

“Choosing to Care” or was it “Hobson’s Choice”?

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A thesis submitted in partial fulfilment of the Masters of Occupational Therapy by Project

At Otago Polytechnic, Dunedin, New Zealand

15 December 2014

Abstract

With the shifting of costs and responsibility for care of the frail elderly from formal healthcare providers to informal caregivers, the perspective of family caregivers is one the occupational therapy profession can ill afford to ignore. The origin of this inquiry was as a result of the researcher taking on the role as informal caregiver for her frail elderly mother for the last two years of her mother's life. Literature highlights the ageing population and the knowledge that social policies and strategies are focused on supporting ageing-in-place. Little attention has been given to the transition for individuals who have taken on the role of informal caregiver for a frail elderly parent.

The aim of this study is to explore the experiences for adult children who agree to take their frail elderly parent home with them, as part of the discharge planning process from an acute hospital setting. A qualitative interpretive descriptive method was used. The study consisted of 3 participants who were interviewed for 60-75 minutes using a semi-structured interview guide. The participants had all looked after their frail elderly parent for periods ranging from two to ten years, and were asked questions pertaining to their role in discharge planning, to their transition into the informal caregiving role and their experiences as an informal caregiver. The three themes that developed were: 1) informed choice 2) acknowledgement and 3) determination, strength and resourcefulness. The idioms of "Hobson's choice" and "between a rock and a hard place" both illustrate how informal caregivers often describe the situations they found themselves in. Understanding of the transition and experiences of these informal caregivers can assist occupational therapists working in this area. A new model of transition called "Imparted Model of Transitioning into Informal Caregiving" is presented to support other family members in making an informed decision before taking on this role of being an informal caregiver, and to alleviate family concerns in relation to the discharge process. It is hoped that an increased understanding can lead to better support services to the caregivers themselves and thus indirectly, lead to better care for the elderly.

Dedication

I dedicate my research project to my mother, Maureen Sherlock, who was the inspiration for this work.

Acknowledgements

I would like to take this opportunity to express my gratitude to everyone who supported me throughout the course of this Masters of Occupational Therapy project. I am thankful for all the guidance, invaluable constructive criticism and friendly advice during the project work.

I am grateful for the support given to me from my family, Graeme, Jack and Rosie.

I would like to acknowledge the participants that took the time to be interviewed and share their experiences and thoughts with me.

I would also like to thank my supervisor Dr Mary Butler, who provided endless support and maintained her enthusiasm, even when mine waned.

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1. Chapter 1: Introduction

This chapter gives an overview of the research project. This study is an exploration of the experiences of informal caregivers in relation to the significant changes in their occupations when they take on the role of caring for a parent.

The first section of this chapter describes the researcher's personal interest and reasons for conducting this study. The next section discusses the background information and explores why this research is justified and important for occupational therapists and other health professionals practicing in the New Zealand context. The third section describes the aims of the research project and the research question itself. Lastly, an outline of the framework of the thesis will be given.

1.1 Reflection on Researcher's Interest

The origin for this inquiry is now a part of my family history, and it would be difficult to convey its meaning without setting the scene.

My parents, Maureen and Jack, immigrated to New Zealand in the early 1960's. They brought with them their hopes and desire to be able to give us children (three of us at that time) a better lifestyle and increased educational and economic opportunities. Mum and Dad were not £5 or £10 Poms, and we were lucky enough to get free passage, as Dad had a job lined up with the telegraph branch of the New Zealand Post Office in Wellington. So in 1963 we had completed the move from Fulham London and settled into "Nappy Valley" or Wainuiomata in the Hutt Valley.

Mum and Dad were both interesting people in their own right. Dad had fought in the Second World War as a Paratrooper. He was one of the lucky survivors of the Battle of Arnhem. Mum a few years younger, talked about her painful experiences as a young evacuee and later her fond memories of her nursing training at King's College London.

Later, when both in their eighties, Mum and Dad demonstrated great resilience. Mum had become increasingly frail as a result of rheumatoid arthritis, TIA's (transient ischemic attacks) and epilepsy. She was also showing signs of some executive dysfunction, but managed pretty well using memory strategies. Dad was relatively fit and strong, though had become legally blind due to macular degeneration. Together, they were a wonderful team and were able to maintain their independence in the same home they moved into in 1963. Though neither of

them was now able to drive, they were experts in using the local buses, trains and local taxi services. They were members of many social clubs, and were seldom home. One of their proudest accomplishments was that from a family with three children who settled into Wainuiomata, they were now parents of five, grandparents of 13 and great-grandparents of seven.

Things changed quite unexpectedly in November 2010, Armistice Day. Dad was a flag bearer at the Remembrance Day Celebrations at St Pauls Cathedral in Wellington. On leaving the cathedral, Dad slipped on the bottom step and hit his head. As a consequence, he unfortunately died three weeks later. Mum was obviously in shock but was sure she would manage living alone in Wainuiomata. Immediately after the funeral, my brothers and sisters thought she should have a few weeks with me in Palmerston North. Being a model occupational therapist, I had already ensured my house was modified to meet the physical needs of both Mum and Dad, so it made sense that Mum came to stay with my family. Also, my older sister lived in Palmerston North, and being a district nurse we were a good support for each other and Mum.

Mum stayed with us over December and Christmas and then returned to her own home for the New Year, which was her wish. As a family we knew she would find it difficult, as she had never acknowledged openly the amount of support Dad had been giving her over the past few years especially. Dad did most of the housework, washing, and ironing and due to his love of food ensured they both ate well. We, however, respected Mum's wish and tried to visit every couple of weeks to keep an eye on her. Over the next six months, we could see Mum was physically deteriorating but she remained determined to stay put. The benefit of the doubt which we had given her, however was vividly questioned when she was admitted to the local hospital. She was primarily admitted due to gall-stones, but she was now only 36kg in weight and needed more daily support.

During this acute hospital admission, I agreed that Mum could come and live with us in Palmerston North on her discharge. In hindsight I did not realise and had absolutely no idea of the commitment I had made: neither the physical and emotional energy required, nor the impact it would have on me and the life-style of the whole family. My family consisted of myself, my husband Graeme and children aged 17 and 19 years. And to be perfectly honest, at that time I assumed the commitment was for 3 – 6 months due to mum's obvious frailty.

At the time of making this 'decision' I was a senior occupational therapist. I knew that the job of an informal caregiver was not easy and that some people coped better than others. Over

the past 25 years I had provided professional support for numerous carers in the community who had taken on this role. Further to this, I had current experience of being part of a multidisciplinary team (MDT) responsible for the discharge planning process for frail elderly patients being discharged into the care of family members. Because of this I believed I had above average knowledge regarding the amount of practical support that family members could expect from paid formal services for their loved one, once they were discharged from hospital. However, even with all this knowledge, I quickly began to see that I wasn't adequately prepared for the role I had willingly taken on.

I faced challenges at many levels over the time that Mum lived with me. It felt as though I had lost control of 'time'. I needed to build my life around a schedule imposed both by the needs of my mother, both physical and mental, and also around the schedule imposed by the medical and social support services that we were utilising. In addition, there was a need to assist Mum in being able to sustain her role as matriarch of her loving extended family. As a consequence, I found that it was necessary to put my own personal goals on hold, in relation to recreation, education and work. There were many activities that were lost at that time.

It was important to me, that I do the best job possible, and that her quality of life was improved as a result of moving in with us. At the very least it was imperative that her quality of life was maintained. However, this was a bigger challenge than I imagined. The structures and social supports were unavailable to assist in this process. It was a time of conflict, constant questioning and second guessing. What I thought needed to happen was the exact opposite of what happened: I made a choice to care, but I question whether it was an informed choice? I needed to have a workable plan, but it was not possible to plan when Mum's medical condition, physical and cognitive status changed day to day. I supposedly was a key person in relation to her care, however this role was often not acknowledged by the medical team and therefore my expert knowledge was not utilised to the fullest. I aimed to encourage Mum to maintain her maximum level of independence and also attempted to spread the carer workload to other family members. However, I was her main carer and we got into a routine which in fact increased her level of dependence on me.

It did not last forever, and my mother passed away after two years. Ironically, as with Dad, it was as a result of a fall. However, the experience changed my life and led me to the point of wanting to do this research. In particular, I was interested in understanding the transition into the caregiving role following the discharge of a parent from an acute hospital setting.

Two years is a long time to accumulate stories about what we had experienced as a family in being the primary caregivers of my mother who had progressively become more and more dependent. However, I would like to share a few short narratives to further set the scene.

I had just come home from work, and stood at my mother's bedroom door. She asked permission to have a cup of coffee. Her electric jug, cups, spoons and coffee were on the stand I had set up for her use, beside her dressing table.

I thought back to when I was younger. Mum was a coffee addict. We all were, from a very young age. I remember giving my younger brother coffee in a bottle. Coffee making was a task we all took on, a rite of passage as we grew older. We took it in turns to make the 7 individual cups of coffee, to the liking of each family member. We would balance the 7 cups on a tray, and carry them with pride into the sitting room.

Having Mum ask permission took me back a bit. "Of course you can have a cup of coffee" I snapped back. Aware of my sharpness, I asked if I could make it for her.

Mum said she was scared to be left alone at home. She was feeling lost and muddled.

This was not the strong assertive mother that I was use too. Though she had been failing physically and becoming frailer; her strength of personality had always shone through.

Now she was becoming increasingly dependent and reliant on me for the majority of her activities of daily living. She was asking me for permission and assistance with all decisions or choices she needed to make.

Stating out loud that she was scared and did not want to be left alone really brought home that I wasn't prepared for this. I was already providing supervision and assistance 16 hours a day Monday to Friday and 24 hours a day in the weekend.

I was now needed to try and sort out a plan to enable Mum to feel safe during the day, which still allowed me to continue in paid employment. She had a personal carer for 1.5 hours in the morning (Monday to Friday) after we left for work, and a diversional therapist spent 2 hours every afternoon (Monday to Friday) with Mum, so she was alone for about 4 hours a day if neither of the children were home from school or polytechnic.

I had always said that while her quality of life was being improved, or at least maintained, she

was better off staying with us. When her quality of life could not be maintained then rest-home or hospital level care was the next option.

I hadn't foreseen this. I had hoped she would have maintained a period of independence for a portion of the day.

In the eulogy at my mother's funeral my sister gave a lovely presentation about my mother's life. A few funny stories were included.

One which everyone found hilariously funny, and I can appreciate to a point included myself.

There was the morning I came downstairs to mums room. It had not been a broken night sleep for her (and myself) so I thought things must have been ok overnight. When I spoke to her at her bedroom door, she was a bit agitated. She said she was concerned over the spelling of a word in her diary.

Mum had kept diaries over the past few years, as a memory aid. The use had increased to the point where she had several diaries on the go. Different sizes and different weights that she carried around with her in different bags etc. She had become more and more obsessed with her diaries and lists, which I assume was directly related to her cognitive decline.

In her diary she made notes regarding pills and at what time she had taken them. She also wrote what time she passed urine and/or faeces. This was probably due to her background as a registered nurse. Closer to her death, I had the job of jotting down this information for her, as her writing became illegible.

Anyway on this morning, she was concerned that she had spelt "taser" wrong in her diary. I asked her what she meant. She explained that she was worried she had spelt taser wrong, was it with a "z" or a "s". I asked her to explain a little, and she was talking about the weapon that gives you an electric shock. So I reassured her it was with a "s". Even googled it, on her computer situated in her room. I was obviously interested why she wanted to know

She showed me her diary, and I was shocked to read that she had written that at 1.36am Elizabeth had shocked her with a taser. I suspect she had been listening or watching discovery or crime TV on Sky overnight. However, I reassured her that I had not used a taser on her.

The funny thing was that she was more concerned over her spelling than her belief that I had shocked her overnight. I reassured her that I hadn't, and that we didn't have a taser in the house. It didn't appear to take much to convince her.

However, it did worry me that she had been through that experience overnight. I was also worried that the personal carer, diversional therapist and my family would not be so easily convinced.

So I can sort of see the funny side of that situation. But it is a situation that could be misunderstood.

During those two years my family and I made a few sacrifices to ensure that Mum's quality of life was maintained as much as possible. She did become the centre of the family activities, routines and schedules. My children were required at times to granny-sit and also accompany her in taxi rides to medical and personal appointments during working hours. They obviously needed to share the attention and time they would normally have received from both Graeme and myself. Notably, family holidays did not happen over this time and any local family activities evolved around meeting Mum's needs. Personally, I gave up my involvement in the Girl Guide Movement and concentrated my energies on meeting Mum's needs and maintaining full-time work. In relation to work during that two year period I also gave up my position as clinical coordinator and worked solely as a clinician, with the aim of reducing stress levels in relation to managing occupational therapy staff.

Looking back over those two years, I can also say that I was blessed in many ways. I was with and saw my mother at her strongest and at her most vulnerable. I shared with her some really sad times, but some really fun times. We got to know each other, in ways that would not have been possible if we did not both agree to take this challenging journey together. We did a great deal of reminiscing together. My children also got to know their grandmother a great deal more, than any of their cousins had. And Graeme became the "favourite son-in-law" much to the annoyance of the other sons-in-law.

What did surprise me, however, was my lack of awareness and knowledge of what actually was involved in the occupation of an informal caregiver. I understood this was the supervision and/or assistance with basic activities of daily living and the provision of household management duties. What I did not realise was just how many other tasks would be required. Tasks that immediately come to mind include:

- Managing Mum's weekly finances.
- Dealing with WINZ, ACC, IRD, Private Insurance companies etc.
- Making and attending specialist, GP, podiatrist, dental appointments etc.
- Advocating and dealing with gatekeepers for services.
- Coordinating formal support services.
- Coordinating extended family to be available to assist as needed.
- Sourcing support groups for mum.
- Sourcing social activities that were part of her previous routine i.e. Girl Guide Movement, prayer and religious observances. Providing or organising transport to enable attendance.
- Enable mum to continue carrying out her role as matriarch to her large extended family. Attending extended family activities and special occasions.
- Assisting with private correspondence i.e. Christmas cards, birthday cards, correspondence to family overseas etc.
- Supervising/assisting with medications.
- Providing a diet that suits her taste, physical need and wishes.
- Assisting with private shopping, present buying and personal errands.
- Being aware of or organising mums weekly schedule.
- Monitoring her physical, cognitive and mental health.
- Monitoring her compensatory equipment i.e. hospital bed, air-alternating mattress, wheelchair, ROHO cushion, stair-lift, commode, over-toilet frame etc.
- The amount of laundering clothes and linen increased significantly at times due to acute illness, incontinence, spillages etc.
- Setting up and problem solving technology equipment for mums use i.e. computer, Skype, SKY, cell-phone, DVD, CD, radio etc.
- Being available for emergency assistance i.e. when unwell, when lost or scared.
- Being available over-night, being responsive to the call-bell.
- Being available to provide assistance when mum on occasion was admitted into hospital.
- Keeping extended family informed about mums status and progress.
- Assisting mum with planning her own funeral.

What I was totally surprised about, but did not really understand the impact of it (until being affected by it), was the lack of formal social supports that people are entitled to. Because

mum lived with us and didn't hold a community services card, she was also not entitled to any home-help. She was assessed as needing personal care support, and initially was allocated one hour a day, Monday to Friday. With some advocating on her behalf, this level of assistance was increased from 1 to 1 and ½ hours a day, Monday to Friday, which was greatly appreciated. Towards the end of the two years, assistance was requested for respite care. However as I her primary caregiver, was in paid employment and therefore did not meet the definition of full-time caregiver, Mum was not entitled to this paid support either. Night sitting was also explored, but denied. Now looking back, we should have self-funded those services, but as is often said 'hindsight is often twenty twenty'.

A service which Mum paid for, and made a significant difference to her quality of life, was a diversional therapist/companion for 2 hours each afternoon, Monday to Friday. Mum looked forward to this time with Jane, and did a range of activities both in the home and out in the community. This service was well worth the money spent, and made a difference to the viability of Mum remaining with us.

1.2 Justification for the Study

As a result of my experience I wanted to complete this study because I believe it is important to highlights the issue of informal caregivers who are not prepared for caring and do not fully understand what they are taking on. Often the decision is made quickly: the patient is medically stable after some critical event and discharge planning becomes the focus of the hospital team. Usually there is pressure on the 'bed' and this pressure is increased when the patient makes a clearly informed decision that rest home care is not an option for them. In this case, there can be an easy assumption, on the part of both family members and health professionals, that the nearest available family member will take on the role. It appears the assessment of whether that proposed person is suitable or has adequate resources to be a caregiver can be cursory: there is little attention paid to the sustainability of the care situation and the carer is largely left to their own devices, with inadequate supports.

I believed that this research can contribute to the literature in a number of different ways: by describing the extent to which families feel prepared and supported when they commenced this role; the degree to which they were informed when they agreed to take on this role. It also aims to provide a structure for occupational therapists to work with current and prospective informal family caregivers to enable a smoother transition into the informal family caregiving role.

As long as informal caregivers continue to be a significant source of patient support post-discharge, it is imperative that they are appropriately resourced and informed. The work will always be intense, but occupational therapists can help with the transition into and out of the role in ways that reduce frustrations and concerns. This exploratory project aims to help the multi-disciplinary team to arrive at a better understanding of how to approach a potential carer. It is hoped that increased understanding can lead to better support services to the caregivers themselves and thus, indirectly, lead to better care for the elderly. Further to this it may help to achieve a better understanding of the sustainability of the care being undertaken by a family member. As family caregivers continue to support so much of the elder care in New Zealand, their perspective is one that occupational therapy as a profession can ill afford to ignore.

1.3 Project Aims and Research Objectives

Research Aims:

- This study is an exploration of the transition into informal family caregiving for a frail elderly parent following the discharge from an acute hospital setting.
- To develop a framework that can assist occupational therapists to conceptualise the transition issues for carers at the point of discharge.

Research Objectives:

- To understand retrospectively the transition experience of family members who took on the informal caregiver role for their frail elderly parent following the discharge from an acute hospital setting, for at least a period of three months and had their parent living in the family member's home.
- To understand how supported and prepared these family members believed they were, prior to committing to this role.
- To explore changes in their occupations when they abruptly take on the role of caring for a parent.
- To describe the discharge from a hospital admission within the context of a transition into caring.
- To develop recommendations for occupational therapists working in this area, to assist other family members in making an informed decision before taking on this role of being an informal caregiver.

- To develop recommendations to alleviate family concerns in relation to the discharge process.
- To describe what helps and hinders the family caregiver in beginning to engage in caregiving roles and occupations.

1.4 Structure of Thesis

This first chapter gave an overview of the research project. It also included a reflection of the personal interest of the researcher. It was because of this personal experience, that this study was conducted to explore the experiences of informal caregivers in relation to the significant changes in their occupations when they take on the role of caring for a parent. It is hoped that increased understanding can lead to better support services to the caregivers themselves and thus, indirectly, lead to better care for the elderly.

Chapter Two will present the relevant literature on the topic of informal caregiving. The review will focus on six major themes: background of caregiving of the elderly, definition and nature of informal caregiving, discharge processes, transition and stages of care, models of transition and relevant occupational therapy literature.

Chapter Three will describe the chosen methodology, interpretive descriptive. The underlying philosophical understanding is also explained. The results and key themes that were identified from the data collected are presented in Chapter Four.

Chapter Five considers implications of the findings. It includes discussion regarding the role of occupational therapy in the transition of family members into the caregiving role. In particular, recommendations on how this area of practice including the use of a theoretical framework can be further developed.

1.5 Summary

This chapter has described the background and development of the research question, explored why this research is justified and the importance for occupational therapists in the New Zealand context. Finally, an outline of the framework of the thesis itself was given.

2. Chapter 2: Literature

There is an increasingly large amount of international and local literature on the topic of informal caregiving. This review will focus on six major themes: background of caregiving for the elderly internationally and in New Zealand; definition and nature of informal caregiving; discharge process; transition and stages of care; models of transition and finally relevant occupational therapy research. Although the literature centres on these themes in a range of contexts, this chapter will largely concentrate on their application to the transition into informal family caregiving for a frail elderly parent following the discharge from an acute hospital setting.

