members of severe or moderately severe dementia patients. Their aim was to investigate end-of-life decision making for nursing home residents with dementia. Participants were chosen to include economic and ethnic diversity. All had relatives with CPS (Cognitive Performance Scores) of between four and six. They found dementia deprived people of the opportunity to complete their lives in a way consistent with their plans. This manifested with physical, emotional and identity loss resulting in an inability to engage in any meaningful day-to-day life. Similarly, changes to family member's life story followed; changed roles, changed retirement plans and breached fidelities. ⁽¹⁸⁾

Albinsson and Strang's unique study looked at the existential concerns of families of late stage dementia patients, such as freedom, responsibility, isolation and meaning. Five of the 12 children interviewed spoke of having lost their parents in that they were no longer their protectors, advisors or providers of security. The authors defined a new role definition for children caring for their parents as "*being a parent to one's own parent*". ⁽⁴⁵⁾ This has been previously described as "*the loneliness of being one's own parent.*"

Caregivers in Strang's study on transition to long-term care were often oblivious to the increasing responsibilities and strain as their loved ones worsened. Frequently it was a critical event that forced the realisation of their situation and that the relationships between them had changed. They spoke of past crises and the notion of looming crises over and over again. ⁽²¹⁾ The move to a care facility involved yet another role shift. Roles had to be redefined with caregivers deciding on how they would be involved in the care of their loved one. This is often dictated by the attitude of the home and the staff. ⁽⁴¹⁾ In Moyle's study people felt their lives were always on display and no longer their own and that their relationships had been intruded on by strangers. ⁽²⁴⁾

Often negotiating the change from being the one providing total care to being a family caregiver at the home is particularly distressing for family. This is difficult to redefine as family attempt to retain some form of control and continuity. ^(21,24,43) Spouse caregivers seemed particularly affected often covering for their spouses, reluctant to accept the diagnosis or help. ⁽¹⁹⁾ Hennings and Froggatt conducted a longitudinal narrative study of spouse caregivers of people with advanced dementia in old age homes. Unlike most other retrospective cross sectional studies which look at an interpretation at a particular place and time, this study used sequential interviews, diaries and narrative analysis to delve deeply into the experience of these spouse caregivers. They found that, like the dementia patients themselves, their spouses found themselves in an ambiguous position in terms of their identity in society with no particular "*classification.*" One woman stated that had her husband died she could have started a new life for herself. Spouses found themselves struggling to live in two worlds, in both of which their identity was undefined: the nursing home and the outside world of society. ⁽⁸⁾

Thus it would seem, as was concluded in Bramble's study and supported by Maas, that dementia is *'truly a family problem'* the traumas of which do not end with placement in a long-term care facility.^(19,44)

2.2. FAMILIES PERCEPTIONS OF THE NEEDS OF THE PATIENT

DIGNITY/IDENTITY

Many studies have found that preservation of dignity and identity often override concerns of physical care. An extensive and rigorous study by Duncan and Morgan conducted 30 focus groups and ten individual interviews. There was little consistency between the makeups of focus groups, some were mixed, and some were more specific such as spouses or children only, or home carers vs people in care. The result of this was that different issues were more important to different groups and thus not comparable and ultimately only the data of those with family in care was used. There was diversity of income and education, relationships and settings. Questions were unstructured allowing different emphases to emerge in different groups. By far the most pressing concern was that of treating the patient with dignity, as a person rather than a disease. Quality of care was seen as an inseparable combination of not only technical ability but personal sensitivity.⁽³⁵⁾⁽³⁵⁾ Hertzberg found that caregivers wanted their family members to be treated as they had been at home and that in fact their efforts to hold on to some control was linked with the need for their family member to be treated with dignity and respect.⁽⁴³⁾⁽⁴³⁾

Using grounded theory, Lau *et al's* study investigated how family and staff formed collaborative relationships in a home in Taiwan. It is unclear what level of cognitive impairment residents in the study suffered from as their MMSE scores at time of the study were not. At admission these ranged from 0-24. This variation means that the families interviewed would have been at a very different stage of their dementia journey and had very different needs regarding staff input. They looked at the family members' perspective of this relationship and found that rules reinforcing task focused care rather than person centred care added significantly to patient and family burden. The authors refer to social penetration strategies such as the sharing of personal information by family and staff, influencing the formation of positive relationships,. This facilitated the recognition of their loved ones, themselves and staff members as individuals and people and promoted respectful interactions on all fronts.⁽⁴⁶⁾ Robinson *et al* looked at two models of care, comparing a facility modelled on a home environment with more traditional models. What they found in both was an expectation that the staff relate to the *"person underneath the disease."* Where this was done moral was high no matter which model of care it was in.⁽⁴⁷⁾

The preservation of the person's identity as their family understand it seems vital. The issue of which clothes their relatives wore assumed great importance and was brought up by every participant of Moyle's study. These clothes were seen as *"a way of keeping your loved one as much as possible as they were"*, and the act of buying the clothes the *"only thing that relatives can do"*. They further mentioned that *"clothing gives people dignity"*.⁽²⁴⁾ This was confirmed by the

difficulty several family members expressed when seeing their loved one in other people's clothing.⁽¹⁹⁾

The same findings are seen in the study by Cherry *et al* in New South Wales, Australia. Participants were purposively sampled through an advertisement and had all been caregivers of dementia sufferers who had died between 1 and 5 years previous to the study. The researchers did not comment on possible recall bias that may have occurred due to the large discrepancies in time since death of the patients. None the less best quality of life care was associated with the extent to which participants thought their loved one had positively experience care given. Of the three indicators which emerged as important to families, one was treatment with respect and dignity.⁽⁴⁸⁾⁽⁴⁸⁾ How families and staff assess the sufferer's quality of life, is closely bound to their perceptions of worth of the patient as a dementia sufferer, which in turn translates into the need to preserve their dignity.⁽⁴⁹⁾

PHYSICAL CARE

Physical care and symptoms seem to feature far less than concerns about dignity in moderately severe to severe dementia care and even in the very last stages of life. Very little is actually mentioned at all in the various studies but where there is mention it is often regarding pain control, breathing and freedom from "*unpleasant symptoms*". This is seen on a par with dignity.^(4, 40)

Reference is repeatedly made to the poor or absent attention to symptom control at end-of-life, with Godwin and Waters noting that patients with dementia are commonly given only half the level of analgesia of their counterparts with similar conditions.⁽¹⁶⁾ Bosek *et al* randomly selected 100 family caregivers, from the participants of a national study of 1500 caregivers of persons with late-stage dementia who had died in a nursing home. Through structured telephone interviews about decisions made in the persons last three days of life, they identified symptom management as an area which family members felt needed improvement, including things like shortness of breath, bedsores and pain.⁽⁵⁰⁾ Catherine and Julia Rowlands' review of the literature on palliative care received by people with dementia, and the challenges and barriers to its delivery, reveals that this is often due to the fact that the terminal phase of dementia is not recognised by health care providers.⁽¹⁾

2.3. NEEDS OF THE FAMILY

COMMUNICATION

Poor communication perhaps more than anything else seems to underlie many of the problems experienced by family members of dementia sufferers in old age homes. In a literature review on the accounts of family carers regarding dying with dementia in care homes, there was often a lack of verbal communication between the professionals and family. This poor to non-existent communication between family and staff along with a lack of understanding of disease meant that

they often saw palliative options as “*giving up*”.⁽³⁾ Caregivers expressed a real need for some sort of regular or formal meetings with staff members, regardless of which professional this was.⁽⁴¹⁾ The study by Hertzberg and Ekman placed relatives and staff members in focus groups together. Both sides agreed that only very essential information was communicated to relatives and only if permission was needed for something. Staff acknowledged that they knew relatives were anxious about disturbing or upsetting them and again felt a formal channel of communication would benefit all.⁽⁴³⁾

The lack in flow of communication is not a one way thing. Caron et al’s study found a need for family caregivers to be more forthcoming in their communication with health care providers who in turn should invite them to communicate their needs.⁽²⁰⁾ Lau recommended interventions to facilitate “*self-disclosure*” between staff and family and thus promote more effective care⁽⁴⁶⁾ and Bramble found family caregivers felt an ongoing need and responsibility to communicate their relative’s disabilities and needs.⁽¹⁹⁾ Both Hertzberg and Casarett pointed out that misunderstanding and frustrations on both sides created major obstacles to a good relationship between staff and family.^(26,51) The need to acknowledge and credit staff when measures were taken to improve communication is also stressed.^(26,41)

Often carers come from different cultural, religious or ethnic backgrounds. Gill Livingston *et al.* conducted individual interviews with staff members at a Jewish nursing home in London. The study included only those caring for people with dementia. Although only one home was used the purpose was to assess not only care at the end-of-life but whether religious and cultural differences affected that care. The significance of this study was that none of the staff shared a common background with the residents and yet they felt, despite this, the delivery of care was not affected. They felt connected to the residents and the difficulties they had discussing death seemed to be rooted in the need to protect residents and their families rather than differing viewpoints.⁽⁵²⁾

This is pertinent to South Africa where many homes have carers and residents from vastly different cultures. In 2000 a study was conducted looking at the composition of old age homes in South Africa with regards to staff and residents. Although the study is 14 years old there is little reason to believe that there have been any major changes since then. In the 140 Homes sampled 83. 69% of the residents were white, 51.1 % of the nursing staff were black, 28. 4% were white and 17% were ‘coloured’. Although this was not broken down into the different provinces, it is likely that there would be a higher percentage of ‘coloured’ staff in the Western Cape Province where this study was conducted.⁽⁵³⁾

While Livingston’s study is reassuring in that staff showed genuine concern for the residents all too often racial prejudice exacerbate discontent within the nursing home environment. In a study looking at race relations and care giving relationships Berdes and Eckert quote from Foner’s research. Her findings concluded that “racial differences feed into and intensify, rather

than create, divisions between groups in the nursing home.” In their study 56% of participants had experienced racism from residents, 23% from family and 40% from fellow staff.⁽⁵⁴⁾

Often those families seen as difficult by health care providers are those whose lack of information and communication cause anxiety, distrust and alienation. Thus there is a need to build trust and to have a presence. This applies particularly to senior nursing staff and doctors where often a virtual absence is noted.⁽³⁵⁾ As is stated in Caron *et al*, “A climate of trust exists when the caregiver perceives that the care team intervenes in the best interests of their relative.”⁽⁴¹⁾ Lack of communication and provision of information was found at admission,⁽¹⁹⁾ through the nursing home stay (where regular contact, ongoing information and a personalised approach were found lacking)⁽⁴¹⁾ and in the terminal phase of life.

As part of a national survey conducted throughout the United States on end-of-life care, Sheilds *et al* conducted telephonic interviews with 54 descendants of dementia sufferers who had died in nursing homes. The participants were selected on the basis of being noted informants on the death certificate and need not necessarily have been the person closest to or present throughout the deceased’s death. Similarly length of stay in the home varied from days to years which means time available to form relationships with staff would be very different. What they found however was that participants wanted more and reliable information from staff. When they did get the information language used needed to be accessible, as articulated by one participant who said “You know, I’m not a doctor or nurse and some of these medical terms they throw at you, I’m sorry, I don’t understand them.” Doctors were often singled out as simply not being there.^(43,55)

A UK study using focus groups including GPs, palliative care specialists, consultant geriatricians and hospice looked specifically at the provision of end-of-life palliative care for dementia patients. Although many of these resources are scarce in our environment, attempting to apply one of the dominant themes that emerged is resource independent. This theme entitled “The long view,” emphasised the need for planning ahead and developing relationships over a long period of time in order to assist care and decision-making later in the disease trajectory.⁽⁵⁶⁾

RECOGNITION OF FAMILY/TEAM WORK

The natural progression from issues of communication is the need for family members to be recognised for what they know and can contribute. The logical conclusion of both these issues would be the ability to work in a team to improve the care of the patient and family and ease the work load of the staff. Maas *et al* developed tools to measure outcomes of family involvement in care intervention. The psychometric properties of these tools were not firmly established, and the sample was predominantly white woman, 60% of whom had tertiary level education. This makes it difficult to apply the findings to more diverse populations. Their findings were none the less represented in many other studies; staff members are often not receptive to family participation in patient care or the contribution that the family’s knowledge could make to care.^{(44) (44)}

This often causes conflict which is stressful for both staff and families.^(19,35,44,57) Hertzberg's study speaks of the traditional nursing expectations of a "good family". The family is seen as a backdrop with the nursing staff responsible for the total care of the patient i.e. routine, regimented care. The antithesis of this would be non-traditional nursing where there is no single correct pattern of family/nursing involvement, allowing for interaction and role flexibility for the benefit of both.⁽⁵¹⁾ The lack of attention to this important relationship dynamic seems to stem from the misapprehension that families cease to want to play a part in the caregiving role after admission to the facility- "*the myth of abandonment.*"⁽³⁵⁾

Where the effort has been made on both parts to establish a team the benefits have been tremendous. Once the carer's values, beliefs and knowledge had been recognised they felt validated. There was a positive effect when respect, kindness and sensitivity were shown. When active participation was encouraged and relationships with professionals developed, feelings of loss and stress decreased.⁽³⁾ Families formed and used relationships to positively influence staff and to be part of a team.^(35,41) Lau's Taiwanese study showed that strategies such as looking at the situation from each other's perspectives and setting realistic goals helped develop better collaboration between family and nursing home staff.⁽⁴⁶⁾

Being asked their opinions and invited to participate in tasks made families feel welcomed and necessary and vice versa. Above all they wanted to be taken seriously, they wanted their narratives about the residents past life history to be taken into account and they wanted to have influence on the care received.⁽⁴³⁾ Ryan *et al's* study of staff views acknowledged that the use of knowledge from those who have known the dementia patients for a long period as well as close relationships between them and health care professionals were central to decision-making, but, in their experience, rarely capitalised on.⁽⁵⁷⁾⁽⁵⁷⁾ Finally as pointed out by Caron a relationship of trust and quality should be built from the first interaction, upon entering the home and maintained over the months or years ahead.⁽⁴¹⁾

2.4. FAMILY PERCEPTIONS OF STAFF MEMBERS

One of the most common recurring themes pertaining to staff members was staff shortages and high staff turnover, which made relationship building very difficult.^(35,40,44,51,55) Sheild *et al.* found that whilst families were aware of and sympathetic to how burdened and overworked staff members were this did not diminish their anxiety about the well-being of their loved ones or the concern over lack of attention to compassionate care.⁽⁵⁵⁾

A further theme running through the literature was the fear and anxiety family members felt about complaining to staff. Whether this was ever borne out in reality was not clear but seemed to make no difference to the way people felt. Participants in Moyle's study felt that sharing their knowledge would create conflict, stating that "*relatives don't like to complain.*"⁽²⁴⁾ Others found that criticism either produced no effect or a negative outcome to themselves and the resident. They tried to minimise poor care by making excuses for staff.⁽⁴³⁾ Yet there was a constant call for

better trained personnel who could provide higher levels of personal care.^(35,44,55) The result of this was hyper-vigilance with spot checks on “*how things are when we are not there*”, an obvious erosion of trust.^(26,40,43)

Fear of retribution was not limited to family; junior staff were also disempowered and afraid to speak out. Andersen et al looked at the style of home management and its influence on resident outcomes in 164 homes in Texas. Where a less authoritarian more collaborative and communicative style was used there was less aggressive patient behaviour, less restraint use and fewer complications from falls and immobility. They concluded that greater communication and the ability of lower level staff to participate in decision making without fear of retribution translated into these positive patient outcomes.⁽⁵⁸⁾

Perold’s study found that 43% of the 145 homes which responded to their questionnaire had professional nurses in place as managers.⁽⁵³⁾ Having a nursing degree does not necessarily enable one to perform the complex tasks of managing an old age facility. In the United Kingdom, the USA and Australia managers of care facilities are required to have a minimum set of qualifications. These include managerial qualifications which cover communication skills, policy development and work place management.⁽⁵⁹⁻⁶¹⁾ In South Africa there is no requirement for health service administrators to meet any licensing requirements. This is not to say that no managers have training, the CPOA provides an in house Home Management Diploma,⁽⁶²⁾ but there is no standardised legal requirement.

Physicians particularly were singled out for criticism, their lack of presence causing anger and puzzlement. They are often referred to as “*missing in action*” and in fact some people have never even met the nursing home doctor assigned to their family member. This has often been linked to poor diagnoses, decision-making and symptom management, as well as inappropriate hospitalisation.⁽⁵⁵⁾ Similarly this was found with registered nurses; however nurse aides often elicited positive responses, “*taking the place of the family carer*”.⁽³⁵⁾

Once again when people had positive experiences with staff, respondent’s satisfaction with care was high. They were grateful and saw the provision of compassionate care to them and their loved ones as going beyond the call of duty, particularly when staff were stretched through lack of resources.⁽⁵⁵⁾

2.5. UNDERSTANDING OF DISEASE

The section on family’s understanding of the disease process is included as much for its absence in the literature as for what has been written. Considering how difficult it is for people and their families to live with this illness the lack of emphasis on family education, which could only serve to ease the situation, is surprising.

Much is said about the need for medical staff to communicate about the patient’s condition but very little about input on the disease itself. Part of the Caring for Relatives with Dementia (CARD)

study involved looking at abusive behaviour experienced by carers. Three experienced psychiatrists interviewed carers consecutively referred from five UK Community Health teams. Using two different scales they measured the effect of psychological and physical abuse and the outcome of how rewarding their relationship with the care recipient was. Although, unlike this study, these were all home based participants, over a third had experienced some form of abuse. There were many variables taken into account, however the conclusion was that carers who understood that neuropsychiatric and abusive symptoms were part of the dementing illness could cope better and continue to have a more rewarding relationship.^{(23) (23)}

A UK study done by Adamson et al looked at the understanding of dementia in African/Caribbean and South Asian families. Although the carers were often second or third generation most of the patients were first-generation with their cultures firmly rooted in their country of origin. Importantly respondents were given the choice of speaking through an interpreter as cultural expression of the phenomenon of dementia could have confounded the results. In the African/Caribbean group there was awareness rather than an understanding of dementia which had not been there before the diagnosis was made. In the South Asian group the majority had never heard of the condition before their relative had developed it. Once the diagnosis had been made however there was huge variation in what knowledge people had about the cause and effect of the disease. The result was that families often blamed the care recipient for behaviours directly related to the disease. This increased the breakdown of relationships and could negatively affect relationships and care provision. The authors note however that this is not specific to these populations. A qualitative study on the majority population found there was a general lack of understanding by the community and kin regarding dementia.^{(63) (63)}

In contrast, as part of a vast study called the Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life (CASCADE) study conducted over four years amongst 22 nursing homes, proxies of patients with moderate to severe dementia were asked whether they understood the type of clinical complications expected in advanced dementia, and whether a nursing home physician had informed them of the prognosis or the clinical complications expected in advanced dementia. A majority (81, 4%) of the 323 people interviewed felt they understood which clinical complications to expect but only 32.5% said a physician had counselled them about these complications.⁽¹²⁾ Similarly in a study in the UK, even after having been given precise medical information, participants were not prepared for the progression of the illness with its behavioural, psychological and physical elements.⁽⁶⁴⁾

In the literature review by Henning's one of the main sources of uncertainty was a lack of knowledge about treatment options and illness trajectory, and non-recognition of dementia as a terminal illness.⁽³⁾ It is in this context that family members will need to make end-of-life decisions. Forbes found most family members could not even conceptualise the trajectory of the disease and dying process and thus were forced to make decisions with limited knowledge, unaware of what they didn't know. They had little understanding of terminal conditions common in advanced

dementia such as dysphasia or deteriorating cognition.⁽¹⁸⁾ Ironically Albinsson's study on existential concerns showed that families perceived dementia as even worse than end-stage cancer due to the devastating, long-lasting suffering they went through.⁽⁴⁵⁾

None of this is surprising considering the lack of understanding of dementia as a life limiting and terminal illness found in many studies among health care providers. This seems to be across the board. In Ryan's study a specialist palliative care team focus group commented that dementia was not a disease but something that just happens to people. The GP focus group believed that dementia was not terminal and the hospice focus group who felt that dementia demanded very specialised care that they were not able to give.⁽⁵⁷⁾⁽⁵⁷⁾

In their discussion, Chang *et al* reviewed the literature and found that repeated mention of the lack of education around symptom management for nursing staff in the US, UK and Australia. They concluded that the need for families and staff to be educated about dementia was one of the most important measures in supporting those families.⁽¹⁵⁾ Smythe *et al's* survey questioned 360 medical staff, nurses, doctors and allied health workers about their perceptions of their own knowledge of dementia. They found that GP's in Australia had very little geriatric specific training during their undergraduate training and therefore reported a specific knowledge gap.⁽¹⁷⁾ Doctors may feel ill equipped with knowledge or they may be uneasy about facing the inevitable and painful decline with family and patient.

Study after study conclude the same thing, families have very poor understanding of disease trajectory or even the fact that dementia is a terminal illness. For these people whose distress has already eroded their capacity to think and make decisions, the huge vacuum left by this lack of knowledge is greatly magnified^(8,18,45,47,65) If primary care doctors are ignorant about and afraid to face dementia, they can offer little hope to the patients and families they see.

2.6. END-OF-LIFE

Severe, end stage dementia is characterised by neurocognitive decline including confusion and behavioural changes which give way to apathy and decreasing levels on consciousness. Ability to communicate deteriorates and disappears. Functional independence including mobility and ability to perform activities of daily living (ADL's) gradually become eroded and ability to eat moves from loss of appetite to inability to swallow. (Shuster 2000)⁽¹⁵⁾

This definition illustrates the difficulty of defining when dementia has reached its final stages and when end-of-life issues need to be considered appropriate. It could be argued that end-of-life refers to the prolonged and unpredictable dying experience which occurs once many people are admitted to an old age home. However it is the last months or weeks that are being referred to in this section.

