

**Quality of life in residential care: a qualitative study of perspectives of people with dementia, their family members and healthcare staff.**

**By**

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## **ABSTRACT**

As our population ages so too will the number of people with dementia increase. For some time there have been concerns expressed by campaigners for people with dementia about quality of life and the safety and quality of care delivered for those in rest homes, particularly for residents in the specialised dementia rest homes. Little is known about the quality of life of people with dementia from their own subjective points of view, in particular in reference to the corresponding opinions of family members and healthcare workers.

The aim of this study was to look at views of quality of life for residents living in a specialist dementia level rest home, and how they were expressed. The study gathered data from four “cases” covering three viewpoints in each case: the resident with a moderate dementia, a key family member and a key residential healthcare worker involved in their care.

The study used a qualitative method, analysing data from these twelve recorded and transcribed interviews. The interviews were semi-structured following the line of questioning of the Quality Of Life–Alzheimer’s Disease (QOL-AD) assessment (Thorgrimsen, Selwood & Spector, 2003) (Appendix 1) followed by some more open-ended questions. Data were analysed and interpreted according to key themes and phrases and explored for similarities and differences using descriptive methodology.

The main findings of this study are that quality of life has many dimensions and has differing meanings to each participant. The person with dementia’s subjective viewpoint is important in rating their own quality of life, however, using the “three voices” (resident, family and healthcare worker) made an authentic contribution, enabling a more comprehensive understanding of quality of life for the residents living with dementia. Despite being given a diagnosis of dementia, resident participants demonstrated awareness and an acceptance of their condition. Each resident participant described a better quality of life for themselves than that reflected in the opinions of the family members and healthcare workers. Another significant finding was that family relationships were seen to be important to the resident’s quality of life, not only as part of physical closeness but also as emotional attachment.

These findings may lessen the degree of guilt and distress for family members in such situations. Studies of this type may also assist healthcare workers develop their ability to

intervene to improve the quality of life of individuals with dementia rather than simply dealing with more medical or basic care aspects of the condition.

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## **CHAPTER 1 - INTRODUCTION**

### **1.1 THE RESEARCHER AND THE FOUNDATION OF A THESIS**

My interest in older people began at a very young age. My grandfather came to stay with my parents for a fortnight's holiday just after they were married and there he stayed until he died many years later.

Growing up with an older person in the home could be very restricting for us as children; I was the youngest and the only girl with three other siblings. I have memories of my grandfather being very old and grumpy. He hardly spoke to us and when he did it was usually in a non-sensical garbled tone.

He smoked a pipe and I remember the burn holes in his shirts and trousers. His personal hygiene was taken care of by sponging himself at the sink; he could not make it up the stairs to use the bath.

As children we did not see him. He spent all his days and nights in the "front room" watching television, eating his meals and sleeping. When we did catch a glimpse of him he hardly knew who we were.

He became frailer and chair-bound, I helped mom tend to his cares when I could. In those days there were no supports readily available and people looked after their own, mom would never agree to him being "put away".

In the very early 1980s at 17 years of age I began working at a local psychiatric hospital near my home within the County District of Staffordshire in the United Kingdom. People with dementia were considered an annoyance and were locked away in large psychiatric hospitals or were hidden at home. Following the end of World War II a quarter of admissions to this hospital were people with dementia. Several factors had played a part in this. Firstly life expectancy had increased and secondly women were now working and could no longer take care of their "dementing" parents. This had led to the increase in numbers of people with dementia who did not actually require skilled psychiatric treatment but there was nowhere else they could go. There was little knowledge about the condition and little thought was given to treating people with dementia with either medications or other therapy, or to providing any kind of support for their families and care givers.

As with many psychiatric institutions across the country psychiatric hospitals were typically large, several hundred beds in size, very old buildings, and providing care on large, open, multi-bedded wards. The elderly populations in these facilities were long-stay psychiatric patients who had grown old in the hospital wards and the majority of patients were the elderly demented.

My first day of employment was on a 32 bedded ward for women with dementia. The ward was referred to as a Nightingale ward. There was a lack of privacy for the patient as there were no curtains separating beds from one another. On each “toilet round” the patients would line up and sit side by side on commodes. The daily ward routines were rigid to ensure the smooth running of the ward, which were often seen to deny individual needs. Patients had no control or say over what happened: all decisions were made by staff. Patients were deprived of normal social roles and had restricted contact with life outside of the hospital. Patients would eat, sleep and play in the same place. It is fair to say that the patients were depersonalized.

The patients themselves typically presented as being oblivious to the surroundings around them. They appeared to have resigned and accepted that things would go on as they are. They remained apathetic with no signs of initiative and a lack of interest. Further down the track in psychiatry this would be known as institutionalization; the patients behaved in this way because their environment had reconditioned them.

As a young student little attention was paid to understanding the concept quality of life as it was experienced by patients. However I found that I would often ask myself, would I be satisfied if I were living their life? If not then how can this situation be improved?

It was then that it became obvious that my grandfather had begun the dementing process. I now wonder what quality of life was like for him, the losses he must have had. Was he happy and content in his front room, was he depressed? I now compare his life to those on the ward, was it any different? For a number of the patients on the ward they had lived there for most of their life. Others were placed there because families could no longer take care of them. I often reflected what quality of life is and what makes a person’s life better? Is it to be with your family or to be with strangers? Was my grandfather’s life any better than the patients on the ward? He had chosen to isolate himself from the family but he remained in a family in his own home. For the patients in the hospital they had no choice but to be in the environment

around them and share the company of others, and perhaps would not know anything different.

From my early experience of nursing people with dementia my observation was that no-one actually sat down with their patient to talk about their likes and dislikes. Depression was never addressed. Visits from family and friends did not occur and when someone actually did they were never approached by staff, except to obtain money in order to purchase items such as chocolate, sweets and toiletries. A stigma remained around psychiatric asylums, particularly in those days before the start of the hospital closures in the early 1990s.

I could go on more; however this thesis is not about my grandfather's ageing or how the elderly in psychiatric institutions were cared for in those days, but is about "what makes a person's life worth living"? Life in residential care for the elderly with dementia has come a long way since those days and has improved immensely. I personally believe that change and research is good if it enables a person to live more comfortably and be free from distress. Therefore we should continue to search for ways to make things even better for people with dementia who are in residential care in order to improve their quality of life. People with dementia living in specialised rest homes are some of the most vulnerable people in society. They depend on the staff to ensure that they receive the best possible care to meet their needs.

From the beginning of my nurse training and from my own personal experience I have continued to take a keen interest in monitoring and managing quality of life for the elderly with dementia. For the past eleven years I have been working for a District Health Board as a nurse specialising in older person's mental health. The last six of those years have been working alongside a Psychogeriatrician responsible for the placement for those with dementia into residential dementia care.

My philosophy of care is that people deserve respect, dignity and to receive treatment that is fair. Within the medical team all should be working together for the good of an individual in providing the best possible care. I believe the environment in which someone lives should be therapeutically beneficial. This can be helpful in gaining personal trust whereby a person will feel safe and free from distress. Nursing care should be individualised and patient-centred providing the individual with a sense of security and feelings of self-worth.

Over the years I have often considered the life of someone with dementia within specialised dementia rest home care and have tried to put myself into their shoes in an attempt to find out exactly what it is like for the person to live with this illness. This may be partly due to my own insecurity and concerns about the possibility that I or members of my family could one day be diagnosed with the condition. I have also heard negative comments from people about their relative or individuals having this “awful disease” and being “imprisoned” in care. I have listened to nursing staff caring for people with dementia asking others to put them out of their misery should they suffer the same way. I have asked myself, could this person’s life be so bad that they would wish themselves dead? This interest and question has progressed over the years and has brought me to the conclusion that I will never know unless I try to find out from the people most directly involved in this situation, therefore these thoughts have brought me to my own piece of research.

## **1.2 AIM OF THE STUDY**

From the researcher’s background and beliefs the topic for this thesis was simple to choose. The researcher wished to conduct a study to investigate individual perspectives on quality of life of someone with a dementia. The aim was to obtain and explore views about quality of life from residents, family and healthcare workers.

The aim of this research project was to find out what people with dementia, who live in a dementia rest home think about their quality of life and to compare their views with what a key family member and a key healthcare worker at the rest home think about the resident’s quality of life. The researcher gathered these views by talking with participants basing the discussion on a commonly used questionnaire called the Quality Of Life–Alzheimer’s Disease (QOL-AD) (Thorgrimsen et al., 2003). It was hoped that by following this guideline the interview would open out into a full discussion about their thoughts, feelings and opinions. After all the interviews were completed the researcher looked for key themes and phrases, similarities and differences between people’s perspectives. It was hoped that a better understanding of quality of life from the resident’s perspective would be gained, and to contribute to those in clinical practice in a way that would add to evidence-based knowledge. It was hoped that this study would contribute to the research literature and also the researcher’s practice.

The study was planned to show how significant others may contribute to, develop or hinder in what they believe is a good quality of life. It was believed that there was potential for the study to assist in development of appropriate policies and processes, designed to improve quality of life for people with dementia.

There is also potential for the particular participant triads to improve their understanding of each other's perspectives, with possible direct effects upon their quality of life, from the process of participating. This study is intended to increase knowledge in providing education and solutions to those experiencing dementia, be it for those working within organisations or as a family caregiver.

The expectation is that those involved in dementia care will express awareness of what they believe is a good quality of life, which may (or may not be) similar or consistent with the views of the person with dementia.

### **1.3 STRUCTURE OF THE THESIS**

This chapter has given the reader the aim of the research study and how it was developed from the early days in my nursing career and my compassion in making a difference to ensure people with dementia have a good quality of life.

Chapter 2 will briefly define dementia and background information relating to the impact dementia has on the person, their family and society.

Chapter 3 explores the literature published that relates to quality of life within the elderly with dementia. Within this chapter quality of life is defined, the domains of quality of life are explored, and questions why is quality of life measured. What determines quality of life in dementia is outlined. This chapter also looks at the research considering various perspectives relating to quality of life in dementia.

Chapter 4 will discuss and describe the research process. It will briefly look at including people with dementia in research along with consent and assent and the use of appropriate measurement tools in research. It outlines the selection of the study design and method used in the selection of participants. It also outlines the data collection and analysis. An outline of issues around rigour and validity, strengths and limitations, ethical approval, and

responsibilities of the researcher will be given. It will also look at the Treaty of Waitangi, confidentiality and minimization of harm.

Chapter 5 presents the findings from the four cases of interviews.

Chapter 6 discusses the findings.

Chapter 7 concludes the thesis. The overall aims of the thesis will be reviewed. It will discuss implications, recommendations for further professional development and my own personal thoughts.

## **CHAPTER 2 - DEMENTIA AND ITS EFFECTS**

### **THE BACKGROUND**

#### **2.1 INTRODUCTION**

The main focus of this chapter is to take a look at dementia and its associated symptoms. These not only bring challenges for the individual but also their families, friends and wider society. The chapter will address these challenges and the background which led the Ministry of Health (MoH) to develop various strategies and policies to assist District Health Boards improve the quality of life for people with dementia.

#### **2.2 WHAT IS DEMENTIA?**

Pearce (2003) suggests dementia is a progressive, degenerative incurable disease that affects the brain structure and its functioning resulting in a loss of memory, judgement, intellect and motor skills. There may also be behaviour, mood and personality changes. Due to the severity of such loss of intellectual function and memory dementia typically leads on to a dysfunction in activities of daily living. The nature of the condition and its effects not only affects the person with dementia but also changes the lives of family and friends.

Perkins (2006) wrote that dementia is a term that describes as many as a hundred different disorders, the most common ones being:

- Alzheimer's disease accounts for 50-60% of all dementia cases. Its characteristics involve abnormal plaques and tangles in the brain resulting in memory difficulties among other symptoms.
- Vascular dementia accounts for 10-20% of dementias. Formerly known as multi-infarct dementia, resulting from significant brain damage caused by cerebrovascular disease. The onset may be sudden, following a major stroke, or gradual, following a number of mini-strokes or small vessel disease.
- Mixed Alzheimer's disease and vascular dementia account for less than 10% of dementias and features more than one type of dementia. For example, some people with dementia have features of both Alzheimer's disease and vascular dementia.

- Lewy body dementia accounts for 10-20% of all dementias in which abnormal brain cells called Lewy bodies, form in parts of the brain. The progress of the dementia in Lewy Body Dementia is more rapid than the dementia in Alzheimer's disease.
- Fronto-temporal dementia accounts for less than 10% of all dementias. Damage starts in the front part of the brain, with emotional, motivational and/or behavioural symptoms and/or language deficits commonly occurring in the early stages.

Alzheimer's disease and other dementias are still not well known or understood. There are no firm physical tests that can give a firm diagnosis of Alzheimer's or most other dementia disorders, therefore a thorough comprehensive clinical evaluation is required by clinicians who have knowledge of dementia as well as knowledge of the person's social and cultural history (Kawas, 2003).

Physical and neurological examinations including a careful testing of cognitive status add to the diagnosis and will contribute to good care outcomes. There are two cases of internationally accepted criteria: The Diagnostic and Statistical Manual of Psychiatric Disorders (DSMIV-TR) (American Psychiatric Association, 2000) which is a manual that defines dementia as well as all other psychiatric disorders. This manual covers all mental health disorders in adults and also children. It lists causes of the illness, the statistics, and prognosis and treatment options. Within this manual dementia is defined as impairment in memory, and one or more of the following: a disturbance in language, difficulty with completing motor activities, difficulty in recognizing objects, difficulty with planning and making judgments. There is also the European-based International Classification of Disease (ICD) (World Health Organisation, (WHO) 1992).

Thomas and O'Brien (2003) state in their literature there is no cure for dementia. However, the control of vascular risk factors, such as high blood pressure, and the use of a cholinesterase inhibitor medication may slow down, or temporarily improve, the decline in some people. In addition, for some many of the symptoms that occur with dementia, such as depression, agitation, hallucinations and delusions, may be controlled or alleviated by taking appropriate medications. Of significance is the variation of symptoms which can occur during the illness progression. This suggests that dementia is unique; no two individuals will be affected in the same way. Accordingly the provision of care for these people and their families will be different, so the best approach would be to focus on the needs of the individual with dementia at the time.

## **2.3 DEMENTIA AND ITS IMPACTS ON THE INDIVIDUAL**

Dementia affects people in different ways. For some the symptoms may impact negatively on a person's quality of life, the most prominent feature is cognitive losses of short and long term memory (Aggarwal et al., 2003). Some may have difficulty with language, communication, processing information and making decisions (Aggarwal et al., 2003). People with dementia will speak of losing abilities to complete activities, such as self-care (for example eating, bathing and dressing) (Bond, Corner, Lilley & Ellwood, 2002). Other characteristics are changes in personality, emotional disturbances, the loss of relationships and the loss of one's "personhood" (Harman & Clare, 2006). All these features can cause the person to experience fear, embarrassment, guilt, anxiety and agitation leading to a loss of independence and the requirement for assistance and intervention with their activities of daily living (Schermer, 2003).

Some people with dementia identify that there is a difference between what they believe is happening to them and what others think. Due to the stigma of the disease individuals with dementia express their concern about others finding out their diagnosis (Harman & Clare, 2006). They become fearful of the limitations that will be placed upon them in regard to possible risks such as their inability to drive and the fear that others will be forced to take over the responsibility for them (Burgener & Dickerson-Putman, 1999).

While there are many different forms of dementia with time in most cases severe physical and cognitive disability occurs. There is a huge likelihood that a person with dementia will develop co-morbidities from which they may die. Along the way, co-morbidities add to the possible complications of dementia making caring for those with the condition more complicated.

### **2.3.1 Early Diagnosis**

There is reluctance to make an early diagnosis of dementia due to its poor prognosis. The stigma often seen around dementia is associated with presumed poor quality of life which can lead onto the belief that there is nothing to offer a person with such a deteriorating disease (Katsuno, 2005). Medical professionals will often attempt to protect an individual from such stigma particularly in the very early stages of the condition. The phrase "wait and see" will

often be used. Furthermore the option of treatment with medications or psychological counseling is often questioned in regards to its usefulness (Moniz-Cook & Malthorpe, 2009).

Early recognition, assessment and diagnosis are important, not only to differentiate dementia from other possibly reversible conditions, but also to assist with best available treatments and interventions, and with planning for the future in terms of both care provision and personal arrangements (Perkins, 2006). Early diagnosis can also maximize quality of life and offer a person with dementia the opportunity to be involved in clinical trials (Santacruz, & Swagerty, 2001).

Research conducted by Manthorpe (2011), looked at people's experiences of their transition from mild cognitive impairment to a formal diagnosis of dementia. Participants were asked to comment on their "journey" from the time problems were first identified and they were thought to need help. They were asked to tell researchers their experiences of having an early diagnosis. Many participants believed that information before and after diagnosis could be better. A few were surprised by the amount of tests they were asked to complete, the time it actually took and the number of professionals they were required to see. Some participants would have liked more education around the symptoms of the condition and an explanation as to why these symptoms were occurring. Others reported that they could not remember or understand what they had been told and would have preferred written information. A lack of specialist counseling was also identified particularly if a suggestion was made that depression might be a factor. Others found the actual assessment process alarming and felt they were poorly informed of the process. The findings suggested a medical professional that a person knows well and trusts such as their own General Practitioner (GP) might best give the process of assessment, diagnosis and treatment to a person with a suspected diagnosis of dementia. In such a case, the GP is easily accessible for reassurance and support.

The diagnosis of dementia can bring with it various emotional responses (Aggarwal et al., 2003). Many will express uncertainty of what the future might hold for them. Will they become a burden on their families? They may have thoughts that they have let everyone down (Harman & Clare, 2006). Some will wish for their own death (Phinney & Chelsa, 2003).

It is important to talk about end of life dementia on first diagnosis. It is valuable to establish how the person with dementia and their families feel, what knowledge they have about the illness and what plans they may want nearer the time of their death. It is especially important to nominate a proxy to make decisions on the patient's behalf when he or she no longer is

able. The Protection of Personal and Property Rights Act 1988 introduced the concept of an enduring power of attorney (EPOA). This is an authority set up by a legal adviser. It is permission given by an individual to someone else to look after their affairs and welfare. It remains in place should the individual lose their capacity to make or communicate decisions and is deemed mentally incapable following an assessment by a medical doctor (Alzheimer's New Zealand, 2006).

Despite being given a diagnosis of dementia, most people with the condition will carry on living their lives by keeping with their usual routines and daily activities (Aggarwal et al., 2003). The process of dementia does not occur instantly but is a gradual progression and most people with dementia will adapt to the challenges it brings. Therefore, advanced directives (known as living wills) must be carefully considered because an individual's earlier opinions about specific treatments may not be the same as their beliefs later on in the illness (Alzheimer's New Zealand, 2006). Advanced directives attempt to give instructions about what specific treatments should be given or withheld under certain medical situations should the patient become incompetent of making their own decisions. A person is nominated as their proxy who is able to communicate a person's wishes when that person is incapable. Their role is only to ensure a person's wishes are met, they are not there to make a decision. The directive should be reviewed regularly and can be revoked at any time. It is not a form for euthanasia. A person is allowed to refuse treatment; however, they are not allowed to ask for steps to take place whereby their life is ended (Hoffenberg, 2006).

Alzheimer's Disease International (ADI) (2011) works for an improved quality of life for people with dementia and their carers around the world, believing that policy and practice should be based on the best available evidence. Their recent World Alzheimer Report in 2011 describes the benefits of early diagnosis and intervention. It emphasizes that everyone with dementia is entitled to a 'timely' diagnosis when they and their families first identify and express concerns resulting in them asking for advice, treatment or support. The report suggests that the impact of having a diagnosis of dementia is affected by the way a person is informed. If people with dementia and their families were to feel supported and well informed now, then the negative emotions of anger and shock will be lessened in the future. Being given a diagnosis early will allow time for individuals and their family to plan ahead whilst they still have the ability or capacity to do so. Education regarding dementia and support service availability is important and needs to be timely. Use of medications may improve

cognition and improve quality of life and dementia sufferers need to be given the opportunity to assist in research projects.

The report offers advice and recommendations to enhance early diagnosis of dementia. It suggests implementing education programmes in primary care, providing easily accessible dementia care services for the diagnosis of dementia and the promotion of effective interaction between health systems. It suggests that effective therapeutic interventions and medications that are likely to delay “institutionalization” should commence earlier in the disease. It also calls on governments to invest now in treatments that will save the economy in the future (Alzheimer’s Disease International World Alzheimer Report, 2011).

## **2.4 DEMENTIA AND ITS IMPACTS ON FAMILIES**

Not only can dementia be devastating for the person with dementia but also for family members. More often than not a significant portion of care is given by individual family members if care is to be provided at home. Furthermore, each member of the family experiences grief and loss over the situation in their own way and in their own time. Some members of the family may feel anger or resentment; some may cope by seeking out information and support, while others can remain in denial or avoidance for some time (Alzheimer’s Association, USA, 2007). The Alzheimer’s Association, USA, (2007) believes special considerations must be given to dementia in all its forms. The person with dementia and their family will experience feelings of loss and grief well before a person actually dies. Their grief will be associated with loss of:

- Finance.
- Companionship.
- Control.
- Future plans.
- Status.
- Activities.
- The person as they used to be.
- Changes to lifestyles and relationships (Alzheimer’s Association, USA, 2007).

