

**A Descriptive Research Study on Factors that Impact Upon  
The Quality of Life of Elderly Women with Comorbid Chronic  
Illnesses; Three Women's Perspectives.**

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## **Abstract**

### **Background**

Women live longer than men and are more likely to live alone; this makes dealing with chronic illnesses more of a challenge for older women. Therefore, an understanding of what living with chronic illness is like for these women is essential in ensuring health professionals can meet their health needs.

### **Aim of Research**

The aim of this research study is to explore factors that older women living with comorbid chronic illnesses identify as key to maintaining or improving their quality of life.

### **Design**

This study uses a qualitative approach, with a descriptive methodology. Face-to-face interviews were conducted with three women over the age of 80 who had been diagnosed with more than one chronic illness. These interviews were audiotaped, and the data analysed using thematic analysis.

### **Findings**

What emerged from this analysis of older women was the need for them to create meaning in their life, which is further explicated through three main themes: (1) coping with changing health, (2) the impact of family, and (3) attitude. Attitude to life and having a positive outlook were all factors these participants expressed as being essential to maintaining their quality of life.

### **Conclusion**

The quality of life of these participants is enhanced by the ability of these women to create meaning in their life. They do this by integrating their wealth of past experience into their present, reflecting back on their lives, but still gaining enjoyment from the here and now. Understanding of how chronic illness impacts, and is managed, by these women leads health care professionals to a greater understanding of being older and living with comorbid chronic illness. The findings of this research may assist nurses working alongside older people to focus on the making of meaning,

which may facilitate these people to retain a sense of autonomy and control over their life.

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## **CHAPTER ONE: Introduction to Research**

Caring for the older person poses unique challenges, as the natural ageing process, the high incidence of comorbidities of chronic illness, and societies view of older adults all impact upon how these people receive and manage treatment. Geriatric medicine is a relatively new concept, and promotes optimising the care and well being of the elderly. Few physicians were interested in looking after older people at the beginning of the 20<sup>th</sup> century, until Marjory Warren created the first geriatric unit in the United Kingdom, in 1935. She strongly believed that elderly people with chronic conditions should be separated from other sick people, and treated in a separate geriatric assessment unit within the general hospital. This model of care offered sick older people the best chance of diagnosis and treatment, and she also ushered in a change of attitude of all medical and nursing staff toward elderly patients (Barton & Mulley, 2003).

With the current ageing population worldwide, we must continue to explore ways of optimising the quality of life of our elderly population to ensure that old age is lived with meaning, not just with longer years. If New Zealand is serious about this, we must consider ways of supporting our older adults and their families, ensuring that we take a whole person approach to the care of our older adults with co-morbidities and complex disabilities. Although older adults have comorbid chronic illnesses which affect decisions about medication, exercise, diet, and other areas of daily living, it is still not clear how multiple diseases interact, and the effect they have on daily life (Gold, 1994). Research into factors that older adults themselves find supportive, or otherwise, must be explored to ensure that resources are targeted to the most beneficial areas of health care. In this chapter I introduce my research question, the aims of my research, and briefly touch on the Liaison Nurse role within the Assessment, Treatment and Rehabilitation team in Kapiti, New Zealand, of which I am a member.

### **Research Question and Aims of the Research Project**

With my background of nursing in the community, I assist and advise many people who live with comorbid chronic illnesses. The impact of chronic illness



can be dire, especially so for women. They live longer than men, are more likely to experience decline in function, are less likely to recover from disability, and greater numbers live alone (Morrissey, 1998). I realised that I needed to understand, from their point of view, how older women manage their health on a day-to-day basis, what they found helpful to support them, and what was not. My question evolved thus;

What factors do elderly women themselves identify as impacting upon their quality of life when living with comorbid chronic illnesses?

The aim of my research project is to explore factors that older women living with chronic illness identify as key to maintaining or improving their quality of life. This will assist nurses to better understand how they can effectively support these women. As Morse and Johnson (1991) maintain, it is only by eliciting first-hand descriptions of the client's experience with illness can an understanding of the client's needs be developed and anticipated.

### **Justification for this Research**

The prevalence and impact of chronic illness on everyday life is a driving force for nursing care worldwide. Chronic illness is defined in the Mosby's Dictionary (1994) as any illness that persists over a long period of time and affects physical, emotional, intellectual, social, or spiritual functioning. Chronic illnesses are often invisible or misunderstood, and little is known about the experience of living with chronicity from the perspective of the elderly. Nurses are left to assume for themselves how illness impacts the everyday lives of the patients for whom they care (Hodges, Keeley, & Grier, 2001). The elderly have much to teach us about day to day living with chronic illnesses and the comorbidities more than one chronic illness can bring. As nurses caring for an increasingly larger older population, there is a lot to learn about the actual experience of ageing, and the health problems age can bring.

There is a good deal of research on individual chronic illnesses, such as depression (Birrer & Vemuri, 2004; Loughlin, 2004; Ugarrisa, 2002; Wolff &

Agree, 2004), chronic obstructive pulmonary disease (Engstrom, Persson, Larsson, & Sullivan, 2001; Mador, Bozkanat, Aggarwal, Shaffer, & Kufel, 2004; Slavin, 2004), chronic pain (Dysvid, Natvig, Eikeland, & Lindstrom, 2005; Higgins, Madjar, & Walton, 2004; Roberto, 1994; Walker, Holloway, & Sofaer, 1999; Widar, Ahlstrom, & Ek, 2003), and osteoporosis (Bianchi, Orsini, Saraifoger, Radaelli, & Betti, 2005; Kessenich & Guyatt, 1998; Kotz, Deleget, Cohen, & Kurata, 2004; Kumar, Verma, Wilson, & LaFontaine, 2005). However, the vast majority of this research is quantitative. There is very little qualitative research from the client's point of view, and even less again that discusses what it is like to live with more than one chronic illness. When more than one chronic illness is discussed, it is often in conjunction with depression, such as Eriksson et al. (2004) who researched depression after stroke, Lin et al. (2004) who conducted research regarding depression and arthritis pain, and Brown, Majumdar, Newman, and Johnson (2006) who studied depression and new onset Type 2 diabetes.

Although the majority of research around chronic illness is quantitative, there is some research that investigates how older people themselves view their lives living with chronic illness, and that use a similar the methodology and method to this project. For example, Morrissey (1998) reports on her findings from a North American longitudinal descriptive study of 15 women aged between 76 and 92 years, who were living alone. She discovered that reminiscence is a very effective tool for accessing the inner world of the elderly woman, which highlighted some insights into factors that contributed to an elderly woman's ability to continue living alone in the community. In Kralik, Koch, Price & Howard's (2003) Australian-based research, they invited nine people to write an autobiographic account of their life and experiences of living with illness. Williams (2004) conducted semi-structured interviews with 12 clients to better understand how patients with comorbidities experience nursing care during acute hospital admissions.

Roberto, Gigliotti, and Husser (2005) examined older women's experiences with multiple health conditions, and the daily challenges and care practices they undertook to maintain independence. Dewar (2001) used face-to-face

interviews to understand what protecting strategies sufferers of catastrophic illnesses and injuries used to cope with everyday life. However, this study used participants ranging in ages from 18 to 75 years, outside the age group of the participants recruited for my research. Beitz and Goldberg (2005) also used interviews to understand the lived experience of chronic wounds. They discuss the role of chronic illness, and the identified themes revolved around the context of other chronic illness, such as diabetes, cardiovascular disease, osteoporosis, or arthritis.

None of the above mentioned research was conducted within New Zealand. This research study is important, therefore, to begin to build a picture of what chronic illness means to older women in New Zealand, and in the case of this study, the Kapiti Coast. This greater understanding of the experience of living with chronic illness and its impact upon quality of life means interventions and resources can be better targeted to those areas identified by women themselves.

### **Background to this study**

Elderly women take longer to recover from acute problems, experience more chronic illness, tend to experience unfavourable socio-economic conditions, partially due to their longer life expectancies and as a consequent, reduction in social support, as well as limitations of financial resources (Gold, 1994; Turk, Okifuji, & Scharff, 1994). With these factors in mind, I undertook my research recruiting only elderly women who live alone. As Smeltzer and Zimmerman (2005) explain, women with disabilities are the most knowledgeable source of information about their own healthcare needs. To be effective and enduring, health promotion interventions must be individualized and tailored to the woman's abilities, resources, values and perspective on quality of life (Stuifberg, Becker, Rogers, Timmerman, & Kullberg, 1999). Until the body of knowledge of these perspectives is increased by undertaking research, nursing cannot hope to adequately meet the needs of the older women with chronic illnesses.

As people age, there is a natural decline in physical and psychological function, however, people respond to the ageing process in different ways. My role is that of Liaison Nurse in the community Assessment, Treatment, and Rehabilitation team, based on the Kapiti Coast. This position means I come in contact with older people every day. I began to think about what it might be like to grow old while dealing with chronic illnesses and how the resulting disabilities are managed. The most common long term goal of the clients I meet is to remain in their own home for as long as possible. A large part of my role is to help to facilitate and support this goal. Therefore, it is important to understand what factors assist or hinder this long-term goal, and the best way to find this out was to ask the women themselves. By the sharing of their stories, these women were able to express in their own words what their life is like for them, what is important to them, and what they find helpful to their everyday life.

### **Introduction to the Methodology**

I used a descriptive methodology because this methodology allowed me to answer the research question and aim. Little is known about living with comorbid chronic illnesses and how they impact upon the quality of life of the older adult. Descriptive research is used when not much is known about a particular subject, as it builds a picture of the topic as it happens naturally, and uses everyday language. There is no New Zealand research about how chronic illness impacts upon the older person, so the use of this methodology will form the basis for future research on this topic.

The use of a qualitative approach for this study has allowed me to gather these women's' stories to uncover the reality of living with chronic illnesses, and the comorbidities that having more than one chronic illness brings. Their perspective on how they manage on a daily basis and the impact chronic illness has on their ability to cope gives us, as health professionals, the best insight into living with chronic illness. It is only by really understanding the lived experience can we begin to provide health care interventions that truly make a difference to quality of life.

## **Overview of the Thesis**

This chapter has outlined the research question and the aims of this study. I have explained the justification for my study, and how it adds to the body of nursing knowledge regarding the older woman and chronic illness. There is no research conducted in New Zealand examining the impact of comorbid chronic illnesses, therefore a descriptive methodology has been used in this study. I have briefly discussed the qualitative approach, and why this approach was used for this study.

Chapter Two gives an overview of the Kapiti community rehabilitation team, of which I am a member, and clearly positions me within the research study. Explanations of the assessment, treatment, and rehabilitation phases are discussed, as is the role of the nurse within the team. Also outlined is the multidisciplinary team, the different disciplines that make up the team, and some of the tensions and challenges that can arise when dealing with problems from differing perspectives.

Chapter Three explores the factors that I anticipated may have impacted upon the quality of life of the participants in this research. This chapter draws upon my experience of working with elderly people in the community. The implications of chronic illness is analysed, and current literature supporting each topic is presented. What emerges from this chapter is a picture of what it may be like to be an older adult living on the Kapiti Coast, and the impact that chronic illness and the ageing process may have on an individual.

The research methodology used in this research is explained in Chapter Four. I explore the qualitative approach, and the methodology employed for this study, which is descriptive research. I use interviews as the method of data generation, and I explain the process I undertook to complete the interviews, and how the data from the interviews is analysed. Ethical considerations are discussed, as are inclusion and exclusion criteria. The participants are also introduced in this

chapter, and a brief outline of each woman and some of her background is explored.

Chapter Five describes the findings uncovered from the interviews conducted with the participants. An overarching theme of making meaning in life is described through the themes of coping with changing health, family, and attitude. In this chapter excerpts from the participant's stories are related, and some discussion takes place regarding these using supporting literature.

More in-depth discussion takes place in Chapter Six. The three main themes are explored in more detail, and the way in which these women find meaning in their life is illustrated. I have highlighted the implications for nursing, particularly in New Zealand, as there is no previous research available regarding this subject using this methodology in this country. Limitations to this study are expressed, as are the implications for further research.

## **Conclusion**

This chapter has introduced this research project. Caring for the older adult with chronic illnesses, and the comorbidities that these produce, poses challenges for the health professional that chooses to work with this group of people. The aim of this study is to understand the factors that the older women themselves identify as impacting upon their quality of life as they live with chronic illnesses.

There is a dearth of research on this topic within the New Zealand context, and this study is a beginning to address this lack of knowledge in this area. By using a descriptive methodology, further research can be undertaken to build a larger picture of the older woman living daily with chronic illness and disability. The qualitative approach has allowed me to hear these women's stories to better understand what life is like for them, and to uncover the themes that they identify as beneficial or otherwise to them and how they make meaning in their lives.

Chapter Two positions me within this study, and discusses the Kapiti community rehabilitation team, of which I am the nurse within the team. Assessment, treatment, and rehabilitation are the cornerstones of the rehabilitation ethos, and these are explored in the next chapter. The multidisciplinary team is introduced, and some of the challenges and strengths of working within such a team are discussed.

## **CHAPTER TWO: The Kapiti Community Assessment, Treatment and Rehabilitation Team**

### **Introduction**

Rehabilitation is made up of three phases – assessment, treatment, and rehabilitation. This chapter presents an overview of the Kapiti Community rehabilitation team, and explains the different options available to people who live on the Kapiti Coast. Working within a multidisciplinary team has its own strengths and challenges, as each discipline has a differing viewpoint about a particular problem and the way to solve that problem. Some of these challenges are discussed in this chapter. Each phase of the rehabilitation process is explored, and the role of the nurse is described. Goal setting with a client is an integral part of rehabilitation, and this is discussed, including some of the current literature on this subject.

### **Overview of the Community Rehabilitation Team**

Capital and Coast District Health Board (CCDHB) offers both inpatient and community rehabilitation. There are two inpatient wards at Kenepuru Hospital, in addition to three community teams – one based at Wellington Hospital, one at Kenepuru Hospital, and the third in Paraparaumu. The community teams are multidisciplinary which are made up of many different disciplines, and includes Physiotherapists, Occupational Therapists, a Geriatrician, and Social Workers. We meet regularly to discuss how clients are progressing toward meeting the goals that have previously been set with the client. Each discipline has different skills and clinical experience and it is this diversity that enables the team to assist clients to achieve their goals, and makes working in a team both challenging and rewarding.

Rehabilitation is about the maintenance of existing abilities and roles, the promotion of health, the prevention of further impairment, the prevention and reduction of disability – it is about people's lives and the reconstruction of those lives in the wake of injury, illness, or surgery (Pryor, 2000). Successful rehabilitation is holistic and involves many aspects of provision of care. Not only does it involve therapeutic activities, but it is also concerned with



preventative measures and the recognition of barriers that exist to achieving goals. Rehabilitation is a long-term, interdisciplinary, whole-systems approach to motivating and assisting people to gain, and then maintain, their highest level of function (Young, 2004). Rehabilitation is a way of thinking, not a way of doing. It focuses on trying to help each client achieve their own goals, thinking how each obstacle can be overcome, and applying several interventions for a single problem until the goal is achieved (Wade, 2002). It is rewarding for all team members, and encouraging for clients, when a particular goal is achieved, and new goals can be set with the client. This focuses both client and team toward the future, and inspires us all to continue striving toward the achievement of further goals, each step building on the last.

In my role as the Liaison Nurse in the community Assessment, Treatment and Rehabilitation team on the Kapiti Coast, I work closely with people who suffer from chronic illness. Although this service accepts clients over the age of 16 years, by far the vast majority are aged over 65 years. This is of an age when multiple chronic illnesses are more likely to occur.

Presently, New Zealand has a relatively young population, with only 11.5 percent of people over the age of 65 years. This proportion of elderly is projected to grow steadily to about 13 percent by 2010, and then more rapidly to 22 percent by 2031, and 25 percent by 2051 (Ministry of Health, 2002). Currently, however, the Kapiti Coast has nearly twice the population of people over the age of 65 years than the rest of New Zealand (Kapiti Coast District Census, 2001), so it is not surprising that we mostly treat people in this older age bracket. The Kapiti Coast is largely flat, and has a mild climate. People are attracted to the area for their retirement years, which is a major contributor to the amount of older people in the area. There are many retirement villages and residential care facilities on the Kapiti Coast, meeting many different levels of care.

### **Assessment**

Assessment is the first step in the process of rehabilitation, which may be undertaken by many people from many professions, or simply involve one

profession (Wade, 1998). In the Kapiti community rehabilitation team, the first step in the assessment process usually involves two people from two different professions, and together with the client, they complete a multi-disciplinary team (MDT) assessment. This assessment highlights any problem areas, and enables the patient to begin the goal-setting process. Any problem areas are discussed, and permission gained to refer on to the appropriate discipline that is best suited to meet the need or problem. As Wade (1998) explains, the more areas of expertise covered by an assessment, the more benefit there is likely to be for the client.

As previously stated, the majority of clients that are referred to the rehabilitation team are over the age of 65 years. This age group presents unique challenges for the rehabilitation team when assessing, such as ensuring the client can hear, follow, and understand the questions. It is sometimes a challenge just to make the appointment by telephone, as the explanations about referrals, an outline of the team, and the reason for a visit can be difficult to explain and can be confusing, especially if the client already has involvement from other health care professionals such as the District Nurses or care providers.

Assessment is the cornerstone of gerontological nursing (Olenek, Skowronski, & Schmaltz, 2003), and never more so than in the community setting. Rehabilitative principles of establishing and maintaining a good quality of life can only be applied satisfactorily if good assessments have been made (Young, 2004). As Wade (2002) points out, the quality of decisions made and actions undertaken is dependent upon the quality and quantity of information available, which is gathered through assessment. Concern from clients has been expressed, however, that they are assessed too much, and are often asked the same questions by many different people. This year has seen changes in the way community referrals are handled in response to this criticism. All community referrals are sent to One-Point-of-Entry, at the Care Co-ordination Centre, which is run by a private company called Nurse Maude, who contracts to CCDHB. They screen referrals, and send them on to the appropriate service. If the referral is requesting assistance at home, then one of their Care Managers completes, with the client, an interRAI assessment. This is a comprehensive

assessment tool, which was developed by an international research and development collaboration, and was designed for use by health or social care professionals who have been trained in its application (interRai UK, 2002). Once a Care Manager completes this assessment, recommendations are made as to how best the client can be supported to remain as independent as possible in their own home.

This assessment process can be both good and bad for the rehabilitation process. Care at home, such as personal cares, can be put in place before the rehabilitation team have completed their assessment of what resources may help a client remain independent as possible. For example, the request may be for a showering assessment, with a view to having rails or a shower stool. If the Care Manager has already put personal cares in place, it is more difficult to keep a person independent, as they can soon become to rely on a carer at home. As Godfrey (2001) points out, the provision of home care to older people with high dependency needs may significantly reduce their abilities in carrying out some activities of daily living, and can increase dependency.

On the other hand, this new system works on a restorative model where carers assist a client to maintain function, often after the rehabilitation team have assisted the client to return to their previous level of function. The care providers working under this model have Occupational Therapists and Physiotherapists on their team who oversee the input that carers are giving to a client. This is a more flexible delivery of care, where time is allocated to a client, but this can be used in many different ways depending upon need at the time. An example would be a client who has arthritis with fluctuating ability due to pain. One week that person may be unable to vacuum, but the next week has greater ability and is able to complete some household chores. The client and carer can set goals each week, to try to enable the client to maintain some abilities and be able to achieve some small goals that would decrease the feeling of dependence. Another example is of a person who has reached a certain level of mobility. The carer would be in a position to go for a walk with a client, thereby assisting to maintain mobility, which is extremely important in a disease such as Parkinsons Disease.

So, we may have a client that is assessed using the interRAI assessment, who is then referred to the Assessment, Treatment, and Rehabilitation team, who then visit and complete their own individual assessments. While the team member may attempt to reuse a lot of the data already collected by the interRAI assessment, each discipline has its own focus and range of questions that need to be asked to achieve a solution to a particular problem. Also, the medical condition of an elderly person with multiple chronic problems can change quickly, sometimes quite dramatically, and clinicians must always ensure that information is up-to-date. Wade (2002) contends that this diagnostic process completed by a rehabilitation team member should not be termed an assessment, but rather seen as a rehabilitation diagnosis, a similar process to making a medical diagnosis. This process of assessment is a diagnostic, analytic process, which should end with the making of a formulation and the setting of goals.