The conflicted way that death is viewed by many family members, underlies the trauma of the decisions they will be forced to make. This is expressed by a spouse in the study by Hennings and

Froggatt when she says “*I wish he was dead/wish he was fully alive,*” or another who stated that there were worse things than death. In their literature review they found that the death of the person with dementia was seen as both a blessing and a tragedy, but there was a fear that they would feel responsible or guilty following withdrawal of treatment rather than seeing this as appropriate.⁽³⁾ Death was acceptable if it was caused by events out of the control of the family such as a stroke or during sleep. It was forbidden if there was a treatable condition such as pneumonia or if a physician had not declared the resident terminal.⁽¹⁸⁾

A wide-ranging study by Schultz et al looked at end-of-life care and the effects of bereavement on family caregivers of persons with dementia. This was conducted over a four-year period with 217 caregivers at six sites in the US. Although these carers were all home based they had access to services as out-patients. Over 90% believed in some measure that death came as a relief to the patient and 72%’s that it was at least in part a relief to them. Within a year levels of depressive symptoms were below the levels reported when they were actively caregiving. Only a minority used bereavement services. In contrast the relatives of those who had institutionalised family members did not show this recovery, which suggests that relief from providing daily care alone does not account for recovery from bereavement.⁽²⁷⁾ Moyle’s study supports this finding, where moving to a care facility is seen as a step closer to death and losing this person altogether, an event that was both longed for and feared.⁽²⁴⁾

ADVANCED CARE DIRECTIVES (ACD’S)

In 1991 the Patient Self Determination Act was implemented in the USA. This required all institutions including nursing homes to inform patients of their right to participate in decision-making and advance care directives (ACD’s). Numerous factors have been found to influence people’s desire to complete ACD’s; education, class and race all seeming to have an impact. Advanced care planning is not necessarily the same and is an ongoing process as the patient’s condition changes.⁽¹⁸⁾ UK policy as laid out by the Royal College of Physicians and the Department of Health includes advance care planning as part of good dementia care. Further guidance states that end-of-life decisions need to be discussed and documented for patients likely to die within 12 months.⁽⁵²⁾

In Holland there is a high level of awareness of a patient’s rights to die with palliation when they or their families feel it to be appropriate. Rurup *et al* conducted an extensive study funded by the Ministry of Health Welfare and Sports in Holland. This looked mainly at issues of artificial hydration and nutrition (AHN) but included ACD’s as well. Thirty nine nursing homes from three different regions participated, with 75 physicians, 136 relatives and 178 nurses. All had been involved with or were related to patients where a decision regarding AHN had been made. In the Netherlands nursing home medicine is a separate medical specialty, and nursing home physicians are employed by the nursing home. This makes them ideally placed and qualified to discuss and inform patients, family members and nursing staff about ACD’s. Despite this and even though

doctors, nurses and families all agreed this should be done on admission, it only occurred in 68% of cases. Only 35% of nurses 47% of relatives and 15% of physicians fully agreed that refusal of food and/or drink should be respected and only 37% of physicians agreed that ACD's should be followed.⁽⁶⁶⁾

In their study on end-of-life planning, Godwin and Waters' went a step further than most others by including the dementia sufferers themselves in the interviews. The interviews in their study were held with a triad of the family member, home carer and patient. All patients had been assessed using the Guys Advanced Dementia Schedule as having severe dementia but were still able to speak a few words. Although questions asked of patients were simpler than those asked of family and staff they were, by their very nature, quite existential in part at least and it is debatable how much of the recorded responses were mere interpretations of the carer, family or researcher. In addition being in the presence of the resident may have impacted on the answers surrounding planning of end-of-life given by family and staff. They found that procedures for establishing and updating views were not in place any except one of their eight research settings. Family and staff reacted to the subject as if they had not given it much thought, or if they had it was regarding funeral arrangements.⁽¹⁶⁾

Although Wettle's USA study was not focused specifically on dementia but on bereavement experiences in nursing homes, he found that over 80%' of the residents had completed ACD's. The respondents however had hardly ever used those directives in guiding the end-of-life care of their deceased loved ones.^{(40)(40,40)} Van der Steen surveyed family members posted as next of kin on death certificates. This was done three months after the death of the dementia patient. Over 30% of the respondents were unaware of the patient's wishes, and a half did not know their feelings about preference for dying.⁽⁴⁾

Findings by numerous researchers that many of the problems of dementia care and particularly end-of-life care could be addressed with advanced planning, highlights the lack of this in countries supposedly well prepared. The situation in a country such as South Africa where little to no emphasis is placed on ACD's could be much worse.

PALLIATIVE DECISION MAKING

In the literature review by Jean Hennings it was found that:

- Family members generally wished to be involved in decision-making.
- Those who did not wanted their values to be reflected in decisions made on their behalf.
- At times of crisis they felt uncomfortable, stressed, fearful and guilty when making decisions.
- They felt uncomfortable making decisions that seemed to hasten death.

- They used a range of values to make decisions including quality of life, previously expressed wishes, religion, the personal history of the patient and the preservation of dignity and comfort.
- They wanted frequent contact with staff, seeking empathy, reassurance, understanding, guidance and reassurance.
- They attempted to personalise relationships with professionals to achieve these needs.

The same review revealed that the lack of the above resulted in palliative care as being seen as less than optimal if not neglectful.⁽³⁾Families strongly felt that they did not want to be seen as giving up or giving sub optimal care.⁽¹⁹⁾Caron noted that few caregivers were fully aware of their role as decision makers at the end-of-life and hypothesised that this could be due to the few occasions that existed to either discuss or fulfil this role.⁽⁴¹⁾

Often when decisions are made it is in a time of crisis and pressure usually because health care workers have failed to recognise the resident has begun to die. This means conversations about end-of-life have not been initiated timeously.⁽⁴⁰⁾It was not only this lack of recognition that was found to be problematic; staff were often uncomfortable talking to relatives about death. They worry about accuracy, appropriateness or being held to account. Some view their role as being to preserve life even against the family's wishes.⁽⁵²⁾

This was shown to be unfounded in the study by Strang et al in Canada. The goal of this study was to determine the views of caregivers on the relevance and benefits of hospice to themselves or to patients. In order to do this the subject of death and dying had to be broached. The interviews were done before, during and after placement, and therefore death was neither necessarily imminent nor even considered. The most important feature to caregivers was avoidance of hospital and aggressive treatment. Only six percent found the discussions distressing. The caregivers were willing to consider enrolment after only a general description of hospice services.

This supported previous findings that caregivers in general embrace the concept of palliative care for the dementia, even if they are caregivers of patients with moderate dementia. Many saw the benefits as being more relevant to themselves than to the patient.⁽²¹⁾⁽²¹⁾ All this suggests that preparing families for death and participation in end-of-life decisions, as well as families and staff acknowledging dementia as a terminal illness, will lessen the suffering and depression of these family members as well as preventing complicated grieving processes later on.

As no research has been done within South Africa on this subject, none has been included in the above review. One cannot therefore necessarily extrapolate it to our context. There are numerous layers of societal differences and old scars which complicate our circumstances; cultural, historical, economic, geographic, availability of resources, race and religion. However, the fact remains that by 2050 South Africa's over 60's population will increase from 7% to comprising 13% of the population, an estimated 6, 6 million people. Kalula *et al's* study of patients attending their memory clinic in Cape Town, found that only 6% of the current over 60's were institutionalised.

⁽¹⁰⁾ Ogunniyi *et al* points out that the Developing World (including South Africa) cannot meet the resource demand for institution based dementia care and that the dominant culture favours extended family and therefore home care.^{(67)(67,67)} However, urbanisation, the HIV epidemic, migration, immigration and more families sending children away to school means that home care of elderly relatives with dementia will become more and more strained and the need for institutionalised care more acute.

2.7. RATIONALE FOR STUDY

If currently 6% of the elderly population in South Africa live in care facilities this translates to approximately 858 000 people. With an elderly population set to double within the next 35 years as well as rapid urbanisation, it is likely that this number will become much higher. Within this ageing population a high proportion are likely to be suffering from dementia. In addition to this very few people have access to specialised dementia care or palliative expertise. Thus the burden of care falls on primary care doctors, nursing staff and family members.

Investigating the delivery of palliative care to dementia patients and their families in old age homes in Cape Town as perceived by that family, is therefore necessary. It is uncharted territory and therefore could provide invaluable insights into perceived gaps in care and communication for all levels of care staff within these homes as well as for the primary care doctors associated with them. This could only serve to contribute towards improving the care of these patients, the experience of their family members and ultimately the overall betterment of the caring experience for staff in the institutions involved.

AIM

To explore the delivery of palliative care to dementia patients and their families in old age homes in Cape Town as perceived by the family members, as well as the barriers to and facilitators of their involvement in that care.

OBJECTIVES

1. To understand the vulnerabilities of families of dementia patients in order to ascertain their and the patients particular needs.
2. To explore the perceptions of family members of the functioning and attitudes of the homes with regards to care of their loved ones
3. To explore the level of comfort and opportunity family members feel they have to be involved in the care of their loved ones, as well as the facilitators and barriers to that involvement.
4. To gauge the understanding that family members have of dementia, palliative and end-of-life options.

CHAPTER 3 - STUDY METHODOLOGY

3.1. METHODOLOGY

STUDY DESIGN

This is a qualitative study using Interpretative phenomenological analysis (IPA) as a research methodology. In keeping with IPA the sample size is relatively small and homogenous in that it is composed of people who share a common and very particular experience.

STUDY SITES

Although only four sites were initially envisaged, it was necessary to expand this due to the fact that in the facilities selected either there were not enough people who matched the selection criteria or, as was the case of one participant, his mother died during the course of the study period. The initial sites included:

Helen Keller Old Age Home in Pinelands and Fairmead in Rondebosch: both are middle income, historically white areas and both homes cater largely to this demographic.

Pinelands Place in pinelands was added when an extra participant was needed to replace the person who withdrew from the study.

GH Starke in Hanover Park and Arcadia in Athlone: Both are lower income areas, historically 'coloured' areas and both homes cater largely to this demographic.

Each home selected has a frail care section accommodating people suffering from dementia. (Appendix 1)

STUDY POPULATION

Family members of dementia patients in the frail care units formed the population in this study, including spouses, children and siblings.

SELECTION CRITERIA: inclusion and exclusion.

All interviewees were over the age of 18.

No people were excluded for financial reasons – e.g. inability to afford transport as long as reimbursement was within reason.

The Bedford Nursing Disease Severity Scale (BANS-s) (Appendix 2.) was used to select patients whose family members were eligible. The cut off score was 18.

Family members of those patients who had significant motor disability prior to the diagnosis of dementia were excluded. This did not include patients who had had strokes when already suffering from moderately severe dementia.

Any family member was eligible regardless of their relationship to the patient, provided they visited on a fairly regular basis.

SAMPLING METHOD

Sampling was purposive. The nature of what was being studied demanded a particular focus on a specific group of people who all shared in the phenomenon under investigation; in this case the experience of being family members of advanced dementia patients in old age homes in Cape Town. In order to achieve the stated aim of this research project, this was a necessary way of targeting the research subjects. In line with IPA the sample was as homogenous as possible whilst still allowing for some diversity in sex, age, socioeconomic and cultural background and educational level.

SAMPLE SIZE

The primary concern of IPA is a detailed account of individual experience; therefore the issue is with quality not quantity. This allows the researcher to benefit from a concentrated focus on a small number of cases. Typically IPA studies range from three to ten participants although some studies have used only one very detailed study. In order to achieve both a deeper understanding of the individual participant whilst still managing to get a sense of dominant or divergent trends amongst a homogenous group the sample size for this study was ten participants.

DATA COLLECTION TOOLS

To facilitate the emergence of the participants own story an interview guide was drawn up using, where-ever possible, open ended, non-directional questions. This was used as a framework only and could be altered if necessary during the course of the interview participants' particular concerns dictate that new themes be included.

The interview guide was drawn up over time, starting with an initial investigation of relevant literature followed by input from Jill Robson the Western Cape Regional Director for Alzheimer's South Africa as well as colleagues and patients from within my practice who have had experience of the situation. It was then further informed by a more in depth review of the literature read by the researcher in preparation for this study. It was structured to allow participants to begin with their own story of the entry of dementia into their lives and then lead into the understanding of the illness and the suffering it brings. Further sections look at barriers to care given and opportunities to be involved in that care (Appendix 3). The guide was reviewed by three people who have either had or currently have close family members with dementia in homes in Cape Town, as well as two people who have experience and qualifications in psychology.

RECRUITMENT

Once the homes were identified, management was approached for permission to use the facility. This included The CPOA (Cape Peninsula Organisation for the Aged), the chief matron at Helen

Keller and the board at GH Starke. Information regarding the study (Appendix 4.) was submitted to the CPOA via e-mail. The other homes were visited personally first where the information was given in oral and written form. Permission was received from all the homes. The senior nursing staffs were contacted and meetings were set up to describe the study and what would be needed from the staff concerned.

The BANS-s was used to identify potential patients. This is an observational scale which requires no direct contact with the patient but does require a level of familiarity with the patient's condition. Thus, although dementia patients are in themselves a vulnerable population, there was no direct involvement with them in the study, nor were they approached by any researcher involved in the study.

At the meetings with staff, the researcher went through the BANS-s in detail to ensure clarity about the correct methods of administering and interpreting the test. This was to minimise confusion regarding application and terminology. The researcher remained available at all times to assist if questions arose. The staff were then left with the information and contacted the researcher a few days later with potential participants. All potential participants had been phoned by the staff first to ascertain their willingness to be contacted and for permission to give their contact details to the researcher.

Each identified family member was contacted by the researcher by phone – this was followed up by e-mail where more detailed information was given in written form (Appendix 5) to assist in deciding on participation in the study. At the same time consent forms were forwarded for completion. No potential participant was obliged or coerced to take part. All candidates gave consent to be interviewed, however one potential participant withdrew after his mother died. An additional participant was approached to replace the potential participant who had withdrawn. Meeting places were set at the convenience of the interviewee. The places chosen were outside of the old age homes and all offered a suitable degree of privacy, either in the person's home, work place or at the researcher's place of work. Participants were able to withdraw at any point without supplying reasons. They were provided with written information sheets and again fully informed orally at the time of the interview. Each participant was asked to sign informed consent as described in the section on ethics (Appendix 6).

DATA COLLECTION

Data was collected by means of in-depth semi-structured interviews lasting between 30-80 minutes. All interviews were conducted by the researcher which assisted in enhancing consistency. All interviews were conducted in English by choice of the participants. The interviewer had no relationship with the nursing homes' staff or the residents in this study. After consent for both the interview and taping was confirmed and signed the interviews were conducted and audio recorded. At the conclusion of each interview field notes were made recording the researcher's perceptions of any non-verbal behaviours contributing to the interview

as a whole. The interview guide provided the framework for the interview. Each participant led with their own agenda and priorities and the pattern and order of questions and prompts were changed accordingly. Some participants spent more time on issues that were not necessarily as important to other participants and some needed to talk about things that were not directly part of the study but informed it none the less. Although unanticipated, background stories made up a significant portion of all the interviews and were clearly important to the participants.

DISTRESS PROTOCOL

Whilst doing qualitative research, there is an obligation to try and foresee and balance potential positive and negative outcomes. Painful emotions and memories may be triggered and ongoing consent may be needed at different points. In view of this provision was made to offer a counselling session should the interviewee become distressed during the interview and need assistance afterwards. This would have been organised and funded by the researcher with a professional trauma counsellor. If at any stage the researcher perceived that the participant felt a question was inappropriate or uncomfortable she immediately enquired whether the participant was comfortable to continue or simply changed the line of questioning. At times a simple break in the interview with the recorder switched off was all that was needed. None of the participants felt unable to answer questions asked.

For two of the participants the interview evoked very strong feelings of sadness which moved them to tears. One of them became very emotional discussing her perception of her sisters suffering and her inability to express it. A further participant became very angry and agitated when describing both the experience of having sacrificed her life for her mothers and her interaction with the two old age homes she had been part of. With 18 years' experience as a family practitioner, the researcher drew on this to provide a safe space for these emotions to be expressed while at the same time moving them towards a place where they could move on to the next topic while at the same time feeling acknowledged and heard. By reflecting their feelings back to them and validating them they were able to move through the pain without judgement and even have a sense of catharsis. As one participant put it, *"You're going to have to be a psychologist, psychiatrist too."*

Although none of the participants chose to withdraw from the study, it was necessary to stop the interview during one, switch off the tape and allow time for the participant to regain her composure. During this time, the interviewer sat quietly giving her space to recover and then enquired whether she would like to stop or if there was anything she preferred not to discuss. When the interview continued it was the participant's choice to continue with the same subject that had been under discussion. Two of the participants asked for help with more information and were put in contact with Alzheimer's South Africa. One did not ask for help but the interviewer enquired about whether she felt she would like more input or someone to talk to about her mother and how she was coping. She declined the latter but was happy to have the extra information and guidance on dementia.

DATA MANAGEMENT

Data was transcribed verbatim by the researcher. All names and place names were anonymised and replaced by coding. Pauses and non-verbal utterances were included, however the exact length of pauses was not needed as analysis in IPA focuses on the content of the account rather than the rhythm and flow of the account. During transcription wide margins were left on each side and space left between lines for ease of coding. The recordings were backed up on a laptop computer with a confidential password and then locked away in a secure location at the researchers' home and kept till the study was complete, after which they were destroyed. Only the researcher had access to the taped interviews. Transcriptions were similarly kept in a safe place at all times.

3.2. ETHICAL CONSIDERATIONS

Ethical approval was given by UCT HREC thus giving permission for this research to be conducted.

The four tenets of medical ethics are as applicable to qualitative research as to any other aspect of medicine. Thus autonomy, justice, beneficence and non-maleficence should be upper most in the researchers mind at all times. As is often the case there is a constant tension between autonomy- that is the right of the participant to privacy, and justice- that is the need to produce research and make generalisations for the good of others. If prescribed ethical principles are followed then undue harm can be avoided and the participant's rights protected.

VULNERABLE POPULATIONS

In this case the potential vulnerable population was the dementia patients. No direct contact was made by either the researcher or nursing staff for the purpose of this study. Although not directly involved there is a degree of possible juridic vulnerability of both the participants and the dementia sufferers as described by Kipnis.⁽⁶⁸⁾ Here the concern may be (and indeed often was) that persons in authority had the power to and would penalise the family and or patient if information was supplied. Constant reassurance was given that interviews would be anonymised and coded and no information pertaining directly to a subject would be passed on to the old age homes. In addition participants were subject to emotional vulnerability. The very process of talking about their loved ones brought up painful issues. At times there were issues that revealed themselves which had not been previously fully realised or which had never even been considered. This caused some distress for a few of the participants. (See distress protocol)

ACCESS TO PARTICIPANTS

No direct contact was made with any participant until permission had been obtained via the nursing staff. Only then were contact details given to the researcher. Permission was requested from old age facilities used. It was not the aim of this study to vilify or criticise any one facility. Every precaution was taken not to prejudice participants in any way during data collection and

both positive and negative experiences were elicited. The interview question guide was made available to all facilities involved.

INFORMED CONSENT

This is perhaps one of the most important aspects of ethics in the research process. In order to safeguard the rights of the subject every aspect of the consent process must be transparent, clear and fully understood. Thus clear, unambiguous language was used in the written consent information and clarified verbally to assure consistency with the appropriate level of education of the participant. Care was taken to avoid biased information and medical jargon. Oral and verbal consent was explained in the person's home language and sufficient time given to consider the implications prior to the interview. (Consent forms and information was e-mailed at least a week prior to the interview.) Signed consent is not irrevocable. At any time the subject may withdraw consent for any part of or the whole of the interview without explanation and disallow its use in the study. They should be reassured that there will be no repercussions to them or their loved ones in this case.

CONFIDENTIALITY

The handling of data has been detailed above. Consideration was given to the fact that even though coding has been used to avoid identification of subjects, in smaller communities such as old age homes, direct quotes could lead to the identification of those people. Care was therefore taken when using these quotes. Subjects were informed of who would receive the finished study and if and where it will be published. In addition they will receive a copy of the finished study themselves.

3.3. THEORETICAL FRAMEWORK: INTERPERATIVE PHENOMENOLOGICAL ANALYSIS (IPA)

In order to clarify the processes of analysis carried out in this study it is necessary to have an understanding of the method chosen for this purpose. To this end a short introduction to Interperative Phenomenological Analysis follows.

IPA's first appearance came with the publication of a paper by Jonathan Smith in 1996, in which he argued that psychology needed an approach able to capture the experiential and qualitative whilst still being applicable to mainstream psychology. He felt that a quantitative approach was needed which was centred in psychology rather than being imported from another discipline. Although IPA is seen as a psychology research tool, this can easily be extended to other disciplines where there is an interest in psychological questions.

There are three key areas of philosophy which inform IPA: hermeneutics, idiography and phenomenology.