The literature by Cayton (2003) suggests the lives of family carers become isolated as the dementia affects the relationship between them and the person with dementia. The

relationship before the dementia would have most likely been strong with a long history between the two people. It not only affects the loss of the relationship but also affects a change in roles which family can find difficult to manage. The physical and intimate assistance that the family member may now need to give to the person with dementia, along with the learning of new skills can be quite demanding for someone in a caring role. The family member may also lose their own independence; they may have relied on their partner with dementia to drive and are now unable to; they may have enjoyed a holiday but now their partner becomes too confused in an unfamiliar environment.

Social networks become threatened mainly due to poor communication and the stigma of the condition. Friends and other family members find it difficult in talking with someone with dementia. Accordingly, this will lead on to further isolation of the family member from society and in turn has implications on society. More often than not, adult children and spouses of people with dementia are likely to take on the care giving role, and will exhibit higher levels of depression and anxiety (Schulz, O'Brien, Bookwala & Fleissner, 1995). It is suggested that caring for a relative with dementia increases the carer's levels of depression and anxiety. The use of psychotropic medication is seen to be higher among those caring for a relative with dementia than the use of psychotropic medication use in non-caregivers. However, consideration must be given to the individuality of each caregiver. Their experience and outcomes may be in part related to gender, cohort, ethnicity, social class and their own health status (Montgomery, 1999). Carers in some cases may have to resign from employment resulting in a loss of earnings and socialisation that goes with employment.

The stress and high demands in caring for a family member with dementia can impact on the carer's ability to provide continued care resulting in the need to seek other community supports or residential care placement (Schulz et al., 1995). The decision to use external supports or to place their relative into dementia care can also be quite stressful to carers (Levesque, Ducharme & La Chance, 2000). The person who had been their relative's main carer will more often than not have feelings of loss, helplessness, guilt and loneliness. Once in residential care, the redundant carer will often doubt that their relative is receiving the same adequate care as they were when living at home and that their relative's dementia has further deteriorated (Perkins, 2006).

## **2.5 DEMENTIA AND ITS IMPACTS ON CARE PROVIDERS**

### **2.5.1 Residential care**

Not all people with dementia have family members who can care for them. They may be living alone, family members may live overseas or family members may be unable to cope with their care. Care at home with supports may be possible. However for those people with high and complex needs placement in a residential care setting may be the only option. One of the reasons that people with dementia enter residential care is because of unmanageable behaviour, such as wandering, hallucinations and delusions. Consequently there is a need for different levels of residential care in the various stages of the disease to address changes in need as the disease progresses (Perkins, 2006).

There are currently four levels of aged residential care: rest home, specialist dementia care, long-stay hospital care and specialised hospital dementia care. The person's eligibility and the appropriate level of care are determined by the Needs Assessment Service Coordination (NASC) (Alzheimer's New Zealand, Residential Care for people with Dementia, 2006).

### **2.5.2 Changes in Care**

When a person's behavioural care needs increase within a residential care facility and the sufferer's behaviours are too difficult for the rest home to manage, an assessment by a Psychogeriatric service is required to ensure the appropriate level of care is provided. Staff of the rest home will request a reassessment by specialists and ask for the resident to be transferred to a specialised facility better suited to the needs of the person with dementia (Alzheimer's New Zealand, Residential Care for people with Dementia, 2006). It may mean that the person requires a more secure environment or require care to be delivered by specially trained staff. People who have dementia and exhibit challenging behaviours benefit from care in specialised dementia units. These units work closely with and have clinical oversight from psychogeriatric community teams (MoH, 2010).

### **2.5.3 Challenges for the Workforce**

The old nursing concept in caring for someone with dementia was mainly related to ensuring basic needs were met, that they were comfortable. Over the years nurses and other medical

professionals have searched for treatments and supported models of care upon which to base their practice. The treatment approach of care relates to the management of the symptoms of dementia such as aggression or other challenging behaviour with medications; the supported model of care relates to the skills of trained staff in managing these behaviours with non-pharmacological approaches (Royal College of Nursing, 2004).

Johan Vos (2011), a previous national director of Alzheimer's New Zealand believes that people caring for those with dementia need to be adequately trained and identified that basic skills in dementia care are underestimated. Vos from his investigative work found that organisations were reluctant to pay for dementia training because of staff turnover, their financial situation and the inability to provide suitable supervision of staff who are training.

Within dementia rest homes there are approximately 350 nurses and 1400 caregivers working in this area (Thornton, 2010). However, some suggest these units are often not staffed appropriately, and staff do not have the appropriate knowledge of dementia. The Thornton report shows there are a shortage of trained dementia staff. As a result, about 90% of the care in rest homes is provided by unqualified staff or care assistants. Care assistants are mainly female, and are one of the lowest paid workforces in New Zealand. Their work is unregulated and inexperienced individuals are being employed. The Health and Disability Commissioner has drawn attention to many cases of poor care and neglect within rest homes and suggests that its workforce is near crisis point. Facilities that employ an undertrained, underregulated, overworked and underpaid workforce will face major challenges. As a result of this staff will have very little value placed on the work that they complete, will have very little time for the residents and will only deliver the basic need requirements. Very little time will be given to staff education and supervision that is needed within the specialist dementia rest homes. Current estimates for staff turnover are increasing, with 50% of caregivers staying with an employer for more than four years (Thornton, 2010). The increased problems with retaining staff will see the high usage of agency staff and inconsistencies in delivery of resident's plans of care.

Many New Zealand nurses are avoiding work in aged care facilities due to the poor wages, heavy workloads, the boundaries of professional responsibility and the fear of being referred to the Nursing Council. High demand and pressure upon staff see a high usage of medications in an attempt to control challenging behaviours resulting in a high rate of injuries from falls

and medication errors. This will have a follow-on effect of an increase in acute hospitalizations which will put additional pressure on hospital and medical services.

## **2.6 DEMENTIA AND ITS IMPACTS ON SOCIETY**

Not only are there major implications and considerations for the person with dementia, their families and carers but also for society.

It is estimated in New Zealand that currently 5% of people over the age of 65 years and 20% of people over 80 years have dementia. By 2051 it is expected that people over the age of 65 years will make up 25% of our population. As our population ages so will the number of people with dementia (MoH, 2002). By 2050 2.7% of the New Zealand population will have dementia. Presently in New Zealand dementia affects 40,746 people. By 2026 it is estimated that 74,821 people will be living with dementia. There will be 12,333 new cases of dementia each year (Access Economics, 2008). One other issue for social services and the provision of care is that the percentage of older people is more concentrated in urban areas (89% of people aged over 85 years). There is no data found relating to dementia and its effects on Māori. However projections of susceptibility to mental illness are a source of the likelihood of Māori being affected with dementia in later life (New Zealand Council of Christian Social Services, 2009).

The implications of the increasing numbers of people with dementia worldwide and for the country are clearly enormous. In New Zealand there is a lack of data that is able to be gathered across District Health Boards. Despite this in 2008 the total financial cost of dementia was estimated at \$712.9 million, 61.1% for healthcare and 38.9% for other costs. Measures were used to calculate the cost of institutional care and community care. It was estimated that reducing the average time people with dementia spend living in residential care by three months would save \$60.3 million per year. After deducting the estimated cost of community care during this additional time at home, the cost benefit of delaying the entry of people with dementia into care by three months was estimated at \$31.8 million (Access Economics, 2008). Provision in delaying placement of people with dementia into care and the development of community supports clearly shows benefits to the economy. Those people with dementia remaining at home may be a burden on family, and community resources will be consumed. Figures show that 50% of those with mild dementia live in their own homes supported by community services (Access Economics, 2008).

An analysis of the costs of dementia carried out in the United Kingdom showed that the cost of Alzheimer's disease is larger than combining the cost of stroke, cancer and heart disease put together (New Zealand Council of Christian Social Services, 2009). To lessen the degree of burden, the main focus of dementia care is the promotion of well-being and optimizing quality of life. In response to these growing numbers of elderly with dementia and the economic burden it brings, Alzheimer's New Zealand (2010) developed a National Dementia Strategy with an action plan that ensures needs of people with dementia are recognised and are supported. This strategy would effectively ensure that support services would be cost effective and would meet the demands of the increasing numbers of those with dementia.

People with dementia can be cared for within a residential care facility. Data shows that 60-70% of people living in residential care have some form of dementia (New Zealand Government, 2011). Figures from 2005 showed that there were 9,831 people aged over 65 in rest homes, 2,068 were in dementia units, 8,251 in geriatric hospitals, 507 in psychogeriatric care.

Projections from the Aged Residential Care Services (ARCS) predict demand for dementia services will increase by 160% between 2008 and 2026. This means an additional 250 dementia beds will be required every year between those dates. We know therefore the demand for residential dementia care beds is growing across New Zealand and the need to expand on these have been identified. Presently in parts of New Zealand the shortage of dementia care beds necessitates the person with dementia to be placed out of their own district this in turn puts further burden and stress on family.

It is only in recent times that countries, in particular New Zealand have begun to plan for the growth of an ageing population, or for the arrival of financial, legal and policy issues around dementia. Support services and placement in residential care within New Zealand is means tested following clinical assessment. All New Zealand District Health Boards presently subsidise the elderly who are entitled. Families themselves often become trapped in the complications of entitlement and funding of their relatives residential care placement (A Report into Aged Care, 2010).

## **2.7 PUBLIC POLICY**

For some time, concerns have been expressed by campaigners of people with dementia about quality of care delivered in residential settings. To deny good quality of care to people with

dementia can have major repercussions for an individual's quality of life. In New Zealand, as many countries around the world public policies and strategies have been developed to address issues related to the quality of care and life for people with dementia in specialist dementia rest homes.

Negative publicity about the poor standards of care within many rest homes particularly the specialist dementia care units were reported to the Health and Disability Commissioner (Lewis, 2002). This prompted the MoH to take on an audit of 12 rest homes in Canterbury and the report by Dr Hazel Lewis (2002), showed poor standards of care particularly in specialist dementia care units. From Lewis's paper 26 recommendations were made to the MoH, recommendation 18 anticipated that the MoH develop standards within dementia residential care. Guidelines were introduced in response to this which were produced to ensure the best possible care is being delivered and acknowledgement of quality of life.

Within New Zealand it appears that bad publicity continues. In 2009 there were 342 complaints about rest homes to the Health and Disability Commissioner. Complaints laid were about the lack of appropriate knowledge and experience in specialist areas such as dementia care, poor communication with families and legal representatives, wound care, falls including fractures, poor nutrition and fluid intake, medication, end-of-life care, and poor coordination of care. A recent strategy from the MoH called to adopt dementia as a national health priority. The strategy developed new guidelines to assist District Health Boards and the MoH in breaking down the barriers faced by older people within mental health, addiction, disability and chronic conditions when attempting to access services that would meet their health needs (MoH, 2010).

The strategy's main aim was to recognise dementia, provide funding for medications, improve on early diagnosis and support for family, develop the workforce capacity that will ensure quality care delivery and increase research in dementia. Their aim was to promote good practice, improve the quality of services and how they are to be delivered and to help DHBs be cost effective within their existing budget and funds (MoH, 2010).

## **2.8 CONCLUSION**

This chapter has defined dementia and the effects the condition has on a person, their family, the demand on supports and services and the economic burden on wider society.

While dementia can pose problems with management and placement of someone with the need for specialist residential care, early diagnosis of dementia, improvements in dementia training and education and the access to specialist dementia medical teams are necessary to ensure the promotion of quality of life. From the bad publicity that has been reported from within New Zealand there needed to be changes to policy made in order to protect our most vulnerable individuals.

The next chapter explores the literature published that relates to quality of life within the elderly with dementia.

## **CHAPTER 3 - THE LITERATURE**

### **3.1 INTRODUCTION**

The purpose of this chapter is to review the literature on quality of life that relates to people with dementia within residential care. The researcher believed that quality of life in dementia was a diverse term and from her personal experience had been viewed mainly from an objective notion rather than from the individual's outlook. The researcher's aim was to gain knowledge of quality of life for someone with dementia, what the individual and others determine is a good quality of life and how quality of life for someone with dementia is measured. Based on the knowledge gained from the literature review, the researcher was led to her chosen research methodology.

### **3.2 LITERATURE SEARCH METHOD**

A literature search was conducted between 2009 and 2011 on different views of quality of life for residents living in specialist dementia level rest home care and on how they are expressed. Due to the limited literature in New Zealand, overseas literature was also included.

A thorough search of the world-wide-web was conducted manually by the researcher placing the following phrase: "differing opinions of quality of life in dementia care rest homes" yielding 9,340 results. This was narrowed down to 7,600 by keeping the literature within a twenty five year period of time. The researcher felt this timeframe was justified in order to reference Kitwood's revolutionary work concerning dementia.

The researcher scrupulously searched her way through the mass of articles and by viewing the abstract chose the relevant articles; this included the source or journal where she would be able to view the text in full. As a result of this search, access to the journal and articles was gained through the University of Otago Library where the researcher is a student.

Whilst retrieving the articles from the journal site a further search was completed within that site by placing in the phrases dementia, quality of life, residential care and opinions. Articles were retrieved from the following journal sites:

- Quality Of Life Research
- Journal of Clinical Nursing

- American Psychiatric Nurses Association
- Nursing Ethics
- Gerontological Nursing
- Journal of Geriatric Psychiatry and neurology
- International Psychogeriatrics
- Western Journal of Nursing Research
- Age and Ageing
- Journal of Gerontology
- The Canadian Journal of Neurological Science
- The British Journal of Psychiatry
- The Gerontologist
- Dementia
- The Advances in Psychiatric Treatment

In case important and relevant literature had been missed the researcher was able to gain off campus access to the Ovid resource databases (Ovid nursing, Embase and PubMed ) through the library of the University of Otago. The search was conducted using a combination of relevant words: dementia, quality of life and opinions. By placing in these words the researcher was given 7234 results, which were then narrowed down to 227 by combining them with residential care.

A search of Proquest was completed in seeking studies related to the determinants of quality of life in dementia. The author initially gathered 22,657 articles by placing in the word dementia these were narrowed down to 16 articles by using the key-phrases: interventions, therapeutic, quality of life, family interventions, residential care and environmental aspects of care.

From comparing publications within these searches the researcher was aware of the repetition of literature already retrieved, and was therefore confident that all articles relevant to the research topic had been accessed. The researcher also accessed and cited further works referenced within other publications.

The researcher in following the Dixon-Woods guideline had prepared her own criteria in ensuring the publications chosen for this literature review were relevant. Initially the researcher read the introductory chapter or section to understand the beliefs of the author, the

clarity and coherence of the research, the validity and credibility, use of appropriate and rigorous methods and if the research conducted was ethically sound (Dixon-Woods, Shaw, Aggarwal & Smith, 2004). A large number of the articles were irrelevant publications and were classified as outside the scope of this study.

Once assessed as relevant the researcher prepared summary notes on each paper and further analysis took place which identified the central principle or theme which was then carefully categorized into topics. Most of these topics are used in following sections of this literature review.

From the material reviewed the following provides an overview of research literature relevant to residential care settings: **Section 3.3** - how quality of life is defined and the domains of quality of life, **Section 3.4** - why measure quality of life, **Section 3.5** - what determines quality of life in dementia, and **Section 3.6** - opinions about quality of life in dementia.

### **3.3 DEFINITIONS AND DOMAINS OF QUALITY OF LIFE**

The population is living longer and much research has been completed on keeping people alive yet very little is spent on ensuring a good quality of life in older age and finding ways to measure it. There is seemingly a lack of awareness when it comes to how ageing maps out, particularly in the quality of life in people with dementia (Selwood, Thorgrimsen, & Orrell, 2005). There are many who believe that quality of life regardless of age and disabilities should be addressed equally (Bond, 1999).

Some suggest that those that contribute more to society such as those in employment are seen to have a better quality of life than perhaps those that are retired or those that may have a disability, particularly those that are elderly (Bodner & Cohen-Fridel, 2010; Hausdorff, Levy, & Wei, 1999).

A local qualitative study recently asked older people receiving small amounts of support in a community setting, what “Quality of life” meant to them, and the resultant findings suggest that it is important to understand the meaning of this term, as much as to develop ways of “measuring” such a qualitative dimension (Hambleton, Keeling, & McKenzie, 2008, 2009).

Quality of life is often discussed yet many find it difficult to define quality of life. Regardless, some agreement has surfaced since the World Health Organisation (WHO) in 1947 defined

quality of life as “a multidimensional concept”. Quality of life is not a single entity and the WHO has developed a useful description in that it can be seen as “a state of complete physical, mental and social well-being” (WHO 1996, pg 6). The WHO (1996, pg 5) went on to describe quality of life as being “the individual’s perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations and standards”.

Walker (2004) in his attempt to define quality of life in the elderly uses the terms ‘successful ageing’, ‘positive ageing’ and ‘healthy ageing’. It is common in quality of life research to focus on the health-related quality of life (HRQOL) and disregard is given to other domains. If HRQOL is considered the most important part in the quality of life of a person with dementia then their quality of life when measured will be seen to decline as the illness progresses. Therefore measuring health-related quality of life for those with dementia is much more challenging for clinicians to measure than for those without dementia. If other domains of quality of life are assessed and measured such as participating in meaningful activities the person’s quality of life will seemingly change. Despite this there are emerging different perspectives that are now more holistic and more reflective. Life patterns influence expectations of life; the way people resolve issues in their earlier days affects the important meanings of quality of life in their later years (Walker, 2004).

Studies on quality of life in dementia suggest that other people’s perceptions of overall quality of life focus on the person’s physical health and material well-being, family and social relationships, community and active social activities, personal development, achievements (including their learning education and working life) experiences and values, life happiness and satisfaction (Boyer, Novella, Morrone, Jolly, & Blanchard, 2004; Sands, Ferreira, Stewart, Brod, & Yaffe, 2004).

For some cultures a person’s quality of life is often judged by what they are able to do in society including the ability to function well: cognitively, socially, sexually and emotionally. For some the maintenance of psychological well-being, health, and the ability to perform daily activities is of importance (Bodner, Cohen-Fridel, & Yaretsky, 2011).

In addition it must be emphasized that the subjective quality of life of a person with dementia will be naturally different from another person’s perspectives. Quality of life is seen to be a

personal experience which is often shaped from incidents throughout a person's life (Bond, 1999).

Measuring quality of life in the elderly is often more difficult than measuring quality of life in younger people. In older people, changes with ageing such as sensory impairment, poor mobility, and cognitive impairment can impact on quality of life and the ability to measure it as a concept. It has been considered that people who are elderly and handicapped such as those with dementia have a low quality of life and are hidden away from society (Bodner et al., 2011). There are many methods used that are able to measure dimensions of quality of life, but few have been adapted or validated in the elderly particularly for those with cognitive impairment, (Lapid et al., 2011).

Quality of life is often seen focusing on the domains of a person's health, functioning, (which is the ability to do and enjoy meaningful activities), social support and contact (attachment and living environment), life satisfaction (including financial, physical and mental) and an individual's well-being (affect, mood and energy) (Bond, 1999; Brod, Stewart, Sands, & Walton, 1999; Droes et al., 2006; Lawton, 1994; Pearlman & Uhlmann, 1991). For the person with dementia, their declining memory and cognitive abilities can impact greatly on a good quality of life; due to the deficits in cognition it becomes difficult for an individual to express or communicate their needs successfully (Perkins, 2006; Walters, Iliffe, & Orrell, 2001).

Maslow (1954) said that everyone has needs (safety, affiliation and development to an affective level) that will allow them to experience 'self actualisation'. His theory is often seen as a pyramid of five levels; self-actualisation (the achievements of an individual), esteem (self esteem and esteem from others), belonging (love, affection, being a part of groups), safety (shelter, removal from danger) and physiological (health, food, sleep). The lower four levels are associated with physiological needs. For example we need to maintain our body to provide it fuel, to keep ourselves safe, to feel being part of society or a group, to be given respect from others. Once these needs are met we are able to reach the top of the pyramid, of full personhood. For example if we are ill we will concentrate on getting well before we worry about what others may think of us (Maslow, 1954).

Structural models of nursing care are often used to measure a person's quality of life. Lawton's (1994) model of quality of life for older people with dementia used four quality of life domains, those being: cognitive functioning; ability to complete everyday tasks; to engage

appropriately in meaningful activities; and balancing positive and negative emotion. These four domains are an example of quality of life being multidimensional around objective and subjective measures of contentment. Lawton (1994) claimed these factors are necessary to assess quality of life in the elderly but can also be seen expanding out into: behavioural competence, objective environment, perceived quality of life and psychological well-being.

Some suggest that quality of life and its elements vary from person to person and encompass mental, physical, social and spiritual wellbeing. People have differing views of what quality of life means which signifies that one measurement strategy will not be suitable for all. Establishing what is quality of life for people with dementia is just as difficult as defining it. Quality of life in dementia therefore cannot be defined without looking at its sub domains.

### **3.4 WHY MEASURE QUALITY OF LIFE IN DEMENTIA?**

It is the responsibility of all clinicians to measure quality of life in people with cognitive impairment. Measuring quality of life in people with dementia is important in determining the best care and outcome measures for a person. This is particularly significant because of the impact the symptoms have on the person with dementia, their families and also the economy and healthcare (Selai & Trimble, 1999).

Currently there are no cures or treatments that significantly alter the pattern of the condition. Therefore quality of life assessments and measurements provide the foundation for an individual's plan of care which is appropriate to their needs and summarizes the appropriate intervention for a person with dementia (Hall, Opio, Dodd, & Higgenson, 2011; Logsdon, Gibbons, McCurry, & Teri, 2002, 2007).

