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**'Being There' when one's spouse
is hospitalised in a non-local tertiary centre.**

**A thesis presented in fulfilment of
the requirements for the degree of**

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ABSTRACT

Illness that requires hospitalisation is a potential cause of anxiety for the entire family. Furthermore, increases in technology and specialisation of hospital services have resulted in increasing numbers of patients being transferred to centralised tertiary hospitals. There is limited international and national literature that explores the phenomenon of having one's spouse hospitalised in non-local tertiary centres. Therefore, this study was conducted with the aim of exploring the experiences of those whose spouses were hospitalised in non-local tertiary settings. Understanding of the experiences of 14 people affected by such hospitalisations was underpinned by a Heideggerian phenomenological perspective.

Three major themes emerged from this study. Those who have their spouse hospitalised in non-local tertiary settings spend time waiting; a time best described as *being-in-suspense*. Despite *being-in-suspense* the research participants adjusted to their understanding of the situation; a period of time interpreted as *fitting being out-of-town into being-in-the-world*. The final theme that emerged from this study is that there were times when the research participants perceived that they were alone, unable to support or be supported by their spouses: *being with and without others*.

Overall the findings of this research indicate that those whose spouses were hospitalised in a non-local tertiary centre lived day by day, with little or no social support, awaiting outcomes over which they had limited control. The worst potential outcome for these individuals would be that of the spouse's death in the non-local centre. When the outcomes of the non-local hospitalisation could be predicted, the events of living day by day were manageable. It also emerged from conducting this study that in living day by day, the supporting spouse dealt with the circumstances by being focussed on the temporality of the present and a vision of a positive future. However, their spouses were not always able to conceive the future in such a positive way. Nurses and other health professionals must remain cognisant of the fact that while they are familiar with the everydayness of non-local hospitalisations,

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CHAPTER ONE

BACKGROUND TO THE STUDY.

1.1 Introduction.

Illness and the discovery of disease that requires hospitalisation, whether insidious or of sudden onset, causes stress and anxiety for both the patient and the family.

Nurses use a variety of strategies to minimise family stress during this time (Agazio, Ephraim, Flaherty, & Gurney, 2003; Coulter, 1989; Daley, 1984; Keizer, 1992; Leske, 1991; Long, 1997; Nethercott, 1993; Rukholm, Bailey, & Coutu-Wakulczyk, 1992; Tan & Simmonds, 1998; Twibell, 1998). However, nurses do not always provide the support that the patient perceives is essential for coping with the illness (Kettunen, Solovieva, Laamanen, & Santavirta, 1999; Stewart, Davidson, Meade, Hirth, & Makrides, 2000).

The impact of non-local tertiary hospitalisations on family members, when the local hospital cannot provide the necessary services and the patient is transferred to a bigger setting, is a phenomenon that has not been widely explored by researchers either nationally or internationally. While there is limited research on the effect of coping with a child hospitalised out-of-town (Agazio et al., 2003; Tan & Simmonds, 1998), there appears to be little research regarding the hospitalisation of the spouse or partner out-of-town (Agazio et al., 2003; Mercer, 2002).

The focus of this study is to explore the experiences of such non-local tertiary hospitalisation on supporting spouses using Heideggerian phenomenology. The purpose of this chapter is to explore the background to the study, and outline the health reforms that occurred in the latter part of the last century, which regionalised services and resulted in hospital closures. The chapter concludes with the overall structure of the thesis.

1.2 Background To My Thinking.

There are two main triggers that stimulated my interest in undertaking this study, with my assumptions about the experience of non-local hospitalisation being presented in Chapter 4.4.1. The first trigger came about in 1995 when it was

announced that there was to be a national breast screening campaign, commencing 1998. At the time I was teaching a post-registration course for nurses who were working with women who either had lumps in their breast and faced surgery, or women who had already had a mastectomy. Prior to the initiation of a national breast-screening programme, there were two pilot programmes, one in the Waikato and the other in Dunedin. What I discovered in facilitating the post-registration course was that women who lived close to Waikato could have a wedge resection, and a course of radiotherapy; an option not available in the geographical area that I was working in at the time. The opportunity to have a wedge resection was not only related to medical specialisation, but also to the availability of radiotherapy. I began to question what it would be like to live in a regional area that did not offer radiotherapy services at the local hospital, and be required to make the choice between having a mastectomy in the local hospital, or have the breast-conserving surgery, but be away from home for six weeks. How do these women weigh up their options?

The second background trigger began in 1999, when an 81-year-old man who lived in Whakatane needed to be admitted to Tauranga hospital for a prostatectomy. Whakatane hospital has some 150 beds, but this relatively routine procedure was no longer provided in that setting. At the time there was no direct bus service between the two centres, as the bus went via Rotorua, turning a one-hour road trip into a four-hour journey. The 81-year-old also had many complications of diabetes mellitus, including a past history of coronary artery disease. However, the need to be sent to Tauranga was not based on these complications, but on the fact that this surgery is no longer offered at the local hospital. Despite his medical history, both he and his wife were very fit. They had only recently given up golf, played bridge, enjoyed developing competency on the computer and were out and about visiting their daughters who all lived in cities around the North Island. Both he and his wife were still capable of driving.

On the first post-operative day, he was to be discharged. However, he was feeling unwell. Despite this, his 78-year-old wife brought him back to Whakatane, because they wanted to be home. That night he was admitted to Whakatane hospital with a myocardial infarction, pneumonia, and septicaemia. He was

finally discharged after a further two weeks in hospital. Although he had a prolonged stay in Whakatane hospital, both he and his wife were happy as there was some normality to his wife's day and she had the comfort of their own bed at night.

This incident generated thinking about other scenarios. What if this man's wife could not drive, or he lived alone? What if it had been a younger couple and his wife in paid employment? How do couples keep a household running when one is hospitalised, say for the six-week radiotherapy treatment alluded to earlier? What are the financial and social implications for those who are admitted to non-local tertiary centres? Furthermore, do we, as nurses, know what challenges and stresses couples who are affected by out-of-town hospitalisation, even for a short period of time, face? Does the healthy spouse put pressure on the hospitalised relative to get better quickly, so they can both go home?

Geographically, New Zealand is a 270,000-km² country, consisting of two major islands surrounded by other smaller islands, inhabited by a population of four million. The country, a maximum of 300km wide but approximately 2000km long, has 12 major cities in the North Island, and four in the bigger, but more sparsely populated South Island. The population of the cities ranges from 35,000 in the smallest, to a population of over a million people living in Auckland. Although each of these cities has a regional hospital that meets the majority of health care needs, there are only five tertiary hospitals in the country; two in the South Island, and three in the North Island. The tertiary hospitals treat complex medical conditions and also offer specialist services, such as transplants, that are not available in regional areas. Such specialisation has resulted in more people being transferred to non-local tertiary hospitals.

The 1990 New Zealand health reforms resulted in rationalisation and regionalisation of services. In conjunction with this, increased technology has also resulted in more specialist treatment offered only in the tertiary centres. Has the expertise resultant from regionalisation and increased technology overshadowed the humanistic aspects of treating illnesses, resulting in bureaucracies being oblivious to the social cost of out-of-town transfer? Before

this question is fully explored, it is necessary to provide an overview of the 1990 New Zealand health reforms.

1.3 The Health Reforms.

The structure of the New Zealand health care system has been under constant review since it was established in 1938 (Bloom, 2000; Hindle & Perkins, 2000). In reading the ministerial reports issued over the last two decades, it is easy to become confused with titles and roles of those purchasing and providing health care. Whilst it is not intended to provide an in-depth study of the New Zealand health care system in this chapter, it is necessary to provide an overview in order for the reader to appreciate why some services are not available locally.

As early as 1938, according to Bloom (2000), the government recognised that without appropriate intervention, rationing would result because of increased demand on capped services. By 1970, it was becoming apparent that financial pressure was beginning to cripple the public health care system. Reports were issued that expenditure on health services in New Zealand was high in comparison with international standards; 6.5% of national income (Hindle & Perkins, 2000). The government responded to the pressure by reducing the actual health funding expenditure (Bowie & Shirley, 1994). During the 1980s, 88% of the total health expenditure came from public funding, but during the early 1990s, this was reduced by almost 10% (Bowie & Shirley, 1994). In addition, during the 1980s the healthcare system became dependent on the consumers with resources or finances to access the private rather than the public sector for elective treatment (Hindle & Perkins, 2000), and the government began to implement a programme of more radical reform. The health reforms were coupled with other reforms to the New Zealand economy. These reforms, which resulted in corporatisation of services and establishment of state-owned enterprises (Bloom, 2000), have gathered momentum since the 1980s. As pointed out by Lovelace (2000):

...the word 'reform' leads one to think of something that needs to be fixed and afterwards left alone. During the 1980s and 1990s, however, health care reforms became almost a permanent fixture in health policy (p. xvi).