PHENOMENOLOGY

This is the study of the experience of being human. Investigators identify a phenomenon or reality or experience that can be described as people 'live' the experience. Therefore the person's exact words are the focus of data collected. ⁽²⁹⁾Phenomenology originated with Husserl who believed that the lived experience could be perceived and understood in a manner uncontaminated by their past experience. He was concerned about finding the essence of experience rather than the way it was experienced for a particular person. ⁽⁶⁹⁾

HERMENEUTICS

Hermeneutics is the theory of interpretation or sense making. ⁽⁶⁹⁾ It is the process of bringing out what is normally hidden in human experience and relationships. Hermeneutics goes beyond description of core concepts to find meanings embedded in common life practices. These meanings may not be apparent to the participants but can be gleaned from the narratives they produce. ⁽³¹⁾ It looks at the relationship between the historical context of the texts' production and the context of its interpretation. ⁽⁶⁹⁾ Thus while phenomenology uncovers meaning, hermeneutics interprets this meaning. ⁽³⁰⁾

THE HERMENEUTIC CIRCLE

This describes the dynamic relationship between the part and the whole. To understand the one, one must understand the other. There is an inherent circularity moving from the participant as focus to the researcher as focus, with an attempt to make sense of the former's story whilst acknowledging the latter's preconceptions and biases. It is a key tenant of IPA that the process of analysis is iterative, moving backwards and forwards in a range of different ways whilst analysing the data rather than completing steps one after the other. ⁽⁶⁹⁾

IDIOGRAPHY

Idiography is concerned with the particular as opposed to making claims on a group level (nomothetic). There is a commitment to the particular in the depth of detail and analysis. There is a need to understand how a particular phenomenon has been understood from the perspective of a particular person in a particular place. Rather than rejecting generalisations it establishes them by locating them in the particular, where a given person can offer a unique perspective on their relationship to or involvement in the phenomenon of interest. ⁽⁶⁹⁾

RECRUITMENT

Participants in IPA studies are purposively recruited to represent a broadly homogenous sample. However, too narrow and homogenous a sample may pose problems when evaluating transferability. To overcome this, the account should be rich and transparent enough and sufficiently related to current literature to enable the reader to evaluate this transferability. ⁽³³⁾ Numbers recruited are often limited to between three and ten. Whilst this may seem an

insignificant number the iterative processes of analysis is intense and time-consuming. In IPA less is more with in-depth analysis taking precedence over the broader, shallower, descriptive analysis of the many participants seen in grounded theory and thematic analysis.^(30,69)

THE THEORY OF ANALYSIS

IPA recognises the role of the analyst in understanding the lived experience of the participant. It attempts as far as possible to gain insight and perspective of the phenomenon being studied whilst acknowledging the researchers beliefs, previous experiences and expertise. This brings an understanding that these are not biases, but necessary to make sense of the experiences of others and in fact to be used as an interpretive tool. Thus there is a two stage interpretation or double hermeneutic where the researcher tries to make sense of the participant who is in turn trying to make sense of his own experience.^(30,33,69)

Whilst the deeper analysis may be seen as losing the original meaning, Smith et al encouraged researchers to 'go beyond' the apparent content. Despite this IPA is firmly anchored in the participants experience using direct quotes and metaphors both within the theme titles or the written results. Thus IPA aims to go beyond standard thematic analysis.^{(70) (69)}

Each case is approached on its own terms attempting to bracket ideas that emerged from the earlier cases. Thus there is an evolving nature where earlier ideas may be superseded by new ones.⁽³³⁾

It is important to note that IPA by its very nature is the analytical account of one researcher or research team. Whilst the finished product should have veracity and credibility, it may not be the only possible interpretation. IPA does not seek to find the only answer or truth, but the meanings must be logical and plausible and must be true to the words of the participant and 'strike a chord' with the reader.^(33,71)

Analysis is described as an iterative and inductive cycle moving from the particular to the shared and from the descriptive to the interpretive. This involves line by line analysis moving from the apparent to the deeper meaning of language to the interpretive. There is identification of emergent patterns emphasising convergence and divergence first for single cases and then across multiple cases. There is dialogue between the researchers, their coded data and their own knowledge to make sense of the meaning these issues have for participants. The format of the final narrative must allow for analysed data to be traced from initial comments to the final structure of the themes.⁽⁶⁹⁾

Within IPA and quantitative research in general focus is on transferability rather than generalisation. Reid et al (2005) proposed that commonalities across accounts could lead to useful insights which could have wider implications, and Caldwell (2008) argued that findings from IPA studies could influence and contribute to theory in the broader sense. Thus Smith et al advise IPA

researchers to think in terms of “*theoretical transferability rather than empirical generalizability.*”

(33)

3.4. ANALYSIS OF THE STUDY

STEP 1: READING AND RE-READING

This involved the immersing of oneself in the written transcript. The first reading was accompanied by listening to the audio recording whilst the second was without it. Any thoughts or observations during this time were noted in a book for later use. This process gave a sense of the chronological order of the interview as well as an overview of recurrent themes, concerns and contradictions.

STEP 2: INITIAL NOTING

This was a 3 level process involving the noting of descriptive, linguistic and conceptual comments. The aim was the production of a detailed set of comments on the data. The process involved line by line analysis and moved from the subject’s interpretation of their own experience, to the meaning of the actual language they use to more abstract concepts. The former helped the researcher to make sense of the meaning in the participants account. All this was done whilst staying true to the participants words and lived experience. The page was divided so that each level of commentary was noted on the same page, moving from the left margin towards the right, each in a different colour.

Descriptive comments

This focused on the actual content of what the subject said, taking the text at face value. The process really concentrated on how the person saw their experience in the context of their own world, experiences and expectations.

Linguistic comments

This looked at the use of language, pauses, laughter, repetition, emphasis, tone, fluency, metaphor etc. The aim was to uncover the implied meaning and emotion behind the words that may or may not have been linked to the content.

Conceptual comments

This involved a shift towards seeing the participants overall understanding of the subject under discussion at a more conceptual level. It involved a deeper level of interpretation that was often interrogative. Self-reflection was necessary as there is a need to draw on personal and professional experience. There was a shift to a deeper level of probing, looking at time frames and the meaning of the part in the context of the whole. Every step was clearly documented to allow for auditing later on.

Thus the process of initial noting may be shown in the following example from Interview 5.

DESCRIPTIVE COMMENTS	TEXT <i>(linguistic comments)</i>	CONCEPTUAL COMMENTS
<u>Helpless against disease, to give her quality care/guilt</u> <u>Guilt /abandoned. Projection of mothers wants and needs</u>	<p style="text-align: right;">Dementia, place,</p> <p>situation</p> <p>110. Because you can't make <i>it</i> better. <i>2nd person</i> <i>all on me</i> <i>You</i> can't give her, <i>you yourself</i> can't give her the care that you would like her to have.</p> <p>Repetition/emphasis</p> <p>111. <i>You yourself</i> can't look after her <i>Blame, perpetual, victim</i> <i>which she will. I know</i> that that is what <i>wants ALL of me</i> <i>she wants.</i></p>	<p>Painful emotion-shift to 2nd person. Powerless to restore mother- isolated with the burden.</p> <p>Will never be able to do enough to allay guilt.</p> <p>Feels condemned by mother, but resentful of her life eclipsed by mother/disease: imprisoned</p>

STEP 3: DEVELOPING EMERGENT THEMES

By now the researcher had a familiarity and a comprehensive understanding of the interview as well as a substantial set of data looking at the different parts and levels of understanding of the text. At this stage there was a move away from the transcript to using this data set with the aim of reducing the large amount of information. This was done by focusing on specific pieces of transcript whilst still recalling the whole. All 3 levels of analysis were drawn together to produce a clear, short statement of what was important overall. Themes were in the form of a phrase which revealed the psychological essence of the text (conceptual) but remain grounded. Again the researcher's interpretation was closely involved and the end product was an expression of both the participants and the researcher's interpretation of the experience.

STEP 4: SUPERORDINATE THEMES

This involved taking the themes which had been developed chronologically and looking for patterns, meanings and contextualisation which tied them together. Not all the emergent themes were included, depending on whether they related to the overall aim of the project. Some of the superordinate themes were further broken down into subthemes.

A table was created showing the move from the transcript, to the emergent themes to the superordinate themes. This included the line number before each emergent theme. The process was repeated independently for each interview.

STEP 5: LOOKING FOR PATTERNS ACROSS CASES

Having established super-ordinate themes the researcher then looked across the cases trying to find connections, convergence or divergence, recurrence, commonality or individuality. In doing this some super-ordinate themes were subsumed by others, some sub-themes became super-ordinate themes and some merged and re-formed as a sense of clarity across the whole developed. Key themes were illustrated by particular examples with every attempt made to maintain an idiographic focus despite making 'group' claims.

The transcripts, results and discussion were reviewed by a colleague with the qualifications of Social Work Honours as well as qualifications and extensive experience in psychotherapy. This was to ensure major inconsistencies in interpretations and representation of participants accounts of their experiences. With the material collected and analysed according to the procedures above it was possible to formulate a picture of the most dominant themes and concerns that the participants expressed. The next section presents these as they emerged concentrating on the commonality of experience whilst highlighting individual perceptions.

CHAPTER 4 – RESULTS

INTRODUCTION

The following chapter is the result of the in-depth analysis of the raw data collected from the ten participants in the study. Looking for common threads and themes throughout all interviews the researcher hoped to achieve a body of knowledge that would allow for some transferability to this particular population in the wider community. In doing this every effort was made not to minimise the individual experience of each participant, neither was the experience of “*outliers*” discounted. Doing this would have run contrary to the aims of IPA and detracted from the richness of the knowledge gained through this form of analysis.

Themes that emerged and were used in these results were those that were pertinent to the objectives of this study and highlighted the perceptions, misconceptions and emotional turmoil pertaining to this most difficult of experiences.

A total of eight interviews were conducted. One interview included two sisters and a brother who preferred to be interviewed together and as each account was different they were analysed individually. Therefore the total number of interviews analysed was ten. Two people were interviewed from Helen Keller and two from GH Starke, four (group of three siblings) from Erica Place and one each from Fairmead and Pinelands Place.

In order to better understand the context of the individual’s experience of this phenomenon it is important to have some perspective of each participant within the setting of their own lives. The way one experiences any event is wholly determined by one’s past and present as well as ones future expectations. Everything that has gone into making an individual human being will determine their interpretation of a particular event and will make the experience theirs and theirs alone. Although the group of participants in the study was homogenous in that they all shared the situation being investigated, there were significant differences amongst them as indicated below. This was done purposely in order to gauge whether themes were particular to a home or were common to all participants regardless of the above differences.

SOCIO-DEMOGRAPHIC PROFILE OF PARTICIPANTS AND RESIDENTS

PARTICIPANT	A	B	C	D	E
Age of resident	82 (A)	96 (VD)	72 (A)	75 (A)	77 (VD)
Age of participant	56	68	78	82	52
Relationship to resident	Son	Daughter	Sister	Husband	Daughter
Sex of resident	F	F	F	F	F
Sex of participant	M	F	F	M	F
Ethnicity	White	White	'Coloured'	White	White
Educational level of participant	Grade 12	Tertiary	College	Tertiary	Grade 12
Time since diagnosis	No official diagnosis (10years)	5 Years	5 years	14 years	8 years
Residents previously cared for at home	No	No	No	Yes	Yes
Time in the home	2 Years	3 years	18months	5,5 years	4 years

	F	G	H	I	J
Age of resident	80 (A)	76 (AD)	85 (VD)	85 (VD)	85(VD)
Age of participant	56	48	62	60	52
Relationship to resident	Daughter	Daughter	Daughter	Daughter	Son
Sex of resident	F	F	F	F	F
Sex of participant	F	F	F	F	M
Ethnicity	'Coloured'	'Coloured'	White	White	'Coloured'
Educational level of participant	Grade 11	College	College	College	College
Time since diagnosis	No official diagnosis (10 years)	11 years	No official diagnosis 5 years	No official diagnosis 5 years	No official diagnosis 5 years
Residents previously cared for at home	No	yes	No	no	No
Time in the home	2 years	10years (7 full time 3 years in day care 18months in frail care)	2 years	2 years	2 years

AD- Alzheimer's disease

VD- Vascular Dementia

DOMINANT THEMES

Whilst reading through the transcripts of the interviews it became clear that there could be no understanding of what family members were feeling, nor of their expectations, satisfactions or disappointments, unless there was some insight into what they had already gone through. This applied particularly to the placement of their loved one in an institution. With this in mind the themes that emerged followed a logical pattern, beginning with the emotional burden of multiple losses (including the sense of betrayal with placement), followed by the impact of the understanding or misunderstanding of the disease itself. It then moved on to perceptions of the 'ruling system' within the home, the unhealed wounds of racial division in South Africa, confusion and abandonment surrounding end-of-life issues and finally, identifying the needs of family members and thus, in their eyes, the needs of the patients.

4.1. THE BURDEN OF MULTIPLE LOSSES

It soon became apparent that the emotional toll on the loved ones of dementia patients was immense and left them with a deep sense of confusion. Unlike most other illnesses the very nature of this syndrome subjects family members to endless blows and ever-changing goalposts. This is illustrated in the following sub-themes.

A SERIES OF DEATHS

Most of the participants expressed, in various ways, the fact that their loved one seemed to have been taken from them in ever increasing increments, both physically and mentally. The inability to achieve closure after a loss and the resultant prolonged pain of mourning was almost palpable in the sadness of the following reflections.

In interview seven, in a deeply poignant moment, the daughter (G) reflects,

- *And why she's still alive? uhm, you know, how many times must I mourn her death? I've written her eulogy twice already in coming to terms with all of this. It's all ready; her funeral arrangements have been made. It's stupid but I don't know what else to do. Uhm, ja, she's- it's like you mourn someone and then you move on. But, uhm you mourn and then you come back and you see this "person."(G,186-190)*

The deep sense of loss of the mother she knew being dead and mourned, eulogised and honoured is mocked by the very presence of "this person," this impostor who will not die. She is ("stupidly") stuck in this endless horror that has become her reality.

This sense of sequential loss and mourning is echoed in interview one as this son (A) reflects on the stepwise withdrawal of his mother away from him. She is lost; piece after piece, till his desertion is complete and with a sweep of his hand he symbolically closes her eyes in death.

- *Ja she's the communicating less and less. Even when her speech was bad after the stroke, she was communicating even with her eyes or trying to say things, but now she kind of almost stops communicating (indicates with sweep of hand over eyes). (A, 98-101)*

For many it was the physical indicators that were the tangible presence of these losses. There is a sense of bewilderment, of the physical body betraying the psyche, both through its deterioration and paradoxically its survival, as the essence of who the person was, was no longer there. Thus in interview four the husband (D) tells us of his wife's inability to take part in activities, but it is the sense of her body being an empty vessel that one is left with, rather than this being a purely physical disability.

- *Take for example they have occupational therapy from 9-12 every day and the girls sit in the middle, they play games, they do puzzles, exercises. J Sits there. (Gestures) Can't take it in, can't watch television and she sat there (D, 173-174)*
- *Ahm but it's been a steady downhill and.... loss of....well she was walking around a bit, initially with a frame, having her meals here with her sister and it's just been a steady deterioration (B, 17-18)*
- *It has already started with her walking; she would start losing her balance and just fall, which she was doing. She will eventually not be able to walk, she will eventually have to go into a wheelchair which we've been there, she will eventually become bedridden. (E, 87-89)*

In the last two excerpts the pain and utter sense of abandonment of the mother figure that is there but gone is clear. It is "obvious" to this son (J) that it is his mother, but is the pity he expresses for himself, for his loss, for the torture of witnessing this "woman," or for his mother, the victim of the disease?

- *And now it's now, haai, I almost think haai shame, you know this is the same woman and obviously that's my mother and you will look at it and it's quite damaging, so probably me and her children feel more hurt. (J, 172-173)*

Finally, in Interview six this daughter (F) seems to synthesise all these emotions. As her mother vocalises the diseases rejection of her daughter's identity, there is a plea for the restoration of this bond, a plea that is left answerless, leaving her no choice but to retreat in defeat again.

- *she say to me now why you calling me mommy. I say can't I just call, cause my mommy's gone, wouldn't you like to be my mother. And she'll tell me, she'll let me know. She'll let me know. Then I leave her. (F, 132-136)*

THE ULTIMATE BETRAYAL

The act of moving their loved one into an old age home was unanimously seen as a betrayal of the first order. Not one of the people interviewed would have chosen placement in a frail care as their first choice. Most still expressed regret that they could not change the situation, but felt trapped

by their personal situations. There was a deep sense of having failed the person who trusted them. This act at times felt so unforgivable that it eroded their sense of self - respect and inevitably, for most, tainted their entire relationship with the old age home itself.

For most it was as if the choice is being made for them. They were literally standing at a crossroads and yet there is only one path they were able to take. The choice made fundamentally changed all their lives. For H this act of disloyalty was compounded by the shame of having moved their mother to a place below her 'station' in life. There is a sense of utter disbelief and shock, of being caught unaware, ambushed by this illness.

- *Bad, bad. I didn't know whether I was coming or going. I had her in the car, myself, my youngest daughter, my oldest daughter and M, and we coming up the N7 going into V drive, she has a house in SE and now we at this robot and I'm standing in the middle lane and I say left or right. Left is to her house, Right is to the home (F, line 103-106)*
- *Well, she'd always told me, because her sister was here and that it was the last place she would ever want to be. (Softly) but what else can you do? Because she needed to move, mainly to be sure, that she took her medication. Ahm ja, so.. (B, line 24-26)*
- *I, I really don't know (very softly). Really. You know if I had my way I would take her and get someone to take care of her. But then my hands are tied. (C,173-176)*
- *My husband and my children basically forced it because when they saw how much strain, pressure it was putting on me, they kind of put me in a situation where it was- you have to do something. It took me weeks and then at first I had to go every day. (E, line 54-56)*
- *Very difficult, not an easy decision to make at all. Um, your whole life changes. Your whole, your whole life changes,,,,just, just.. (G, line 50-51)*
- *Into a home in A. It, it was a big shock to the system, mom has always lived in a decent house in town her whole life. Never had to go into townships. Mom..... (H, line 82-83)*
- *But it wasn't that easy, none of us felt completely happy about my mom eventually going to the CPOA, but at that specific stage it was the only solution at that stage. (J line 101-102)*

The exception in this sub-theme lies with D. His solution surrounding the decision to move his wife was to move with her. There was no thought of abandonment; it was merely an extension of his role of primary carer. He maintained his presence in her life with the same level of dedication as he had previously. This "positive" decision impacted in every facet of his interaction with and outlook on the old age home.

- *Well I had a carer at home and I realised if I go, ahm, what happens? Meanwhile I'll put her somewhere so that she can be in a continuous monitored position. That's why I came here.
.....No not at all. It was the obvious decision, ja (D,64-65)*

INSTITUTIONALISATION: RELIEF OR BURDEN?

For most the rationale behind institutionalisation was to relieve the burden of the care which they were struggling to or could not provide for their family member. Logically it should follow that having taken this step there would have been a lessening of their suffering, a feeling of relief. As in many other studies this was not so. All expressed relief regarding the physical safety of their loved one; however the emotional burden seems to have increased out of all proportion to this. The most dominant emotional theme in all but interviews two and four was guilt. This was pervasive and at times almost crippling. In the extract below G is imprisoned by the thought that her mother has recognised her treachery. Even as she struggles to physically escape her guilt overwhelms her.

- *Uhm, it was like she was (crying) holding me, holding my hand so tightly, she wouldn't let me go. ((Long pause) I had to go. (crying) Its like, does she know? Please, please don't let her know. (small laugh) Don't let her understand what's happening that she's seeing me leaving her. (G, 193-195)*

The burden of guilt revolved not only around the issue of abandonment but extended into a feeling of shame for the "sin" of continuing a normal life. This survivor guilt seemed to be a consequence of the utter powerlessness in the face of dementia, so great that there was no choice but to hand over to strangers.

- *No, it doesn't lessen the burden, no...no. You worry about it more and you feel guilty about it more. So lessened the burden as in physically it's lessened the burden, I don't have to physically go do anything, but emotionally it doesn't lessen the burden. (A, 115-117)*
- *. But that you see the person deteriorating while you're still carrying along and you think: what if? So ja.....(A, 80-81)*
- *No in fact in some ways it's actually made it worse, because you feel so guilty about putting them there in their last time of need when they really need good care. And you put them there and you see how poor the care is and just, it racks you with guilt. Makes you feel terrible. (E, 49-51)*
- *It's hard. It took me you know, I felt, what had I done? Had I put her in a place that because I want to carry on with my life. And I'm sitting between a bus and a hard place and I'm thinking shoo how do I cope? (F, 114-116)*
- *Sometimes I'm honest I forget about my mom completely for a while a week or 2 and then haai shame, my mom's in the home, I didn't see her now for 2 weeks, then it feels, it feels very bad. (J, 460-461)*

Again, one wonders who the "shame" is for, his or her suffering, after all it is his pain, he who is feeling "very bad."

Once more in interview four the context of the situation changes the response. Here the burden is not one of the guilt of the already perpetrated betrayal of abandonment, but one of the fear of an abandonment to come. His coping centres on his ability to control all aspects of his wife's

management as he is totally out of control of her decline. Thus D has forsaken his own life pleasures in order to fulfil this need to remain utterly committed to his wife to the end. It is the spectre of his end and the inability of any other person to maintain the fragile identity of his wife that haunts him.

- *And we used to have breakfast on Saturday mornings and I said no, I can't, it's out now. I'm not leaving J alone. But the biggest problem I've got, I'm just trying to work on it, is when I go, 'cause I'm getting older, Ahm, who's going to look after her.....(D,164-166)*
- *I put her clothes out every day, buy her clothes when she needs them. Ahm that's the kind of thing that not everyone will do (D,168)*

DISEMPOWERMENT AND ISOLATION

In terms of understanding the context of how participants felt about the institutionalisation of their loved ones, this is perhaps the most revealing of the themes that emerged. The helplessness and desperation is clear. The answers below were in response to the question "What makes you suffer most about this disease." Each person identifies areas which for them seems to typify the loss of what they needed most and what they can no longer have or "fix". Thus for A it is the disease as a whole which has vanquished the 'son protector'. In Interview two the daughter (B) cannot restore the emotional connection, whilst in Interview three for the sister (C) it is the act of being able to nourish and sustain that is removed. The daughter in Interview five (E) had looked after her mother for most of her adult life- this then is her source of pain, she no longer has any control, she is utterly alone and purposeless with regards to her mother.

- *That there's nothing I can do about it. I feel very powerless, very. It makes me feel desperate sometimes, but I do the ostrich approach I suppose. I just stick my head in the sand.....(A,106-107)*
- *I don't know if if she's thinking that way anymore, but this is the most difficult thing I find is not really knowing how she's actually feeling. (B, 113-115)*
- *I don't know, really. I don't know because now she doesn't do anything and at the moment they are feeding her, they are feeding her. Because she doesn't eat, she doesn't eat. She does try to eat, but.(C,117-118)*
- *Because you can't make it better. You can't give her, you yourself can't give her the care that you would like her to have. You yourself can't look after her which she will, I know that that is what she wants.(E, 110-111)*

The extract below is the most poignant as D's entire coping strategy revolves around control: understanding the medical process, overseeing the minutia of day to day care, even protecting the staff. Suddenly he is left helpless and alone and it is his frustration, his inability to express his distress that one sees.

- *I don't know, I don't know what she can understand or hear, I don't know And if she can hear certain things, I think the frustration of not being able to express herself might be*

what's upsetting her, but she doesn't look upset. We try and keep her happy and laugh..., she doesn't laugh of course, they don't, so it's hard to, to, to decide now what upsets her. (D, 79-82)

G's suffering and complete isolation as she slips into a world that no-one else may enter, leaves her only powerless to save her mom. No-one will be coming to save her- she is utterly, irrevocably alone.