### **My Role as Liaison Nurse**

Assessment is a pivotal role for me as the Liaison Nurse in the rehabilitation team. Good and thorough assessment is important to ensure effective care delivery, and is vital when admission to a higher level of care is being considered, such as moving from a rest home environment, to a hospital level of care. This type of move requires a Liaison Nurse to complete the assessment, and I complete these with several hats on. Firstly, with my background in rehabilitation, I look at whether or not there is rehabilitation potential to avoid a client moving to a greater level of care. If, for example, they have had a fall and lost their confidence in mobilising, the client, family, and myself set goals. This may result in the rest of the community team undertaking rehabilitation with the client in the facility, or if the case is complex, I may place them on the waiting list for an inpatient rehabilitation bed. Secondly, I am seen as an independent person, with no vested interest in the care facility. Residential care beds are always under pressure on the Kapiti Coast, so it is my job to ensure that only people requiring this higher level of care receive it. Finally, I also assess as to whether this is an acute event and may be reversible, which may result in the person being admitted to public hospital. When hospital level of care is indicated, I complete a Specialist Report, which is counter-signed by the

Geriatrician in our team, who may review people from a medical point of view if there is concern about medical issues.

My assessment begins as soon as contact is made with a client. Once an appointment is made, and I home visit, I am checking to see if the person has remembered the appointment, how they look physically, are they appropriately dressed, is the house warm (in winter), too warm (in summer), are there any access problems to the house, and how easy it is to move around within the house i.e. any mats, furniture in the way and so forth. The multi-disciplinary team assessment is then completed with the client. The nursing focus in this assessment is on medications, pain, chronic illness, bladder problems, bowel problems, sleeping, any weight loss, and blood pressure may be taken. However, each member of a team such as the rehabilitation team must have some understanding of each other's professions, and learn to pick up on clues that the client may give to ensure that each person receives all of the expertise they need to remain independent. It is important, for example, that time frames of a particular disability are understood. In the past I have worked with a gentleman who complained of a sore knee, and his goal was to improve his range of movement of the knee. When the Physiotherapist visited and delved a bit deeper, it was found that he had actually injured his knee during the Second World War! After such a time period, there was no possibility of increasing the mobility of his knee.

### **Goal Setting**

Goal setting refers to the identification of, and agreement on, a target or targets that the patient, therapist, or team works towards over a specific period of time (Wade, 1999). Goal-directed behaviour is a distinctive feature of human behaviour, and it is of great importance that goal setting in the rehabilitative environment include the client in the setting of goals, to ensure that clients' feel in control of their health outcomes (Playford et al., 2000). Goals serve to define and focus the rehabilitative treatment plan, and can be used as the outcome criteria for evaluating the efficacy of care (Haas, 1993).

Uncertainty surrounds the actual process of establishing goals – who should set them, and who should decide which goals are of most importance? Rehabilitation practice is directed at teaching patients and families to accommodate as much as possible chronic impairment. Yet people interpret information and assess risks and benefits, pain and cost, health and disability differently. This may lead to conflict. For example, health professionals assume and expect that clients will seek and generally follow their advice. They may find it uncomfortable to permit clients and their families to do things their own way, particularly if they perceive that time, money and effort are wasted, or a needlessly poor outcome might result (Haas, 1993).

The contemporary trend in the care of older adults to include goals signals an important shift in that care. There is more emphasis on the client role, client preferences, family involvement, and the functioning of multi-disciplinary teams (Glazier, Schuman, Keltx, Vally, & Glazier, 2004). Goal setting by clients does affect outcomes. Those who make a functional, independence focused goal statement on admission to a rehabilitation ward have significantly higher functional outcomes than those who do not. Those who did not set goals also have a considerably longer stay on the rehabilitation ward (Ponte-Allan & Giles, 1998). Goal planning, the setting of goals with the client, is associated with more behavioural change, may improve the long-term effectiveness of interventions, and setting both short-term and long-term goals is more effective than setting only long-term goals (Wade, 1998).

The literature on goal setting is largely around physical outcomes, such as mobility, negotiating stairs, and independence with bathing and dressing (Liu, McNeil, & Greenwood, 2004; Monaghan, Channell, McDowell, & Sharma, 2004; Parry, 2004; Ponte-Allan & Giles, 1998). Using the keywords nursing and goal setting, there is little research that relates to nurses setting goals with clients. Most of the research is around goal setting for the work environment, education for nurses, or career goals (Asselin, 2001; Cumbie, Weinert, Luparell, Conley, & Smith, 2005; McConnell, 1999; Mooney, 2003). However, nurses play an essential role in the rehabilitation process, and more research is

needed to understand ways in which nurses can improve the quality of life of their clients (Secrest & Thomas, 1999).

In their study on the use of individual goal setting with women with multiple sclerosis, Stuifbergen, Becker, Timmerman, & Kullberg (2003) discovered that although participants could easily identify specific behaviours they wished to change, they usually needed substantial assistance to write goals that were clear and measurable. They also discovered that in the context of changing behaviour, goal setting itself might become an intervention used to increase or sustain motivation for changing behaviour. In an earlier study by Stuifbergen et al., (1999), they note that their participants continually observed that while they can obtain general health information from public media and other sources and specific disease information from their health professionals, they are unable to find sources or assistance with integrating these two components to promote their health within the context of chronic disease. For example, achieving sufficient physical activity to promote health and prevent diseases related to a sedentary lifestyle without exacerbating their disease symptoms can be a fine balance to maintain. Nurses can assist with setting meaningful goals for change and addressing the barriers, resources and skills necessary to change health behaviours.

In the community rehabilitation team, goals are set with the client when the multi-disciplinary team assessment is completed. These goals are reviewed regularly at the team meeting to discuss how each discipline is assisting to achieve each goal, and once all goals have been achieved, discussion takes place with the client and discharge is begun. Goal-setting is not without its critics, however. As Playford et al. (2000) report, the advantages of goal-setting for both teamwork and the efficiency of rehabilitation is clear. The difficulties that can arise centre around the perceived benefits for the clients, as goal-setting may be seen as being owned by professionals, performed for their benefit in a context that may not be sensitive to the clients needs. By setting goals with a client in their own environment, the goals can be more personal and more appropriate to that person, which may in turn mean a higher likelihood of a person meeting that goal.

### **Treatment and the Role of the Nurse**

Going hand-in-hand with goal setting is the treatment phase. In the community, after goals have been set, an action plan is decided to achieve the goals. This may be to achieve a certain walking distance, or to maintain independence in some way. For example, a client may wish to be able to mobilise to the letterbox, be able to keep track of appointments, remain independent with daily activities, manage medications better, or maintain their health. By breaking these goals down to small chunks, there is a greater likelihood to achieve the larger goal.

Treatment in the rehabilitation team is often seen as largely being undertaken by the Physiotherapist and the Occupational Therapist. In fact, much of the research regarding rehabilitation involves Physiotherapists and Occupational Therapists, or psychiatric rehabilitation (Baker, Marshak, Rice, & Zimmerman, 2001; Duff, Evans, & Kennedy, 2003; Evans & Hardy, 2002; Parry, 2004; Rudnick, 2002). The research available about the role of the rehabilitation nurse is generally concentrated on the hospital-based nurse, with a particular focus on stroke rehabilitation. This research discusses the nursing role of providing an environment conducive for rehabilitation, co-ordinating, collecting, and communicating information between clients, their families, and other professionals, assessing physical well-being, and reinforcing the input of other professional groups (Burton, 2000; Greene, 2002; Kirkevold, 1997). Carbone, (1999) conducted research on the rehabilitation nurse after open-heart surgery, in both the hospital and home setting, and concludes that nurses' knowledge of the physiology of the surgical procedure and related nursing interventions can guide standards of care. These standards can enhance continuity of care, reduce hospital readmission rates, and promote better client health outcomes in both of these different settings.

Clients, however, can have difficulty describing how they experience the rehabilitation nurse. In her study on how stroke survivors and their support persons experienced nurses in rehabilitation, Secret (2002) found that while these people perceived nurses as helpful and as being there when they were needed, none articulated a therapeutic benefit. This could be, as Summers and



Nowicki (2004) maintain, that there is insufficient inpatient time with clients before they are discharged to an outpatient setting, which can be the beginning of fragmented care, and ultimately lead to an inability to return to a previous level of functioning. Alternatively, Nolan and Nolan (1999) suggest this could be because of a lack of nurse training in this area. They reviewed curricula offered to nurses in the United Kingdom during their nurse training, and discovered that there was a lack of explicit, well-integrated and systematic attempts to address issues such as rehabilitation and the wider needs of disabled and chronically ill people. They also discovered similar results when they looked at programmes geared to the older adult. They found great store was placed on fostering positive attitudes towards older people and in promoting healthy ageing, but the older adult with ongoing needs received little attention. As Flesner (2004) points out, inclusion in health professional educational curriculum of information on the ageing population is essential for future health care providers to be responsive to their needs and demands.

There is a dearth of research on the role of a community based rehabilitation nurse. One of the few studies conducted in this area is set within a background of private insurance, such as Medicare, where it is difficult to have inpatient rehabilitation fully funded. This study uses Orem's General Theory of Nursing, in particular the supportive-educative system of nursing, to highlight the role of the community rehabilitation nurse as educator, clinician, consultant, collaborator, advocate, and researcher (Brillhart, Heard, & Kruse, 2001). Community rehabilitation team members must have adequate knowledge and expertise to confidently act as a resource to other health professionals involved in the management of people undergoing rehabilitation (Sloggett, 2001). The Liaison Nurse is well placed to assist these groups to ensure that they receive the assistance and health care that is required. I spend a lot of time on the telephone giving advice to care facilities, practice nurses, clients, and families about the best way to go about accessing services, and how best to manage chronic illness and disability in the community setting.

I work very closely with the Gerontologist in our team. I complete home visits with her at times, and am the bridge between the client, family, and the medical

specialist. If medications are changed, I follow-up to ensure that there are no side effects, and the effectiveness of the new or altered medication dose. This is particularly important in the treatment of Parkinson's disease, where medications are often tweaked to ensure maximum ability with minimal side effects. I then remain in close contact with the consultant either by e-mail or telephone, and pass on suggested changes to the General Practitioner (GP). If the consultant sees clients on an outpatient basis that have not been seen at home, I make a follow-up visit in the client's home. This is an important aspect of care, as often people are not aware of what is available to them to ensure safety at home. This also gives me an idea about how they are managing in their environment, and I can make suggestions that may make things easier for them, such as ways to effectively manage their medications, or ways to support care givers. This type of specialised care can be effective when the nurse is working in a well defined role in actually delivering clinical care such as medication monitoring, rather than only co-ordination of existing services, especially when those services are of variable quality (Hobbs & Murray, 1999).

New Zealand's Best Practice Evidence-Based Guideline (Ministry of Health, 2003) states that assessment in the home environment is the most effective for the older adult, as assessment in other settings can create a barrier to access, particularly for those with transport, mobility, and/or financial difficulties, and these barriers are a risk to the effectiveness of any assessment programme. Home visiting means that the client usually feels more relaxed in his or her own home. I enjoy this change in power. As a nurse in the hospital, wearing a uniform, people may feel disempowered and at the mercy of the health system. I do not wear a uniform in the community, and as I am in their own environment, I believe people feel more empowered. They are more likely to decline interventions if they do not feel they are appropriate, and tend to have more input into their care. Visiting at home also makes it easier to form a relationship with people, as the environment gives clues as to what their interests may be and makes striking up and continuing conversation a smoother process. This forming of a therapeutic relationship is extremely important to ensure better health outcomes for clients.

### **The Multidisciplinary Team**

Disability among older people is often multicausal, requiring input from several professional disciplines to investigate and manage medical issues and rehabilitation needs (Wells, Seabrook, Stolee, Borrie, & Knoefel, 2003). These different professions make up a rehabilitation team, such as the team of which I am a member. While we are referred to, by way of our assessment process, a multidisciplinary team, we operate as an interdisciplinary team, whereby each discipline has an understanding of others in the team, and care is decided jointly between practitioners. However, labels are relatively unimportant – what is important is what the team does, and how they do it to improve health outcomes (McCallin, 2001). The emphasis of the integrated team is on the skills available within that team, and flexibility across traditional role boundaries in order that the needs of the population served are met as far as possible (Griffiths, Austin, & Luker, 2004).

The prerequisites of teamwork are having a common purpose and responsibility, a clear understanding of the professional's own skills function and those of others, the pooling of skills and knowledge, and facilitation or leadership (Griffiths et al., 2004). Working in an interdisciplinary team, however, means a blurring of boundaries, which can cause some conflict between disciplines, caused by tensions around power, authority and recognition of each others communication styles (Milligan, Gilroy, Katz, Rodan, & Subramanian, 1999). Conflict is inevitable when groups of diverse people made up of different disciplines have different perspectives, different information about clients, and possibly different goals (Mukamel et al., 2006).

Interestingly, Schlosberg and Sisk (2000) explain how they ran a semester-long course focusing on a science/policy interface. The students on this course noted that working in an interdisciplinary model gave them a greater perspective on their own discipline, in addition to letting them learn about what had been “foreign territory”. This crossing over between professionals allows each to see events from a different viewpoint, and in the case of the rehabilitation team, allows us to work in a holistic manner, encompassing the whole person.

How well teamwork improves patient outcomes may depend on how well team members can collaborate (Leipzig et al., 2002). However, effective collaboration is only possible if there is a sound basis of understanding and mutual respect and this can be mistaken as a given (Fitzsimmons & White, 1997). This is sometimes true of the rehabilitation team – often access criteria to this team can be seen by different disciplines in different lights. For example, an elderly person may have recently been discharged from hospital with pneumonia. Theoretically, this person should not come to the rehabilitation team, but should be seen by the therapies team, who deal with personal health issues, rather than disability. However, this elderly person may have other chronic health issues, which the pneumonia has impacted upon, causing a decrease in level of function. Good communication between the team members is essential to ensure best outcomes for each individual client, and that age and comorbidities are factored into the decision as to which team would best suit a client's needs.

## **Conclusion**

Rehabilitation can play a vital part in the older person's wish to maintain function and independence. A common goal that the team encounters is the wish to remain at home for as long as possible. By working as a multidisciplinary team in conjunction with the client, this goal is frequently achieved, despite often severe limitations and disabilities. This chapter has discussed the multidisciplinary team, and how it functions on the Kapiti Coast. Assessment, treatment, and rehabilitation have been explained and discussed. The role of the liaison nurse within the team has been explored, as has the use of goal setting with the rehabilitation setting.

The next chapter attempts to paint a picture of what it may be like to age while living on the Kapiti Coast. Chronic illness and its impact upon the older adult are discussed. As we age, things that we took for granted, such as being able to drive, maintain mobility, and generally care for ourselves are no longer as easy as they used to be. Some of the factors that influence autonomy and control of one's life are discussed in the next chapter. Some are true for many older people, and some are more pertinent to living in the Kapiti area.

## **CHAPTER THREE: The Experience of Ageing**

### **Introduction**

This chapter explores some of the factors I believed might have impacted upon the participants of my research, drawing on my experience of nursing elderly women in the community. As we age we are more likely to suffer from at least one chronic illness. Living with chronic illness can consume vast amounts of time, finances, physical and psychological resources, and can impact upon many people – the person, their family, neighbours, support agencies, health agencies, and society at large. Preserving function, keeping positive, and maintaining quality of life becomes all the more harder when you may no longer be able to drive, complete your own personal cares, have difficulty remembering recent events, and previously supportive friends are no longer able to help you. This chapter investigates these issues, and presents some of the published literature that deals with the many facets of this research subject.

### **Chronic Illness**

The ageing population is a worldwide phenomenon, and with this are increasing social, economic and political concerns about the health and care needs of individuals in later life (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002; Beckett et al., 1996; Gijsen et al., 2000; Scanlon-Mogel & Roberto, 2004). With this increasing life expectancy, older adults can expect to live with at least one chronic illness during the later part of their lives (Penrod, Gueldner & Poon, 2003). There is also a growing body of evidence that older people are at risk for multiple, comorbid conditions, which, as the population ages, will become a common occurrence (Gijsen et al., 2000). The burden of meeting the needs of this growing number of people will fall upon already overstretched health care services that are struggling to cope with the demands of acute care, let alone the needs of those with long-term health conditions (Barlow et al., 2002).

Chronic illnesses are not curable; rather they are lifelong concerns that often require changes in lifestyle to manage or control symptoms and potentially life-threatening outcomes. Living with more than one chronic illness impacts upon a

persons' life in many ways and presents a complex interplay of risk factors, symptoms, and treatment regimes. Older adults have to learn to interpret, and respond effectively to, complex ways of managing their health in the face of chronicity (Penrod, et al., 2003). Research into the effect specific combinations of conditions on outcomes are important for individual patient care as well as for health care policy, because a large amount of health gain can be achieved by prevention or early recognition and adequate treatment of comorbid diseases (Gijsen et al, 2000).

The World Health Organisation states that chronic diseases are the leading cause of mortality in the world, representing 60% of all deaths, and estimates that chronic disease will be the leading cause of disability by 2020 (World Health Organisation website, 2006). As the focus of health care moves from the institution to the community, it becomes increasingly important for nurses to gain an understanding of how people adjust to the impact of chronic illness in everyday living, giving a greater breadth of knowledge necessary to further understand the influence of health on quality of life (Marr, 1991; Roberto et al., 2005).

So, what is quality of life? Measurement of quality of life is a challenge, and the subjective components of quality of life are difficult to assess. There is a lack of consensus in the research regarding quality of life, which, in part, reflects the fact that quality of life has a different meaning for different people (Ellingson & Conn, 2000; Kempen, Ormel, Brilman & Relyweld, 1997).

The World Health Organisation (1996) defines quality of life as;

Quality of life is defined as individual's perceptions of their position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, incorporating in a complex way a person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment (p. 17).

Living with chronic illnesses and their manifestations affects daily functioning and influences the quality of life of older people (Kemp, Husser, Roberto & Gigliotti, 2004). Studies have found that being dependent on others is one of the greatest fears of older adults and that maintaining independence is a goal that has been rated as integral to their quality of life (Gignac, Cott, & Badley, 2000; Mor, Wilcox, Rakowski & Hiris, 1994). Yet, despite the value placed on remaining independent by many older adults and health professionals, we know relatively little about the factors associated with adults' perceptions of their independence and dependence (Gignac et al., 2000).

People use different coping strategies when living with chronic illness. They adapt their lifestyle by slowing down their pace and the amount of activities they perform and impose a degree of dependency on them to prevent or avoid future pain and disability or to leave themselves with the time and energy to focus on other tasks (Gignac, et al., 2000; Kemp et al., 2004). They may think about others who they perceive as being worse off, not dwelling on the problem, have a positive outlook, use distraction, or try to carry on as usual (Marr, 1991). Some people use past success for determining what to do in the present, but one thing is clear – the effectiveness of coping strategies becomes more complicated in chronic comorbidity, and the constant challenge to find effective ways of coping with chronic disease (Penrod et al., 2003).

Since comorbidity in general is significantly related to mortality, functional status, quality of life and other aspects of health care, studies on the relationship between diseases and outcomes should take comorbidity into account (Gijssen et al., 2000). The importance of comorbidity is clear, due to its high prevalence in older populations and its impact on health and health care, however little has been written about comorbidities, especially from a nursing perspective. It is difficult to define exactly what a comorbidity is from a nursing perspective, however, clearly medicalised conceptualisations of comorbidity fail to capture adequately the underlying health care needs of patients (Gijssen et al., 2000; Williams, 2004). Co-ordinated and seamless delivery of care may improve this group of patient's satisfaction and corresponding well-being, factors that have

the potential to reduce complications, readmission rates and associated healthcare costs. Opportunities exist to expand the role of nursing by utilizing episodic events to review the overall management and care of patients (Williams, 2004). Promoting independence, limiting disability, preventing secondary problems, and promoting wise use of health services are all necessary components of minimising the effects of shrinking resources as larger numbers of older persons require services. Attending to quality of life and the importance of helping persons adjust to and manage their health problems is a way of avoiding more costly situations such as nursing homes and hospitals (Kemp, et al., 2004; Nesbitt & Heidrich, 2000).

Acute events bring patients back into hospital, and it is during these stays that management of acute problems take precedence over comorbidity. In some instances, management of an acute event can cause comorbid diseases to become symptomatic. However, Williams (2004) found that most of the patients did not expect care of and attention to comorbidities, as they reported that their chronic illnesses were incurable and could not be helped. The acute care setting does not fully acknowledge or accommodate the comprehensive care that these patients require, because the primary interest is the diagnosis that caused admission. Often, they are discharged back home once they have recovered from the acute episode, with no thought given to any changes in their comorbidities. Their length of stay is often shortened due to a system desperate to maintain or reduce total bed days, and older patients, with their complex needs and prolonged medical and functional recovery can be perceived as a problem (Elder, 2001). This is where admission to a rehabilitation ward can be a great advantage as time is taken to ensure a return to previous level of function, and discharge planning can be more carefully thought out. An admission to hospital may be preceded by a visit to the GP, involving cost and the ability to access transport, which can be of great difficulty to some older people.