Figure 1.1 depicts an outline of the public health sector in situ prior to the health reforms.

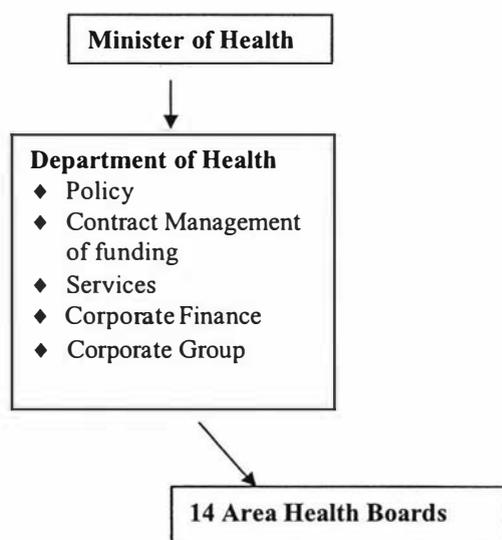


FIGURE 1.1 NEW ZEALAND PUBLIC HEALTH SYSTEM, 1992

Source: Dow, D. (1995). *Safeguarding the Public Health: A History of the New Zealand Department of Health*

Prior to the reforms, the Minister of Health was effectively head of a department responsible for policy, contract management, service provision and finance (Bloom, 2000). The *Area Health Board Act* (1983) replaced the previous Hospital Boards and Health Development Units with 14 Area Health Boards, which had the responsibility for planning and delivering health services. Each board was guided by the Health Charter which included a principle to resource health services to those population groups most affected by health problems causing death, disease and disability (Clark, 1989). The result of decentralisation drew attention to effectiveness and efficiency of services, which became the criteria for allocation of funds (Poutasi, 2000).

Figures 1.2 – 1.4 illustrate the government funding arms of the New Zealand public health system as a result of the reforms. Figure 1.2 focuses on the formation of business models with four health funding authorities. As illustrated in Figure 1.3, by 1999 the health providers were contracted to one funding authority only. The role of the Ministry of Health as funder and monitor is illustrated in Figure 1.4.

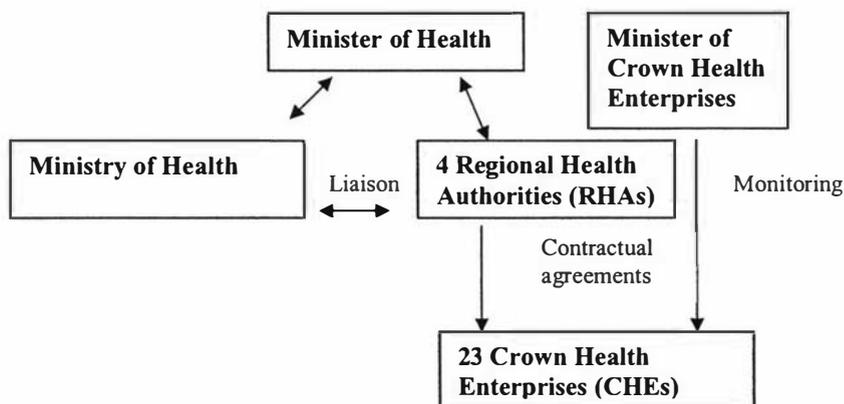


FIGURE 1.2 STRUCTURE OF THE NEW ZEALAND PUBLIC HEALTH SYSTEM, 1993 HEALTH REFORMS

Source: Scott, C. (1994). *Reforms of New Zealand Health Care System*.

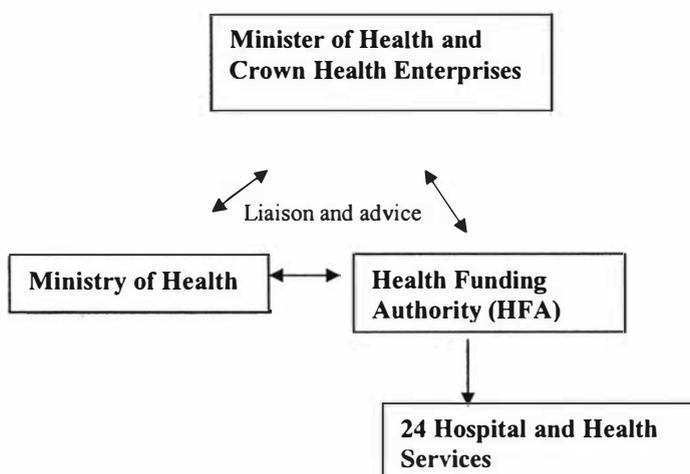


FIGURE 1.3 STRUCTURE OF THE NEW ZEALAND PUBLIC HEALTH SYSTEM 1999, WITH ONE FUNDING AUTHORITY

Source: Ministry of Health (1999). *Facts about health and disability in NZ*.

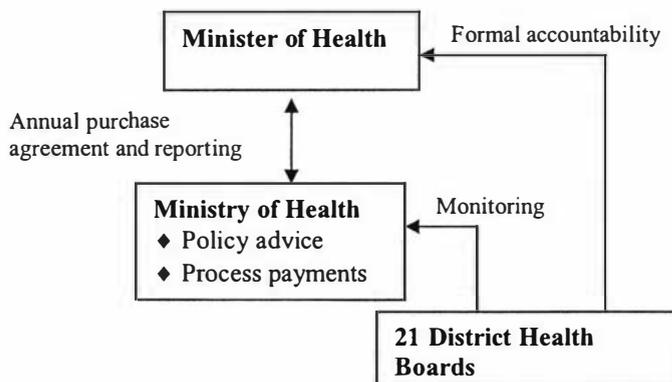


FIGURE 1.4 STRUCTURE OF THE NEW ZEALAND PUBLIC HEALTH SYSTEM, 2004.

Source: Ministry of Health (2004). *Statement of Intent 2004/2005*.

Further reforms during the 1990s resulted in the Area Health Boards being converted into limited liability companies called Crown Health Enterprises (CHEs), imposing a financial discipline beyond the ethos of the Area Health Boards (Selman, Wade, & Walters, 1994). The outcome of imposing business frameworks on CHEs (later called Hospital and Health Services and now known as District Health Boards) commercialised health and destroyed any opportunities for co-operation between organisations, resulting in competition for contracts and subsequently for funding (Bowie & Shirley, 1994).

Such competition between services affects individuals who require specialist services (Degeling, Sage, Kennedy, Perkins, & Zhang, 1999), as the CHEs were charged with planning, purchasing and providing health services. The culture changed from one in which the government provided the money to one where the CHEs demonstrated an ability to contract themselves to the government as health services providers. The adaptation from service provider to purchaser not only needed the support of New Zealand health professionals, the concept also needed the support of the general population.

Consultation strategies were established in order to seek the communities' opinions of the impact of health strategies. For example, following the publication of *Purchasing Directions 1994/95*, the Central Regional Health Authority (1994b) received over 200 submissions. Many of the submissions came from rural areas, which expressed concern about the lack of local health services. The main issue of concern related to local access to services, with most people wanting access to the same range of services as people who live in larger towns. At the time the Regional Health Authority (RHA) accepted that access issues needed to be resolved and planned to determine the specific population groups most affected (Central Regional Health Authority, 1994a). For example, the Central Regional Health Authority planned to ensure that necessary services from outside the region continued to be provided through key national and tertiary providers (Central Regional Health Authority, 1994a), within a market that encouraged competitive and comparative pricing. The competitive market and capped funding from the Health Funding Authority led to downsizing and

reconfiguration of hospitals, who were forced to reduce the number of beds, and centralise core services (Gauld, 2001).