- *, I have never felt so much pain. Yoh, I don't think. You know (voice breaks, gathers herself) I'm.....it's like a secret world that I'm in because you communicate differently with them, I go into this world, no-one knows you know uhm and I'm...but... and then you go into this Narnia place (ironic laugh) and you talk to my mom, and you sing to her and we sing and we dance and we....ah.... I don't know ahm. I really, it's.....(G, 181-185)*

4.2. UNDERSTANDING OF DISEASE

The importance of understanding what is happening to one's loved one in order to cope may seem self-evident, however the findings in this study show that for all the participants, at least at some level this is not happening. Three of the eight patients had not been formally diagnosed meaning that there would have been no way for their families to clearly understand what to expect from the future even if they had had knowledge about the disease. Two of the participants got clear and sufficient information about the medical facts of the disease from their doctors and three more (the siblings in Interview eight) got some input when their mother was hospitalised prior to her admission to the home. Two had been to meetings hosted by Alzheimer's South Africa (1 went only once as she found it too traumatic.) None received any information from the homes either verbally or in written form.

For B (who had the highest level of education) this was a natural, expected decline rather than a disease. She had not looked for further information nor did she want it. The implications of this were that she had no idea of what was to come, nor of the decisions she may face later on.

- *Well my husbands a doctor and we've sort of discussed things, but we haven't. I mean to me it's been a natural decline..... So I just assumed with my mom, that at this age that's what happened. Ahm ja (B, 64-67)*
- *How does the dementia kill you? I mean in, my understanding is that your body functions just all giving up. Giving up. So to me it's just like been a natural progression, backwards, downwards. (B, 204-206)*

This absence of input and guidance had a deep impact on the emotional state of family members. In the quote below, an already traumatised and guilt ridden A is further burdened by the belief that by moving his mother to the home he has exacerbated her disease – he is the cause of her decline.

- *Because I don't know how much of her state she's in now was, was, was, was a part of, of the move to the home. I don't know if putting her in the home speeded up the dementia process or if it was just co-incidental, but if I was being really critical I would say it speeded the process up.(A, 149-151)*

For a few there was awareness, a vague hearsay of what was happening. The source of this information was nebulous and mostly self-taught. Above all, the quotes below leave one with a feeling of being lost. There is no control, no way to anticipate or plan. In many ways it is as if the insecurity and unpredictability of the disease are being mirrored for these family members.

- *I've seen it now progressing with my sister. She's probably going to die from that, or whatever because she's got diabetes also. And at the moment she's sitting in a wheelchair because her knees have given in.(C, 111-112)*
- *It's just that, they say that the dementia is when your brain is not functioning the way it should be, your cells die off and whatever, so you start becoming forgetful. (C 104-105)*
- *It's what I've read on the internet and done some things, looked up myself and things like that. It's what I've read on the internet and done some things, looked up myself and things like that.(H,155)*
- *I understand that it's eating away at the brain and the synapses are no longer connecting like they should and it will be different for every single person because you don't know where or how it's going to eat away at the brain. Is that a?..(G, 119-121)*
- *I, I just feel that with the clots mom is more likely to die of some clotting problem or lack of blood flow or have a stroke or heart attack. I think that is probably before she just sits and does nothing. (I,503-504)*

In contrast, those who had been given knowledge by people they trusted or by their own research were empowered. Their battle was defined in that they had a clearer picture of what lay ahead and what it was that was causing this. Ironically even this did not address their emotional crises and challenges – there was a clear divide between 'knowledge' and the 'total picture' of their suffering. For all three of the people below this split is glaringly obvious. D has used his powerful weapon of knowledge to block out any possible need for emotional support. E, despite her clear understanding of the disease and its effect still feels her mother will wilfully continue to torture her by prolonging her (E's) suffering and F, despite having made the effort to educate herself on the illness remains susceptible to popular mythology and struggles to marry the two.

- *Well, I've spoken to the neurologist Dr T originally. Ahm, I think even the psychiatrists there's a smattering of knowledge about Alzheimer's, but I've read a lot about it. I'll take on many a person as far as that goes(D,125-127)*
- *I was told once there was somebody coming to talk about Alzheimer's, I said ja, ja. It was a nurse I think, part of the Alzheimer group, who I have phoned in the past once or twice, didn't find they were very helpful at all you know. Come to our meetings. I said no I'm busy*

I've got a wife to look after. But my knowledge I got is from reading and updating myself with the latest things (D, 135-138)

- *So my understanding is that you basically have a bad stroke and it might take her out, or she'll have a bad stroke and she'll be even worse than what she is. But so far she's just had small strokes that have kind of lengthened the process (E, 90-92).*
- *Because my mother will drag her death out, I promise you that. She, she won't be like my father, here the one minute and gone the next. I doubt it. Because she's holding so tightly on to me particularly.(E, 235-2360*
- *So I said OK it happened, she's gone past the stage of talking about my father, she's past the stage of undressing herself naked because this is all part of the illness. I would walk in there at home and my mother's just sitting in a diaper, (laughs) you know. And now, what is happening now, she doesn't want to participate in nothing, she's not sick, she's never had the flu,(F, 98-99)*
- *. Some people have this thing about ah you don't drink enough coffee, or you drink too much coffee. My mother was a reader. My father was also a reader. He was the only one that drank tea or coffee, my mother never touched it. She never drank, she never smoked. (F, 139-141)*

Perhaps the attempt of J to make sense of what is happening to his mother, of what this disease actually is, sums up all of the above.

- *I'm assuming that because of the blockages and the lack of blood flow to the brain that is affected as well. Well I look at dementia as sort of severe forgetfulness, it's not Alzheimer's totally, it's a stage sort of in between, because she goes through stages when she does remember quite a lot, while the next time she may not know my name exactly but she knows exactly that she has children named A, P, J and P, she knows that, so ah it affects things that are, I don't know how to explain but yes it's just a very bad case of, as I see it, of dementia.(J, 119-123)*

As he starts his explanation it is at the level of his understanding of the medical facts, rational and comforting. This rapidly deteriorates into confusion: she doesn't quite have Alzheimer's, she's not really demented and she is on the edge of "normal". At this point she's still salvageable, still his mother. She has acceptable moments where they can all hide from this awful reality, there is still hope. By the end he is completely lost as is his mother. She has progressed, in the space of 6 lines, from forgetfulness to "a very bad case of.....dementia." His total ignorance of what is happening leaves him helpless, angry and confused.

4.3. THE SYSTEM THAT RULES: PERCEPTION OR TRUTH, DOES IT MATTER?

Having looked at where the participants are coming from in terms of their emotional state and understanding of the disease there is now a platform to understand how they perceive the

institutions their loved ones are in. I have broken this section down to look at the different sectors of the 'system': the nursing staff, the home/administration and the doctors.

NURSING STAFF: THE NURSE AIDES

The nurse aides or nursing assistants are the hub of nursing care. They are the ones who, day in and day out, deal with the minutiae of patient care. As such they are usually the people who have most contact with visiting family members. The attitudes and feelings towards these staff members varied from deeply appreciative, to reservedly understanding, to hostile.

In the following three extracts A, B and D are deeply appreciative. There is a feeling that these carers are going beyond what is expected, that they are adopting the role of family. The word caring is used over and over and it is clear that this total care given to the patients allows the family to feel safe and valued and cared for themselves.

- *Shhew, I don't know how they do it, quite honestly..... I think on the ground level what I see in that frail care, unless they just do it when I'm there.(A, 204-206)*
- *It's clean, ahm they seem caring. I get a lot of nice ahm conversation and nice feeling from some of the staff that are actually physically doing the work, in the kitchen, doing the beds.(A, 126-128)*
- *But they were very concerned for my aunt J that, that she would have like to have seen her daughter and they really tried hard to convince me to get her to come. And I was trying anyway. So they're caring about the people and they see needs and they identify them and they do convey them. So I thought that was very caring of them. They kept on saying why doesn't Mrs X daughter come visit (B, 145-148)*
- *The pluses with the staff are, are that they're very caring. One morning at 4 o'clock I got knocked up to say your wife's having a fit. Went downstairs and there was the one girl C lying in the bed cradling my wife in her arms..... That to me is more important than their skills and knowledge.(D,36-40)*

For some this admiration is tempered. It is more a feeling of pity, of understanding that the situation that the carers find them-selves in is often difficult. They are seen as essentially good people who are not allowed to express this due to the constraints placed on them. Although there is sympathy for the individuals, the very fact that these constraints exist is seen to further jeopardise the care given to their loved ones and therefore the final feeling is one of negativity towards the very people who were pitied.

- *They're not coping, they're not coping. They feel that they're, there long service in this place with E that has been there for such a long time, has been taken away. They have been with our parents longer than the new management and sisters there and they know how these people the old people operate, they know what there ailments are, but they get told.(F,264-267)*

- *Hopelessly under staffed, hopelessly. I think they're hopelessly under paid which is what makes them resentful as well. Ahm they don't have training, in my opinion, proper. They're not nurses, they're not qualified nurses. They're basically just taken off the street, come there for an interview for a job. (E, 192-194)*
- *They are wonderful caring people and they are not being treated very well. And these are the people who have to look after my mom, and some of them have been there for a while and others there's a huge turnover. Like the 3rd person in a year who is to be my mom's main caregiver and I've got to to introduce myself, explain myself to her and so on (G, 256-259)*

This sense of confusion is encapsulated below – G obviously has deep empathy towards the carers yet she is critical of their inability to care for the patients. But who is it that cannot be treated better – are the carers oblivious of their own rights or oblivious of the way to treat patients better? Is this a statement of sympathy or a questioning of the treatment given?

- *And.... a lot of them are really uneducated, the most amazing hearts. But they don't know any better way. They don't know that they can be treated better. (G, 315-316)*

For others there was no positive side. There was only distrust, abandonment and anger. There was absolutely no feeling of connection, no point of engagement or mutual understanding.

- *But there's the TV set there they don't watch it, they just sit, and sometimes sit and sleep in the wheelchair. And then I don't see anybody around. There's no staff. (C, 221-222)*
- *Ah, I don't know because there, there was a time when because my mom isn't wheelchair bound or anything, she could still walk around and they had in lock up.... Where they can't move round, because she wanders around (H, 397-398)*
- *They may think they're being helpful but honestly they treat people like, not like bad but like really, like you know sort of, not people that are important. And that, that's quite sad to see.(J, 212-213)*

Routine and keeping to the schedule is often seen to take precedence over patient care or attention to the person herself. The idea of faceless people who must be processed by the correct shift at the correct time reinforced the wall between staff and family for H and E. For D however, who had chosen to come into the system and to be an active part of it, it was an opportunity to help, to participate and alleviate the strain.

- *. Because on one occasion uhm I brought mom home later than uhm, uhm 6, 7 and they were most upset because the night staff is coming now or we are the night staff and we don't put people to bed. It all gets done by the day staff and if the day staff wants to leave early at 5,6 O'clock then mom must get put to bed.(H, 549-551)*
- *They wake the elderly folk up, they've got to get them washed, teeth done, hair whatever before breakfast is served. So there's this huge mad rush to try and get them all done, and it's a quick thing.(E, 121-123)*

- *Now if you've got 3 girls and you've got to feed 6 people..... Ah, you know your staff are still busy washing people and they've got to start feeding otherwise they'll be running behind schedule. So there are the pressure, pressure times.(D, 202-205)*

Of note is the fact that in five out of the eight interviews the problem of constantly changing staff was mentioned. It was a cause of grave concern, participants were either forced to start over and over with new staff members or give up forging relationships altogether. J's comments below vocalise this common sentiment perfectly. The problem is two way, there simply is no time to build these most vital of emotional connections, not only between the "people there" but between the extension of them – their family

- *If it is any suggestion, maybe for what I believe is constant rotation with regard to the staff there and that must be a problem, because nobody of the nursing staff can build a relationship with the patient. So therefore I mean, therefore they come and go, so there's no real connection between, I think between the staff and the people there. (J, 216-218)*

NURSING STAFF: THE SENIOR STAFF

Whilst there was quite a lot of sympathy and admiration for the nurse aides and carers when it came to the senior nursing staff there was less empathy. A and F express this as a feeling of distance. It as if the Sisters' were placed somewhere out of reach, resulting in a type of disquiet where information is withheld: a lack of sincerity. G's way of handling this impasse is to try and manipulate the system. She feels that to get things done for her mother she must almost deviously sweet talk her way round an otherwise impenetrable wall. For all three there is an unmistakable sense of them vs. us, where the 'us' is the loser. The end result is a watchful distrust.

- *We just need a little bit more impact and bit more sincerity from your management and from your sister, from your nursing sister (F, 177-178)*
- *imagine, uhm She's set in her ways and isn't really open, you've really got to be wise and you've got to be so, round the way about uhm, you know taking my mommy for a walk or whatever. (G, 276-277)*
- *Don't just walk through, you know what I mean. Don't just walk through and say.....ah, hello. No. Take the time, look at the resident's feet and see if it's clean. (F,353-355)*

For E the anger and hostility towards the senior staff is much more apparent. She is almost incredulous at the thought that the sister may be a positive person in her life. There is no doubt that she feels utterly betrayed. This is exacerbated in the second quote where she feels victimised – she is now a clearly defined enemy – singled out and isolated. The distress that this causes her compounds her already extremely vulnerable and precarious state of mind.

- *What nursing staff? The sister in charge, the staff nurse? Not very, sometimes I will find them sitting, my mom's in a double room, she's got N is in the room with her. N's got an old*

computer and she plays patience. Sometimes I find the Staff nurse is sitting at N's computer (E, 196-198)

- *So she said to me- you're the only person that complains and I knew we were going to have a problem with you because I knew you took your mother out the other home. . That of course upset me, and I mean I'm in such a fragile state (E, 143-144)*

In contrast for the two people who had positive experiences the impact on their overall sense of being contained and safe within the constraints of an unrelenting and unpredictable disease is clear. The benefit of having senior staff on-side permeated down to the junior staff and family members creating a safety net for all.

- *I think they do, yes, ja. No Sr G, I love Sr G 's sort of, it's all calm and quiet and things just go there's no pandemonium or drama. There's no drama (B,102-103)*
- *We've got a lot of changes with the sisters, we've got new ones again, but they're good (D, 209)*

THE HOME/MANAGEMENT

At the other end of the spectrum is the management. Of all ten interviews only one had anything positive to say and that was really as a part of the whole experience rather than the management themselves. Now there is not just distance there is an insurmountable barrier. D's use of the word authoritative describes this sentiment perfectly. This is an institution and, in the eyes of the participants, 'they' are the bosses. In the 'home' where they have put their mother, sisters H and I are officially shut out. They are definitely visitors and not a part of the whole. Ironically they are shut out at meal times. Feeding is nurturing, it is one of the few avenues left for bonding and providing a connection where all the normal channels have been severed by the disease, and it is officially closed. For these participants this is a dictatorship not a democracy

- *They're very authoritative in their management. The managers can't make decisions, they make them all. I don't like their kind of management but anyhow that's how it works. (D, 181-183)*
- *Because they don't want you to visit certain times. They've got a sign - No visitors after this this, no visitors after that. (H, 481)Lunch times and things like that. (I,482)*
- *. Because there're always signs, you can't do this or you can't go in there and uhm.....*
- *I've always, I've always found that there is not a lot of communication from management or middle management, that's always been; to me that's always been a thing. They don't tell you much. So it would have been more....and...ja,ja (A, 129-131)*

For F the lack of personal interest translates into dire repercussions. It is not hard to extrapolate her own feelings of despondency. She and C are both unheard and de-personalised. Effectively they and their loved ones have been written off – they have become commodities rather than people. Similarly G and J are isolated and abandoned by management. They feel completely marginalised, there simply is no-one there for them.

- *The home could be more involved, be more involved with the residents. Don't just walk through, you know what I mean. Don't just walk through and say....ah, hello...Listen to their complaints, it may be doesn't mean a thing, it's a load of, load of crap at times, but you need to listen. If you don't listen, if your top staff, manage staff is not listening to the resident, they feel despondent, they become depressed and they die. (F, 353-357)*
- *The only people I can complain to is the admin staff, because like now, on Monday, because her lower denture disappeared. Now they tell me that she only came with a top denture. I said no, I brought her in myself. She had a set of dentures. (C, 210-212)*
- *But unfortunately their whole system of what they're doing is bad management. I've really seen bad management. Nobody talks to anyone, they don't work together as a team, they're all there for each other, for themselves. (G, 254-256)*
- So the home didn't tell you that she'd fallen?
No, only one of the other residents, old ladies actually said your mom fell and I actually followed up, I'm not sure of the exact detail but we were..... (J, 364-366)

E is so alienated and traumatised by her experiences at the home that her interpretation of their responses goes far further than mere rejection. For her the home has actively and almost vindictively sabotaged what little identity her mother has left.

- *I've tried to offer that information, I've tried to. I mean I've told them my mother likes to bath and what did they do? They stuck all the chairs, the wheelchairs into the bath area, and then they go and pull out the bath. There's no ways she will ever get a bath again (E, 185-187)*

For every single participant the driving force behind institutionalising their loved one was safety. The guilt of abandonment, as previously discussed, was ever present. Both these things reflected in their responses to the perceived attitude of the management. The safety is a trade-off but this does not diminish the anger and disappointment that they feel. No level of care will ever be enough to salve the guilt as G so clearly says. At the end though they are all resigned. It seems they are defeated both by the disease and the system. There is bleakness: they have given up.

- *No, (sigh) my opinion, the type of care, the quality of care is very poor. I've been now, it's the second home I've been, so I went through the same thing at N as I'm going with HK. Ahm, there is no attention to detail. (E, 38-40)*
- *Angry, I'm angry that there's, that because of bad management my mom is being affected. I really do feel that she's being, that she isn't being treated well. Because it's my perception and some of it I know is fact and some of it is my perception and I feel guilty because, because I'm not the one looking after her and I should be looking after her. (G, 290-293)*
- *Our expectations have got lower and lower. That's why I said, its acceptance. (H, 553)*
- *Even with my other sister, who's not here. I mean she was the one who was totally against my mom going to that home, she said no way, I mean that is the pits. That is sort of rock*

bottom. And even now she's sort of well at least she's has this and least she has that. That's the feeling. (J, 559-561)

The final quote is perhaps the most shocking and sums up much of what has been seen above. For D it has been made clear – for management all are dispensable. There are no people only replaceable entities: staff, patients and their family members are in abundant supply.

- *One day one of the, the head of HR, I know them all very well, said to me – agh what are you worried about the staff for, they're two for a penny man. If they go we can get more, there are plenty of them. There are many more staff then there are jobs. And that's the wrong attitude to have. I've always learnt that in our organisation that I worked for, that people are your greatest asset. (D, 185-188)*

4.4. "SOUNDS TERRIBLY RACIST, BUT..."

Although not every participant brought up the issue of race, 5 out of 8 at least alluded to it. It would seem from these interviews that South Africa's recent past of Apartheid is still very present in the psyche of the participants. For E (a white woman), F (a 'coloured' woman) and G (a 'coloured' woman) there is an apologetic, embarrassed sharing of a confidence. Again whether this is perception or truth it is very real to them. There is correlation of race with poor performance. Furthermore both G and E feel their race is held against them, that they are resented and punished for not being black. Specifically for E, the projection of her guilt regarding the country's past may well colour her assumptions of the staffs' attitude towards her mother. This seems to further increase her sense of isolation.

- *Ahm, there's others sounds terribly racist, but I find the coloured staff are better than the blacks. It just is, it's the truth, there's just no doubt about it. I really, I found it here at N and I find it there (E, 163-164)*
- *And I don't know, I could sound a bit racist..... Ahm, they both a little bit too lax, far too lax. (referring to the black sister and manager) (F, 176)*
- *And the black ones, walking with cell phones, working hours hey – put it off please, there's a lady looking for you inside there (F, 376-377)*
- *ah and so let's, let's just be honest, the black ladies will completely ignore me, the coloured ladies will still take notice of me, and I'm not, and I come and I joke and I'd try to, but they would just look at me and then they'd speak to each other. (G, 248-249)*
- *and I'm going to say this, not the fact that she's white and apartheid, she was in that era when apartheid was at its prime. And why should I look after your mother she's white, I really don't want to actually have to do this, because that is a factor, it's a huge factor. She's not just a white person that voted for apartheid. She never did anyway. (E, 257-260)*

The old divisions are also a very important factor in how acceptable a home is to the community. The reality is that people's lives and beliefs are entrenched as stated below. F is quite explicit and

adamant about where she and the others within the home and area stand. For her it is fact and it is being disregarded and that is unacceptable.

- *Look I did ask them one day this is a coloured area and a coloured home how come they've got a black person in charge? Not that I, well I suppose I was racist there, I said how come they've got a black person in charge? There is a fight or a disagreement between the blacks and the coloureds in that place, believe you me and it's hectic. It's hectic. (F, 223-226)*

For I (a white woman) the issue is more subtle. She is incredulous and shocked to the core at the turn of events that has brought her mother so low. In this case it is not the disease but a financial and class issue. There is no malice; it is more a feeling of having failed her mother, allowing her to descend to the wrong side of the track, away from her decent life to the 'townships'.

- *It, it was a big shock to the system, mom has always lived in a decent house in town her whole life. Never had to go into townships. Mom.....(I, 82-83)*

D is a firm ally of all the staff and in fact went to great lengths in the interview to explain his knowledge of the difficult lives many of them lead. Despite this the use of words 'African girl' unmask old patterns deeply rooted in South Africa's past as opposed to the references to the white staff as sisters.

- *So we've got white qualified sister on duty in the day time now and a white sister on night duty, the old one, she's good fun and good, she's on the night. And we've got a Sr P, an African girl from Zululand whose a staff nurse and very good.(D, 212-214)*

4.5. END-OF-LIFE: CONFUSION AND ABANDONMENT

IS THIS A LIFE WORTH SALVAGING?

Dementia is a terminal disease and each one of the participants would need to face end-of-life issues and critical decision making in the middle to near future. The way they viewed their loved ones quality of life would be central to how they would feel about making those life and death decisions. Gauging the quality of their loved ones life was a highly emotive and painful process for all participants. It forced them to face the cruel reality of what the disease had done to their loved ones and often the fact that they were in many ways gone.