## **Transport**

Driving is often a sign of independence for older adults, and the loss of a license has been associated with depression and decreased self-esteem (Corcoran,



2003). In their study of worsening depressive symptoms in older adults who stopped driving, Fonda, Wallace, and Herzog (2001) found that driving cessation signified to many that they had reached old age and its stigma of dependency and/or the constriction of access to necessary and recreational activities. Morrissey (1998) also reports this, saying that the availability of transport influenced the amount of interaction older people have with their social world. Their world was likely to contract when relatives, friends, or neighbours on whom they depend on for transportation become incapacitated or die. Activities are curtailed and companionship lost, an example of 'involuntary' disengagement.

As the population ages, the numbers of older drivers on the road will increase (Fonda et al., 2001; McKnight, 2003). Older adults are at a greater risk of being killed or injured in a motor vehicle crash. Older drivers tend to compensate for their deficiencies by driving more slowly and avoiding situations that present the greatest threat so they do not necessarily pose a greater threat to the public than any other age group, therefore their disproportionate representation in the statistics is more a sign of their frailty rather than the way they drive (McKnight, 2003). Older drivers do, however, limit or avoid driving. In their study into why older people restrict their driving, Ragland, Satariano, & MacLeod (2004) discovered that problems with eyesight represent the leading reason given by both men and women to stop or restrict their driving.

On the Kapiti Coast public transport is very limited, particularly in the Waikanae area. In their recent report, the Kapiti Coast Community Report (2006) cites transport to support services one of the top five priorities for the district. They note that many of the support services for Kapiti are delivered in different parts of the district or completely outside of Kapiti, and state the importance of reliable and flexible public transport. Older people do have access to half-price taxi-chits, but there is still a cost involved for them, which they may find difficult to meet. There is also a voluntary organisation called Kapiti Carers, who, for a donation for petrol, will take an elderly person to a health appointment, most often at Kenepuru or Wellington hospitals. This cost can become a major concern to people who have chronic comorbidities,

especially when coupled with the cost of attending a visit to their GP. In their paper reporting on the findings from the 2002 Commonwealth Fund International Health Policy Survey of Sicker Adults in the United States, the United Kingdom, Australia, and New Zealand, Blendon, Schoen, DesRoches, Osborn, & Zopert (2003) discovered that New Zealanders and US adults are the most likely to report that they did not get needed medical care because of the cost. This is of great concern as early interventions by GP's when dealing with chronic illness can often mean an admission to hospital can be avoided, thereby saving health dollars.

### **Access to General Practitioners**

There are 800 Kapiti Coast patients waiting to register with a GP (Iserles, 2006). This need is identified as top priority in the Kapiti Coast Community Report (2006). Together, the Kapiti Primary Health Organisation (PHO), the Capital and Coast District Health Board, and the Ministry of Health are working together to address this crisis. There is presently a recruitment drive underway in the United Kingdom for additional GPs for the Kapiti communities. The need to have a regular GP is extremely important for the elderly, and especially those with chronic illness. GPs also value this, as personal continuity is particularly important when patients have multiple or complex problems (Guthrie & Wyke, 2006). To be able to practice self-determination, and to participate in the care process, the patient has to be well informed about his or her illness and treatment options (Eldh, Ehnfors & Ekman, 2006). Unfortunately, due to sheer numbers, it can be difficult for a patient to see their regular GP and often see another doctor within the same practice. This becomes a barrier to continuity, good communication and creating a relationship that is essential for continuity of care.

As in other countries, long-stay geriatric wards in New Zealand have been closed, and their frail elderly occupants have been discharged to residential facilities. The medical care of these residents becomes the responsibility of the GP in charge of that facility, adding to GPs already heavy burden (Craig, 1995; Kavanagh & Knapp, 1998). This is particularly true of the Kapiti Coast, where

there are a high number of residential facilities. This, coupled with the higher than average numbers of elderly living on the Kapiti Coast, mean that GPs are struggling to meet the needs of the often complex elderly person. Interestingly, Iliffe et al., (1992) discovered, in their study to test the hypothesis that elderly people living alone are an at risk group, that GPs do not have substantially greater overall workload as a consequence of caring for elderly living alone rather than those living with others. So it is the overall greater numbers of elderly on the Kapiti Coast, rather than one particular group, which impact upon the workload of local GPs.

With hospital stays shorter than ever, community care acquires greater relevance. GPs are well placed to deliver interventions designed to promote health and wellbeing of their elderly patients, as elderly people are often frequent attendees (Bernabei et al., 1998; Kerse, Flicker, Jolley, Arroll, & Young, 1999). The lack of GP availability on the Kapiti Coast means that opportunities of preventing hospital admissions and increasing quality of life may be missed as GPs are forced to restrict time spent with each patient. Indeed, in my role as liaison nurse, I often hear from my patients that their GP only spent 10-15 minutes with them, and typed on the computer the whole time, and they came away with the feeling that they “had not been listened to.” This perception that length of time spent with a patient and the level of response to the patients concerns may act as a barrier to obtaining necessary treatment and explaining preventative care (Fitzpatrick, Powe, Cooper, Ives, & Robbins, 2004). GPs also acknowledge that the main barrier to older patients involvement in their own care was lack of time to deal with complex agendas, and this can affect health outcomes (Barry, Bradley, Britten, Stevenson, & Barber, 2000; Wetzels et al., 2004).

The difficulties the older person may encounter in accessing a GP may have additional implications. For example, the comorbidities of chronic illnesses, if left untreated, can impact upon the older adults mobility. A dire consequence of this can be an increased risk of falling. Suffering a fall and sustaining injury can be catastrophic for the older person, as discussed in the following section.

## **Falls and Mobility**

In New Zealand, one third of older people living in private homes and about half of those in institutions will fall each year, and is the most common cause of injury and a major cause of hospitalisation in older people (Health of Older People Strategy, Ministry of Health, 2002). Not surprisingly, fear of falling is common among elderly people who have fallen in the past, even among those who have not fallen recently, and is associated with increased morbidity, disability, social isolation, a lower quality of life, and possible early entry into residential care (Biderman, Cwikel, Fried, & Galinsky, 2002; Lawlor, Patel, & Ebrahim, 2003). Chronic diseases may increase the risk of falls through the effects of the disease and other factors, such as reduced physical activity, muscle weakness, and poor balance (Lawlor et al. 2003).

Much of the research about falling compares tools to assess for risk of falls such as the research conducted by Close, Hooper, Glucksman, Jackson and Swift, (2003); Davison, Bond, Dawson, Steen and Kenny (2005); and Perell, Nelson, Goldman and Luther (2001). This research does not highlight how the fear of falling impacts upon the quality of life of an elderly person living alone at home. Hip fracture, the most serious consequence of osteoporosis, due to its association with excess mortality and morbidity, is also represented in the research largely as quantitative data, which again does not express what this serious result of falling means to the elderly population (Boonen, Autier, Barette, Vanderschueren, Lips, & Haentjens, 2003; Johnell & Kanis, 2004; Wildner, Sangha, Clark, Doring, & Manstetten, 2002).

Fear of falling can contribute markedly to a restriction in activity. Exercise is important for older adults as it assists to prevent, delay, and manage many chronic illnesses common with advancing age, while increasing mobility and energy which contributes to enhanced perceived quality of life (Ellingson & Conn, 2000). In their study of older adults' beliefs regarding physical activity and exercise, Scanlon-Mogel and Roberto (2004) found that the participants believed that their participation in regular exercise assisted them in keeping up with their activities of daily living and social engagements and enabled them to

remain extremely independent. Their decision to be physically active and participate in formal exercise programmes promoted good health, improved adaptation to their social environment, and helped them to successfully manage the ageing process.

The overall picture is worse for women. Not only do women have more disabilities than men, they also live longer with diminished quality of life, and need more assistance from others and the health care system (Beckett et al., 1996; Manton, 1988; Murtagh & Hubert, 2004), and are more likely than men to restrict their activity out of fear (Fletcher & Hirdes, 2004). However, in their study of the effects of physical activity among elderly women, Ourania, Yvoni, Christos, and Ionannis (2003) discovered that physical abilities of sedentary elderly women can significantly improve after 10 weeks of exercise, and that as little as once a week participation is capable of vastly improving the physical abilities of these women.

On the Kapiti Coast, there are formal exercise programmes available, such as Tai Chi, a balance-training programme. Tai Chi has been found to significantly improve functional balance, reduce the likelihood of falling, and promotes well-being (Chen, Snyder, & Krichbaum, 2001; Li, Harmer, Fisher, & McAuley, 2004). Individual groups, such as the Arthritis Foundation and Stroke Foundation also run exercise programmes. These types of community based programmes linking socialization with exercise may meet multiple needs of the older adult, such as social contact, as well as keeping fit (Ellingson & Conn, 2000), although they do raise the issues of cost and access to transport.

The Accident Compensation Corporation (ACC), through local GPs, offers the Otago Falls Prevention programme, which is conducted in participants' homes in the Kapiti region. The Capital Coast Rehabilitation team offers physiotherapy in clients' own homes, for a set period of time, while goals that have been set by the client are met. However, at the time of writing, there is a long waiting list of clients for physiotherapy, some waiting up to two months to be seen. Physiotherapy can also be accessed through the Therapies Service of Capital and Coast Health, for people who do not require a multi-disciplinary

approach that the Rehabilitation team provide. Again, this is for a set period, but can be undertaken either in clients' homes, or on an outpatient basis. The ability to be able to mobilise can impact upon how other everyday activities are carried out, as a decrease in mobility can indicate a general overall decrease in function. It is essential, therefore, that maximum mobility be maintained to ensure overall quality of life.

### **Activities of Daily Living**

Despite the value placed on independence by many older adults and health professionals, there is little research about the factors associated with older adults' perceptions of their independence and dependence (Gignac et al., 2000). Older adults are often faced with the challenge of maintaining activity and well-being under difficult circumstances (Duke, Leventhal, Brownlee, & Leventhal, 2002). Maintenance of an independent lifestyle is the ability to perform self-care, to be involved in pleasurable activities, to engage in sexual function, and to perform social roles with family and friends, all of which may be compromised with a decline in functional ability (Gustavsson & Bränholm, 2003).

The loss of the ability to perform self-cares and other roles can be devastating. This loss of ability is a common barrier to successful self-management as chronic conditions often occur as comorbidities (Coleman & Newton, 2005). When a chronically ill person engages in usual activity it fosters a sense of feeling normal and allows people to maintain a degree of control over their own lives. Often chronically ill people resist their lives becoming medicalized and try to find a balance between asking for help and coping without (Gustavsson & Bränholm, 2003; Ong, Jordan, Richardson, & Croft, 1999). Early identification of this loss of independence is needed to initiate an adequate management strategy; the earlier in the downward process this is started, the more effective it will be (Nourhashemi et al., 2001). A major paradox of people who try to maintain a wellness perspective is that they are often required to assume the sick role if they are to receive health care services. They must justify the need for assistance at home by focusing on their limitations, symptoms, and disability, not their wellness (Paterson, 2001).

Older adults experience growing demands on their attention mechanisms, such as difficulties with vision, hearing, and mobility, which require them to expend significant attentional effort to negotiate activities of daily living. Thus, they are faced with higher attentional demands at a period in life when they have reduced capacity to direct their attention (Jansen & Keller, 2003). This, coupled with chronic illness, can severely impact upon their ability to attend to daily tasks that were once completed with little or no thought. Assessments into the needs of this group are critical to support the older adult to remain at home. For the vast majority of older people and their families, the home is the preferred residence in which to grow old, to “age in place” (Gitlin, 2003). As Hinck (2004) explains, being at home is extremely important, and is both a physical space and a state of being that allows people to be self-determining, remain connected to their meaningful past, and maintain their privacy.

In New Zealand, everyone who is assessed as needing assistance with personal cares can receive this help at home at no cost, as it is not means-tested. Sometimes the supplying of equipment is enough to enable an older person to continue to complete tasks such as showering independently, and enables them to maintain a greater sense of self-sufficiency (Mathieson, Kronenfeld, & Keith, 2002). If individuals retain control and make decisions about the amount of assistance they wish to receive, they may not view their dependence negatively, or as reflecting a sense of helplessness or inability to cope. However, people tend to overestimate their own competence because of this need to remain in control, which often results in under-utilization of health and other resources (Gignac et al., 2000; Ong et al., 1999).

Health professionals must always be aware that when a client changes from nondisabled to disabled in activities of daily living, this can mean a major transition that often reflects substantial worsening of disease (Guralnik et al. 1999). Often multiple hospital admissions result from worsening of chronic illness. In one study Boyd, Xue, Guralnik, and Fried (2005) report that one third of older patients hospitalised for acute medical illness declined in the ability to complete at least one activity of daily living at discharge, which persisted for at

least six months. They also found that repeated hospitalisations conferred cumulative risk, potentially resulting from heightened vulnerability or incomplete functional recovery after each hospitalisation. A change in diet, surroundings, and decreased mobility can mean that the older adult is discharged from hospital having lost weight and still recovering from their illness that often means they are very tired. Proper nutrition at home can assist to return the older adult to pre-admission condition, however there are many other factors that impinge upon the ability to prepare and eat healthy food.

## **Nutrition**

Nutrition plays an important part in maintaining independence and ability to perform activities of daily living. Food is closely associated with identity and has cultural and religious significance to many (Manthorpe & Watson, 2003). There is, however, relatively little information available about food consumption and nutrient intakes of older persons living alone (Holcomb, 1995). The scant research available regarding women and nutrition is conflicting. In their study on frailty in community-dwelling older women, Nourhashemi et al. (2001) found that women who were totally independent had significantly lower weight and body mass index (BMI) than those who were not. Low weight and BMI play an important role in physical disability in elderly persons. Shatenstein, Payette, Nadon and Gray-Donald (2003) however, report that women eat a significantly higher proportion of healthy foods than men. They point out that while it is tempting to suggest that women typically select higher quality food than men, we must remember that women have traditionally been largely responsible for all family food purchases and preparation. Thus this lifetime habit of being more attentive to food is a more probable explanation.

Difficulties in food preparation may aggravate nutrition problems, especially in those living alone. The use of specialised equipment can assist these people to continue to be as independent as possible in the kitchen, and improve quality of life (Kelsheimer & Hawkins, 2000). On the Kapiti Coast there are many options of frozen meals available through church groups, private providers, Meals on Wheels from the hospital, and hot meals that can often be purchased by people



living in retirement villages that also have residential facilities attached to them. This type of social dining can provide an environment that decreases social isolation and loneliness, which helps to buffer against depressive symptoms (Bisschop, Kriegsman, Beekman, & Deeg, 2004).

## **Depression**

Depression is not a normal part of aging (Birrer & Vemuri, 2004) and is one of the most common and treatable of all mental disorders in older adults, but when combined with chronic illness challenges even the strongest of adaptive resources (Bisschob et al., 2004). Depression caused by helplessness and hopelessness has a particularly strong association with progression of chronic illness and mortality. As the elderly population grows, so too will the numbers of elderly people with depression, as chronic illnesses are more common in old age than in any other age. This, combined with death of loved ones, loss of social support, and reduced physical strength can trigger a major depressive episode, and mean that elderly adults are vulnerable to poor outcomes (Birrer & Vemuri, 2004; Bisschop et al., 2004; Piven, 2001; Schroder, 2003).

In her study of elderly women's explanation of depression, Ugarriza (2002) reports that most of the women she interviewed said their depression was a result of changes in their health. The second most common reason was the death of family members, most often death of a husband. We know that women live longer than men, so are more likely to suffer the grief and loss of losing a life partner. Coupled with chronic illness, this puts them at a higher risk of depression. Depressed women are more likely than depressed men to require help in the home (Larsen, Schroll & Avlund, 2005). When a woman receives some form of care from a caregiver, the risk of depression is again increased if they perceive that the carer is not concerned with their happiness and well-being (Wolff & Agree, 2004).

However, not all older adults with chronic illness, social isolation, living alone, and receiving care suffer from depression. Some people appear more able to cope with life's changes. Schroder (2003) describes this as coping competence,

the ability to cope well, irrespective of stress and crisis. This study discovered that coping competence buffered the detrimental effects of physiological symptoms and functional impairments on depression. Another coping mechanism that has been researched is that of positive outlook on life, which is related to someone's personal character, that is, being an optimist (Ong, Jordan, Richardson, & Croft, 1999). In the next section I will explore some of the many ways people use coping strategies to maintain and improve their functional abilities.

## **Coping**

How people develop through the life-span has been the source of much study and formation of theories. One such theorist is Eric Erikson, whose psychosocial stages of development centred on a persons' relationship to their social environment. He called the developmental stage for the older adult *Integrity versus Despair*, when people try to make sense out of their lives, either seeing life as a meaningful whole or despairing at goals never reached and questions never answered. Theories such as Eriksons' have helped us to realise that human behaviour is shaped by many things, such as the forces of impulse and fantasy, and the pressures of parents and society, which direct our behaviour throughout our lives (Berger, 1986). For example, Elder, cited in Ardel (1997, p. 24), maintain that hardship experiences during the Great Depression have long-lasting effects on individual assertiveness and self-confidence almost 40 years later, and that they vary profoundly for men and women with different levels of personal resources and social support. Hardship experiences made emotionally healthy women with a stable marriage in the 1930s even stronger and more resourceful in their old age. In contrast, emotionally unstable men who lacked a nurturing marital relationship were most adversely affected in old age by economic deprivation in the 1930s.

While many elderly people report that their activities are restricted because of disabilities and diagnosed chronic conditions, the overwhelming majority in this study by Rosenberg and Moore (1997) perceived that their health was good to excellent. A likely explanation is that many elderly people adapt their lifestyle

to their health conditions if they are not severe. Strategies of self-comparison are frequently used as a bench mark of their own progress or decline, and people often compare themselves to others of the same age, older, and even younger in an effort to assess their own health status. While they rely on past successes for determining what to do in the present, older adults creatively adapt new strategies in response to challenges present. However, living with chronicity is a lifelong event, so assessing the effectiveness of coping becomes more protracted, and permeates the day-to-day lives of elders (Penrod et al., 2003). The older adult, however, has a life-long pattern of dealing with stress, but often are not recognised and affirmed for the personality resources and inner strengths that they may have cultivated over the years (Nesbitt & Heidrich, 2000).

Spirituality also plays a part in the ability to cope of some older people. This spiritual dimension of health is described by some as having faith and rediscovering the important things in their life (Burke & Flaherty, 1993). One study by Pressman, Lyons, Larson and Strain (1990) supports the notion that strong religious belief is associated with lower levels of depression, and in the case of this study, showed that this lowered level of depression enabled better response to physical therapy. For some, the search for meaning and purpose appear to be important spiritual coping mechanisms during chronic illness. For others, this need may be reflected in a desire to connect with other sources of support, such as family and friends (Narayanasamy, 2002). Support from family and friends allow older adults to cope with chronicity. Relationships with significant others, of being with and talking with these people, supports hopefulness during chronic illness (Marr, 1991; Raleigh, 1992).

The term self-management is used interchangeably with coping. In their study of nine people with arthritis, Kralik et al., (2004) found that self-management of chronic illness can be both a structure and a process. Health professionals have created structures in their approach to patient education whereby people are passive subjects absorbing information. In contrast, participants in this study described self-management as a dynamic, active process of learning, trailing and exploring the boundaries created by illness. People reconfigure their daily lives and reconstruct their self-identity as they explore their personal limitations that

living with chronic illness brings. Physicians, however, have typically focused on diseases and success of practice is closely linked to curing or at least restoring a person to normal functioning (Blazer, 2006). There may be many obstacles, however, that limit or impact upon a persons' ability to return to a previous level of functioning. One of the common barriers to a complete recovery is pain, which, as I will explain next, can be one of the most difficult barriers to overcome.

## **Pain**

There are few human experiences that are as powerful as pain, yet it remains poorly managed by professionals in a variety of health care settings. It seems incongruous that while scientific research has uncovered many of the biochemical and neurobiological processes of pain and developed sophisticated treatments for its control, many elderly people continue to live with unrelieved pain (Higgins et al., 2004). Chronic pain presents the sufferer with many occasions in which their responses to pain can move them away from health life functioning, and has been related to poor adaptation including depression, which often accompanies low self-esteem (Dysvik et al., 2005; McCracken & Eccleston, 2004). Physical disabilities, helplessness and passive coping have a significant impact on levels of pain and depression, with physical disability being the most significant predictor of pain (Núñez, Sanchez, Nuñez, Casals, Alegre, & Muñoz-Gomez, 2006). In their study of health-related quality of life in persons with long-term pain after a stroke, Widar et al., (2003) discovered that the participants in their study had suffered from pain for almost two years and had a lower health related quality of life than those in other studies on stroke survivors.