Measuring quality of life of individuals with a dementia in a rest home is difficult and is not usually attempted; however it is a necessity to ensure that the delivery of care is appropriate (Maslow & Heck, 2005). Such measures allow family and caregivers to ascertain whether that care plan is making an important difference in the patient's quality of life. These assessments allow researchers to understand which plans of care provide benefit for people with dementia. Quality of life assessments are also necessary as they focus more on the person as a whole rather than concentrating on the condition. In addition, examining the effects of an intervention on quality of life in individuals with dementia may indicate a different but innovative approach to ensure a good life quality (Logsdon et al., 2002).

Sixsmith, Hammond, and Gibson (2008) in their literature suggest quality of life in someone with a diagnosis of dementia becomes a major challenge to health and social care services and researchers are now realizing the importance of measuring quality of life in people with dementia. There is a need to expand services and dementia care beds to meet the demand from the increased numbers of people with dementia. There should also be an awareness of the challenges in the provision of care that ensures a good quality of life. Once quality of life needs for someone with dementia are identified then effective approaches in managing their care can be developed (Thornton, Hatton, & Tatham, 2004).

Those who suffer with dementia have the same basic needs as the rest of the population and are entitled to be treated with equal dignity and respect. They are entitled to a good quality of life (Standards NZ, 2006).

### **3.5 WHAT DETERMINES A GOOD QUALITY OF LIFE IN DEMENTIA?**

Research has found that for people living in care homes with dementia the key determinants of quality of life are related to family, the environment, physical health, sense of humour, independence, ability to communicate, sense of personal identity, ability to engage in activities and spirituality (Mental Health Foundation on behalf of Alzheimer's Society UK 2010). Logsdon et al. (2007) suggest that people with dementia are able to report that their mood, enjoying pleasurable activities and being independent with their self cares are issues that affect their quality of life. Torrington (2006) suggests that several factors would promote well-being and quality of life: functional, cognitive and physiological ability, formal support network, social network, physical environment added to meaningful activities.

The search of the research literature to understand what determines quality of life in dementia predominantly found knowledge, education and quality of care being delivered to those with dementia was of significance. Of importance was the involvement of family within a person's life along with the ability to participate in meaningful activities and the absence of thoughts of feeling alone. The symptoms of dementia have already been discussed in chapter two and the possible devastating effect these can have on someone not only for people with dementia but also the family members or carer. It is suggested that this distress and further deterioration in a person's quality of life can be reduced by the use of medications. Of interest was the actual environment that a person lived in was seen to have some bearing on a person and their quality of life.

The following sections summarise the studies and articles the researcher retrieved to represent the factors which predominantly affect the quality of life of a person with dementia residing in a specialist dementia rest home.

### **3.5.1 Family Involvement**

Berg-Warman and Brodsky (2006) state that older people preferred to be near family in that this increased the quality of their lives. It is often seen that older people move away from their families as a part of seeming independent, however as the need for support and care arises the desire to be nearer family becomes apparent (Silverstone & Horowitz, 1992). Having family involved in their life is seen to give the person with dementia a purpose in life, as family provide the person with dementia the opportunity to reflect on their life and their past achievements (Gaugler, 2005; Hsin & Macer, 2006).

It is known that staff within a rest home can influence or limit families into assisting them with the correct provision of care for their resident. It is often seen that staff focus more on the physical care or needs of the resident, and the families' needs become secondary as staff strive to ensure that their work is done. Within dementia care facilities staff work with families to ensure the delivery of fully comprehensive care. If families feel more appreciated by staff it becomes easier for them to feel accepted and more comfortable to be involved in their relative's care. This also enables staff to positively share their experience in caring for the resident with the family promoting trust through communication (Port et al., 2005; Standards New Zealand, 2005).

Lindgren and Murphy (2002) looked at differing expectations and staff values of care needs within specialized dementia care. They found that to engage in effective communication and care the appropriate approach is important to maintain family involvement. Interestingly their study reflected that staff in rest homes generally wanted assistance from families in the hope that it would lighten their workload and that a better quality of care would be given. Interestingly their findings showed disparity reflecting in the differences of opinions between the patients' health and the family's knowledge of their family member's health.

### **3.5.2 Socialisation and Meaningful Activities**

Studies have shown that social relationships, functional ability and meaningful activities are key elements in the quality of life in the elderly along with their physical health (Gaugler, 2005; Hambleton et al., 2009; Harmer & Orrell, 2008). Contact with others socially contributes to quality of life in that one feels protected and can enjoy opportunities of meeting and helping others (Berg-Warman & Brodsky, 2006). In a study by Cahill et al. (2004) having contact with others was seen as most important in feelings of wellbeing. The study by the Mental Health Foundation on behalf of the Alzheimer's Society UK, (2010) suggests that relationships and socialization is one basic human need and that having dementia does not alter this need. It also implies what is important for a good quality of life for people without dementia is not so different from someone experiencing the condition.

The symptoms of dementia can have a significant impact on a person's quality of life, particularly on socialization and social bonds. Without these contacts or abilities a person can all too often withdraw and become isolated. Therefore social interactions should always be considered to maintain a person's wellbeing and quality of life (Moyle, Kellet, Balllentyne, & Gracie, 2010). In their literature they looked at loneliness in dementia. They found that "an absence of close emotional attachment" (for example not having a partner, or an absence of social engagement with friends and family) can have an impact on a person's quality of life (Moyle et al., 2010, pg 1446). Though dementia often changes the way that the person living with dementia experiences their own self (particularly through changes in their ability to perform familiar tasks), literature by Schulz et al. (1995) shows that relationships with others are still important.

Loneliness can bring on negative thoughts and feelings which can affect a person's physical health and further decline in cognition (Menec, 2003). Moyle et al. (2010) believed that loneliness is primarily a subjective experience. When exploring this concept, the opinions of people with dementia should be gained directly from those with the condition and also from their family member. People with dementia are more inclined to report loneliness than those without the condition. However, there have been very few studies exploring the concept of loneliness from the views of those that have the condition, apart from the work of Moyle et al. (2010). In their study participants commented on the lack of visitors and the loss of relationships through death. Loneliness was also a description expressed by residents when loved ones were living a distance away from them. Interestingly family participants in their

study believed that their relative with dementia would be less lonely when being placed in care and living with others. People with dementia disagreed and would prefer to be with people they knew and were familiar with.

The symptoms of dementia are progressive with impairment in cognition and limitation in engagement in tasks due to poor attention and awareness of the environment. Gigliotti, Jarrott, and Yorgason (2004) believe that past experience draws on emotional memory throughout a person's life and that contributing in some way in activities will hold some value for a person with dementia. Gigliotti et al. (2004) suggests that people with dementia are limited in their performance due to the lack of sensory and perceptual skills. This applies to their connection to the environment around them, which can offer particularly meaningful activities. By completing tasks such as gardening, having their senses stimulated by the wind or the texture of the soil is beneficial to a person's well-being. Accordingly the person with dementia will feel a sense of self gratification and pride in what they do.

The lack of activities in rest homes for people with dementia is often recognised. This suggestion has been often put down to organisational issues such as shortage of staff, attitudes of staff, physical needs having priority over social needs, routines impacting on self-sufficiency and limitations of the environment (Hancock, Woods, Challis, & Orrell, 2006; Hoe, Hancock, Livingston, & Orrell, 2006; Voelkl, Winkelhake, Jeffries, & Yoshioka, 2003; Zimmerman et al., 2005). Consideration is also given to the barriers in communication relating to how severe the dementia may be (Voelkl et al., 2003). Other factors raised around exclusion from activities can be related to the association of negative stereotypes surrounding a person's age, and to the "malignant social psychology" (Kitwood, 1997) and stigma associated with dementia.

From the early 1980s, recreational activities have been used as interventions within residential care settings particularly within dementia care. They have long been recognised as an intervention used by nurses, occupational and diversional therapists and as good practice in order to improve quality of life (National Institute for Clinical Excellence, 2006). Literature suggests that being listened to impacts on a person's quality of life (Jonas-Simpson, Mitchell, Fisher, Jones, & Linscot, 2006). Others have reported that leisure and the associated feelings of empowerment gave people a sense of satisfaction (Atwal, Owen, & Davies, 2003). Reminiscence, music and social activities bring meaning to people with dementia and improve a person's mood and feelings of well-being, (Mozley, 2001) and that a lack of

stimulation can result in apathy of the resident and a reinforcement of dependent behaviour (Lawton & Rubinstein, 2000).

### **3.5.3 Symptoms of Dementia**

For virtually all patients the symptoms of dementia are more than cognitive impairment. Depression, agitation and psychosis are seen in many. Treatment of these symptoms can improve the quality of life for both the patient and the caregiver (Kawas, 2003).

Along with dementia comes depression, anxiety and a dependence on others for cares, all of which impacts on the quality of life of an individual. Dementia and its symptoms of cognitive decline, such as the inability to remember, retain and use knowledge, impact on a person's quality of life (Kawas, 2003). One other factor in determining quality of life of those with dementia is that a person's well-being is influenced by attributes of the person such as their functional, cognitive and physiological ability (Torrington, 2006).

The term behavioural and psychological symptoms of dementia (BPSD) is a diverse term used to describe behavioural symptoms in dementia which include vocal disruption, agitation and restlessness, aggression, resistance to care and psychosis. A significant number of sufferers within residential care will exhibit behavioural problems such as wandering, agitation and care resistance. A number of causes for these symptoms have been identified. Physical causes such as infections may affect mood and behaviour. These symptoms have also been suggested to be reactions when a person with dementia does not understand what is happening to them or may misunderstand the actions of others (Perkins, 2006).

All these symptoms will create a number of problems for care staff particularly when assistance is required for personal cares such as bathing or toileting. The person with dementia is likely to view this as an invasion of their personal space or privacy. Therefore striking out may be the person's only way of attempting to protect themselves (Berry, 2006; Kawas, 2003).

Aggression in dementia within residential care is a key cause of distress for people with dementia and care staff. It can segregate people with dementia from those around them, which in turn leads further to the inability to maintain social interactions and relationships, all of which impacts on a person's quality of life (Cohen-Mansfield, 2001).

### **3.5.4 Knowledge, Education and Quality Care Approaches**

Within the literature review research education for professionals caring for people with dementia is significant. Kazui, Harada, Eguchi, Tokunaga, Endo, and Takeda (2008) in their study investigated whether a resident's quality of life was better within "institutions" whereby care workers had more knowledge about dementia than those professionals that had none. Their findings suggested that having educational programmes for workers led to a large decrease in the use of restraints and showed that cognitive impairment and depression were improved. Overall this study signified an improvement of the quality of life for people with dementia.

Taylor, Harrison-Dening, Duncan, and Kendall (2009) discussed national guidelines developed by the United Kingdom National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence in supporting people with dementia. This work recognised the main therapeutic approaches and when they should be used. The guidelines point out that care should be delivered in a way that promotes independence, believing this is the major therapeutic intervention along with good communication that is appropriate for a patient with dementia and allows for their level of comprehension.

Over the years many have looked at models of patient care and nursing interventions have been explored. Literature suggests that reminiscence is popular and meaningful as a psychosocial intervention in dementia care (Woods, Spector, Jones, Orrell, & Davies, 2005). However other literature suggests that reminiscence is often used as a method of distraction rather than an intervention (Livingston, Johnston, Katona, Paton, & Lyketsos, 2005).

Others have highlighted the need to assist people with dementia to communicate such as validation therapy and person-centred care (Kitwood, 1997). Kitwood and his work looked at improving dementia care by promoting person-centred care. He held a strong belief regarding personhood. He explored the old culture of care, what he described as the "standard paradigm". He suggested this method devalued a person, their psychological needs were unmet and with institutionalization their whole personhood vanished. Kitwood described a new culture of care, identifying different ways of communicating with someone with dementia. His systematic observation tool known as Dementia Care Mapping (DCM) involved making detailed observations of six to eight people with dementia within a care unit for at least six hours. Results would be shared by staff so that they could make appropriate

changes to how they might deliver an improved quality of care. He suggested that by watching and listening carefully to those with dementia, people would be able to interpret behaviours and non-sensical talk. He agreed by learning how to communicate more effectively people would enhance quality of care and quality of life would improve.

Many researchers have suggested that the individual identity of the person with a dementia would remain into the later stages of the condition depending on the demands put on them and how others viewed and cared for them (Kitwood, 1997; Normann, Asplund, & Norberg, 1998; Sabat & Harre 1992). They continue to say that a person with a dementia is able to experience “personhood” as long as other individuals around them understand their needs. Lawton (1994) described the “stripping of personhood” not only affected the person with dementia but also the support and their relationship with family members. He suggested that in order to preserve personhood and provide an enriched caregiving experience then attention must be paid to the needs of the person with dementia.

Many have looked at and tested Kitwood’s model of care. In their study of the DCM, Chenoweth and Jeon (2007) conducted observations within high level secure dementia rest homes in Australia. Their findings showed improvements in carers’ observations and the delivery of quality intervention but there was no evidence to suggest that the residents’ quality of life had improved. It was seen however that the patients’ agitation and depression had decreased. Sormunen, Topo, Eleniemi-Sulkava, Raikkonen, and Sarvimak (2006) also investigated the DCM and its appropriateness within a psychogeriatric unit, a hospital ward, two day care units, two dementia care units and two nursing home units. Observations were made at the same time on different days. Relevant assessment scales were used to gather background characteristics on their participants. The study focused on negative events, and within a 93 hour period 170 episodes of inappropriate treatment were observed. Their findings led onto discussion into how quality of care can be improved. They suggest that nursing staff should be more aware of themselves when delivering care. There is the need to maintain patients’ independence although they acknowledged that this can be difficult due to task orientated work practices. Surprisingly but of great importance is the nurses’ lack of knowledge of dementia and how staff could deal with inappropriate behaviours. The study identified the need to promote studies for those working in this field of nursing including the symptoms and management of someone with dementia.

Other studies have also involved direct observations of therapeutic approaches involving ways of verbal and non-verbal communications. A qualitative study by Perry, Galloway, Bottorff, and Nixon (2005) found personhood can be maintained through good conversational strategies. The study showed with improved communication care becomes centred on the person with dementia rather than the dementia around the person. In turn this enhances an understanding for the carer and the person with dementia. Another study by Zimmerman et al. (2005) looked at dementia care and quality of life in 35 assisted living and 10 nursing homes in the United States of America. Direct observations and assessment of quality of life scores were taken over five minute intervals during three one hour periods. Their findings showed that quality of life for residents was better in units that used a caregiver that delivered regular and consistent care. Residents themselves believed that their quality of care improved when staff were more involved. The study showed that better care was delivered if staff were trained in dementia care.

Of importance is the response of nursing staff to resident's or patients' behaviours. The serial trial intervention (STI) is an assessment and management protocol for meeting the needs of people with late-stage dementia. This approach to care looks at nurses' responses to behaviours of the elderly with dementia, their assessment process, intervention and further management. In the study by Kovach, Kelber, Simpson, and Wells (2006), research was completed on the effectiveness of the STI. Two groups were used, one group using a pharmacological approach and the other the STI. Within this experiment 14 nursing homes and 114 residents with dementia were included. The findings showed that there was a significant difference between the two groups and that the STI is effective in treating distress and behaviours related to dementia. The researchers also found that most care staff become more skilled in dementia care provision through experience rather than completing dementia education training and courses. This study suggested that dementia care is a specialized field of nursing; receiving and having knowledge that ensures delivery of good quality of care is paramount to enhance quality of life in a person with dementia.

Not only does Kitwood (1997) centre his works on the best care of the older people with a dementia, but he also looks at organisational workings of the institutions providing care. Kitwood explains that if there is no structure within the rest home, or inconsistencies with delivering care this will have a negative effect on the patient's well-being and quality of life. He suggests that organisations should ensure that they employ only those with experience of

nursing the older person with a dementia. Staff should receive supervision and be able to develop their skills personally and professionally to avoid “staff burnout”. Perry et al. (2005) and Kovach et al. (2006) also suggest that management should be mindful of staffing levels and “burnout”. Perry et al. (2005) imply that due to various reasons such as poor staffing levels, chore orientated care, high acuity, poor facilities and environmental stimulus, conversational interactions and therapeutic approaches can be limited.

### **3.5.5 The Care Environment**

At home the quality of life of a person with dementia will be determined not only by familiar people but also by the environment around them. In New Zealand the typical dementia residential care units are designed to meet the care needs of people with dementia who are mobile but who show confusion that requires specialist care in a secure environment. Dementia units are small, usually no more than 20 beds. They may have enclosed gardens where residents are free to wander, inside or outside, as they wish, and access to the street is restricted.

Netten (2004) suggested with a move from home to a residential care setting the environment and the people around them are replaced by something unfamiliar and unrecognizable. Replacing the recognizable with an unfamiliar will naturally have consequences for the person with dementia; they will feel increasingly dependent on the people or the environment. This would suggest that the person with dementia is not only reliant on the actual care they receive from the staff around them to maintain their quality of life but become reliant on the external factors such as the building itself. Therefore quality of life will be shaped by the environment around a person and not only by the care a person receives from the care staff.

Many studies have looked at environmental ways of supporting a high quality of life. Brawley’s study (2001) states that “disguising” environments for people with dementia is important. Any environmental factor that makes a person distressed can result in confusion for someone with dementia which may lead onto challenging behaviours. Brawley found that architects and design professionals were unfamiliar with the needs and hazards that dementia poses within any environment. Problems were observed around lighting, acoustics, walking surfaces, stairs, seating and bathrooms. Brawley believed that it is most critical to improve skills in assessing risks around safety of someone within dementia such as risk of falls, (fractures) light deprivation (decrease in vitamin D, depression and sleep disorders).

A study which was completed in Sweden showed there was a connection between good light and quality of life resulting in increased appetite, less agitation and an overall improvement in physical health. The research showed that outside light is beneficial to quality of life in that the open space such as a garden improves sensory stimulation (Brawley, 2001).

In the United States of America, assisted living has been growing as a residential care option. Assisted living provides supervision, domestic assistance, meal preparation, and assistance with activities of daily living. In contrast to other residential care settings there are no licensed quality standards, and monitoring of quality of care. Quality problems in assisted living have however not gone unnoticed with their high cost of residing there, poorly trained staff, shortage of staff, medication errors, and inadequate care provision. Dementia and cognitive impairment of residents is extremely common in assisted living (Samus et al., 2005). Their study evaluated whether resident characteristics and the environment were associated with quality of life in residents with dementia in assisted living accommodation. Their findings showed that symptoms of dementia such as agitation and depression are associated with lower quality of life. They found that the environmental factors such as the homelike setting were not associated with impacting on a resident's quality of life or altering the symptoms of dementia. However there was a modest effect based on the facility size and the connection with managing agitation, this suggests that smaller units are able to better manage the symptoms of agitation.

### **3.5.6 Pharmacology**

The use of drug therapy to optimize quality of life and manage behaviours in dementia is generally reserved for situations where non pharmacological interventions have been unsuccessful (Douglas, James, & Ballard, 2004). In many ways the use of neuroleptics for treating agitation is thought of as a chemical restraint particularly when there are no psychotic symptoms present (Perkins, 2006; Tainsh & Hinshelwood, 1997). The International Psychogeriatric Association (IPA) (2002), state that antipsychotic medication is most effective in the treatment of psychotic symptoms however non-pharmacological interventions should be tried first before medications are used.

There will be times however when certain situations or challenging behaviours require more than a nurse's one on one management skills. Medication is often used to "control" behaviour in these circumstances. It is therefore left to the nurse who has frequent contact with the client

to judge the responses and side effects. Douglas et al. (2004) in their review states that 40% of people with dementia in care facilities are taking neuroleptics. These drugs were first licensed to be used in psychiatric conditions such as schizophrenia and were not intended to be used in dementia. They were used to treat agitation, psychosis and aggression. Evidence suggests that there are small benefits in the short-term treatment of aggression and that the use of neuroleptics in dementia leads to a cognitive decline, excessive sedation, dizziness and unsteadiness, which can lead to increased falls and injuries, as well as parkinsonism, (such as akathisia, tardive dyskinesia), reduced well-being, social withdrawal and can also increase the risk of fatalities (Berry, 2006).

Experts have suggested that evaluation of new pharmacologic agents for patients with dementia such as the cholinesterase inhibitors should include a standard assessment of their quality of life, (Winblad et al., 2001). Cholinesterase inhibitors are medications used for the treatment of dementia has attracted a fair amount of attention following the discovery that cholinergic transmission is affected in Alzheimer's disease. Cholinesterase inhibitors such as Donepezil and Rivastigmine work against cholinesterase, which is a substance that depletes acetylcholine. Acetylcholine is one of the neurotransmitters within the brain that helps nerve cells to communicate with each other. By inhibiting or controlling cholinesterase, these medications lead to an increase in the amount of acetylcholine, which is may be important in maintaining various cognitive functions such as memory. Memantine is another medication used in dementia which acts on the glutamatergic system by blocking NMDA glutamate receptors. This is usually trialed when people are intolerant to the cholinesterase medications.

There is an indication that these medications may be successful in the treatment and the prevention of challenging behaviours without many of the added harmful side effects of antipsychotic medications. Research suggests that these medications have decreased the usage of neuroleptics (Berry, 2006).