- So what do you think gives her quality of life at this point? *Nothing, simple as that, nothing.(A, 103-104)*

For B there is no doubt that death would be a blessing and she is haunted by the possibility that by saving her mother when she was 'salvageable' she has condemned her to live.

- *but she had a high fever and I mean there was no way we shouldn't do anything about her then. I mean if now that sort of thing happened one would just let a pneumonia run its course (B, 8-10)*

- *So afterwards when she was installed here and she started to deteriorate I thought you know did she need to go through this. It would have been easier if she'd just gone. (B, 187-188)*

The pain that G endures witnessing her mother live is far more than any pain that her death might bring. She is desperate for closure, to bury a mother that is for all intents and purposes already dead. She seeks answers not to the reasons for her mother's death but the reasons for her continued life.

- *And why she's still alive? uhm, you know, how many times must I mourn her death? I've written her eulogy twice already in coming to terms with all of this. It's all ready, her funeral arrangements have been made. It's stupid but I don't know what else to do. (G, 186-188)*

Both E and I hope for a swift ending, a finality that will decisively end both their and their loved ones suffering. The alternative is too horrible to contemplate and neither seems to be able to really verbalise what that may be other than in the vaguest of terms: "stuck in a situation", "sits and does nothing".

- *So my hope is just that she has a stroke that takes her out, she's gone finished, and she's got no say in it. But is if she has a stroke that makes her worse, then I'm really going to be stuck in a situation. (E, 232-234)*
- *I, I just feel that with the clots mom is more likely to die of some clotting problem or lack of blood flow*
- *or have a stroke or heart attack. I think that is probably before she just sits and does nothing. (I, 504-505)*

When considering alternatives at the time of death F is clear. There will be no hospital, there will be peace and the haven of her home – this is the closest reference to palliative care that any of the participants gave.

- *you know if push comes to shove, uhm, well if he's in the country at that time he'll probably give us a suggestion, he'll say you know what hospital is just not going to cut it, she'll just be on a drip, just take her home and let her die peacefully, you know. (F, 321-323)*

For D, who has fought his entire battle with knowledge and facts, the lines were extremely blurred. He acknowledges that going to hospital is not a given and yet, within the same thought cannot conceive of a situation which would exclude it. A little later in the interview he is very clear that her death should be natural and not induced. For him there is a real confusion about the concepts of palliation and euthanasia. The area is so grey and forbidden that it seems easier to ignore it altogether.

- *If she had to go to hospital I'd be very careful about what she was going for and what she had to have done, but if she needs medication, medical treatment she must go, they can't do it here. (D, 218-220)*
- *Ahm, no, she will go naturally, I would never allow her to be taken before her time by medication. (D,239)*

Finally for C, there are no options. Although she wept intermittently throughout the interview about the plight of her sister, the thought of her death brings dread and fear. For her death is bad, there is no room for seeing it in any other way.

- *There she was lying with oxygen and a drip, and my heart sank, I thought she was going to die. (C, 247)*

END-OF-LIFE (EOL) PLANNING

All participants were asked whether they had had any discussion with their family member regarding end-of-life wishes, whether they had a living will and whether anyone at the home or any medical professional had discussed EOL issues with them.

Interview	Discussion with patient regarding EOL wishes	Has anyone discussed EOL issues with you?
1	No	No
2	Yes (had a living will)	No
3	No	No
4	No	No
5	Yes	No
6	No	No
7	Yes	No (discussed with Alzheimer's South Africa)
8	No	No

Therefore not one participant had had the benefit of any professional help regarding what to expect and how they may negotiate the decisions ahead. Even those who had clarity about what it was they did not want could not visualise anything further than artificial ventilation. There was no understanding of the wider decisions that may need to be made at the end-of-life such as hospitalisation, artificial hydration or curative medication.

- *she has a living will. She would prefer that she isn't put on any, what's it automated system of any sort and just wants to..... (B, 176)*

- *I have spoken to my siblings. My mother and I have discussed it and she does not want to be resuscitated, she does not want to be left on a machine. If it's her time to go, she wants to go. (Did anyone have those discussions with you when you came into the home?) Oh good grief no. (E, 225-227)*
- *I already know that I wouldn't put her on life support at all, that I wouldn't put her on life support, that when it's her time to go she must go naturally. I wouldn't try to keep her alive. (G, 416-417)*

Most had not really thought about what was to come or how their loved one may die. There was little awareness of the final stages of dementia.

- *when she can't feed herself anymore, then the decision actually comes.(when you can't eat you mean?) Yes, when she can't eat at all, yes. But how does dementia actually kill you? How does the dementia kill you? I mean in, my understanding is that your body functions just all giving up. Giving up. So to me it's just like been a natural progression, backwards, downwards. (B, 23-206)*
- Have you ever thought about the end stage of her life what kind of intervention you would want?
I actually haven't thought of it that way yet. (C, 266)
- Should she get worse have you ever thought about what kind of medical intervention you would want?
No, no (H, 503)
- *No, I'm just more concerned about the present. (EOL) (J, 510)*
- Have you ever thought about the decisions you will have to take closer to her death?
I'm actually thinking of taking her home, to my house. (F, 308)

Thus the contradiction in J's interview: she is confident about making medical decisions but has absolutely no idea of what those decisions might be. She is in effect completely in the dark.

- How do you feel about making medical decisions for your mother?
No, no I don't think that there's no problem there. (H, 492)
- Should she get worse have you ever thought about what kind of medical intervention you would want- if she was in the situation you have described with some of the severe dementia patients?
- *No, no. (H, 503)*

WHO TO TURN TO FOR ANSWERS

From the above it is clear there was a complete lack of volunteered knowledge from those who should know. With the resultant dearth of any preparedness or feeling of empowerment or containment regarding what was to come, who did the participants feel they could turn to for advice on these issues?

All but one of the participants felt they would take decisions after consultation and discussion with family members with whom they were close. This sense of shared responsibility was very important. The enormous burden of making such immense decisions which held the potential of years of guilt and self-reproach needed to be lessened. The choices were ultimately theirs, a very lonely situation to be in, but the act of confirming them with loved ones seems to lighten the load as we see in F's excerpt below.

- Who would you ask for advice about these decisions?

The Lord alone knows and he's not telling me. I want to come in one Wednesday to sit with her to talk to this doctor now. But then again I have like I said my husband, not my husband my nephew, if he's back in the country, because every time he's home he pops in here. (F, 316-318)

In seven of the eight interviews doctors or medical staff were mentioned. The centrality of their role however differed dramatically from interview to interview. Only B felt she had the confidence and relationship with her mother's current doctor that would allow her to take his guidance. She felt contained and supported. There was no feeling of ambivalence about who her team would be.

- *And Anyway his, and I, I always phone my sister and we discuss it, his, his idea is that she'd be much happier here than in hospital and I totally agree and they just keep her comfortable. (his refers to the GP)(B, 159-161)*
- *Yes, yes. I would certainly discuss things with my husband and my sister and see what Dr C had to say and decide from there.(B, 167-168)*

Both E and G referred to GP's that had not seen their mothers for years. Both these doctors had played very positive roles in the earlier stages of the dementia journey but had lost that role once the person moved to the home. E's mother now had a GP who attended most patients in the frail care where she lived and G's mother had no personal doctor as her home used the state day hospital system. Neither had been able to recreate any form of partnership with a new professional, there was simply an empty space where that had been.

- *My own GP, even though she hasn't seen my mom for 4 years, I would still go to L and I would get L's take on it. I still actually go to see L to discuss my mother's health and get her opinion, because I, she's just..... (E, 221-222)*
- *First I actually would go to my husband. Then the decisions that have had to be made, I can only tell you what I've done so far, and that would be Dr B, the dentist person (pause) and my husband and my cousin. People that have been close. (G, 411-413)*

D, who was very reliant on scientific knowledge and facts also needed to reach back into the past for the psychiatrist who had not seen his wife for years. Like the siblings in interview eight the medical staff he will consult are anonymous. For all three of them it is the reassurance that they will be consulting specialists that seems to signify a duty of care fulfilled. They will deliver the best

advice available to their loved ones. All of these specialists or doctors are, at the point of interviewing, completely unknown. They have neither knowledge of the patient, nor any relationship with the family. They are a theoretical comfort, a hope that help will be there.

- *I think I'd weigh it up pretty carefully; I'd consult people about it. (Who). My eldest son whose got a lot of experience with the medical, he's got doctors working for him even though he's not a doctor. I would talk to _____ the psychiatrist, if I needed, if I had to, ahm and to any specialist that's involved. (D, 224-227)*
- *The medical staff.....The specialist, we would take her to the closest hospital is GMC, and we, we took her there. (I, 497-499)*
- *On the advice of doctors obviously.....Definitely we'd take advice from the doctors.(J, 495 and 498)*

For A there is no formal medical backup, in fact he has firmly rejected that possibility. As he has no one within the system to turn to his team is found outside.

- *And I would probably take advice from a cycling friend of mine for the last 12 years, obviously a doctor, retired now..... I'd probably go to I and say what do you think I should do. I wouldn't talk to Dr D about helping me make those decisions (A, 222-225)*

Lastly, at the extreme of isolation and marginalisation from the process is C. Her role as primary carer has been totally removed. She has been completely side-lined. It is as if by the very act of placing her sister in the home she has relinquished all rights regarding her. She is now an onlooker. Furthermore she feels at ease with this. There is no expectation of a right to anything more. Both she and her sister are part of a system where there is no room for discussion or alternatives. It is, in effect, their lot in life.

- *I'm not there, because I mean. You see what actually happens is they **take** her to the hospital, to the Day Hospital. So they don't ask you first? No, they take her to the Day Hospital if they feel there's something wrong with her. They phone me to tell me they've taken her there. And how do you feel about that? I'm Ok with it, if at least they're getting her to be seen by a doctor. (C, 257-262)*

4.6. IDENTIFYING THE NEEDS OF THE FAMILY

The above sections set the context for trying to establish what it is these family members seem to need in order to better negotiate the extremely hard journey they have been forced to undertake. With this background the analysis now turns to trying to establish these needs.

PHYSICAL CARE

Interestingly none of the participants was particularly focused on the physical health care of their loved ones. Physical care and suffering was alluded to at times but these concerns contributed a

very small part of the whole in terms of the needs that were expressed. None the less they were there, both the in the positive and the negative.

For B there was no negative, her perception of the care was completely positive, for D although there were omissions, they were petty in the context of the bigger picture and actually offered him an opportunity to contribute to the team effort.

- *And anytime of the day I've been here and I can ever say once that I've ever been concerned about moms care, at all.(B, 95-96)*
- *Ja, it's all about the people caring, and when they, when they're working hard and they're short of staff on that particular morning, they don't do a proper job. You know they're supposed to, when they see a rash or something out of the ordinary, report it to the sister. Sometime they don't, they forget, ahm. Sometimes they don't wash their feet in the mornings because they're too busy. Little things like that. That's what I do, I'm there all the time, I watch all that you see, ja (D, 113-117)*

For the rest the experience was less positive. The impacts of the lapses in medical care were quite profound. This was perhaps due to the fact that they were so tangible where the emotional impact may have been more difficult to quantify.

- *I don't know whether they didn't give her medication the way they should have, the haloperidol that she was on. Because she was on one in the morning and at night (sobbing, got up, went to the kitchen to get some water) (C, 122-123)*
- *And then she kept on of this pain in her rib, there was pain in her rib area and they're forcing her to walk even though it's extremely painful. So I took her back to L and L found a broken rib. And that was kind of like the last straw for me. (E, 71-72, referring to the previous home)*
- *Monday she had these sores that I could clearly see needed some kind of bactroban or something and she had scratched, there was like a staphylococcal infection and that needs to be seen to. And I was looking at it, surely I mean I know what that is so how come the nurses or somebody isn't seeing that. (G, 212-215)*
- *and I asked – did you take her for a walk and the care giver said "I didn't know she could walk." And this was the 4th day that that volunteer was here..... Which meant they had, nobody had taken, taking her for a walk. So she was sitting in a chair the whole day. She can't get up but she can walk (G,241-244)*
- *Because I go there and other people, they don't take her to occupational therapy. She's sitting there they say oh no your mom doesn't want to go. (H, 185-186)*

For I, there is an incredulity that the very place she has taken her mother to for specialised care is turning to her for help, pleading ignorance on how to tackle her medical condition. They offer no solution, no referral; in fact they demand a solution.

- *Because mom wasn't sleeping, she was walking around at night and they uh, uh, they contacted us to say- your mom is walking around at night, we don't know what to do. (I, 334-335)*

In C's case, the shreds of identity and humanity are stripped by the removal of her glasses. For C, not only is this lack of care, it is adding to the suffering of her sister, taking one of the few senses she has left to rely on.

- *So she's without spectacles. I don't know if she can see properly, because she always never wanted anybody to touch her glasses from her face (C, 213-214)*

The failure of the system to provide basic medication, in this case for pain, has driven F to take on yet another role. She steps in where the home fails to. She extends her caring to include not only her own mother but those elderly she sees as equally vulnerable. She not only supplies the medication but recognises the importance of honouring what the people believe in and truly need.

- *Pain tablets, the Day Hospital doesn't give you the panado's, the this and the that anymore. So I bought one day some green paracetamol. The old people believe in that, they believe in that, they don't want the white ones. (F, 241-243)*

In light of the above one wonders why the participants chose to leave their loved ones where they were? The answer was unanimous. Everyone traded the security of safety and 24hour care for all other disadvantages. Despite how difficult the decision may have been there was no choice. No-one felt equipped for this mammoth task.

- *So very difficult, but when I made the decision I, I was happy I had made the decision because I knew she was safe and I knew she had a doctor caring for her there and she was looking healthy. (A, 53-54)*
- *So from a caring for her safety I think that's been a good thing where she has ahm..... (A, 147)*
- *Because she needed to move, mainly to be sure, that she took her medication. Ahm ja, so.. (B, 25-26)*
- *I, we, we, I had no choice. I had no choice, because I couldn't have her here. I had no choice so I had to, had to put her in a home, because she needed care, 24/7.(C, 179-180)*
- *Well I had a carer at home and I realised if I go, ahm, what happens? Meanwhile I'll put her somewhere so that she can be in a continuous monitored position. That's why I came here. (D, 64-65)*
- *but certainly that main responsibility of uhm, **physically**, of **physically** looking after her. The emotional burden is still the same but the physical burden is oh like, it's not much. (G, 296-298)*
- *and I see she's clean and I see she's ok then I think to myself, you know what, you did the best thing. She's getting 3 meals a day, she's being well looked after. (F, 122-123)*

With that trade there was for some a real sense of sadness, of settling for the basics and forgoing the rest. Their parents are clothed, fed and housed. It is as if they have realised that the less you expect the less you will be disappointed. The fact that they had 'abandoned' their parents somehow made them more unworthy of expecting more. They are beaten by disease and system alike.

- *That's, that's also, and that's as much as uhm.....you know. (Safety) (H, 95)*
- *I said G at least she's dressed, she's got clothes, she's not walking around naked, she's had food, she's had a bed to sleep. But it's awful that your expectations and your standards drop so. (I, 554-556)*
- *That is sort of rock bottom. And even now she's sort of well..... at least she's has this and least she has that. That's the feeling. (J, 560-561)*

FINANCIAL NEEDS

Financial issues may not seem to be an overt source of anxiety with regards to the overall picture of families coping with the late stages of dementia in old age homes. It was however an ever present source of stress for almost all the participants of the study. The lack of clarity that dementia brings with regard to how long a person may live added a layer of financial anxiety which is in itself a further source of guilt. The advent of dementia into their lives had a multi-layered unanticipated effect. The impact of the illness directly affected their own and thus their family's financial security, imposing choices they were not expecting to make.

- *I'm terribly scared of because she doesn't have any medical aid, she doesn't have much money, so when I do make a medical decision this worries me, that I'm going to have to be very.....ah, what's the right word, critical about making the right one (A, 216-219)*
- *I, I think her medical aid has run out and I know that she had quite a large bill from the chemist. So they didn't itemise it, so I said please could I see what's on the, on the account and then I brought it here to the sister. (B, 36-37)*
- *Because then she was getting just on R5000 pension. She would only get out about R500. And then of course I still had to buy her panties and stuff. (C, 101-102)*
- *I'm having to use our monies, our monies, and I'm having to dig into the money that my father left her every month, just to pay the account. (E, 178-179)*
- *And I am not happy with the care that my mom's getting. However uh, it's expensive and if she does go to this home it means that we have to fork out quite a bit of money for her to be there. (G, 210-211)*
- *Even though my mom does have money, if we were to just take from her money it would be depleted, we don't know how long she's going to live. So that would be something, a decision we would have to make. (G, 473-475)*
- *No, I, I've reconciled myself to it because I'm in the situation where my partner passed away 4 years ago, this is part of his deceased estate and I'm struggling. (H, 222-223)*
- *There are other CPOA's but we couldn't afford it. (I, 86)*

- *We thought of trying to get her into a facility and which stage we realised the top facilities are very expensive and then eventually she ended up where she is now. Not all of us are very happy about it. (J, 76-77)*

Ironically D felt he paid a fair price for what he was getting, a fact that was congruent with his entire experience of the home as being generally positive.

- *ahm. Ahm so that could be better they could have more but then you're going to pay more for it. We only pay I think 15 000 a month, only, ja (D, 111-112)*

F's attitude is also in keeping with her attitude to the home. She was aware that the facility she was part of was in a low income bracket and was prepared to forgive and help where possible. She was unforgiving and angry with those she saw as abrogating all responsibility to the home. In this she allied herself with the very people she had previously been at odds with.

- *Right I buy soap, there's forever a shortage of soap, lord alone knows where the hell it goes to, but then again we've got some resident's families who do not want to contribute, that feels it must be done. You must give it to my mother. Not the fact as I say take R50 a week, buy 2 bars of soap, keep it in your car. (F, 248-250)*

DIGNITY AND IDENTITY

Of all the things that really mattered in the overall care of their loved ones, the preservation of dignity and identity, or lack thereof, was dominant. This was the real source of either a profound sense of disquiet and distress or a feeling of containment and warmth. Unlike the physical complaints they were at times harder to quantify and express.

In interview 3, C's description of what is "left" of her sister is full of pathos. She has been stripped of her personhood, her dignity and her physical senses. What she was/ is (always, never) is totally disregarded. The huge feeling of loss far exceeds that which would be expected from the disease only.

- *She had a set of dentures. Now she's, she's she lost the bottom set. She's not wearing her spectacles because she takes them off. So she's without spectacles. I don't know if she can see properly, because she always never wanted anybody to touch her glasses from her face. (C, 212-214)*

Cleanliness was another often mentioned source of distress. On the face of things this may seem a small issue but the significance and deeper implications were pervasive. Words such as smelling and smelly are evocative of rot and garbage, things rather than people, disposable and discarded. The overall message to the families is one of neglect and dismissal of the rights of this group of elderly who have no voice. They have become generic. For both E and G this feeling is confirmed as the elderly are further discarded to sit in a bleak area or wander round soiled: ignored and

disregarded with no identity and no dignity. G's repetition of disbelief echoes and magnifies this apparently small incident into what it truly represents for her.

- *And when I get there and find her dirty and smelling, I get very upset. She's been in diapers for about two years now. She's, she's as good as bedridden. They take her out and put the old folk in that dreadful lounge where they just sit, all morning. (E, 43-45)*
- *and uhm the one lady had wet her pants and uhm we only realised afterwards that the puddle over there was hers. So she's got a wet pants on. I sat there for an hour chatting and nobody sorted her out, nobody sorted her out.(G, 306-308)*
- *And also I think they do need to take a bit more care about the hygiene, because my sister's had to soak her feet sometimes. Like when you wash her give her a good bath, mom was really smelly and stuff. (I, 548-549)*

The same can be said with regards to clothing. Like hygiene clothes are a powerful mark of a person's individuality and identity. Often they were one of the few things that the family member had left to link them to the person they knew. The removal of this symbol of personhood was a powerful blow. By mixing up the clothes people are reduced to a generic mass. The fact that the patient herself may not recognise the difference does nothing to lessen the impact on family members.

- *She walked right past us, she was holding up her pants, her pants was too big for her.(C, 81-82)*
- *Ahm, ahm I mean you take mom the outfits for Xmas and stuff so she'd look nice. All her clothes have now disappeared but that's another thing. I said they will find clothes for mom and they'll give her someone else's clothes, its fine. That was a problem at first. (I, 248-250)*
- *Physical care combined with sort of emotional caring thing as well. People making sure that they actually do bath her and dress her and make sure she gets right clothes. But I mean the fact that she loses her clothes and loses her specs and loses her teeth. (J, 522-524)*

Theft was another recurrent theme in five of the eight interviews. I have highlighted it in terms of identity in this excerpt from C's interview as it typifies the sentiment of all five participants in terms of what was stolen: clothing, luxury toiletries and jewellery. For all it was not really a financial insult, it was a dignity/identity insult as small facets of the person were chipped away. Thus below, this extremely personal ring made for her and her alone, is gone. What is left is the ghost of what was: the impression of her identity.

- *When I came BACK, then my sister was like a zombie. She had lost weight, her rings were stolen. You could still see the impressions of her wedding band and engagement ring her husband had specially made for her at De Beers. (C, 64-66)*

Once again F steps forward to provide the solution rather than watch the suffering. Again she takes on the role of the management: giving the elderly not only something special but the very

basics! It is not that the demands are huge; these are the basic needs of not being soiled or a small, private space to talk or even recognition that people need to feel special and validated.

- *Now I want you to take that R4000 and I want you to give everybody a nice lunch for the old people, either in the week or on a Sunday. Spend it on these old people. If there's change Mrs B don't have family, she needs diapers, please buy her the diapers.(F, 253-255)*
- *And I think it might probably be more comfortable if they put somebody like that into a wheelchair and moved them into an area where you feel more personal space, and not having other people staring and coughing and talking to me while I'm talking to my mom. (A, 199-201)*

The trauma of finding her mother restrained in a chair was dominant in H's interview. Over and over she came back to this event. Her mother sitting in a room with people totally incapacitated with severe dementia caused inexpressible pain. She could not find the words; her mother had been written off to the extent of removing what small amount of ability she had left, being able to walk. She had been packaged for "that section" for the convenience of the staff. Her brother similarly struggles for a way to express what it is he feels is not there. He knows it is dignity that is lacking but cannot put his finger on why. Whatever it is it has left him angry, hostile and betrayed.