In a study undertaken by Walker et al., (1999) on the lived experience of chronic back pain, participants reported how their daily lives were irrevocably changed as a result of back pain, leading to a profound sense of loss that invaded all aspects of their lives. They reported feeling misunderstood and stigmatised and most could see no future for themselves. In their research on low back pain in older women, Leveille et al. (1999) discovered that low back pain has a serious

impact on the daily functioning of these women, and recognised the challenge for clinicians and patients in successfully treating this disabling type of pain. Smith (2003) also undertook research regarding women and chronic pain, although most of the participants in this research were under 65 years of age. Smith reports that chronic pain affects important basic relationships, including emotional and physical intimacy, and that women in chronic pain need to be understood and validated. Family members may be oversolicitous, doing too much and worrying and controlling, or they become angry and try to ignore or minimize the suffering of the person in pain.

There is very little research regarding older women and the impact that pain has upon their families. Roy (1994) reports that, unlike their younger counterparts, elderly pain sufferers are more likely to have a discernible organic basis for their pain, but that, in general, the elderly tend to display a rather fatalistic attitude to pain. However, life issues such as retirement, widowhood, declining physical capacity, and fear of death are relevant issues to older adults, and these changes coupled with illness and pain can produce profound changes in intimate relationships.

Higgins et al. (2004) report that elderly people often do not give a voice to their pain, as to give it a voice was to risk being marginalized further from any social contacts, and meant that the participants often withdrew into their own world. Burke and Flaherty (1993) call this self-controlling coping, where feelings are not expressed, and not letting others know how bad the pain is. They propose that elderly women who use this strategy reflect either socially expected behaviour learnt during their youth, or is a reaction to a modern society that devalues elderly individuals. McCracken and Eccleston (2005) also note in their study that pain can cause elderly people to disengage from important valued aspects of their life. This research examined the relationship between acceptance of chronic pain and patient functioning. Not surprisingly, their data showed that willingness to have pain, and engage in activity regardless of pain, may lead to healthy life functioning, in contrast to struggling with pain and trying to control or avoid pain.

Sinclair (2001) discusses catastrophizing as a coping response to pain, where an extremely exaggerated negative appraisal of painful stimuli affects how individuals cope with pain. He points out that health professionals frequently encounter individuals who have a tendency to catastrophize and its associated negative outcomes. This often comes as a result of a disposition to pessimism and a general perception of lack of control. If effective strategies for addressing this phenomenon can be discovered, interventions may be more effective to prevent this detrimental negative outcome. Non-pharmacologic interventions can have value in the management of pain in the elderly population, such as relaxation and imagery, and can work successfully beside pharmacological therapy (Mobily, 1994). Traditionally, however, the principle approach to treating chronic pain is the use of medications, which can have serious side effects for the elderly population, especially when this group is more likely to be taking several medications at the same time.

### **Polypharmacy**

The joint use of two or more prescription drugs is the simplest definition of polypharmacy (Scanlan, 2005). Frazier (2005) reviewed 16 studies from the United States, Canada, Australia, and Europe, and discovered that 23% of women and 19% of men aged 65 years or older take at least five prescription drugs. This number increases when over-the-counter medications are added. Scanlan (2005) points out that age-related alteration of body composition and function, such as decreased lean body mass, increased body fat, and loss of kidney function, influence the effects of drugs on the older body. He also points out that often elderly subjects are underrepresented in, if not excluded from, clinical trials, so for many drugs there is no substantial evidence regarding their safety and efficacy in the elderly population.

Polypharmacy is a predictor of mortality, independent of age, socio-economic status, or chronic disease status and/or severity, and increases the odds of any single medication being added to a frail older adult's regimen will cause a potentially adverse reaction in that patient (Espino et al., 2006). Unfortunately, today's older adults were brought up in a time when symptoms and debility

were accepted as a normal part of ageing, so are less likely to seek help for dysfunction and thus present at more advanced stages of disease (Resnick & Marcantonio, 1997).

Ensuring appropriate and cost-effective drug use will be an important component of future research on successful ageing, as medications are among the most widely used and highly valued intervention for disease of older adults (Murray & Callahan, 2003). They further point out, however, that while some research must centre on the search for more effective and safer drugs, there is also a tremendous need for more research on improving the use of currently available medications. The current disease-specific treatment guidelines that are uniformly recommended were primarily developed in younger participants without multiple comorbidities (Espino et al., 2006). For example, Resnick and Marcantonio (1997) explain that in a younger patient, incontinence due to involuntary bladder contractions responds to a bladder relaxant. An older patient will not benefit from such a drug if she also has faecal impaction, takes medications that induce confusion, and has impaired mobility due to arthritis. Treating these three factors is more likely to restore continence and may mean a bladder relaxant is not necessary. Solving the problem of polypharmacy, with attention to health outcomes, is central to improving the overall use of drugs in older adults and requires a broad research agenda (Murray & Callahan, 2003).

### **Ageism and Stereotypes**

Society's attitudes and beliefs regarding ageing are culturally embedded and can have a profound effect upon how people view themselves and others who are ageing (Grant, 1996). Ageism is different from other prejudices, as everyone may become a target for this type of discrimination if they live long enough (Palmore, 2001). Ageing stereotypes originate as early as childhood, and are reinforced in adulthood. In old age, these stereotypes can become self-stereotypes (Levy, 2003) and need to be overcome as the problems faced by elderly people are problems for our grandparents, parents, aunts, uncles, and other older people in our lives, not to mention ourselves (Ragan & Bowen, 2001). In their study on the perceptions of young, middle-aged, and elderly

adults on stereotypes, Hummert, Garstka, Shaner and Strahm (1994) found that these three groups have many of the same stereotypes of the elderly, although the two older groups have more complex stereotype sets than do the young adults. Perpetuating stereotypes of ageing keeps younger adults afraid to grow old and to mix with older adults. Eliminating these negative stereotypes will allow a better understanding of ageing, and reintegrate different generations (Arnold, 1993).

Traditionally, ageing has been viewed as a continual process of decline. This belief can lead to disease management rather than proactive intervention (Grant, 1996). Memory is one domain in which age stereotypes are overwhelmingly negative. There is considerable evidence that memory ability changes with age, however memory failures for older people are considered more worrisome than identical failures in young adults. Bieman-Copland and Ryan (1998) believe that stereotypes about memory and ageing leads to exaggerations of age-related changes that occur in memory processes, influencing activities people consider reasonable and appropriate for the older adult.

Hearing loss is another domain that can be affected by stereotypes. Hearing loss is the third most common chronic condition reported by those over the age of 65. Levy, Slade and Gill (2006) point out that among cultures that attach less stigma to old age, several studies have documented that older members of these cultures tend to experience less hearing loss as they age. They maintain that when older adults experience a loss of hearing, stereotypes are activated that could compound this problem.

In trying to live within an ageist society, the expectation to be disabled and helpless becomes self-fulfilling. Grant (1996) reports on one study when three groups of elderly people in a nursing home were given a jigsaw puzzle to complete. Staff actively assisted one group, one was encouraged but received only minimal help, and the last group were given no help at all. The helped group's performance deteriorated, the group with no help increased their speed of performance slightly, but it was the group that received encouragement but no



help that improved their performance, and reported feeling more confident in their abilities.

In addition, later life has tended to be portrayed as asexual. Sexual health is not an issue that is proactively discussed by GPs with older patients. 'Safe sex' is not seen as a topic relevant to discuss with middle aged and older patients, reflecting the belief that it is only young people who engage in risky sexual practices (Gott, Hinchliff & Galena, 2004). In Bells' (1992) study on how elderly are depicted on television, he reports that sexuality is an important absence in the lives of most elderly television characters, and especially in the lives of elderly women. These types of attitudes reflect our society's dominant image that sex is only for the young, healthy, and those with a 'beautiful' body.

Ageism affects women more than men, because as they age, women lose their power. When women are no longer fertile, which society views as productive, they often are considered to be 'problems' (Letvak, 2002). Being female does not relate to successful ageing (Depp & Jeste, 2006) and this inability to successfully integrate the identity and development of old age can result in depression, isolation, and anxiety (Letvak, 2002). In her study reporting on an ageism survey, Palmore (2001) theorized that experiencing sexism would make women more sensitive to other forms of discrimination such as ageism. She discovered, however, little difference between men and women in the frequency that the participants reported ageist experiences. This could be because older people attribute age-related discrimination to other causes, such as sexism or racism (Ragan & Bowen, 2001).

Overall, this view of ageing can be a negative one. Old age can never be cured – society must repeal the assumption that old age itself is a health problem (Peterson, 2001). However, many older adults live full and active lives well into their later years. Successful ageing can involve extending life, expanding wisdom, maintaining function, and minimizing suffering (Landefeld, 2003). In the following section I explore some of the factors that affect successful, or positive, ageing.

## **Successful Ageing**

With the growing numbers of older adults, society is faced with the urgent challenge of promoting a high quality of life for these elders. If we cannot infuse quality of life into these longer years, then this recent longevity revolution may merely translate into a sickness revolution (Carlson, Clark, & Young, 1998). Better management of chronic disease, which is now endemic, would represent a major contribution to successful ageing (Kane, 2003). Psychological well-being has been associated with successful and active ageing (Phillips, Siu, Yeh & Cheng, 2005) and ageing well has become a self-fulfilling prophecy for many older adults who are physically active and exercise regularly (Scanlon-Mogel & Roberto, 2004). A more positive view of ageing as a normal process that is separate from, although at times compounded by, illness and disease processes needs to become the norm rather than the exception. With a more positive view of successful ageing, there would be many implications for moving into the older years with an emphasis on wellness rather than on disease (Gavan, 2003).

There is little published research incorporating the perspectives of older adults on the subject of successful ageing (Montross, et al., 2006). However, one study conducted by Hodges et al., (2001) analysed perceptions about chronic illness among three groups: registered nurses, nursing students, and the elderly. While the students and registered nurses believed that life with chronic illness creates feelings of fear and hopelessness in the elderly, the elderly themselves did not express this. They, in turn, talked of hope and steadfast refusal to give up on life, ideas not mentioned by either nursing students or registered nurses.

It is important to remember that not everyone recognizes health as the most important aspect of successful ageing. To a humanist, health may be less relevant than realizing one's ambitions (Callahan & McHorney, 2003), and to the elder themselves, health may be viewed as only one facet of successful ageing. Wagnild (2003) discusses the concept of resilience and successful ageing. She defines resilience as a positive personality characteristic that

enhances individual adaptation, and has five characteristics; a balanced perspective of life, a sense of purpose in life, the ability to keep going despite setbacks, the recognition of one's unique path and the acceptance of one's life, and the belief in self and your own capabilities. Moore, Metcalf, and Schow (2000) call this ability to be resilient and age successfully finding meaning in life. Meaning is central to life as it allows humans to make sense of our existence in the face of adversity, and is rooted in our desire to feel useful, needed, and cared for (Moore, 1997). Research has been undertaken looking at the factors that assist successful ageing, such as Carlson et al. (1998) who propose that an elder's ability to exercise control, enact healthy lifestyle choices, and live a life that is integrated with his or her personal past are all important factors conducive to successful ageing. The elder's construction of a personally meaningful routine that supports healthy living serves as a crucial bridge in the effort to achieve successful ageing. Easley and Schaller (2003) studied the experience of life after the age of 85 years, and also discovered that one of the strongest and rewarding elements of successful ageing is being able to be active and having control over how your life is structured, despite various health problems.

In his research on the concept of attachment in older adulthood, Cookman (2005) maintains that attachment is as relevant a concept for senior citizens as at other life phases, and that these attachments can help combat stereotypes of older adulthood as only a time of loss and deterioration. He also points out that attachment need not only be to other people, but can mean attachment to pets, places, and cherished possessions. Personal history and past experience can also impact upon older adults ability to successfully age. Ardel (1997) explains that individuals enter old age with a lifetime of experiences that have shaped and transformed their personalities and determine how they deal with the changes of life in the later years. For example, older adults may lower their expectations for health as they age, which may be an important mechanism by which many older adults are able to maintain their life satisfaction despite declining physical health (Sarkisian, Hays & Mangione, 2002).

Stratton and Tadd (2005) undertook research where focus groups were held with young and middle-aged adults on their views of ageing. Both groups thought that intergenerational contact was important to improve understanding and relationships and expressed that they wanted increased opportunities for shared activities and especially to meet the needs of dependent older people as well as those who were fit and healthy. Both groups also described older people as being wise and intelligent, and there was a belief that society could benefit greatly from this wisdom and experience. Wisdom, according to Ardel (1997), tends to increase life satisfaction and stems from psychosocial development built up across the lifespan. Promoting successful ageing is important for today's ageing population, but further research on the factors that affect successful ageing is needed to understand why some individuals achieve this goal, and others do not (Wagnild, 2003).

All of this published literature helps to draw a picture of what ageing in New Zealand may be like. However, none of this research was conducted in New Zealand about people living in New Zealand. This research study begins to help to draw a New Zealand picture, one that may have similarities with overseas studies, but will have its differences too. Likewise, by conducting my research only on women assists in the building of a picture of a particularly vulnerable group. This group is projected to grow in numbers in the future, so the more understanding health professionals gain, the more likely they are to be in a position to facilitate and influence well-being of the older woman.

## **Conclusion**

The ageing process is a natural part of life, but when one's health impacts upon this process, life can be difficult to manage on a daily basis. This chapter has explored some of the more common demands that may impact upon elderly women living on the Kapiti Coast. Chronic illness, lack of GPs, transport issues, pain, and depression can make growing old something younger people do not look forward to. However, as previous research shows, successful ageing can be achieved. The more health professionals are informed about the factors

that assist in achieving successful ageing, the more able they will be to facilitate this goal.

In the next chapter, I introduce my research methodology. I have used a descriptive methodology, with a qualitative approach, and both are explained in this chapter. How I conducted this research study is described, and the ethical considerations given to such a study explored. The inclusion and exclusion criteria I used to recruit the participants are explained, and all three of the women recruited to this study are introduced. The use of thematic analysis to examine the stories that these women shared is described, and validity and reliability of this study is explored.

## **CHAPTER FOUR: Research Methodology**

### **Introduction**

Understanding what affects quality of life for older women with multiple chronic illnesses will mean better targeting of resources, and more meaningful interventions for this group. People themselves can offer significant insights into what promotes their personal well-being, and it is only by asking older women to describe what life is like for them that we will be able to gather the knowledge required to provide the necessary strategies to meet their health needs. Descriptive research is used when there is little or no previous research surrounding a research question, and this is certainly true of the question that is posed in this study, especially in a New Zealand context. This chapter outlines the research methodology that underpins this inquiry. In addition, data collection and analysis method that was undertaken to complete this research study is explained. The participants who agreed to be a part of this study are introduced, and a brief background of each woman is described.

### **Qualitative Research**

A qualitative research interview is a shared journey and the resulting description is not simply the participant's recall of past experiences, but a co-created work emerging from the interaction of researcher and participant (Donalek, 2005). Qualitative nursing research is an approach to gathering data that uses the experiences of the participants to develop nursing theories or nursing frameworks. Researchers have no prior knowledge of the variables – they gather the data first and then develop a framework from the data. This is in contrast to most quantitative research, where the investigators have a particular framework or theory as a basis for their study (Slauenwhite & Simpson, 1998). While the scientific method has been a valuable tool for the development of knowledge in other sciences, it is not the perfect approach for generation of all nursing knowledge. Nursing often has different aims, purposes, and concerns (Brockopp & Hastings-Tolsma, 1995). Qualitative research may seem foreign alongside quantitative methods used in clinical and biomedical research. However, this type of research enables us to access areas not amenable to

quantitative research (Pope & Mays, 1995), such as client's own perspectives on what is meaningful to them.

I chose qualitative research as it is in keeping with my research question and aims of understanding what factors elderly women find impact upon their quality of life when living with chronic illness. Qualitative research is more flexible and fluid in its approach than quantitative statistical methods, which leads some people to think that this makes qualitative research less worthwhile because it appears to not be governed by clear rules. However, most qualitative research assumes that, in order to understand people's behaviour, we must attempt to understand the meanings and interpretations that people give to their behaviour. Metaphors, meanings and interpretations require the more fluid, but no less rigorous, methods employed by qualitative research (Rice & Ezzy, 2000).

One of the unique components of qualitative research is the small number of participants in the study. However, while the number of participants may be fewer than is found in quantitative studies, the depth of questioning and the richness of the data that qualitative research uncovers cannot compare to quantitative research (Slauenwhite & Simpson, 1998). So it is with my research. While my pool of participants is small, this has allowed me to focus in-depth on the stories and themes that came out of the data. This in-depth focus, in turn, allows me to uncover the participant's reality, what it is really like for them on a day-to-day basis, to better understand the factors that influence, and give meaning, to their lives. Qualitative research can be described as a formal process of inquiry, often conducted within a natural setting and characterized by a flexible, emerging design and the collection of primarily narrative data that provides insight and understanding of the meaning of phenomena from the participant's perspective (Dempsey & Dempsey, 2000). Qualitative research findings contain information about the subtleties and complexities of human responses to disease and its treatment that is essential to the construction of effective and developmentally and culturally sensitive interventions (Sandelowski & Barroso, 2003).

## **Descriptive Research**

Descriptive research studies are a form of qualitative research, and can help discover new meaning and to provide new knowledge when there is very little known about a topic (Dempsey & Dempsey, 2000). This is true of my topic of research, particularly in New Zealand. The purpose of a descriptive research project is to provide a picture of situations as they naturally happen (Burns & Grove, 1993). Although no description is free of interpretation, basic or fundamental qualitative description entails a kind of interpretation that is low-inference, and the description in qualitative descriptive studies entails the presentation of the facts of the case in everyday language (Sandelowski, 2000).

## **Examples of Descriptive Research**

Descriptive research is being used to build the body of nursing knowledge, as it allows the researcher to examine a phenomenon of which there is little previous knowledge. For example, Broström, Strömberg, Dahlström, and Fridlund (2001) conducted research to better understand how patients with congestive heart failure experienced their sleep. They used a qualitative, descriptive design, and interviewed 20 patients. They note within their report that in order to meet a patient's individual nursing needs, it is important that nurses have a good understanding of the holistic patient perspective, which is achieved using this methodology. Annells and Koch (2002) undertook an extensive descriptive survey of 90 people over the age of 65 years, living in the community, and conducted interviews to explore their experiences and responses to constipation. They discovered the attitudes, beliefs and preferences of the older person in relation to constipation, and offer a series of recommendations to assist the older person to better manage this problem.

Winslow (2003) employed a methodology called qualitative descriptive study, in which the researcher immersed herself in the data, undertaking several readings to identify explanations or concepts, from which patterns were identified. Koopowitz, Chur-Hansen, Reid, and Blashki (2002) conducted research on the subjective experience of patients who received electroconvulsive



therapy. They explained that they chose a descriptive, qualitative approach, as there was little research available around patients' emotions and experiences regarding this treatment. Overcash (2004) used narrative research in her descriptive design research study to understand the quality of life of older women with breast cancer. The implications for nursing, she reports, is as story-gatherers for the healthcare team, nurses can use the data derived from interviews to document patients' health histories and provide a therapeutic process of coping with illness.

This body of literature builds a picture of this type of research being used to understand the experience of different chronic illnesses. Continuing nursing research into the experience of chronic illness will contribute to the refinement of models of care that emphasize not only physiologic and behavioural variables, but psychosocial, socio-economic, and environmental factors as well as the perspectives of patients and families (Donnelly, 1993). These stories are about experiences of which there is little previous study undertaken using descriptive research, and use different forms of analysis to better understand the point of view of the participant.

### **Qualitative Approach in Descriptive Research Methodology**

Oral or narrative history has existed for centuries, however its usefulness as a method in nursing research has, until recently, gone unacknowledged. As Sandelowski (2000) explains, descriptive research employing a qualitative approach differs from phenomenologic, grounded theory, ethnographic and narrative studies, but may have hues, tones, and textures from these approaches. Nursing has struggled for acceptance and legitimacy as a profession in its own right, and the one method of communication upon which nursing is based has been regarded as unprofessional and inferior (Biedermann, 2001). The use of stories can be a powerful strategy that can contribute to improved quality of health care as well as to the development of new knowledge. The unpredictable stories of our lives belong to the persons authoring them as well as to the whole community, and everyone grows as a result of sharing our stories (Tuyn, 2003). Story telling has been used in a New Zealand context. Hart and Grace (2000) conducted research regarding fatigue in women with Chronic Fatigue Syndrome

to develop an understanding of the issues generated using a discourse analysis of women's stories on fatigue.