2.1 Background of Caregiving of the Elderly Internationally and in New Zealand

This study is grounded in the knowledge that we have an ageing population and current policies/strategies are focused towards supporting ageing-in-place (Ministry of Health, 2002). Similar to other OECD countries, New Zealand has a rapidly ageing population. It has been estimated that by the late 2030's the number of people 65 years of age and over in New Zealand will double to approximately 1.2 million (Ministry of Social Development, 2007). The Maori population is increasing rapidly and by 2026 there will be around 72,000 older Maori- 7% of the older population and 9% of the Maori population (Statistics New Zealand, 2008). The median age is also increasing within the over 65 population in New Zealand, due to declining mortality and increasing lifespan. It has been estimated that the number of older people with a disability will increase by 60% by 2051 (Ministry of Social Development, 2014)

Older people (aged 65+ years) have higher rates of mortality and hospitalisations for most chronic conditions, some infectious diseases and injuries (often from falls), all of which have a significant impact not only for the individual but also for their family/whanau (Ministry of Health, 2006). Therefore, as the population ages, as mentioned above, there will be increasing numbers of people who have a disability, and the number of people required to support them will increase (Ministry of Social Development, 2014).

Research both internationally and locally has reported that the majority of older people have a preference to remain in their own homes rather than move into residential care. Older people aspire to continue living independently for as long as possible. (Bebbington, Darton, &

Netten, 2001; Jorgensen, Arksey, Parsons, Senior & Thomas, 2009; Rolls, Seymour, Froggatt, & Hanratty, 2010). Care in the community has the capacity for the frail elderly person to maintain a better quality of life than they might otherwise experience in long-term care (Jones & Peters, 1992). Further to this, the 'Supporting Older Maori and Pacific Peoples in the Central Region 2012' report by Central Regions District Health Board (2012) states that older Maori have a preference to live at home and elders want their own whanau to look after them. Whanau will try to keep family members at home for as long as possible.

Partially in reply to this phenomenon, ageing-in-place policies and strategies have become an important aspect of elder health. In New Zealand, the Government's Health of Older Peoples Strategy (Ministry of Health, 2002) promotes ageing-in-place and states that ageing-in-place is:

The ability to make choices in later life about where to live and to receive the support needed to do so. A key component of implementing ageing in place is developing services that support older people to continue to live safely in the community (Ministry of Health, 2002, p. 78).

Further to this The Government's Health of Older People Strategy reflects an understanding of the importance of protecting the health and wellbeing of carers as emphasised in objective number eight, as follows:

Older people with high and complex health and disability support needs will have access to flexible, timely and coordinated services and living options that take account of family and whanau carer needs (Ministry of Health, 2002, p. 57).

Clearly in order to support older people to age-in-place, it is necessary to consider the needs of family, whanau and other carers, including the provision of information, training and practical assistance to carers. Ageing-in-place is reliant on the provision of adequate support and attention, particularly of the frail elderly, who need assistance to reside at home and continue being socially engaged (Barrett, Hale, & Butler, 2014).

There is a significant degree of cost saving to governments, in acknowledging the unpaid work of informal carers to the economy and the importance of investing in protecting carers' health and welfare early (Barrett, Hale, & Butler, 2014).

There is a vast and increasing amount of international literature in the area of caring which highlights the burden and stress that caregiver's report they experience when providing care

for their frail older family member (Hoffman & Mitchell, 1998; Yin, Zhou, & Bashfrod, 2002; Ziemba & Lynch-Sauer, 2005; Grov & Eklund, 2008; Coe & van Houtven, 2009; Aggar, Ronaldson & Cameron, 2011).

Recent New Zealand research has uncovered the emotional, financial and social pressures carers experience as they look after elderly relatives. Massey health psychology researcher Horrell (Horrell, Breheny, & Stephens, 2014) examined the experiences of people who look after older adults in the community. She found lack of support and the expectation to provide an increasingly technical level of care were examples of the difficulties carers faced. Horrell says carers experienced both positive and negative emotions highlighting the ambivalence and tension inherent in caring. “I feel as if my life has been put on hold for the last year and half” (Horrell, Breheny, & Stephens, 2014, p. 8).

Davey and Keeling (2004) in a study of employees of two city councils (Wellington and Christchurch) who examined the mix of informal caregiving and work, found the majority of respondents who took care of elderly people indicated they provided care gladly. In addition, Davey and Keeling (2004) found that caregivers of elderly people with issues associated to physical health presented more positively than those respondents caring for people with cognitive issues. They also reported that negative feelings were more likely when the carer had nobody to help them on a regular basis or when caregiving conflicted with other activities including work.

Jorgensen, Parsons, Jacobs and Arksey (2010) research on the characteristics and demographics of the New Zealand caregiver and their unmet support needs in relation to a self-selected group of 300 caregiver participants concluded that there seems to be a contradiction between the value placed on caregivers and what is provided to support them, both materially and psychosocially. “If the government wishes to have more people with disabilities or chronic illness living at home, greater resources are needed to adequately support caregivers” (p. 9). Caregivers need to be assessed, supported and respected within their communities. Other negative impacts include effects on family relationships or on paid employment (Brunton, Fouche, & Jordon, 2007).

In New Zealand, the seminal work of Opie (1991 & 1992) recorded the experiences from a social work prospective of New Zealand caregivers who are looking after confused elderly relatives at home. She describes the often-dramatic changes in their family relationships and the disruption to their everyday lives. Her work highlights that caring is predominately

carried out by women, and proposes that informal carers are central to the structure and operation of the health and welfare system in New Zealand and that the cost and burden of caring is largely endured by the carers themselves, rather than by the state. Barrett, Hale and Gauld (2012), highlight that ageing-in-place is the preferable approach to housing the frail and older population, but question if there is a corresponding understanding of the important role that home-care work plays in achieving this approach.

The role of caregivers to the frail elderly appears to have also increased over time, especially when we consider the continuing reductions in length of hospital admissions and the limited availability and access to residential care places. There have also been cuts in home healthcare and social services, which has the consequence of shifting costs and responsibility for care of the frail elderly from formal healthcare providers to informal caregivers (Grimmer, Moss, & Falco, 2004).

Feinberg (2004) notes that formal and systematic assessment of older people has become a routine part of medical, health and social service settings. Following assessment, health professionals generally use a selection of resources to enable a frail older person to remain at home. Often, success of this is dependent on essential involvement of family and informal caregivers. While practitioners and policy makers have recognised the important role that family and informal caregivers play in providing long-term care to the elderly, there appears to have been little if any attention given to the need for systematic assessment of the situation and well-being of the family or informal caregiver. Therefore, there has been no formal assessment of the caregiver, to determine what assistance they may need. Further to this, research carried out by Brereton and Nolan (2000) supports the need for partnership between professional and informal caregivers. Such a partnership calls for a more complete understanding of how carers' needs change over time and how professional support can be more effective. They highlighted the value of recognising the expertise of the family carer, who has "local knowledge" of the recipient and the care-giving context. They concluded the need for the development of a framework for the preparation of carers needs with reference to information about their ongoing needs throughout the caregiving journey.

2.2 Informal Caregiving

2.2.1 Definition of Informal Caregiving

The informal carer, also known as family carer (Nolan, 2001), is a term and an issue that has gained heightened attention as a result of research highlighting the burden that informal caregiving places on individuals (Goodhead & McDonald, 2007). Compounding the changes and cuts in social services and home-based health care is the reduction in the length of

hospital stays, which has resulted in a shift in the responsibility and cost from healthcare providers to informal caregivers (Feinberg, 2004).

The National Advisory Committee on Health and Disability (2010) defines informal carer as:

Someone who cares for ‘a friend, family member or neighbour who because of sickness, frailty or disability, can’t manage everyday living without help or support ... the role is different from formal care supports and services because it is unpaid and is not based on any formal agreement or service specifications, although it can be the carer’s main occupation (p. 3).

A report by Nikora, Karapu, Hicky and Te Awekotuku prepared for the Ministry of Health in 2004 on “Disabled Maori and Disability Support Options” defines whanau carers as:

A whanau carer is a person who is linked to the person with a disability by whakapapa and who has inherited or assumed the role out of a sense of duty, obligation, and love. Occupying the role of whanau carer may be relative to their status or capacity as a tuakana, teina, mataamua, potiki, mokopuna, whangai, spouse, parent or grandparent. (Nikora, Karapu, Hickey, & Te Awekotuku, 2004, p. 50)

The importance of informal carers is generally understood and New Zealand like many OECD countries has an increasing reliance on informal carers (National Advisory Committee on Health and Disability, 2010, p. 7).

2.2.2 The Nature and Scope of Informal Caregiving

As services have shifted from formal Health Care Providers to informal carers, there has been a change in the nature and scope of the work that informal caregivers are required to carry out. Feinberg (2004) intimates that caregivers now require a greater knowledge with respect to health and medical information and need to seek out and utilise community resources if available. Informal caregivers also have to advocate for the care recipient and for themselves in accessing paid formal services.

Informal caregivers are involved in assisting with tasks that the recipient is no longer able to do for themselves. This may include undertaking personal care, household management and financial tasks. There may also be a requirement to provide supervision and/or assistance with mobility. The informal caregiver is also likely to provide emotional support, companionship and may be required to participate in nursing tasks. In addition to this whanau carers are described as providing: consent, advocacy, community links, facilitating cultural

obligations, maintainer of spiritual sense of being to ensure wellness of wairau (Nikora, Karapu, Hickey, & Te Awekotuku, 2004, p. 51). Wairua is described as meaning spiritual health and includes dignity, cultural identity and personal contentment (Ministry of Health, 2012). Though caregiving can be described as routine and on-going (National Advisory Committee on Health and Disability, 2010), it is also complex and varied. In Opie's study (1992) these daily routines, complications of caring, exhaustion, stress, changing and often deteriorating relationships between carer and recipient, highlighted the understated nature of caring.

Informal caregiving is firmly embedded in the connection or relationship between the recipient and carer. Because of this relationship it is difficult even unconceivable for many prospective caregivers not to provide the care for the recipient, no matter the cost to them personally (Goodhead & McDonald, 2007; Opie A., 1992)

In relation to informal caregivers of parents, there is the added aspect of filial obligation. In many cultures, it is an expectation that adult children will provide some care and consideration for their elderly parents (Stuifbergen & Van Delden, 2011). New Zealand researchers Goodhead and McDonald (2007) suggest it is important to consider the needs of Maori caregivers as an element of whanau wellbeing, and that there may be expectations from professionals and family members that whanau members will be available to care.

This filial obligation results in caregiving that is a different concept than the usual provision of personal care support for an elderly person (Salin, Kaumomen, & Astedt-Kurki, 2009). There is often a component of invisible caring and anticipatory caregiving, when decisions are made to minimise anticipated problems (Hasselkus, 1989; Salin, Kaumomen, & Astedt-Kurki, 2009). Filial caregivers also tend to take on the role of coordinating care and services and ensure the care recipient has their needs met (Goodhead & McDonald, 2007).

Opie (1992), writing about elderly people with dementia proposed that kinship and the current relationship between the caregiver and recipient is at the core of caregiving. She describes the caregiver's motivations as dynamic and fluctuating between commitment, dissociation, obligation and repudiation (p. 108). Caregivers move between these emotional positions in response to the stress involved in the situation.

Some researchers have observed that caregivers often become isolated from wider family support. Hawranik and Strain (2007) reported the theme of 'families are not always supportive' (p. 163). Even though other family members were available, they were not necessarily called upon, nor perceived as supportive, described as having their own lives and

as a consequence could not be counted on. Research hui with whanau carers carried out by Nikora, Karapu, Hickey & Te Awekotuk (2004), reported a common theme. Initially, when caregiving commenced, whanau were supportive and provided help. When, however, the circumstances became long-term, often this assistance/support 'fade[d] away' (p. 61).

Opie, (1990) when studying the care of the confused elderly at home, found that informal caregivers didn't feel supported by formal services. She also remarked that some caregivers tended only to ask for help once the crisis had passed, or alternatively used formal services with significant anxiety about the well-being of their care recipient. Whanau caregivers as reported by Nikora et al. (2004) and informal caregivers of the elderly as reported by Hawranik and Strain (2007) criticised that the medical professionals often acted as if the caregivers were invisible. They did not recognise them as being a key source of data about the health and welfare of the care recipient and failed to acknowledge the crucial linkage between the health-care services and older adults, which informal caregivers provide.

Nolan (2001) highlights that though the support of family is generally accepted as being important in rehabilitation literature, it still appears that families are seldom involved in the rehabilitation process and are often side-lined This issue can be specifically illustrated with respect to discharge planning.

2.3 Discharge Process from Hospital

Australian researchers Grimmer, Moss & Falco (2004) explored how informal caregivers perceived the process of taking on new or an increased caring role, and determined that the systems used in discharge planning (from Australian acute hospital admission) should take greater account of the motivation and needs of carers. The study highlighted the need to predict potential barriers that may negatively impact on the undertaking of the informal caregiving role. They found carers' perceptions of being unprepared for their new tasks, and their frustrations at the long-term and frequently significant changes to their lives brought about by assuming a caring role. The transition can feel traumatic to carers who feel they had little choice and were not sufficiently considered during the discharge planning. The possibility of a gentle transition is further prevented by the reported lack of timely community services specifically in the first few weeks post-discharge.

Nolan (2001, pp. 92-93) also talks of carers who 'feel ill-prepared for their role, lacking essential information and basic caring skills'. Cameron and Gignac (2007) discussed the need for health care professionals to recognise, that the support needs of family caregivers

changed across the care continuum, so to ensure they are providing timely and appropriate education and support.

Nursing research carried out Pereira and Botelho (2011) in Portugal looked at lived experience of individuals taking on the role of informal adult caregiving after an unexpected event involving a relative. Findings recognised that being thrown into the caregiving situation led to a time of chaos, confusion and little reflection. New caregivers not only felt alone and tired, but felt that their own life had no meaning. These researchers reported that the extent to which caregivers feel connected to others, redefined their personal use of time, felt comfortable with their new responsibilities and see themselves as recognised for their work they do, indicates how they are managing this transition and whether they are achieving balance in their new role.

Further nursing research carried out by Brereton and Nolan (2000) supported the need for partnership between professional and informal caregivers. Such a partnership called for a more complete understanding of how carers' needs change over time and how professional support can be more effective. They highlighted the value of recognising the expertise of the family carer, who has "local knowledge" of the recipient and the care-giving context. They concluded the need for the development of a framework for the preparation of carers needs with reference to information about their ongoing needs throughout the caregiving journey.

There is evidence that clinicians need to pay attention to families. Menzies and Hanger (2011) reported the work carried out by a facilitated discharge service at The Princess Margaret Hospital, a 113 bed rehabilitation teaching hospital in Christchurch, which indicated that unplanned readmission occurred in a third of this very frail elderly group. However, only 12% needed residential care, suggesting the reasons for readmission could be resolved. They found that if there were family concerns, there was a 60% likelihood of readmission within 90 days and concluded it would be useful for future studies to look at family concern. Alleviating such concerns may ultimately reduce the number of readmissions.

Further research in Australia by Fitzgerald, Bauer, Koch and King (2011), reports that discharge planning processes for family carers of people with dementia could be substantially improved. It was recommended that hospitals develop policy, process and procedures that take into account the family carer's needs, and that health professionals be educated on communication, consultation and needs of family carers.

The increased frailty of older people has an impact not only for the individual but for their family/whanau, especially when they agree to assume a new or expanded caring role, as part of the discharge plan for their frail parent.

Studies looking at the emotional welfare of informal caregivers additionally show that the degree of having a choice when taking on this role impacts on the ongoing success of caregiving (Grimmer, Moss, & Falco, 2004; Winter, Bouldin, & Andresen, 2010; Schulz, Beach, Cook, Martire, Tomlinson & Monin, 2012). Winter, et al. (2010) reported that caregivers who felt they did not have this choice were more vulnerable to stress and thus more inclined to experience negative health outcomes. And Grimmer, et al. (2004) conclude that patients and ward staff can at times wrongly assume that a particular family member is, or ready to be, assigned the role of informal carer. Further to this, they also concluded that even those family members who were willingly designated as the informal carer, still found many unappreciated obstacles in effectively executing this role. Informal caregivers reported that some of these obstacles interfered with being able to achieve for themselves and for the care recipient, an acceptable quality of life.

Schulz, et al. (2012) propose that it is possible to diminish the consequences of lack of choice in a number of ways. They suggest that in cases where informal caregivers perceive a lack of choice, it may be possible to convey elements of choice in the caregiving process by increasing the caregivers' sense of competence and feelings of effectiveness. In addition to this, they propose another approach, where the caregivers are provided possible choices and options in relation to how challenges can be met. Some of these choices may involve exploring and being offered home-based services, respite care, care recipient monitoring services etc.

In relation to the discharge process, these studies emphasise the necessity for acknowledgement and involvement of informal caregivers by medical staff preceding the recipients discharge to prepare them effectively for the role of caring. Including the setting up of appropriate home-based supports, enabling carers to provide appropriate safe care and assist patients and carers to adequately plan for their future. Clearly carers need to have received sufficient information and guidance to make an informed choice before they accept the role. There is no evidence that occupational therapists in New Zealand are doing any better than other disciplines in regard to supporting prospective and current informal caregivers of the frail elderly.

2.4 Transitions and Stages of Caring

There is little literature that describes the transitional process for family members taking on the care of frail elderly parents. Occupational therapy literature deals philosophically with the transitional and temporal components of occupation (Farnworth & Fossey, 2003; Pemberton & Cox, 2011). Occupational therapists need to consider temporal factors, such as time use, tempo, temporality, occupatiotemporality and temporal adaptation in order to maximize the benefits of occupation. These concepts developed in occupational science, provide the tools to enquire more systematically into the temporal adaptations of carers (Farnworth, 2003). This study focuses on the experience of family members as they transition into the role of informal caregiver and the impact on occupational roles.

Transition has been described as a discontinuity in the life space of a person by Adams, Hayes and Hopson (1976), psychologists interested in generating a model of transitional behaviour. The concept of an interruption or disturbance in the configuration of daily life and the consequences of this change to individuals or groups of people is an important area of concern for occupational therapists (Blair, 2000). Its importance for occupational therapy is situated in its philosophical foundations. Occupational therapy includes the exploration of human occupation in respect to personal health, life satisfaction, and sense of well-being and the management of the adaptive behaviour or competent performance required to perform these occupations (Reed & Sanderson, 1999, pp. 10-11). A discontinuity necessitates a change in habits, routines, and occupational performance, and results in the person involved being subjected to some level of stress. Further to this, Blair proposes that transition is integrally connected with self-esteem and a re-examination of who, what and how the individual is going to be in the new situation (Blair, 2000).

Pereira and Botelho (2011) examined the lived experience of informal caregivers after an unexpected event involving a relative. They determined that the caregiving process was marked by episodes of focussing and de-focussing on caregiving. The make-up of the experience was positively or negatively affected by the lived relationship between the caregiver and recipient, as well as the relationship between the carer and others in their life. They identified four themes regarding this transitional experience: 'losing control over time', 'feeling alone', 'failing expectations' and 'taking care of someone else's life' (p. 2451).

Caregivers expressed that when they initially took on this role, their experience of time did alter in that they had to live for the moment and felt an inability to control time. Time felt like it had been stolen and schedules which they had little control over became feature of their new lives. This phenomenon is also discussed by Barrett, Hale and Butler (2014) in their

research on caregiving situations at different life course stages. They noted that rhythms structure the constitution of the self and the home on a daily basis. The need to provide care in the home could be seen as changing pre-existing structures in time and place; this was more evident when caregiving was commenced suddenly. Caregivers noted there was a loss of personal time, and there needed to be an increase in flexibility in response to the new demands. Due to uncertainty and the unscheduled needs and demands of the care recipient, routines needed to be redesigned frequently by the carer, which at times led to other activities and plans being cancelled.

The second theme reported by Pereira and Botelho (2011) of 'feeling alone' is multi-layered; caregivers can actually be alone and unsupported in the provision of care, and they can also feel alone as a response to missing the care recipient's old self. Barrett, Hale and Butler (2014) also point out that the role of being a caregiver restricts the capacity to get out of the house, or to have quality time with family members within the home. Therefore, as a result of being an informal caregiver, there are demands which result in the need to make adjustments to other personal and social relationships.

Failing expectations is the third theme; this is the discrepancy between what the caregiver believes they need to enable them to carry out their new role effectively, and what is in fact available and offered. This theme is common to many new caregivers at the beginning of the care trajectory in relation to the hospital discharge of the care recipient. Differences in the ward staff's and relatives' perceptions of 'being ready' or 'being well' for discharge are an example of failing expectations. A second example is the discrepancy in response to the request for resources and formal services that meet the individual needs and routines of the carer and recipient. A final example of failing expectations that frequently presents is the disparity between the recognition carers believe they deserve and the recognition they actually receive from the care recipient, health professionals, relatives and friends. It is as if their daily efforts as informal caregivers remain invisible. It is with gratitude that informal caregivers describe the small signs or comments made that provide reassurance, approval and appreciation of their work.