- *That was the most terrible experience, that she's there, there was. And these are the people that really cannot and why was my mom in that section where there's people that just can't. (referring to the restraining of her mother in a chair)(H, 403-404)*
- *Its complex, I mean the general care attitude. Maybe the staff have been trained to sit next to you and to try to be, to treat the, the people with dignity. (J, 210-211)*

The two extracts below sum up the essence of what is lacking. It seems no accident that G opened the interview with these words before any questions were asked. Both are saying-this is my mother, she is part of a whole, she has context, she is an individual, a person.

- *So, I've tried to make sure that the people looking after her know a bit more about her. Doesn't always work because they've got such a turn over, so many different nurses, uhm. The photos are on her door, in her room. Uhm, so when they come in they can see and pictures of us as well. (G, 1-3)*
- *I would actually like, because the staff change at a horrific rate - a board. This is my mother's name, this is what illnesses she's got..... This is her preferences, she does not like meat, don't give it to her. She does not like her tablets in her food don't put it there. She does not like onions; make sure there's no onions in her food. She doesn't like spicy food, it causes her to have indigestion. So that any new one coming in there will know exactly what's wrong with her, will know exactly who to contact, will know exactly why she's on the medicine she's on and also what I would like is to know exactly where she's coming from, background.(E, 247-254)*

For those who had positive experiences the impact on their well-being as well as that of their loved ones was enormous. Again it was not huge events or aspects of care that were important. The physical comfort of touch when there is distress or suffering, the recognition that this person, demented or not may need to see her daughter once more before she died or the very small gesture made by the nurse of remembering to mention her mother's use of her father's name, is all that was needed to provide a feeling of being cared for and of them and their loved ones being recognised as individuals.

- *But they were very concerned for my aunt J that, that she would have like to have seen her daughter and they really tried hard to convince me to get her to come. And I was trying anyway. So they're caring about the people and they see needs and they identify them and they do convey them. So I thought that was very caring of them.(B, 145-148)*
- *One morning at 4 o'clock I got knocked up to say your wife's having a fit. Went downstairs and there was the one girl C lying in the bed cradling my wife in her arms which is good, that's what she needed. And also when people die or they're dying, they tend to hug them, (D, 36-39)*
- *And P is brilliant....and she gets on so well with J. She hugs her, she loves her, you know. Sits with her and they laugh together. When she's watching J she talks with her and laughs. (D, 177-179)*
- *There's one who said P come here. She says is your dad's name G? I said yes my dad's name was G. So she says come here you see that man there your mom thinks that's G she says hello to him every morning. Now that's, so at least she remembered and she asked me about that. It meant a lot to me that they actually showed a bit of interest in mom.(I, 532-535)*

COMMUNICATION

This final section is the culmination of all that has come before it. Communication or the lack thereof is at the core of many of the problems and solutions that have been discussed above. Poor and confusing communication led to fear and alienation whilst clear, good communication resulted in containment and affirmation.

It was abundantly clear from nine of the ten interviews that poor or non-existent communication was the rule rather than the exception. A is so disempowered he cannot fathom even making a suggestion about what he needs. His 'demands' for feedback decrease even within the space of this one sentence, moving from the personal to the generic- accepting any form of communication and inclusion that they may be willing to give.

- *My advice to them if I was, not that I'm going to give them advice, it would be to communicate better with the people that are caring. And you can do it 1 on 1 with them, and you can do it every 3 months even, and you can do it by an email once a month, or even a generic newsletter occasionally. (A, 137-140)*

For others there is vagueness. It seems as if they are not really sure what it is that should be communicated and with whom. For I this really is a glaring gap, even if she makes suggestions she has no idea where they end up, what the system is or if there will be any feedback. She is operating in a vacuum; there is no inclusiveness at all.

- *They don't. I go there, I see that there's no toiletries and I take regularly, but I go there. Uhm, they're not good about communicating about her needs and things like that. (H, 280-281)*
- *No not really I suppose. I've chatted to the general nursing staff and every now and then to the sister and hey, and I ask about mom's condition and they say she's fine.(B, 73-74)*
- *I don't know how the suggestions are taken, but there is, there is some sort of board isn't there? (I, 394)*

Even more extreme is the sad reply of C. It is not a matter of people not talking to her, they are simply absent. She is alone in this. E is not only alone she feels actively victimised. For her the lack of communication is an act of commission not omission. This is the enemy she is referring to; she is engaged in a battle for her mother's identity against both the disease and the home. For F there is the feeling of pure sadness and resignation. It is as if communication is a wistful wish she knows will never be granted.

- *There is a house mother but for my last three visits I haven't seen her to speak to her. Even on Monday when I was there. (C, 182-183)*
- *If there was more communication from the home. If there wasn't this resistance to the fact that I'm not the only one who is complaining. If they would just listen to what her preferences are instead of doing it, this is the way we do it here, we're not going to change for your mother, we not going to give any specific attention to detailed care. (E, 240-242)*
- *Agh, better communication. Communication. Uhm (laughs, long, long pause)..... communication. (G, 258-259)*

Rejection and loneliness is the inevitable result of this lack, thus:

- *I just create my own team, me, myself and I. (F, 281)*
- *Maybe I feel like I'm going to be in the way, and uh.....you know, uhm.....(G, 255)*

FEAR

If there was so much dissatisfaction with channels of communication and various aspects of care one may question why the participants did not complain and try to bring about change. The fear of retribution against either their loved one or themselves, real or perceived, was very prevalent. These people, participants and residents alike, were very vulnerable. They felt exposed and powerless. People they had previously had the power to protect were now beyond that sphere of influence. Their options were limited, financially, emotionally and practically.

- *My advice to them if I was, not that I'm going to give them advice (A, 137)*
- *I'm not going to mention any derogatory things because it may be in your report back to the home. (D, 18)*
- *You not allowed to complain, they take it out on the patient and no you not the only one who's complaining. (E, 151)*
- *No, because uhm, it's not your place, you know what I mean; It's not your place (having her say) (F, 205)*
- *Ahm, I don't know, I really don't know. I never took the chance, I never took the chance. (What were you worried could have happened?) Probably that they'll give me restricted hours to visit my mother or something like that. (F, 208-210)*
- *help but think, Ok so now you're going to get back at us because making complaints. And they can be very nasty (to who?) To my mom. And then we didn't want that effect because one can't (J, 331-332)*

The fear of retribution extends further into lack of trust, a feeling of menace and the subversion of the rights of the patients and the trust of the relatives. There is no peace of mind here. There is a subtle reinforcement of the prior theme of abandonment.

- *But they denied, the staff denied that they were giving her the proper medication. But now that she's back, now that they're giving it to her, I think that they never gave it to her properly,(C,129-130)*
- *you've really got to be wise and you've got to be so, round the way about uhm, you know taking my mommy for a walk or whatever. And then I sometimes feel that they're lying to me. I feel that they're lying about whether they did take my mommy. I never know whether they're telling me the truth or not. It's awful I feel that way,(G, 276-279)*
- *You know and uhm. Or if I come there at 5 the people are going to bed and then I said mom does not want to go to bed now, she can sit here and watch TV. And they like glare at me and I'm sure once I'm gone they probably, you know, cart her off to bed. (I, 379-381)*

ALIENATION

Part of the aim of the study was to ascertain whether family members felt able to or even wanted to be involved in the care of their loved ones, and if not what it was that deterred them. The previous ways of connecting to and maintaining bonds with family members had already been severely damaged by the dementing process and the family were traumatised and alienated from their loved ones prior to admission. Often the only way of maintaining the link was being part of that day to day care, no matter how difficult that may have been. With this gone the distancing of the resident from them was increased.

None of the participants felt they didn't want to be more involved, it was more that they felt helpless. Either there was no direction or avenue that they could find where they could be involved, or they felt hostility towards their involvement. There was a definite rejection of their

need to be part of the team, either implicitly or explicitly. The end result was that their bonding to their loved ones was further broken down and their feeling of alienation compounded.

- *They (his children) feel helpless. So I think you know if people were encouraged, if, if the actual home encouraged and said let's have a family day, why don't you bring all the grandchildren we'll do some.....You know, if they made an effort like that I'm quite sure one would feel better about it. (A, 192-194)*
- *So in that way if I ja 100% would be happy to be involved but there's nothing, there's nothing.....I'm not given any information that says to me why don't you come and do this or that or let's try this. And I would need to be taken to the water and then I would drink (A, 183-186)*
- *So I've always been involved in what meds is best for her, what she should be taking, what is not working for her, what is making her feel grim or lousy. What she should be taking what she shouldn't be taking. And I don't feel that I'm allowed to interfere anymore. (E, 213-214)*
- *I don't know, what am I responsible for, I'm not sure? I'd like to be more involved and I know I can be at any time. I can come there at any time. There's, there's no only visiting hours, you can come there any time, uhm, you don't have to phone or announce or anything you can just arrive. I felt like I wanted to just go and be there when they put my mom to bed the one time. I could have, but you see I don't feel comfortable now. I would have done it with R but.....(G, 482-484)*
- *Because they don't want, they don't want me there during lunch time. So I specifically work right through so I can at least do that. (H, 476-477)*

For B and C there is nothing left that they can see for them to do. They serve no purpose any longer in the lives of their family members. The overwhelming sense is one of having been beaten. Without any avenue for engagement, they have given up; there is nothing left to visit for other than duty.

- *And when she could go outside I would take her for walks and things, take her for drives. I mean now it's not possible. (B, 109-110)*
- *I don't spend much time with her there because there because there's no communication, especially now. I can go anytime, I can walk in anytime(C, 227-228)*

CONTAINMENT AND AFFIRMATION

Where participants found acceptance and were drawn into the lives of their loved ones the emotional reward was great. Small gestures reaped huge benefits: calling in a son to involve him in the physiotherapy, simply responding promptly to a question about medication or noticing a grimace and passing on that information. These seemingly insignificant gestures filled a desperate need to be useful again.

- *And the physiotherapist she was communicative she would phone me and she was actually very nice to talk to about....because she was good..... But if you want to come and join me and see what it's like and assess for yourself, so obviously I did. (A, 180-183)*
- *I think fine because immediately when I had a question about the medication, they were so forthcoming, no look they really, they're good, they really are. (B, 142-143)*
- *When she sits and the girls know I'm coming in today and they tell me when they bathed her she pulled a funny face so we think there's a pain in the elbow or the arm or whatever. (F, 125-127)*

The onus of sharing and establishing bonds between staff and family was not seen as a one way thing. On the contrary many of the participants went out of their way to understand where the staff came from and the challenges they faced. In many ways they did this to win favour and become allies and team members, to ensure that their loved ones were cared for. For some they felt successful, for others not. Eight of the ten participants specifically mentioned the effort that they made to be onside with the staff.

- *What's important to know is their background. Do you know the background of our carers, that live in a little tin shack, they lock those shacks up at night in mid-summer..... (D, 95-96)*
- *Very, I actually defend them against the top hierarchy when they come and get tough. (D, 146)*
- *and I know how horrible the job is. And I can imagine cleaning peoples bums all day long must be the most dreadful job. I would, I couldn't. I mean it was bad enough one person. So I understand how they are. (E, 170- 172)*
- *And I do think that nurses probably don't have the passion. Ask me I was a nurse many years ago (laughs) and I mean we worked very, very hard and we were there, right at the patient. (I, 442-443)*
- *I sometimes go in the mornings so I catch the staff and I do go and say hello to the sister in charge. SO I always go to Sr. N and I greet her and I chat to her and she tells me little titbits, how mom is and ahm(I, 273-274)*

Only D, B and F felt they had succeeded. For them the reward was a greater feeling of connection with not only the staff but their loved one. For D it was the act of washing his wife, for F it was sorting her clothes or cutting her nails, they had a purpose and a connection.

- *I still have to do little things for my mother, like cutting the nails if it's long, what the hell cut the nails.(F, 125)*
- How is your wanting to be involved in the physical care of your mother received?
It's well received; they expect it from everybody which I feel should be. It's your mom, don't walk in there. (F, 229-231)
- *And, and I think, we should probably take a more active part in the home, but we all have such busy lives. (I, 241)*

- *I've actually sometimes sat down there in my old age and washed my wife, dressed her to try and help the other girl. (D, 108-109)*

For G it was the fact that she had a strong connection with a previous carer and had lost it when the person was fired that made her feeling of having been betrayed and abandoned harder to bear. When she spoke of her previous situation the peace of mind and feeling of being held in a safe place were obvious. The trauma of moving her mother had been completely offset by this partnership she had. She was their equal, there were no boundaries or barriers, and “she was family”.

- *So I had a good relationship because my mother was either with J or she was with R. If I come after 5 she's on this side if it's before 5 it's on this side. I can ask her anything, J anything about what's happening she'd be able to tell me. I'd ask R what's happening there and they would be communicating with each other. (G, 285-288)*
- *She was like a family; she was like another member of our family. And R, and R said, and R said (G, 465-466)*

If the participants felt they had no allies within the staff they made allies elsewhere. They needed to have a team of some sort, someone who was on their side and who would look out for them. While for G it was the Alzheimer's support group and for A it was his friend, more often than not this was other residents or other family members. Sadly the result of this was a further polarisation of home and family, even more them and us, even wider gaps to bridge.

- *And one of the residents said to me, I asked her where her rings was, and she said, the nurse took it off in the shower. (C, 67-68)*
- *And of course since then we started talking and since we talked to her we now talking to other people and other people and they've all had the same problem. (E, 149-150)*
- *So when they see me “they didn't check on your mother and this is what happened.” I say, is it? (F, 195-196)*
- *No, only one of the other residents, old ladies actually said your mom fell and I actually followed up, I'm not sure of the exact detail but we were..... (J, 365-366)*
- *And knowing him I think he might even say listen, I'll go and see your mom or I'll phone Dr D on your... for you. (Referring to a friend) (A, 226-227)*
- *The support group, the Alzheimer's support group at the home where my mommy is. They still run it and they were so jacked up, they still are. (G, 150-152)*

CONCLUSION

This chapter attempted to synthesise the experience the ten participants had of the phenomenon under investigation. The themes that were presented began with the emotional state of mind they found themselves in when entering the institution as well as their understanding of the disease. This was important as it determined many of the perceptions of the facility itself. The subsequent themes looked at exploring the aim of this study, which is the delivery of palliative care to the

residents and participants within the homes and the barriers to or facilitators of participation in care that they found. Again palliative care must be seen within its WHO definition, pertaining to the care given to the patient and family in what is likely to be their last year of life.

The next chapter looks at these results in the context of the body of knowledge presented in the literature review and found subsequently in the light of the results of this study.

CHAPTER 5 – DISCUSSION

The aim of this study was to highlight family member's experiences surrounding palliative care of dementia patients in care homes in Cape Town. It confirms many of the findings found in similar studies in North America and Europe. At the same time it exposes elements peculiar to our situation not only in South Africa but to the Western Cape specifically. Like many other studies that set out to investigate a specific phenomenon it soon became apparent that without the context of what the participants had been through no sense could be made of the experience under investigation. The idiographic nature of this study revealed many avenues of questioning not previously anticipated which added to the final body of knowledge under discussion.

5.1. INSTITUTIONALISATION – THE TURNING POINT

The decision to place a family member in a long term care facility is the turning point in the dementia journey that families and patients have been through thus far. Their experiences before placement and the circumstances leading to that decision heavily influence their entire future relationship with the institution and how they will cope with this final stage of the disease and death. In this study not one of the participants chose placement as a preferable option. All were forced into it either by a precipitant crisis or because they simply could no longer cope with the demands of the disease which was shattering their lives. Both Forbes and Caron found that this was one of the most traumatic decisions people had ever taken.^(18,41)

As in the meta-ethnographic by Granheim, those participants in this study who were supported by their families in this decision felt easier about the move. For those who were not, the burden of decision increased the guilt and isolation they already felt. In fact for four of the participants the move was a source of family division and strife and for three of them this had negatively affected relationships within the family itself thus placing a further burden on the primary carer.

The resultant guilt was overwhelming. For most of our participants this feeling of burden and betrayal did not seem to lessen over time and they therefore continued to question the decision they had made and torture themselves about their act of 'treachery'. Others studies corroborate this finding where sentiments of grief and shame come up repeatedly as does the fear of being judged by others.^(8,42,47) Like A, C, E, F and J in our study these studies illustrate the conflict of wanting to visit but not being able to bear witnessing the apparent abandonment and deterioration of their loved one. This was compounded where the perception of care given and communication were poor.

What came to light in this study which was apparent in only a few of the studies reviewed was 'survivor guilt'.⁽²¹⁾ Many of the people in this study had a particular guilt about carrying on with their own lives whilst they had left their love ones behind. It was not only that they worried that they may be judged for 'getting their loved ones out of the way'; it was also the fact that they

were still intact whilst their loved one continued to slip away. Thus, for the participants of this study, the move to care did not really relieve their burden. All negative experiences after placement had to be balanced against the security and 24hour care of their loved ones. Whatever was gained via the peace of mind that their loved one was safe was lost through their anguish of the same decision. This is consistent with many studies where guilt and abandonment neutralise the relief of safety.^(24,39,42,44,51)

The study by Tornatore and Grant looked specifically at family carer burden after placement. They concluded that the perceptions family members have of care within these homes is formed within the context of all they had gone through before and during the move.⁽³⁹⁾ As in this study, without an understanding of the above there is no platform for addressing the issues which emerged subsequently.

5.2. THE POWER OF KNOWLEDGE: WHO HAS IT AND WHO SHARES IT?

As in other studies,^(12,64) the lack of knowledge and understanding of the disease amongst family members was prevalent in almost all the participants of the study. Even for those who had clinical knowledge of the process there was little understanding of what was to come. The emotional and critical times and decisions ahead of them were vague and usually unconsidered.

Adamson's UK study amongst Afro-Caribbean and Asian families found a general lack of understanding of dementia in these communities,⁽⁶³⁾ while an American study found 81,4% of 323 people felt they had a good understanding of what to expect clinically.⁽¹²⁾ In this study however, those who had a better understanding were scattered amongst the different socio-economic, cultural and educational strata. Even D who had gone out of his way to arm himself with as much clinical knowledge about Alzheimer's as possible seemed as vague as the other participants when asked what it was he expected in the months to come.

The dearth of information far predated the patients' admission to the homes. Three of the eight patients had not even been formally diagnosed. One had been diagnosed as having vascular dementia but her son still spoke about her disease as "*not Alzheimer's totally.*" For those that had been given clear information by their doctors at diagnosis, the empowerment and ability to cope with at least the physical aspects of the disease was clear. This feeling of containment persisted even though none of the three doctors in question was still actively involved with the patient. Only one participant had a current relationship with and trust in her mothers' GP.

The rest were left to cobble together information as best they could. This was from acquaintances, the internet and the community and support organisations. Obviously some of this information was far from factual and at times laced with superstition and old prejudices. This is exactly what was found by Stokes et al where participants were reliant on prejudicial and scant societal understanding.⁽⁶⁴⁾ This vacuum of knowledge about the disease, its trajectory and what is available to help fosters feelings of uncertainty when care is handed over to others.⁽⁴²⁾

The lack of shared information by the medical profession or at least appropriate referrals to those who could provide it was clear in this study. South Africa is a resource poor society and access to any medical services for the vast majority of people is erratic at best. For our participants the availability of medical care varied from only state provision to the best private, specialist attention money could buy. Notwithstanding, every single participant had had at least 1 contact with a doctor. The experiences they had at different levels of the system was not linear. Three were given diagnoses by specialists, yet only one felt informed in any way. G made a clear distinction between facts and information when she states how the neurologist gave her facts when she asked for them, but didn't offer information, yet F is given all the information she needs by the local GP. For those dealing with state facilities there was simply nothing. This unwillingness to speak openly about dementia has been looked at by many other studies and includes lack of recognition of dementia as a life limiting illness, lack of doctor's knowledge and reluctance of primary care givers to treat dementia.^(14,15,17,56)

Not one of the people in the group had received any information from the home, whether through management or the staff. This had not been offered and they had not asked. At two of the care homes Alzheimer's South Africa visited for the benefit of families. At one of the care homes this had been initiated by a social worker who had subsequently left and was continued by the families themselves. There was no written material on offer at admission, no offer of referral or help with counselling. It could be argued that this is not the responsibility of old age homes, yet it is in this setting that the participants are spending their final time and it is this group of professionals with which they have most contact and therefore most opportunity to gain insight. Again the question arises, is the knowledge there to share?

In the literature, like their medical counterparts nursing staff were found to be equally ill-equipped with regards to dementia knowledge. Chang *et al's* discussion found that nursing staff were ill prepared to handle dementia care in the moderate to severe stages. The staff in a US study found training in this area was the most poorly addressed and 730 nursing staff surveyed in the UK pointed to a lack of education about dementia as the reason for less effective nursing care.⁽¹⁵⁾ As with GP's Smythe *et al* noted that certified nursing assistants receive the least amount of formal training regarding dementia, yet are responsible for 90% of basic care in Australian homes.⁽¹⁷⁾ There is no local literature to corroborate this, but again if there is no repository of knowledge with this group of professionals who do family members get their information from?

This quote from Albinsson and Strang's study on existential issues in dementia care, sums up many of what our family members felt, "*If only we'd gotten the diagnosis earlier we would have known better, and realized that when things went wrong it was because of the illness.*"⁽⁴⁵⁾ perhaps, had the participants of this study been afforded this opportunity, they would have been absolved of blame and much of the suffering they had endured through ignorance of the situation.

5.3. OLD SUSPICIONS: A SOUTH AFRICAN HERITAGE

Race as an issue between carers and patients and carers and family members is a very poorly researched area. Where research has been done it focuses on racism experienced by carers perpetrated by home hierarchies, patients or families.⁽⁵⁴⁾ Universally nurse aides are subject to poor employment practice, with low occupational status, wages and benefits and there is no doubt from this study that the same is true in this country.