Nursing is in a sense the forum for story telling – the ear for the intimate accounts and personal thoughts that place stories along side nursing practice (Overcash, 2004). The act of constructing stories is a natural human process that helps individuals to understand their experiences and themselves, and allows people to organize and remember events in a coherent fashion while integrating thoughts and feelings. This, in turn, gives individuals a sense of predictability and control over their life (Pennebaker & Seagal, 1999). A story allows us to have a better understanding of the person as an individual, the experience they have had, and the effect it has had on them. This creates an empathy with clinicians, and keeps the impact of illness on the human as an ideal that health professionals must keep central (Redman, 2005). By conducting face-to-face interviews, I have captured these women's stories of living and managing with comorbid chronic illness from the perspective of the sufferers themselves. This gives us an insight into their daily needs, and helps us to understand what gives meaning to their lives while dealing with disability. The following section outlines the interview process I undertook, and the ethical considerations of my research.

## **Method**

This section describes the process I undertook to collect their stories from the women who agreed to be part of this research. The first step to conducting my research, once ethical approval was given, involved placing an advertisement in one of the local Kapiti newspapers, recruiting participants to my study (Appendix 1). Initially I received eight replies. I had not explained in my advertisement that I wished to recruit women who live on their own, for safety reasons. However, at our first telephone contact, five of these women were excluded, as they lived with their spouses. This left three participants, and a letter giving further details was posted out to them. By giving them my work details and asking them to contact me, confirmation of my authenticity was made, and ensured the women felt safe.

All three of these women telephoned again, stating that they wished to continue with the research process and the first appointment for the first interview was made. I visited each of them in their own homes, at a time and date suitable to them, and conducted the first interview, which was audiotaped. Each audiotape was transcribed, which I then read thoroughly several times. I then visited each participant again a few weeks later, and together we went through the transcripts from the first interview to verify the information, and clarification of my interpretation was sought if needed. The interviews undertaken took no more than 90 minutes each. The participants were asked if there was anything more they would like to add before the interview process was concluded.

When analysing these stories, published literature was used as a dialogue partner to aid the interpretations of the participant's stories. Consequently in reporting the results of the interviews, some of the current literature around each theme is used to support my interpretation. This use of literature with data is a major goal of qualitative methods, and the researcher must decide how the findings are reported and supported (Brockopp & Hastings-Tolsma, 1995). Research with human participants requires that ethical approval be sought. This process is explained in the following section, as are some of the ethical considerations I needed to be aware of when conducting research with older adults.

### **Ethical Considerations**

Researchers working with people must always remember that their participants are real, with their own unique personalities and needs (Dempsey & Dempsey, 2000). Respect for human dignity must be maintained at all times, and full disclosure of the research process to the participants must be given. Maintaining ethical guidelines began with the seeking of ethical approval, which was sought and given from the Central Regional Ethics Committee (Appendix 2).

The environment where the interviews took place was at the participants' own choosing. For the purposes of this research, all of the interviews took place in the participants' own home. There were no direct benefits to the participants in being part of this research, however, it is hoped that the information discovered during this study would assist health professionals to better understand the lived

experience of chronic illness in elderly women. In addition, the participants contacted me initially ensuring that they did not feel pressured into taking part.

In most qualitative studies, the potential for harm is related to social or psychological harm, as opposed to physical harm, as often is the case in quantitative studies (Byrne, 2001). Participants were also informed that they were welcome to have a support person present during the interviews. My academic supervisor oversaw the whole research process and was available for assistance if the need arose.

Because I recruited women over the age of 65 years, I had to ensure that I allowed for disabilities caused by the natural ageing process, such as decreased eyesight and hearing. As Robinson (2000) explains, the physical status of the older person, including poor hearing, impaired vision, pain, fatigue, or urinary urgency, can challenge both the participant and interviewer. Both my information sheet (Appendix 3) and consent form (Appendix 4) were presented in large print, and I constantly checked that the women were hearing and understanding my questions.

The audio-tapes were transcribed by a transcriber, who had signed a confidentiality form (Appendix 5). I returned to see the women with the transcribed tapes and together we went through each paragraph to ensure accuracy of the information. This was to minimise any stress about my interpretation of their answers.

Maintaining confidentiality in qualitative research is often more difficult than in quantitative research, as the nature of qualitative research requires that the investigator must get close to the question and present enough direct quotes and detailed description to answer the question (Burns & Grove, 1993). I did not use the participant's names, or those of family members, in any of the research process, but substituted them with pseudonyms. This was to ensure confidentiality, to prevent identities being linked to responses. I was also aware that the Kapiti Coast is a small community, and I have written this thesis so that an individual cannot be identified by a particular event. Each paragraph of the

interview has been numbered, so within the research the pseudonym and the paragraph number of the interview identify quotes from the participants, e.g. (Nancy, paragraph 47.) The following section discusses the inclusion and exclusion criteria used to recruit participants to this study.

### **Inclusion/Exclusion Criteria for Participants**

I recruited women who lived alone, as I felt that they would have a unique view on how they manage living with chronic illness and resulting disability. I requested that they be over the age of 65 years, and it is this age group that have a higher proportion of more than one chronic illness, a chronic illness being one that lasts over six months duration. I chose the area to be that in which I work, between Paekakarekei and Peka Peka, as this area has nearly twice the elderly population as the rest of New Zealand. By conducting my research within this area also means that the results of this study could directly benefit my nursing practice. However, I excluded women who were currently being seen by myself in my role as Liaison Nurse within the Assessment, Treatment, and Rehabilitation team, as participants may feel their contribution could impact upon the healthcare they received. This inclusion and exclusion criteria enabled me to recruit people who could assist me to achieve the aim of my study, which is to explore factors that older women living with comorbid chronic illness identify as key to maintaining or improving their quality of life.

### **The Participants**

The three women who agreed to become a part of this study were all aged over 80 years, so my research became about a group of women who are considered to be very elderly, with a unique set of problems and abilities. These women all elected to undertake the interviews in their own home, thereby ensuring they were in a familiar, comfortable environment. All three women live in their own homes, and all express a desire throughout the interview process to remain in these homes for as long as possible. They all have children who live in the greater Wellington area. The following paragraphs introduce each participant, and give a brief outline of their personal and health history.

## **Nancy**

Nancy was born in England, and has lived in New Zealand for 50 years. She came to New Zealand because of the health of her youngest child, and her and her husband immigrated to New Zealand with three young children. They went on to have another child in this country. She is 82 years old, and her husband passed away 30 years ago. She has one son in Australia, but her other three children all live in the North Island, and she has 11 great-grandchildren. Nancy runs a small business from home through catalogue sales, still drives, and can travel up to 200km per week running her business.

Nancy left school when she was 15 years old, and went to work in her family's business. During the war years, she ran this business herself, under the guidance of her father, as her brother had been called into the army. Upon moving to New Zealand, she had many part-time jobs until her and her husband bought a small business, the first of many they were to own. When her husband passed away, her youngest child was only 16 years old, and Nancy continued to work to support them both, and she did this until she retired at 60 years of age. Not long after this she moved to the Kapiti Coast.

Nancy has osteoporosis, has had a previous myocardial infarction, arthritis with two knee replacements, and Meniere's disease. She takes an active interest in alternative medications, something she attributes to learning from her father. She tries half-doses of alternative treatments, and has learnt to adjust doses that best suit her. Nancy attends her local gym regularly to do weight bearing exercises. The first bone scan Nancy had showed that she was a high risk for stress fractures of the spine. She has regular bone scans, and the last one showed that her bone mass had improved, and she was told that the likelihood of stress fractures in a woman of her age was average, providing she did not suffer a fall.

**Emma**

Emma is the oldest participant, being 88 years old. She was also born in England, and moved to New Zealand when she was 70 years old, to be near her only child. She became a widow at the age of 64 years. Emma lives on the same property as her daughter, but in a separate flat at the back. I included her in the research as, while she does have a daughter next door in the evenings, if she was to be referred to our team, she would be considered to be living on her own. She has two grandchildren, and six great-grandchildren, who all live within the greater Wellington area.

Emma left school when she was 14 years old, and became an apprentice in the clothing industry, until war broke out. This led to her joining a family engineering business repairing and making parts for aeroplanes. She then married, gave birth to Beth, and cared for her family. Emma has a long history of belonging to groups and clubs, and even now gains great pleasure from the friendships she has made. Crosswords are another pleasure, and she tries to complete three a day from her daily newspaper.

Emma has a history of falls, and was recently in hospital with a fractured hip. She has osteoarthritis in her shoulders, high blood pressure, and suffers with hearing loss. Emma wears a hearing aid, and it has taken a lot of perseverance by her to master being able to change the battery. She walks without any aids inside, but prefers to use a stick outside, and has a routine of regular exercise, both outside on fine days, and inside when the weather is bad. She loves living at home, and does not feel anywhere near the stage when she would require permanent care in a care facility.

**Liz**

Liz is the only participant to be born in this country, and is 82 years old. She has lived all over New Zealand, as her husband travelled with his employment. She has two sons, both living in the lower North Island, and six grandchildren. Liz takes a great deal of interest in her grandchildren, and was very involved with them as small children. As they have grown, she sees less of them, but keeps up with what they are doing through her sons. She no longer drives, and

either her family take her out, or she uses taxis. Her husband passed away 19 years ago, and she has lived on her own since that time.

At 16 years of age, Liz left school, and gained employment in a government department. She remained in this position during the war. Prior to her marriage, she also attended University, studying languages, but this ceased when she married. She did, however, return to University study later on in life, at the age of 64 years, which she talked of very enthusiastically. Liz has a great curiosity about her family tree, and has undertaken quite a bit of research on the subject. Her family are encouraging her to write down her own history, and she has started to record this.

Liz, too, has a history of falling for no apparent reason, and is fearful of fracturing her hip. She has a personal alarm to use if she should require medical assistance at any time. Liz has diabetes, heart disease, high blood pressure, angina, and asthma. She manages her diabetes and regularly checks her blood sugars, which tend to run on the low side. Liz is aware of this, and has snacks available should she need them. Her memory, she reports, is not as good as it used to be, but she feels she manages well living at home. Again, like Emma, she talked about not feeling that she needs permanent care, either now or in the immediate future. She is aware, however, that another fall could change this picture completely, and is very careful when walking, using a stick inside, and a walking frame outside.

These three women willingly and openly shared their stories with me, giving full accounts of both their personal lives and their health issues. The way in which this data was dealt with is explored next.

### **Data Collection**

In-depth interviews, using open-ended questions were used to collect the data for this study. However, prior to beginning the interview process with the participants, I met with my supervisor to undertake a practise interview. This was so I could rehearse my questions and to iron out any issues in my



interviewing technique. It soon became apparent that I remained in my role as nurse, rather than researcher. As my supervisor took on the character of an elderly woman with chronic illnesses, who lives alone, I attempted to solve the problems that she described to me. After discussion about this with my supervisor, we agreed that during the actual interviews I would write down these issues as they arose, and set them aside. At the conclusion of the interview, I then referred them back to their health care practitioner for advice about these issues.

Data from the interviews was recorded on audiotape. Initially, I collected demographic information such as age, ethnicity, support networks, chronic illnesses, and how long the participants had lived on their own. I then focused on health issues, and the factors that the women found impacted upon their quality of life, both those that enhanced their quality of life, and those factors that decreased quality of life. I conducted two interviews with each participant, no longer than 90 minutes each.

In the first interview, data was gathered, and at our second meeting we went over the transcript of our first interview to confirm that these transcripts were accurate. I then clarified some of the information they had given me, and asked if there was anything else they would like to add, and all three participants did clarify and expand on aspects of their interviews.

My experience in assessing people in their own homes means that I have had plenty of practice in engaging and listening to people's stories. By using this form of information gathering, instead of say a survey to collect information, allowed me to form a relationship with the participants. This enabled me to gain their trust so that they felt safe to open up their lives to me, and allow me to gain an understanding of what life is like for them as they deal with living with chronic illness. As Pope and Mays (1995) explain, a survey may pick up the public account of a person's life events, but a series of in-depth interviews are needed to get at the private, often contradictory and complex beliefs that people hold.

### **Data Analysis**

Thematic analysis was used to examine the stories that were gathered from the interviews. Qualitative findings most often appear in the form of declarative statements of key or recurring topics or themes (Sandelowski & Barroso, 2002). Data analysis is a circular process of reading, thinking, writing, and re-writing the themes that emerge from the transcripts. By repeatedly listening to the transcripts I was able to sort the data into themes, looking for key words and topics used by each of the women. By immersing myself in the text, I became intimately familiar with the nuances and context of each of the participants. To ensure that I was keeping within the essence of this study, I repeatedly went back to the research question and aims of the study to ground myself as to what my study had set out to achieve.

As I listened to each tape, I noted down themes as they occurred, and organised these into recurring themes from more than one participant. These common themes meant that a picture began to develop of what living with chronic illnesses is like for these women on a day-to-day basis. The main data derived from qualitative research methods are words. This reliance on language is in contrast to the main approach of quantitative research, which relies on the value of numbers as tools for analysis (Roberts & Taylor, 2002). The way these women shared their stories with me was a very humbling and amazing experience, and the information they shared was very personal, but they did this with an incredible openness.

### **Validity and Reliability**

While qualitative research is often criticised for lacking scientific rigour, all research depends on collecting particular sorts of evidence through the prism of particular methods, each of which has its strengths and weaknesses (Mays & Pope, 1995). There are a number of ways that I have attended to these issues. Reliability has been maintained in my study by explaining my background, and positioning myself within the research. I have provided rich description and detail to allow the reader to really understand the phenomena under study. Each paragraph of the transcript has been numbered, and when these excerpts have

been used, the number of the paragraph has been included. This provides an audit trail because each excerpt can be verified.

Validity has been achieved by returning to the participants to go over their transcripts to confirm that they are an accurate account of their experiences. In qualitative research, people are acknowledged as sources of information, and that their own personal awareness is valued as being integral to the meaning that comes out of research. The researcher must acknowledge that people and things may change according to their circumstances, so it is inappropriate to generalise research findings to a wider group of people (Roberts & Taylor, 2002). After analysing the findings from these three particular women, it was evident that there were three emergent themes common to all participants, which will be discussed in Chapter Four.

## **Conclusion**

In this chapter I have explained the research methodology and method that has been used in this research project. Participant's stories were collected by way of face-to-face in-depth interviews, conducted in the participants' own home. This study uses a descriptive methodology, with a qualitative approach. Thematic analysis was used to generate emerging themes that informed the understanding of living with chronic illnesses. I have introduced the participants in this study, and given a brief outline of their living situation, their work life, and the illnesses that affect them. In Chapter Five I discuss the findings of the analysis of the data, weaving in literature on the topics and themes raised by these women. This use of literature assists with the interpretation of the themes that emerge, and helps to begin to make meaning of what it is like to live with comorbid chronic illness.

## **CHAPTER FIVE: Results**

### **Introduction**

This Chapter reports on the findings that emerge from this research. In order for these women to make meaning in their life, three main topics were explicated; (1) coping with changing health, (2) the impact of family, and (3) attitude. These are reoccurring themes that are evident throughout the participant's stories, as these women try to convey how the many illnesses they have impact upon their daily life, and how they compensate and manage their changing abilities and health needs. The participants are all over 80 years old, two being 82 years old, and one 88 years old, and they are all entering the final phase of their lives. Their general optimism shines through, however, and, as one participant put it "I'm deteriorating, but I'm deteriorating healthily", despite her many medical problems (Nancy, paragraph 252).

The ability to create meaning and have quality of life is a subjective phenomenon, and impossible to evaluate without input from the person whose life is the focus of concern. The majority of older adults express the desire to continue living in their own home (Morrissey, 1998), and all of the participants in this study expressed this desire. Gignac et al. (2000) showed older adults are actively engaged in numerous self-care efforts to manage their condition. As age increases, so are the demands placed on the older adult. Maintaining their health to the best of their ability meant that these women continue to live in their own homes and remain relatively independent. Their individual past experiences, their ability to manage their conditions, and their outlook on life all contribute to these women making meaning in their lives, and living in their own home gives such meaning. Finding and maintaining meaning in life is a crucial quest that individuals live as they age, and as people age, their personal meaning perspectives evolve to become more inclusive and integrative of their own experiences (Moore et al., 2006).

### **Coping with Changing Health**

As people age they often experience personal and social losses. As physical health declines, there is often a loss of vitality, and a greater susceptibility to

disease. It becomes increasingly difficult to manage this change in health, and often the older person needs to rely more on practical assistance. They are constantly adapting in many ways to their changing health needs, often on a daily basis. This study highlights that the participants believe that they are indeed coping with their changing health, and this idea is supported in the following sub-themes: equipment and being comfortable, coping strategies, and home help assistance.

### **Equipment and Being Comfortable**

Being able to cope with multiple medical problems means that all of these women require the support of equipment, as well as having items in the home that make life more comfortable. This use of equipment means that these women remain as independent as possible. Being independent is important to these participants, as requiring assistance with showering and other personal cares means a loss of privacy, and the beginning of becoming dependent on others, something they all wish to avoid if at all possible. Nancy explains how she now relies on her shower stool in the shower, which keeps her safe.

“I’ve also got a stool for in the shower. I find now, more times than not, I have to use my shower stool to have a shower – I can’t stay stood [sic] long enough to have a shower.” (Nancy, paragraph 204).

If she did not have the use of the stool, she may require supervision in the shower for safety. Not only would this mean a loss of independence for Nancy, but also her life would be governed by somebody else’s timetable. Having to wait for a carer to arrive to help can be extremely frustrating, and would mean a loss of autonomy for Nancy. Liz, too, talks of the help that equipment gives her. The use of a perching stool enables her to heat her own meals and clean her dishes, again assisting in her ability to remain independent.

“My capabilities are less, I can’t stand very long, but I have got a chair in the kitchen, a high thing to sit on, I don’t like standing for long, but I’ve got the walking frame, and that helps if I feel a bit unsteady, and I am unsteady.” (Liz, paragraph 133).

The ability to complete everyday tasks is essential to well-being. The routine that these tasks give provides structure to her day, a sense of purpose, and a feeling of achievement. Individual achievements and quality of life changes cannot be seen as a pass or fail, as a major accomplishment for one person may be to walk to the bathroom, whereas for another, it may be to be able to stand for five minutes (Glazier et al., 2004). Decline in physical function, Beckett et al. (1996) discovered, is associated with age, and the average pattern of decline appears not to be linear, but to accelerate with increasing age. In addition, women are more likely to experience decline in function, and are less likely to recover from disability. Given the age of these participants, it is not surprising, therefore, that these women require the use of aids to maintain their level of function and a sense of control over their lives. The many modifications to the way the women manage their everyday activities suggests that there is an attitude of acceptance of their situation. This acceptance, and willingness to adjust to their changing situation, means that they can maintain their function and independence.

Liz has noticed a lack of energy in recent years, and this has meant that she has given up some of her leisure activities, both outside and inside her home. Also, the decision to give up her car means that she no longer has the flexibility to travel when and where she wants. She does, however, take great pride in the crafts that she used to do, and has watercolours that she has painted, and quilts that she has made. Liz explains how the tiredness feels.

“The main thing wrong with me is a tiredness and a lack of energy. There’s a certain lack of strength, or a certain weakness, in me that didn’t used to be there. I used to do a lot of things, I’m a quilter, and I used to go to classes, but I haven’t got the energy to do those things now.” (Liz, paragraph 55).

Hart and Grace (2000) conclude from their research into fatigue in women with Chronic Fatigue Syndrome, that fatigue is not a positive, identifiable thing but rather a way of expressing a subjective, negative absence or lack. The women

in their study gave examples of things they could and couldn't do, much like Liz. However, when I asked Liz if giving up her activities had been a difficult thing to do, she expressed that she is accepting of this change in her life, as she feels it is her choice, and this means she still feels in control of her life.

“Not really, I gave them up because of a lack of energy, I gave them up myself. Nobody made me give them up, I gave them up because I just didn't have the energy, and at the moment a car to go to them, and I don't have the energy to do them at home.” (Liz, paragraph 150).

Emma expresses being comfortable in her home is a very important aspect to her life. She showed me the many things she has purchased to ensure this comfort, such as the heaters she has in both lounge and bedroom, and she is particularly pleased with her new electric blanket. She is able to determine for herself when and for how long the blanket would be on for. Emma has found this past winter a very long, cold, and wet one.

“The settings are for all different hours, I could have it on all day and night if I wanted to, but I don't do that. Sometimes I put it on if I thought it was extremely cold, but I put it on about half past four and it was on for five hours before I got to bed. It's been a very cold winter.” (Emma, paragraph 159).

Emma, in particular, feels that a warm, cosy bed is extremely important to her well-being, as is the knowledge that she can go to bed at any time that suits her. Also, once in bed, if she wishes to get up in the night and have a drink, she has the freedom to do this.