Initially, the Regional Health policy guidelines did not contain requirements for the contracts to specify the travel time from place of residence to access secondary or tertiary services. These were not a requirement until 1995/96 (Ministry of Health, 1994/95). At this time 97% of the population lived within the golden hour; that is one hour's drive of a base hospital (Ministry of Health). This hour was considered the most crucial in fostering recovery from major trauma, and the distance was based on road travel, rather than air ambulance services. A base hospital was defined by the Ministry of Health (1994/95, p.84) as:

...one which provided a district trauma service, or equivalent.... These hospitals are capable of the initial management, resuscitation and stabilisation of injured patients. They have a level I or II intensive care unit. Where patients need prolonged ventilation or tertiary surgical management, they would be transferred to an advanced trauma service. There are five hospitals with advanced trauma services (Auckland, Waikato, Wellington, Christchurch and Dunedin).

A consultation draft report identified that medical and surgical services in New Zealand were available to 90% of people within 60 minutes travelling time (English, 1998). More complex specialist services were available within 90 minutes of travelling time.

However, as specialisation of services has increased, travel times to reach those services has also increased. For example, even if those living in Gisborne are transferred to the closest tertiary centre, Waikato, their relatives are required to travel over 300km to be with them. Those who live south of Gisborne, for example Wairoa, fall in the catchment area of the Hawke's Bay District Health Board, and are transferred to Wellington, approximately 450 km away from home. These people do not live within 90 minutes of road travel time from such specialist services. Issues around the provision of services provided by the smaller hospitals continued to be debated where 40% of people in areas such as the Waikato catchment live in communities with populations of less than 10,000

people (Central Regional Health Authority, 1995; Health Funding Authority, 2000c).

A principle of the health reforms was to facilitate equity in the best possible way. For example the following claim was included in the Central Health Authority 1994-1995 annual report:

Central RHA now manages the budget for high cost treatments such as heart or liver transplants, for the CHEs in its region, so that it can make sure everyone in the central region has equal access to these services, and can negotiate the best prices for the treatment needed (Central Regional Health Authority, 1995, p.16).

The Central Regional Health Authority acknowledged in its report that certain operations needed to be performed out of the region or the country. Heart transplants, for example, were all performed at Greenlane Hospital in Auckland, and cost an average of \$60,000 each [1995 costings]. The Central RHA approved seven heart transplant cases during 1994/95. Those requiring liver transplants were sent overseas. The authority recorded approval of two of these overseas operations from the region in the 1994/95 year. The operation cost more than \$140,000 with the RHA contributing \$80,000; the rest of the funding was obtained through private sponsorship or funding. From 1 July 1995, Central RHA intended to pay \$120,000 toward each operation.

‘Covering these costs can lead to major problems for a small CHE’, says Central RHA’s Manager of High Cost Treatment, Jenny Black. ‘We’re now managing the risk for them, and making sure that everyone in the region has the same opportunity to use these services if they need them’ (Central Regional Health Authority, 1995, p.17).

In order to provide access for all, the service delivery systems moved from maintaining clinical targets to a management structure that was focussed on clinical outputs and clinical accountability (Degeling et al., 1999). Furthermore, the introduction of health reforms in New Zealand resulted in the establishment of a waiting list timeframe threshold of six months (MacCormick & Parry, 2003). However, MacCormick and Parry argued that such arbitrary timeframes are inappropriate; elective treatment should be based on severity and potential outcomes of medical conditions. Severity of condition, not geographical location should also direct length of hospital stay.

Although they provide no reason, Cheung, Katzenellenbogen, Baxendine, Pool, and Jackson (2001) contend that during the 1980s people who lived in the Bay of Plenty, Hawke's Bay, Tairāwhiti, Taranaki, Wanganui and Manawatu districts had higher hospital utilisation rates and longer lengths of stay than those in the greater Auckland region. In addition, determinants of length of hospital stay appear to be clinician-driven, rather than patient-morbidity driven (Laing et al., 2004). While Cheung et al. did not discuss the effect of advanced technology on treatment options and transfer to specialist centres, they do predict an overall reduction in hospital utilisation rates due to the introduction of day surgery. In the meantime Clarke (1996) argued that while technological advances have reduced the length of hospital stay, the time that patients stay in hospital varies from country to country irrespective of the technological advances made. For example, she contended that the average length of stay for a patient following cholecystectomy in New Zealand in 1988 is likely to be half that of someone hospitalised in Italy.

Although modern technology has resulted in better surgical techniques, a consequence of this specialisation of services is that more people are required to be transferred to non-local tertiary settings. The usage of advanced technological equipment, and increased specialisation to treat complex medical conditions, has become the norm in the tertiary settings. Therefore, health professionals who see similar cases on a daily basis may overlook the impact on those receiving such treatment. The principle of equal access still forms part of The New Zealand Health Strategies, as it is acknowledged that distance and geographical challenges obstruct easy access to health for rural populations (King, 2002).

1.3.1 The Health Reforms And Access To Health Services.

There is a causal link between socio-economic status, health, and social mobility (Blakely et al., 2002; Cardano, Costa, & Demaria, 2004; Cass, Cunningham, Snelling, & Ayanian, 2003). Poor health is not only a result, it also is a cause of, class location (Cardano et al., 2004). For example, Indigenous Australians make up two per cent of the population of Australia, but 10% of the population receive treatment for end-stage renal disease, while NZ Māori, 15% of the total population, form 32% of the population receiving dialysis treatment (Stewart, McCredie, & McDonald, 2004). The higher incidence of co-morbidities of those

commencing end-stage renal disease treatment reflects the poorer health status of indigenous people (McDonald & Russ, 2003). Overall, the health profile of Aborigines and Māori is poorer, and lower socio-economic status adds to the poor health (Cass, Cunningham, Snelling, Wang, & Hoy, 2003; Cass, Cunningham, Wang, & Hoy, 2001a). Poor health limits the chances of upward social mobility, and often generates an early exit from employment, thus hastening downward mobility (Cardano et al., 2004). Importantly, higher socio-economic status is linked to an individual's ability to access health goods and services (Pearce, Davis, & Sporle, 2002). Opportunities to engage in making lifestyle choices to improve health is directly related to socio-economic status (Contoyannis & Jones, 2004).

In 1998, a five-nation study involving 5000 people identified some issues for delivery of health care within New Zealand (Stuart, 1999). The research, presented at the Australian and New Zealand Health Services Research Conference, concluded that New Zealanders had greater difficulty in accessing health care than those living in Australia, Canada, and the United Kingdom. These difficulties are more apparent in the poorer population, with 31% facing long delays for surgery (Stuart, 1999). Although Stuart's report does not specify the classification of the surgery or whether the delay in consultation with a specialist could be considered reasonable, the report does reinforce the fact that income and access to medical care are intertwined.

Concerns about health and socio-economic status are supported by Blakely et al. (2002) who reported higher mortality rates among the socio-economically deprived from small areas, and Pearce et al. (2002) who contended that 26% of all deaths that occurred in New Zealand males aged between 15-64 years during the years 1995-1997, occurred in those in the lower socio-economic classifications. The incidence of end-stage renal disease is also higher among those of lower economic status (Cass et al., 2001a). What is more, while people may choose to live in rural communities because of family ties and a lower cost of living, access to secondary or tertiary health care services appears to be more difficult (Goodman, Fisher, Stukel, & Chang, 1997). In contrast, whether a patient has cardiac catheterisation (treatment option of choice), or is treated conservatively, is

directly related to geographical location (Fox et al., 2003). Higher morbidity and mortality is correlated with living in rural areas with limited access to health services (Cass, Cunningham, Wang, & Hoy, 2001b).

1.3.2 Focussing The Health Reforms On Individual Needs.

People are transferred to tertiary settings for acute treatment following accidents such as spinal injury, or because they require specialist treatment such as cardiac surgery. In addition, there are six centres that offer radiotherapy for those with cancer. As an example of the numbers transferred for specialist treatment, of the 27,195 residents of the Hawke's Bay region that required hospitalisation in the year ending June 30 1994, 1708 were further transferred to non-local tertiary hospitals. These patients required treatment for cardiology, burns and other tertiary-level services (Central Regional Health Authority, 1996). During 1996-2001 approximately 1000 people were transferred annually (Hawke's Bay District Health Board, 2001). However, as technology improves the number of people requiring transfer increases. It is anticipated that 1.5% of the population that use the regional hospital in 2005 require transfer to tertiary settings (Hawke's Bay District Health Board, 2005).