Following a decision by PHARMAC in 2010 people with dementia now have access to the funded medicine "Donepezil-Rex". Dr Peter Moodie of PHARMAC said that they have always recognised the impact of Alzheimer's disease on patients, their families and caregivers, and the need for treatment that would be funded (PHARMAC media release, 2010).

### **3.6 OPINIONS ABOUT QUALITY OF LIFE IN DEMENTIA**

Not only is there an economic challenge and a demand for increased care provision for the rising numbers of people with dementia, but there is also a challenge in the need to understand the views of people with dementia (Bond, 1999).

Of significance when assessing the quality of life of a person with dementia within a rest home is whether the ratings should be completed by the person with dementia or should also be made by the caregiver and family member.

The subjective experience of dementia is often unheard and is typically dominated by the so-called objective factors or by the bio medical term of the condition, the dementia itself. It is suggested due to the characteristics of older people with dementia, that it is difficult to define and rely on the subjective account of what is a good quality of life (Selai & Trimble, 1999). The person with dementia is often made to look invisible and their accounts are of no substance. Ability to communicate or evaluate issues relating to quality of life may be determined by various clinical features such as a decrease in cognitive abilities, poor insight and judgment and neuropsychiatric conditions such as delusions and agitation (Selai & Trimble, 1999). In the long term people with dementia have no control over treatments and what happens as their life and the effects of the condition progresses.

Some studies suggest one can only measure a person's quality of life through direct questioning of those with dementia (Logsdon, Gibbons, McCurry, & Terri, 2000). Karlawish, Casarett, Klocinski, and Clark (2001) support this view, and go on to say, when attempting to obtain the opinion of the person with dementia in relation to subjective ratings, assessments should be aware of the carer's quality of life.

When obtaining subjective and objective opinions about the quality of life of a person with dementia, one question is: do these opinions correspond and if not in what way do the objective views differ from the subjective? (Scholzel-Dorenbos, 2010).

Evidence suggests that people with dementia downplay their illness whereas healthy people misinterpret the impact that the illness has on the person. This can be explained, by understanding that a person with dementia will adapt to their losses as the disease progresses, suggesting the person with dementia believes their quality of life is maintained (Scholzel-Dorenbos, 2010). It is suggested that people with long term chronic conditions such as

dementia describe theirs as a good life despite their illness which may contradict the opinions of others; this is known as the “disability paradox” (Albrecht & Devlieger, 1999).

The Selection, Optimization, and Compensation (SOC), model of successful aging originally founded by Paul and Margret Baltes explains how individuals maintain important competencies despite age-related losses. Baltes and Baltes (1990) suggested that successful human development is dependent on three components: selection refers to the development and the choosing of goals; optimization applies the means to achieve the goal or development of potential (maximization of gains) and compensation choosing an alternative method to achieve a goal when previous means are not available, ensuring the maintenance of functioning (minimization of losses). This brings us back to the point that objective and subjective opinions about the quality of life of people with dementia will differ as many older people will often say they are in good health when they are suffering from one or more chronic conditions such as dementia. This shows the significance of looking beyond physical health in assessing quality of life.

It is quite common for people to experience dementia and become fearful of developing the condition themselves. The fear is based on perceptions of the suffering they will experience; of being dependant on others, and the loss of one’s identity (Corner & Bond, 2004). Kitwood (1997) and Cheston and Bender (1997) identified in their studies, issues such as fear and losing identity or control of their life with people experiencing dementia. Their studies looked at 3 stages of the dementia experience: fear, frustration and anxiety becoming a state of misery and chaos and then despair and apathy.

These ideas on dementia clearly reflect a negative portrayal of the condition especially when we compare it to people fighting cancer. We see that there is a cure for most cancers and from a study by Patrick, Starks, Cain, Uhlmann, and Pearlman in 1994 most dementias were categorized with conditions “worse than death”. A study by Clarke, Heyan, Pearson, and Watson (1993) asked the opinions of healthcare workers towards people with dementia and most regarded their patients as effectively dead. In response to this some people living in the Netherlands and Belgium have planned advanced directives. To avoid living with dementia, they have planned to refuse all treatment and some have even requested euthanasia should they develop symptoms of the condition. The topic of euthanasia in dementia continues to raise worldwide discussions. Clearly this topic can only be answered by listening to those who live with the condition.

### **3.6.1 Subjective Ratings of Quality of Life**

Sixsmith et al. (2008) state dementia can present many challenges when measuring or assessing a resident's quality of life. It is often thought to be too difficult to obtain the opinion of the person who is cognitively impaired. The person with dementia may have problems understanding the questions asked or give incoherent answers. The validity and reliability of findings may be placed in doubt, especially when dealing with a person with a decline in intellectual capacities, poor semantic and episodic memory, along with a person's capacity to make decisions and their awareness of their own condition. Other researchers agree and question how reliable information is when receiving it subjectively from a person with dementia and if the person is able to fully comprehend what they are being asked. Self-reporting relies heavily on the ability to use language and a good expression of one's situation. Along with cognitive disabilities in dementia other features such as insight, denial and other neuropsychiatric symptoms will complicate the individual's ability to effectively communicate issues relating to their quality of life (Cahill et al., 2004; Rabins, Kasper, Kleiman, Black, & Patrick, 1999).

Listening to their experience of dementia is a requirement before intervention or delivering care, but information is not easily obtained as people with dementia may have difficulty making themselves understood (Holst & Hallberg, 2003). Selai and Trimble (1999) state that the implicit and explicit memory included in a person's cognitive ability are required in order to give an opinion and with impairment in these areas, this would imply that self-rating opinions are no longer possible.

"Lacking insight" in dementia refers to a lack of awareness in relation to cognitive impairment, social functioning and behaviour. Therefore if a person lacks awareness or insight of how their condition may impact on their life then how can someone reliably report what impact the condition has on their quality of life? (Whitehouse, 1999). Having insight however into how the condition affects an individual provides knowledge and respect of a person's values and beliefs (Holst & Hallberg, 2003). There have been a few studies completed about insight and the ability to report on quality of life using clinical judgments of the person with dementia (Ready & Ott, 2003). A study by Trigg, Watts, Jones, and Tod (2010) focused on the patient's insight by using several clinical scales to explore if people with dementia were able to reliably report on questions about their quality of life, even though there were inconsistencies present between patients and proxy ratings. Their findings

suggested that lower levels of awareness or insight of memory function were related to higher levels of quality of life ratings from patients with mild dementia. This implies that people with dementia rate quality of life assessments on a review of their present situation; if that is the case then self-reports are reliable. Insight in dementia masks changes in quality of life received from other sources such as activity of daily living function. The study suggested that discrepancies between self and proxy ratings are the result of two factors the first is related to the functional ability of the person with dementia and the second is how the person with dementia looks at a situation based on their mood that produces functional disability. From their observations they concluded that a measurement of insight should be used in all quality of life assessments. Most believe the further the dementia progresses there is a further loss of insight.

Zanneti et al. (1999) in their study aimed to evaluate the level of insight in people with dementia and examine the relationship with cognitive impairment. From their findings it was concluded that there was preserved insight in the mild stages of dementia and severe lack of insight in the later stages of the condition. They believed that there was a cut off point on the mini mental state examination (MMSE) (Folstein, Folstein, & McHugh, 1975) that followed a noticeable pattern amongst participants; an estimate of where the decline in insight began and ended can be used in association with insight scales. Sixsmith et al. (2008) suggest what appears important to a person's quality of life at one stage of the dementia may appear to be less important later on in the condition. The importance of quality of life differs as the condition progresses. In the early stages of dementia preserving intellect may have seemed significant, however in later stages safety and comfort may be more important. These challenges often result in the exclusion of people with dementia from research. Some would argue the subjective opinion of quality of life is often different from the proxy rating and go on to say that very little attention is paid to the subjective experience (Zanneti et al., 1999). Due to discrepancies in self rating and proxy ratings of quality of life Brod et al., (1999) argued that awareness of the 'feeling states is distinct from awareness of cognitive and functional performance'. This would suggest that the personhood of people with dementia who report on their own quality of life is reliably preserved even though their awareness of their condition is reduced.

### **3.6.2 Proxy Ratings**

There is a lack of knowledge about how a person with dementia actually values their own quality of life and also about how people close to them may attribute to that person their own fear and beliefs (Westius, Andersson, & Kallenberg, 2009). When taking into consideration proxy ratings it is generally assumed that the proxy are aware of the beliefs, values and opinions of the person with dementia (von Essen, 2004). The overall consensus of opinion when evaluating the quality of life of people with dementia is that proxies believe the person's quality of life is lower than the individuals might themselves believe. Therefore there is an unreliability and disparity of opinions in presented data (Logsdon et al., 2007; Westius et al., 2009).

Discussion surrounds the question who should rate a person's quality of life especially when an objective and subjective point of view will differ? People with dementia can have a different perspective on life when compared to someone else with dementia. Their opinion can often be different at various times. Proxy ratings are given by people who are not experiencing the dementia first hand, who often have poor knowledge of the condition and do not understand that people with dementia can usually adapt to their illness. Therefore more often than not, proxy reports will rate a lower quality of life than those actually experiencing the dementia. The proxy's own health and mental state should be taken into account, along with assessing the burden of their relative's condition that has possibly affected their judgement (Logsdon et al., 2007).

Ideally quality of life should be measured through self rating reports, proxy rating and observation by others. It is difficult to assess however whether a person with dementia and a person who has poor knowledge of dementia can provide reliable and accurate accounts of the person's quality of life. One advantage of using proxy rating accounts is that they are able to provide missing information when attempting to ascertain quality of life in a person with severe dementia. Most have suggested that in the case of severe dementia a proxy rating should also be used because of increased unreliability of answers with the progression of the condition (Cahill et al., 2004; Rabins et al., 1999).

Some would say when assessing quality of life of a person with dementia it is nevertheless important to take into account the family or support person's and healthcare worker's view, as these are a valuable source of information in comprehending the experience of someone with

dementia (Clarke, Tucke, & Whitlack, 2008). In addition, listening to the person with dementia is extremely important. Family also felt that their relative with dementia should be given the chance to voice their opinions and said that they felt pressured and overwhelmed if their relative was excluded from giving their own opinions (Clarke et al., 2008). Health care workers may not always know what is best for the person with dementia; their views may be influenced by their own beliefs and priorities and are often idealistic (Kalis, Schermer, & Van Delden, 2005).

Family members may believe that the mind of their relative with dementia has become “emotionally shallow” (Westius et al., 2009). Family members may also believe that the challenging behaviours of a person with dementia are a result of their failing ethical values. McFadden, Ingram, and Baldauf (2000) disagreed; in their study they looked at values of people with dementia and found that values and ethical beliefs remained even though cognitive functioning was impaired.

Bearing in mind that the carer’s (both family and care staff) proxy ratings of quality of life for people with dementia are affected by their own quality of life, proxy ratings can be considered important but should not be used as a substitute. Therefore it can be argued that the quality of life of a person with dementia is best assessed by obtaining self-ratings as well as proxy ratings. Ethically the views of the person with dementia should always be considered regardless of their cognitive disability; equally the level of cognitive impairment should be assessed when considering using proxy ratings (Ready, Ott, & Grace, 2004).

Only a few studies have evaluated self-reports of the quality of life from people suffering from dementia and compared them with proxy reports (Magaziner, Simonsick, & Kashner, 1988). Both self and proxy reports may provide useful yet dissimilar opinions (Selai, Trimble, Rossor, & Harvey, 2001). The study by Sands et al. (2004) compared the inconsistencies between patients with dementia and family caregivers' ratings of the patients' quality of life and attempted to ascertain whether the discrepancies were related to patient traits and/or caregiver traits. A sample of patients with mild to moderate and severe dementia and their family member rated five domains of the patient’s subjective quality of life. Their findings suggested that the agreement between patients and family was low and that family rated patients' quality of life lower than patients rated their own in all five domains. The study suggested that these inconsistencies between patients' and family ratings were not associated with the patients' cognitive ability, their functioning, or the family’s reports of aggressive,

attention-seeking, or sexually inappropriate behaviours, nor how the patient and family member were related and what sort of relationship they were having at the time. However, discrepancies were connected with level of family burden and the patients' reports of depressive symptoms. Patients with depression were more consistent with family's answers. Interestingly family members who reported thoughts of a higher level of burden rated patients' quality of life lower than did patients in all five domains of quality of life. Sands et al. (2004) concluded that inconsistencies in ratings between patients and their proxy were related to the level of family burden and not the patient's unreliable answers.

In the similar study by Boyer et al. (2004) research was undertaken to find out if quality of life ratings by people with dementia and their family and or other proxies (care staff) were in agreement, whether the proxy characteristics influenced their answers and whether their answers were biased in any way. Their findings suggested that patients with a MMSE > 9 were able to give reliable answers. The researchers discovered that patients were unreliable with their answers if they were unable to complete at least two items out of five in the orientation dimension of the MMSE, less than three out of eight in the language dimension. There was less agreement between patient and proxy reports using the tests on memory recall and visuo-constructive memory, and these were not linked to whether or not the patient could be interviewed meaningfully. Proxy ratings made by non-family members closely reflected the opinions of the patient. Family proxies over-estimated the disability of "physical mobility, isolation, sleep, emotional reactivity and energy". Inconsistencies in opinion were greater when the proxy was a spouse or was someone who had regular contact with the patient. The study showed that opinions varied according to certain characteristics of the proxy. This would suggest a reflection of family or carer burden.

Professional caregivers are also open in giving their opinions about quality of life of individuals in their care. Hoe et al. (2006) in their study looked at the views of staff and their patients as to their quality of life. A total of 238 residents with dementia in 24 residential homes throughout the United Kingdom participated in the study. Various assessment tools and scales were used that looked at level of cognition, severity of dementia, assessment of mood/anxiety, assessment of needs and abilities, and measures of challenging behaviours. Mental health researchers conducted interviews and information was also gathered by observation and nursing note documentation. Interestingly the study's findings showed that the residents' ratings of their own quality of life was associated with

depression and anxiety, whereas staff ratings of the residents' quality of life was related to the level of dependency and challenging behaviours. Due to the disparity between the two results the authors conclude that one cannot be acting on the patient's behalf without having an awareness of how the resident truly feels, and that for professionals, identifying a poor quality of life should be of utmost importance in caring for someone with dementia.

Evidence shows from recent research that staff within residential care rates the residents' quality of life differently from the way the resident would rate their own (Novella et al., 2001). In this study health-related quality of life was examined in a sample of people with dementia and their proxies using a questionnaire. Their findings revealed poor to medium agreement overall, though agreement on observed physical functioning was apparent. It found that spouses and professional caregivers agreed more than did children and nurse aides. Findings also suggested that agreement between patients and proxies decreased in those with severe dementia, and proxies rated the patients as having a lower quality of life than the patients themselves rated. These results suggest that consideration of the patients' opinion about their own health-related quality of life is most important and that proxy opinions should be carefully used. It is important to determine whether the relationship between the caregiver and patient is associated with any discrepancies between patient and caregiver ratings of patients' quality of life. It is important to understand why this should be the case. In doing so, researchers will be able to determine the appropriate method to assess the residents' experience of dementia, their quality of life and best treatments.

Few studies have been conducted to look at views of quality of life for residents living in a specialist dementia level rest home, and how they are expressed by gathering data from the viewpoints of the resident, their family member and healthcare worker. From those that have, there has been a range of findings (Droes et al., 2006; Gerritsen et al., 2007; Hoe et al., 2006; Huang, Chang, Tang, Chiu, & Weng, 2009; Kalis et al., 2005; Lindgren & Murphy, 2002). Researchers now acknowledge that the subjective factor or the person's own opinion based on the actual experience of the condition is meaningful. At all times self-rating reports should be the main focus when evaluating quality of life. It becomes an issue when deciding who should rate quality of life in a person with dementia when opinions between objective and subjective assessments become contradictory. It is commonly known that a person with dementia may respond differently to a question about their quality of life at different times. Objective

assessments will be completed by health professionals and will predominantly reflect the biomedical model (Scholzel-Dorenbos, 2010).

### **3.7 INCLUDING PEOPLE WITH DEMENTIA IN RESEARCH**

Bond (1999) in his literature suggests dementia has become a challenge to scientists in the development, promotion and marketing of pharmacological treatments. Accordingly many scientists believe they may improve a person's life, but along the way some may lose sight of the perspectives of a person with dementia. Bond (1999) suggests that scientists become more focused on the condition and by giving a person a "label", the person with dementia is often seen as a victim thus losing individuality. With the recent funded treatments for dementia it has become important to assess quality of life for people with dementia and the field is now witnessing a change in care delivery. Clinicians are moving away from the medical model to a more person-centred approach. There is a growing awareness that people with dementia have a role to play in care practices as these people along with their caregivers are members of society who are most affected by the condition. It is therefore reasonable that these people are involved in any research outcomes relevant to their condition. The personal experience of someone with dementia is now being addressed.

Ettema, Droes, de Lange, Mellenbergh, and Ribbe (2005) in their study raised doubts about the capacity of people with dementia to be included in research due to the decline in their cognitive abilities. Thorgrimsen et al. (2003) however believed that the grounds for such exclusion lacked real evidence.

More recently, it is being acknowledged that people with dementia are able to provide responses as to how the disease has affected the way they see themselves, are able to give a clear description and understanding of what they are experiencing, they are reliable in expressing opinions, rate their own quality of life and are able to effectively make their needs known (Aggarwal et al., 2003; Brod et al., 1999; Burgener & Dickerson-Putman, 1999; Karminder, Williams, Zimmerman, & Umen, 2007; Kolanowski, Litaker, & Catalano, 2002; Logsdon et al., 2002; Mozley et al., 1999; The Mental Health Foundation, 2010).

Researchers maintain that the views of people with dementia are essential in attempting to find out how the disease truly affects an individual and most importantly researchers suggest

that the subjective point of view of the person with dementia better meets the individual's care needs (Sabat, 2002; Trigg, Watts, Jones, & Skevington, 2007).

The Care Keys project was a study in the United Kingdom that would allow care managers and planners to evaluate the service they provided for people with dementia. Challenges were that the person with dementia may not be able to articulate ideas and opinions but also there could be a danger that the person with dementia may not be included in the associated research. Therefore they integrated the voice of the person with dementia along with third party opinions using measurable scales. Their findings showed that cognitive and functional disability was not a predictor of quality of life in a person with dementia and that social networks and the environment played a significant part (Sixsmith et al., 2008).

In qualitative research people with dementia have typically not been included as informants due to their cognitive difficulties, as qualitative research often relies on having interviews or answers to questions therefore good verbal skills and communication are necessary. Qualitative research is often dependant on a subjective approach and focuses on an understanding and exploration of the meanings to the participants. Research of a qualitative nature is reliant on a good relationship between the researcher and the participants. The research is driven by the researcher in that the findings are her understanding of what she interprets or sees. The researcher attempts to find a meaning to statements made by participants and develops themes from the data.

### **3.8 CONCLUSION**

This chapter has reviewed a large amount of literature about quality of life for people with dementia. The researcher believes this review has covered relevant literature with an analytical examination of key research in the thesis area. The researcher found the literature search relating to the question time consuming but interesting to find the vast number of articles one can retrieve relating to the topic. Following the Dixon-Woods guideline the researcher ensured the publications chosen for this literature review were relevant. Publications were categorized into topics that were placed into headings which were then used in making this chapter come together.

This review has discussed domains of quality of life. There is a great interest in ensuring a good quality of life for a person with dementia, possibly because there is no cure for the

illness. Quality of life in dementia is difficult to define without looking at its domains and the determinants of quality of life. From the literature reviewed the determinants of quality of life showed the importance for staff and family carers to acquire the skills and knowledge relating to the condition and management of dementia; for example listening to the person with dementia is essential. Each person with dementia will respond differently to one approach than to another.

The main theme that emerged from this review was that skillful communication enhances a good quality of care and life. Some of the evidence showed the significance that staff involved in dementia care should be aware of the research such as national guidelines that are set out to assist in the care of someone with a dementia. Evidence also shows that organisations should encourage staff to develop their knowledge and skills surrounding dementia care. Receiving clinical supervision was also seen as significant along with appropriate staffing levels in avoiding “staff burnout.”

Literature indicated the importance of the utilisation of meaningful activities and socialisation. While activities and socialisation cannot cure dementia, it has been shown to give people with dementia a sense of meaning to their lives and generally improve many aspects of the quality of life of those who have it. The literature indicates that quality of life is not only determined by familiar people but also supported by the environment they are living in. People with dementia are reliant on the care they receive from staff but also become dependent on external factors around them.

Symptoms of dementia are of significance when discussing quality of life; treatment of these symptoms not only improves the quality of life for people with dementia but also lessens concerns for their family and care staff. Many of the articles show the importance of keeping the family involved in the plan of care ensuring a sense of empowerment on all sides. With caution there is the possible use of medications to reduce the symptoms of dementia when other methods have been unsuccessful

The literature confirms the challenge in the need to understand the views of people with dementia and to include people with dementia in research. Of importance is the discussion around who should assess and measure the quality of life for people with dementia. Most studies show that quality of life is usually measured from objective points of view. However, proxies may have a different perspective about quality of life when comparing it to people

with dementia. Many would question the reliability of the subjective opinion about their own quality of life due to the deterioration in their cognition and communication difficulties. Literature also suggests that a person's beliefs, values and opinions change over time and what may have seemed important at one stage maybe completely different later. Therefore proxy ratings should be carefully used.