“I've got such a lovely bed in there and anyway, the bed was so comfortable, I didn't get up until half past nine this morning, and if you live in a home, you probably couldn't do that. And during the night sometimes, well I have to get up in the night to go to the toilet, if it's 4 o'clockish, I always go to the toilet and come and have a cup of tea – that's something else I couldn't do.” (Emma, paragraphs 60, 62, and 64).

This type of independence is essential to these women's health and well-being. Being able to do things when they want, and at their own pace, is important and contributes significantly to their quality of life. This sense of being at home is more than just the walls within which they live. It is the overall knowledge that their time is their own, they can do as they please, without having to answer to anyone else's time frames, rules, or regulations. This ability to retain control over their environment gives meaning in their lives and helps them to maintain a sense of self.

Being no longer able to drive was a big loss of independence for Liz. Her lack of her own transport has been another reason to give up her leisure activities. This is, however, another choice made by her, and may make this an easier change to cope with.

“At 80 I gave my car to my grand-daughter, I didn't want to be a driver at 80 causing accidents and all that.” (Liz, paragraph 53).

As Easley and Schaller (2003) state, this change means that women have to depend on others or limit the activities available to them. This dependence on others can become a major factor in alteration of well-being. It can create a sense of dependence that these women try to avoid if at all possible. However, Liz made this choice herself which appears to make this loss of independence more bearable for her.

Liz was the only participant who spoke of not having much will to live, but also has set herself a goal which she is aiming toward.

“I think that people like me, in my age group, particularly if they are partially disabled, don't have much will to live. I'm looking forward to doing the 'No Falls' programme, I want to walk around the block with the walker like I was before. It's my impression that it gives people like me a bit of a will to live.” (Liz, paragraph 144).



On one hand, she feels she doesn't have much will to live, but on the other is looking forward to returning to one of her previous activities. As her decreased mobility is caused by falling, she is under the Accident Compensation Corporation for her rehabilitation, and is following up on this, keeping contact with her Case Manager to ensure that she does receive the 'No Falls' programme of falls prevention. This is of particular importance to Liz, as she is a diabetic, and as Gregg, Mangione, Cauley and Thompson (2002) report, older women with diabetes are twice as likely to become unable to perform physical and household tasks, leading to loss of independence.

Nancy is still driving which enables her to continue with her job, a job that gives her much pleasure and motivation. When I asked Nancy at our second interview what gave meaning to her life, she stated that after her spiritual beliefs and her family, her employment meant the most to her. She took great pride from what the driving instructor said to her.

“Oh, yes, I got my license in June for my second lot of driving tests, and he even told me I was a good driver and as I got out of the car he said, “It's good to be with someone over 80 who knows what they're doing.” (Nancy, paragraph 106).

She is still very engaged in life, with her job and her gym work, meeting friends on a weekly basis for lunch, and her family. However, Nancy is realistic about what the future may hold for her, but does not seem to be daunted by any possible changes in her health. She can drive up to 200km a week in the course of her employment, but also thinks ahead to the time when she may no longer be able to drive, and is taking steps to ensure she retains as much independence as possible.

“When I thought I was going to lose my car when I started my job, I said to my youngest son, I was going to get a mobility scooter, he was HORRIFIED – he said, “they're for the aged”. Oh, he really went off the deep end about it and I said, well stop thinking about it as being something for the aged, think about it as something that's transport,

because that's why I am getting it." (Nancy, paragraphs 178 and 180).

This type of acceptance of possibilities, and thinking about strategies around problems, shows a sense of wisdom, an understanding that human limitations are a part of life. As Ardel (1997) explains, the older adult enters old age with a lifetime of experiences that have shaped their personalities, which, in turn, can make some situations unbearable for some, but tolerable for others. Nancy is anticipating a possible change in her circumstances, but instead of giving up, is putting in place an alternative that is acceptable to her, if not some of her family members.

Using equipment to manage living with chronic illness is part of everyday life for all of these women, particularly walking aids. The inability to stand for any length of time has many implications in daily life, but shower stools and perching stools were found to be of benefit. Likewise the use of a trolley on casters means that these women can carry their drinks, meals, and other items around their home, making these tasks that we take for granted easy and achievable for this group of women. Often it can be the inability to complete these little tasks that can become disheartening, and makes living alone that bit harder.

The acceptance and use of these aids appears to make life that bit easier for these women. This adjustment to using equipment in the home is a strategy used by these women to maintain their safety in the home. The next section discusses other coping strategies that these women employ to enable them to manage their changing health needs.

### **Coping Strategies**

Morrissey (1998) maintains that an elderly woman's ability to continue the lifestyle 'living alone' is to some extent dependent upon her ability to construct a lifestyle that is acceptable to her. The women in this study have all adjusted their lifestyle to suit their capabilities and general health, making allowances for their energy levels, pain, and disabilities. They all used different coping

strategies to manage their health and their declining physical function. Nancy explains how she manages her back pain:

“If I walk from here to my letter box and back, I’m in pain and I mean severe pain and yet, if I sit down for a minute, I could to the same distance again. I don’t have to sit down long, but I do have to keep sitting down.”  
(Nancy, paragraph 202).

This understanding of her limitations and adjustment to those limitations means Nancy judges herself and her capabilities on a regular basis, knowing herself and her body. Allowing the extra time that any physical effort may take, and allowing her body to take that time, shows that Nancy uses a coping strategy that works for her.

Like Scanlon-Mogel and Roberto (2004) whose participants believed that their participation in regular exercise assisted them in keeping up with their activities of daily living, which enabled them to remain independent, these ladies, too, think exercise is crucial to their well-being. Nancy discusses her use of a local, private gym, which she attends most mornings.

“The gym – exercise, very, very important and especially so, as I can’t do any walking.” (Nancy, paragraph 202).

Emma also judges herself to ensure that she has enough energy left to return home when she is out walking. The outside conditions are very important to her, as she cannot tolerate the cold, and the wind makes it impossible for her to walk outside. If the weather means she cannot get outside, then she has set herself a walking programme around her house, to ensure that she gets daily exercise.

“But, when I can get out, I do have a good half hour. I walk for quarter of an hour and then think it’s about time I went back, so I do judge myself but I don’t – that half-hour is not from when I go out the gate, but out the door, because then I’ve got all the steps as well so it’s more than half and hour,

really.” (Emma, paragraph 117).

Penrod et al., (2003) describe this process as ‘checking on myself’, an internal and external reflection used in reappraisal of a particular situation, where the body is monitored for clues that a current form of action is effective in meeting the challenges of daily life. Emma knows that she must not walk so far that she would be unable to return home, and considers many factors when deciding how far to walk each day.

Liz also checks on herself. She must constantly assess her body and its limitations. She realises that as a diabetic she must ensure regular food intake, and understands she needs to keep her diet healthy. However, she also gets very tired, so that when she does cook, she tends to make larger quantities that can be stored in her freezer.

“I’ll cook a big pot of soup, which will last me about a week. I prefer to buy things in Woolworths that are already prepared, so I don’t have to. I’ve got an electric frypan, and I’ve just bought a new microwave.” (Liz, paragraph 55).

As Kralik et al., (2004) maintain, self-management is a dynamic, active process of learning, trailing and exploring the boundaries created by illness. Liz sits on a high stool in her kitchen to prepare her meals and clean her dishes, enabling her to continue to complete everyday tasks, tasks that she has probably undertaken all of her life. For Liz, sitting while preparing or heating her meals means she does not get too fatigued, and assists her to ensure a regular food intake.

The ability to be able to make a cup of tea independently is very important for Emma. She may wish to make a hot drink any time of the day or night, and needs to be able to manage this without calling on her daughter. Emma describes how she problem solved this difficulty.

“I kept thinking and thinking that little jug doesn’t weigh much, it’s just a plastic thing I used to keep orange juice in, so I just take the top off and use the [little] jug to put water in [the kettle].” (Emma, paragraph 177).

This adaptive process ensures Emma can make herself a hot drink independently and safely. These types of coping strategies and adaptations are essential to these women remaining independent and safe in their own homes. As Gignac et al., (2000) discovered in their research, older adults with disabilities are not passive or dependent, but rather actively engaged in numerous self-care efforts to manage their condition. The women in this study are proactive in their coping strategies, rather than reactive, anticipating their limitations and problems they may encounter, drawing on their past experiences to assist them to solve problems and maintain order in their lives. They do, however, rely on others to assist in maintaining order in their homes and to complete tasks that they themselves can no longer safely undertake, such as home help.

### **Home Help**

All of the women in this study have assistance with their housework. One is happy with the tasks undertaken by her home help, but the two other participants had reservations about the tasks that can be undertaken under their contract. These two women have also had several different people to assist over time;

“They’re not trained properly and the people – one of them wouldn’t even move the chairs from around the table to back in under the table and when I questioned it, I questioned the people in the office – they said, no, that’s spring cleaning – to move the chairs – it’s ridiculous. It’s stupid. They vacuum just the middle where they can see – nothing is moved, it doesn’t matter whether it’s on casters or not. They don’t do anything high.” (Nancy, paragraph 166).

Unfortunately, home help guidelines are strict, and do not include ‘spring cleaning’, although what this actually means is different for different people. Nancy felt so incensed by this, she made contact with the providers to seek

clarification about these guidelines, but was disappointed with what she discovered. Emma feels that her home help is very quick, and feels that the job done is not as good as it could be;

“I do get very annoyed with them, others will offer, do you want this done, I didn’t have to ask, this one I’ve got to ask. If you ask her to do anything, it’s so quick.” (Emma, paragraph 247).

Previously, Emma had a home help person who became very close to her, and she obviously missed the connection that she had made with this woman;

“I had one (home help), the first one, for three and a half years, she was company, you know, and she was just like a daughter at the end, you know.” (Emma, paragraph 247).

Having a home help person that takes time with these women is important to them. One feels she isn’t listened to, and that the woman completes the tasks too quickly. Home help is not just about completing tasks, these women appreciate the company, and want to connect with the person who is coming into their home. Forming relationships with people is important to all of us, but it is essential that the older woman feel safe and comfortable around the people that are entering their personal environment.

### **Summary**

These women constantly adapted to their changing health, checking on themselves, and altering their day-to-day lives to take into account the many different health factors impacting upon them. The use of equipment in the home assisted them to complete activities of daily living, whilst remaining safe. This attention to safety ensures that they can live in their own homes, with a minimum of outside help. All of these participants had assistance with housework, with varying degrees of success. They all employed coping strategies to manage their health needs, and adjusted these sometimes on an hourly basis. This movement between checking on themselves and coping strategies means they can maintain their quality of life while living with

disability. The next section discusses family, and how family support also impacts upon their quality of life. Family plays an enormous part in these women's lives, and helps to give meaning to their lives.

## **Family**

Having family support around them is essential to these women's ability to cope with their health conditions and remain at home. Not surprisingly, family plays an important part in these women's lives, whether it is practical support, or just knowing that there is someone they can call on if and when the need arises. As Moore et al., (2006) contend, as individuals search for meaning in their lives, there comes an acceptance and recognition of the importance of connections to self, others, and the world. The theme of 'family' will be explored in the following through the sub-themes: knowing that they are there, family pride, and family support.

### **Knowing that they are there**

Family is an important part of life, and the connectedness to significant others is crucial to our well-being. Emma lives alone, but her daughter lives in an adjoining house. Her daughter works during the day, but knowing that someone was returning to the property in the evening meant Emma felt supported and secure.

"I have got Beth who comes home of the evenings and I think that makes a lot of difference to me. If I was on the property on my own, and I didn't have anybody to come home [next door] in the evenings then I might be lonely." (Emma, paragraph 95).

As Mack, Salmoni, Viverais-Dressler, Porter and Garg (1997) explain, the ability of an older adult to remain in independent living is very much related to the resources provided by family, friends, and neighbours. While Emma needs very little hands-on assistance from her daughter, the fact that she is close by is important to her. Emma identifies that she may be lonely if Beth did not live so close. Elderly people can often feel isolated, especially as their ability to get

around decreases, but having even just one person that we feel connected to can make a huge difference.

Liz describes how her world has changed, as outside activities have decreased and friends have passed away, making her world of social contact much smaller than it used to be. She acknowledges that she is reliant on her family to provide her social contact, and her interest in the outside world.

“...because in the long run, it’s your family that your world closes [down] to.” (Liz, paragraph 139).

As Moore (1997) points out, when friends die, bodies fail, and the ability to control events and circumstances in life diminishes, some older people feel that all they have left is the love and compassion of those they perceive to be the most significant in their lives. Liz appears particularly close to one of her grandsons, and mentions him often in our interviews, although she does not see a great deal of him at present. Her sons both give support, and are in close telephone contact.

Nancy also uses the telephone to keep in close contact with her family. She knows that they will provide assistance if required, but is reluctant to ask them, as she feels that this is a sign of diminishing independence;

“I’ve only got to ask, I know that. The trouble is, up to recent years I’ve always been able to do things for myself, anyway, it comes hard, but I do ask if I really can’t do [something].” (Nancy, paragraph 271).

As Morrissey (1998) discovered, the support given by relatives and friends is often intangible. Knowing that family are ‘there’ if needed gives reassurance, and provides confidence that help would be given should it be needed. These women appreciate all that their families do for them, but do not wish to be a burden to them, and will often try to find solutions to problems before asking for help. Their social networks, while perhaps not great in numbers, appear strong and supportive, and all three women discussed how helpful these relationships



are to them. These women are all inextricably linked with their families, and these links provide them with a great sense of pride.

### **Family Pride**

Expression of pride in how family members have achieved in their own lives was another theme to emerge, and is significant to Liz in particular. She is also very interested in her past family history, and has undertaken some research into her forebears. On my second visit, she had photographs out to show me of her family, and also two very old family bibles. Although she had told me previously that “I’m not a religious person”, she took great pleasure in the old Bibles as being a link to her past. Liz speaks very highly of both her children and her grandchildren, and their academic achievements;

“Both my son’s are graduates, Simon, he’s [he has a] Masters, and my other son is a biochemist, my husband was a [sic] Master of Philosophy. And Craig, he’s quite academic Craig, dear old Craig (grandson).” (Liz paragraph 69).

Emma is very proud of her daughter. Her daughter had cared for her own husband, who had suffered with Alzheimers disease, until his death. This had happened several years ago, and her daughter was now in a new relationship;

“I’ve got a daughter on the spot, although I don’t see her all day, I see her in the evenings, you know, and I am truly happy that things have gone well for her.” (Emma, paragraph 274).

Emma, understandably, wants the best for her daughter, and appears reassured that her daughter has found happiness. We all want the best for our children, and even though Emma’s daughter is nearing retirement age herself, her happiness is still an important facet of Emma’s life. These women all told stories of their families, and the pride that they feel toward their family members is evident in their transcripts. Family get-togethers feature in all of these women’s stories, and they derived great pleasure in relaying these stories to me. They all acknowledge that while they remain as independent as possible, they do

rely on their families to some extent, and recognise that the support their families give them is integral to their ability to remain independent at home.

### **Family Support**

While some participants feel their family is there if needed but they don't feel they require regular support, one in particular feels if it weren't for her family support she would not be able to remain at home;

“I mean, I don't think I could have managed on my own otherwise. I mean, if there is something that I haven't got, with regards to the fridge, I always go and find it, I just go through there and help meself [sic] to milk, bread, anything I like, anything she's got there.” (Emma, paragraph 207).

The knowledge that she just has to go next door to get anything she needs gives Emma confidence, and means she does not feel alone. While she may not see her daughter daily, telephone contact is a daily occurrence, to ensure that Emma is managing and remains well. This type of contact makes Emma feel less vulnerable, while maintaining her autonomy.

### **Summary**

Families are important to all of us. These women know that they can call on their families if needed, although they try to keep their interactions with family on a more social basis, and only request help when all other means have been explored. They enjoy being with their family members, and often rely on them to provide social contact. Families give these women a continued interest in the outside world, and while their ability to participate actively on a daily basis with the world at large may be restricted at times, they gain great pleasure from being with family.

How these women deal with the restrictions their health puts upon them is directly related to their attitude to life. They all identified that they felt they had a positive attitude to life, and feel that this attitude affects the way they manage the many challenges they face. Next, I explore the concept of attitude, and how these women make the most of what they have, despite their many health issues.

## **Attitude**

Accepting what comes in life and being optimistic are all qualities that the women in this study portrayed. While they all have varying degrees of disability, which often change from day to day, they all show a resilience to life's' knocks and set backs. They pick themselves up and continue on. This is seen in their attitudes of making the best of the situation and trying to make meaning during difficult times of their lives. The following sections discuss the three sub-themes that emerged from the participants' stories about making meaning in their life in their older age. These sub-themes are spiritual beliefs and past experiences, just getting on/participation, and making meaning and quality of life.

### **Spiritual beliefs and past experiences**

How people deal with their illness is affected by the images of illness built up by past experience, and influences how they act when illness becomes an important aspect of their own experience (Viney, 1983). These women have built up their own images of their illnesses, and how they manage these on a day-to-day basis. Through each of these woman's stories, it is apparent that things have not always been easy for them. They all possess enormous inner strength, and tackle the challenges they now face with the experiences of past adversity. For Nancy, her spiritual beliefs enable her to deal with her chronic conditions as she feels strongly that it is through God that she is able to survive through difficult circumstances;

“I think it was through my children that I came to clearly know the Lord and something happened and he helped me step by step ‘till I got to this point and it was something – and I said “I can’t do it without your help” and I meant it, I really couldn’t. I am a very independent person and, even more so since my husband died – you have to be when you are on your own.”  
(Nancy, paragraph 222).

Her spirituality supports Nancy through her changing health conditions. By asking for help, not of her children, but of her God, enables Nancy to remain independent. Her strong faith is key to her having a sense of purpose and meaning in life, and enables her to rise above her suffering.

These women all expressed a philosophy of life that integrates changes and challenges as part of life, and views these as opportunities for growth. This attitude means that they can be proactive about their health, such as Emma, who belongs to a variety of clubs, some of which have exercise classes, that she participates in;

“When I was 65, I was very, very busy and into everything. I belonged to the first keep fit associate they had in England – over 65’s, and I was 65 then.”  
(Emma, paragraph 6).

This habit of exercise started at a younger age means that Emma has placed a high value on exercise for many years, and this motivates her to continue. By integrating her past to her present situation, she understands that she needs to maintain her physical abilities as best she can to enable her continued independence. True to her spirit, Emma even expresses some benefits to her disability;

“There is a bus stop there, which is very handy for me, and I sit in there sometimes and have a talk to whoever is sitting on the seat, and I must say, the bus drivers are very good, very good indeed, ‘cos with a stick, people take a lot more notice of you than if there wasn’t [sic].” (Emma, paragraph 137).

Emma finds pleasure in everyday activities, simple things that most of us take for granted. This strong sense of enjoyment in the small things in life gives meaning to ordinary things. For Emma, being able to enjoy and eat anything she likes featured in her interviews. She knows that eating healthy food is important, and identifies this as influential to her overall health;

“I think being able to eat, being able to chew, eat toast and anything I like has been a big help to me.” (Emma, paragraph, 171).

This ability to still be able to bite and chew delights her and she describes in detail the many foods she continues to enjoy, which she feels is because she still has most of her own teeth. She can still eat an apple, and relishes her ability to do this ‘just like the kids’.

Nancy’s past experience of visiting her mother in England and finding her health had deteriorated greatly influences how Nancy now copes with her own health. Her mother is a very different person to the one Nancy remembers;

“I got the shock of my life when I saw my mum, who’d been very, very straight and yes, she was in bed but her chin was almost on her tum [sic], her spine had virtually collapsed with osteoporosis, and of course when I came back, she died.” (Nancy, paragraph 140).

This prompted Nancy to join an osteoporosis organisation, which she was actively involved in for a number of years. She organised seminars for this group, and found companionship with people who suffered with the same medical condition very comforting. Being with people who have the same illness or disability can be very encouraging, and the exchanging of ideas and ways of coping with a particular chronic illness can be empowering.

These women all talked about their past in a positive manner. They have overcome much hardship, and all women talk of the war years, and the influence the war had on their lives. The war years particularly impacted upon their education, and meant that these women left school to take up employment. Emma, in particular, describes how difficult it was to access food and goods in England because of rationing, but still speaks fondly of how she met her husband during the war, and the social activities they did together.

Nancy’s husband died when her youngest son was only 16 years old, so she had spent a good deal of her life raising him alone. When her husband died, she

continued to work, as financially she could not afford to stop. Also, her husband was in the middle of renovating their home when he died, and she had completed the renovations with the help of her sons. She is immensely proud of this, and went on to renovate the home she now lives in.