The need to transfer patients to tertiary centres does not affect the Hawke's Bay region alone. The Auckland District Health Board estimates that 47% of patients using their services are those from areas other than Auckland itself (Auckland District Health Board, 2005). For example, Binning (2004) reported on the story of a teenager from Nelson who is required to travel to Auckland regularly for specialist allergy services. A further report in the New Zealand Herald ("North to South, Patient transfers expensive," 2004) noted that members of the Northland District Health Board expressed concern that, on an annual basis, \$40 million, or 13% of the total budget, is being spent on patient transfers to Auckland.

Other areas also report a correlation between geographical location and transfer for treatment. For example, there is inequitable access to renal transplantation for 48% of the indigenous Australian population who must travel hundreds of kilometres to access treatment for end-stage renal disease (Cass et al., 2003). Furthermore, almost 27% of those referred were less likely to receive a kidney

transplant as they were referred in later stages of the disease (Cass et al., 2002). These claims are supported by McDonald and Russ (2003), who also acknowledge that distance to service and subsequent dislocation from social support and employment, may account for the disproportionate number of Māori and Aboriginal with poor end-stage renal outcomes. In New Zealand, between 1989 and 1999, 182 patients received liver transplants for Hepatitis C-related cirrhosis. Of this number, five were treated in Auckland, the only New Zealand centre that performs this operation (Zelner et al., 2003); the rest were transferred to Australia. Although Auckland did not begin liver transplant surgery until 1998, by 2001 they had performed 87 liver transplants on adults (Johnston, 2001). Johnston went on to report that in 2002 it was anticipated that New Zealand children would also be able to access liver transplant services in Auckland. At the time of the newspaper report, children were required to travel to Australia, where the family may wait for a year before a suitable donor is found, and then for the child to recover from the operation. The Ministry of Health provided an \$180,000 assistance package for a child, including travel and accommodation costs for parental support (Johnston, 2001). While questions about the social cost of the separation on family members during these times remain unanswered, there is financial support for parents accompanying a child out-of-town. In contrast, the guidelines to subsidise the accommodation and travel costs for adults are less well established.

In 2000, the then Health Funding Authority (HFA) drafted a proposal to introduce a national travel and accommodation policy. At the time the HFA noted that individual Regional Health Authorities provided funding to those who needed to travel out-of-town for specialist treatment in an ad hoc way. Eligibility for financial assistance appeared to be based on the Community Services Card¹, distance to service and frequency of travel (Health Funding Authority, 2000a). Despite receiving 346 submissions and meeting with 1000 people (Health Funding Authority, 2000b), the policy was only approved in August 2005, and financial assistance for support persons is provided inconsistently. Figure 1.5 outlines the patient's eligibility for travel assistance, and Figure 1.6 details the

¹ Community Services Card provides those on lower incomes (less than \$32,069.00 for a couple with no children) with cheaper access to medical and pharmaceutical care.

criteria for a support person to accompany the patient. The details in italics and bold highlight aspects for those affected by non-local hospitalisations.

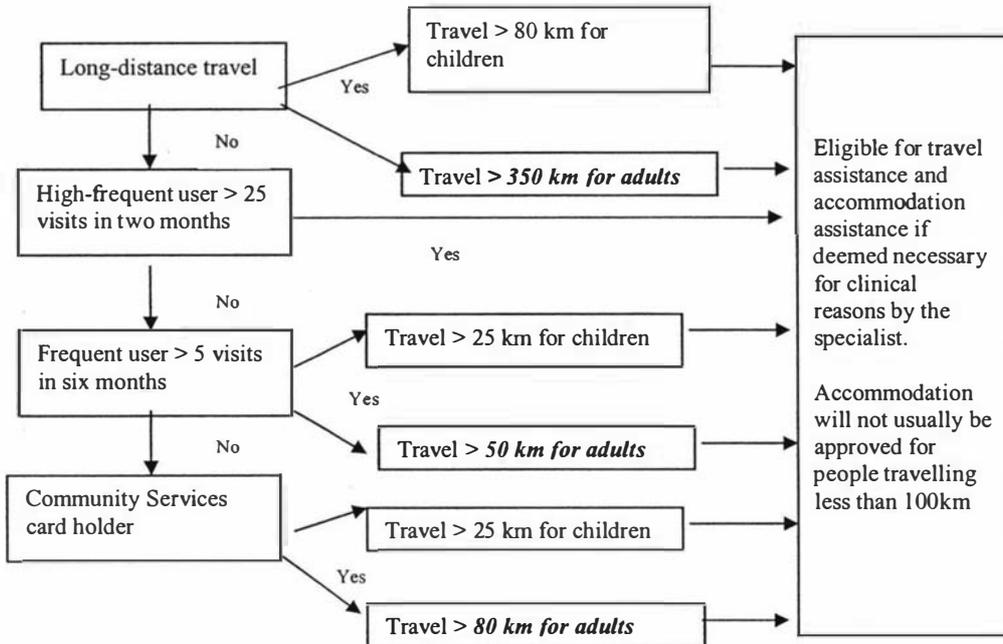


FIGURE 1.5 ELIGIBILITY CRITERIA FOR TRANSPORT AND ACCOMMODATION ASSISTANCE
 Source: Ministry of Health. (2005). *National Travel Assistance Policy*

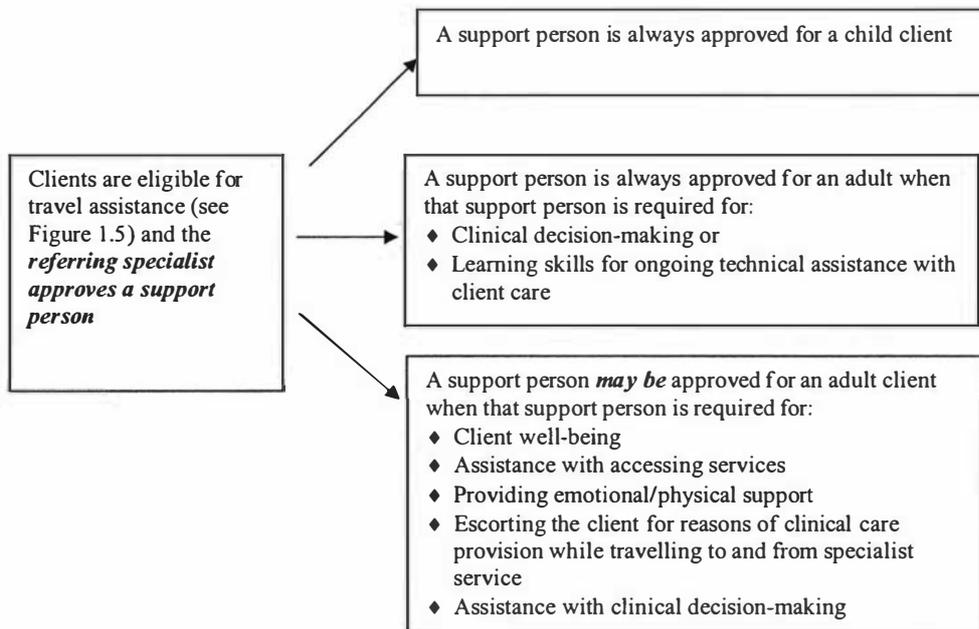


FIGURE 1.6 ELIGIBILITY CRITERIA FOR SUPPORT PERSON ACCOMPANIMENT
 Source: Ministry of Health. (2005). *National Travel Assistance Policy*

The 2005 National Travel Assistance Policy (Ministry of Health, 2005) recommends that the support person for an adult requiring specialist services may be eligible for assistance. The referring specialist must endorse travel assistance for the support person. Anecdotally I have been told of some severely debilitated patients, who do not have a community services card, being told that they will receive reimbursement for a bus ticket to the tertiary centre 400km away. Furthermore, these people do not qualify for financial reimbursement for their support person accompaniment.

In addition to the cost of transport, those who are required to travel out-of-town also need to take sick leave if they are in paid employment. Binning (2004) reports that the Nelson teenager's need to travel to Auckland for specialist services, results in both her and her mother taking a day off school and work for the hour-long appointment.