The final theme proposed by Pereira and Botelho (2011) is called 'taking over someone else's life'. This is illustrated by carers when they take on extra activities and responsibilities, which the care recipient previously did, often without preparation in these tasks i.e. taking over the organisation of medications, financial management tasks, maintaining contact with important people in their lives. By taking over these responsibilities, taking control and making decisions for the care recipient, there can often be a shift in the balance of power in

pre-existing relationships. This can become a source of conflict between the care recipient and carer at times, especially if the dependent's abilities fluctuate, or as the dependent relative starts to recover. Another common reaction reported by new caregivers, as a consequence of the experiences they now have to face, is to self-reflect. This self-reflection relates to being a care-giver, but also about the impermanence and unpredictability of life, about the loss of functional independence and the meaning of life generally.

Family caregivers are juggling a range of tasks and responsibilities while also dealing with central questions of life such as their own mortality, as well as with relationships with significant people who may be in distress, in pain, and dying (Ziemba & Lynch-Sauer, 2005). As a consequence, providing care to frail elderly parents can be a significant test for adult children.

The commencement of caregiving is characterised by the rapid immersion into a new domain of providing care for a dependent loved one. The immediate focus for the carer is very limited, with the rest of the carer's life often said to be 'put on hold'. Understandably, this time is often a period of chaos and confusion. Caregivers describe time as 'slipping away' and of 'losing control of time'. They not only feel alone, but also tired. As well as this, they often do not feel rewarded or appreciated.

The transition to caregiving is complex; each informal carer and their family are obviously unique, and while family members appear willing to take on the caring role, they could be doing so with inadequate choices and preparation. A study by Aggar, Ronaldson and Cameron (2011) looks at self-esteem in carers of frail older people, and proposes that there is a need for an assessment of the caregiving reactions in carers. The ability of health professionals to identify and respect the carer's context and detect those carers at risk for anxiety and depression is vital. Carer assessment also has the potential to identify what relevant information and education is required and what clinical and community based support services the carer may benefit from (Feinberg, 2004).

Brereton and Nolan (2000) propose that there needs to be a merger of professional and carer expertise to assist carers to feel more recognised as key components in the care-giving situation. This would facilitate the transition into informal caregiving. They suggest that in order for this to be achieved, a framework for the preparation of informal carers needs to be developed which focuses not only on the initial transition, but also on the carer's ongoing needs throughout the care-giving journey. In regards to the New Zealand context, no literature, including occupational therapy, was identified that provides such a framework that

would assist in the preparation of the informal care giver. Further to this, no occupational therapy literature was identified that considered the role that choice plays in that transition.

2.5 Transitional Models

To assist with the proposed research outcomes, possible frameworks or models were explored, focusing on the initial transition of the family member's journey into caregiving of their frail elderly parent.

Literature searches identified a number of transitional models or frameworks, the majority coming from the field of psychology (Adams, Hayes, & Hopson, 1976; Burnes, 2004; Suc, Prokosch, & Ganslandt, 2009; Hiatt & Creasey, 2012). Though many of these models focused on change management in the corporate world, some of these could be adapted to accommodate the needs of prospective carers. Further transition models were generated from the areas of occupational science and nursing (Nicolson, 1990; Cameron & Gignac, 2007). Again, aspects of these could be adapted for the use of occupational therapists working with prospective caregivers.

Only a single related transitional model was identified from the occupational therapy literature, which included discharge planning and focused on the patient's journey from an acute hospital setting into the home (Gage, Cook, & Freyday-Field, 1997). Though not directly related to the transition of informal caregivers, aspects of the model are still relevant to this study.

2.5.1 Model of Transitional Behaviour

Psychologists Adams, Hayes and Hopson (1976) were interested in generating a model of transitional behaviour, which could be used to illustrate the phases of transition. Blair (2000) suggests this could be a tool to generate a conversation with people who are currently in the process of a transition and are still trying to understand what is happening to them and their daily life.

Adams, et al. (1976) emphasise the importance of being able to understanding transition depends on whether a change in one's daily routine is an intentional change, a sudden change, or an evolving awareness that one is shifting into a new life stage. They further highlight that this change is characterised by movement in stability and sets off a cycle of reactions and emotional responses which are predictable. Their model is conceptualised and has seven stages or phases with simultaneous effects upon self-esteem. The transition journey involves moving through the following stages: 1) immobilisation 2) minimisation 3) depression 4) acceptance of reality and letting go 5) testing 6) searching for meaning and 7) internalisation.

2.5.2 The ADKAR Model

A further model of change is proposed by Hiatt and Creasey (2012), who have experience in the field of change management. Change management is described as being the application of different ideas from the fields of engineering, business and psychology. As organisations have needed to change more frequently for survival, the body of knowledge now known as ‘change management’ has also grown.

The ADKAR model has been developed by Hiatt (Hiatt & Creasey, 2012) and focuses on five actions and outcomes necessary for an individual to successfully change. It is relatively simple and has practical applications. Stage 1 = **A**wareness of the need for change; Stage 2 = **D**esire to support and participate in the change; Stage 3 = **K**nowledge of how to change; Stage 4 = **A**bility to implement the change; Stage 5 = **R**einforcement to sustain the change.

2.5.3 Unfreezing-Change/Transition-Refreeze Model

In 1947 Kurt Lewin, a social psychologist, proposed a model which has been considered the beginning of contemporary theories of change management (Burnes, 2004; Kritsonis, 2004-2005; Suc, Prokosch, & Ganslandt, 2009). Kurt Lewin theorised a three-stage change model that is generally known as the ‘unfreezing-change/transition-refreeze’ model. It is proposed that there is a need for prior learning to be rejected and replaced. The first stage named “unfreezing” is related to becoming motivated to change. This is followed by the “changing/transition” stage where what needs to be changed is identified. Finally, the “refreezing” stage is when the change made becomes permanent.

The first or unfreeze stage is vital as it is about getting ready to change. There needs to be the understanding that change is necessary and that a shift from the person’s current comfort zone is required. This stage is about preparing ourselves, or others, prior to the change. The more the person feels the change is necessary, or more urgent it is, the more motivated they are to make the change. Unfreezing and getting motivated for change is also about weighing up the pros and cons, before you take any action.

The transition or change stage is the part of the process which has been described as the inner movement or journey that is made in reaction to a change. People are ‘unfrozen’ and move towards a new way of being. It is often the hardest stage, due to people feeling afraid and unsure. People may need to be given time to understand and support is vital here in the form of training and coaching. Mistakes are expected as part of this process. The use of role models and enabling people to develop their own solutions is also helpful. People will often

need plenty of time to take things in and through ongoing communication they will feel more involved and connected to the process.

Finally, the freeze or refreeze stage is about establishing stability once the change has happened. These changes are accepted and are now the norm, new habits have been formed. People at this stage become comfortable with their new routines. It is important to recognise that we continually change, so this stage of freezing may be temporary. It is recommended to recognise and celebrate success as a standard part of the change process.

2.5.4 The Transition Cycle

Nicolson (1990) in the context of work-role transition proposed a process model called “The Transition Cycle”. There are four phases or stages to this circular model; 1) preparation 2) encounter 3) adjustment and 4) stabilisation. Preparation involves developing helpful expectations, aims, drives, motives and feelings. Encounter phase is when the person becomes familiar with the new circumstances, builds confidence in coping and is tries to make sense of the new situation. The adjustment phase involves making personal change and developing new roles and relationships. Finally, the fourth phase of stabilisation assumes that the change or transition reaches a settled position. Successful transition, however, will involve continued monitoring and making adjustment to counter changes in the environment.

The basis of the ‘Transition Cycle’ model is the assumption that each stage is distinct, there is a strong interdependence and what happens in one stage strongly influences the next stage strongly. It is also proposed that cycles can recur and have an accumulative effect, so if an individual has negative experiences, fails or is disappointed at earlier stages, this can result in cycles of dissatisfaction. Likewise, successful transitions will work to increase confidence and success.

This is a process model which identifies transitions as encounters through time and deliberate changes in adjustments.

2.5.5 Timing It Right Framework

A health science and public health based framework in the field of stroke rehabilitation called ‘Timing It Right’ has been proposed by researchers Cameron and Gignac (2007) with the aim of ascertaining gaps in informal caregiver training, preparation, assistance and support for family caregivers of stroke survivors’.

Our ‘Timing It Right’ framework highlights family caregivers changing experiences and corresponding support needs across the care continuum. Five different phases of caregiver support are discussed: (1) event/diagnosis; (2) stabilisation; (3)

preparation; (4) implementation; (5) adaptation. The first two phases occur during acute care, the third occurs during acute care and/or in-patient rehabilitation, and the final two phases occur in the community. (Cameron & Gignac, 2007, p. 1).

Though this framework is specifically for caregivers of stroke survivors and draws on existing observational research and the clinical care pathway of stroke, it has the potential to be adapted and enhanced for wider use.

2.5.6 Elements of Transition Model

The only applicable occupational therapy model of transition found in the literature search was the “Elements of Transition Model” presented by Gage, Cook and Fryday-Field (1997) following an exploratory study aimed to understand the patients experience of the transition to community living after discharge from an acute care hospital. This model is based on the foundation of the patient’s perception of self-efficacy. It is then proposed that self-efficacy influenced, and was influenced by the following elements: the patient’s intrapersonal resources, support of family and friends, formal home based services, equipment and modification service provision and the prospects to be meaningfully engaged in desired activities and occupations.

Gage, Cook, and Freyday-Field (1997) suggests that if health professionals ask pertinent questions in relation to the above mentioned elements, this may result in a more successful transition. Examples of proposed questions are: Do the family and friends of the patient have adequate information and support? Have appropriate services been put in place to meet the patients needs? Have we made the most of adaptive equipment and processes for this patient?

Though no single transition model or framework was identified that was specifically focused on the possible needs of prospective informal caregivers for their frail elderly parent, there is the potential for one or more to be adapted for use by occupational therapists working in this field.

2.6 Occupational Therapy

Based on an ethnographic study of 15 informal family caregivers who were providing care for frail older people in the community, Hasselkus (1989), an American occupational therapist, proposes that there is a need for occupational therapists to recognise the family caregiver as a lay practitioner who engages in clinical reasoning in their own right. Hasselkus emphasises the need for the professional-caregiver relationship to be viewed as a partnership which involves the exchange of expertise, beliefs and interests.

Corcoran (1992, 2003 & 2011; Donovan & Corcoran, 2010) an American occupational therapist, has interviewed nearly 100 family caregivers who care for family members who have Alzheimer's disease. However, the principles can be applied to general caregivers as well. Corcoran reports that caregivers have differing styles, and if occupational therapists want to effectively harness each individual's caregiving abilities, they must identify how they approach the caregiver's role and what unique skills they can offer. Corcoran's research categorised caregivers into four specific groups: facilitating caregivers, who tended to focus on emotional health; balancing caregivers, who managed to maintain a balance between their own and the care recipients needs; advocating caregivers, who are particularly mindful of the care recipient's well-being; and directing caregivers, who focus on the physical health of the recipients.

Corcoran proposed that "we can begin to tailor caregiving interventions not by trying to change anyone's style but by offering suggestions that are consistent with style," (Waite, 2012, p. 15). Corcoran notes that "evidence suggests that such tailored interventions are more culturally relevant, support health behaviours, and reduce health disparities. Because tailored caregiver skill building interventions are designed to reflect the caregiver's intrinsic attitudes and beliefs, adherence is likely to improve, and the likelihood of successful outcome will increase" (2011, p. 472).

Greven (2007) an American staff occupational therapist who works in home health care with the geriatric population, shares her experience as a caregiver of ten years for her husband, who has quadriplegia as a result of a accident. She reports that:

Caregiver's needs can be neglected or even ignored by health care professionals, who are focused on their client (p. 25).

Wouldn't it be wonderful if health care professionals could start meeting the needs of the caregivers as well as the needs of care recipients? We can start by providing them with family and community resources (respite care, family support, home health care, support groups, exercise groups, counseling, mentoring, and equipment), empathy, understanding, and permission to take care of themselves first. Then, and only then, will caregivers be able to enjoy the rewards of caring for themselves and a loved one (p. 26).

There is limited New Zealand research on occupational therapy in relation to working with informal family caregivers as part of the discharge process of the frail elderly. Armstrong (2008) who has worked as an occupational therapist in a range of rehabilitation settings both in the UK and NZ considered the benefits, challenges of interdisciplinary, client-centred, goal setting in rehabilitation. Armstrong noted that

Goal setting therefore provides an opportunity for these expectations to be identified and discussed. It is not for the therapists to make assumptions about what these expectations may be as often assumptions are incorrect. In the authors experience the process of client-centred goal setting provides a number of communication methods in the early stages which can lead to a better understanding of the service, the client, their lives, their relationships and their environment. The process provides for open communication and encourages therapists to include family members. The fact they are drawn in earlier leads to less conflict in the later stages (Armstrong, 2008, p. 22).

Murphy (2014) explored how New Zealand occupational therapists working in acute settings understand and negotiate risk taking in discharge planning with older adults and their families. The need for not only involving the patient with discharge planning, but the value of including families especially adult children is emphasised. They are often the gap fillers between what formal community services can provide and what the patient may need. The participants agreed that support from family makes discharge easier and also has a positive influence on the therapist's perceptions on the overall risks that their patient may face post discharge. Further to this, however, while participants acknowledged that families played a key role to enable discharge of their family member, they also believed that families can also generate difficulties for therapists in relation to discharge planning by creating seemingly unnecessary barriers. Murphy (2014), however, suggests that it is important to note in her study that all the discussion and descriptions about communication between therapist and family represented one-way communication only, from the therapist to the family. This finding highlights the need for further exploration to gain knowledge and understanding from the family members' perspective regarding these perceived barriers at the time of discharge.

Of particular relevance to this current research is Murphy's (2014) research which also demonstrated that with an informed perspective of actual (rather than perceived) risks, it is possible that some carers might be supported to take on the work of caring, whereas others might recognise they are being unrealistic and decide that it is not possible.

2.7 Summary

This chapter has provided an overview of the literature available both internationally and in New Zealand regarding the background of caregiving of the elderly and explored the nature and scope of informal caregiving. It outlined the current evidence with respect to the current practices in relation to the discharge process from acute hospital settings to the home of the frail elderly patient. An overview of literature was provided regarding transitions and stages of caring, focusing on the current evidence regarding what is required to assist family members with smooth transitioning into caring. Transitional models and frameworks were presented in order to provide a background of the key elements or features currently being used by health professionals both within and outside the field of occupational therapy, with the aim of assisting clients/patients with transition or change management. Finally, relevant occupational therapy literature was reviewed both internationally and from New Zealand.

This research project aims to add to the body of literature regarding the current experiences of informal family caregivers for frail elderly parents following a discharge from an acute hospital setting, in the New Zealand context, following the Government's Health of Older Peoples Strategy implementation (Ministry of Health, 2002) and the ageing-in-place policies and strategies generally. It aims to explore the challenges and barriers that informal family caregivers are experiencing in their attempt to provide the best care for their parents.

Furthermore, it aims to contribute to the body of understanding of occupational therapy practices with informal family caregivers, including the development of a new model of transition for this area of work.

3. Chapter 3: Methodology

This chapter gives an overview of the design method and research methodology. In particular, it describes the naturalistic inquiry approach, qualitative research design and specifics regarding the interpretive descriptive method used. Further information is provided regarding the use of the semi-structured interview, sampling, saturation, and inclusion criteria and data analysis. Other considerations included were: reflexivity, trustworthiness, credibility, transferability, confirmability and authenticity. The process regarding ethics approval and required consultation is also detailed.

3.1 Methodology

For this research project a naturalistic inquiry approach or paradigm has been utilised. This means the research has been carried out with people within their natural environment, not in a laboratory or controlled setting (Holloway, 2008). The aim is to study the phenomenon in its natural state, as much as practical. The intention is to make sense of, or understand phenomena in relation to the meanings people bring to them (Frank & Polkinghorne, 2010).

Key truisms of naturalist inquiry, as outlined by Lincoln and Guba (1985), are to provide a philosophical groundwork for research design such as the researcher and the object or subject of the inquiry interrelate to influence one another; therefore, the knower and known become blended. Further to this they remind us that there are numerous formed realities that are only able to be studied holistically. Reality is therefore complicated, related to context, constructed and, at the end of the day, subjective. No a priori theory is able to embrace the numerous realities that we are likely to encounter; rather, theory must surface or be grounded in the data.

A qualitative research design was the ideal methodology to achieve this. Qualitative research is concerned with the understanding of experiences and behaviour, and the meanings and interpretations that people attach to these (Holloway, 2008). Qualitative research gives the researcher the potential to complete a study that involves the participants' experience and how they perceive a situation and its effect on their lives. Qualitative research deals with phenomena that are tricky or impractical to quantify mathematically, such as beliefs, meanings, attributes and symbols. This is often the case with respect to research in health care as answers to questions may not be easily answered by quantitative methods, for example when considering lay and professional health beliefs. Qualitative research emphasises that

people do not live in a vacuum that social environment has significant influence. (Holloway, 2008).

Qualitative research offers a variety of methods to be used for identifying what is really important to both patients and carers. It can also be used to identify and detect obstacles to change and the reasons improvement does not occur (Al-Busaidi, 2008). Qualitative research has been described as the methodology of choice for occupational therapy research as it can assist researchers to engender rich data, which can highlight issues of quality, as well as increase awareness of the patients and families/caregivers experience of health care (Kielhofner, 2006; Krefling, 1991). Qualitative research is ideal for “why”, “how” and “what” questions when interested in human behaviours, motivations, perspectives and obstacles (Neergaard, Olesen, Andersen, & Sondergaard, 2009). Furthermore, Neergaard et al. (2009) propose that qualitative research is suitable for “problem identification, hypothesis generation, theory formation and concept development” (p. 2).

The specific qualitative method used in this research project was interpretive descriptive. This method was selected for a number of reasons, including the size of the project, the time frame available for the research, and the fact that it is geared to the clinician (Thorne, 2008). An interpretive descriptive method expands further than just description and into the area of “so what” that drives all applied disciplines (Thorne, 2008, p. 33). Paterson and Higgs (2005) propose that interpretive and applied inquiry go together because “judgment artistry in professional practice can be better studied through an interpretive lens compared to an empirical lens” (p. 342). Hunt (2009), states that the purpose of interpretive description is to generate knowledge that is relevant within the clinical context of applied health disciplines. He further expands this and proposes that one of its strengths is the orientation towards the development of practice-relevant answers, and its attention to disciplinary biases and dedications. Thorne (2008) says

I see it as a way of naming and referencing the kind of well-founded logic that clinical researchers have been coming up with in many of what I would consider the most highly respected applications of qualitative research within the health domain (p. 35).

Though Thorne focus is primarily nursing, her notions and suggestions have worth for all clinical practitioners.

Of importance in this research project, is that the interpretive descriptive approach recognises the clinical hands-on and theoretical knowledge that research brings to a project. The researchers’ clinical expertise and accumulated practice knowledge in respect to the

phenomenon being studied is taken into account and becomes the stage on which to design the project, and aids to establish its predicted boundaries. Of significance, clinical expertise is acknowledged as a suitable beginning point for orienting research (Hunt, 2009).

Thorne (2008) emphasises the applied nature of interpretive description and focuses on a question of inquiry relevant to practice, so that the research is most worthwhile to the clinician with respect to the social nature of practice work and practical action.

In summary:

The foundation of interpretive description is the smaller scale qualitative investigation of a clinical phenomenon of interest to the discipline for the purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding (Thorne, Kirkham, & O'Flynn-Magee, 2004, p. 5).

This method is also being used by health practitioners looking at non-clinical questions such as disability and community based care issues. For example, O'Connor (2007) used the interpretive descriptive method to explore the ways in which family members of elderly people were identified as the family caregivers, which increased understanding of the consequences of this significant identity transition in the context of caring.

Thorne (2008) reminds us that there is a need for new knowledge pertaining to the personal, tacit, first-hand and patterned aspects of the human experience of health. This helps to increase our understanding of the particular context being studied, so to help us guide decisions that will enable us to apply evidence to the lives of real people.

Because this research is also driven to some extent by the participants, it provides an opportunity for the voices of the informal carers to be heard. This has the potential to empower participants and could affect change. This research is focused on a small group of people and the researcher is looking for patterns in relationships and meaning. Patton (1996) explained that the goal of understanding is not necessarily to foretell what might transpire, but instead to understand in depth the features or facets of the situation and to gain knowledge regarding the meaning made by participants in regards to what was happening to them at that moment. The purpose of qualitative research is to honestly and straightforwardly present outcomes to other people who have an interest in the topic being researched.