Emma had immigrated to New Zealand at the age of 70, leaving behind her friends with whom she had spent many enjoyable times. She spoke at length of their outings on the bus with their free bus passes, and how they would take a packed lunch but always purchase a pot of tea wherever they went. She has built a new life here, and has made many new friends, however they are not 'life-time' friends such as she had in England. Emma told me about the first friend she made in New Zealand. She had met her at a meeting, when she had said something 'typically English' – "could you come at four o'clock, and have a cup of tea?" Emma said she had received a lot of invitations, "oh, come when you like", but said that the "come at four o'clock" made such a difference. The New Zealand way of "call in when you like" was unfamiliar to Emma, who was used to a more formal type of invitation. By having an actual time to visit gave Emma confidence that she would be expected and welcomed.

Liz had travelled all over New Zealand with her husband's employment, and had friends spread all over the country. She had attended university up until her marriage, but had returned to adult education at the age of 64. She felt this was a positive thing in her life, and had enjoyed the experience. She discussed her collection of family history, and she shared some of this information with me. Her family are encouraging her to write her own history, which she is considering. This connection between the present and the past appears to be very important to her, as it seems to give her a sense of continuity of life, a passing down of history from one generation to another. Liz describes this as "like putting a jigsaw together" but feels with her energy levels she would need someone else to assist her with this. The following sub-theme of just getting on/participation explores how these women just 'get on' with life, and some of the social activities they are still involved in.

### **Just Getting On/Participation**

All of the women talked about coping with their many disabilities by making the most of what they had, and getting on with life. In Moore et al's., (2006) study of the quest for meaning in ageing, they discuss how it is in continuing to have a rich and satisfying life, even if it is a struggle, which contributes to a sense of meaning and purpose in life.

“I work, as I said [and] I ignore as much as I possibly can any pain – that’s why I like my job, it gives the brain something to think about besides pain and if you can keep your brain occupied, it doesn’t think about your pain anywhere near as much” (Nancy, paragraph 240).

Emma uses problem solving to work out the best way to achieve a particular goal, calling on her past experiences, and taking her time to ensure that she has found the best possible solution. This confidence in herself and her abilities shows through her interviews. Taking risks and challenging herself to solve a problem shows that Emma is determined to cope independently of others.

“...if I have any trouble, I think, well how do I get over this?” (Emma, paragraph 173).

This perseverance, Wagnild (2003) maintains, is one of five characteristics that comprises resilience, which enhances individual adaptation and positively influences the process of successful aging. Their attitude and the way in which these women adapt to their changing health needs seems to make them philosophical about their health and resulting disabilities.

Two of the women are very active in their social activities. Emma relies on volunteers to take her to her various activities. She has recently gone to a movie with her Age Concern visitor, which she enjoyed greatly. Nancy still drives, which means she can get to her various groups and the gym independently. Driving means she is still able to work.

“I belong to two Country Women’s Institutes, and I enjoy both of those too, so I’ve got a lot to go to, and since I’ve been out of hospital, I’ve joined Age Concern and I go out with them sometimes, too”. (Emma, paragraph 93).

This type of engagement in life, of participating and being involved, was a major positive theme discovered by Easley and Schaller (2003) in their study of the experience of being a woman over the age of 85 years. Being a part of life and having an interest in other people all contribute to the sense of well-being that Emma appears to enjoy. For Nancy, it is her job that keeps her mind off her disabilities and enables her to live her life to the fullest.

“(my job) keeps me moving, even on days when I don’t want to do anything, it keeps the brain from thinking about the aches and pains.” (Nancy, paragraph 277.)

Loss of friends, and lack of transport impacts upon Liz. She now uses a taxi to take her shopping, but appears philosophical about this change in her life. She appears to accept this as how her life now is;

“It’s just a fact of life, I just have to accept it [that I am no longer able to do the things I used to do]. I suppose if I was terribly enthusiastic, I could get somewhere. Most of my friends are dead, because I’m 82.” (Liz, paragraph 75).

As Easley and Schaller (2003) state, being dependent on others, for example when a person can no longer drive their car, can limit their choice of activities outside the home. This dependence can become a factor in altering well-being, however, this narrowing of social life to accommodate physical decline does not necessarily include a negative emotional state (Burke & Flaherty, 1993). Liz went on to say that she had given up her car voluntarily, and felt that she had accepted this as she had felt in control of this decision. Having control over



one's life and making decisions for one contributes to making meaning and quality of life, which is discussed in the following section.

### **Making Meaning and Quality of Life**

Making meaning in their lives is a thread that weaves its way throughout these interviews. This search for meaning helps people to make sense of their life, despite the setbacks and difficulties they have encountered along the way. An engaged and active lifestyle keeps the older adult in touch with the world around them. This engagement in life helps to maintain mental and physical health, and adds to quality of life.

Living in their own homes is a positive experience for all of the participants in this study. They all expressed the idea that going into permanent residential care would affect their quality of life. Emma discusses the thought of going into permanent care, and how she thinks this would impact upon her life;

“The physio over the road told me I should go into a home and be looked after. Well, I thought, if that had been right, I doubt if I'd still be alive today, if I'd gone into a home, because I just don't like crowds and crowds of people and I do like, well I like doing things for myself.” (Emma, paragraph 56).

Liz, too, mentions going into care, and that she has made it clear to her family that she wishes to remain at home for as long as she can. She also states she would not want to live with her family, as she feels this would be a burden to them.

Nancy feels that her positive outlook on life impacts upon her health, and the way she manages her health problems. Keeping her mind busy and not dwelling on her problems is how Nancy copes with her chronic illnesses. This positive outlook on life means Nancy continues living a meaningful and productive life;

“Oh yes, very definitely yes. There's no point in... if I was to stop and dwell on the things I can't do, I know they catch up with me in-between times, but if I was to think about my aches and pains and what I can't do all

the time and nothing else, I would be like some of these other women of my age – they do nothing and they can't do anything. No – you've got to have a positive outlook.” (Nancy, paragraph 214).

This comparison by Nancy to ‘imagined others’ who do nothing and cannot do anything, is a way for her to cope with threats to her health. Buunk, Gibbons and Visser (2002) describe this as social comparison, where people draw conclusions about their own health characteristics by comparing themselves to actual or imagined other individuals. By keeping a positive outlook and focusing on things other than her health, Nancy expresses that she will not become like others who do nothing – whether she knows anyone like this or not. This comparison keeps Nancy from dwelling on her disabilities, and letting them stop her from doing the things in life that she enjoys.

Two of the three women in my study were actively engaged in life and they participated in many outside activities. The third felt that she was not as active and had given up some of her past leisure activities, but felt that the choice was hers, and that having choices gave her control over her life. All three women enjoy talking about their past, and where they have come from. This discussion about their past still provided pleasure to them, and the values and attitudes continue to guide them in the present. As one participant said when we were discussing the History Channel on Sky Television – “I’m part of history and I can remember some of the things during the war, ‘cos I was in England, everything that went on.”

Their strong family connections and the support that family gives them assists them to remain as independent as possible. They express pride in their family, from their own children through to grandchildren and great-grandchildren. Knowing that they have people to call on if needed makes them feel secure, and they enjoy the contact and regular telephone calls. One woman is curious about her own genealogy, and has spent considerable time and energy researching her ancestors. She has a desire to form a link between her past and her present, and is considering recording in some way her own story, and that of her own family. This linking with the past and present enables her to make meaning in her life,

and gives her life a sense of purpose. The ability to integrate a sense of past, present, and future is an important task of later life, and is an over-riding theme that threads throughout the interviews.

### **Conclusion**

This chapter has discussed the three main themes that emerged from the interviews undertaken with the research participants. These themes of coping, family, and attitude are discussed by all of the women participating, as they each share their own unique view on life. Their ability to look back on their lives and feel satisfied, and to look ahead with anticipation contributes to their making meaning in their lives. In the following chapter, I will discuss these findings, and explore them in more depth, based around the three major themes of coping with changing health, family, and attitude. This discussion focuses on what these women feel is important to them, and how these three overall ideas fit in with the current literature on these subjects. How these women make meaning in their life despite their many health problems is highlighted, and shows how their attitude effects the way in which they function with ever-changing health problems.

## **CHAPTER SIX: Discussion and Conclusion**

### **Introduction**

Chapter Five explains the major overarching theme of creating meaning in life, through the themes of coping with changing health, family, and attitude. By using the stories of each of the women to highlight both the practical ways in which they manage their comorbid chronic illnesses and what living with those illnesses actually means to them, a picture begins to evolve of how these women cope and what is important to them. In this chapter, the contributions of nursing knowledge will be highlighted. In addition, the findings will be explored in light of what is known about this issue. This chapter also provides a conclusion of this thesis, including the implications of the research findings for nursing practice and the limitations of the study. Finally, it offers suggestions for further research to broaden nursing knowledge of this subject, particularly in a New Zealand context.

### **Revisiting the aim**

We are living with an increasingly ageing population. As people age, they are more likely to develop chronic illnesses, often impacting upon their everyday life. As a nurse working in the community with older people, gaining a better understanding of what this actually means to these people will assist me in my everyday practice. This study also begins to fill a gap in the literature, as it is set in a New Zealand context, an area of which there is no published research. The aim of this study, therefore, evolved to the following;

To explore factors that older women living with comorbid chronic illness identify as key to maintaining or improving their quality of life.

### **Discussion**

At the beginning of my journey to complete this research study, I asked myself questions about what it was that I really wanted to understand about being older and living with chronic illness. I meet many different people in my job, with many different illnesses, and many different ways of dealing with the disabilities that chronic illness can cause. After giving much thought and reading about this subject, I came to the conclusion that quality of life was a major concern for this

group. What was it that affected the quality of life of this group of people? What made things easier or harder? How did living with chronic illness affect them on a daily basis? As this project continued to evolve and develop, the aim of exploring the factors that women themselves identify as key to maintaining or improving their quality of life resulted. Once I had met the women who had agreed to share their stories with me, I began to better understand what they felt impacted upon their quality of life. They had many illnesses, were of advanced age, and yet they enjoyed life and were able to self-manage much of their disabilities. There is so much more to their lives than managing their chronic illnesses – they are not defined by those illnesses, or the resulting disabilities chronic illness can bring.

After further investigation, analysis, and reflection, I realised that these women all had created meaning in their life – they had integrated their wealth of past experience into their present, reflecting back but still gaining enjoyment from the here and now, looking forward to life, and participating as much as possible, accommodating their many disabilities. This making meaning in life appears to impact upon their attitudes and outlook, thereby giving quality to their lives. As Moore et al. (2006) discovered, making meaning in life has significant implications for quality of life in old age. This became even more apparent once I began to analyse the stories that these women have shared with me. This analysis has led to the emergence of three main themes. The following discussion of these themes will assist nurses to better understand the problems and solutions these women have identified as being important to them, and how they manage them in daily life.

### **Coping with Changing Health**

The ability of these women to adapt to and self-manage their chronic illnesses impacts upon their daily life. They have life-long patterns of dealing with stress and coping in adverse situations, and managing their health conditions is no exception. For example, Liz is very aware of her diabetes, and ensures that she monitors her blood sugar levels, and her diet. Emma goes for a walk every day, outside when the weather is fine, and inside when it is cold and wet, and attends an organised exercise class. Liz attends the gym daily to complete weight

bearing exercises for her bone mass, a symptom of osteoporosis that she is acutely aware of. These women all acknowledge that these health measures are up to them, that they determine their levels of fitness and health, and try to keep themselves mobile and healthy. Stuijbergen et al., (1999) support this view, stating that health promoting behaviours not only enhance quality of life, they also have a positive social aspect, as they provide an opportunity to meet with others, both those with and without disabilities. This contact can be important for some people, certainly Emma and Nancy, and adds to their quality of life.

Coping with changing health needs is a challenge that these women all rose to. As Duke et al., (2002) point out, successful adaptation to chronic illnesses depends to an increasing degree on the individuals internal resources. Past experience is also very important, as individuals' beliefs and behaviours cannot be understood from just one point in time. People do not just suddenly appear aged in their 80s – they have undertaken a long journey through life and have been profoundly shaped by particular joys, sorrows, and triumphs (Carlson et al., 1998). Emma has a long history of regular, organised exercise, and Nancy had been very moved by the experience of seeing her mother's degeneration due to osteoporosis. Liz, too, expressed a keen desire to return to her previous mobility of walking around the block, something she had not done since a fall earlier in the year. Liz felt achieving this goal would give her a will to live, in particular being able to access the outside world. In Scanlon-Mogel and Roberto's (2004) study of older adults and exercise, their participants reported a belief that regular exercise assisted them in keeping up with their activities of daily living, which enabled them to remain more independent, an important aspect of quality of life. These women, too, believe that regular exercise has many health benefits for them, reflecting a 'use it or lose it' philosophy.

Liz was very aware that a fracture at her age could be disastrous, and could well be an injury that she would struggle to recover fully from. She was restricting her mobility at home, until she had undergone the Falls Prevention Programme offered through the ACC. As Fletcher and Hirdes (2004) state, being female and spending long periods of time alone during the day are predictors of restriction of activity because of fear of falling. Liz is in a conflicting

therapeutic dilemma – with her history of falls and long periods of being alone, she has an understandable fear of falling, but realises that she needs to keep her activity levels up to maintain her overall health. Liz is very keen for this programme to start, and is actively pursuing her ACC Case Manager to ensure that she receives this education and exercise programme.

In my role as Liaison Nurse, I have met some older adults who have declined equipment that has been recommended, citing that the world would view them as old, a view they do not wish to be a part of. Not so the participants in this study, who understand that these concessions to their disabilities assist them in remaining safe in their homes. In fact, Emma and Nancy completely turn what some people would describe as negatives into positives. They express how much these items support them, from shower chairs and perching stools, to walking frames and walking sticks. In the case of Emma, she feels having a stick makes her visible in public, and means that she receives preferential treatment. Nancy, too, has no qualms about confronting the possibility that she may have to give up her driving license at some stage, and is looking ahead to purchasing a mobility scooter. She has had to placate her son, who was distressed that she would be thinking like that, giving in to older age. For Nancy, however, the need to be able to continue with her part time job meant a lot to her, and if a mobility scooter was the only way to continue, she was prepared to do this. After her religious beliefs and family, Nancy feels that her employment is what gives meaning in her life. The structure her work gives to her life, and the people she meets through this work, adds to her quality of life, and keeps her mind off her sometimes painful illnesses. There is a need to normalise the use of equipment by older people to minimize negative stereotypes traditionally associated with such items.

Morrissey (1998) states that previous research findings show that the majority of older adults express the desire to continue living in their own homes, and that was certainly the wish of these participants. They all feel, quite rightly, that they are not ready to go into permanent care, and all express the hope that they will never have to face this decision. Emma gives several examples of what she feels she would not be able to do if she was in care, and talks at length about the

things she has in her home to ensure her comfort, such as a new electric blanket, and her heaters which she uses when feeling cold. The fact that she can get up in the night and make herself a cup of tea if she wishes, and her autonomy over when she retires at night are very important to her. She is very happy in her environment, and took great pride in showing me around her house. Phillips et al. (2005) examined the impact of the environment on the older person, and their results show that psychological well-being is overwhelmingly the result of the environment meeting an individual's needs and expectations, which is certainly true of Emma.

Home is not just bricks and mortar, however. In Hinck's (2004) study on the lived experience of oldest-old adults, the participants describe home as being both a physical space and a state of being that allows self-determination, connection to their meaningful past, and maintaining of privacy. These women have minimal assistance at home, all only requiring assistance with their housework. While they do not have to pay for this service, the cost to them is the loss of privacy and becoming a part of someone else's timetable. Two of the women feel that the standard of work is very low, and they express frustration at their inability to undertake this work themselves. The fact that they have a stranger coming regularly into their homes means that they have to be very trusting of these assistants. Understandably, they wish to connect in some way with the assistant, and describe previous assistants with whom they had become very close. As Wolff and Agree (2004) state, balanced relationships with carers increases well-being because they support feelings of self-worth and self-esteem. Unfortunately, there is a shrinking number of people willing to take on this often poorly paid work, and it can be almost impossible to replace an assistant even if their work is not up to your standard.

Liz talks of how much she misses her husband, but finds her home a place where she can recall happy memories. She pointed out several trees in her garden that were in flower, which her and her husband had planted. These attract many birds to her garden and she enjoys watching and listening to them. Nancy is very proud of her home, and the fact that she has completely redecorated it since she had moved there. Her husband had never lived in this home, as he



passed away while they were living in their family home. Nancy decided to move to a smaller property that she felt she could better manage once she was on her own. All of these women live in houses that have been properly maintained and are well appointed. Housing can play a critical role in maintaining the health and independence of the older adult. Evans, Kantrowitz, and Eshelman (2002) undertook research to better understand the implications of living conditions on the psychological well-being among an elderly population. They discovered that housing quality is associated with positive affect among older adults living in the community, and that this group of people feel more attached to their home than those in poorer housing. This research confirms their findings as also important in the New Zealand setting.

This sense of attachment and feeling of belonging in the community is important to the women in this research, as they appear to feel secure and comfortable in their homes, thereby impacting upon their quality of life by giving them a greater sense of independence. They all talk of neighbours that they chat to in the street, the local businesses they support, and the sense of belonging that this brings. A sense of belonging, of being connected to a community, and of being engaged in that community, contributes to making meaning in life, of being a part of something bigger than oneself and ones family.

### **Family**

The impact of family upon these ladies lives is not a surprising finding. The need for a close, intimate relationship with those we love and who love us is a basic human experience, and age does not lessen this need (Easley & Schaller, 2003; Keyes, 2002; Steverink & Lindengerg, 2006). All of these women talk of their families and the pleasure and interest they gain from various members of their families. They all have family photographs prominently displayed, and some showed me photograph albums of children, grandchildren, and great-grandchildren. They all have frequent contact with family members, primarily by telephone, and this is an important connection for them. Emma sees her daughter most days, as she lives next door, and she described to me with great delight how Beth will sometimes cook her roast potatoes when she has the oven on. Liz talks of outings with her family, and the lunches they have in cafes in

the area. These treats that family can provide give these women untold enjoyment, and they are something that the women look forward to.

Liz has delved into her own family history, and discovered that her family has strong links to the Kapiti area. This link to the past gives her life meaning, and she is writing down her own history to be added to that of her ancestors, thereby stamping her own identity on her family history for her own children and grandchildren. She hopes that the addition of her past will enable her family to remember her, to gain an understanding of her life before they were born, and to appreciate how her life inextricably fits into their past. Liz takes an active interest in her grandchildren and spent a lot of time telling me of their attributes and the achievements they have made, and their hopes for the future.

Education is of great importance to Liz's family, and they are all excelling in the academic world, which makes Liz very proud. As Moore (1997) explains after conducting a study on meaning in life and suicide in older adults, as friends die, the body fails, and our control over events and circumstances in life diminishes, all that some older people have left is the love and compassion of those they perceive to be closest to them. Liz acknowledges this, as she told me that her world had closed down to her family, and it is through them that she maintains the majority of her contact with the outside world.

The contact and encouragement from family members that each of these women receive keeps them interested in others, gives meaning to their lives, and helps them to maintain a positive outlook on life. Wolff and Agree (2004) support this finding, stating that frequent phone calls and visits by family may remind individuals that they are loved and that their health is important to others, thereby providing them with a sense of purpose and an incentive to sustain their physical and mental well-being. These women all describe this kind of help, such as phone calls, travel to appointments, and practical help, as support from their family and they do not feel that this was 'care' in any way. The word 'care' is used to describe assistance from outside their social circle, as in home help, or going into residential care. Rather, they see this family assistance as part of their ongoing relationship within the family, although Emma did admit

that she felt she could not remain living at home without the support and assistance of her daughter. These relationships as portrayed by these three women are more of a partnership. By working together to solve the problems living with chronic illness brings enables them to remain relatively independent and to maintain their autonomy.

These close relationships fulfil a fundamental emotional need. Steverink and Lindenberg (2006) describe the three basic social needs as affection, behavioural confirmation and status. Affection, they maintain, is met by relationships that give you the feeling of being loved, trusted and accepted, and that others are willing to help you without expecting anything in return. Affection is the love you get for being who you are, regardless of your assets (status) or actions (behavioural confirmation). The maintenance of these needs is necessary for healthy functioning and well-being.

All of the women in this study express their love of their family, and of being loved. Liz talks of how she still misses her husband, how his death changed her life, but that the closeness of her children and grandchildren is a substitute for her, and talks of how lucky she feels having them in her life. Emma reminisces about how she met her husband and their early courting years, and these memories bring her great pleasure. She also enjoys retelling these accounts of her early years to her daughter, thereby keeping his memory alive. Nancy talks of knowing that her family is around her, and while she likes to be as independent as possible, understands that they are only too willing to assist her should she need any help. It is this underlying support and encouragement from family that gives meaning to the lives of these women. The quest for meaning is rooted in a yearning for connectedness and in a desire to feel useful, needed and cared for (Moore, 1997). The women in my study all talk of their grandchildren and how they have ongoing relationships with them. This feeling of still being needed and still being part of the family is important to them. These feelings influence how they cope with daily life, as is attitude, another theme that these women identify as impacting upon their quality of life. This is discussed in the following section.