On the other hand, it is unrealistic to expect specialist services in every regional centre. Nonetheless, does the specialisation of health care mean that more people can expect to be hospitalised in a non-local tertiary setting? What are the experiences of the spouses of these people? Does the cost of providing support to the hospitalised person jeopardise the career of the spouse, thus creating further financial strain, and even poorer access to health? As will be demonstrated in Chapter Two, there appears to be no national or international research that addresses the experiences of those with spouses/partners hospitalised in another setting, hence the need for the current study.

1.4 Research Question And Methodological Approach.

The research question is: what are the experiences of those who have a spouse hospitalised in a non-local tertiary centre? Understanding the experiences of those who have their spouse hospitalised in another city is best explored by the use of phenomenology. Other qualitative methodologies such as grounded theory are based on pragmatic approach to knowledge development, rather than philosophical approaches that explore abstract concepts (Denscombe, 2003). Furthermore while ethnography can be used to search everyday experiences, its aim is to determine a group's culture (Denscombe, 2003). An alternative

approach to understanding the phenomenon would be to use narrative analysis. Although it is reported that narrative analysis is gaining popularity (Kim, 2006), at the commencement of the current study narrative analysis was a research approach for which there was little expertise in the department in which I was enrolled as a doctoral candidate. Furthermore, narrative analysis focuses on the processes involved in producing and analysing the story, not necessarily the story itself. The process of analysis is founded on selection of a theoretical framework, closely aligning itself to discourse analysis (Kim). In contrast, this study does not set out to determine causality or probability of a phenomenon, but rather to enable readers to “understand it from the inside” (van Manen, 1990, p.8); hermeneutic understanding. This understanding involves listening to the stories with an openness that enables us to hear and see things through others’ eyes (Denscombe, 2003). The study into the experiences of having one’s spouse hospitalised in another city is founded on a Heideggerian approach to understanding being, enabling readers of the study to identify with the experiences as the research participants’ stories are revealed.

In the current study, the experiences of 14 partners/spouses of those hospitalised in a non-local tertiary setting are explored. While some may question that this is not a huge number of participants, it is the depth of the analysis of the experiences of having a spouse in the setting that will provide insight for nurses, rather than a superficial breadth of the experiences of many.

Throughout this thesis there is potential confusion in usage of the word, ‘spouse’. Much of the literature used the word spouse in discussion as the supporting spouse, and person requiring hospitalisation as the patient. Other literature specifically differentiates between supporting and sick spouse. In order to avoid confusing readers of this thesis I use the term ‘research participants’ to indicate the supporting spouse in the current study, and the term ‘supporting spouse’ when discussing the literature in conjunction with research findings. Naturally, the term spouse is all encompassing to mean those in a long-term relationship. In addition, throughout this thesis I intermingle the phrases out-of-town and non-local tertiary centre. All references to hospitalisation are those of transfer from one of the cities to one of the five tertiary or specialist centres throughout New Zealand. This

thesis is not about people who live in rural areas, whose spouse is transferred to the nearest base hospital, but about people who are affected by transfer to settings many kilometres from their place of residence.

1.5 Chapter Review And Structure Of The Thesis.

It is apparent that the health reforms have resulted in improved rationalisation of services. In addition, technological innovations now provide greater opportunities for reduction of mortality, although improved diagnostic tools probably have resulted in increased knowledge of morbidity. What is not apparent as a result of the specialisation of services is the effect on those who live in centres that do not offer such specialisations.

Having one's spouse hospitalised in a non-local tertiary setting is a challenging time if both the outcomes and the length of stay in the centre are unpredictable. Those who are required to travel for specialist services are not only challenged to receive treatment in a timely manner, they may also be financially challenged as treatment in the non-local tertiary centre may disrupt continued employment opportunities for both the patient and the supporting relatives. The couples also spend much of their time waiting for the outcome, devoid of normal social support, and unable to visualise the future. However, they are also required to focus on sustaining their own careers, business and family concerns.

The experiences of 14 people are presented throughout the nine chapters of this thesis. In Chapter Two a review of the literature explores the effects of illness and hospitalisation on spouses and family members. Some of the literature explores the effects of specialisation of treatment on individuals, and the effect of hospitalisation on relatives. However, there is a dearth of literature that explores the effects on supporting relatives in out-of-town hospital settings. There are articles that focus on the families' needs when a relative has been hospitalised. Most of this literature focuses on the intensive care or coronary care settings, possibly because of the nature of the illness. Literature that relates to the impact of distance on treatment options is also discussed.

The philosophical underpinnings that guide understanding of the phenomenon of having one's spouse hospitalised in a tertiary centre are presented in Chapter Three.

In Chapter Four readers of the thesis are introduced to the research participants, their spouses, and some of the medical conditions that caused the out-of-town hospitalisation. In addition, ethical considerations, the methods of data collection, and processes used in data analysis are presented.

Overall there are three chapters in which the findings are presented: Chapters Five, Six, and Seven. The findings presented in Chapter Five address the times that the research participants had to wait. The waiting resulted in being-in-suspense as the research participant or spouse waited for a diagnosis; waited for the transfer to the non-local tertiary centre; or waited for the treatment to be effective enough before the spouse could be returned home. In addition to waiting for positive outcomes, the research participants faced times when the spouse might die, resulting in them being-in-suspense-of-death.

In Chapter Six I present the findings of the everydayness of having one's spouse hospitalised in the non-local tertiary setting. Those who accompanied their spouses needed to fill in the long days waiting by the bedside, or entertained themselves alone in the strange environment when their spouses were incapable of participating in conversation or activities of daily living. Other research participants stayed at home, where they struggled to maintain the household and be both mother and father to the children who missed the hospitalised parent.

In Chapter Seven, I present the times when the research participants experienced such isolation from familiarity that they felt alone in the world. In this chapter, the prospects of coping and being-in-the-world are raised. The sense of isolation was exacerbated if there was no interpersonal connection with the health professionals in the out-of-town centre. In Chapter Seven I discuss times when the research participants felt even their spouses added to the sense of isolation in this strange world.

The thesis that emerged from this study is that the supporting spouses lived day by day, with little or no social support, awaiting outcomes over which they had limited control. In living day by day, the supporting spouses coped by focussing on the temporality of the present. These findings are discussed in Chapter Eight. In addition, Heidegger's concepts of care and concern are applied to both the research participants and the health professionals. I make recommendations for health professionals, funding authorities, and nursing education. In addition, I also identify the limitations of the thesis.

In the final chapter of this thesis, Chapter Nine, the research findings and recommendations are summarised.

In presenting this thesis, I have used excerpts from the research participants' stories. At times I have also used excerpts from the research participants' spouse when it added depth to some of the issues under discussion. In order to make use of the excerpts, and to avoid disruption to the words that these people used, I have not included every hesitation or broken sentence. The words describing the experiences are pivotal to understanding the experiences when one's spouse is hospitalised out-of-town, not the hesitations or fillers used in telling the story.

CHAPTER TWO LITERATURE REVIEW.

2.1 Introduction.

As identified in Chapter One, the purpose of the current study is to explore the experiences of those whose spouse is hospitalised in a non-local tertiary centre. There is literature that focuses on the needs of children and their parents when a child is hospitalised in another centre (Long, 1997; Nethercott, 1993; Tan & Simmonds, 1998), but there appears to be less research on the needs of adult patients. There is also literature that refers to some concerns such as the need for information, access to their loved ones and coming to terms with future prospects that families of relatives in critical care settings face, but any additional concerns experienced by those who have a spouse hospitalised in an out-of-town centre remain an area that requires research. What is the effect on the family when one's spouse is hospitalised in a non-local tertiary centre, and how does the supporting spouse maintain a career/paid employment and/or run the household, as well as support the hospitalised partner?

With these questions in mind, literature on the experiences of families of hospitalised adults, those with chronic illness and anticipating the loss of a spouse, or reports exploring the identified needs of rural families were accessed via the Web of Science, ProQuest, Medline, CINAHL, Cochrane, ERIC, and INNZ databases. No time limits were established when accessing the articles, in order to gain access to as broad a range of articles as possible. Searches using terms such as 'distance, families and hospitalisation', 'social support and hospitalisation', 'rural and hospitalisation' and 'acute hospitalisation and social support' yielded mixed results. More success was achieved by including the terms 'spouse and illness'. When the words 'New Zealand' were added to the combinations, several medical articles, and two nursing articles of value were identified. Although no prior study focuses on families' experiences of having an adult partner of the household hospitalised out-of-town, 89 position papers and research articles are included in this literature review. Of those articles 83 were research reports, and the

remaining six position papers or literature review reports; 38 of the research studies were based in America, 14 in Britain, 13 in Scandinavia, 10 in Australasia and the remaining 8 research studies were conducted in other European and Middle Eastern Countries.