3.2 Method and Data Collection

3.2.1 Interview

This study was conducted using semi-structured interviews. This type of interview as described by Holloway (2008) has a specific research agenda and by Burgess (1984) as a “conversation with a purpose” (p. 102). The participants are given the opportunity to describe the situation in their own words and in their own time. By asking participants to explore and review their experience, the interviewer encourages the participants to think about and express how they found the transition into informal caregiving.

The participants were interviewed individually in a setting of their own choice. In each case, it was in their own homes. Individual interviews were used, as opposed to group interviews or focus groups, because of the ability to obtain more detailed information about the meaning of the phenomenon being researched from each individual participant. In a group situation participants may be unwilling to speak about some aspect of their experience in front of others. Also, there is the risk that a participant’s story could contaminate other participants’ stories. Individual interviews therefore ensure the independence of respondents (Fox, 2006).

With semi-structured interviewing, the open-ended nature of the question defines the topic under investigation, but also provides opportunities for the interviewer and interviewee to discuss some topics in more detail. The semi-structured interview has the advantage of allowing the researcher to give some guidance and direction during this data collecting process. Although the researcher did not ask the questions in exactly the same way for each participant, the tighter structure of this kind of interview ensured that the important information about the research was collected. This type of interview also provides the opportunity for each participant to share their own thoughts and feelings to the degree that they feel comfortable (Holloway, 2008).

The questions are contained in the interview guide (appendix A). The guide was used to ensure that similar types of data from the informants were gathered and that important issues were not missed. The interview guide was purposely influenced and guided in part by ‘The Occupational Performance History Interview -version 2.1’ [OPHI-II] (Kielhofner, et al., 2004) and the ‘Engagement in Meaningful Activities Survey’ (Goldberg, Brintnell, & Goldberg, 2002; Eakman, 2014). The decision to utilise these tools was made because aspects of the occupational roles, occupational settings, occupational choices, sense of accomplishment, feeling of control and personal value questions were believed to be relevant when exploring transitioning into the role of carer and the impact on occupational roles.

There was also a small amount of demographic information collected, including approximate information about services and help required by the care recipient.

Data was collected by digital recording, with permission of the participants, and later these tracks were transcribed. Notes were taken to record non-verbal behaviours and the context of the interview i.e. location, background demographic data.

A significant shift in the researcher's understanding of how to conduct an interview was required due to extensive experience using the interview as an initial assessment in the clinical setting. Clinical interviewing is quite different in that the interviewer takes a lead, is often very directive because specific information is sought. In contrast, the research interviewer has to learn not to lead (Thorne, 2008).

To ensure that the interview objectives were met, and that the right questions had not been forgotten or omitted, a pilot study was conducted using the draft interview guide. A colleague who works as a district nurse agreed to be interviewed. The advantages of completing this pilot study were that it gave the researcher an opportunity to practise the questions and gain some confidence in doing so. The pilot participant was given the opportunity to raise issues about confusion or uncertainty or just ask questions about the study. The audio tape of the interview, also gave the study supervisor an opportunity to provide feedback on the interviewer's technique. The pilot interview highlighted the need to have a list of possible prompts and cues (appendix B) for the interviewer so to encourage the participant to expand their responses to some questions. From the feedback the necessary changes were made before commencing the full study.

In the findings chapter of this thesis, direct quotes from the transcripts were used to illustrate the emerging themes. These quotes will be presented in italics and indented. At the end of each quote, the pseudonym of the participant is identified and the page of the transcript that the quote originated is also noted. For ease of reading, words are sometimes added to ensure the meaning is not lost. Such additional words are identified in brackets and are not italicised.

3.3 Sampling

It has frequently been observed that samples for qualitative studies are generally smaller than those used in quantitative studies (Ritchie, Lewis, & Elam, 2003). There is a point of diminishing return to a qualitative sample i.e. as the study proceeds additional data do not necessarily lead to more information. This is because qualitative research is concerned with meaning (Crouch & McKenzie, 2006), and one occurrence of a piece of data is all that is required to ensure that it becomes a part of the analysis framework. As qualitative research

can be labour intensive, analysing a large sample can be time-consuming and not practical for the proposed research project.

The concept of representation is a complex one, and it is important to remember that the study will not actually “represent” anything other than what it is. Thorne (2008) proposes that in the qualitative research world, it is better if we realise that representation benefits us best as one of those broad social ideas that has merit by keeping it in mind, but not technically achievable. Thus, Thorne indicates there is not a fundamentally correct way to sample, but that it is an essential requirement that the study is conducted on the basis of some transparent sampling rationality, and therefore we report on our findings in relation to what we understand our sample represents.

In this study the aim was to use purposive sampling. Purposive sampling starts with the purpose in mind and the sample is thus selected to include people of interest and exclude those who do not suit the purpose. Purposive sampling (Holloway, 2008) ensures that the participants have the experience and knowledge of the phenomenon being studied.

The original intention was that participants were to be chosen or selected through “Aged Concern”, “Alzheimer’s support groups” and the local “Stroke Club”. However, when contact was made with the contact people for these groups (the gate keepers), permission to gain access to their members was not given. The reasons for this restriction were based on a number of reasons. One reason was that their carer support groups were primarily for husbands and wives who were caring for their partners, and not carers of parents. Another reason was the gate keepers did not want to place additional demands on the members of their support groups, and believed that being asked to take part in a research project could be an additional stress which they could avoid. Contact was made with the Otago Carers Support Network who offered to organise contact with possible subjects. However, this needed to be carried out in Dunedin and strategically would have been difficult for the researcher.

Unfortunately, there is not a similar group to the Otago Carers Support Network in the Manawatu which could be utilised. The NZ Carers Association agreed to advertise on their Facebook page about the proposed research; however, for reasons outside the researcher’s influence, this did not occur and therefore this access to possible volunteers was prevented.

As a result of the difficulty with locating participants, it was decided to incorporate convenience sampling, namely, people who are closest at hand and met the inclusion criteria described below. The participants were located, not through the support groups which were

initially thought to be the most obvious place to target, but through a local church community and through word of mouth, in the researcher's place of work.

Because of the depth of the interviews and the subsequent analysis, the sample is small. For this study, three individuals who have taken on the role of informal caregiver for their frail elderly parent following a planned discharge from Hospital were recruited.

3.3.1 Inclusion Criteria

The plan involved choosing participants to minimise diversity to capitalise on the opportunity to capture in-depth perspectives. Participants were chosen so the following characteristics or circumstances were included:

- Family members who have cared for a frail older parent in the family member's home for three months or more.
- The parent was discharged directly from an acute hospital setting to the care giver's home.

3.3.2 Saturation

Saturation is defined by Holloway (2008) as an ideal in qualitative research when data collection and analysis have been completed and additional samples do not regenerate new ideas. However, as outlined by Thorne (2008) in the context of health research, it is unlikely that one can assert that no new variations could be generated. Likewise, in this research project due to the uniqueness of each caring relationship which was evident even in this small sample, it would be impossible to reach the point of saturation in the researcher's opinion. However, this did not negate the richness of the data collected or the knowledge and understanding that was still able to be generated.

3.4 Data Analysis

Interpretive descriptive research study produces a large amount of new data, often unstructured, which needs to be coded, categorised and analysed (Thorne, Kirkham, & O'Flynn-Magee, 2004). Reflexive notes were taken to record non-verbal behaviours and interview context i.e. location, background demographic data. Following the data collection process the next stages were reading for meaning, listening to the taped interviews and reviewing memos and field notes from observations (Thorne, 2008).

For this research project, data analysis occurred through thematic analysis, which involves recording or identifying passages of text or images that are linked by a common theme or idea allowing you to index the text into categories and therefore establish a "framework of thematic ideas about it" (Gibbs, 2007). Morse (1992) proposes that it is essential to view the

text in a theoretical or analytical way, rather than merely approaching it with a descriptive focus and for this reason the concept of transition will be applied to the data. Thorough reading took place during this process to ensure that all relevant ideas in the text were identified. Following this reading, the researcher focused on role transitioning, relationships, formal and informal supports, impact on other occupational roles, preparedness and strategies used by the caregiver.

Once the interviews were transcribed, the raw data was placed on a word document table as illustrated in appendix C. Three columns were added and labelled “code”, “initial themes” and lastly “refined themes”. I listened, read and re-read the raw data. I highlighted interesting aspects of the data and generated initial codes. This process was also done by my research supervisor for one of the interviews. Once I had completed this process for the three transcripts, I then printed off the codes and physically cut them into labels and pinned them onto a very large notice board. This enabled me to search for broader themes. I worked on re-arranging these lists of codes under various themes for several weeks. The codes and then the initial themes were discussed several times with my research supervisor, and then later the initial themes became more refined.

3.5 Reflexivity

According to Holloway (2008) reflexivity involves serious reflection on what has been done and thought about in a qualitative research project. This is particularly relevant in this instance, so that I acknowledge my own experiences and own context in relation to this study. It was therefore important at all times for me to be open with the study supervisor, so to be critically aware or be reflective regarding my role in this research project.

Being a health professional as well as a past informal caregiver, there was also a need that I demonstrate awareness of my own socially located and constituted knowledge, and that I acknowledge my own preconceptions, personal and professional assumptions, while attempting to understand the effect they have on the data.

Thorne (2008) in relation to interpretive descriptive research, stresses the importance for researchers to constrain their influence on the study, and recognise and take responsibility for the honoured position and capacity they have to shape and analyse the collected data. Further to this, Thorne (2008) reminds us that:

Simply by being what and who we are, we will have influenced what is revealed to us and the material that we will be using when we construct our accounts of the study. We can't completely avoid this influence, but we can be mindful of it and take steps to

ensure that we are as aware as we can possibly be of the way it plays out and the meaning that our study process will have on the eventual product (p. 117).

3.6 Trustworthiness

Rigour is linked to honesty, trustworthiness and valid evidence (Krefting, 1991; Savin-Baden & Fisher, 2002; Holloway, 2008). Guba and Lincoln (1989) add the notion of authenticity, which they explain as being when the researchers report fairly and present the participants' perspectives. To help ensure rigour in this proposed research project, triangulation was one method utilised. Triangulation is a process of drawing from several references to draw conclusions about what constitutes the truth (Polit, Beck, & Hungler, 2001). Multiple data sources were used in terms of different research participants to gather information about the same topic.

The data were analysed by more than one researcher to get different perspectives and to enable discussion regarding codes/themes and categories. The supervisor (person with research experience) was used to challenge me regarding the legitimacy of the categories and themes.

Member checking was also used, which in this case involved returning transcripts to the participants for their feedback regarding the findings and interpretations made. For this project, I checked the interpretation of data by presenting a written copy of the findings chapter and offered each member a copy of their interview transcript. Member checking technique ensures that the researcher has recorded the members' viewpoints accurately which helped decrease the chance of misinterpretation (Krefting, 1991).

3.6.1 Credibility

Credibility refers to the ability of participants to recognise their experiences in the research findings (Krefting, 1991). The strategy of sharing the research material with the participant i.e. member checking, ensured that I had correctly interpreted the participant's perspective into data. Member checking therefore eliminates or at least minimises the chances of misrepresentation.

Peer-debriefing, sometimes referred to as peer review as discussed by Lincoln and Guba (1985) was also used to enhance credibility. This was used with the research study supervisor during the research project, including the design stage and also when analysing the data to check coding and themes. One of the aims of this was to minimise bias, which in turn helped to assure credibility and plausibility of the research conclusions.

3.6.2 Transferability

According to Curtin and Fossey (2007) qualitative approaches do not generally assert to be generalisable. However, in aiming for credibility, the findings of qualitative research projects should ideally be transferable. That is, readers of the research project's article should be able to decide from the detail provided, whether they can apply the findings to other situations or contexts. The ability to apply the findings to other contexts or settings is dependent on "thick description". Thick description as outlined by Holloway (2008, p. 229) aims to give readers a sense of the emotions, thoughts and perceptions of research participants. Thick description builds up a clear picture of the individuals in the context of their culture and the setting in which they live.

3.6.3. Confirmability

Confirmability means the degree that the outcomes could be confirmed or verified by other people. It is also related to the ability for the research to demonstrate that the conclusions or findings were not shaped by the researcher's own expectations and experiences. This fact is most important because of the risk of bias within the design and within the conclusions of the research project. Bias was possible because of my professional experience and personal experience of being an informal caregiver. To eliminate this bias, reflective supervision was used throughout the research project. The formation of themes was also checked by the supervisor, with the purpose of eliminating any possible bias.

3.6.4 Authenticity

According to Guba and Lincoln (1989) a piece of research is authentic when the researchers report fairly and present the participants' standpoints, and when it enables them to understand and improve their situation and empowers them.

3.7 Ethics

Ethics in all sorts of inquiry needs to be linked to moral principles, professional standards, as well as to appropriate conduct and honesty of the researchers. It can ensure respect for the human rights and dignity of each participant. Consideration, respect and appreciation were given to each participant for the gift of time and their sharing of private thoughts, beliefs, feelings and views. In addition, I ensured that my own interests as a researcher and the importance of the research never took priority over the welfare of the participants (Holloway, 2008).

Participants were given as much information as possible from the beginning and more detailed information at the end of the data collection. Consent was given in verbal and written form and a consent form was utilised (appendix D).

To ensure confidentiality, information collected was only seen by the researcher, supervisor or individual participants. Information was stored on a computer and accessed using logon details. Recorded data will be destroyed after a period of five years following collection and analysis. Participants and their family members would remain anonymous in the research through the use of pseudonyms and changing of key data as necessary.

Ethical permission was gained on the 26 August 2014 through the Otago Polytechnic Ethics Committee (appendix E). There were however a number of concerns raised from the initial ethics request which needed to be dealt with before permission was finally given. Firstly, the committee members highlighted that there was a lack of information regarding recruitment. Additional information was provided in that recruitment of participants was to be through community carer support groups. The plan was to contact Manawatu Alzheimer's Society, Manawatu based Stroke Groups, Age Concern and Manawatu Parkinson's Society. Attached is a copy of the recruitment letter (appendix F).

The second concern raised was the fact that no potential harm had been identified by the researcher. This was revisited and further information was provided in that all the participants will have the capacity to make informed decisions. There was no pressure put on potential participants to sign up to this study. I did not in any way convey to potential participants that their participation was their responsibility. Voluntary participation was stressed. In addition, I assured the Ethics Committee Members that I am a senior occupational therapist, who has been working as a clinician since 1986. I am aware that the role of a researcher is different from a clinician providing therapy. However, I would use the strategies and practices that I have been utilising over my long career.

The third issue raised was the concern that the participants may be vulnerable due to their own grief and perhaps unspoken fatigue. It may also be beyond the researcher's scope to refer participants to a health body if indicated. The Ethics Committee recommended that the issue of vulnerability to participants and the researcher needed to be worked through with the research supervisor.

I reflected on these concerns in consultation with the research supervisor and additional information was given. With respect to vulnerability of the participants due to possible grief and fatigue, I confirmed that I am a skilled clinician and would tailor the interview accordingly to minimize the impact of the questions. If the full interview could not be completed due to these factors, the client's needs would take precedence over the research project's agenda. If during the research interview, it became apparent that the participant

needed therapeutic or medical assistance, then I would suggest to them that they visit their GP.

In relation to my own emotional vulnerability, it has been 16 months since the death of my mother. The grieving process has been worked through, and I have returned to my usual work and study routine over the past 14 months. I have had no difficulties with unexpected grief reactions since returning to normal occupations.

I am aware that in this project I am not a therapist; however, I used the strategies in place as a therapist. I used my research supervisor to provide support throughout the research project, so to discuss any issues or reactions that arose. If unexpected emotional reactions did arise, then these were discussed in the regular supervision sessions. As well as this, if necessary, I have access to supervision in the work place and EAP provisions at work.

The fourth area of concern raised by the Ethics Committee was due to whanau support not being offered as part of the research design structure. I will not be involving whanau support for myself due to privacy and confidentiality issues. Instead, the normal practice is to ensure that the supervisor or delegated person is aware of my proposed timetable and has the address where interviews were planned to be carried out. I always have a cell phone with me on home visits. I plan to carry out the usual safety precautions when entering a person's home. For example will park on the road for a quick retreat. When interviewing in the home, I will be aware of exits, and sit in a position to minimize risk to self.

Whanau support for the participants will be offered if necessary. However, I am very aware that having someone else present could impact on the information being given and collected. Having said this, Whanau support will not be discouraged. In one of the interviews, a family member was present, namely, the husband of one of the participants.

The Ethics Committee also raised a concern that the participants could choose a setting of their own choice for the interview i.e. their homes. As mentioned in the participant's information sheet and letter, a place of the participant's choosing was used. However, if their home was their preferred option, I accommodated this. From my own experience, seeing a person in their own environment evened out the issue of power as people have more control and feel more comfortable in their own homes.

I have extensive experience working in both mental health and physical health. In both areas of practice occupational therapists are often the link between the health facility and the community. Carrying out interviews and assessments in the community, in peoples own

homes is a key area of practice. Because of this, occupational therapists have procedures in place to ensure the safety of both the client/participant and the therapist/researcher. A key area of information gained by an occupational therapist is related to the home environment and how the client interacts with that environment.

Finally, the Ethics Committee also pointed out that the consent form submitted for their reference was unclear regarding when participants were free to withdraw and that the information sheet lacked information regarding where potential support was available for the participants.

In response to this the consent form was amended so that the participants were free to withdraw at any time without giving reasons and without any disadvantage (appendix D).

The information sheet was amended and included the following statement: If during or following your participation in this research project you should be upset by the memories that might be invoked, it is important that you gain support from your carers support group or visit your GP (appendix G).

3.8 Consultation

Consultation with Maori was done via the Kaitohotohu Office at Otago Polytechnic. Copy of correspondence is attached (appendix H).

The Kaitohutohu Office, requested further information regarding the research supervisor and confirmation that the researcher had viewed the Moodle page designed for Otago Polytechnic Students by the Kaitohutohu Office.

In response to these questions I advised Gina Huakau that Dr Mary Butler (Senior Lecturer, School of Occupational Therapy) was the research supervisor and confirmed that the recommended Moodle page had been reviewed. Consultation with the Kaitohotohu Office was initiated. Copy of correspondence is attached (appendix G).

Further consultation was carried out with a member of the internal Maori Reference Group at my place of work, Enable New Zealand, Palmerston North. The aim being to be able to request that they recommend a person to be the cultural advisor for this study, should any participants identify as Maori.

Enable New Zealand is a business identity of MidCentral District Health Board, based in Palmerston North. Therefore, the internal Maori Reference Group mentioned is part of the Manawhenua Hauora, which is a consortium of all four iwi who have manawhenua status in Manawatu, Horowhenua, Tararua and Otaki districts. The roopu comprises representatives

from Ngati Raukawa, Muaupoko, Rangitaane and Ngati Kahungunu. Manawhenua Hauora was established to advance iwi Maori Health and to work together with the DHB to achieve the best possible health outcomes for iwi Maori people residing in the district (MidCentral District Health Board, 2013). Consultation with this group was appropriate because they represented the population from which the sample was to be drawn. In the end, this was not necessary.

Consultation as discussed previously was also carried out with personnel (the gate keepers) at the local Stroke Group, Alzheimer's support groups and Aged Concern in order to help with the most appropriate way to access prospective participants. Contact was also made with Otago Carers Support Group and New Zealand Carers Network, to seek advice regarding the best way to access prospective participants.

3.9 Summary

This chapter has explored and discussed the methodology and interpretive descriptive method utilised to carry out this research project. It discusses the use of the semi-structured interview and how it fits into qualitative research. The difficulties in gaining access to research participants have been outlined, and how the need for convenience sampling was utilised. The ethical approval process in particular has been described in detail. Trustworthiness and reflexivity were also outlined, to demonstrate how these criteria were met in this research project.

4. Chapter 4: Findings

In this chapter the results of the data analysis are presented. The first section describes the demographic make-up of the three participants. This is followed by a review of the purpose and objectives of the project, which the data is then organised in response to. The essential themes will then be presented, followed by a summary of the chapter.

4.1 Demographics

The three participants were all women in their 50's of European descent, living in urban situations in the Manawatu region. They had all looked after their mothers in the participants' homes and one was still doing this.