The racial divide and suspicion that emerged from many of the participants was unforeseen at the start of the study. South Africa has a long history of institutionalised and legalised racism and division. It has only been 20 years since democracy and the abolition of those laws. A new constitution and new laws do not eradicate the decades of mistrust and anger resulting from the Apartheid system. The Western Cape is peculiar amongst all the other provinces as a consequence of its historic Coloured labour preference policy. This resulted in a large so called 'Coloured' population and a relatively smaller black population. Racial divisions are therefore more complex as many of this population group have old antagonisms not only towards the white population but specifically towards the Xhosa population within the area.

Unlike all other studies on race relations in this context the staff of old age facilities in South Africa are predominantly drawn from the majority race group in the country. Ironically being in the majority does not translate into power as old socio-economic divides and imbalances persist. As this study's participants were limited to two of the three main population groups in this province, it was the attitude of these groups that emerged. What was found was a definite racist attitude from some of the participants towards staff. This was almost exclusively towards the black staff and was most marked from the 'coloured' participants. However what was different was that some participants felt they were being discriminated against because of their race. E honestly felt her mother was being punished for the sins of Apartheid and F felt purposely excluded by the use of a language she did not understand. This added barrier generated by our past must be acknowledged in order to address communication gaps.

5.4. PERCEPTIONS AND ASSUMPTIONS

In this study, the discontent and unhappiness participants felt with the homes their loved ones were in was often based on perceptions of staff attitudes and assumptions of what people believed was the truth. This was most evident when participants discussed how their complaints were received or spontaneously expressed reticence about giving negative feedback to the researcher. These participants feared the hierarchy within the institutions. By and large there was a fundamental flaw with communication and perceptions family had about staff and management. Nine out of ten participants were totally without the means to assert their needs. It was simply not within their frame of reference to complain enough to rock the boat. Rightly or wrongly, even if they had advice they were not going to give it. It was not their place.

Even the most empowered of all the participants, D was unwilling to give any negative feedback without the strong reassurance of anonymity. There was a definite but ill-defined belief that there would be retribution either towards themselves or their loved ones. In both Moyle's and Hertzberg's studies there was a fear of creating conflict if information about their loved one was shared.^(24,43) Further mention of this finding is hard to find in the existing literature, particularly the expression of fear of direct retribution to family members. However, it is key to healing rifts between family and staff: no-one will risk honesty at the perceived cost of unnamed punishment.

Having established that families reactions to institutionalisation are heavily influenced by the context of their past, it is how the various people who staff the facilities are perceived that will further determine relationships which develop between them. This in turn will dictate the level of satisfaction and emotional reassurance that will be experienced.

THE CAREGIVERS

Not all staff members are seen in the same way. In this study admiration was expressed for the work that nurse aides did, by the majority of the participants. Many of them acknowledged how difficult the work was and how bad the conditions of employment were. They were concerned that they may suffer at the hands of their employers. Despite this understanding and empathy the overriding concern for their loved ones in many ways neutralised this. Staff shortages and staff turnover was cited by all participants. The obvious outcome of this was felt to be a poorer standard of care and communication, an inability to form bonds or simply burnout when it came to establishing yet another staff/family connection. The pity and empathy they felt could not compare with their deep disquiet.

A large body of research has shown that nurse aides are viewed far more favourably than their more qualified counterparts. These are the people who have taken on the immediate practical day to day role. As such, they spent the most time with their loved ones, they were in a position to really know the patients and thus to pass on that information. Often participants felt staff had little more knowledge or experience than they had themselves. Whether people identified with them more or realised the need to win them over as being more vital, there is no doubt that if there were positive outlooks about any group of staff, they were directed in the main to the nurse aides.^(35,40,55,72) Similarly, the theme of staff turnover and staff shortages which sabotage the building of relationships between patient and nurse and family and nurse recur in the literature.^(19,21,40,43,55,73)

Where these participants had bonded with the care staff the reward was clear. D truly made an immense effort to align himself with the staff, he protected them, he assisted them and he excused their lapses. He had a place with them, the place he had lost in the community he left to be with his wife. Although physical care was important to the participants it was emotional care and recognition of person that really mattered. They judged the staff on care given and that meant total care. Small gestures had enormous significance like noticing a grimace or holding the

hand of a dying person. For them this care was more important than their knowledge or skills. If there was evidence of more serious care transgressions, these were often dismissed. The literature confirms this; total care is seen as not only attending to physical needs but encompassing all facets of need.^(35,39,44,48,55,73)

The senior staff and home management were not perceived with any fondness or sympathy by the participants in this study. For all but two the sense of distance and dislocation from senior nursing staff was strong. They were the enemy, the opponents. If they were present at all it was as if they were “*walking through*” not seeing people. They were felt to lack humility and sincerity. The management’s image was by far the worst. They were an authoritarian force, unseen and all powerful. These participants felt totally powerless, angry and distrustful; they had been betrayed and therefore needed to counter subversive behaviour with subversive tactics. Their expectations of care for their loved ones had been eroded leading them to expect less and less and become more and more defensive. All in all it was as if to management they, like the nurse aides, were a dispensable commodity, easy to replace. The end result was a vacuum of leadership. There was no-where to go, no-one to guide them in this alien new world.

Duncan *et al*’s Oregon based study looked at categories of staff and how they were perceived. Not only were nurse aides mentioned far more often and more positively, but the registered nurses were noted for their absence and lack of hands on care.⁽³⁵⁾ Most other studies do not separate staff members specifically although positive mention is made of nurse aides more often.

Like most other studies, for the participants in this study who perceived staff positively the entire journey was transformed, there was no feeling of alienation and threat and above all no assumption that they needed to protect their loved ones. The need to find surreptitious ways to achieve a goal was replaced by a warmth and appreciation. The participants became champions of the professional nurses, but not of the administrators

The reality in Cape Town is that old age facilities are scarce, particularly for low income groups. Waiting lists are long and ‘good homes’ very difficult to access. The fact that the senior sisters often have managerial duties may also have a strong impact on why families perceive them as absent from care. Even where there are separate managers the burden of administrative duties for senior nursing staff is high, leaving them little time for hands on care. This was clearly not communicated to or understood by families in this study. Furthermore, unlike in many other countries, there is no legal requirement for managers of old age homes to have qualifications specific to this role.⁽⁵⁹⁻⁶¹⁾

It is no accident that the most positive and constructive ethos of most homes is located where staff have least power. They are connected to and have intimate knowledge of the residents and opportunity to connect meaningfully with families. Those who are weighed down with and focused on administrative tasks are alienated from the people they serve. If management was more inclusive, taking the opinions of all role players into account, patient care and family

satisfaction would definitely be improved.⁽⁵⁸⁾ It may even improve the experience of the managers and senior staff, making them feel more connected to the ‘team.’

5.5. PREPARING FOR THE END

The complex and unpredictable disease trajectory of dementia makes end-of-life preparation very difficult for family members. The lack of understanding by medical professionals of dementia as a terminal disease, as well as their reluctance to discuss dementia with patient and family at an early stage means the opportunities for advanced care planning are often missed. Poor relationships with staff in general leave family members isolated in decision making and a vague understanding of disease progression means they have no idea what decisions await them even if living wills have been made.

PLANNING AHEAD

In the current study only 37% of the participants family members had living wills however not one of them had a clear idea of the decisions that they may need to make later on. A number of family members were clear and adamant about life support, but further than that they simply had not considered what other situations may arise. They were rooted in the now, no- one had prepared them for eventualities such as dysphagia, pneumonia, intravenous medication and hospitalisation. With no forethought, when these situations did arise they would be forced to make decisions under duress and with little guidance. This could lead to guilt and confusion whatever the decision made. Again this hinges on provision of knowledge as discussed above. Understanding and preparation can go a long way towards making what could be unbearable easier to face.

This is not unique to this study. Despite provisions made in well-resourced societies advanced care directives (ACD'S) are not common. In Forbes' study in Middle America patients with directives were in the minority and even when they did exist participants in the study were not sure whether they would follow them or not.⁽¹⁸⁾ In the study by Godwin and Waters family and staff had hardly considered end-of-life issues at all. Most commonly even when there were ACD's either the family were unaware of them or often chose not to follow them.^(4,40)

This confusion surrounding what decisions may need to be made and what in reality the directives in ACD's mean is a common finding. Families are often unaware of what their role or duty is at the end-of-life and have little to no understanding of the concept of palliative care. They may view it as inferior, failing to provide the care that their loved ones have a right to.^(3,18,40,41) For the respondents in the current study palliative care was not even a concept they were aware of. One or two spoke of keeping their loved ones comfortable at death and not wanting them to die in hospital, but this was vague and uninformed.

DEATH: CURSE OR BLESSING?

Many of the variables which influence how death and the process of dying are viewed, such as culture, religion, previous life views and even the attitude of health care workers, are beyond the scope of this study. However the way the participants viewed end-of-life issues depended very much on how they saw the quality of life of their loved ones at the point of interview. Quality of life is subjective and thus varies from one person to another. Determining someone else's quality of life is even more complex. It is influenced not only by what the dementia sufferer's physical capabilities are, or what they are perceived to feel or experience, but the environment they are in and the way they are treated by those around them.⁽⁴⁸⁾

The participants in this study's attitude towards death were inexorably linked to their beliefs about quality of life. Life was: *"downhill," "deterioration," can't take it in, just sat there, "my mommy's gone."* Little seems to be left from the perspective of these family members. D made a huge effort to recreate his loved one, hiring a carer to stimulate her who in his words *"Sits with her and they laugh together. When she's watching J she talks with her and laughs."* Essentially though they are all searching for remnants of their loved ones, looking for a reason to believe they are living rather than existing.

Russell's study found that most family members conflated quality of care with quality of life.⁽⁴⁸⁾ This was not the overtly the case in this study although indirectly it clearly influenced the overall subjective experience. Much reference was made to the lack of emotional care and the desire for it. Determination of quality of life is really an assessment of how family members feel their loved one may be experiencing their own lives. Whether this is true or not is not pertinent as it is the positive or negative perceptions that will influence family burden.

The way individual worth is linked to dementia as a disease impacts heavily on quality of care and thus family and patient suffering. The participants in Moyle *et al's* study identified two ways of ameliorating this. One by staff spending time talking to and sitting with the resident and two by staff spending time on activities tailored to the specific interests of the resident.⁽⁴⁹⁾ Both these were seen to enhance the quality of life of the resident. Although this may not be realistic in our environment it is the principle that must be extracted from the study.

In many ways some of the participants had come to terms with death in that the person they have known and loved is gone. In the words of G, *"And why she's still alive? uhm, you know, how many times must I mourn her death?"* That said the ongoing physical 'living' of their loved ones was often a source of suffering for them and, in their opinions, their loved ones. Some hoped for a swift death, with the alternative being too awful to contemplate. Death seemed both welcomed if quick and feared if long and agonising. The suffering they endured by witnessing this slow death seems to eclipse any suffering that the patient may feel. As was found in the study by Forbes *et al,*

there was the conflict of both fearing and longing for death and yet again the guilt that that engendered.⁽¹⁸⁾

5.6. CROSSING BRIDGES AND HEALING RIFTS: WHAT DO PEOPLE NEED?

PHYSICAL CARE AND FINANCIAL PRESSURES

Although emotional and psychological issues are prominent in the findings of this research they cannot be separated from the all too solid and ever present anxieties that exist with regards to the physical care of their relatives and the unforeseen financial pressures that long term intensive dementia care imposes. In this study the frail care residents were not yet totally bed-ridden and had moderately severe dementia. Their physical needs did not therefore include issues such as pain relief but they needed to be assisted with almost all activities of daily living (ADL's). Anxieties surrounding the physical revolved mainly around cleanliness and clothing, issues more to do with dignity and identity which will be discussed later.

This was not to say that physical care issues were not important. Where care was good it was deeply appreciated as in the case of A, B and D, and where there was lack of care the opposite was true, however in the context of the interviews as a whole the participants were less preoccupied with these issues than the psychological issues. This is consistent with the literature reviewed in this study. Mostly when physical care was mentioned it was regarding the safety of the resident or terminal care. For all participants safety had been one of the key drivers that forced the move to a facility. One after another participants spoke of less physical burden and increased safety; it was the trade-off for all the emotional turmoil that the move may have brought.⁽²¹⁾

In contrast, financial issues were mentioned in every interview, even though none of the interview guide questions referred to them specifically. Although the literature review done in a study by Ritchie and Ledesert in 1992 found that financial burden was one of five issues found to contribute most to carer burden and this was confirmed by their study,⁽²⁵⁾ there is only fleeting mention of this in other studies.^(38,45)

Different countries have different mechanisms in place to cater for their elderly population. Where more state aid is available or where medical insurance caters for care this may ameliorate financial burden. Where this is not available, the mounting costs often coincide with a time in the lives of families where family financial obligations are high. In this study every level of socio-economic status had something to say about finance, from the wealthiest to the poorest. Even in homes that had social grants from the state, issues like buying diapers or toiletries came to the fore. Finance is not an issue of numbers; it is integrally woven into the fabric that contributes to the family carer burden as a whole.

THE PERSON INSIDE THE DISEASE: PRESERVATION OF DIGNITY AND IDENTITY

Maintaining the person inside the disease was one of the most overriding themes that emerged from this research. The incremental loss of the essence of personhood was a slow torture for each and every one of the participants consistent with the literature on dementia care. The attempts that family members had made to keep any shred of dignity and identity alive and the way they perceived the care homes attempts to either maintain or disregard these issues was core to their relationships with the institutions and their staff. Issues such as the loss of dentures or glasses were far more than just physical impediments, they were violations of identity, " *she always never wanted anybody to touch her glasses from her face*" the soul of the person denied. For F the urgency of preservation of person was so uppermost in her mind, she opened the interview with it before any questions were asked, and E suggested a board with information of what her mother was, her taste in food her background, in fact what it was that made her her.

Three things stood out in this theme, clothing, cleanliness and theft. Clothing and hygiene were constant sources of discontent. It would seem from the accounts given that in many of the homes dressing residents in their own clothing or clothing that fitted them was not viewed with much importance. For the families however buying clothing for and seeing their loved ones in these items was one of the few avenues left to maintain the individuality and dignity of their loved one. I's relinquishing of this battle signifies another piece of her mother's dignity and identity removed, this time not by the disease but by the home. This has been reiterated by other studies.^(19,21,24) Furthermore, Moyle et al's 2014 publication showed that as residents became more ill they seemed to become less valued, a marker of which, for family, was finding them in the same clothes week after week.⁽⁴⁹⁾

Similarly cleanliness was a powerful marker of the rejection of the resident's value and worth. Words like smelly evoke images of refuse, discarded and unwanted, and four of the eight participants made mention of the cleanliness of residents feet. This is more significant than it may appear. It is often a marker of how people manage to take care of themselves and in many cultures the washing of another's feet holds symbolic meaning as a sign of humility and valuing of even the 'lowest' of society. The subliminal impact of this act of omission cannot be ignored.

Where the staff is not seen to respect the resident as an individual, the family is left to struggle with their own demons of maintaining that identity and with the staffs' negation of their loved ones value. This has been shown in many studies all over the developed world.^(35,39,42,43,48,49,51,74) The contrary is also found to be true, as in a study where staff that was seen to be compassionate and to care about more than the physical and schedule produced high levels of family satisfaction.⁽³⁹⁾ This seems to be true no matter what type of care model was used in Robinson *et al's* study.⁽⁴⁷⁾

The expectations of our participants were not high, expensive or always time consuming. The comfort of mentioning a husbands' name, the reassuring of a loved one in distress or the request for far away family to be contacted. All these were mentioned and remembered specifically by the participants. As in Granheim's meta-ethnographic study, staff that showed genuine interest and care was thought to provide good care.⁽⁴²⁾ One wonders if the staff even realised how significant they were, and whether the families realised how important it was to acknowledge their kindness.

5.7. FAMILIES DEFINING A NEW ROLE: FORGEING PARTNERSHIPS AND MUTUAL VALUE

LOSS OF ROLE

Amongst all other diseases dementia is perhaps the one that affects family members as much if not ultimately more than the afflicted person themselves. As the person changes so do the roles that have been in place throughout life. The traditional parent/child, spouse or sibling roles all change. Re-negotiating these roles is difficult and dependant on previous relationships and bonds.

These participants felt lost and bereft of their purpose. Whether it was as protector, full time carer, husband and companion or loving daughter and friend, it was gone. It had been replaced by that of warden and decision maker as the person was replaced by the disease. By the time the decision was made to move, a new form of relationship had often been formed. It may not have been the same as it was but there were still very strong bonds based on lifelong relationships, what the person had been and the new purpose the carer had found in looking after them.

The move to care does not remove the carer role; it does not lessen the bonds between family members nor the feeling of responsibility for the resident. Defining a new role after admission seemed to be very hard for the participants of this study. Many of the new avenues of care that had been re-formed were handed over to the new carers. This was in effect the reason for the move in most cases; the family could no longer cope physically with their loved one and they needed help, and yet the void left seemed to be unanticipated as they moved from everything to nothing.

For the two who were integrated in and felt happy with the care of their loved ones there was a role and a purpose as well as a way to remain bonded to their loved ones. Brambles' study in Brisbane confirmed this where those who had been informed about and included in the home felt less grief than those who felt that the system had totally replaced them.⁽¹⁹⁾ For the others, as in Graneheims review, the loss of control that carers felt actually approximated grief. She described this move as "*a disaster in which they were helpless.*"⁽⁴²⁾

For the participants in this study this pattern could not have been clearer. One person encapsulated both sides of the coin. G's initial relationship with the two people responsible for her mother's care was excellent. The way she felt about them epitomised all that signifies an inclusive, collaborative and mutually respectful team approach to care. They were part of the

family and fulfilled the role of that extension. More importantly, she too was still very much part of her mother's care team. The success of the whole revolved around good communication and a strong mutual respect and visible mutual validation. When that system was removed G's entire role fell apart. She had no purpose, she was cut out. Her new role was to be a vigilant protector in a war against the home. She felt she needed to be scheming and devious to get what she needed for her mother; there was no mutual trust and no peace of mind.

Participants were looking for a way to participate but they simply had no idea where they belonged. All they needed was guidance, but if the home saw no place for them, they certainly would not have been able to visualise it for themselves. In fact, in one of the homes it was at the very time that family could have been both of help to staff and have had a tangible way of playing a part in their loved ones lives that they were shut out by the rules: at lunch time- a time of nurturing and a potential avenue for team building. These participants felt they were *"not allowed to interfere,"* or they *"don't feel comfortable now,"* or simply *"they don't want me there during lunch time."* In the words of A, *"And I would need to be taken to the water and then I would drink."*

On the flip side, for the participants who were in the team there was a role. D had very carefully carved out and protected that role. It gave him purpose and replaced the traditional protector/companion role he had had with his wife. Not only was he still her protector but he guarded the rights of all those in his team, this time against the authority of the homes management. He had made it his business to find out about the carers as people, just as he expected them to acknowledge his wife as a person. Where ever there was an attempt to bridge the divide, it came from the side of the family, not the staff. They often went out of their way to approach the staff on a human level with varying levels of success. Unfortunately, although many of them recognised the difficulty of the nursing jobs done, nowhere was mention made of communicating this to the staff themselves.

What has been discussed above is not an unnoticed phenomenon, nor is it surprising. The fact that families have deeply bonded relationships and that these bonds continue after nursing home placement is well established.⁽²¹⁾ Similarly, the confusion of who plays what role within the nursing home has been shown in many studies. In the context of all that has been discussed there was probably little other possible outcome for most. The blatant distrust of staff shown by many of the participants did little to decrease their burden; on the contrary it placed them in the role of policing the care. The fact that many of them were afraid to complain meant that even that role left them increasingly impotent.

Tornatore *et al* speak of just this phenomenon as family expectations drop so their vigilance over their loved ones increases. They point out a need for staff to provide opportunity to participate in care by breaking down traditional caregiver tasks within the nursing home environment.⁽³⁹⁾ Robinson *et al* found that a collaborative approach fostered a feeling of not only the resident but the family being cared for. This was done by encouraging family involvement and increasing communication about resident's actions and behaviour. It also served to alleviate family guilt and

thus lessen burden.⁽⁴⁷⁾ Both these outcomes were found repeatedly, with empowerment and burden reduction on the one hand and disempowerment and alienation on the other.

(19,20,24,35,42,44,48,75)

It is the presence or lack of channels of communication that underlie all these issues. In all interviews there were challenges on this front. Even B who felt the staff were forthcoming and open with her did not really know much about the day to day of her mother's care and was slightly surprised when she thought about it. For her it was not really an issue as she didn't feel the need for more, but for others there seemed to be an insurmountable wall between themselves and various levels of the staffing structure. They craved some communication at whatever level. It is not just a matter of wanting to complain, it is more a need for information, to find a footing in treacherous waters. When F was asked for suggestions on improving things she answered, "Agh, better communication. Communication. Uhm (laughs, long, long pause)..... Communication."

There are many reasons for this as discussed above and as found in other studies, staff turnover, cultural and language differences, racism, poor role definition, authoritarian management, rigid routines, poor intra-staff communication and understaffing. All these were expressed from the perspective of family, however interestingly in the study by Tornatore, similar issues came up in the staff interviews. From their point of view it was the same things that hampered communication with family. They too valued respect and cooperation and were quick to point out that families often criticized but seldom offered praise.^{(39)(39,39)} Almost all studies reviewed on this topic had some input about the need for better communication and the positive outcomes for all involved where this had occurred. Moyle found it maintained hope,⁽²⁴⁾ Cohen et al recognised that communication enhanced transparency and mutual accountability and respect,⁽²⁸⁾ and Hertzberg's study reiterated that family felt heard, valued and acknowledged when their opinions were taken into account.⁽⁴³⁾ The consensus is self-evident, but unfortunately the exception and not the norm.

5.8. LIMITATIONS

Although interview material, information and consent documents were translated into Afrikaans and the option of either language was offered, all interviews were conducted in English at the request of the participants. Only English or Afrikaans speakers were considered as the interviewer was proficient in these languages. The fact that no participants chose Afrikaans may indicate a bias in the actual sample by excluding people whose home language was Afrikaans or may indicate that participants felt they would like to accommodate the interviewer. The researcher was however limited by the suggestions of the nursing staff in the various homes.