However most of the literature in this review suggests that people with mild to moderate dementia are able to provide valid and reliable reports about their own quality of life. For those with severe dementia a proxy report alongside the subjective ratings can be sought in order to provide missing information. Nevertheless most studies conclude that it is possible to use the perspectives or opinions of a person with dementia when looking at quality of life though there may be difficulties encountered when doing so. Nevertheless the reason for measuring quality of life by listening to people with dementia within a residential care setting is simple: to ensure a clear interpretation of the best approach for the person in their care in order to promote quality of life.

## **CHAPTER 4 - STUDY DESIGN, METHODOLOGY AND RESEARCH PROCESS**

### **4.1 INTRODUCTION**

This chapter will present the research design, method and process used to gather and investigate individual perspectives on quality of life for someone with dementia. It will explore ethical considerations and consent/assent for people with dementia. The researcher will also discuss the researcher's responsibility in minimising harm to participants.

### **4.2 STUDY DESIGN AND METHODOLOGY**

Qualitative research has much to offer healthcare and is well suited for nursing investigations as it incorporates a subjective approach and focuses on the understanding of human experiences and explores the meanings of what is actually being said (Munhall & Boyd, 1999). There is a strong theoretical basis for choosing qualitative method in a study of this type in that such a study would rely on the relationship between the researcher and participants. Research in nursing is a methodical means of examining something of interest and importance, the aim being to complement knowledge and improve on cost effective care and improved nursing practice (Burns & Grove, 2001).

Qualitative description (QD) was adopted to guide this piece of research. QD is optimal for collecting data in regards to an individual's perspective, is mainly inductive and suitable for the development of concepts. The researcher felt this was the most suitable method in her study which is based on the design specifics by Sandelowski (2000). This piece of research used purposive sampling, used structured open ended questioning, and coding systems in its analysis which matched the data collected and presented a straight description of the participant's thoughts and opinions.

### **4.3 DATA COLLECTION AND ANALYSIS**

Within QD, data can come from various sources, but often consists of interview transcripts that are usually open ended and can be exploratory or based on "focusing questions". It attempts to discover events or experiences through the collection and then analysis of the data (Thorne, 2000). In this study data were collected from face to face interviews with three

participants of the four cases, twelve study participants in all. The interview style for this study took on the form as an open ended questionnaire (QOL-AD) (Thorgrimsen et al., 2003) which elicited narrative consideration of meaningful constructs.

The researcher informally opened up the interviews for all participants by asking them how they felt about each quality of life domain listed in the QOL-AD. For example, the researcher opened an exploration of how the resident rated their own physical health by asking the question “Do you keep physically well?” and so on through the QOL-AD topics. During interviews with the family member and healthcare staff, the researcher asked similar questions related to the resident, for example “Do you believe (the resident) keeps good health?” and so forth. The researcher used the QOL-AD purely as a means to provide some structure to the interview and open up a line of conversation, not as a tool to directly measure a person’s quality of life. Numerical ratings were not collected.

A further two questions were asked following on from the QOL-AD questionnaire topics. These questions were: “Can you tell me in general what does the term “quality of life” mean to you?” and “Can you describe to me your views on how dementia has affected (the resident’s) quality of life in this rest home?”

The researcher’s aim was to attempt to build a holistic and detailed picture by gathering in-depth information within a normal relaxed setting. This qualitative approach was used whereby themes would be developed on the basis of the data collected. It centres itself around real life descriptions. Quantitative research however is more formal and objective insofar as statistical evidence is obtained to offer answers to questions. Larger numbers are required than is possible in a study of this size and type.

Each case of three participant interviews took place on the same day at the rest home over a period of four months. All interviews followed the QOL-AD with a further two questions, and as hoped opened out into a wider interview. All interviews were audio taped. Each questionnaire and interview took approximately 45 minutes to complete, including a general chat to help make the participants and setting more relaxed.

All interviews were tape recorded and later transcribed by the researcher. Schneider, Elliott, Biondo-Wood, and Haber (2003) believe it is important that qualitative richness is not lost through transcription therefore it is important for the researcher to document the manner and

behaviour of the participant. One way of retaining this is for the researcher to listen to the tape whilst reading the transcript, in the initial analysis. Once the first verbal data had been transcribed the process of data analysis began.

Qualitative content analysis is often chosen when analysing data in QD. In this case the researcher had in mind a list of categories predetermined around the domains of the QOL-AD questionnaire. Each case was transcribed and analysed individually. Each line of every transcript was explored and each meaningful line given a code. This creative process opened up the data which indicated the meaning of the segment. The identified codes were the researcher's interpretation of the data developed from key phrases and most common answers. For example the researcher asked participants if family were important. One participant in the interview believed they were "very important". This meaning was coded "Family positive". The same participant suggested family could also be "an extreme frustration" this was coded "Family negative".

The researcher penciled in the codes over the meaningful phrases on the original transcript. Along with the penciled codes, for each case of three interviews the researcher compiled a table listing the QOL-AD domains and outlined a summary of each of the three viewpoints of each domain. From there the researcher explored the given codes often referring back to the original transcript and compiled table and continued to revise and refine the coding system. The researcher made the decision as to what was important as some text was not relevant to the study or sometimes overlapped into other codes. Through this process of coding the researcher ended up with 125 codes over all 12 transcripts which were transferred into an alphabetical index book. Within this book the researcher indicated which participant the code belonged to and the page number where the code could be found on the original transcript. Once the relevant codes had been selected and indexed they were further interpreted into themes. Themes were recognised and developed by exploring patterns and variations and observation for differing and contradictions of opinions from the 12 interviews.

#### **4.4 RESEARCH SETTING**

The study took place within a specialist dementia rest home. The unit comprises 20 beds for people with mild to moderate dementia. Dementia rest home level of care is for individuals requiring 24 hour supervision with 'activities of daily living' (ADLs), with additional security provided for individuals who are at risk of wandering and becoming lost due to memory loss

and confusion. Clients may also have associated inappropriate behaviours including verbal outbursts and/or difficulties with toileting.

Currently the unit has one Registered Nurse who works full time during the week between the hours of 9.00am till 5.00pm. After hours and at weekends a Registered Nurse from the hospital unit within the facility is available to offer nursing input. There are ten healthcare staff rostered to work shifts. Shifts involve staff working morning, afternoon and night shifts.

## **4.5 RECRUITMENT METHODS**

For this piece of research purposive sampling (choosing subjects with direct experience of quality of life within a dementia rest home setting) was chosen; this ensured that each participant had some characteristics in common with others in the study and would be able to provide information that was required for the study which would ensure rich data.

The study was designed to obtain three viewpoints in respect of each of four residents' qualities of life: from the resident, the family member and healthcare worker. Each set of three viewpoints was called a 'case'. This sample size was chosen purely based on the availability of potential participants that matched the researcher's inclusion criteria. Within qualitative research sample size is not so relevant as long as the data is rich in information. Therefore, the researcher felt the sample size would be adequate in that the participants would be able to provide all information which would be required for the study. Fayers (2005) states experience shows that six to eight participants are adequate in situations where similar issues are apparent.

### **4.5.1 Resident**

Firstly the researcher approached the Manager of a specialist dementia rest home to assist in this piece of research. The researcher explained to the Manager the research proposal and the aim. The Manager gave her consent to proceed with the study in this facility. The researcher initially asked the Rest Home Manager to indicate people with dementia under their care who they thought might be able and willing to participate in the quality of life interview and study process. Four residents were asked to participate who had a mild to moderate dementia and had lived within the home for at least one month, having been admitted for long-term (not respite) care. There were no criteria for age, gender or ethnicity. The level of cognitive

impairment was defined by the Registered Nurse and recorded in the rest home's care plan. Each resident required a family member and relevant healthcare worker to take part in the study. Recruitment took place in the four cases in sequence, so contact relating to participation was made in a timely manner.

The Manager gave these people and their principal family/ whānau member / supporter a printed information sheet and an invitation to participate in the study and elicit whether or not they would be happy to be approached by the researcher (Appendix 2). (In addition, where relevant the resident's Enduring Power of Attorney for Personal Care and Welfare also received this information).

Following ethical approval (see chapter 4.8) the researcher asked the Manager to give an opinion about whether or not the person would be able to give informed consent or whether they would only be able to give assent to participate (see chapter 4.9). The researcher met with the resident and their family member to explain fully the research project. Should the family member refuse for their relative to take part then recruitment would not proceed.

#### **4.5.2 Family**

The inclusion criteria for the four family members or support person to be a participant were spouse, sibling, son or daughter and/or friend. There were no age or gender limitations. The research design required that each family member should know the resident well and visit at least once every two weeks.

#### **4.5.3 Healthcare worker**

The Manager and RN of the rest home discussed the research project and gave information sheets (Appendix 3) to interested healthcare workers to take part. Those healthcare workers who volunteered were allocated residents who were known well to them. Both day and night shift healthcare workers within the dementia rest home were asked to participate. There were no age, gender or qualification exclusion criteria. However, staff were required to have knowledge of caring for someone with dementia and to have been employed within the dementia rest home for at least six months. Once the four staff were identified, the researcher completed a consent form with them (Appendix 6). (See table 1 for participant's data).

## **4.6 USE OF MEASUREMENT TOOLS AND INTERVIEWS IN RESEARCH**

Several studies suggest that many tools used to measure quality of life in the person with dementia have been proven to be valid and reliable (Logsdon et al., 2002; Ready & Ott, 2003), but this study did not use any quantitative statistics due to the small numbers. However, all interviews were based upon the QOL-AD (Thorgrimsen et al., 2003) questionnaire. Ready and Ott (2003) in their review of quality of life measures in dementia suggests that the QOL-AD questionnaire is most suitable when incorporating and measuring subjective and objective opinions. This questionnaire was chosen by the researcher as it was originally developed to evaluate the impact cognitive impairment has on a person's quality of life by assigning scores to various domains. The questionnaire focuses on quality of life domains that are thought of as important for people with dementia. It is a simple clear questionnaire that enables the interviewer to obtain thoughts on a person's relationship with significant others, any concerns they may have about their finances, their physical condition, their mood and their life as a whole. The person with dementia (resident) completes the questionnaire about their own quality of life; their proxy also completes it about the resident's quality of life. There are 13 items and each are rated on a 4 point scale 1 being poor and 4 being excellent, total scores range from 13-52 (Thorgrimsen et al., 2003). The QOL-AD has been found to be a trustworthy tool incorporating the viewpoint of the person with dementia and also a broad method in measuring quality of life from a caregiver and family member perspective (Merchant & Hope, 2004). It was hoped and expected that the verbal responses surrounding questions relating to each item from this questionnaire would open out to a more open-ended set of questioning, contributing data which would be well suited to qualitative analysis.

Other studies suggest that the use of quantitative measurement instruments is likely to miss important factors and the opinion of persons looking after those with dementia is essential (Banerjee et al., 2005). Another study by the Mental Health Foundation (2010) suggests there are arguments raised about the use of generic quality of life measures for those with dementia in that they may not be precise in picking up on key features. However using tools designed purely for those with dementia may focus more on the negativity of the condition. The researcher therefore chose a qualitative method of gathering and analysing this data.

## **4.7 RIGOUR AND VALIDITY**

The criteria for validity in qualitative research has much to do with the idea that the study must be replicable and measure what it aims to measure (Denzin & Lincoln, 1994). The design of this study could be easily replicated or repeated in a similar setting. While the design and research process make it possible to assess validation and reliability, it is also acknowledged that it is not possible to generalize beyond the findings derived from this study. Trustworthiness in qualitative research builds on the understanding that knowledge is dependent on the participant's circumstances. People's opinions and experiences are valuable and important in the interpretations that arise from qualitative research (Roberts & Taylor, 1998).

Lack of rigour in qualitative research can result from inconsistency in the approach being used to gather and analyse the data. The QOL-AD questionnaire was used as an interview guide in all interviews so that very similar information was given and similar fields of information were covered by each participant from each of the four cases. This supports reliability of the findings within the study.

Some researchers believe that increasing the number of participants, the time spent with participants and triangulation of the data will enrich the findings (Moore & Hollett, 2003). Poor methods used in gathering and analysing the data can also account for inadequate and unreliable findings (Burns & Grove, 1997). For people with severe dementia some researchers have completed several interview sessions with their participants to assure validity (Snyder, 2003). However, these extended methods are beyond the scope of a Masters project, using a single researcher under supervision. In these circumstances clear design of the study, professional conduct during data collection and continuing supervision during analysis and writing, all support "quality assurance" of this study in terms of validity, reliability and trustworthiness.

## **4.8 ETHICAL CONSIDERATIONS AND APPROVAL**

In protecting human subjects in this research against anxiety and discomfort precautions were taken. The study asked for voluntary participants therefore there was no coercion on the researcher's or the Manager's part. The researcher holds a nursing qualification and has knowledge of nursing an individual with a dementia. Therefore she has her own professional

responsibility and ethical codes to follow within her scope of practice, which ensures confidentiality is maintained. During the collection of data the researcher separated her professional role from her researcher's role by arranging for a colleague to provide professional support to the clients and facility staff.

On handing out the information sheets to family members and staff whom she deemed the most appropriate, the Manager then asked all participants for their permission for the researcher to follow up with a telephone call to confirm their willingness to be part of the study. A time to meet was then agreed upon.

All interviews were conducted in a non-prejudicial respectful manner, and it was believed that sensitivity to participants, beliefs, lifestyles, backgrounds and cultures was demonstrated. The study minimised risk and followed an ethical framework. It considered respect for autonomy, avoidance of harm (non malificence); there were no incentives for the research (beneficence), and appropriate consideration was given to the interests of those participating in the research (justice) (Schneider et al., 2003). The researcher abided by current New Zealand legislation including the Human Rights Act (1993), the Privacy Act (1993) and the Health Information Privacy Code (1994).

Schneider et al. (2003) state that written informed consent needs to be obtained from all participants with any research study. In the case of residents with severe cognitive impairment, who may be less capable of making decisions for themselves, the researcher spent more time with them to explain the study. The next of kin or support person was asked to sign consent on their behalf if they failed to understand fully. Family members and healthcare workers who were invited to participate also signed a consent form.

From the literature by Schneider et al. (2003), if at any time the participant feels any discomfort or anxiety, the study should be placed on hold until it is deemed possible to continue. Consideration was given should participants wish to "drop out" of the study at anytime. There was ongoing monitoring by the researcher to ensure the safety of the participants, by being available to participants who required further explanations. Those involved in the study were informed of all that was expected from them.

Confidentiality was maintained throughout the study as each participant was allocated a study number and full names not used. Pseudonyms or study numbers are used in any reports of this

study. Raw data was kept in a locked cabinet and computer software only accessible to the researcher via a password. Schneider et al. (2003) state that all data should be stored securely and not accessible to those who are unauthorized.

Before the study took place approval from the relevant regional New Zealand Health and Disability Ethics Committee was gained. The ethics committee provides protection for participants in research studies. Approval needed to be obtained due to the format of the study in that interviews and questionnaires would be completed in order to collect health related data. An ethics committee research proposal form was downloaded from the appropriate site. ([www.ethicscommittee.health.govt.nz](http://www.ethicscommittee.health.govt.nz)). Ethical approval was obtained. (Ethics reference number URB/10/10/041). If at any time data collection strategies needed to be changed the researcher was aware that she would need to confirm any amendments with the ethics committee.

#### **4.9 CONSENT AND ASSENT**

People who reside in dementia specialty rest home care may have a range of impairments related to their dementia and may or may not be able to give informed consent to participate in a study of this kind. The principles guiding inclusion of people with potential impairments of capacity in research are that competency is never assumed to be absent, that competency to participate is assessed carefully, and that every care is taken to follow proper processes to protect participants and to engage in good quality research.

Consent is given when a person gives a written statement agreeing to take part in a study. Assent is a verbal statement of a person to agree to take part which is obtained when a person may lack a sufficient understanding of the research to give written agreement, as in this case their proxy may sign the consent on their behalf (Lai & Karlawash, 2007). In their paper Lai and Karlawash (2007) suggest that one is considered to have capacity or insight, if they understand the features of the research and are aware of the outcomes in regards to their participation.

These potentially consenting / assenting people, together with their key supporters and whomever else they wished to be present, were approached by the researcher to explain the study and obtain informed consent or assent (Appendix 4 and 5). Consideration had been taken into account prior to the interviews, that in the event whereby participants with

dementia who were thought not able to give informed consent due to their cognitive limitations, inclusion in the study continued to proceed if they unambiguously assented to take part. In that case they would be deemed able to participate, and their key family member and (if different) their legal guardian would give permission for their involvement. In this situation formal proxy consent is covered by the approval of the Ethics Committee.

#### **4.10 RESPONSIBILITIES OF THE RESEARCHER**

Qualitative research requires effective communication and the ability for the researcher to be able to show empathy to the participants that they encounter but also to show neutrality in the analysis of the findings (Proctor, 2001). In obtaining meaningful information in research of this type it is essential that the investigator has knowledge of dementia and an understanding of quality of life in dementia. The investigator must be patient and sensitive and have the ability to make a person feel comfortable during interviews.

The researcher is responsible to the participants and also to the reader. The researcher becomes responsible for discovering and interpreting the importance of what is found from the research and draws her own conclusions. She is inevitably a human instrument of data collection, and her reports should be rich in detail of the participants' experiences (Proctor, 2001).

During interviews the researcher believed that she showed unconditional positive regard to all participants, was non-judgemental whilst being true to her research process. The researcher was able to utilise effective communication skills she had gained from her experience and knowledge as a psychiatric nurse. At the same time, this project required the development of research skills based on a programme of postgraduate study.

The researcher took into consideration the communication difficulties that she may encounter during resident interviews as suggested by Moore and Hollett (2003). To ensure that interviews were optimal the researcher liaised with staff to ensure the most suitable time whereby the resident would be less restless and irritable. All interviews were completed within a quiet familiar environment with little distraction. At times the researcher found one resident to be a little tangential and needed to be redirected back onto the track of conversation. Several other techniques have been used and found useful when attempting to redirect participants (Robinson, 2000). Residents were allowed time to respond to questions

and when showing signs of distress, reassurance was offered to them. The researcher monitored participants' signs of distress and if it was felt that they were becoming anxious or unsettled, she had in mind that she would end the interview.

#### **4.11 CONFIDENTIALITY OF THE DATA**

All data related to this study was stored on the researcher's home computer secured with a password. All other material such as audio tapes, backup copies of transcripts and notes were kept securely in a locked filing cabinet at her home and were backed up by the two supervisors. In line with the requirement of the University's regulations, in undertaking this research all data will be securely stored for five years and can be accessed via the University of Otago, Christchurch. After this time the audiotapes will be erased and transcripts destroyed.

#### **4.12 TREATY OF WAITANGI**

In the region in which this study was carried out Māori population rates are amongst the lowest in New Zealand. The researcher was aware there was one resident of Māori descent in the dementia rest home and it was hoped they would be able and willing to participate. The researcher had intended that this involvement might provide exploratory information of some similarities and differences between Maori Kaumatua and Whānau views of quality of life and those of Pakeha participants; as such information has not been published to date. The researcher believed that this research would recognise benefits for Māori and Pakeha.

The researcher had contacted the Kaumatua of the Māori Mental Health Service and agreed to assist in accompanying her if required in gaining consent/assent from Māori participants, if they wished to take part. However the resident unfortunately did not meet the inclusion criteria.

#### **4.13 MINIMISATION OF HARM TO PARTICIPANTS**

Prior to the commencement of the research, potential participants were given an information sheet (Appendix 2 and 3) which included details of how the researcher may be contacted. No risk or harm for participants was anticipated in the study, as participation was purely voluntary and participants were able to withdraw at any time.

To reduce the risk that residents lacked capacity in making a decision to participate in the study, the researcher asked for their consent whilst a family member was present. This method of double-informed consent followed the recommendations from the Alzheimer's Association (2004).

Minimising risks for participants was extremely important to the researcher during this piece of research. During interviews she was vigilant for the verbal and non-verbal signs of tiredness or anxiety. Consideration had been given prior to the interviews that if this were to happen the researcher would offer the choice of stopping the interview.

#### **4.14 DISSEMINATION OF THE FINDINGS**

The researcher asked all participants if they would like brief summary feedback from the study, recognizing that this might not be available until the thesis is completed and examined. Feedback to the Registered Nurse, Manager and rest home staff will be given at the study's end. All participants will be fully anonymised. This study will support the researcher to offer guidance regarding a good quality of life to policy makers at the rest home. The researcher will offer to present her findings at a peer review session within the wider District Health Board Community Hospital. A copy of the thesis based on this research study will be held in the staff library. The researcher plans to publish her findings within relevant nursing journals and thus contribute to continuing research and development of quality care settings for people with dementia in New Zealand.

#### **4.15 CONCLUSION**

This chapter has presented the study's design, data collection and analysis and the ethical considerations acknowledging the consent and assent process for people with dementia. This research design has provided a clear description of the methods by the researcher to explore quality of life for people within a dementia rest home setting from three viewpoints. The findings which resulted from this design and method will be presented within the next chapters.

## CHAPTER 5 - THE FINDINGS

### 5.1 INTRODUCTION

The aim of this study was to look at views of quality of life for residents living in a specialist dementia level rest home, and how they are expressed. This study gathered data from four “cases” covering three viewpoints in each case: the resident with a moderate dementia, their family member and healthcare worker. Table 1 introduces those who were participants in the study, once they were recruited following the contact and recruitment steps outlined in the previous chapter.