4.1.1 Annie

Annie was married at the time that her mother came and lived with them. Unfortunately, her husband passed away due to an illness during the time that she provided care for her mother. Annie has no children. She has an older sister who lived out of town and was not involved in the care of their mother. Her mother lived in a Granny Flat on her property for approximately 13 years. This move was instigated following the death of Annie's father. Initially she was relatively independent, but became frailer over time. The last two to three years especially required increasing amounts of supervision and assistance. During this time Annie was not in paid employment. There were also formal personal care services being received. In the last 12 months of her mother's life, there were numerous hospital admissions and subsequent discharges back home. Her mother died in December 2013, eight months prior to this interview, in her own bed, with her daughter (and cats) at her side.

4.1.2 Barbara

Barbara is a wife, a mother and a grandmother. Her mother moved in with her and her husband 10 years ago after the death of Barbara's father. Barbara has one younger brother, who lives locally and provides some support. Her mother was initially relatively independent, and has been driving until very recently. Her mother is still alive and living with them. Barbara has continued to work full-time and her husband is now retired. They receive no formal social support. Her mother has become frailer in recent times, requiring regular trips to the Accident and Emergency Department and one hospital admission.

4.1.3 Carmel

Carmel is married and is a mother. Her mother moved in with her and her husband following a hospital discharge in 2004. Carmel's father died in an accident in 1999. Her mother lived in her own home with some formal social supports up until 2004. Following a hospital

admission, it was believed her mother had only five months to live, and that she could not return home alone. It was decided that she would move from her home to her eldest daughter's home in another city. Carmel had been living with her husband of four years at that time. All their adult children lived independently. In fact, her mother lived another four and half years. She lived with Carmel for the first two years of that time. She was not entitled to any formal social support services in this situation, so Carmel provided assistance and support as required. Her mother became increasingly frail and less mobile over that two year period, and became increasingly demanding of her time. Carmel managed to maintain part-time paid work while her mother lived with her. After the two years, it was a family decision to move their mother back to her previous location to be closer to her friends and known community. She moved into her son's home. He was single, and able to maintain full-time shift work, while caring for his mother. There was one other daughter, but due to location she was unable to provide practical support. The son provided supervision and assistance for his mother as required for a two year period. As a result of increasing frailty, and specifically incontinence, it was decided by the family that a move to a rest-home was then indicated. Their mother reluctantly moved into a local rest-home, and passed away after five months in 2007. During the last four and half years of her life there were several hospital admissions and subsequent discharges.

4.1.4 Overview

Two of the three participants were married, and both recognised that caregiving would not have been possible without the support of their husbands. All of the daughters described their mothers as strong-willed women. This resulted in tension, especially in the transition period when their mothers were struggling to maintain some independence and control of their situation. Without exception, all the daughters took their role seriously and felt responsible for their mothers' well-being 24/7. Even when their mothers were in respite or in hospital, the caregiver role did not cease.

4.2 Purpose

The purpose of this study was to explore the transition into informal family caregiving for a frail elderly parent following the discharge from an acute hospital setting. The aim was to investigate the experience of family members who took on the informal caregiving role for their frail elderly parent in the caregiver's home. Additional aims were to increase occupational therapists' understanding of how supported and prepared family members believed they were, and to explore changes in the family members' occupations when they abruptly took on the role of caring for a parent. The study also explored the discharge process

within the context of a transition into caring as this is a significant opportunity for occupational therapists to intervene.

Through listening to the participants' stories, the following emerging themes were identified: a) informed choice b) acknowledgement and c) determination, strength and resourcefulness.

4.3 Findings – Emerging Themes

4.3.1 Informed Choice

The first and strongest theme was in relation to the choice that was made to commence informal family caregiving. The participants discussed and disclosed the basis for their decision: an unacceptable alternative, the need for speed when the decision was made and what knowledge and experience they had regarding what the role of informal caregiver involved.

Annie, Barbara and Carmel all stated they did make a choice and did agree to take on the role as an informal caregiver for their parent. However, when looking back, they also conceded they did not clearly appreciate what they had agreed to take on. Sub-themes that emerged regarding choice based on the unknown included: time frames and the uncertainty, knowledge regarding formal supports, knowledge regarding tasks and duties involved and knowledge regarding the physical and emotional challenge of informal caregiving. This theme of 'an informed choice' will be discussed and supported by quotes from interviews with the participants.

4.3.1.a Choice Based on Quick Decision Making

For two of the three participants, the choice to accept the role of being an informal caregiver was described as being a quick decision. The speed and lack of thought did not reflect the importance and complexity of the role they agreed to take on. Carmel recalls that the decision was made on the spot during a phone conversation with her brother.

Yes it was, he rang up, and we just decided right then and there. (Carmel, pg. 8).

The timing of discharges for their parents from the Accident and Emergency Department (A&E) and/or the hospital wards back into their care also had an impact. There was general agreement that these decisions were made quickly and felt out of their control. There was consensus that decisions with respect to discharges appeared to be based on the requirements of the hospital schedules or need to clear beds. The informal caregivers indicated that little consideration was outwardly given regarding the context of each of the elderly parent's discharge destination.

Annie illustrated the speed of discharges back into the care of the informal caregivers, even when the carer voiced concerns about an ability to manage or the likelihood that the discharge was going to have a negative outcome.

She was doing good, well, on the Thursday they decided to discharge her for the Friday morning. Well, I get up there on the Friday morning and she has got chronic diarrhoea. And they still discharged her. Against my better judgement. And I said to them, "I am not happy with this. I do not want her to go home in this condition". And they said, "no, she is being discharged and that is all there is to it. If she gets worse, she will have to come back". (Annie, pg. 31).

4.3.1.b. 'Hobson's Choice' or 'Between a Rock and a Hard Place'

A consistent theme that emerged was that the choice between providing care or not providing care was a dilemma and difficult for the prospective carers because they were faced with a choice between two unsatisfactory or unattractive options. For Annie, however, the decision was more like 'Hobson's Choice' in that she felt there was only one option since rest-home care was inconceivable. The care recipients had all made it clear to their daughters that they had no intention of going into a rest-home and therefore the choice of accepting the role of caregiving by their daughters was made because the alternative choice was less acceptable or conceivable at that time.

Well yes. Everybody has choices in life. Yes I did have a choice, I had two choices, either look after her, or stick her in a home. So that wasn't an option so, no I chose to do what I thought was best. (Annie, pg. 33).

4.3.1.c. Choice Based On the Unknown

A common experience voiced by all the participants was that their decision was based on the unknown. They did not factor into the equation the impact this decision could have on other areas of their lives, for example work, interests, physical and emotional well-being and on other people important to them. Retrospectively, they were very aware that they knew little of what the role involved, what tasks and skills were required and length of time of the commitment they had made.

4.3.1.c.i. Time Frames and the Uncertainty

When exploring the known and unknown facets of caregiving, all of the participants raised the notion that there was no obvious time schedule or time frame once they agreed to take on the caregiving role. At times they felt 'there wasn't a light at the end of the tunnel'. This caused some anxiety, especially when the job got challenging, and when they were particularly tired

and fatigued. Further to this, due to lack of time frames, planning ahead for their future was difficult for them all.

We didn't think about long term, no, we anticipated that Mum would pass away quite quickly. I know that sounds quite horrible, but that is what we were told. It is what the doctor had told my brother, which he told us. So we didn't anticipate long term care. At all. Did we? (Carmel, pg. 10).

No. Nobody knows for how long. And it is something that needs to be thought about. (Barbara, pg. 22).

Yeah, so basically you put your life on hold, because you're not in the right frame of mind to be socialising anyway, because all you are doing are focusing on this one thing and this is the most important thing, thinking, well you know she is not going to be here forever. But while I am focusing on this, I can't have a social life because I need, and I am too tired anyway. (Annie, pg. 11).

A further comment made by Annie highlights the uncertainty of time frames and also the determination of carers to continue to care for as long as they can until it is taken out of their hands.

You know unless it got to a stage, you know like if she had dementia, you know dementia and Alzheimer's and you know like if her kidneys hadn't failed and all her multiple other issues, I would have still had her at home. Unless, you know, you don't know until she has you know a condition like Alzheimer's or dementia then you face that but no I'd always have her at home if I could. Yeah. I was always very adamant about that. But you don't know until the situation changes, that is what I was going to say there. (Annie, pg. 3).

4.3.1.c.ii. Knowledge Regarding Formal Supports

All of the participants reported a lack of knowledge regarding what specific formal services were available and what was the entitlement was either for themselves or their parents', prior to taking on the role of the informal carer. There was an assumption that community supports would be available; however, for two of the three participants this was not the case when they made enquiries post-discharge.

No. And yeah that was just the way it was. We didn't know you could get help. Really did we? We did try at one stage to get some help. (Carmel, pg. 29).

4.3.1.c.iii. Knowledge Regarding Tasks and Duties Involved

There was a general lack of knowledge regarding the scope of tasks and duties that would become part of the participants' routines and their responsibility as the informal caregiver. These tasks and duties became apparent post-discharge as the need arose, either immediately or as their parent deteriorated over time. All participants commented that they received minimal or no instruction or information regarding scope of duties and tasks involved in informal caregiving from any health professionals prior to accepting the role.

I don't think you are ever prepared. And I don't think you fully know, what you are taking on, or what you are going to go through... (Barbara, pg. 4)

Barbara also shared the following comment on the need for communication from health professionals so that informal carers have an increased understanding of what is expected of them, in the continued care of their parent.

Be there. Talk to people. Let people know what to expect. What not to expect. What you shouldn't expect from your parent and stuff like that. And just, communication is really important. And I don't think a great deal of communication happens when people are sick. You are just chucked in the ... But I do think that communication is extremely important, so that you actually go away understanding what has happened. And what you can expect from there on in. (Barbara, pg. 20)

4.3.1.c.iv. Knowledge Regarding the Physical and Emotional Challenge

The physical and emotional challenge was raised by all of the participants, which impacted on their capacity to carry on doing activities and occupations that were important to them. Carmel talked about her preparation for her mother moving in, and commented that they cleared out a bedroom, were mindful that their new house had safety rails in place and they knew where to obtain compensatory equipment. However, Carmel and her husband soon realised that caregiving involved more than those environmental and equipment issues.

We didn't realise the emotional impact. (Carmel, pg. 10).

Annie who provided care for her mother for 13 years, and more intensive care over the last year prior to her death. She made the following comments to describe some of the challenges she experienced especially in the last year.

Oh yeah, everything, all my social activities and everything virtually went on the back burner. Because I couldn't leave her like ... but like towards the end I actually had to get some of my friends, they'd have to come and sit with mum so that I could actually,

you know like go out and pay bills or go shopping. Well it actually got to the stage where my friend actually went and did my shopping and things like that, so that I could stay with her, because I didn't want to leave her for long periods of time.
(Annie, pg. 11).

4.3.2. Acknowledgment

In spite of knowing that the job of being an informal caregiver was valuable and vital to enable their parent to remain living in the community within their own family, the carers also suffered from a sense that they were not acknowledged for the work they carried out. They all suggested that there was a lack of recognition of their role, their duties and the degree of responsibility they agreed to take on.

This lack of acknowledgment/recognition was perpetuated to varying degrees, by hospital staff, GPs, community health professionals and formal caregivers. The stories shared pointed to the impact this lack of acknowledgement had on aspects necessary for effective and efficient transition into caregiving. Sub-themes emerged in respect to the lack of acknowledgement regarding the complexity of the informal caregiving role, the role the informal caregivers play in discharge planning, the need for adequate support to sustain and maintain the caring relationship and the need for adequate education to sustain and maintain the caring relationship.

4.3.2.a. Acknowledgement of the Complexity of the Caregiver Role

There was consensus from the participants that they did not feel their role and the complexity of the role were acknowledged sufficiently by the majority of the health professionals who were involved with them and their parents. This lack of acknowledgement and/or understanding of what the job involved undermined their aspirations to do the best they could, which was always (and for Barbara still is) the aim.

Carmel expressed the need for prospective carers to be aware that this role represented a major change to your life-style.

Will, just be aware that it is a major change to your life. You just don't get up and go out when you feel like it. Because you have to think about them being at home alone all day. And you can't just go out and leave them alone at night, at home alone on their own. You can't just get up and go away on a holiday. Because they are so much slower. I don't think we took her away on a holiday, did we? No. Because you just can't. You have all their stuff to pack up, and they can't move the same, and they

don't really want to go on holiday anyway. Not away. You have to be aware that everything they do, is so much slower, than the way you are used to doing it. You just have to slow your pace down. You have just got to be aware that they are frailer, and they cannot move around, but they are determined to do it anyway. Even if you would rather they didn't. (Carmel, pg.14).

The participants consistently voiced frustration and worry about not being able to do the best for their mothers in relation to limitations in time and energy. They worried about and felt responsible for their parent's safety at all times, 24/7. This was the case for all of the participants, including Barbara who worked full-time and Carmel who worked part-time.

She was by herself, but we did worry about her. The ambulance got called a couple of times. We got security, see that little white block over there that was for St Johns Ambulance. (Carmel, pg.12).

She was able to do that, for nearly all the time that she was with us. She would get up and she used to do things. The washing, a bit of hand washing, she used to like, she used to do the vegetables. For a long time she would get the potatoes peeled, she liked doing that. I didn't like her hanging out the washing. She used to insist on doing that at times too, didn't she. It was always scary because you would always think she was going to fall. They used to like to do things. But she did quite enjoy that. (Carmel, pg.13).

All the participants felt they could not easily leave their parent unattended overnight. This was felt particularly strongly by the participants who spent time away from the home during the day for work. This was illustrated well by a comment from Carmel who worked part-time during the week.

I don't think she wanted us not to go out, but anytime we went out, we couldn't just leave her at home. It wasn't fair, so we took her with us, everywhere we went. (Carmel, pg.15)

The need to schedule your life around their parent was expressed by all the participants. This, as expected impacted on the dynamics of the household generally.

I have over the last year found because Mum is a diabetic, meals have to be at a reasonable time and I have played sport over the last actual eight years, nine years,

actually I have been playing sport most of the time. And I have given up, on a few things just to try and be home and it doesn't always work. (Barbara, pg.8).

Even when their parents were in respite care or in hospital, the participants conveyed that their duties and time expenditure did not reduce significantly, as illustrated in stories shared by Annie:

It was like, it was more draining I reckon her being in the hospital, than having her out of hospital... I was having to go up there three times a day, like first thing in the morning I'd have to go up because I'd need to see the doctors. Because every day you needed to see them, to change this or to change that, so then by the time you mucked around, sometimes you wouldn't get home to about nearly lunch time. And then I would go back in the afternoons because she might need a clean nightie, or some food or whatever. And then I would go up a night to make sure that, you know to feed her her tea, because unfortunately if you don't have somebody there, they just haven't got the time and the carers and the staff, that's just it, she would be starving to death. And half the time she wanted Alfredo pasta anyway. Yeah, she went through a stage when she had that for about 4 weeks in a row. But yeah, it is very draining. (Annie, pg.13).

Because the Hospice, was on a Monday and I just found that I couldn't cope ...because if she wasn't at home, she was in the hospital and because I worked 10.00 o'clock until 1.00, that was three hours, then I needed to see doctors and things like that, so I gave that up... I also with Age Concern because I did voluntary for them, I put that on the back burner too. But the Saint Johns 'caring caller' I knocked off one client, but I did ring the other one periodically every two to three weeks and give her an update. So yeh basically, that was all put on hold for a year. (Annie, pg.15).

The awareness of the possible impact on other family members and the dynamics of the household were not considered to any great depth by Carmel prior to feeling the effects of it.

It did make quite a difference with our relationship, because you always had that extra person there. (Carmel, pg.17). But, it got very difficult because my husband and I hadn't been together that long. And it was very hard for him, if he played his music loud, and he is very keen of his music. We also had a very big dog which Mum didn't like. (Carmel, pg.1).

4.3.2.b. Acknowledgement of the Role Informal Caregivers Play in Discharge Planning

All the participants conveyed the lack of acknowledgement they felt in relation to discharge planning, a time when they had a great deal of knowledge to share about their parent. This lack of acknowledgement of the informal caregiver's role was also an issue when the family member first agreed to take on the new role. At this time, the family member was disadvantaged further, because often they 'didn't know what they didn't know', so missed the limited opportunity to ask pertinent questions.

Annie, who had the opportunity to be involved in numerous discharges with her mother in the last 12 months of her life, vividly illustrated the lack of acknowledgment she experienced.

Really you have to stand your ground, especially with the so called professionals. Because sometimesthe professionals have got a piece of paper that says I am a doctor, I am a specialist, or I am a Charge Nurse, or I am a this or I am a that, but they don't actually know that patient and how they are in their own home. And sometimes the family member is trying to stress to them... that you know best because you are with them virtually 24 seven. (Annie, pg. 7).

Carmel made the following comment as a new carer about her experience about the discharge process:

There wasn't really any, 'how do you think you are going to cope'? Nobody asked you how you were going to get on, or what was going to happen.... They didn't say take her to the doctor or anything. Get her checked out or anything. Just go home. You're discharged. So great, so home you go. Just carry on, as before. (Carmel, pg. 39).

Annie, who experienced numerous admissions along with her mother, perceived that her informal caring skills were negatively judged by the multidisciplinary team (MDT) as a result of her mother's numerous re-admissions due to acute infections. At these times she did not feel supported by the MTD, and experienced pressure to have her mother placed into a rest-home, which she resisted.

Because they reckoned I couldn't cope any longer, because of her condition. And I said 'I can cope, it's you people who are failing me'. And what do you mean by that, but you are. 'Because you are not getting her condition under control'. (Annie, pg.34).

Participants also described the experience of inaccurate information being gathered from their parent, which impacted on their entitlement to community services. Carmel shared the following situation:

No. And because Mum is sitting there telling them she can do this and she can do that. And anything else, when she blimming well couldn't. She wouldn't play the game, so to speak, there is a game you have to play to get the help, isn't there? And she didn't want to play that game. So, no we didn't get any real help no. (Carmel, pg.29)

4.3.2.c. Acknowledgement Regarding the Need for Adequate Support

All the participants answered with consternation when they were asked to describe what support they had received, when accepting the role of informal caregiver. They all agreed that they could have benefited from support services, not only at the beginning of caring, but as unanticipated needs arose and as their parents condition deteriorated.

Annie reported that though her mother did receive formal support services, she often believed it was not adequate, especially as her mother's needs increased.

Because I couldn't leave her like, OK, you're allocated as muchcare as we could get through "Elite Care" but like towards the end I actually had to get some of my friends, they'd have to come and sit with mum. (Annie, pg. 11).

Annie also indicated that to ensure there was a smooth transition from hospital to home she needed to insist that the services were back in place before her mother returned home. She learnt from experience that if she did not initiate this, it did not necessarily happen.

No. That was one thing I always made sure before I left. That everything, you know, like the provider Elite Care, they were always notified so when she come home the next day the carers would be back on to their roster. Yeah, because I thought, it was no good for me. Like you get home say on Monday and they don't start again until Wednesday or something, no I always made sure that everything like that was spot on, yep no mucking around . Yep. (Annie, pg.14).

Lack of acknowledgment was also felt in relation to their specific situation, and participants believed that health professionals were comparing them with those who were worse off.

It's no use saying, oh don't worry about it, you know there are worse off people, but no, you worry about your situation, because your situation is the main one. We know

there are other people out there with other problems, but they've got other people that should be fighting for them. (Annie, pg.7).

Neither Barbara's nor Carmel's mothers received formal social services while living with them. Barbara, who still looks after her mother, indicated during this interview that she would appreciate the opportunity to talk to someone about this.

But, yeh, don't have any personal care. 'I like to talk to somebody about that'. 'Yes, that, and respite care'. Umm something that we need to look into. That gives Mum a break from us and us a break from Mum. (Barbara, pg.3).

After the arrival of her mother, Carmel contacted the local Needs Assessment and Service Coordination (NASC) service and requested an assessment. She made the following comments:

Yes I did. So I can't say they were overly helpful. Really were they? Not really. (Carmel, pg.11)

When asked what assistance they offered, she replied:

Nothing. No. [Laughter]. (Carmel, pg.11).