- It must be stated that in doing this a large section of the Western Cape population, specifically the Xhosa population, was excluded. This will limit the transferability of the results of the study, particularly with regards to the excluded groups.

- The interpretation and discussion of the results of this study are that of the researcher only. This is in line with IPA which allows for the fact that the interpretation of a single researcher is valid as long as it is true to the words of the participants and is logical and plausible. Therefore it need not be a limitation as long as results are seen as transferable rather than generalizable.
- While there is bias in all research, it was not the intention of this study to portray nursing staff or administrators in a bad light. The topic explored was from the viewpoint of family only and therefore did not show how staff felt about the same issues, a topic that needs to be covered in further studies.
- Participants in this study are those who visit their loved ones regularly. This excludes those who were infrequent visitors who may have their own reasons for this which could add depth and value to a study such as this.

5.9. APPLYING THE TENENTS OF IPA

The three tenets of IPA, phenomenology, hermeneutics and idiography were applied throughout the study, from analysis of the raw data through to the formulation of the conclusions and recommendations.

Once the interviews were collected the first and second readings were to look at and get a feeling for what it was that rooted the person in their particular version of this shared story. It was a face value word for word reading: this is me, in my experience, in my words, now. It was the phenomenon of that individual living their experience at that moment – descriptive and apparent. Once that was done, I was left with a definite overview of the interview as a whole, its chronology and overriding themes as well what general emotional overlay there was within the narrative.

From there the move was towards a deeper analytical level, no longer taking each word or phrase at face value, but looking at what the words and grammar themselves meant, what they implied or what was left unsaid. This process was not rooted in the actual experience, in fact often finding the meaning in the language may not have related to the particular text at all. This meant that the “lived” experience which is a phenomenological tenant of IPA was to some extent “tainted” as the researcher’s own knowledge and experience was introduced into the process.

This was part of the process of IPA, acknowledging that the process of analysis must take into account the life experience of both researcher and participant and how that affects the process of interpretation. This second level of analysis of the apparent meaning of words then revealed a whole different level of meaning and emotion. This was the beginning of the hermaneutic cycle , a dynamic, non-linear process which was continued with the 4th reading where deeper concepts were extracted. The process was a constant shift from how the participant perceived what had happened to them and how the interviewer used her own experience; knowledge and world view to shape and form that into a conceptual framework. This process moved back and forth rather

than in a linear fashion and forced the researcher to re-shape and re-form ideas with each new interview. (Each interview was handled entirely separately, attempting as far as possible to have a blank slate, not influenced by prior analyses.)

This process was by definition idiographic as at this point in the analysis of each interview the focus was still heavily on the individual experience. The intense depth and detail of the analysis encompassed the move from descriptive to linguistic to conceptual. Finally the iterative nature of the conceptual analysis itself comprising the analyst and participants attempts to make sense of the experience left a unique picture of the particular experience of this participant of the phenomenon under investigation.

Only with that idiographic base firmly in place could the move towards finding commonality begin. This was then the search for emergent and superordinate themes and finally the establishment of connections, convergence or divergence, recurrence, commonality or individuality. Although the ultimate aim was to find a generalizable message that could be used to enhance or inform care within the context of this study, the individual was never lost, and each participants voice remained offering a unique perspective on the phenomenon of interest.

Therefore if one looks at the themes that emerged, whilst there may have been a strong sense of commonality, the individual experience of the particular phenomenon further informed the ultimate recommendations. For example, each person's prior journey shaped their ongoing relationships with staff. This needed to be explored and acknowledged to maximise those relationships. The complex co-dependant relationship which participant E had with her mother tainted every facet of her ability to find a place in the homes care team, whilst for participant B, her mother's prior independence and separate existence meant she expected and wanted less of a role. Both felt guilt over placement of their mothers in the homes but their expression of that guilt and the help they would need was informed by their particular life experience.

This idiographic focus within the whole can be seen within each of the emergent themes and recommendations. A further example would be the complex issue of race and suspicion. This important and prevalent theme came to the fore and stood out strongly as a point of concern, yet the individual experience of the particular phenomenon was not homogenous. It moved from the very real feeling of E's mother being persecuted on the basis of her race to D making the point in a definitive way that white and black staff could both be good. To the age old splits between "coloured's" and "blacks". The ultimate conclusion that this is a very present and real issue that needs to be addressed is thus again informed by the particular unique experience, enhancing the generalisation rather than rejecting it.

CHAPTER 6 - CONCLUSION AND RECOMMENDATIONS

The initial aim of this study was to assess how family members of dementia patients in Cape Town old age homes view the palliative care provided to their loved ones as well as the barriers to and facilitators of their involvement in that care. What soon emerged however was the realisation that with a disease like dementia provision of care to patients cannot be separated from provision of care to family members. This is in line with palliative principles which see the patient in the context of their entire family. However in this scenario it would seem family often suffer more than the patient him or herself and yet are often completely neglected or worse still made to suffer more through acts of commission or omission on the part of health care professionals. Thus the aim developed to include the provision of palliative care to family members as well.

In order to understand the vulnerabilities these participants ascertaining their background stories was as important as their current experiences. One could not separate this from the latter as relationships between family and staff in the homes was so heavily influenced by what had come before. This applied to the decision making and act of moving loved ones to an old age facility in particular. Families who had been orientated to and included in the homes from the start continued to have positive outcomes and vice –versa.

Vulnerability was exacerbated by lack of disease understanding on all levels, scientifically, emotionally and simply knowing what to expect in the future. It left the participants powerless on at least one of those levels if not on all. This paucity of knowledge was not limited to the families, but seemed to be common amongst the nursing staff and at least some of the doctors mentioned. The result of this was a feeling of being set adrift in a rudderless ship. There was no-one to lead and no one to turn to.

The biggest barriers to a positive perception of care were the negative perceptions of the staff as a whole. Family members were often afraid of complaining in case there was some form of retribution meted out to them or their loved one. Staff turnover and lack of staff were 2 very real barriers. This prevented any meaningful relationships being formed between staff and resident and staff and family. Lack of time and rigid adherence to schedule further compromised what family saw as total care. Physical care was not as much of an issue as recognition of identity and personhood of both resident and family. Emotional sensitivity and preservation of dignity was valued above technical expertise as it left families feeling cared for.

Small gestures went a long way in reassuring and comforting family members. Nurse aides were seen in a far more positive light than more senior nursing staff, but even an understanding and appreciation of the poor working conditions was not enough to excuse what was seen as neglect. Managerial staff was the enemy to every participant but one. They were seen as distant and authoritarian. Residents, families and nursing staff were perceived to be victims of this authority. Doctors were barely part of the picture at all. Racial issues inherited from South Africa's past

complicated cultural differences and fostered discord or at least a suspicion of it. This formed part of the bigger problem of poor communication networks and role confusion.

In many cases family felt unwelcome. They had no idea what their new role was or how they could fit in as part of this new team. Most of the participants were bereft, they had lost the person they knew and had been betrayed by the homes they had chosen. Above all they had swapped safety of their loved ones for all else. Whatever indignities they felt had followed had to be excused for this overriding purpose. Their new role was impotent guardian, watchful on behalf of their loved one, deviously looking for a way to influence care. For those who had been embraced by the staff the feeling of containment and satisfaction with care was obvious. Family members still sought an active role in their loved ones lives, for some they had made it their business to carve this out, for others they were simply shut out.

Lack of understanding extended to preparation for end-of-life. Again participants were totally in the dark about the possible scenarios they may have to face in the final stages of the disease. Even those whose family members had living wills had not thought further than "life-support." Even more alarming was the fact that no-one had ever had this discussion with them or offered them any information. It was not that they would not have been receptive; almost all of them felt that the quality of life of their loved ones was poor at best. They were primed for a discussion on palliative care, it was just not forthcoming.

RECOMMENDATIONS FOR CHANGE

The outcomes of this study cannot be generalised to all homes in Cape Town, however they can be transferred and perhaps some suggestions could be applied for the betterment of resident, family and staff.

The lack of knowledge is an area that can be addressed on a number of levels:

- Most simply resource centres could be set up at each facility which could make written, audio and film material available to staff and family on a loan basis. Contact information for nongovernmental organisations such as Alzheimer's South Africa and Dementia South Africa could be made available as well as professionals who have an interest in or specialise in dementia. Alternately or additionally packs of information could be made available to families on admission to a facility.
- On a broader scale, education around geriatrics and dementia specifically should be made part of curricula for both medical and nursing staff. Training in this field should be a prerequisite for all courses run for nurse aides.
- Alzheimer's South Africa and Dementia South Africa run training courses for nursing home staff and support groups for families. All homes should be encouraged to invite these organisations in on a regular basis.

Communication channels need to be established early on and to be maintained:

- Management in the home must change its image from one of authoritarian bully to part of the team as a whole. To do this all levels of staff must be given a chance to give their input on how things are run without fear of victimisation. Different staff members have unique access to different aspects of the care home and residents lives. Their input and the people themselves should be valued.
- Families should be interviewed about the residents on admission. This interview should include not only medical but personal information about the person, their likes and dislikes and some of their family and professional background. It may be useful to ask family to put this information as well as some photos on a board. This could be to put up in the residents room for staff to see. It would help staff members relate to residents and bridge gaps when new staff come in
- Regular meetings should be scheduled between staff and families. These need not be one on one but can be group meetings and they need not be very frequent. This could provide an opportunity for both concerns and praise to be raised. It is paramount that families feel heard and validated but it is no less important that family have an opportunity to hear and appreciate the staff. This way misconceptions and assumptions can be avoided.
- Although time is always an issue, staff should be sensitised to the struggles that family face regarding loss of person and role. Issues such as clothing and cleanliness should be discussed in particular as they may not be aware of the significance of these things. If staff feel clothing provided is unwieldy they can discuss this with families to find a compromise.
- Racial issues cannot be shied away from or denied. Whilst it is always desirable to integrate all aspects of society it may be prudent to be sensitive to the feelings of communities and not to force situations on them before they are ready. Candid conversations about people's inbuilt prejudices and suspicions can only take place in an environment of trust.
- Old age homes should make a structured effort to find opportunities for families to participate in the care of their loved ones. Meal times in particular are an opportunity for bonding and nurturing and would ease the burden on staff. Activities where staff, family and residents take part would foster a team spirit. Allocation of other tasks may also help in understaffed situations. Some homes have administration committees however a committee made up of families and different staff representatives could be formed to plan these activities as well as fund raising for the home.
- End-of-life issues cannot be left till crisis points arrive. All families and residents with dementia should be afforded an opportunity to discuss what they can expect later in the disease and what decisions they may be forced to make. Options which may be available to them can then be offered. Realistically in a country such as South Africa palliative services are limited and this task will fall to senior nursing staff, social workers or primary care doctors. Ideally each home should have an assigned doctor who is educated about

these issues and would be available should families chose to use them. This comes back to training and education as well as funding.

- At the very least senior staff and primary care doctors should be cognisant of palliative care and what may or may not be appropriate to offer families as options in the closing stages of life. Even if it is only given at the last minute, some form of guidance needs to be available for families at this difficult time.

RECOMMENDATIONS FOR FURTHER RESEARCH

The research field of dementia and family carers is virtually untapped in South Africa; therefore scope for further studies is wide. The following areas would add significantly to knowledge in this country and help to reform thinking and practice in this field.

- Similar research encompassing different cultural and ethnic groups in South Africa.
- Research on nursing staffs views on relationships within old age homes.
- Research on nursing staff views on relationships and sharing care with family members.
- Investigation into what palliative care is actually given in old age homes in South Africa at the end-of-life.
- Investigation into doctors understanding of dementia as a terminal disease and the need for palliative care
- Looking at how to implement more inclusive and consultative managerial styles and whether this changes relationship and care patterns.

This study adds valuable insights into how families feel about the palliative care dementia patients and by extension themselves, receive in old age homes in Cape Town. Furthermore, it clarifies the barriers to and facilitators of their involvement in that care. Aiding communication and breaking down barriers between staff and administration in old age homes on the one hand and family members on the other can only serve to enhance the experience of the last stages of life for dementia patients and family alike.

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APPENDICES

APPENDIX 1 – TARRIFFS AND STAFFING OF OLD AGE HOMES IN THE STUDY

	<u>Day Shift</u>	<u>Night Shift</u>	<u>Weekend</u>	<u>Frail care beds</u>	<u>Fees for home</u>
	06H30-18H30	18H30-06H30			
<u>Helen Keller</u> <u>Pinelands</u>	Senior sister(till 16H00) senior staff nurse, 6 carers	Senior Staff Nurse and 2 carers	No Sister present- on call 24hours	35	R11 500
	07H00 -19h00	19h00-07H00	Weekend		
<u>Fairmead Annex</u> <u>Rondebosch</u> <u>(CPOA)</u>	1 Senior sister (till 15H00) 1 Professional Nurse 1 enrolled Nurse Auxiliary 3 Carers	1 Professional Nurse 1 enrolled Nurse Auxiliary 2 carers	Same as weekdays but no Senior Sister	35	R17 059 - R18 719
<u>Pinelands Place</u> <u>Pinelands</u> <u>(CPOA)</u>	1 Senior sister (till 15H00) 1 Professional Nurse 1 enrolled Nurse Auxiliary 3 Carers	1 Professional Nurse 1 enrolled Nurse Auxiliary 2 carers	Same as weekdays but no Senior Sister	31	R14 771- R16 879
<u>Erica Place</u> <u>Athlone</u> <u>(CPOA)</u>	1 Senior sister (till 15H00) or 1 Professional Nurse 1 enrolled Nurse Auxiliary 7 Carers	1 Professional Nurse 1 Enrolled Nurse Auxiliary 3 Carers	Same shifts as weekday but no Senior Sister	81	R702.00 of Old Age Pension / Disability Grant Or R5000- R6000
<u>GH Starke Old Age Home</u> <u>Hanover Park</u>	Patients are on the general floors and not in the frail care- There is 1 house mother and 1 carer per floor at any time.	There is a frail care with 12 beds in the same home with 1 Sister and 1 Enrolled Nurse Auxiliary at a time but neither patient was in the frail care		78 people per floor	75 -80 % of Income

APPENDIX 2 - BEDFORD ALZHEIMERS DISEASE SEVERITY SCALE (BANS-s)DRESSING

- (1) Usually independent
- (2) Requires minimal assistance
- (3) Requires reasonable care but is not totally dependent
- (4) Completely dependent

SLEEP

- (1) Regular sleep-wake cycle
- (2) Sometimes irregular sleep-wake cycle
- (3) Frequently irregular
- (4) Sleep-wake cycle severely disturbed.

SPEECH

- (1) Preserved
- (2) Slight inability to speak
- (3) Occasional inability
- (4) Complete aphasia

MOBILITY

- (1) Walks independently
- (2) Sometimes walks independently
- (3) Only walks with assistance
- (4) Unable to walk even with help

MUSCLE TONE

- (1) Normal tone and joint mobility
- (2) Partially impaired joint mobility and tone
- (3) Partial increased tone and rigidity
- (4) Contractures

EYE CONTACT

- (1) Maintained
- (2) Mainly maintained
- (3) Rarely maintained
- (4) Completely lost

EATING

- (1) Independent
- (2) Requires minimal assistance
- (3) Requires moderate assistance or coercion
- (4) Completely dependent

TOTAL SCORE OUT OF 28

(Volicer L, Hurley AC, Lathi DC, Kowall NW, J.Gerontology, 49: M223-M226, 1994)

APPENDIX 3 - QUESTION GUIDE FOR INTERVIEWS

Describe the journey you took from realising that something was changing with your family member to admission here. (Prompts: how long did they care for person at home, tipping point, who was involved in decision, how it made them feel, regrets, options that were available to them?)

- What are your thoughts and understanding of this illness? (how you got information about it? It's course)
- What do you think makes your loved one suffer most,
- What about their illness makes you suffer most?

Barriers to care

- What has gone well and what could have been better since your loved one came to live here?(you and patient - quality of life)
- Can you describe how you feel about communication with doctors and nurses, nurse aides here? (prompts –response to your suggestions/interventions/complaints/access to professionals)
- How do you feel the staff cope? (why well, why not, division of labour)

Opportunity to be involved

- How is the caregiving you do here different from the caregiving you did at home?
- What kinds of things make the care giving easier or harder for you to give in the old age home?
- How do you feel about making medical decisions for your loved one? (Acute intervention, guidance, from whom, how, most difficult decisions)
- How does talking about the end of your loved ones life make you feel? (Have you thought about it? Did you discuss their wishes with them or the doctors? Advance Care Directives? What would help)
- Do you have any suggestions that could have made or could make this journey easier for you?

APPENDIX 4 - PERMISSION LETTER FOR OLD AGE HOME AUTHORITIES

Date

The Facility Manager

Address

Dear Sir/Madam,

I am writing to ask permission to involve your frail care unit in my study. My name is Dr Deborah Lee Miller and I am currently enrolled for a Masters in Palliative Care at UCT.

The subject of my project is the exploration of the delivery of care to advanced dementia patients in old age homes in Cape Town as perceived by their family members. This will be a cross sectional qualitative study. I hope to interview a total of 16 family members from 4 different areas in Cape Town.

As you know dementia is an ever increasing problem that has to be accommodated in a very limited number of facilities. Providing quality care is challenging in a setting of high costs, limited staff numbers and scarce resources. Family members are often in a state of anxiety, confusion, guilt and sadness when faced with this very cruel illness, and placing a loved one in an old age home is an extremely difficult decision for most. On the other hand, advanced dementia is a very challenging condition for caregivers and skills and patience are often tested to the limit. Very often there may be difficulties with communication channels between staff and family, leaving both resentful and angry, when, in fact, both are trying to achieve the same goal; best care for the patient.

In conducting this study I am hoping to identify what family members understand about the condition of advanced dementia. It is with regard to the identification of these family members that I am requesting access and assistance. As the study is limited to people with advanced dementia I will need to identify these patients and then approach the family member who is most involved with them. This will mean asking the senior sister to decide which patient may fit the study criteria. To assist with this I have used a short rating system called the Bedford Nursing Disease Severity Scale. This is easy to apply and does not require any interference with the patient at all, providing they are known to the staff member. I will be available to clarify and assist with any questions when this is done. It should not take longer than 10-15minutes. I will then ask that the Sister contact the family member to get permission to give me their number.

Once the family member agrees to be interviewed, there will be no further contact with the old age home. This study will not be beginning until we have full ethical approval. The results of the study will be disseminated to each facility that offered assistance as well as the staff who helped and the people interviewed.

No research of this kind has been conducted in Cape Town and the nature of our society means that we have many communities with different cultures within our boundaries. With this in mind I am hoping that you will be able to assist as it is vital that each area is represented equally, to try and get a picture of differences that may occur across cultural and economic barriers.

I look forward to hearing from you and hope you will consider my request favourably. If you have any ethical concerns you may raise them with the UCT Research Ethics Committee, contact:

Name:

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 6338

If you have any questions please do not hesitate to contact me.

Sincerely

Dr Lee Miller

021 6895141

0832667044

ptraub@telkomsa.net

10 Rosendale R

APPENDIX 5- INFORMATION SHEET FOR FAMILIES

Information Sheet for: Family perceptions of palliative care for dementia patients in old age homes in Cape Town

Thank you for considering taking part in this study. The study is a research study aimed at understanding the experience of people who have family members with advanced dementia in old age homes. The study is undertaken as part of a master's degree within the division of Family Medicine at the University of Cape Town.

This sheet will explain what the study is about so that you can decide if you would like to take part in it. If you have any other questions please feel free to contact the researcher at 0832667044 or email at ptraub@telkomsa.net. Please take your time in deciding if you would like to take part.

What is the purpose of the study?

I am looking at the experiences and feelings of family members whose relatives have advanced dementia and live in old age homes. I specifically want to find out how the family members feel about the palliative care that is being provided. This means care for the total wellbeing of your relative. I would also like to find out how you feel you fit into the care team.

Do I have to take part?

No, you do not have to take part. If you do decide to take part, you may withdraw at any time before, during or after the interview without giving any reason. Whether or not you take part your relatives care will not be affected in any way at all. If you agree to participate you will be asked to sign a consent form to show you have agreed. Please take your time and feel free to discuss it with anyone you would like to talk it over with.

What will happen if I take part?

The researcher will contact you and arrange a place and time to meet with you which will be convenient. They will be asking you for about an hour of your time. If you need money for transport this will be provided. You will be asked questions about your relative's condition and how you have felt about it and coped with it. You will also be asked about how you feel about the care given to your relative by the nursing home staff and doctors, both good and bad. We would like to find out if you think you would like to be or how you could be more involved in the care of your relative. It would also be very important to find out how you feel things could be improved.

Benefits of the study

Although the study may not benefit your relative directly, it is hoped that when it is completed the information will help staff in old age homes understand what family members are experiencing. The benefits could be to families' staff and patients, as better communication could help make positive changes to dementia care in these homes.

Will my taking part in this study be kept confidential?

All the information which we collect during the interview will be kept strictly confidential. All your personal details will be kept separately from the study and all names will be removed and replaced by a number. No-one outside the study will have access to the information you give us. This will apply to the name of your relative and the old age home they live in.

How will I know about the results of the study?

At the end of the study a report will be sent to the old age homes that agreed to us having access to their patients and to all participants of the study.

Who is organising the research?

If you need to talk to anyone about this research, you can contact the following people.

If you have any questions about the study:

Dr Lee Miller

021 6895141

0832667044

If you have any questions about your human rights of any ethical issues about the study:

Faculty of Health Sciences Human Research Ethics Committee

NAME

Research Ethics Committee

E 52 Room 24, Old Main Building, Groote Schuur Hospital, Observatory

Telephone: 021 406 633

APPENDIX 6 – CONSENT FORM

**Consent form: To explore the delivery of palliative care to dementia patients in old age homes
in Cape Town as perceived by their family members.**

1. I confirm that I have read and understand the information sheet and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving a reason, without my family members care being affected.

3. I agree to take part in the above study.

Name _____

Signature _____

Date _____

Researcher: Signature _____

Date: _____

Witness: Name

Signature _____

Date: _____