TABLE 1 Participant’s Data

|                                    | AGE | GENDER | MARITAL STATUS                                     | TIME IN REST HOME | FAMILY MEMBER                                                     | HEALTHCARE WORKER                                     |
|------------------------------------|-----|--------|----------------------------------------------------|-------------------|-------------------------------------------------------------------|-------------------------------------------------------|
| <b>RESIDENT 1</b><br><br><b>R1</b> | 92  | FEMALE | WIDOW                                              | 3 YEARS           | <b>F1</b><br>DAUGHTER<br>VISITS<br>TWICE A<br>WEEK                | <b>S1</b><br><br>FEMALE DAY<br>STAFF FOR 10<br>YEARS  |
| <b>RESIDENT 2</b><br><br><b>R2</b> | 76  | MALE   | SECOND<br>MARRIAGE<br>FIRST WIFE<br>DECEASED       | 18 MONTHS         | <b>F2</b><br><br>SECOND<br>WIFE VISITS<br>MOST DAYS               | <b>S2</b><br><br>FEMALE DAY<br>STAFF FOR 6<br>YEARS   |
| <b>RESIDENT 3</b><br><br><b>R3</b> | 83  | FEMALE | TWICE<br>WIDOWED                                   | 2 YEARS           | <b>F3</b><br><br>DAUGHTER<br>VISITS<br>WEEKLY                     | <b>S3</b><br><br>FEMALE DAY<br>STAFF FOR<br>2½ YEARS  |
| <b>RESIDENT 4</b><br><br><b>R4</b> | 85  | FEMALE | SECOND<br>MARRIAGE<br>FIRST<br>HUSBAND<br>DECEASED | 3 YEARS           | <b>F4</b><br><br>SECOND<br>HUSBAND<br>VISITS<br>ALTERNATE<br>DAYS | <b>S4</b><br><br>FEMALE DAY<br>STAFF FOR 18<br>MONTHS |

Each participant in this study was asked to comment on the thirteen categories of the Quality Of Life-Alzheimer's Disease (QOL-AD) assessment (Thorgrimsen et al., 2003) about the resident and a further two open ended questions. All twelve interviews were recorded and later transcribed. The researcher then analysed, interpreted and coded the data according to key themes and phrases, and explored for similarities and differences. Following analysis of the data the most frequent and significant concepts mentioned from the three perspectives revealed five central themes about what contributes to a good quality of life for the resident living in the dementia rest home.

This chapter will now continue to present the findings from this qualitative piece of research by the use of actual participants' quotes. The researcher felt that this way of presenting the findings would allow the reader to have a better understanding of the participants' thoughts and feelings about the residents' quality of life within a dementia care rest home and how those views are expressed.

The identified five themes are placed in order of significance and the frequency of which they were mentioned by each of the three participants over the four cases and are as follows:

1. **Feeling Lucky** – An expression that all four residents used.
2. **People Who Are Close** – Those people who are involved in the residents life and are seen as important; that is, their family, spouse and friends.
3. **Meaningful Activity** – Activity that is, keeping themselves busy or joining in activities in the present as well as satisfaction gained from reflecting on past achievements.
4. **Awareness, Impact and Acceptance of Dementia** – This identified an awareness the resident had of their condition, the impact dementia had on their life and acceptance of their losses.
5. **Adequate Care** – The actual physical assistance a resident received and the care given within a supportive environment.

These themes will now be developed in presenting the findings. Each theme will be developed individually and examples and quotes taken from participant's interviews will be presented. Each case will be numbered 1 to 4 with R used to denote the resident, F the family member and S to indicate the healthcare worker interviewed in each case. Where necessary "I" is used to signify the interviewer (researcher).

## 5.2 FEELING LUCKY

“Feeling lucky” emerged as the core category as this was an expression that all four residents used in the context of talking about their life generally in the home, in the interviews. The use of the exact term, by all four residents suggests this is a dominant and shared point of consistency, which in itself qualifies it to be considered a dominant theme. Feeling lucky has varied meanings within each interview, and when looked at in all four residents’ transcripts: having a sense of security, being independent, keeping active, meeting friends and seeing family were significant. All resident participants felt that they were lucky, as a good quality of life meant that a person could continue to live in ways that they are used to which included having family around them, having no concerns, being happy and reminiscing on achievements. As the following extracts from the interviews show, phrases mentioning “luck” were used in varying ways.

Resident 1 stated that she felt lucky because she was still able to enjoy activities such as going out on trips with others. “I think I’m happy. I enjoy my life I go on bus trips. We are very lucky.”

This statement showed an interesting switch from the use of “I” to “We”. This could be interpreted to mean either or both the resident’s family or the other residents within the home. In either case, it appears to signify an important link between the individual resident and a collective identity shared with others as part of “feeling lucky”.

R1 uses two terms (happiness and enjoyment) before summarizing these as “lucky”. In contrast, the family member interviewed in case 1 had mixed feelings about her mother’s wellbeing in the home: her language also uses three different terms (happiness, contentment, improvement – of two types) but has no simple summary expression “feeling lucky”.

F1 - “She’s the happiest here (pause). She would be upset if she had to move now (pause). I don’t think she is contented really (pause). Her health has actually improved. Life has improved here, physically, maybe not mentally.”

While the family member and staff interviewed in case 1 tended not to use the phrase such as “feeling lucky” as a key part of what quality of life means in the context of residential care for people with dementia, they believed that the resident was content and happy with their life. They believed that as physical health had improved following admission into the rest home

the resident had become more comfortable, and was getting more out of life than what they were doing at home.

S1 - “No, she is quite content with being here. She is aware of where she is and why she is here. She reads the notices in the office. She reads the notice that says it is possible for people with dementia to improve, and it gives her a wee bit of hope. It’s not completely downhill.”

From the interviews within case 2 the resident believed that he was “pretty lucky.” This statement was used in the context of the resident’s quality of life within the rest home. The family and healthcare worker of case 2 did not identify the actual theme of being “lucky” however suggested that the resident was fortunate in that he had made friends, was still able to enjoy a social life and having activities available such as the garden and going for walks.

F2 – “He has made friends and that. They have a social hour between 4 and 5 tonight.”

S2 – “We have got the garden here and that helps him and we always take him out for long walks.”

Resident 3 placed emphasis on the pleasant surroundings and environment, saying she was in a good place and grateful of the good care she was receiving from staff. She also recognised that there were people who were worse than her.

R3 - “I think I am pretty lucky to be in such a nice place and people do anything for you. I can’t growl. There are a lot of people worse than me.”

Family 3 made a comment about her mother’s mobility in the context which suggested that being “lucky” was related to the resident’s physical wellbeing. F3 also commented that R3 may not be so “lucky” mainly because of the symptoms of the dementia or the fact she was not as active within the rest home as she was when she lived at home.

F3 – “She keeps pretty good but I have noticed that her mobility has really slowed down since she has been in here. And I don’t know whether that is just part of the disease or you know whether she is just not getting the exercise as she was at home.”

The same family member and also the healthcare worker interviewed in case 3 believed happiness and entertainment within the rest home could be related to a person’s “luck”.

F3 – “Generally in here when I come in she’s good. I think she really is quite happy here and they seem to be always doing things like entertaining. And I think she gets a lot more out of her life being here than she was at home.”

S3 – “She often says that she is happy here”.

Resident 4 considered she was “lucky” in that she was still able to do things she used to enjoy. “I’m doing the things I like to do.... So I reckon I’m very lucky.”

By comparing opinions comments and language over the four cases we can see differences in views. Overall, residents stressed “feeling lucky” in their general evaluations of quality of life. Feeling lucky suggests that a person is having their basic needs met along with a more positive dimension of life.

## **5.3 PEOPLE WHO ARE CLOSE**

The result of this study showed that interacting with others is a natural way of life and is an easy task for everyone to perform including people with dementia. It also recognises that social engagement does not require a person to hold specific cognitive abilities. The findings suggest that people with dementia want and are still able to experience pleasure and joy from interactions with other people.

This study indicates that having people around seemingly lessens family’s concerns about the resident’s perceived loneliness and isolation. Close people were seen to offer support and comfort for the resident, in turn improving the resident’s mood and quality of life.

Over all four cases of the three viewpoints, having people close to residents was found to be an important factor in the quality of life of a person with dementia. Close people included family, friends and spouse. All residents expressed that their family and friends were important to them. Even though some of the residents felt that they did not see them that often or felt they did not have regular visitors.

### **5.3.1 Family**

In this study family involvement and the role of the family both physically and also emotionally was seen to contribute positively and fundamentally to the resident’s quality of life. Family was seen to continue to play an important role in their relative’s life. Residents

valued their family members in providing support and kindness and the positive feelings they had of being involved in their family's lives. In interviews residents spoke of their parents, siblings, children, grandchildren and great-grandchildren. For some residents, other family members did not visit them on a regular basis; however this did not appear to have a negative impact or be a negative reflection on how the resident felt about them, as family members continued to dominate the conversation.

R1 - "I love the family. Four children. The door opens and there's the family and talk about laugh."

I - "How does seeing the family make you feel?"

R1 - "I cry. I'm a big baby I love my great-grandson he laughs at me."

In response F1 said that family was vital in the resident's life. R1 would become quite excitable when she knew they were coming to visit.

F1 - "Family is extremely important to her. Loves visits from family.... she adores her great-grandchildren, and I haven't told her there's another one coming in April. It's a bit early to tell her. When I told her her family was coming that week she kept looking behind me for them."

The healthcare worker in case 1 believed that family were important to R1 though recognised that this could also be a frustration to her as family mainly focused on the negativity of the dementia.

S1 - "Family is very important they are also an extreme frustration. They don't understand her condition. They ask her too many questions. I think she feels degraded really. She feels that her condition is brought to the fore. She's always reminded that she has got a problem."

Resident 2 commented that his family (sons) was important but did not speak about them in a fond way but in a way that they were acting as a source of security for him in that they were looking after the family farm. Family 2 commented that family involvement had never been so important to R2 because he had always been a hard working man who did not have much time for his children.

F2 - “No not really because he used to stay out for a long time on the farm and he wouldn’t come in until it was news time. And by then the children had had their meal and never saw much of the children.”

All participants in case 3 felt that family was important to the resident.

R3 - “Oh yes couldn’t do without them.”

F3 – “I think it is. Well she will always ask how they are.”

S3 commented that she thought family were important to R3 as she often talked to staff about other family members and was always keen to talk about her involvement with family.

S3 – “Oh very yes. She will talk about what they got up to and that. When we see the photos and things like that, yes. And she always participates in their weddings and she gets quite excited. She will comment that it was nice to see them.”

At one stage during the interview resident 4 became quite tearful when reminiscing about her parents though with reassurance and redirection away from that particular topic the resident agreed to carry on. Interestingly R4 commented more about her parents than her children or siblings and when the investigator attempted to distract from her parents she focused again on her mother. The researcher was able to use cues such as photographs in the resident’s room which was useful in enabling the resident to move on and become more focused on further parts of the interview.

R4 - “Oh yes my mother and father helped me do all the things I wanted to do.”

I - “Have you children?”(Interviewer points to a photograph).

R4 - “I’ve got two daughters and they visit as well and mom (resident’s mother) usually goes and gets them.”

S4 also commented that R4 only really spoke about her mother and father and had difficulty remaining focused on other family members.

### 5.3.2 Friends

Three out of the four cases in this study believed that staying in contact with friends and the desire to have them visit was an important factor in the resident's life. The three cases believed that friends were significant in contributing to the resident's quality of life particularly friends from the past who continue to visit.

Three out of the four residents continued to think of old friends even though key relationships with other residents and staff had now been formed within the rest home.

The residents' perception of sharing conversation with others enabled them to have feelings of self-worth and lessened feelings of loneliness. Comments were made by residents which showed they enjoyed company and were always glad to see their friends.

R1 - "Oh yes always had friends, I'm glad to see them when they visit. We get encouragement don't we?"

All participants of case 3 believed that friends were an important part in her life and continue to be.

R3 - "Oh yes I've still got them oh yes they all come and see me."

F3 - "Yes especially while she was living at home. Really good friends. She can talk still really good of old times."

S3 - "I know that she gets some visitors and she's got a friend, a photo in her room. And it was a very dear friend that passed away and she will tell you that it was a good friend and she had passed away. So I would say that has been very important. I think she just gets on with everyone really."

Resident 4 suggested that friends who visited often were more important and wanted to ensure that she gave them more of her time than her newly made friends.

I - "Have you made friends with the other residents here?"

R4 - "Oh I have lots of friends. Yes it's the company you know. I really enjoy someone coming for a cup of tea. I have to make sure our old friends have a day to themselves."

F4 agreed that old close friends were more important to R4 than friends that she had recently made within the rest home.

F1 and S1 said that friends were important in R1's life however the symptoms of her dementia made it difficult to remember names. This added to her confusion and confabulation about other residents in the home.

F1 - "Friends are important to her, I think so. Has made a friend with one she seems to like her... She tells stories about the other residents. But she thinks they are real because of the memory she gets all mixed up it's the dementia I think....always been a people person always out doing for other people."

S1 - "All her friends in the past. She shows me cards and talks about people that she worked with that still visit her. She again gets frustrated with trying to work out their names, she remembers them. She has made friends here."

All participants in case 2 including the resident identified that friends did not play an important part in the resident's life, and comments from the case suggested that this was partly related to the resident's earlier work experience; they were too busy to socialize.

R2 - "Just friends from early on. I'd be lying if I said they were important. I'm not a good communicator. I've always had something to do, working on the farm."

F2 - "He doesn't make friends. He doesn't like mixing with people. He's been like that for a long long time. Whether that's part of it (work life) I don't know."

S2 - "Doesn't, hasn't really come up. The only visitor other than his wife and his children is his brother. I would say possibly a compact unit and didn't socialise a lot."

Central to this theme was the finding that people with dementia enjoy companionship with people that are known to them from the past rather than newly made friends. However being surrounded by unfamiliar people did not appear to impact on their desire to interact with others.

### 5.3.3 Spouse

The theme 'spouse' was identified to be of importance to all participants interviewed. The role of marriage continued to be a source of happiness to all four residents even for those who were now widowed.

In case 1 the death of a spouse had occurred prior to admission to the rest home. F1 and S1 believed that the death of the spouse had been accepted by the resident. F1 had never heard R1 talk of her father.

F1 – “Dad died 27 years ago, took her a wee while to handle it. I’m pleased she has accepted it now. She doesn’t talk much about him now, but marriage was important at the time.”

S1 – “She just says that she had a happy marriage....”

S1 reported that R1 would reminisce about her husband mainly when photographs triggered her memory. S1 – “She talks about him, ‘there’s father in the photo’ she is grounded in time.”

Resident 2 displayed more emotionally charged comments and appeared more dependent on his present (second) wife visiting him. He commented that his wife may not understand his condition, and that she would think less of him.

R2 – “I don’t see her much. I try not to let it get between us. I don’t know if she loves me as much. I would like to do more for her. I hope she understands. I would like to see my wife more I don’t want to pester her though. She’s busy with the farm. I often wonder if she accepts me as I am now. I can feel a little insecure. I haven’t got the ability as I used.”

F2 and S2 said that the resident was very much focused on his present wife and his belief that she had not visited impacted negatively on his mood.

F2 – “Very important. This is his second marriage. He tells people that I haven’t been to see him. He can worry about me not being here. And what I can do about that I don’t know. He forgets I’ve been here.”

S2 – “His wife is the first thing on his mind and she is on his mind all day long. I would say that it is a very strong marriage because my understanding is that it is the second marriage and there is no mention of the first wife. If we ask that question then yes it’s everything to him.”

Resident 3 had experienced two marriages and two spousal deaths again prior to her placement in the rest home. She would only talk about her husbands when a situation or a memory would prompt her.

R3 - "Well I think about them but you know it was nothing, not my first marriage you know and because he was the father of all the kiddies. Something crops up you know we've been somewhere and I've gone there again and it's brought back the memories that we've been there. I don't dwell on it or anything like that, I just you know."

F3 stated that R3's marriages had been important but did not talk about her husbands' much. "Not really unless we bring it up to her. I think it's just that she just forgets about it."

S3 believed the resident's marriage to her first husband was important as he was the father of all her children.

S3 - "Yes she's had a couple of marriages. Yes she brings that up every now and then. I'm not sure that she remembers her first married name but she does talk about her first (husband) the name and the name of her (first) husband, and that she has been married."

R4 had been married twice though did not mention this in our interview. She stated that marriage was important to her, however from the following comment it is difficult to ascertain whether she is commenting on her first or second marriage.

R4 - "We were pals, friends, lovers and companions a long time ago..... We have known each other since we were children. He makes me feel that I am there for a reason."

Interestingly F4 reported that he believed the resident thought her second marriage more important now than it ever was. He believed this was part of her condition. He also commented that she is now much more loving and pleased to see him than she was in the past.

F4 - "2 years ago she didn't recognise me at all. I was the man who did the garden, the cooking. Her husband was away working and coming back sometime. I kept saying, look now, we've been married 50 years. And she looked at me. "Married. You. Married an old man like you." You have to laugh! She has become very affectionate and loving and you wonder what is happening in the mind. Different personality altogether. She is loving and happy and smiling."

S4 believed that R4 was happy when F4 visited her, but did not comment that the marriage was important to the resident.

S4 – “Oh yes she’s delighted when he turns up and takes her out. She laughs with him. It’s hard to know if she’s talking about her husband or her dad sometimes.”

From drawing upon S4 statement the researcher agreed that it was hard to distinguish whether R4 was talking about her husband or her father.

All resident participants expressed the importance of having “people who are close” in their lives, those people included family members, spouse, old and new friends. Residents fondly talked of significant people who remain physically attached; for example those that continued to visit them in the home. For those significant others who did not necessarily visit the residents for various reasons (deceased or living overseas), nonetheless they continued to have some meaning and purpose in the resident’s life.

## **5.4 MEANINGFUL ACTIVITY**

This study identified participation in activities is essential in maintaining a person’s well-being. It was seen to provide distraction from the symptoms of dementia for the resident and help the person focus on positive aspects of life in turn improving the resident’s quality of life. By simply carrying out everyday tasks or by being part of social activities enabled the resident to feel better about themselves by giving them a sense of achievement. Within the findings meaningful activity was identified as both what residents were doing in the present and what residents had achieved in the past.

### **5.4.1 The Present**

#### **5.4.1.1 Chores**

Residents enjoyed functional activities that filled their day and brought them a sense of fulfillment and meaning. Feelings of being valued were raised by residents in their ability to complete small chores. All residents were happy to help out with everyday chores.

F1 reported that R1 often spoke of completing odd jobs and helping out but had not actually seen her do as much as what R1 said she was doing.

F1 – “She says she does a lot of things but it’s like all of them. I have not actually seen her do it.”

S1 reported that R1 was able to complete rest home tasks that are set for her by staff.

S1 – “She does want to help. She can manage quite a bit of the task, she lays the tables, helps with the morning tea trolley, replaces glasses in the bedrooms, makes own bed and tidies room.”

From speaking with R1 it was clear that she enjoyed helping out but knew her capabilities; there were times that she felt very tired and had difficulty performing tasks.

Resident 2 was keen and eager to help out whenever he could; this was evidenced by comments made by all participants of case 2.

R2 - “Well I get asked occasionally. More than happy to help.”

F2 – “Yes they have a garden out there and he waters the plants.”

S2 commented that R2 was sprightly and extremely active with good energy levels.

S2 – “He’s really good. He’s actually one of our key helpers. A lot of our activities centre around activities of daily living. Like dishes, setting tables, collecting the dishes after meals, anything like that. The gardening and he’s always one of the first to organize and come and help. So he’s spot on.”

From my interview with R3 and R4 even though the resident was unable to actually complete these chores in the home these residents still had the satisfaction and belief they were carrying out these activities and were of some importance. R3 and R4 spoke of completing domestic duties as if they were still participating in these activities such as cooking and cleaning. Residents felt that they had some meaning and purpose to life, in doing such things.

R3 - “I like to do most of the housework the washing ironing, go and do the groceries. Oh yes I wash up the dishes because there’s not much and a knife and fork and plate. And I cook most of the vegetables.”

R4 - “I help in the garden if there’s time I’ll come in and see if she (mother) wants help in the house.”

F4 said that resident 4 was not able to manage many chores now due to a decline in her energy levels and lack of interest.

F4 – “Because her interests have reduced over the years and this terrible thing (dementia) has begun to take effect. And her energy and interests have been naturally affected as well.”

#### **5.4.1.2 Social and Fun Activities**

Social, fun activities were significant to each resident, being outdoors in the garden, on bus rides on a nice day. Being physically active such as walking and joining in stimulating activities such as housie and quizzes were of importance to the residents. Family and healthcare workers commented that the resident’s interest in social activities had declined and felt the dementia had contributed to this.

Resident 1 spoke of enjoying social activities and thought it was fun to join in. She showed disappointment that she was unable to read. “Enjoy housie they had peanuts. I walk with a stick and get around... I can’t read now.”

F1 believed that most pleasurable activities were not so important for their relative.

F1 – “She does like music she loves music. I haven’t seen her doing a great lot. I don’t know if she goes on that many van rides.”

S1 believed that joining in social or fun activities was not so important for R1 as staff felt she often held herself back. Staff felt this was due to the high standing R1 had in her past work history and perhaps that R1 may believe she would fail in completing the task and look silly.