Another component of informal caregiving that illustrates this emerging sub-theme of lack of support was in relation to the experience of watching your elderly parent lose their functional independence on a daily basis. Carmel had the following to say, and illustrates that emotional support and/or counselling may have been beneficial at this time:

For me, it was seeing how much she had deteriorated. Mum was already quite a plump little lady, and her weight just fell off her. Down to a size 8 or 10. And everything was sagging, and trying to get bras and things for her was so disappointing because she was quite proud. And I tried to getting her a proper fitting bra, it was virtually impossible. Things like that. Were quite challenging and having her just nicely dressed and then her hair fell out. She got very stressed...and her hair starting falling out and she was devastated. So we took her to the wig place, Georgie's Wigs, and she bought a wig, but it wasn't quite right. But she used to wear it for a while. And then gradually her hair grew back. I don't know what happened there? She got a bit stressed, and then her hair grew back again. But that was quite distressing for me to see her deteriorating. (Carmel, pg.22)

In response to the question about “what advice they would give to other family members who were thinking of taking on the role of informal caregiver for a parent”, they had a number of suggestions in relation to the benefits of seeking and receiving support. This ranged from the persistent request for information and formal support services.

But you have really got to ask, and don't be afraid to ask. Because at the end of the day if you don't ask, you don't find out. Don't care if you ask ten times the same question, because sometimes I would ask the same thing twenty times or ten times because I had to get it right in my mind. I can process things, but I have to know what I am processing first. I [had] to, you know, kind of sift through the important parts... you have got to... take care of yourself, even though you're so fatigued and stuff like that. But you have to get as much help as you can, you've got to, especially care ... agencies, and you have to push the issue (Annie, pg. 7).

When asked “if they had any advice they would like to give the multi-disciplinary team regarding preparation needed for taking on the caregiving role”, they suggested that communication to and from the MDT would have been a good start. Also, having information about what to expect, if taking on the role of informal caregiver. All the participants felt being told what not to expect regarding community support and follow-up would also have been useful, so that their expectations were more realistic from the beginning. There was also consensus regarding the need to receive reassurance and encouragement along the way, and just being asked ‘how’s it going’ would have been appreciated.

Be there. Talk to people. Let people know what to expect. What not to expect. What you shouldn't expect from your parent and stuff like that. And just, the communication, communication is really important. And I don't think a great deal of communication happens when people are sick. You are just chucked in the ... I don't know how many times I have sat in that blasted accident and emergency over the years, only once for myself, twice actually twice, the rest of times, it's been for husband, it's been for Mum, it's been for the kids, and you just, they deal with you as best as they can, because they have to move on to the next person. But I do think that communication is extremely important, so that you actually go away, understanding what has happened. And what you can expect from there on in. (Barbara, pg.20).

Will, yes I wish they told a little bit about what to expect, and yep perhaps provided a bit of equipment and stuff. And even if that had sent someone around to see how she was coping. (Carmel, pg.32).

4.3.2.d. Acknowledgment Regarding the Need for Adequate Education

As with the need for support, all the participants agreed that they would have benefited from education, especially when they started the role. They conveyed that more education could have helped with maintaining and sustaining their caring relationship. As a consequence, they learnt from trial and error and through on the job experience. They were all hungry for knowledge and information, and felt at times they were expected 'to just get on with it'.

Ah, What Education? (Annie, pg.16)

Not that I know of [in relation to education)]. Not that I remember. (Barbara, pg.17)

Educational areas of concerns that the participants mentioned were in relation to having to organise and/or oversee medications, manual handling, and use of equipment, sourcing support, falls prevention, medical conditions and monitoring physical status. They also would have appreciated feedback regarding how they were doing:

And even to be shown how to lift an old person. To help them stand up. I nearly put my back out one day. And my brother pointed out, that you put your hand underneath. You know things like that, you can do some damage to yourself. Trying to help. And that day she got stuck between the cabinet and the bed. Will if we had known we could of made a bigger gap, maybe between the bed and the cabinet.... Yeah. So things like how to lift people. Or I don't know, how to make sure they didn't fall over. She was great for trying to walk without her walking stick. Or her mobility thing, what do you call it, that push along thing. She didn't like using them. 'I'm alright I've got my stick'. (Carmel, pg.33).

Oh there was an issue once with Mum, she always found it hard to swallow because she had that goitre. But it did shrink, and she always had a problem with taking tablets, and I did too. And sometimes she was taking like in the morning at breakfast time she was taking thirteen tablets. Well you imagine after about five, I'm just about gagging... the manager of Enliven, she came around to do her 12 monthly interviewee thing. And I just happen to say to her about this, and she said look, there is a tip here I can give you. And I said 'what's that'? And she said, 'does your mother like

yoghurt'? And I said, 'yes she loves yoghurt'. She said 'right, get a dessert spoon full of yoghurt, she said put four or five tablets on, put it in her mouth and get her to swallow. And then she said you do another spoonful'. You don't put the 13 tablets all on the one thing, and I tell you it works, it was the easiest thing to do. But you see I never thought of that, 'cause sometimes it would take us half an hour to get her tablets down in the morning ... it made life a lot easier, so from then onwards we had the yoghurt yeh. So it was little simple tips like that. (Annie, pg.17).

4.3.3 Determination, Strength and Resourcefulness

As described, though there were many challenges for all of the participants in providing the care for their mothers, they all demonstrated determination, strength and resourcefulness. Some of this was as a consequence of needing to meet needs in relation to caregiving that were not being met by other means. Sub-themes that emerged which under-lined their determination, strength and resourcefulness were: the natural progression into caregiving role, duty and reciprocity, compensation or rewards and negotiation with health professionals.

4.3.3.a. Natural Progression of Life Roles

There was a common premise regarding the taking on of the role as a natural progression in life and also an element of a familial history regarding informal caregiving. Annie's comments illustrate how she believed it was a natural role:

But I kind of took over the role of looking after things and making sure that she was looked after and, and then it kept on, and then as she got older and then frailer and sicker and then I just naturally took on the role, it didn't really, kind of like you have to do it or designated to do it. I just did it. Yep. Everybody is different, so it is just hands on, just get on and do it. Yeah, people say 'how did you do it'? Well, I don't know I just did it, its natural I suppose, I don't know, I can't explain it. (Annie, pg. 1).

The element of a family history of providing informal caregiving was evident with one of the participants. Barbara and her husband provided care for his father for six months, prior to him moving into a rest home. That decision for rest home placement was based on the fact he was not safe to be left at home alone during the day. In addition to this, Barbara's mother had previously cared for her mother, and her mother had done the same, and therefore gave a sense that she felt it was natural to carry out this work.

Yeah, you know. I mean, Mum had her Mum living with us for about four years. And she had her mother living with her. Yep, so it has been kind of like pass it down.

(Barbara, pg.4)

4.3.3.b. Duty and Reciprocity

There was an element of duty and reciprocity shared by all of the participants when asked about the reason they volunteered or were identified as the prospective carer.

I was the oldest daughter, and I was there. Yeah. We didn't even really think about it. (laughter) 'She is Family'. (Carmel, pg. 9).

I think too, always at the back of my mind, I always thought to myself that 'Mum had to look after me and she always did'. Even though (I was) her baby. She always looked after me, and I think 'well put something back in it'. She looked after me, had to provide for me, so I think 'what the hell!' (Annie, pg. 19).

4.3.3.c. Rewards and Compensation

A source of some of the strength that was demonstrated was the rewards or compensation that each participant believed they received from taking on this role. All of the participants were pleased that they were able to do this for their mothers. They were happy to share the rewards and blessings they believed they received while their mothers lived with them. They enjoyed having them and valued the time they spent together. Though they all admitted it was tough going and a challenge, they did not regret it completely and all but one would do it again.

Rewards received were varied as each caring relationship was varied and unique. Rewards that were experienced and shared by the participants included feelings of joy, happiness and pride in knowing they did their best and generally felt appreciated by their mothers. They treasured the opportunity to share special times and had the opportunity to learn more about their family history.

Well she appreciated me doing it, and she said if it wasn't for me she would of ended up in a rest home... Yes, so really to know that I did the best I could for her and you just don't give up. (Annie, pg.28).

Knowing that I prolonged her life. A bit, and that she had enjoyed most of it, you know with us. And I had lovely talks with Mum. We talked about the family and the history. I wish I talked more, and that I had written it down too. But it's too late, it's gone. But I did enjoy, and I did enjoy her friendship. Yeah, to be able to go home and

go and chat to Mum. She understood, and she enjoyed listening to what we had been up too. She did enjoy that. (Carmel, pg.25).

4.3.3.d. Negotiation with Health Professionals

Through necessity they had become more resourceful and for some more assertive in asking for assistance and attention from the health professionals at the point of discharge.

And then sometimes I just needed to talk to myself ... you know how sometimes you talk to yourself in your mind saying, come on get a grip, now what would Edward say to you, that's my husband. What would Edward say to me? He would say now Annie, take one step at a time. We'll look at the picture, look at the big picture. We will look at the main points. The main points are, dit, dit, dit. So then I would sit down and I'd write, write, dit, dit, dit, what's the most important thing, and that is what I would do. And I would take my piece of paper along with me, and say now, you listen here. I have this to say to you today (Annie, pg.22).

4.4 Summary

This chapter has summarised the findings of the data analysis. It described the demographic make-up of the three participants and presented the three emerging themes of: 1) informed choice 2) acknowledgement and 3) determination, strength and resourcefulness.

The next chapter will discuss the implications of the findings in relation to the transition into informal family caregiving, make connections with the literature and propose recommendations for occupational therapy practice, education and future studies.

5. Chapter 5: Discussion

This final chapter discusses the implications from the findings presented in Chapter Four and connects findings with the literature reviewed in Chapter Two. The purpose of this study was to increase the understanding of the experience of family members who took on the informal caregiving role for their frail elderly parent in the caregiver's home, following a discharge from an acute hospital setting and to explore the discharge process within the context of a transition into caring. The relevance and significance of the study will be presented, as well as a comparison with recent literature.

Finally, implications and recommendations will be considered for occupational therapy practice, education and future studies, focusing on the objectives presented in Chapter One: to develop recommendations for occupational therapists working in this area; to assist other family members in making an informed decision before taking on this role of an informal caregiver; to develop recommendations to alleviate family concerns in relation to the discharge process; to describe what helps and hinders the family caregiver when beginning to engage in caregiving roles and occupations. To further assist occupational therapists, a new model of transition named "The Imparted Model of Transitioning into Informal Caregiving" is presented.

5.1 Personal Reflection

Having experienced caring for my frail elderly mother for two years, I found the job/role more challenging than I ever envisaged. At the time, I thought perhaps it was more difficult for me, being an occupational therapist, because I had higher expectations of what needs I should be meeting. However, during this research project and having interviewed the three participants, there was evidence that they also saw the holistic needs of their mothers, not just basic activities of daily living. This then significantly widened the job we had agreed to take on.

Knowledge transfer is a real issue in this area of practice. There is clearly copious amounts of literature describing the issue of burden for informal caregivers. However, from my experience of being a member of several multi-disciplinary teams, I would question if all members considered the breadth of these tasks that informal caregivers are taking on. All too often it seems that understanding is limited to the tasks that health professionals see and are involved in, in the hospital setting. I wonder whether MDT members have the time to

consider the client in relation to the community and home context which they are returning to. Are they really considering the holistic needs of their patients when regarding discharge planning, or are they clearing the bed? Do they have adequate information regarding the skills, knowledge and readiness of the identified informal caregiver? Do they really care? This sounds a bit harsh, but once their patient is discharged, there is little follow-up, to review how successful or unsuccessful the transition has been. It appears that for two of the three participants in this study, there was no follow-up or referrals to community services post discharge at all. Does a generic discharge summary to the GP count as discharge follow-up? Does a generic referral to the District Nursing Service, which can be completed with a phone call in the first week post-discharge, also count?

I found the experience of being an informal caregiving a time of conflict, a time of extremes and opposites. At times I did feel as though I was 'between a rock and a hard place' when I was faced with a choice between two unsatisfactory options. An example of this was the choice of resigning from being Mum's informal caregiver and placing her in hospital level care or resigning from being clinical coordinator at work to reduce my work load and level of responsibility when not at home.

Another idiom which illustrates how it felt at times was "Hobson's choice" or having no real choice at all: take it or leave it. This is what it felt like when we were being offered five hours of personal care support a week, which all informal caregivers soon learn is not five hours; in reality it is assistance with certain specified tasks such as showering and dressing. If the formal carer is able to complete this in 45-50 minutes, then that is the actual time they provide to meet their service obligation. When these five hours a week formal support were offered, I was shocked as this meant in my way of thinking, I was responsible for the remaining 163 hours a week. I was surprised, and because of my professional knowledge, should not have been, but it was really upsetting that Mum's and my needs were assessed at this minimal level. Because I became tearful at this assessment conclusion, out of kindness some discretion was shown and we were allocated another two and half hours a week. Therefore, I was responsible for only 160.5 hours a week and so we accepted the seven and half hours of support to cover Monday to Friday while I worked full-time. Yes we had a choice, take the seven and half hours a week or leave it, after all 'it's more than five hours a week, isn't it'?

Finally I have to say, that like the three participants in this study, I felt compensated or rewarded for providing the care that Mum needed. I came to know Mum more intimately

than would normally have been possible. I was present when she was the most vulnerable and I saw the strength of personality she maintained right through until the day she died. Though it was tough at times, we maintained a healthy daughter-mother relationship throughout the last two years of her life. We had only a few harsh words for each other, when either of us was too tired, fatigued or in too much pain, to be civil. We had some fun times during those two years, experiences we wouldn't have had if she had not lived with me. My children and husband also had these good times and came to know Mum in more ways than would otherwise have been feasible.

5.2 Overview

This study grew from both a personal and professional need to understand the experiences of adult caregivers of their elderly parents. Experiences focused on were in specifically relation to the transition into caregiving specifically. A naturalistic enquiry approach or paradigm, and a qualitative research design using interpretive descriptive methodology were used.

Themes from the analysis of the semi-structured interview transcripts were used to describe and understand the experiences of family members who took on the informal caregiver role for their frail elderly parent. The three participants each came from differing perspectives and contexts. There were, however, shared experiences and opinions regarding life as an informal caregiver. They were all happy to share their stories, and were keen for the lessons they had learnt be used to the advantage of prospective informal caregivers. The sample was from similar cultural backgrounds and all lived in an urban setting close to a large public hospital. Because of this, it could be debated that there is narrow generalisation of the findings.

When reviewing the sample as a whole, it needs to be said that the participants were careful not to be disrespectful about their mothers. There was a reluctance to express negative experiences and negative comments were often cushioned in humour. All of the daughters were pleased with themselves that they had been able to provide this support for their mothers. Though at times challenging, two of the three participants would do it again, and the third participant would hesitate before making the same decision again.

5.3. Summary of Findings

The findings support the New Zealand literature regarding the emotional and social pressures carers experience as they look after elderly relatives (Horrell, Breheny, & Stephens, 2014) and reiterates what Horrell's statements about both the positive and negative emotions

highlighting the ambivalence and tension inherent in caring. Horrell et al's findings about carers putting their lives on hold are also evident in this study.

The work of Opie (1991 & 1992) highlighting the dramatic changes in the carers' family relationships and the disruption to their everyday lives was evident in this study, and Opie's proposal that the cost and burden of caring is largely endured by the carers themselves, rather than by the state is supported. Furthermore, the conclusion of Jorgensen, Parsons, Jacobs, and Arksey (2010) that there seems to be a contradiction between the value we place on caregivers and what we provide to support them, both materially and psychosocially, is also supported.

The themes that emerged from this study were: 1) informed choice 2) acknowledgement and 3) determination, strength and resourcefulness. All of these themes in the researcher's opinion are equally important when considering caregiver experiences in relation to the process of transition.

Australian researchers Grimmer, Moss and Falco (2004), explored how informal caregivers perceived the process of taking on new or an increased caring role, and determined that the systems used in discharge planning should take greater account of the motivation and needs of carers. They found that the transition can feel traumatic to carers who feel they had little choice and were not sufficiently considered during the discharge planning. Pereira and Botelho's (2011) research findings recognised that being foisted into the caregiving situation led to a time of chaos, confusion and little reflection.

The transition to caregiving is complex. The three participants and their situations are obviously unique, and while they appeared willing to take on the caring role, on reflection, they all agreed that this choice was based on inadequate choices and preparation. The fact that this was the case is a vital finding, when considering the process of transitioning. The transitional models presented earlier (Adams, Hayes, & Hopson, 1976; Hiatt & Creasey, 2012; Burnes, 2004; Kritsonis, 2004-2005) stress the relevance of this choice.

Adams, et al. (1976) remind us that a major point in being able to understand transitions is to consider whether a change in one's daily routine is an intentional change, a sudden change, or an evolving awareness that one is shifting into a new life stage which is characterised by a change in stability. These changes set off a cycle of reactions and emotional responses which are predictable, as outlined in their seven stage transition model. The ADKAR model also stresses the importance of choice in transition, with the first two steps of the five step model, being 1) Awareness of the need for change and 2) Desire to support and participate in the change (Hiatt & Creasey, 2012). The more the person feels the change is necessary, or

urgent, the more motivated they are to make the change. Kurt Lewin in his three stage change model, known as “unfreezing-change/transition-refreeze” model, indicates that the first step, unfreezing, requires becoming motivated for change, which requires weighing up the pros and cons, before you take any action (Burnes, 2004; Kritsonis, 2004-2005).

All of these transitional models indicate that the process of transition is more difficult if the person involved did not have a choice or their choice was un-informed, with little knowledge of or preparation for what the next step involves. It is therefore proposed that the participants in this study were not assisted or eased into the role of informal caregiving, but were left to their own devices and therefore did go through a period of stress and uneasiness. Not to dismiss that making an informed choice would eliminate this uneasiness, but certainly has the potential to minimise it.

The second emerging theme, lack of acknowledgement, is also a key finding when the transition into caring is considered. All of the participants voiced concerns that their role and its importance were often ignored by the health practitioners making the plans for their parents. This is particularly concerning in relation to discharge planning. In addition, the duties that constitute the job of being an informal caregiver were not (if known) acknowledged by the multi-disciplinary team and shared with the prospective caregivers. This is supported by Barrett, Hale and Gauld (2012) who highlighted that ageing-in-place is the preferable approach to housing the frail and older population, but question if there is a corresponding understanding of the important role that home-care work plays in achieving this approach.

The experience of the three participants also supports what Feinberg (2004) findings that while practitioners and policy makers have recognised the important role that family and informal caregivers play in providing long-term care for the elderly, there appears to have been little attention given to the need for assessing individual situations and the well-being of the informal caregiver. Further to this, Brereton and Nolan (2000) remind us of the need for partnership between professional and informal caregivers. They highlighted the value of recognising the expertise of the family carer, who has the ‘local knowledge’ of the recipient and the care-giving context. The three participants in this study did not experience recognition or acknowledgment of their expertise, which limited the strength of any discharge planning, to the detriment of both the care recipient and themselves.

Emerging sub-themes of lack of acknowledgement are also key players in the transition process involving the importance of education and support. The three participants were

motivated and determined to do a good job, as the informal caregiver for their parent. They were hungry for knowledge and the development of skills to assist in that process, and had insight into what skills and support they needed. Unfortunately, they all found that education and support were lacking during and after the discharge process. This lack of education and support is the opposite of what is recommended in the models of transition already described.

The ADKAR model's (Hiatt & Creasey, 2012) third step "knowledge of how to change", fourth step "ability to implement the change" and fifth step "reinforcement to sustain the change" are purported to be necessary for an individual to successfully complete the transition. These steps highlight the need for the transfer of knowledge by coaching and mentoring. It is also proposed that once the knowledge about how to change is in place, the performance or practice of the individual needs to be supported. This may involve time and is achieved through practice, coaching and feedback. To ensure that changes are maintained, positive feedback, recognition, assessing performance and taking corrective action are also suggested.

The "transition or change" phase of Kurt Lewin's "unfreezing-change/transition-refreeze" model, (Burnes, 2004; Kritsonis, 2004-2005) is the inner movement or journey that is made in reaction to a change. The model proposes that at this stage, people often feel afraid and unsure, and therefore may need to be given time. Understanding and support is vital here in the form of training and coaching. Mistakes are expected as part of this process and the use of role models and enabling people to develop their own solutions are seen as helpful.

This need for training and information was also highlighted in the framework called "Timing It Right" proposed by researchers Cameron and Gignac (2007), which they suggested could be used to ascertain gaps in informal caregiving training. The third stage of their framework is called "preparation" and ideally happens prior to the patient returning home. They describe this stage when the carer often wonders "am I up to the job?" They particularly want training and information from medical and allied staff to help with the provision of physical care in the home. Furthermore, they want education about signs of potential problems, to be given feedback and have their caregiving skills appraised to build their self-confidence. The next stage in their framework is also relevant regarding what the three participants' experiences, and is the stage where the caregiver is "learning the ropes" as they attempt to transfer the skills they learnt in hospital to assisting their family member in the home. At this stage there are many duties/tasks that the caregiver needs to coordinate and may experience

difficulty in doing so. Emotionally, they may be uncertain regarding their abilities and often feel inadequate.