Despite the lack of literature that specifically focuses on the experience of those whose spouse has been hospitalised in a non-local tertiary centre, there is value in referring to the literature that addresses family needs during stages of the illness continuum, including hospitalisation, discharge, and facing death. The body of literature around these topics is addressed in this chapter.

The chapter begins with a discussion of the stresses among spouses and families due to hospitalisation during the acute stages of ill-health. Some of the stresses include the families' needs to be with a relative in critical care units (Carr & Clarke, 1997; Mendonca & Warren, 1998; Twibell, 1998), and the need for proximity and involvement in care (Coulter, 1988; Appleyard et al., 2000). In addition to the need for families to be with their sick relatives, some of the literature explores the need for the relatives to maintain personal well-being in a hospital setting. Furthermore, irrespective of the location of the hospitalisation, it is vital that literature that explores the impact of hospitalisation of one member of a family on all family members is critiqued. There is emotional turmoil associated with having a spouse ill enough to require hospitalisation, and rehabilitation (Kosco & Warren, 2000; Mendonca & Warren, 1998; Stewart et al., 2000). Other articles in this review address the stress associated with the burden of care and grief experienced by the spouses and sick partners with life changing or chronic illnesses (Duke, 1998; Kettunen et al., 1999). These articles are included because having an illness that causes hospitalisation in a tertiary centre does not occur in isolation; it occurs on a continuum from wellness to rehabilitation and affects all members of the household. In addition, the literature was explored for articles addressing the influence of distance from a health centre on treatment options. What decisions do couples make when the distance from home to the service is several hundred kilometres? The issues identified in the literature are

critically analysed in the following sections: family needs during the acute stage; impact of the illness on the spouse or family; the balancing act of distance and treatment options.

2.2 Family Needs During The Acute Stage.

Acute critical hospitalisation causes distress and a sense of uncertainty for the relatives (Appleyard et al., 2000; Carr & Clarke, 1997; Daley, 1984; Leske, 1991), with nurses striving to meet the needs of families as well as care for the critically ill patient (Appleyard et al., 2000; Giuliano, Giuliano, Bloniasz, Quirk, & Wood, 2000; Leske, 1991; Medland & Estwing Ferrans, 1998; Mendonca & Warren, 1998; Rukholm et al., 1992). Twenty-five identified articles examined the specific needs of families at this time. The families' needs fell into two categories: the need to be with the ill person, and the personal needs of the supporting relatives.

2.2.1 The Need To Be With And Keep Watch Over The Sick Relative.

Much of the literature argues that when a loved one is hospitalised with sudden illness, family members provide support in the best way possible, by being at the bedside and maintaining watch (Coulter, 1989; Daley, 1984; Plowfield, 1999). Carr and Clarke (1997) who conducted an ethnographic study defined the need to maintain watch as vigilance and propose that vigilance demands the family pay constant attention to the needs of the ill member. In maintaining vigilance, by spending the hours beside the bedside, family members demonstrate a commitment to care (Carr & Clarke), which fosters better experiences of the hospitalisation (Giuliano et al., 2000; Rukholm et al., 1992). Furthermore, vigilance provides family members with a sense of control over the potential illness outcomes (Leske, 1991; Rukholm et al., 1992; Twibell, 1998), and, if possible, protects the patient from harm (Agazio et al., 2003; Carr & Clarke, 1997; Darbyshire, 1994).

In the meantime, nurses frequently overlook the contribution that the patient's family can make toward care (Minicucci, 1998). For example, Appleyard et al. (2000) were surprised that findings of their American research based on an

adaptation of family systems theory revealed that spouses demonstrated a commitment to spend more than 6 hours a day visiting a loved one in a coronary care unit, but do not explore this commitment to care in their study. Maintaining vigilance appears to serve two purposes for the relatives: letting the sick relative know they are there (Plowfield, 1999); and allaying the fear that something will happen whilst they are away from the hospital (Leske, 1991). Both purposes require that there are opportunities for relatives to be physically close to their loved ones.

Proximity and being involved in giving personal care, or assisting in turning the patients, provide the relatives with consolation and assurance that they are contributing to the patient's recovery or comfort were findings from a British grounded theory study conducted by Coulter (1989). Nurses who encourage the families to participate in patient care can also facilitate the families' ability to cope with the crisis (Twibell, 1998). Twibell (1998) used the Jalowiec Coping Scale's scores to measure the effectiveness of specific coping strategies. The value of providing personal care is especially significant if recovery is not likely (Twibell, 1988). This proposal is supported by Appleyard et al. (2000) who argued that families not only find comfort in assisting with the personal care, they also provide a critical link to facilitate an understanding of the patient's needs. In addition to emotionally supporting the relatives, the opportunity to provide personal care assists the relatives in overcoming the fear of the technology that sustains life, and helps the relatives sustain hope (Chartier & Coutu-Wakulczyk, 1989; Coulter, 1989). In order to maintain vigilance and emotional contact, relatives need to have ready access to their sick relative (Appleyard et al., 2000; Leske, 1991; Plowfield, 1999).

Although nurses appear to acknowledge the family role in maintaining vigilance, in much of the literature (Carr & Clarke, 1997; Leske, 1991; Minicucci, 1998; Plowfield, 1999) family members are at the mercy of the nurses to determine whether the family has the right to visit or to have information. For example the nurses bend the visiting policy rules, and senior nurses recognise that the relatives' need to visit at any time is not always met

(Kosco & Warren, 2000). Other literature reports that nurses do not trust family members to visit in such a way that the visit will not be detrimental to the patient's health (Clarke, 2000; Leske, 1991; Plowfield, 1999). Nurses describe this detrimental visiting as wanting to sit by the patient, thus preventing the patient from sleeping. If relatives are reliant on permission from the health professionals to visit their loved one, what happens to those who are from out of town and have few other activities to engage in during the day, or have to drive for a long time to see their sick loved one? Plowfield (1999) reported that one family received permission to visit, drove for two hours only to be turned away at the door.

Relatives are not only at the nurses' mercy to determine whether they are able to visit, but nurses often determine the length of time that the family are able to stay in critical care units. Thus family members view visiting privileges as an indication of the prognosis (Plowfield, 1999). These findings emerged from Plowfield's phenomenological study based in USA. In contrast, Merz (1998) proposed in a position paper that allowing spouses some control over visiting hours and the hospital room environment gives family members a sense of control over the well-being of their sick relatives at a time when they feel powerless to manage their loved one's ill-health.

Not only do nurses alter the visiting hours, they also regulate them to meet nursing needs, such as restricting visiting rights during the hour-long change of shift discussions (Giuliano et al., 2000), who used the Juran model to initiate a quality improvement programme in an American hospital.

Anecdotally, restriction to the length of time that a person may visit occurs in New Zealand hospital departments as well, including preventing visitations during change-over of shifts. Those staying at the non-local tertiary centre will need to find activities other than being by the bedside during that hour-long period of time. Others, who may have driven some distance to see their relatives, could find that their time with the relative is limited if they arrive during nurses' change-over times. Families who have driven to a non-local tertiary centre need to see the sick relative to determine for themselves the

patient's progress, and may perceive such visiting restrictions focus on the nurses' needs rather than on patients' needs. If relatives cannot visit the patient they need progress reports from the nursing staff.

Families argue that the receipt of progress reports assists them to come to terms with the severity of the illness, and provides them with the opportunity to gain a sense of control over the situation (Fareed, 1996; Mellon & Northouse, 2001). These findings are supported by other researchers (Coulter, 1989; Daley, 1984; Leske, 1991; Medland & Estwing Ferrans, 1998), who claimed that the families' need for progress information is most important of all needs when their relative is acutely ill. Relatives also measure nurses' competency by critiquing the nurse's interpersonal skills (Fosbinder, 1994). Supporting spouses, who have limited contact with the nursing staff or who can not get information from the nursing staff, feel that the spouse is being neglected, and that the health professionals are not interested in the family unit (Kettunen et al., 1999; Rantanen, Kaunonen, Åstedt-Kurki, & Tarkka, 2004).