S1 – “She does have the ability to have fun but again due to her job she has always made herself do things but doesn’t want to make herself appear silly. She reacts well to pleasant things, enjoys walks up to the shops, she watches a little TV, and enjoys the music.”

R2 felt that fun things were not a big part of his life. However it was clear that singing and being outdoors were events that not only he but all other residents enjoyed which gave them great pleasure. “I like singing. I go to sing-along’s. And gardening.”

F2 and S2 believed that having fun was not so important to resident 2.

F2 – “He used to like to play cards. I don’t know that he can play now. Nothing else really.”

S2 – “Singing and gardening although it is a chore it is also something that he enjoys having been a farmer.”

F2 believed that her husband was not so physically active and commented on her concern about the restrictions on his freedom as he was now in a secure unit.

F2 – “He keeps very good physically; he likes his walks and that. But here he’s sort of shut in and he can’t go for walks, I didn’t realize that when he was brought here. It was lockable. I thought he would be able to wander around the garden.”

R3 enjoyed meeting others and going out on van rides.

R3 - “We meet in the lounge and chat and go out for one or two bus drives.”

Family believed R3 lost interest in fun activities and commented this was because of her dementia.

F3 – “She’s got some knitting there but it’s just getting her to do it. Sometimes she will start and she can do a couple of rows but then she either loses interest or she can’t remember what she’s knitting. So yes she will just put it down. It’s (dementia) certainly changed her life because she was into everything she was pretty active and pretty social.”

Staff found R3 to be sociable, active, and was always jovial who showed a great sense of humour and who was always cracking jokes.

S3 – “Oh she’s there if something is happening she’s there. Her latest is she tells us she is going to strip off and dance on the table. We worry how she’s going to get up there. Oh she’s very jovial. She’s lovely. She likes a good joke.”

R4 commented many times about her animals and continued to show an interest in them during our interview. S4 also believed that animals were the main source of her enjoyment and continued to have an interest often talking about her dogs and horses.

Family however believed that R4 had now lost all interest in that part of her life, particularly if he took her a drive out in the car and they passed horses in the field, she no longer commented on them.

F4 – “She was in a business rearing foals with her friend and she was in the riding club, secretary all her life, 25 years. She was the secretary of a riding club and then she entered into dressage competitions, which was a big thing. But no interest now, no interest and very little interest in horses now. You go past a field and see young horses and foals and mares not really interested. Funny. Yes.”

S4 believed that R4’s poor sleep pattern and high anxiety levels made her more lethargic and impacted on her ability to join in social activities.

S4 – “She has periods of anxiety and worry. She wears herself out, but other times when she is settled she is good. She loves to go for walks and things like that when she’s settled. Her pain in her knee which restricts her a bit. Some nights (sleeps) not so well. Up and down a fair bit in the night. On these occasions she’s very tired the next day.”

R4 was very much relaxed, she did not complain of feeling tired or that she suffered with pain whilst I conducted the interview. This may be due to the fact that she was happy to engage in conversation with the interviewer and her pain had been controlled with medication.

#### **5.4.2 The Past**

Past achievements in the residents’ lives such as work and family were seen to contribute to their quality of life and can explain some of the residents’ patterns of behaviour. Being able to help when residents can or even talk about their interests showed a satisfaction in their life along with some independence. It is also a reminder that the resident who has difficulty communicating still has something to contribute.

R1 was seen to be always trying to help out with nursing staff even though she had difficulty with communicating. She was often found out in the corridor watching for untoward occurrences that may involve other residents hurting themselves. R1 would often make comments to the nurse to take a rest, and she would be regularly found assisting other residents out of their chairs.

S1 – “She is checking out that I don’t need a hand. (R1) likes to check out that everyone is not doing what they (other resident’s) shouldn’t. She also helps out a lot of people, that they are ok and does the nurse thing, are you alright, you look tired. Helping the other residents and then she worries about the staff, are overworking, do you need to sit down, have a break. She

is more concerned for everyone, which I think at times tires her out. Her job has impacted on her a lot. That's when she feels tired because 'I'm ninety and I don't want people to think I have to do that and I might not be able', and worried that she cannot carry on."

F1 – "I think she thinks she is still working. And she does keep an eye on some of the residents. That's what the staff has said to me. She goes and gets them. She has in the past, has tried to pick others off the floor, and she got told off for that."

Throughout the interview R2 talked about his working life over the years on the farm and from other comments the pride he had knowing family had taken over his business. "I've done all I need to I think. Setting up the farm."

From comments made by staff R2 was always one of the first to help out and they felt that his work experience and happiness in his achievements showed itself in him playing a big role in the unit. "He plays a big role in the wing and everything that goes on in here."

From comments made by R3 during the interview it was apparent that domestic chores such as cooking and cleaning had been a big part in her life. The resident commented that chores had become difficult for her to manage

R3 - "Well I found it hard to you know to do everything and I like the place just right and you always think that you do better than somebody else so."

R4 during the interview regularly talked about their work with animals and the enjoyment they found riding horses and taking dogs for walks.

For all participants "meaningful activity" was a concept used to encompass everyday chores as well as social and fun activities that residents completed daily. Some residents exhibited the idea and gave the impression to others that they continue to be actively involved in chores around the rest home, which was not the case. This suggests residents had beliefs they were making some kind of contribution within the rest home which was an important factor in the resident's life.

## **5.5 AWARENESS, IMPACT AND ACCEPTANCE OF DEMENTIA**

Resident participants in this study were distinctly aware of their condition. Residents spoke of the impact dementia had placed on their quality of life however they also spoke of their

acceptance and adjustment of their own losses. From the resident interviews it appears they saw dementia initially as a burden, but then gradually became to accept the losses that the condition brings with it. From the family's point of view they appeared to feel only their own loss at first, but had gradually begun to appreciate but not necessarily accept the loss that the resident was experiencing.

All participants talked about a loss or decline in the resident's functional ability relating to independence and communication. Some responses illustrated being taken away from familiarity such as their home and family had impacted negatively on the resident's quality of life. Other comments made were in relation to frustration about the resident's condition and the effect and impact dementia had on the resident's ability to complete tasks. One resident expressed her annoyance at her inability to recognise people she knew from her past. For some residents using humour and talking about their dementia had become a strategy they used to accept and manage the condition.

### **5.5.1 Independence**

Resident 1 spoke of a loss of her familiar home and her independence:

R1- "My condition has affected me. Lived in my own home and when I was moved here I had to build a home here. I was independent but then I had to get more (help)."

S1 identified that dementia had placed an element of frustration upon the resident due to her dependency on the staff.

S1 – "I think it has caused frustration for her. It's taken away her independence and her ability to choose what she's doing as much as she would in the community."

F2 also believed the dementia had made their relative more dependent on others which had impacted on his mood. "He does get depressed now and again. Because he's aware of his condition and has made him more dependent on others."

### **5.5.2 Communication**

R1 also spoke of the difficulties with communicating with others. Noticeably throughout the interview resident 1 found it very difficult to express herself and had frequent word finding

pauses and substitutions of words. She was clearly frustrated and embarrassed about losing her ability to communicate but even so remained content to continue to talk with me. “When I’m talking to somebody I can completely leave it. I’m not much good now.”

This statement showed awareness this resident’s difficulty in communicating but did not show that this loss affected her in a negative way. She remained an active individual within the rest home who clearly enjoyed helping others particularly residents in need of assistance.

However F1 believed that the dementia had affected the resident’s quality of life in the rest home. They spoke of the loss of her ability to communicate.

F1 – “Her ability to communicate with other people really. My brother in Auckland will ring up and say I can’t communicate with her and she goes off on different tangents. And that makes life difficult.”

At home R3 said she had become isolated and other people and friends had stopped visiting. Family believed this was because of the poor communication and lack of conversation.

### **5.5.3 Family**

F1 spoke of other family members not visiting her mother because they preferred to remember her before her illness and disliked seeing her the way she is now.

F1 – “And that’s probably one of the reasons my brother doesn’t come that often, because they find it difficult. They don’t like visiting mum here because they know what she was like, and they don’t like seeing her the way she is now.”

S4 believed that dementia and placement in the rest home had taken R4 away from her family life.

S4 – “It’s taken her away from living with her immediate family and being able to enjoy a lot of things that she would possibly be able to still do. She would still love to be out there (at home).”

R2 commented that he felt insecure as a result of his condition. He believed that he did not see his wife as often as he would like and questioned whether his wife may think less of him or

may no longer love him. He showed signs that he was experiencing grief over the separation between him and his wife, due to his move to the rest home.

#### **5.5.4 Loss of Abilities**

R1 spoke with the researcher about her limits and the loss of her ability to help others and that she had become aware of the restrictions placed on her.

R1 - "I do get tired especially now I haven't got the proper type (meaning ability) as I should have. I have been helping quite a bit doing the afternoon teas. I need a little more rest these days I can go to sleep easily, it's a nuisance. There are days I don't sometimes help. I'm not ready."

Family and residents all spoke of losing the ability to recognise people who were important to them.

F3 - "She really got quite upset, and I could see she was looking around the lounge and like, she just didn't recognise anybody. Yesterday I could tell that there was nothing (recognition). She was looking at them (friends) and thinking I've never seen them before. Don't leave me here. I want to go home."

R4 - "Oh yes the people that I really respected and liked. I didn't recognise them and I thought there was something wrong with my brain."

I - "Did it affect you in not knowing who people were?"

R4 - "Yes."

I - "And how did that make you feel?"

R4 - "Well in a strange place and I didn't like it really without anybody I knew, you see."

R2 appeared to display recognition and had begun to accept his condition and his losses in relation to helping out in the home and on the farm. He was aware and had begun to accept that his condition would not improve.

R3 recognised and commented on the impact the symptoms of her dementia had on her life and her inability to do things she would easily have done before her illness.

R3 - “It has probably (made a difference) because I turn a lot of things down because I’m embarrassed to when they ask me to do things I know I can’t do I don’t like to say no.”

Two healthcare workers did not believe that dementia had greatly impacted on the resident’s abilities and quality of life.

S2 – “He’s quite late coming into our care so it may be overall the impact won’t be as great than others, because he’s had longer at home and longer to deteriorate. So from what I see there has not been a huge impact overall.”

S3 – “I don’t see how it has negatively impacted on her life. Her quality of life here is pretty good. She’s a happy lovely lady and a joy to help. She knows what’s going on around the place.”

Family member 4 believed dementia had changed his wife’s personality, and had had a positive impact on her quality of life; he felt she had become a happier more placid person.

F4 – “As I said first of all. Now she has changed and she is very happy. Yes generally I think it has worked out well overall. I am quite happy now everything has gone well for both her and for me.”

I – “Do you think the dementia has changed her into being someone that is happy?”

F4 – “I don’t know, I have thought of this. Before she was up front sometimes and always yes very full of life. She’s an awful lot more placid now. What you don’t know is, is it because she’s here or is it part of the course, her dementia. I don’t know, why this change and it was quite a sudden change, it wasn’t gradual. It was peculiar. Don’t know what’s going to happen next, she could go back.”

One family member identified that their own quality of life had improved since their family member had been placed in care. However one other family member commented that her husband’s placement had impacted negatively on her own quality of life resulting in her own insecurities and decline in her own mental health.

### **5.5.5 Humour**

Using humour is one strategy people with dementia will use in order to avoid stressful situations. Resident 1 showed insight into her memory loss and knew that it was a bad thing but had also come to accept it. She also had insight that she was in a secure environment and displayed humour to the researcher as she commented that she was hoping for a key to enable her to unlock the door.

R1 - "Pretty awful I have to admit it. I realize I'm here for life and you are not going to win but I would like something on my finger to open the door." (Laughter).

S2 - "He jokes about it a lot, little things, that he may have done something and he's realised that it wasn't quite how I (he) should have done it."

Resident 2 also used laughter and humour in order to distract the interviewer from his failing memory.

Through various losses residents displayed an awareness of how dementia had impacted on their life. Resident responses offered brief negative comments about their condition which was soon lost in conversation and humour. Family members, healthcare staff and indeed the researcher of this study, identified strategies that resident's used to accept and manage symptoms of their condition.

## **5.6 ADEQUATE CARE**

"Adequate care" to participants within this study was seen to be related to ensuring the maintenance of the residents' comfort by the delivery of supportive nursing care. Family members agreed that their relative was reasonably physically well and believed the placement of the resident within the home may be responsible for this.

From the findings in this research one of the four residents commented on the good care she received within the home as a component that had bearing on her quality of life.

Resident 1 was from a healthcare working background which suggests that her work ethic had impacted on her experience in the rest home.

R1 - “Physically keeping well. When you pass the nurse, they are very good to me. I had my bath properly in that room. That was really nice and the one said you can do it. I’m quite happy.”

R1 also remarked that a good quality of life was knowing that nurses like the interviewer were working to optimize patients care. “I like the belief that people like you are working well.”

F1 commented that her mother’s physical health had improved due to the fact that an infection had been treated and the correct medications prescribed and given. F1 said that life had improved with the physical care that R1 was now receiving.

F2 believed that the resident’s life was good now with the care they were receiving and that they had now begun to accept being in the rest home.

On the whole all family members were very happy with the nursing care of the resident within the home. However two family members added that their resident had lost their independence and their mobility had decreased.

Healthcare workers commented on the negativity of ill health and the importance of maintaining health and physical wellbeing and that quality of life was influenced most strongly by levels of dependency on nursing staff. Healthcare workers generally spoke of having basic needs met, being healthy and maintaining independence.

Within this study “adequate care” was also suggested to be involved around the resident’s social engagement. Three of the residents talked about feeling supported and secure with good people and staff around them. Family believed that staff who offered company, friendship, humour and emotional support was just as important as those providing physical care.

F3 commented that she believed her mother was receiving good care as the staff seemed to always keep her mother busy, she commented that her mother had gained more from her life now that she had been placed in the rest home. She also reported that when the resident was living at home R3 complained about being lonely, but since living in the rest home that had changed.

F3 – “Because at home she had become quite isolated and people kind of stopped visiting because you didn’t get much conversation and things like that. So she was always

complaining about being lonely, where she has never complained about being lonely since she has been here.”

In this case the family member described “adequate care” as comprising socialisation and activities in order to lessen her mother’s loneliness and isolation.

Family and healthcare workers commented that the environment was relevant to receiving “adequate care” whereby residents at risk of wandering from an unlocked rest home would remain safe whilst promoting and encouraging freedom and independence. In addition comments were made by one resident that the physical environment was significant to him receiving “adequate care” and his quality of life.

## **5.7 CONCLUSION**

This chapter has presented the findings from the viewpoints of people with dementia, their family member and also healthcare staff. This methodological approach of qualitative description put forward a powerful interpretation of the meanings and an understanding of the experiences of quality of life within a dementia rest home. These meanings will now be discussed further in the next chapter.

## **CHAPTER 6 - DISCUSSION**

### **6.1 INTRODUCTION**

The prime focus of this study was to look at views of quality of life for residents living in a specialist dementia rest home. The previous chapter presents the views of people with dementia, their family member and staff member about the resident's quality of life within the rest home at the time the data was gathered.

The objective of this chapter is to discuss the findings from the previous chapter, to address and develop the researcher's interpretations of the expressed opinions of all participants and link these to the literature reviewed and to the purpose of the study.

The researcher was solely responsible for conducting all interviews, the transcription of the interviews, close reading of the texts, creation of categories from key phrases and the continuous refining and interpretation of the category system.

Following the categorization of themes of most common and significant responses within the four cases and from the three perspectives the researcher looked for patterns and variations, and for differing and contradictory opinions.

### **6.2 WHAT THIS STUDY HAS FOUND**

On the initial categorization of themes the researcher recognised the fact that quality of life has many dimensions and meanings to all participants over the four cases. The researcher noted that according to a participant's description about quality of life, many of the identified themes were seen to integrate and weave in and out of other themes. Initially the researcher found seven themes that were seen as contributing to a good quality of life. Upon discussion with her supervisors it was felt by the researcher that two of these identified themes overlapped into two other categories. The themes were therefore narrowed down to five. One overlapping and overarching theme was "living a life worth living." This was deemed to include all other confirmed themes. The other overlapping theme was "past achievements" which was seen to link well into "meaningful activities" as presented in chapter 5.4.

The theme "feeling lucky", even though it can be perceived as relating to other themes in this study such as having people who are close, meaningful activity, receiving adequate care,

having an awareness of the impacts of their condition and accepting their losses was a phrase that all four residents used, and none of the other participants. For this reason, the researcher felt that this was a most significant finding of this study and deserved the right to be placed in a category of its own. The fact that this phrase was used by all residents reinforced the fact that quality of life is made up of many dimensions which encompasses the existence of a person's sense of security, independence, keeping active, meeting friends and seeing and reminiscing about family. Therefore quality of life is not determined solely in relation to being both physically and mentally healthy, it is also about the meaning of a person's life with many other factors playing an important part.

Notably from this study it is clear that factors affecting quality of life continue to be important even though the symptoms of dementia will impact on them. What one person believes is important may not be so important to another. Quality of life therefore is defined by an individual, their life course and the circumstances they find themselves in. What may have had meaning to someone thirty years ago may be very different and less important now.

Furthermore this finding suggests that the resident's perspective about their own quality of life is not necessarily influenced by dementia. How residents in this study feel about their own quality of life may be very different to how it may have been many years ago and is very different from the perspectives of the family members and the staff who took part in this study.

Dementia undoubtedly affects a person's life in many complex ways. However what was striking to the researcher in this study was that dementia does not appear (in these four cases), to be as devastating as others may think. Residents' comments suggested that they believed they were really quite well and there were other individuals not so lucky.

It appears that despite being given a diagnosis of dementia, as with many other chronic and disabling conditions, individuals will report a higher quality of life than "others" would expect. Previous knowledge of quality of life in dementia suggests that many people with dementia are able to accept, adjust and live a good life. Most people with dementia will often minimise the impact the symptoms of dementia have on their life. This finding confirms the literature by Albrecht and Devlieger (1999). Their discussion around the "disability paradox" found that people with chronic disease consistently rate their quality of life highly.

Another interesting point is that three out of four residents viewed themselves as requiring no assistance from others to meet their needs. This may be due to the resident's lack of recall in short term memory. It becomes clear from this study that family and staff have very different ideas as to how dementia may affect an individual. Family and staff informants appeared to rate the resident's quality of life lower than the residents did themselves. Family and staff did not feel that residents were particularly "lucky", believing that the condition had impacted on the residents life in terms of the resident's loss of abilities, communication, friends, family members, independence and socialisation.

This research confirms along with the reviewed literature, that researchers, clinicians and lay people all find it difficult to define quality of life particularly for people with dementia. Some would suggest that it encompasses a person's physical ability; a person's standing in society, happiness and satisfaction, and relationships with others. Other researchers would suggest that the maintenance of psychological health is paramount in order to maintain a good quality of life.

Measurements of cognitive, functional and behavioural outcomes are used worldwide to assess the correct interventions for people with dementia; however measuring health related quality of life is more challenging for clinicians. Generic measurement tools focus on the negative aspects of dementia and are not seen to be sensitive enough to pick up issues related to the condition. Quality of life for people with dementia must be understood as being multidimensional and should not only focus on health aspects or social interactions but also on a person's strengths, achievements and goals in life.

Therefore establishing what is a good quality of life for people with dementia is as difficult as defining it. Assessment of the subjective perspectives and experiences of dementia becomes difficult owing to people's differing views of what quality of life means to them. It is often suggested that people with dementia are unable to give a reliable opinion about their own quality of life due to a decrease in their cognitive abilities, lack of awareness and judgment and concurrent neuropsychiatric conditions.

This research finds (consistent with other studies) that people with dementia are able to express their views about quality of life, are interviewable and are able to maintain and express quality of life following a diagnosis and placement in a specialized unit.

The symptoms of dementia may impact on a person's ability to remember and communicate. However as the literature and this study suggest, people with dementia can rate their own quality of life. While proxy ratings are valuable, they are not a replacement for the resident's opinions.

The researcher agrees that the subjective viewpoint is important when rating one's own quality of life. However using the three voices (resident, family and staff member) in obtaining views of the resident's quality of life was extremely valuable as each added unique contributions to this research. By adopting this method the researcher believes that this piece of qualitative research is rich in description and true to the participant's thoughts and feelings. It has brought meaning and value to quality of life experiences for all those that are affected by dementia.

Some lack of agreement between residents, family and care staff opinions in this study was evident within certain aspects of quality of life. In these aspects there was a strong conceptual significance in the differences between resident participants' opinions and the views expressed by family and care staff. This study has typically shown contradictory beliefs and opinions between the person with dementia and the views of others. However the researcher firmly believes that the proxy opinions also added value to the research. Using proxy comments in the findings enabled a better understanding of the resident's life which in turn allows the study to become more person-centred.

Another most significant finding from this study shows that "people who are close" is not primarily about physical closeness but also emotional closeness. Even though residents did not see other family members, wider relationships continue to be of importance and play a significant role in their life. This finding is consistent with the research by Harmer and Orrell (2008) and Berg-Warman and Brodsky (2006).

Residents in this study felt by talking about their family or spouse, a link is maintained in their relationship and the resident did not feel they had been forgotten or abandoned. The importance of family, spouse and friends is a human need, and even if the person has a dementia there is no reason why this should be less significant or different from those without dementia.