A further emerging sub-theme supported in literature in relation to the lack of acknowledgement is the forfeit of time and activities. Pereira and Botelho's (2011) study identified the theme of "losing control over time". Barrett, Hale and Butler (2014) noted that rhythms structure the constitution of the self and the home on a daily basis. The need to provide care in the home can be seen as changing pre-existing structures in time and place, which is more often evident when caregiving is commenced suddenly. The pressing demands of this new situation imposed on the carer makes them think about how they could live their lives. On commencement of caregiving there is a loss of personal time, and flexibility is needed to respond to the new demands of the situation. Due to uncertainty and the unscheduled needs and demands of the care recipient, routines need to be frequently redesigned by the carer, which at times leads to other activities and plans being cancelled.

The emerging sub-theme, impact on others, was not an unexpected theme as it is frequently recounted in the literature. Pereira and Botelho (2011) described this concept as "feeling alone". They recount that caregivers can be alone and unsupported in the provision of care and they can also feel alone as a response to missing the care recipient's old self. Barrett, Hale and Butler (2014) also point out the role of being a caregiver restricts the capacity to get out of the house, or have quality time with family members within the home. Therefore as a result of being an informal caregiver, there are demands which result in the need to make adjustments to other personal and social relationships.

The third and final emerging theme is in relation to the compensation or rewards that the caregivers experienced which gave them the motivation and strength to carry on with providing the care they agreed to do. The three participants shared a range of rewards that were as unique as each care situation. They enjoyed having their mothers living with them and valued the time they were able to spend together. They appreciated the opportunity to recollect and talk about their family history. Being able to fulfil their mother's wishes to remain living in the community for as long as possible, was also a reward in itself.

This research project adds to the literature, the significance of acknowledging the family member who is planning to take on the role of informal caregiver for their parents, and acknowledges the complexity of the role. If they do not acknowledge that person or assume other MDT members are responsible for this, or trivialise what they do, how can the informal family caregiver be effectively included in the rehabilitation and discharge planning process

of their patient? Education and support from the health service cannot be accessed by informal caregivers if they are not acknowledged by the health practitioners in that service.

This research project has also shown that there is a perception by caregivers that many health professionals do not know what informal caregiving involves. This has highlighted the need for occupational therapists and the wider MDT members to acknowledge the complexity of the informal caregiving role. Again, how can they assist the prospective carer to making an informed decision to commence caregiving or for current caregivers to continue caring, if they do not know what they are asking them to do?

5.4 Recommendations

There is little current research that describes the role of occupational therapy in the transition into informal family caregiving for a frail elderly parent. Only one occupational therapy transition model was found, and that was in relation to the patients' (not the caregivers') experiences in making the transition from an acute care hospital to their homes in the community. In this research I have explored how supported and prepared informal caregivers believed they were, prior to and after committing to this role. I have also explored the discharge process as experienced within the context of a transition into caring.

5.4.1. Occupational Therapy

It is recommended that occupational therapists working in this area assist prospective informal caregivers to make an informed decision before taking on this role. Occupational therapists have the knowledge regarding the breadth of tasks or activities that this occupation is likely to involve. This is important so that the prospective caregiver realises the commitment they are making. Prospective caregivers need to know that their role is beyond just providing supervision or assistance with basic activities of daily living. Table 1 provides a list of duties that a family informal caregiver may be responsible for, which was generated from the participants' experiences and combined with the researchers. Nikora et al. (2004, p. 51) as previously outlined in chapter 2, provide a description of what whanau carers do which is closely reflected in what the participants of this study also described; provision of emotional support, companionship, nursing, consent, advocacy, community links, facilitating cultural obligations, and maintaining a spiritual sense of being to ensure wellness of wairua. Wairua is described as spiritual health and includes dignity, cultural identity and personal contentment (Ministry of Health, 2012).

Table 1 Responsibilities Assumed By Informal Family Caregiver

Function	Examples of Tasks
Provide assistance with basic activities of daily living	<ul style="list-style-type: none"> • Showering • Oral cares • Dressing • Toileting and use of incontinence products • Eating and drinking • Assistance with transfers and mobility • Prompt engagement in health care • Encourage healthy diet, exercise and treatment adherence
Provide Emotional Support	<ul style="list-style-type: none"> • Being strong • Discussing ongoing challenges • Problem solving and conflict resolution • Lifting spirits • Being available for medical emergencies • Being available overnight, being responsive to call-bell • Sourcing support groups for care recipient
Health service utilisation	<ul style="list-style-type: none"> • Schedule follow-up appointments • Attend appointments and clarify care recipients history • Raise concerns and issues to the providers
Advocate	<ul style="list-style-type: none"> • Advocate and deal with gatekeepers for services • Select and co-ordinate care across providers and services • Make medical decisions • Power of Attorney
Provide assistance with Instrumental activities of daily living	<ul style="list-style-type: none"> • Coordinate weekly schedule • Shopping • Meal preparation • Purchase food and medications • Cleaning and laundry duties • Use of telephone, computer, satellite/cable TV etc. • Private correspondence i.e. Christmas cards, birthday cards, letters etc.
Driver	<ul style="list-style-type: none"> • Provide transportation to medical appointments • Provide transportation to personal appointments i.e. dentist, hairdresser, podiatrist, manicurist etc.
Financial Manager	<ul style="list-style-type: none"> • Oversee finances, including insurance and tax issues • Organise bill payment including for private support services
Health Provider	<ul style="list-style-type: none"> • Organise and administer medications • Dress wounds • Monitor health status (physical, cognitive and mental health) • Organise and operate compensatory equipment i.e. electric hospital bed, pressure relieving mattresses and cushions, wheelchairs, strollers etc. • Organise modification to environment • Being available to assist when care recipient is admitted into hospital
Leisure convenor	<ul style="list-style-type: none"> • Coordinate and support leisure and recreational activities
Social role facilitator	<ul style="list-style-type: none"> • Support with the adherence to cultural/religious/faith observances • Support the fulfilment of previous roles i.e. grandparent, club member etc. • Coordinate extended family gatherings
Coordinate family involvement	<ul style="list-style-type: none"> • Coordinate extended family to be available to assist as needed • Keep extended family informed about care recipients status and progress
Miscellaneous duties	<ul style="list-style-type: none"> • Planning or assisting care recipient with planning their funeral

Occupational therapists working in this area also have the responsibility to inform and support prospective informal caregivers regarding the possible emotional and social challenges they may encounter so they can be more prepared. Occupational therapists have the skills to provide education regarding the importance of a balanced life style, relaxation, stress management, exercise, work simplification, energy conservation, time management, assertiveness, communication skills, problem solving, goal setting and grief management.

Occupational therapists have practical knowledge regarding manual handling, use of compensation equipment, environmental modifications and strategies to maximise independence with functional mobility and activities of daily living. However, it seems that this knowledge is not always shared with family caregivers.

In relation to the concept and consequence of the degree of choice in taking on the role of an informal carer, literature indicates that this impacts on the ongoing success of caregiving and the vulnerability to stress and illness (Grimmer, Moss, & Falco, 2004; Winter, Bouldin, & Andresen, 2010; Schulz, et al., 2012). It is therefore important that occupational therapists look at ways to diminish the consequences of lack of choice. Schulz, et al. (2012) suggest that it may be possible to convey elements of choice in the caregiving process by increasing the caregiver's competence and feelings of effectiveness. Another strategy proposed is when the caregiver is provided possible choices and options in relation to how challenges can be met. Some of these choices could be the exploration and utilisation of home-based services, respite care, support groups, family support etc. It is important for therapists not to limit suggestions to funded services, and provide options for self-funding as appropriate.

The emerging themes recorded in this study could be used as part of the education in describing what helps and hinders family caregivers in the beginning to engage in the caregiving roles and occupations. The need to acknowledge the caregiver in the discharge process is vitally important for occupational therapists and the MDT as a whole.

Furthermore, it is necessary for all health professionals working in this area to utilise the family members expertise regarding the care-recipient and the social context, and to utilise their local knowledge to the benefit of the care-recipient (Feinberg, 2004; Brereton & Nolan, 2000).

A model of transition is recommended to be used as a tool by occupational therapists when assisting family caregivers in engaging in that role. However, the models previously described do not adequately take into account the themes that have emerged from this study. Therefore, a new model was purposefully formulated to ensure that practising occupational

therapists, who have large busy caseloads, can direct their limited available time for the maximum benefit. The model provides a framework to structure the skills, knowledge and expertise that occupational therapists already have to enable them to effectively and efficiently work with prospective and current informal family caregivers in the transitioning process.

5.4.2 Imparted Model of Transitioning into Informal Caregiving

The “Imparted Model of Transitioning into Informal Caregiving” as shown in Figure 1 is a model that illustrates the steps required and what will assist informal family caregivers in successfully transitioning into caring for their frail elderly family member. It is not unlike the ADARK Model (Hiatt & Creasey, 2012) in that it has sequential steps or actions. It is also closely aligned to the “Timing it Right Framework” (Cameron & Gignac, 2007) which identifies acute care, rehabilitation and community care stages in relation to stroke survivors and their caregivers. Specific elements of the “Timing it Right Framework” are also used as a scaffold to build on, but are adapted to meet the occupational needs identified in the findings chapter for the informal caregivers of their frail elderly family member.

Though not explicit in the representation of the model, occupational therapists would benefit from having knowledge of the self-esteem changes during transitions as outlined in the “Changes in Transitional Behaviour” model (Adams, Hayes, & Hopson, 1976) which highlights the possible cycle of reactions and emotional responses that people experience during change. In addition to this, an understanding of “the transition cycle” (Nicolson, 1990) is required as the basis of this model emphasises that each stage is distinct, and that what happens in one stage strongly influences the next stage. It also recaps the notion that the cycle can recur and has an accumulative effect; therefore, if a carer has negative experiences or disappointments in the earlier stages, this can lead to cycles of dissatisfaction. Conversely, successful transitions can work to increase confidence and success.

As already alluded to, the proposed model is aimed at occupational therapists and is constructed to recognise and emphasise the importance of informal carers making an informed choice, being acknowledged as a key person in the process, having their strengths and resourcefulness acknowledged and being able to weight up the cost and compensation.

I	Investigate and instruct what is involved in informal caregiving with the proposed carer. <u>Acknowledge</u> the complexity of the role.
M	Measure up the pros and cons (cost and <u>compensation</u>) / consider strength and determination of families / facilitate an <u>informed choice</u>
P	Preparation/training/ building skills to enable smoother transition into caring role.
A	<u>Acknowledgement</u> by MTD of informal caregiver / involve carer in rehabilitation programme/involve in discharge planning including identification of community supports that would be beneficial.
R	Role of informal care giver commences.
T	Transfer of skills/knowledge from hospital to the home.
E	Evaluation of the transition to the home / <u>acknowledge</u> the changes that may have occurred with respect to other roles/responsibilities and dynamics in the home.
D	Defend, support and reinforce the carer so to maintain the transition.

Figure 1 The Imparted Model of Transitioning into Informal Caregiving

The acronym of imparted is used for ease of remembering the stages recommended to be used in assisting the family member transitioning into care. Impart has the meaning of communicate, teach, instruct, inform, convey, disclose and reveal (The Free Dictionary, 2014; Oxford Dictionaries, 2014). Aspects of all of these actions will be applied by the occupational therapist in assisting in the utilisation of this model

5.4.2.a. Initial Phase – “What does it involve”?

I	Investigate and instruct what is involved in informal caregiving with the proposed carer. <u>Acknowledge</u> the complexity of the role.
M	Measure up the pro’s and con’s (cost and <u>compensation</u>), consider strength and determination of families / facilitate an <u>informed choice</u>

Figure 2 Initial Phase - What does it involve?

The “Imparted Model of Transitioning into Informal Caregiving” consists of four phases, and each phase has two components to consider. Not unlike other models discussed e.g. ADARK Model (Hiatt & Creasey, 2012), “Timing it Right Framework” (Cameron & Gignac, 2007), this model has an awareness stage called “what does it involve?”, as shown in Figure 2, with the aim of exploring and gaining an understanding of what is involved in being an informal

caregiver. The occupational therapist has a good understanding of the complexity of informal caregiving, along with the up-to-date assessment information regarding the functional ability of the frail elderly person being cared for. Therefore, they are in the ideal position to consider and assess the capacity of the prospective carer to take on the role and to ensure they have realistic expectations of what will be required.

As previously outlined, Murphy (2014) highlighted the differences in how risk can be understood by patients, their families and the therapist. The participants of that study identified that one of the best ways of dealing with different understandings of risks was for therapists to share their knowledge and to be aware of how a patient and their family construed the risk. Murphy (2014) purported that this awareness could potentially open communication that will reduce the barriers that the participants identified as coming from families.

Like the Lewin's Change Model (Burnes, 2004; Kritsonis, 2004-2005; Suc, Prokosch, & Ganslandt, 2009) the proposed model supports the need for the weighing up of the pros and cons. Consideration of the strength and determination of families is also pertinent. The costs and compensation of being an informal carer ideally need to be considered before any decision is made, and should include reference to the impact this may have on other people and on the dynamics of the household. The occupational therapist should assist with this process to enable the prospective carer to make an informed choice before accepting the role.

This stage is concerned with preparing the prospective caregiver prior to accepting the role or accepting a change in demands and responsibility.

5.4.2.b. Phase 2 – Preparation and Planning

P	Preparation/training/ building skills to enable smoother transition into caring role.
A	<u>Acknowledgement</u> by MTD of informal caregiver / involve carer in rehabilitation programme/involve in discharge planning including identification of community supports that could be beneficial.

Figure 3 Phase 2 - Preparation and Planning

The next phase relates to the rehabilitation and discharge planning stage, as shown in Figure 3. This phase focuses on the acknowledgement of the informal caregiver and they should now be actively involved in the rehabilitation programme of their family member. They start (if it has not happened already) to receive training and education to assist with the role they

have agreed to take on. Ideally, this should be provided by all the relevant MTD members that are involved in the treatment of the care recipient.

From the occupational therapy perspective, the informal caregiver should now be given the opportunity to participate in self-care and functional mobility activities with their parent. This would be an ideal situation to provide education on strategies to maximise their parent's level of functional independence. Instruction and education on manual handling, falls prevention, pressure distribution strategies and the use of compensatory equipment if appropriate, may also be relevant and timely.

Through role modelling, the occupational therapist has the opportunity to convey, instruct and teach problem solving strategies and the benefits of goal setting. As indicated, the occupational therapist may also provide instruction and education on a range of other elements which may enhance the ability for the informal carer to transition more smoothly into the role. As previously outlined, these elements could include any of the following: the importance of a balanced life style, relaxation, stress management, exercise, work simplification, energy conservation, time management, assertiveness, advocacy and communication skills and grief management.

Dependent on MDT role definitions, the occupational therapist may or may not be responsible for assisting with education on how to access services in relation to medical alarms, call-bells, discounted taxi vouchers, mobility parking, continence services, medication blister packs, podiatry services, orthotic services, meals on wheels, ezy-meals, and community support groups etc. If not primarily responsible, there should be a useful level of knowledge so the carer can be directed towards the appropriate member of the MDT to explore these options further.

The informal caregiver should now be involved in the discharge planning process and the identification of community supports (formal, informal, funded and self-funded) that could be utilised has commenced. Post-discharge follow-up services are clearly defined so the informal caregiver has realistic expectations regarding this and can make alternative plans if needed. To assist in the transition to the next stage, home visits and home trials could be utilised to support the informal caregiver more effectively.

Not unlike the "feeling ready" phase in the "Elements of Transition Model" (Gage, Cook, & Freyday-Field, 1997), the carer needs to feel prepared and believe they can function safely and successfully once carrying out their role in the home. This is also likely to include the need for adequate home care services and assistive devices for use with the care recipient.

5.4.2.c. Phase 3 – Initiation of Caregiving Role

R	Role of informal care giver commences.
T	Transfer of skills/knowledge from hospital to the home.

Figure 4 Phase 3 - Initiation of Caregiving Role

The third phase, as outlined in Figure 4, is the post-discharge phase and requires appropriate follow-up. The informal caregiver is now the primary carer for their family member once they are back at home full-time. They are now working on transferring all the skills and knowledge they obtained from the MDT into their home context. If home-visits and trial discharges had been utilised in Phase 2, some of this transfer of skills would have been more closely supported by the MDT.

Ideally, the occupational therapist should consider a post-discharge home visit to provide an opportunity to assist with any issues or problems that have arisen, or with any difficulties with the transferring of practices and strategies from hospital to the home. The equipment and environmental modifications that may have been organised already can be re-assessed to check effectiveness. The opportunity should be taken to provide feedback including positive reinforcement on their achievements, progress made and work completed already, in relation to the caregiving role.

The carer should be given the opportunity to discuss how their routines are developing, how they are coordinating all the caregiving duties that they may now be responsible for, and how they are integrating their new responsibilities with their old. Strategies to share the load with other family members and friends should be encouraged or at least discussed, as should the mention of carer support groups available in the community and social media avenues such as Carers New Zealand.

This opportunity of visiting the carer and care recipient in the home can be used to ensure that services are in place and meeting needs. Dependent on local service structure, there may now be the need for the hospital occupational therapist to do a handover to a community-based occupational therapy service.

5.4.2.d. Phase 4 – Maintain and Sustain the Caregiver

E	Evaluation of the transition to the home / <u>acknowledge</u> the changes that may have occurred with respect to other roles/responsibilities and dynamics in the home.
D	Defend, support and reinforce the carer so to maintain the transition.

Figure 5 Phase 4 - Maintain and Sustain the Caregiver

The final phase, as outlined in Figure 5, involves evaluating how the caring process is going. As mentioned above, this may need to be carried out by the community occupational therapy service. The aim being to maintain and sustain the caregiving role, and ensure that the carer is receiving acknowledgement and being recognised for their work.

It is likely that a routine has been established, and hopefully the informal carer is feeling more comfortable and confident in their ability to support their parent in daily activities.

Reinforcement in the use of resources previously introduced to assist them with managing and balancing their global responsibilities and roles may need to be re-visited.

It is important that it is acknowledged that the caring relationship is not constant, not static and there will be ups and downs along the way. The carer should be reminded and encouraged to utilise goal setting and problem solving skills previously taught. They should feel comfortable and know that they can access further assistance in the way of consultation and assessment from health and social services if required for their parent or themselves. If these services do not accept self-referrals, then they should feel confident in seeking access via their family GP.

Carers should also be reminded that if they are not entitled to government funded services, which they believe are now required, they should not discount self-funding or exploring other avenues. For example, extended family may consider assisting financially to enhance the carer's or care recipient's quality of life. Family, friends and volunteers could also be utilised to spread the work load and provide some respite if needed for the carer.

Finally, it is important that the occupational therapists be reassured that what has been outlined, is not beyond the skills and knowledge they already possess. Having the time to utilise the proposed framework in its entirety is the ideal, but will not be realistic in many facilities due to time and staffing restraints. There are likely to be concerns about an increase

in work load; however, it is envisaged a great deal of the education and support will happen in parallel to the care recipient's rehabilitation programme. A large number of the interventions recommended, are likely to be occurring already, but in an ad-hoc fashion, as a more reactive response rather than a proactive one. The key point here is to be proactive rather than reactive.

If, as the model suggests, the caregiver has made an informed choice, is acknowledged and actively involved in the discharge planning, it is envisaged that re-admissions and failed discharges will be reduced and that our frail elderly patients will benefit from a more confident, competent and happier carer in the home.

5.5. Strength and Limitations of this Study

The results have undoubtedly been influenced by the researcher's personal preconceptions and biases regarding this topic. However, throughout the research process assumptions were identified and discussed with the study supervisor to increase reflexivity. The recorded interviews and the verbatim transcripts were reviewed and coded by the research project supervisor, to ensure that the researcher was open to the findings.

There is no assumption that findings will be generalised to other caregivers in other settings, though demographic information has been provided for readers to determine whether the findings are applicable in their practice area.

Participants were provided with summarised transcripts of their interviews, and also given the opportunity to read the findings and discussion chapter for their feedback. This member checking ensured that the researcher had recorded the members' viewpoints accurately to minimise the possibility of misinterpretation and give credibility to the study because it provides assurance that participants have recognised their experiences in the research findings. Peer review by the research project supervisor during the entire research project also enhances credibility.