Nurses, however, view relatives' need for such information from nurses as disruptive to the provision of care (Medland & Estwing Ferrans, 1998). Nurses wishing to concentrate on caring for the sick patient rather than the entire family, and who find attending to relatives' needs disruptive, have developed strategies to restrict the number of enquiries about the relatives' well-being (Appleyard et al., 2000; Medland & Estwing Ferrans, 1998). Such strategies include having lay people available to wait with the family during times of visiting, and structured times for family members to have telephone contact with critical care units, thus strengthening relatives' trust in the health professionals during the critical incidents.

The families trust health professionals to look after their sick relative in the hope of them receiving the best care. Relatives gain this confidence and trust in the staff during the time of maintaining watch as the health professionals care for the sick relative, and the family wait for positive outcomes (Carr & Clarke, 1997). Results of the literature reviews conducted by Hickey (1990)

and Minicucci (1998) found that relatives rate reassurance that the patient is receiving the best possible care as one of the most important factors in reducing stress at this time. In fact, families argued that their need for assurances of receiving the best possible care as most important in the initial 72-hour period of acute crisis (Daley, 1984). Other research confirms that family members want to know the relative is receiving the best care possible and express gratefulness that the relative is in expert hands (Plowfield, 1999; Rukholm et al., 1992; Twibell, 1998). In addition, in spite of their patient being transferred from regional hospitals, which resulted in long distance travel to support them, relatives in Plowfield's study put faith in the advanced institution. Plowfield (1999) did not identify whether this group of people, some of whom she identified as over four hours drive away from home, had any specific needs. The social cost to family members of ensuring that their relatives received the best possible care were not clearly articulated. Furthermore, none of these writers discussed the emotional strain facing couples that may be affected by non-local tertiary hospitalisation.

2.2.2 Personal Needs Of The Family.

Families put aside their own needs in order to spend as much time with their relative (Coulter, 1989; Daley, 1984). In fact, relatives identified their personal needs as least important of all the needs to be met during the time of hospitalisation of a family member in a critical care unit (Daley, 1984). However, because Daley's American exploratory research focussed on the perceived needs of the family during the first 72 hours of a crisis situation, their personal needs may be discounted at this time. In contrast to her findings, parents who accompany their children to tertiary centres complained that the long hours spent at the child's bedside and difficulty engaging in activities to meet their own needs, such as accessing the cafeteria facilities, added to their stress of having a child hospitalised (Agazio et al., 2003; Tan & Simmonds, 1998). Research by Carr and Clarke (1997) to explore the perceptions of daily living of those staying with hospitalised relatives revealed that relatives demonstrated an ability to care for themselves, and asked little of the hospital and staff to assist with their own needs of rest and respite from

maintaining a personal watch. While Carr and Clarke (1997) acknowledged that some participants in their research were from out-of-town, the only specifically identified need of this population group was recognition that there is need for a separate space to accommodate those maintaining vigilance.

Many other research studies do identify family members' needs during the time that a relative is critically ill. For example, Daley (1984) and Coulter (1989) undertook research to determine the perceived immediate needs of families in intensive care settings. They both reported that families had strong needs for close proximity, information and social support. Findings from an exploratory study conducted in America by Mendonca and Warren (1998) found that family members ranked assurance, proximity, and information as the most important factors during the period after admission; findings supported by other researchers (Plowfield, 1999; Twibell, 1998; Carr & Clarke, 1997; Leske, 1991). The development and implementation of strategies that would address the need for close proximity and information formed the basis of a quality improvement programme initiated by Giuliano et al. (2000). Families also require access to resources such as a telephone and a waiting room in close proximity to hospital units (Hickey, 1990). Coulter (1989) recommended that providing information about accommodation and meals, included in an information book given out on admission, would make the family feel welcomed. However, is it merely information about accommodation that an accompanying spouse needs at this time?

Any opportunities that relatives have had to discuss their personal needs are not included in the literature. For example, researchers such as Mendonca and Warren (1998), Kosco and Warren (2000), and Leske (1991) used the Critical Care Family Needs Inventory (CCFNI) initially developed by Molter (1979) and modified by Leske to determine their findings. The inventory contains 45 family needs statements that are grouped into categories including the need for assurance, proximity, and information (Leske, 1991). Mendonca and Warren (1998) added categories of support and comfort into their discussion. The CCFNI ranks each need on a Likert scale. While there may be benefit in using

such an inventory, it is important to recognise that the questionnaire contains pre-determined criteria of needs identified by nurses. This is particularly significant if the inventory is used when the family member is transferred to a non-local tertiary setting; a setting that is everyday for the nurses. Nurses working in such tertiary settings may not identify accommodation, nutritional, or respite needs for example, and therefore may not provide relatives with the opportunity to comment on their satisfaction of such needs. There do not appear to be inventories developed by relatives, and therefore, any conclusions based on findings that use nurse-oriented inventories would have limited application to addressing family needs in similar situations.

So far, in this literature review, discussions about the physical resources have been centred in acute care settings. This limits understanding of the experiences when one's spouse is hospitalised out-of-town in relation to three aspects. First of all, if the patients are acutely ill during this time, the family's needs could be rated as low priority. As identified, any individual needs of the family of the acutely ill do not receive high priority in the literature. The second aspect that limits understanding is that in most intensive care settings there is some sort of family room, which can cater for relatives short-term. However, the family rooms are traditionally reserved for those whose loved one is dying in the critical care unit, and unlike the relatives in Plowfield's (1999) research who slept in the room beside the patient, tertiary hospitals in New Zealand are unable to accommodate relatives of adult patients in such a manner. Can families who are from out-of-town use the family room attached to the critical care unit if their loved one is not dying? Leske (1991) reported that families who maintain watch over their loved ones expressed concern that they were 'camping' in the waiting room in their desire to be as close as possible to their loved ones. Do those who are from out-of-town express the same sentiments?

The third problematic aspect of the research that focuses on the intensive care setting is that the sick relative may be in the unit for a short period of time. Most families have social support if the sick relative is in critical care units for

a short period of time, especially if that unit is in the local setting. But what need for social support occurs once the acute phase is over? The social support provided by the family has been identified as pivotal to the well-being of the ill patient (Carr & Clarke, 1997; Daley, 1984; Leske, 1991; Stewart et al., 2000). However, what is the situation if the supporting spouse is providing vigilance at the bedside in a strange city? Where does this spouse draw personal social support from in this instance as they maintain vigilance over their sick partner? These questions have not been addressed in the literature.

2.3 Impact Of The Illness On The Spouse/Family.

Spouses of hospitalised patients face the possible loss of partner, prolonged or poor recovery, and changes to career and social activities (Miller & Wikoff, 1989; Thompson & Cordle, 1988), and the fear of potential death drives the need to maintain vigilance. While the perceived needs of the family and the role health professionals play in meeting those needs have been explored in the previous section, the impact of an illness that could lead to non-local tertiary hospitalisation needs to be explored.

A critique of forty additional articles has been included in this section, as well as inclusion of some key aspects of previously discussed articles. The additional articles were selected because of specific reference to the spouse's role in recovery, grief through loss of a spouse or loss of life as it was, and coping with chronicity. Four aspects emerged from the articles: emotional turmoil associated with the illness; the spouses' involvement in rehabilitative processes; a burden of care; and anticipatory grief. The emotional turmoil itself impacts on the family in two stages, during the diagnostic/ pre-treatment stages, and secondly during the times that the families come to terms with life-changing decisions and possible chronicity.

2.3.1 Emotional Turmoil.

During times of critical illness, families face uncertainty over the medical outcome, fear of death, financial stress and turmoil over being in an unfamiliar

environment (Maughan, Heyman, & Matthews, 2002; Stewart et al., 2000). In addition, as Leske (2000) pointed out, in instances of acute illness there is little time for the family to prepare for the experience of waiting during a critical illness. This is supported by other literature (Forsberg-Wärleby, Möller, & Blomstrand, 2002; Kettunen et al., 1999; Thompson & Cordle, 1988) in which the impact of the emotional turmoil that spouses reported they lived through was related to the degree of warning that they had of myocardial infarction or cerebral vascular accident. Kettunen et al. (1999) concluded from their study based in Finland that the spouse's fears could be overwhelming at times of acute illness, affecting the patient's potential for recovery. Thompson and Cordle (1988) discovered through their descriptive study based in Britain that the wives of those who had myocardial infarctions all reported high levels of anxiety and distress at the future prospects and necessary lifestyle changes because the wives felt they had limited opportunities to ask questions.