For most residents whose family did not visit regularly they continued to express great joy when family members were spoken of and photographs viewed. The work of Berg-Warman

and Brodsky (2006) and Gaugler (2008) supports these findings and goes on to suggest that family involvement and the use of reminiscence are important in keeping a person's identity and enhancing their quality of life. Work by Livingston et al. (2005) on the other hand suggests that reminiscence is often used as a method of distraction rather as an intervention with little benefit. However during this research this suggestion was not substantiated as reminiscence appeared to enhance the participant/interviewer relationship.

Individuals go through life and build a personal history that is unique. Who a person is or becomes is linked to that history and if that becomes lost then identity is also lost. Literature reinforces the need to gain a full personal history to assist in emphasizing a person's self worth. For some with dementia who develop disorientation to present time, memory from the past though vague at times will often exist.

All four residents showed a sense of pride and achievement when discussing past life events and were seen to become quite relaxed and confident in the way they interacted in this part of the interview. This finding offers support for good practice: family involvement in care, benefits patient, family and professional carer in the development of person-centred care.

Of further significance is the fact that during interviews residents appeared to enjoy the social interaction with the researcher. There was a lot of humour and lots of laughter. Other local research with older people in a community setting suggests that social relationships are central to a person's quality of life (Hambleton et al., 2008). Berg et al. (2006) and Cahill et al. (2004) also suggest that social contact with others provides a feeling of security and adds to an improvement in wellbeing.

Importantly in this research residents spoke of friends and how happy they were to see them and also of joining in conversation and activities with other residents. Several other studies show social interaction as being an important activity for most people living with dementia (Alzheimer's Society UK, 2010; Atwal et al., 2003).

Shared activities are seen as significantly important to the resident's life from all three perspectives in this research with activities such as singing and van rides being frequently mentioned. A study by Harmer and Orrell (2008) suggested that singing increased social participation in people with dementia. They suggested that it places limited demands on a person with poor cognition thus promoting memories from the past. Participants' opinions in this research in regard to meaningful activity are consistent with this literature. Singing within

the rest home is highlighted as an important part of their life. Outings and van rides were also seen as a most common enjoyable activity for the residents in Harmer and Orrell's study which showed a noticeable rise in the spirits of the residents.

Of interest is that all residents spoke of one significant activity: being out in the garden, helping in the garden or talking about their nice garden. In Gigliotti's (2004) study horticultural therapy was seen to add benefits to an individual which promoted personhood. Harmer and Orrell (2008) in their study show that people with dementia find meaning in types of activity that filled their psychological needs rather than solely their physical needs. Gardening and being outdoors is clearly a shared meaningful activity for all these local study participants.

Furthermore of significance in this study was that all residents' standard of living and past working life experiences were seen to continue through to the present. An interesting point is the fact that two residents believed they continued to be active in the rest home even though they were not actually physically participating in chores. In this way, the researcher believed the residents felt a continuing sense of achievement as identified also in the study by Harmer and Orrell (2008). Family and staff participants on the other hand were seemingly more focused on what was happening in the here and now. Most family members believed the symptoms of dementia held the residents back from joining in activities. This is reinforced by the study by Harmer and Orrell (2008) suggesting that family members felt the decline in their relative's cognition led to them having difficulty engaging in activities.

One resident recognised her limitations in performing chores and would often tell staff that she was too tired. Family and staff agreed that the resident would not participate in too many activities but identified she held herself back for fear letting others down. Holst and Halberg (2003) also found that residents that withdrew from activities could be seen as a way of a defense method as the resident did not want to be seen as a failure.

Other researchers have suggested that staff and family appreciated what made activities meaningful was built upon the resident's past beliefs and values; individual identity was reinforced by recalling past activities (Harmer & Orrell, 2008). For some with dementia who develop disorientation to present time, memory from the past though vague at times will often exist.

The most prominent step in the process of adjusting to the dementia is learning to accept it. Throughout the interviews residents in this study showed awareness in relation to their dementia. Each discussed the impact the dementia had had on their quality of life and various ways they had adopted to accept their losses. All residents recounted a number of factors in accepting their dementia, using humour, attempting to help others and maintaining some hope. By adopting these coping strategies it appeared that residents showed awareness and were more focused on continuing with their lives rather than dwelling on their misfortune.

Dementia is a disease that triggers many emotions. Literature by Schulz et al. (1995) suggests that in the past people who had dementia were poorly understood by those around them. Consequently there are many misunderstandings that need to be addressed. It is often common for a person with dementia to refer to themselves as "stupid" and have a very negative view of them self.

These feelings of embarrassment can easily surface. Naturally it is embarrassing for people to be unable to remember what just happened or when things go wrong. A person's pride and self-esteem may be shaken. This often leads to isolation and withdrawal from social activities. Embarrassment may be most often felt by individuals with dementia who have lost a degree of self-control or judgement but also retain some insight.

One resident displayed a grieving process believing that he may have lost his wife due to his illness. Grief is a natural reaction when there is gradual loss of cognitive function not only for the carer but also for the sufferer. It is a great loss, when what people had together begins to change over time and many will miss what they shared in the past.

Accordingly, a person may feel guilty because they are unable to perform the same tasks as in the past resulting in a person becoming more reliant on family as their carer. Therefore it is important for the person with dementia to accept their feelings of embarrassment and guilt and know where they are coming from. It is often difficult to avoid negative feelings but it is important for individuals to understand them and avoid isolating themselves.

### **6.3 STRENGTHS AND LIMITATIONS OF THIS STUDY**

A most important strength of using qualitative research in this study was that the data it brought from interviews were rich in description and true to the person's thoughts and feelings at the time of the interviews. The QOL-AD questionnaire was used as a guide for all

participants whilst conducting interviews, so that the same information was given and obtained. This allowed the researcher to be more focused on exploring within the areas of inquiry outlined in the QOL-AD. Using this guide also allowed her to keep to an appropriate time schedule and would keep the interviews more focused. Whilst using a tape recorder during interviews, it was also helpful to take notes in case of technical failure and also to make observations of any non-verbal context of their statements; for example if a participant's comments were congruent with their body language, facial expressions, tone of voice.

This study may be seen to have two principal limitations. Firstly the small sample size. However a small sample size is congruent with qualitative research as it provides rich data of opinions. This data is shared by all participants which alerts the reader to the possibility that others will experience the same thoughts about quality of life in a specialised dementia rest home. Secondly participants were drawn from only one specialised dementia rest home. A person's quality of life can be misinterpreted and judged as relating to quality of nursing care. The researcher therefore chose only one dementia rest home as she did not wish this study to suggest or prompt people to believe this study was attempting to find out if the quality of nursing care is better in one particular specialised dementia rest home than another.

One other perceived limitation of this study was the possibility of the lack of impartiality on behalf of the researcher. The perspectives of the researcher may have influenced her findings as she was the sole researcher who became involved with the participants. However several steps were taken to minimise this risk. First, the researcher interviewed each resident before their family member and healthcare worker, and was previously unaware of the resident's progress within the rest home. During the period of data collection the researcher was involved with the rest home in a research capacity only, as alternative arrangements had been made for her colleague to assist in providing nursing support to the home during the period of study. Again, the independence of the two supervisors (one a Psychogeriatrician and one a social scientist) was a further protection against researcher bias. However, it is nevertheless considered that an appropriate interview technique is well suited to record the "lived experience" of a fluctuating condition such as dementia.

## **CHAPTER 7 - THE CONCLUSION**

Completing this study was related to my own personal thinking about quality of life for people with dementia which had entered my life over the years during my nursing career. I had found that dementia was often poorly understood, both personally and professionally in ways which implied that people with dementia were seen as having no purpose in life and having no opinions of their own.

The importance of considering quality of life in dementia becomes paramount. Quality of life issues for people with dementia are varied but mostly include the non-cognitive issues of apathy, depression, agitation, sleep difficulties, loss of autonomy and social isolation. The psychiatric symptoms such as agitation and aggression are emphasized for most people with dementia. Dementia becomes conceived as a frightening illness, but these symptoms are displayed usually as a result of confusion and anxiety and are not necessarily the specific symptoms of dementia. The progression of dementia more often than not renders the person to become increasingly dependent on family, professional carers and, in the later stages, institutional care. There is no cure for dementia therefore knowledge of dementia, the importance of early diagnosis following a clinical comprehensive assessment and the appropriate treatment of the symptoms is seen to be the best management available.

Reports and predictions confirm that the number of people with dementia will increase both because of the ageing of the population and the improved rate of diagnosis. The rising numbers are likely to have major implications for health and social care and to become a major force in demand for care homes specifically the specialist dementia care rest homes.

Within New Zealand caring for people with dementia will not only utilise a large proportion of the country's resources but will also represent a huge emotional and financial burden on family members and carers. The social and economic burden of dementia must be viewed from two different perspectives. Firstly the suffering and social restrictions experienced by the patient and family; and secondly the economic burden which will need to be shared by society as a whole. In years to come, health-care systems not only in New Zealand but around the world will be placed under increasing pressure.

Changes to policy, standards and guidelines have already been made in caring for people with dementia. To ensure that legislation is adhered to, education for people with dementia, family

and all healthcare workers including General Practitioners will play a valuable and significant role. There is the need to work on and design an appropriate knowledge base for staff about quality of life of a person with dementia and how to deliver person-centred care. This becomes the responsibility of the rest home in supporting their staff to develop their knowledge base and skills through study.

Having knowledge about how dementia may or may not impact on a person's quality of life could be seen to lessen the degree of guilt and distress for family members. With improved knowledge early detection of dementia will be promoted. Benefits include commencement of treatment to relieve symptoms and maximize independence and for longer; allowing time to plan for the future with decision making; allowing time for education for the individual and family members. Furthermore, care professionals with increased knowledge will develop their ability to intervene to improve the quality of life of individuals with dementia, rather than to change other aspects and symptoms of the disease. Assessment of quality of life is important when considering the positive states and 'personhood' in dementia, in contrast to most other measures of dementia that focus on the negative aspects of the condition. Apart from legal policy all Registered Nurses have a duty as part of their scope of practice to show evidence that the nurse is able to practice safely in relation to professional, legal, ethical and cultural issues and is accountable for her own actions whilst ensuring the patient's safety and quality of life.

The combination of the participant interviews and extensive search of literature resulted in a plentiful collection of research results about quality of life in someone with dementia. Studies suggest that quality of life is difficult to define because it is subjective and has many domains. However great strides have been made in recent years to conceptualize, define, and systematically measure quality of life in dementia. There are many factors outside the person's dementia that affect their quality of life which demonstrates the importance of avoiding assumptions. One common assumption is that following a diagnosis of dementia and placement in residential care, appreciation of aspects of a person's life is pointless because it will have no impact on quality of life.

The voice of people with dementia is often left out of research in favour of proxy reports. However quality of life is purely a personal thing and can be seen to change over the time of a person's life. These changes are often influenced by the environment, a person's outlook and circumstances.

Many argue that clinical assessments should rely on self reports, though others suggest due to cognitive impairment the person may lack insight, not easily understand the questions asked or have difficulty expressing themselves or remembering information. Quality of life in a person with dementia is subjective, and such an understanding is part of the notion of person-centred. However within research of this type the “three voices” ensured a richer, clearer description and a more full understanding of the life of people with dementia.

It is however now clear that a person with mild to moderate dementia is able to give a reliable account of their quality of life and commonly people with chronic conditions such as dementia see themselves as “lucky” and will downplay the symptoms of their illness.

From this research it appears that people with dementia in rest homes may not always need antidepressants but seek a life that is worth living. Therefore there is a need to learn how to hear what people with dementia are saying and for those that are not able to communicate, to develop skills in interpretation of emotions and needs from their actions.

People with dementia view social activity and family interaction as being extremely important to their quality of life along with remembering past achievements. Certainly visits by family members within rest home settings are seen to have a therapeutic benefit to people with dementia. Interestingly for those whose families are not physically a part of the resident’s life, these past relationships continue to remain an important component of the resident’s quality of life. Therefore emotional contact or recalling family members and friends can be just as important as having a face to face connection.

## **7.1 PERSONAL THOUGHTS AND PROFESSIONAL DEVELOPMENT**

This thesis evolved from my own personal and professional experiences with older people and their quality of life. Completing this research and thesis was not without its challenges however despite this it has been a worthwhile and rewarding experience. Not only has it provided me with the opportunity to contribute to an area of nursing that is difficult but it has allowed me to further develop my professional and personal growth. While this has only been a small contribution to nursing research it is my hope that the findings will be presented to a wider audience within the field of nursing and also assist in a better understanding of quality of life for family members.

The findings from this piece of research and other literature that I have viewed have allowed a better understanding of quality of life and how organisations can nurture or obstruct what they believe is a good quality of life. To assist in bringing about change in attitudes and beliefs the researcher believes the answers lie in listening to people with dementia. Furthermore in addressing quality of life in people with dementia, knowledge needs to be gained from professional carers, learning from families and growing on what was important for their relative before and after being given a diagnosis of dementia.

## **LIST OF APPENDICES**

**Appendix 1.** The Quality of Life – Alzheimer’s Disease Questionnaire

**Appendix 2.** Information Sheet for resident’s and family member.

**Appendix 3.** Information Sheet for healthcare worker.

**Appendix 4.** Consent form for resident.

**Appendix 5.** Consent form for family member

**Appendix 6.** Consent form for healthcare worker.

## Appendix 1

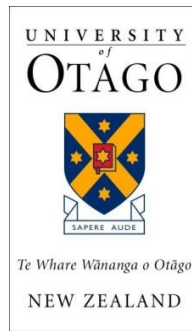
### The QOL-AD

Instructions: Interviewer administers according to standard instructions. Circle participant responses.

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|                                       |      |      |      |           |
|---------------------------------------|------|------|------|-----------|
| Physical health                       | Poor | Fair | Good | Excellent |
| Energy                                | Poor | Fair | Good | Excellent |
| Mood                                  | Poor | Fair | Good | Excellent |
| Living situation                      | Poor | Fair | Good | Excellent |
| Memory                                | Poor | Fair | Good | Excellent |
| Family                                | Poor | Fair | Good | Excellent |
| Marriage                              | Poor | Fair | Good | Excellent |
| Friends                               | Poor | Fair | Good | Excellent |
| Self as a whole                       | Poor | Fair | Good | Excellent |
| Ability to do chores around the house | Poor | Fair | Good | Excellent |
| Ability to do things for fun          | Poor | Fair | Good | Excellent |
| Money                                 | Poor | Fair | Good | Excellent |
| Life as a whole                       | Poor | Fair | Good | Excellent |

## Appendix 2



### Living A Good Life

A study for people

living in a dementia rest home and those

who care for them

**You are invited to take part in this study (For resident, family member/friend).**

My name is Di Evans. I am employed by .....as a Clinical Nurse Specialist.

I am currently enrolled in post graduate study with Otago University, Christchurch.

As part of my study I am investigating the views of resident's quality of life in a dementia rest home alongside the views of the family member and care staff.

This study will help the researchers to understand, value and to improve quality of life in dementia care.

I am seeking a small number of resident's and a family member in each case to take part. The manager has identified you as a suitable candidate to take part in this study.

For each resident a care worker who knows you (the resident) well will also be invited to participate.

Your participation is entirely voluntary and choosing not to take part in or withdrawing from the study will not affect the way you or your family member is treated within the rest home. If you would like to be involved please let the manager know and I will arrange to meet with you to ensure that you understand what is involved in the study. If you decide to take part and have 45 minutes to spare I will meet with you at the home to talk about your (the resident) quality of life. All interviews will be audiotaped. . All written details from the interviews will be kept securely within the University of Otago and destroyed after 10 years.

This study is confidential so no personal details will be passed onto anyone else.

Brief summary feedback from the study, will be available once the study is completed.

This study has received ethical approval from the Upper South B Regional Ethics Committee, ethics reference number URB/10/10/041.

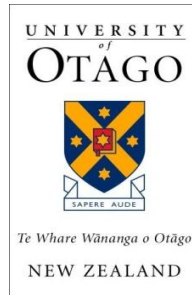
The Manager of the rest home has given permission for this study to take place.

This study is being supervised by Dr Sally Keeling and Dr Matthew Croucher, Princess Margaret Hospital, Christchurch.

If you have any questions about the study please feel free to contact me.

(Contact details were given to all participants prior to the commencement of this study. In order to preserve confidentiality the researchers details have been omitted on this form).

## Appendix 3



### Living A Good Life

A study for people

living in a dementia rest home and those

who care for them

You are invited to take part in this study (Healthcare worker).

My name is Di Evans. I am employed by.....as a Clinical Nurse Specialist.

I am currently enrolled in post graduate study with Otago University Christchurch.

As part of my study I am investigating the views of resident's quality of life in a dementia rest home alongside the views of the family and care staff.

This study will help the researchers to understand, value and to improve quality of life in

dementia care.

The manager has chosen suitable residents and their family member to take part in this study and you are invited to take part as you know the resident well.

Your participation is entirely voluntary and choosing not to take part or withdrawing from the study will not affect your work within the care home.

If you would like to be involved please let the manager know and I will arrange to meet with you to ensure that you understand what is involved in the study. If you decide to take part and have 45 minutes to spare I will meet with you at the home to talk about the resident's quality of life. All interviews will be audiotaped. All written details from the interviews will be kept securely within the University of Otago and destroyed after 10 years.

This study is confidential so no personal details will be passed onto anyone else.

Brief summary feedback from the study, will be available once the study is completed.

This study has received ethical approval from the Upper South B Regional

Ethics Committee, ethics reference number URB/10/10/041.

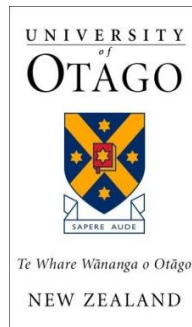
The Manager of the rest home has given permission for this study to take place.

This study is being supervised by Dr Sally Keeling and Dr Matthew Croucher, Princess Margaret Hospital, Christchurch.

If you have any questions about the study please feel free to contact me.

(Contact details were given to all participants prior to the commencement of this study. In order to preserve confidentiality the researchers details have been omitted on this form).

## Appendix 4



### Living A Good Life

A study for people living in a dementia rest home and those who care for them.

#### Consent form : Resident

It is my choice to take part in this study. I can withdraw at any time and it will not affect my care.

This study is confidential. No personal details will be contained in any written reports.

I can contact the researcher if I want further information about this study.

Taking part in this study will involve the researcher asking me questions about my experience of quality of life in this rest home. I do not have to answer questions that I don't want to.

I understand that the researcher will be interviewing my chosen family member (.....) and a care staff member who knows me well, similar questions about quality of life.

My interview will take approximately 45 minutes to complete.

My interview will be audio taped by the researcher.

I have had the chance to read about the study and talk about it with the researcher and my family member.

I have had enough time to think about taking part in this study.

I ..... (Resident's full name) hereby agree to take part in this study.

Signature: .....

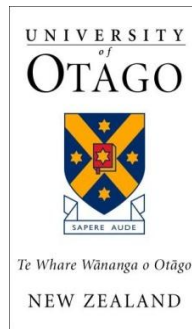
Date: .....

I ..... (researcher) confirm that I have explained the nature and purpose of this study to the participant whose name is printed above:

Signature .....

Date .....

## Appendix 5



### Living A Good Life

A study for people living in a dementia rest home and those who care for them.

Consent form: Family member

It is my choice to take part in this study. I can withdraw at any time and it will not affect the care of my family member.

This study is confidential. No personal details will be contained in any written reports.

I can contact the researcher if I want further information about this study.

Taking part in this study will involve the researcher asking me questions about my family member's quality of life within the rest home. I do not have to answer questions that I don't want to.

I understand that the researcher will be interviewing my resident family member and a care staff member who knows them well, similar questions about quality of life.

My interview will take approximately 45 minutes to complete.

My interview will be audio taped by the researcher.

I have had the chance to read about the study and talk about it with my family member and the researcher.

I have had enough time to think about taking part in this study.

I confirm that my relative ..... has consented to participate in this study. I support them to take part.

My            relationship            to            my            relative            is:  
.....

I ..... (full name) hereby agree to take part in this study.

Signature: .....

Date: .....

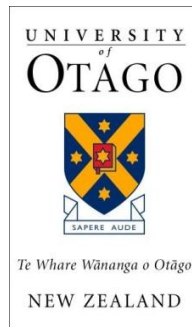
**Proxy assent (if resident is unable to give informed consent for the study):**

I confirm that my relative has given their agreement to participate in this study even though they may not understand the study completely.

Signature.....

Date.....

## Appendix 6



### Living A Good Life

A study for people living in a dementia rest home and those who care for them.

#### Consent form: Healthcare worker

It is my choice to take part in this study. I can stop taking part at any time and it will not affect my work at the rest home.

This study is confidential. No personal details will be contained in any written reports.

I can contact the researcher if I want further information about this study.

Taking part in this study will involve the researcher asking me questions about .....(named resident's) quality of life. I do not have to answer questions that I don't want to.

I understand that (following their consent) the researcher will be asking this resident and their chosen family member similar questions about the resident's quality of life.

My interview will take approximately 45 minutes to complete.

My interview will be audio taped by the researcher.

I have had the chance to read about the study and talk about it with the researcher.

I have had enough time to think about taking part in this study.

I ..... (full name) hereby agree to take part in this study.

Signature: .....

Date: .....

I ..... (researcher) confirm that I have explained the nature and purpose of this study to the participant whose name is printed above:

Signature .....

Date .....

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