The fact that all the participants in this study were women of a similar age and of European descent could be seen as a limitation. However, it was decided to choose participants to minimise diversity and capitalise on the opportunity to capture in-depth perspectives. However, it is acknowledged that even with this minimisation of diversity it has not been possible to approach data saturation.

Dependability in relation to qualitative research is determined when findings are authentically based on the collected data. This was ensured by including verbatim quotes, frequent supervision and rich descriptions of the research process.

A necessary weakness of this study is that it is part of a postgraduate programme, and therefore limited by a short time frame and restricted resources. This had an influence on the data collection in terms of the number of interviews conducted.

5.6. Recommendations for Future Research

It became apparent in relation to the difficulty with accessing participants via caregiver support groups in the community that the gatekeepers were indicating that their group members were caregivers for husbands and wives, not adult children caring for parents. This was unexpected, and perhaps indicative that family members who are caring for frail parents are unaware of these support groups, or feel they are not suitable to meet their needs or perhaps they do not have the time to search for and/or use this support. This phenomenon would be interesting to investigate further, in order to find the best avenues for supporting this group.

Another area of interest generated, which was touched on in the personal reflection section above, is in relation to whether an informal caregiver with a medical background is advantaged or disadvantaged compared to the caregiver with no medical background. Does this impact more or less on the transition into caregiving, the expectations and ability to cope with the complex needs of their parent? Is there more room for them to feel shut out or not involved enough with the medical staff caring for their family member? I would suspect that informal caregivers with a formal medical training place higher expectations on themselves to meet the holistic needs of their parent.

Widening the demographic background of the participants would also be interesting, to compare differences regarding culture and ethnicity and how this affects transitioning into caring, as would comparing how the sex of the informal caregiver impacts on transition i.e. a son being the primary carer.

In this study, two of the participants mentioned that perhaps it would have been better if they did not work. There are obvious benefits to being in paid employment, which would be lost if the informal caregiver took this route. It would therefore be beneficial to explore this phenomenon in more detail i.e. the financial, social, employability factors, for example.

As mentioned in the introductory chapter, the researcher employed a diversional therapist to work with her mother each afternoon for two hours every afternoon. This service needed to

be self-funded and took some searching to find. The benefits were significant to both the caregiver and the care recipient. This is an area of community health care, which would benefit from further research. The benefits of this service specifically in relation to transition into caring, immediately come to mind.

As the need for informal caregivers increases due to an ageing population and the policies/strategies that put an emphasis on ageing-in-place, it would be interesting to expand the research presented here to cover different periods of the caregiver journey beyond the initial transition phases.

Finally, research regarding the use of the proposed “Imparted Model of Transitioning into Informal Caregiving” would be a natural consequence of this research project. A grounded theory approach could be used to test this model and the benefits of its use by occupational therapists would be valuable. Furthermore, its impact on prospective and practicing informal caregivers would be valid. This model could be adapted and used more widely by occupational therapists in other areas of practice, where transitioning in different contexts would also be worth researching.

5.7. Conclusion

In conclusion, this study has explored the experiences of the transition into informal family caregiving for a frail elderly parent following the discharge from an acute hospital setting. The project aimed to help occupational therapists and the wider MDT to reach a better understanding of how to approach a potential carer. It is hoped that the findings of this research project will lead to better support services to the caregivers and thus, indirectly, to better care for their parents. The three emerging themes: 1) informed choice 2) acknowledgement and 3) determination, strength and resourcefulness, were presented for the use of occupational therapists who work in this area, to increase their understanding of what is involved in informal caregiving, specifically in relation to the transition into care.

This research has highlighted the importance of increasing the MDT’s understanding of the need for the prospective carer making an informed choice when agreeing to embark on this journey. It is also necessary for the informal caregivers to be acknowledged and their role and skills recognised by the professional practitioners.

Models of transitioning were outlined and a recommendation was made to use the proposed “Imparted Model of Transitioning into Informal Caregiving”. This new model was presented to assist occupational therapists to become more conscious of providing necessary support

and education to prospective caregivers. The importance of occupational therapists being involved in facilitating the prospective carer to be able to make an informed choice was stressed, as was the vital role that occupational therapists could play as an acknowledger of the complexity of the informal family caregiving role.

To conclude, the idiom of “Hobson’s choice” goes some way to convey how informal family caregivers feel when they agree to care for their frail elderly family member. It could be argued that all carers made a free choice. However, it is apparent that although the decision to take on the significant and important role of caring for a family member is a free choice, it is not always an informed choice. As a consequence, I propose that it is unjust that people are put in this position of making this choice, without all the facts.

I believe that health professionals (including myself) have not always considered the complexity of caring, and have taken advantage of the feelings and expectations of “duty”, “reciprocity” and the “natural progression into this role” that perspective family carers often experience. Having now been an informal caregiver, I am acutely aware that I didn’t know the scope of that role and therefore was not in a position to adequately support the informal family caregivers’ that I worked with as the occupational therapist for their family members. I also did not consider the process of transitioning into caregiving and did not utilise a model of transition to assist them at this important time of their life.

Hobson’s choice means no real choice at all. I am hopeful that by acknowledging the complexity of the role, involving prospective carers in the discharge planning process, acknowledging the need for and provision of adequate support and education, this will enable family members to transition into caring more smoothly. Through the proposed transition model, it is hoped they will feel more actively involved and valued, more aware of what is expected, more prepared and therefore more able to make continued informed choices along their caregiving journey.

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Appendices

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Appendix A: Interview Guide

Interview Format

"This study is an exploration of the experience of the transition into caregiving for informal caregivers who take an ageing parent to live in their own home".

Occupational Roles/Occupational Choices

How did you come to take on the role of being the informal caregiver for your parent?

Was this anticipated or a quick decision?

If anticipated, what sort of planning and preparation had you put in place already for this role? Were other people involved in this decision? Looking back, how do you think you could have been more prepared?

If it was a quick decision, were you adequately prepared for the role? Were other people involved in this decision?

What advice would you give other family members who were planning to take on this role?

Engagement in Meaningful Activities

How did starting the commencement of caregiving affect all the other activities in your life?

In addition to caregiving, was there anything else that took up a lot of your time and energy that was really important to you? (family, work, studies).

Did you have any ongoing hobbies/projects/religious activities that **remained** part of your routine? Did you have any hobbies/projects/religious activities that were part of your routine **prior** to being an informal caregiver, which you gave up? Tell me about them – how often? What did you like about it? (Did you anticipate this loss of activities?)

Occupational Settings (environment)

How did caring for your parent in your own home affect the dynamics of the home?

Who did you live with?

Are there other important people in your life? (i.e. children, grandchildren, extended family, friends etc).

Is there anyone at home/in your family who makes life stressful or difficult for you and/or for your parent? Had this situation changed over the period of caregiving?

If you needed help with something, can/could you expect your family/spouse etc. to give you a hand? Can you give me an example? Has the amount of help provided changed over the period of caregiving? (Describe).

If you were feeling depressed or upset, could you expect your family/spouse etc. to give you support? Can you give me an example? Has the amount of support provided changed over the period of caregiving? (Describe).

Activity/Occupational Choices

When you ran or run into obstacles or difficulties, how did/do you handle it? Can you give me an example?

When first carrying out caregiving tasks, were there times when you felt you couldn't go on looking after your parent? How did you deal with these times? What did you do?

What do you think was the biggest challenge you have had to face when caring for your parent?

How do you think you handled this situation? Can you give me an example of some decisions you've made that illustrate this? Looking back, would you now handle it differently?

Do you feel your relationship with family, friends etc changed because of your responsibilities?

Looking back, what were the things that made caregiving difficult or stressful for you when you first took on this role?

What was the most rewarding thing for you about caring for your loved one?

When you first took on this role what qualities and personal strengths did you bring to your caring role?

Is there any advice you would like to give other family members regarding obstacles/difficulties/challenges that they are likely to encounter?

Knowing what you know now, is there anything that would have been helpful in relation to the discharge planning at the beginning of the process? Is there any advice you would like to give the multi-disciplinary team regarding preparation needed for taking on the caregiving role?

Knowing what you know now, would you agree to take on this role of informal caregiver for your parent? (Expand).

If yes - Would you do anything differently? What were the best things?

If no- what would need to change for you to agree to take on the role?

Finally, when you agreed to take on the caregiving role for your parent, do you now believe you had a choice? (Describe)

Appendix B: Prompt Sheet

Prompts

Can you give me another example of that?

Does that happen all the time?

Did that happen all the time?

Really!

Go on

No way

Tell me more

I never knew that

I don't understand

Could you elaborate or be more specific

When

How

Appendix C: Stages of Data Analysis

		Initial Codes	Initial Themes	Refined Themes
M	And then she came and lived with us in 2004. And yeh, it was fine, everything was good, but she got quite bossy . As she got older she got bossier. She didn't see herself as bossy.		Changes the dynamics of other relationships.	Informed choice, based on the unknown.
Resear cher	No			
M	But, it got very difficult because Kerry and I hadn't been together that long. And it was very hard for him, if he played his music loud, and he is very keen of his music. We also had a very big dog,	Effected dynamics with husband and the household.	Experienced fatigue/tiredness due to constancy of caring	Complexity of the caregiving role (Acknowledgment)
Resear cher	Yep			
M	That she wasn't keen on. Um, and It just did, get difficult.			
Resear cher	Right		Aware of wider needs of Mother, beyond basic needs of daily living.	Complexity of the caregiving role (Acknowledgment)
M	And then she got sick. And you know, she was getting sick and my brother said, right I will give you a break and I will take her for a while, so took her up to W...., where she knew people too, she was from W....	Became frailer Needed a break, and brother took over care		
Resear cher	Yes		Determination, Strength and Resourcefulness	
M	She didn't know anyone here, not a soul. And so she went up there to live with him., um, for a while	Mother missed the support of her previous community		

Appendix D: Consent Form

Consent Form

Project title: Time to Care

“This study is an exploration of the transition into informal family caregiving for a frail elderly parent following the discharge from an acute hospital setting.”

I have read the information sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

- My participation in the project is entirely voluntary.
- I am free to withdraw at any time without giving reasons and without any disadvantage
- The data (including audio tapes) will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for five years after which it will be destroyed
- Results of this project may be published but any data included will in no way be linked to any specific participant without prior consent. You may request a copy of the results of the project.

I agree to take part in this project under the conditions set out in the Information Sheet.

..... (signature of participant)

..... (date)

..... (signature of researcher)

This project has been reviewed and approved by the Otago Polytechnic Research Ethics Committee.

Appendix E: Ethics Approval from Otago Polytechnic Ethics Committee



26 August 2014
Elizabeth Edens
37 Seaforth Avenue
Milson
Palmerston North 4414.

Dear Elizabeth

Re: Application for Ethics Consent
Reference Number: 586
Application Title: *Time To Care*

Thank you for your application for ethics approval for this project.

The review panel has considered your revised application including responses to questions and issues raised. We are pleased to inform you that you we are satisfied with the revisions made and confirm ethical approval for the project.

Many thanks for your careful responses to our recommendations.

We wish you well with your work and remind you that at the conclusion of your research you should send a brief report with findings and/or conclusions to the Ethics Committee. All correspondence regarding this application should include the reference number assigned to it.

Regards

Richard Humphrey
Chair, Ethics Committee
Otago Polytechnic

Appendix F: Recruitment Letter

Elizabeth Edens
37 Seaforth Avenue
Milson
Palmerston North 4414

date

Dear ,

My name is Elizabeth Edens. I am a master student in Otago Polytechnic School of Occupational Therapy and am conducting this research project in partial fulfillment of my degree requirements working under the supervision of Dr. Mary Butler.

The aim of this research project is to explore the experiences for individuals who have taken on the role of informal caregiver for a frail elderly parent following the discharge from an acute hospital setting.

We know that caregiving can be very stressful and this project aims to help make the transition into caregiving a little less painful. I hope to gather information that would be useful to know at the point of discharge, for both family members and medical staff

My belief is that increased understanding can lead to better support services to the caregivers themselves and thus, indirectly, can lead to better care for the elderly. Further to this it may help to achieve a better understanding of the sustainability of the care being undertaken by a family member.

I am looking for family members who have cared for a frail older parent in the family members own home for 3 months or more, following their parents discharge directly from an acute hospital setting. I hope to recruit 4-6 individuals in total.

Should you agree to take part in this project you will be asked to participate in an interview of approximately 60-90 minutes in a setting of your own choice. If you want to, feel free to bring Whanau support. The interview will be audio-taped.

Your participation in this research study is completely voluntary. You do not have to participate. You may stop any anytime without giving reasons for your withdrawal. You can also withdraw any information that has already been supplied. You can also refuse to answer any particular question, and ask for the audio to be turned off at any stage.

The data collected will be securely stored in such a way that only those mentioned above will have access to it. At the end of the project any personal information will be destroyed for any raw data on which the results are based. This will be retained in

secure storage for a period of five years, after which it will be destroyed. The principles of anonymity and confidentiality will be adhered to throughout this project.

Your name will not be given to anyone other than the research team. All the information collected from you or about you will be kept confidential.

Results of this project may be published but any data included will in no way be linked to any specific participant without prior consent. You may request a copy of the results of the project.

If during or following your participation in this research project should you be upset by the memories that might be invoked, it is important that you gain support from your carers support group or visit your GP.

If you have any questions about the project, either now or in the future, please feel free to contact either:

Elizabeth Edens NZROT
Master's Student (Occupational Therapy)
Department of Occupational Therapy
Otago Polytechnic
Phone: 06 353 6960 / 027 6913777
Email: g.e.edens@xtra.co.nz

Dr. Mary Butler NZROT
Research Supervisor
Department of Occupational Therapy
Otago Polytechnic
Email: mary.butler@op.ac.nz

Thank you for your consideration.

Regards

Elizabeth Edens

Appendix G: Participant Information Sheet

Participant Information Sheet Time to Care

Hello / kia ora,

My name is Elizabeth Edens. I am a masters student in Otago Polytechnic School of Occupational Therapy and am conducting this research project in partial fulfillment of my degree requirements working under the supervision of Dr. Mary Butler.

The aim of this research project is to explore the experiences for individuals who have taken on the role of informal caregiver for a frail elderly parent following the discharge from an acute hospital setting. It is hoped that this information can lead to a better understanding of how family caregivers manage the transition into care.

I am hoping to recruit four to six individuals who have cared for a frail older parent in the family member's home for 3 months or more, following their parents discharge directly from an acute hospital setting.

Your Involvement:

Should you agree to take part in this project you will be asked to participate in an interview of approximately 60-90 minutes in a setting of your own choice. The interview will be audio-taped.

Your participation in this research study is completely voluntary. You do not have to participate. You may stop any anytime without giving reasons for your withdrawal. You can also withdraw any information up to the point when you have viewed and corrected the transcript. You can also refuse to answer any particular question, and ask for the audio to be turned off at any stage.

Confidentiality and Protection:

The data collected will be securely stored in such a way that only my supervisor and I will have access to it. At the end of the project data will be retained in secure storage for a period of five years, after which it will be destroyed.

Results of this project may be published but all the data will be anonymised, using pseudonyms and any particularly identifying information will be omitted or changed.

You may request a copy of the results of the project.

If during or following your participation in this research project should you be upset by the memories that might be invoked, it is important that you gain support from your carers support group or visit your GP.

If you have any questions about the project, either now or in the future, please feel free to contact either:

Elizabeth Edens NZROT
Master's Student (Occupational Therapy)
Department of Occupational Therapy
Otago Polytechnic
Phone: 06 353 6960 / 027 6913777
Email: g.e.edens@xtra.co.nz
or

Dr. Mary Butler NZROT
Research Supervisor
Department of Occupational Therapy
Otago Polytechnic
Email: mary.butler@op.ac.nz

Appendix H: Consultation with the Kaitohotohu Office Otago Polytechnic

Elizabeth Edens
37 Seaforth Avenue
Milson
PALMERSTON NORTH 4414

2 June 2014

Khyla Russell
Kaitohutohu Office
Otago Polytechnic
Forth Street
Private Bag 1910
DUNEDIN 9054

Dear Professor Russell

Re: Elizabeth Edens - Student No: 05004919

I am writing to request an opportunity to engage with the Kaitohutohu Office, to discuss my proposed research project.

I am a post-graduate student working towards an Occupational Therapy Masters. I will be using a qualitative research methodology and a qualitative descriptive approach. The study is an exploration of the experience of informal caregivers/daughters in relation to the significant changes in their occupations when they abruptly take on the role of caring for a parent. I am based in the Manawatu and will carry out the research in this region.

This study is grounded in the fact of an ageing population and the policies/strategies that have put an emphasis on ageing in place (Ministry of Health [MOH], 2002, p21). Similar to other OECD countries, New Zealand has a rapidly ageing population. It has been estimated that by the late 2020's there will be more than one million New Zealanders aged 65 years and over (Ministry of Social Development [MSD], 2008). The Maori population is increasing rapidly and by 2026 there will be around 72,000 older Maori- 7% of the older population and 9% of the Maori population (Statistics NZ, 2008). Older people (aged 65+ years) have higher rates of mortality and hospitalisations for most chronic conditions, some infectious diseases and injuries (often from falls), all of which have a significant impact not only for the individual but also for their family/whanau (MOH, 2006). Therefore as the population ages, there will be increasing numbers of people who have a disability, and the number of people required to support them will increase (MSD, 2008).

One of my aims is to understand how supported and prepared these daughters are, prior to committing to the role of informal caregiver to their parent. And then to develop recommendations for occupational therapists working in this area, to assist other daughters in making an informed decision before taking on this role.

As outlined in the Te Ara Tika document (The Putaiora Writing Group, 2010), I am aware that I need to explore the ethical dimensions of tikanga in relation to my research proposal. From my experience as a community occupational therapist, I have observed that Kuia and Kaumatua are often cared for by their whanau and less frequently cared for in rest-homes. This is supported in the 'Supporting Older Maori & Pacific Peoples in the Central Region 2012' report (Central Regions District Health Boards, 2012) which states that older Maori have a preference to live at home and elders

want their own whanau to look after them. Whanau will try to keep family members at home for as long as possible. Therefore I believe that this research is relevant to Maori and non-Maori, and the results also have the potential to be of benefit to both.

Possible participants will be chosen or selected following advertising in a Manawatu local newspaper, also contact will be made with "Aged Concern "and local "Stroke Club. Because of the depth of the proposed interviews and subsequent analysis, the sample will be small. As I am a New Zealander of European descent, the research will not be conducted by Maori. Should any participants identify as Maori I would be grateful for your assistance and I know that I would benefit from consultation regarding culturally appropriate behaviour, interactions and research processes.

In addition to this I also have the opportunity to consult with members of the internal Maori Reference Group at my place of work, Enable New Zealand, Palmerston North. I could request, if you are supportive, that they recommend a person to be the cultural advisor for this study.

Enable New Zealand is a business identity of MidCentral District Health Board, based in Palmerston North. Therefore the internal Maori Reference Group mentioned is part of the Manawhenua Hauora, which is a consortium of all four iwi who have manawhenua status in Manawatu, Horowhenua, Tararua and Otaki districts. The roopu comprises representatives from Ngati Raukawa, Muaupoko, Rangitaane and Ngati Kahungunu. Manawhenua Hauora was established to advance iwi Maori Health and to work together with the DHB to achieve the best possible health outcomes for iwi Maori people residing in the district (MDHB, 2013).

Consultation with personnel at the local Stroke Group and Aged Concern will also be required in the identification of prospective participants.

I look forward to hearing from you.

Regards

Elizabeth Edens

To: Elizabeth Edens
CC: Mary Butler
17 June 2014

Kia ora Elizabeth, thank you for sharing you well-thought outline of your Masters project. This indeed is a relevant and interesting project and I think it's interesting to focus on daughters especially in the context of whanau. I think you have shown that you have carefully considered some of the ethical areas in research and you have done well to specifically relate these to Maori. I only have a couple additional questions; 1. Who is your supervisor?

2. Did you see our Moodle page for students? You mentioned Te Ara Tika but just checking you've managed to have a look at this resource too.

Thanks again, Gina

To: Gina Huakau, Kaitohutohu
CC: Mary Butler
Date: 24 June 2014

Dear Gina

Thank you for your e-mail regarding my research project.

In response to your questions, my supervisor is Dr Mary Butler.

Yes I have referred to the Moodle page for students, and found it interesting and informative.

Yours sincerely, Elizabeth Edens

To: Elizabeth Edens
From: Gina Huakau
Date: 25 June 2014

Thanks Elizabeth for your response. Happy for you to proceed to Ethics, good luck with your research, best Gina