### **Attitude**

Accepting what comes in life, being optimistic, having strong religious or spiritual beliefs, and acceptance of health problems were all key themes in research undertaken by Easley and Schaller (2003). Having a positive attitude was a factor that the women in this research project identify as being crucial to their quality of life. They talk of “attitude of mind” and “you’ve got to have a positive outlook.” This outlook on life contributes to morale, which is linked to quality of life and life satisfaction. In their study on morale, von Heideken Wågert et al. (2005) found that living in your own home and not feeling lonely were strong social factors that increased morale. These three women all live in their own homes, and none report feelings of loneliness. They all express the thought, however, that to give up their home would in some way decrease their well-being and their sense of autonomy. These women are constantly adapting to their changing health needs to ensure they keep themselves as safe at home as possible and as healthy as possible. As Gooberman-Hill and Ebrahim (2006) explain, how people cope or adapt to change is related to their expectations for the future. The participants in this study understand that remaining safe and managing their own health directly impacts upon their ability to remain living alone in their own environment.

This sense of control over the participant’s lives is important. As Carlson et al., (1998) assert, often the spectre of dependence hovers ominously over the heads of older people. Emma discusses the sense of control she has over her environment and her time, choosing when to go to bed at night, have a cup of tea, or go for a walk. Liz too, speaks of control, explaining the losses in her life, such as her car, were of her own volition. This ability to determine for themselves how and when to live their lives was essential to their well-being and quality of life.

Only Nancy spoke of her spiritual beliefs, and identified her beliefs as giving her meaning in her life. Research by Kirby, Coleman and Daley (2004) support this finding, stating that spiritual beliefs can be a significant factor in maintaining a sense of well-being. Liz states that she does not have any spiritual beliefs, but that the thought of her life ending does not worry her. As Neikrug

(2003) explains, it is a mistake to think that the majority of older people are overcome by constant worry, instead very few elders worry about their own personal mortality. Emma, too, did not express any spiritual belief, and was too busy with an active social life to give any thought to her death. These social activities are important to Emma, and give her a great deal of enjoyment and quality of life. In their study of the link between perceptual speed, a form of cognitive testing, and social participation, Lövdén, Ghisletta and Lindenberger (2005) discovered that an engaged and active lifestyle alleviates decline in perceptual speed. This active engagement in life and positive adaptation are factors that enhance older people's ability to age successfully.

Nancy keeps her mind active with her job, and maintaining an interest in her clients. She deals with ordering product and payment for these products, which means she must focus her attention to ensure that these are all completed correctly. Nancy finds that this focus on other things other than her health and disabilities is of great benefit to her. As she says, she can only focus on one thing at a time, and if it is her work, then she is not thinking about her pain or disabilities, which gives her a reprieve from her health problems.

We all strive to be masters of our own destiny, and these women were no different. Remaining in control of their lives and having structure to their day were vital to these women's quality of life. As Burke and Flaherty (1993) explain, the cultural significance of the role that older adults are allotted within society may account for this prevailing need to maintain a sense of self-control and a sense of pride in preserving independence in spite of declining function. These women all express pride in what they can still manage to do for themselves, and they all feel that they keep in relatively good health, despite their many health conditions. This has a direct effect upon their activity levels, as older adults are more likely to reduce or abandon activities in response to illness if they assessed their health as fair or poor. Being optimistic about life and being responsive to self-management of health can help maintain positive well-being and quality of life (Duke et al. 2002). Taking pride in how health and disability is managed and not 'giving in' to ill-health give these women a sense of meaning and enable them to carry on. Meaning is central to life in that

it allows humans to make sense of their existence in the face of adversity and chaos, or during times of relative calm. (Moore, 1997). The next section will discuss the implications for nursing knowledge and practice.

### **Implications for Nursing**

Understanding the lived experience of one person or group of people makes it easier to understand similar experiences for other people (Hinck, 2004). While this study is based on a small participant group, it backs up other research completed in this area, such as Easley and Schaller (2003) and Moore et al., (2006). There is a dearth of research from a New Zealand point of view, with all of the current research coming from overseas. It is important that nurses practicing in New Zealand understand the New Zealand context. This will ensure that nursing is conducted in a way that is meaningful and relevant to the older person living in this country.

As Moore et al., (2006) explains, the relevance of personal life stories is assuming increasing prominence in the gerontology literature, and nurses need to understand the significance of their older client's life stories and how they live their lives with meaning. The understandings that emerge from this will allow nurses to better support and facilitate healthy behaviours and assist older adults to remain living in their homes safely. If nurses believe that life can remain potentially meaningful regardless of circumstances, then a major role exists for nurses to facilitate a reconstruction of meaning for many older adults who have experienced life-changing events, an idea that is supported by Moore, (1997). Nurses are in a position to promote successful ageing. Encouraging healthy practices and maintaining an active lifestyle improve health, and this is no different for older adults.

The findings from this study show that the use of equipment and aids must be normalised to change society's view that getting older and needing assistance is negative. Instead, ageing must be seen as a part of the human experience, not an illness or disease. In our culture of youth and beauty, ageing is something that must be fought against, and vast amounts of money are spent on preserving

looks and bodies. This study supports the idea that while growing old is inevitable, it is not the end of a useful and fulfilled life – rather it is a stage that can have many rewards and challenges. Nursing must promote successful ageing to ensure that growing old need not be something to be feared. It is a time of life when we can look back on our life and create meaning, while still looking forward to the challenges that age brings.

Nurses have long been concerned with self-care and health promotion and as the focus of care shifts to the community setting, nurses must enhance the self-care wellness activities of older people (Chambers Clark, 1998). Living with chronic illness often means the older person must create a balance in life between health needs and maintaining wellness. For example, a person may have congestive heart failure and become short of breath upon exertion. Nurses are well placed to provide expertise and advice about the therapeutic benefits of exercise, while understanding that exercise may be limited due to breathlessness. Together, the nurse and the client can develop a plan to maintain optimum health and ensure that each day is lived to its fullest within the confines of the illness. Living life to the fullest is a goal that must not be discounted simply because a person is elderly and has chronic illness. While they must be taken into account, by working together and understanding what is important to the client, steps can be undertaken to achieve this goal.

Taking time with people to listen and really hear their stories is important, both for nurses and the older person. Building a therapeutic relationship with another person takes time, but the more time nurses can spend with their clients the greater the understanding of the issues faced by that client. By listening to the stories that the participants in this study shared with me, it became apparent what was important to them, and how they had created meaning in their lives. They all had positive attitudes to ageing, and had accepted both the limitations and the challenges that their illnesses imposed upon them. This acceptance of these limitations, having a positive attitude, just getting on with life, and accepting assistance when needed contributes to their successful ageing.

### **Implications for the Multidisciplinary Team**

With the current shift to shorter hospital admissions, adequate community care must be a priority for governments, not only with more resources being placed in the community, but a greater understanding of what older adults themselves find helpful to maintain their health and remain living in the community. Input from elderly people regarding what they want and need from health providers is a necessary step in evaluating the effectiveness of available health services. Working alongside older people to assist them to accommodate their disabilities while maintaining function is a challenge, not only for the gerontological nurse, but also for all members of the multidisciplinary team.

The overwhelming wish of the majority of people is to remain living in their own homes, which has implications for all disciplines. For example, assessments and interventions by Occupational Therapists and Physiotherapists ensure that maintenance of function, independence, and safety are supported and encouraged. This support and encouragement contributes to a feeling of well-being and accomplishment. The identification of the need to maintain contact with family and friends, and to be able to continue to participate in outside activities has implications for Social Workers, who can assist to find ways around barriers to these needs. By offering advice based on current research, such as this study, ensures that interventions are based on what the older adult needs, rather than what health care professionals assume they need.

For my role of Liaison Nurse within the team, this study highlights the need to be able to spend time with clients to hear their stories. This greater understanding of the client's needs and wishes enables the nurse to offer appropriate advice and interventions tailored to that particular person. The Liaison Nurse is also better placed to offer support and encouragement, to ensure that assessments are completed accurately, and that there is clear understanding between the client and the rest of the team. By walking alongside the older adult and assisting that person to overcome barriers and challenges, the Liaison Nurse can begin to facilitate positive and successful ageing, thereby helping to create meaning in life.



## **Limitations**

Rigour has been achieved in this research by the maintenance and reporting of the audit trail, which will allow others to assess the significance of this research. This type of rigour enhances credibility and allows other researchers to decide whether this research is worthy of being relied upon as a basis for decision making and conducting further research (Rice & Ezzy, 2000). The main ways in which qualitative researchers ensure the retest reliability of their analysis is in maintaining meticulous records of interviews and observations. While it is possible to analyse such data single-handedly, as I have done, reliability may be enhanced by the analysis of the data by skilled qualitative researchers and comparing results (Mays & Pope, 1995).

This study allowed participants to self-select themselves to be a part of this research study by answering an advertisement in a local newspaper. There was an assumption by the researcher that women who selected themselves and were able to make contact with the researcher, understand the information letter, and re-contact the researcher were cognitively able to understand the concept of this research. Also, the ability to complete all these steps may have attracted a particular type of woman, one who is motivated and has an interest in her health. These women live in an area of the country that has a reasonably high socio-economic profile. Two of the women were not originally from New Zealand, so findings may be different if all participants were New Zealand born.

The experience of growing old in New Zealand is changing. Low wages and poor employment conditions for carers, the privatisation of care facilities for the elderly, and the ageing of the population means that how New Zealand cares for our older people has become an issue for society at large. The older adult is becoming a target for politicians, as their voting power increases, and they become a force not to be ignored. This research study does not uncover the power structures prevalent in New Zealand at this time, but that is not what this study is about.

A study of this nature has only limited applicability to others, however descriptive research is used when there is little previous research conducted, and this is very true of this type of research within the New Zealand situation. This research provides a base, a building block, from which to understand what it is to be older and have comorbid chronic illness. Other research can build on this study, and in doing so add to our picture of growing old in New Zealand. This will assist to ensure that interventions by New Zealand health professionals are tailored to the older adult living in New Zealand.

### **Implications for Further Research**

The three women who participated in this study all appear to be ageing in a positive manner. One still maintains a part-time job, and all three spoke of making the most of what they had. This positive attitude to ageing contributes to their sense of meaning and purpose in life. They all own their own homes, and have done so for many years. They all have caring, close families, who provide support and assistance if and when it is needed. Results from women who have less stable living situations, family input, and a less positive attitude may yield different results. These women all appeared to have a reasonable standard of living. As Wagnild (2003) states, individuals with low incomes are at an increased risk for health problems and are less able to participate in health promotion strategies. Again, women from a lower socio-economic group, and in rented accommodation, may show a different attitude to ageing and quality of life.

More research is needed with different ethnic, cultural, gender, and geographic factors in relation to quality of life and chronic illness. For example, how do people compare that live in other parts of the country, rural versus urban? This research was undertaken on the Kapiti Coast, which has a higher than average older population. Results may be different from a large city, or from a small country town. Does gender affect quality of life, and the factors that enhance or detract from this? Women live longer than men, so therefore have to manage with disabilities over a longer period. Do men cope differently with their disabilities? Men may have a completely different view of what quality of life

means to them, and the impact that chronic illness has on their lives. Do men who live alone have differing views to those who live with others? The support of living with a spouse or family member may alter views of quality of life. Further research on this topic would increase our knowledge and enhance our understanding of ageing in New Zealand, and the effect that chronic illness has on older New Zealanders.

## **Study Overview**

Chapter One introduced this research study, explaining the research question and aims of this research. The impact of chronic illness on everyday life of the older person, and the lack of New Zealand research on this subject, is the justification for conducting this study. Women tend to live longer than men, take longer to recover from acute events, and suffer from more chronic illness, therefore this study was limited to women only, to capture their unique experience. This led to the development of the aim of this study, which is to explore the factors that impact upon the quality of life of elderly women with comorbid chronic illnesses.

Chapter Two gives an overview of the Community Rehabilitation Team. Assessment and treatment are all important facets of rehabilitation, and these are discussed in this chapter. The role of the Liaison Nurse within the Rehabilitation Team is explored. The setting of goals and the partnership that results between the health practitioner and the client to achieve these goals is examined. Rehabilitation is about teamwork, and the multidisciplinary team and the way in which they work together, with the client, is explained.

Chapter Three focuses on what it may be like to be elderly and living on the Kapiti Coast. Chronic illness and the impact this has on the elderly population is explained, and published literature is used to support the idea of quality of life and what this may mean to the older adult. In this chapter I have, with my background of working with the elderly, anticipated some of the issues that the participants may have found impacting upon their quality of life. This understanding of the issues builds a picture of what growing old on the Kapiti

Coast may mean for older people, and some of the strengths and challenges living there may pose for these people.

Chapter Four explains and discusses my chosen research design, which is descriptive methodology. This type of methodology is used when not much is known about a subject, which is true of understanding the impact of comorbid chronic illness in a New Zealand context. This methodology uses a qualitative approach, which enabled me to gather these participants' stories. The use of stories to understand the lived experience can be a powerful way to better understand those experiences. This increased understanding can improve quality of health care and assist in the development of new knowledge. Face-to-face interviews were used to gather these stories, and how these are analysed is explained. Ethical considerations and my inclusion and exclusion criteria are discussed, and the participants are introduced in this chapter.

Chapter Five introduces the three main themes that emerged from the findings. These are coping with changing health, the importance of family, and attitude. Each of these main themes is divided in three sub-themes, and each sub-theme is fully explored, using the words of the participants themselves. I have used some literature in this chapter to support these findings, and to aid in my interpretation. These three themes all help these women to create and find meaning in their lives, which contributes to their ability to age successfully.

Chapter Six is the final chapter, and expands on Chapter Five by delving deeper into each main theme. The implications for nursing that this research uncovers are explored. As the focus of health care moves from a hospital setting to that of the community, nurses must have a good understanding of what living in the community with comorbid chronic illnesses means to the older person. This will assist in interventions that are better tailored to individuals health needs. The limitations of this study are set out, and the implications for further research are discussed. This research was undertaken on a small group of elderly women, who all live in their own homes, and have supportive families close by. Further research on people with different ethnic, cultural, gender, and

geographical factors is needed to further expand our understand on living with comorbid chronic illnesses within New Zealand.

## **Conclusion**

All countries will be faced with a growing older population with different health and disability issues over the next ten to twenty years. Many Western countries have recognised that the post World War II 'baby boomers' will retire from the workforce during this period which will have a significant impact on the delivery of health and disability services (Ministry of Health, 2004). Improving the ability of health care systems to respond to the demands of older people with chronic illness is one of the greatest challenges of our time. Society is confronted with the urgent challenge of promoting a high quality of life for an ever-increasing ageing population. If we only increase life expectancy without adding quality of life and meaning to life, it is hard to see the merit in maintaining healthy practices. This is particularly so for women, as women have a greater likelihood of living longer, and thereby, are more likely to suffer from chronic illness and functional decline.

The older adult must begin to actively involve themselves in their health and discover ways that assist them to manage their changing health needs. Modern health care is moving away from the paternalistic model of health care that sites the patient in the role of passive recipient. Now people with chronic illness are invited to be partners in decision making about their health care (Barlow et al., 2002; Paterson, 2001). Nursing is in a position to assist in this partnership, offering advice and information to people with chronic illness to ensure the best possible health outcomes.

This research demonstrates that the participant's quality of life stems from the ability to create meaning through coping with change, family, and attitude. It is important that health care professionals support the process of making meaning in life. Through listening and being attentive to the life story of the older adult, nursing can facilitate making meaning in life, despite the sometimes overwhelming challenges that older adults with chronic illness face. Nurses can

assist the elderly to find meaning in everyday experiences, and to draw upon how they have overcome challenges and adversity in the past and to use these experiences to solve present problems. This interweaving of past and present, of maintaining quality of life, and the ability to transcend difficult life circumstances enables the older person to find meaning in life.

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APPENDIX 1

**RESEARCH STUDY**

**Are you a woman over the age of 65 years?**

**Do you live in the Kapiti area?**

**Do you have more than one long-term medical problem?**

**Would you like to take part in a research study?**

I am undertaking a research study as part of my Masters of Nursing. I want to know what impacts upon the quality of life of the older woman with multiple medical problems.

*If you would like more information please contact me:*

**Pauline Lowe 298 6069 ext. 4214**

KN027/FR



**Central Regional Ethics Committee**

Ministry of Health  
Level 2, 1-3 The Terrace  
PO Box 5013  
Wellington  
Phone (04) 496 2405  
Fax (04) 496 2191

**1 September 2006**

**Pauline Lowe  
15 Toenga Road  
Pukerua Bay  
Porirua**

**Att: Pauline Lowe**

Dear Pauline

**CEN/06/07/062 - Increasing understanding of factors that impact upon the quality of life of elderly women with multiple chronic illness**

The above study has been given ethical approval by the **Central Regional Ethics Committee**.

**Accreditation**

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

**Progress Reports**

The study is approved until **December 2007**. The Committee will review the approved application annually and notify the Primary Investigator if it withdraws approval. It is the Primary Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **September 2007**. The report form is available on <http://www.newhealth.govt.nz/ethicscommittees>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

**Amendments**

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

**Please quote the above ethics committee reference number in all correspondence.**

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

**Claire Yendoll  
Central Ethics Committee Administrator**

Email: [claire\\_yendoll@moh.govt.nz](mailto:claire_yendoll@moh.govt.nz)

## APPENDIX 3

Graduate School of Nursing and Midwifery

**Participant information sheet**  
**Face-to-face interviews**

Project title – What factors impact upon the quality of life of elderly women with multiple chronic illnesses?

Researcher name – Pauline Lowe

Dear Madam,

Thank you for your reply to my recent advertisement. I am a Registered Nurse completing my Masters Degree in Nursing. I wish to undertake a small research project in which you may be interested.

My area of research is as the title sounds – a wish to understand what factors affect the quality of life of women over the age of 65 years who have more than one long-term illness. I believe this research would help health professionals be more aware of the concerns of older woman.

Your agreement to be part of my study would mean that I would visit you at a place you felt comfortable in, probably your home. I would talk with you about the things that help or do not help you enjoy your life, what makes things easier for you, and what makes things harder. We would talk about your health, and what this means to you. I would tape this interview, and I would have the tape typed up. I would bring the typed pages to you, and we would go through them together, to

make sure that you agreed with what had been written. Each meeting would take no longer than 90 minutes. You may like to have a support person present during the interviews.

I will not use your name in my research; I would give you a different name, so that your information would remain confidential. I would return the tape to you at the end of my study, and a summary of the things I find out during my study, if you would like this. The information that is collected from you would be securely stored for ten years.

If you wish to be a part of my research study, please contact me;

Pauline Lowe

298 6069 ext. 4214.

## APPENDIX 4

## CONSENT FORM

This is to say that I agree to be a part of a research study about the factors that impact upon the quality of life of women over the age of sixty-five, who live in the Kapiti area.

I will not be at risk by being part of this study, and I will not receive any payment for being in this study. I understand that I can withdraw from this study at any time, without giving a reason, and without my future healthcare being affected. It is hoped that the information that this study uncovers may help women like me in the future.

Pauline Lowe will interview me in a place suggested by me. We will meet twice, and talk face-to-face. Pauline will talk to me about the things that I find helpful and not so helpful in maintaining my quality of life. We will discuss my health, and what my illnesses mean to me. Pauline will tape this talk, and return the second time to go over our conversation once it has been written up, to make sure I agree with what has been said.

My real name will not be used at any time, and all information I share with Pauline will be kept confidential.

If I have any further questions during this research, I can contact Pauline Lowe on (04) 298 6069 ext. 4214, or her supervisor, Karen McBride-Henry on (04) 385 5999 , ext. 6433. For ethical concerns, I can contact The Chair, Central Ethics Committee, C/- Ministry of Health, 2<sup>nd</sup> Floor, 1-3 The Terrace, P.O.Box 5013, Wellington.

Pauline will return my audio tape to me when her research project is finished, and will give me a summary of what she found if I would like this.

-----  
-----  
Participant's  
Date

Signature

-----  
-----  
Researcher's  
Date

signature

APPENDIX 5

Confidentiality Form for Transcriber

I..... agree to keep all information that I transcribe confidential. I will not disclose any part of the transcripts to any other person, other than Pauline Lowe, Lead Investigator.

Signed.....

Date.....