Unfortunately, a theme in many articles is that spouses' or family members' fears are not recognised during this critical stage (Daley, 1984; Leske, 1991; Stewart et al., 2000; Twibell, 1998). For example, Daley (1984) found that despite good intentions, hospital staff members direct attention to the life of the patient and often forget family members. While Daley's findings are dated, they are supported by more recent literature (Kosco & Warren, 2000; Mendonca & Warren, 1998; Moszczyński & Haney, 2002). Findings from a Canadian-based thematic analysis conducted by Moszczyński & Haney (2002) found that rural nurses, who transfer critically ill patients to a larger centre, reported feeling guilty that the patient acuity meant that the nurses could not both treat the patient and address the concerns that family members had at the same time. In addition, the possibilities for nurses to care for the family unit are diminishing as a result of a reduction of resources, increased specialisation (Kettunen, et al. 1999), and overwhelming workloads (Strandberg, Åström, & Norberg, 2002).

Couples waiting for treatment are also fearful and anxious during the waiting time (Jónsdóttir & Baldursdóttir, 1998; Koivula, Tarkka, Tarkka, Laippala, & Paunonen-Ilmonen, 2002; Merz, 1998). Those waiting for coronary artery bypass grafts (CABG) report that having coronary artery disease not only has a negative effect on their personal lives but also the daily lives of their families (Jónsdóttir & Baldursdóttir). In this quantitative study, the mean waiting time was reported to be five to six months, and over 50% of the population on the waiting list were required to travel out of town for the surgical treatment that is performed in only one centre in Iceland. It is implied throughout their research report that the transfer out of town is accepted, and anticipated to cause less stress than previous treatment options of being sent to Great Britain.

Patients waiting for CABG surgery also face intense fear while still at home (Koivula et al., 2002). The source of patients' anticipatory fear was a deterioration of health and dependency on others for care. Furthermore, the postponement of heart surgery adds to hospital expenses and has long-term effects on those awaiting the surgery (Jónsdóttir & Baldursdóttir, 1998). Spouses of 45% of those requiring coronary bypass surgery in New Zealand report acute anxiety and ill health (Mulgan & Logan, 1990). Fear of deteriorating health is not exclusively related to waiting for coronary surgery. Although Connolly et al. (2002) did not identify the source of fear, they acknowledged that while the New Zealand treatment options of pre-operative radiation was effective in reducing the size of a colorectal tumour, the three to four month delay in surgery exacerbated the psychological distress. This causes me to question whether the transfer to a non-local tertiary centre may not cause a quandary if the spouse's illness is so severe that it requires treatment that is only available in such tertiary centres. Would having treatment in a non-local tertiary centre be more important than having the spouse receive quality social support in the local hospital, but not have access to specialised treatment? Alternatively, does social support for the spouse and the sick partner minimise the fear of the unknown?

Fear of unknown outcomes is another common theme in the literature as the impact of the illness on the family causes supporting spouses to re-evaluate their future as a couple (Hanger, Walker, Paterson, McBride, & Sainsbury, 1998; Kettunen et al., 1999; Maughan et al., 2002; Merz, 1998; Stewart et al., 2000). Supporting spouses with perceptions that the illness will have negative outcomes, and an extreme fear of death, can have detrimental effects on the health of sick spouses according to Figueiras and Weinman (2003) who conducted a quantitative study with Portuguese couples. These fears can be exacerbated if nurses fail to prepare family members for the fact that their acutely ill loved one is unconscious (Rukholm et al., 1992), or the supporting spouses feel uncertain of their role as future caregivers (Forsberg-Wärleby et al., 2002; Strandberg et al., 2002). Maughan et al. (2002), in conducting their British-based research on the impact on women of gynaecological problems, found that the men reported that they were excluded during the diagnostic processes, and thus their fear of the unknown was not addressed. The uncertainty associated with waiting for transplant surgery can lead to both the patients and their spouses sensing a loss of control (Merz, 1998). Merz proposed that the supporting spouses of those awaiting transplant surgery require focussed nursing care to ensure that they are provided with strategies to cope with the associated stress of supporting a sick spouse. According to Kettunen et al. (1999) the severity of illness, in the case of their research a myocardial infarction, does not determine the degree to which supporting spouses experience the emotional turmoil. They contended that the spouse's fears are difficult to predict and relate to the spouse's personality and previous experience of disease as well as the health professionals' reaction to the patient's illness.

Nurses' therapeutic interventions influence the family's ability to cope during critical incidents (Noyes, 1999), a process that Minicucci (1998) described as facilitating nursing presence. Presence involves nursing the patient group, rather than focussing only on the sick individual (Minicucci, 1998). Ironically however, although Minicucci suggests that nurses need to be active in facilitating presence and utilising relatives in a care partnership, literature

identifies that nurses avoid spending time with family for fear of seeming intrusive (Kettunen et al., 1999; Rantanen et al., 2004). Certainly patients in Britain identify that knowing that nurses were accessible, and a sense of 'being with' them added to assurance that they were being cared for were findings from a phenomenological study conducted by Fareed (1996). Providing information and emotional support, and being competent are the most effective nursing interventions to facilitate coping (Koller, 1991). The role nurses play in facilitating coping is a focus of quantitative research undertaken by Rukholm et al. (1992) who claimed that nurses can use their presence to care for families coping with unexpected crises by familiarising the relatives with the physical environment and give reassurance that nursing care needs are being met. Nurses can also assist relatives cope with critical incidences by encouraging them to generate a sense of hope and address each issue as it arises, rather than try and foresee the future (Cutcliffe, 1996; Hunsucker, Flannery, & Frank, 2000; Koller, 1991). These suggestions are supported by Twibell's (1998) research which confirmed that the most positive coping strategies that family members can use during times of critical incidences are problem-solving coping responses, and maintaining a positive outlook. Twibell (1998) argued that negative coping strategies, such as a fatalistic outlook on the patient's prognosis, are detrimental to the patient. It is interesting to note that Twibell's comparative research especially focussed on the perceptions of the nurse to determine how families ought to cope, and minimise any ineffective coping factors that the nurses believe will be harmful to the patient's well-being.

Other researchers (Clark, 2002; Leske, 2003; Northouse et al., 2003) used a family hardiness index to measure the degree of coping that caregivers use during time of caring for functionally impaired family members. The family hardiness index uses a 20-item Likert instrument with four subscales to determine commitment, confidence, challenge, and degree of control that family members demonstrate during time of distress (Mellon & Northouse, 2001). Reference to it has been included in this literature review because of the correlation between hardiness and coping strategies. Family support

enhances family hardiness, which in turn has a positive effect on quality of life (Northouse et al., 2003). Researchers who explore coping strategies and family hardiness tend to argue that emotion-focussed strategies are connected with poor adjustment while usage of problem-solving strategies demonstrates high levels of adjustment during crisis situations (Dewar & Morse, 1995). However, coping and problem-solving strategies can only be internalised if the outcome can be predicted.

Although nobody is able to predict an outcome with absolute certainty, experienced nurses are in a privileged position in being able to assist families come to terms with the sick relative's condition and the future prospects (Carr & Clarke, 1997; Nolan & Nolan, 1998; Thompson & Cordle, 1988). For example, Carr and Clarke (1997) described the process of nurses encouraging a husband, whose wife had a poor prognosis, to go home for short periods of time in order to gradually become used to the future prospect of an empty house.

In order to overcome the period of transition from wellness to chronic illness or even death, family members need to develop a visitation schedule, return to work, and attend to their own personal needs (Leske, 1991). Other researchers, such as Plowfield (1999), suggested that not all families should spend the long hours waiting at the hospital; they could be kept busy at home. This busyness means the families can control the stress with greater ease. While these strategies assist the supporting spouse to return to some sense of normality, they are not realistic for those who have accompanied their spouse to a non-local tertiary setting. Do families whose sick relative has been transferred to a bigger centre keep busy at home? It would seem that returning to work and maintaining a visitation schedule would be difficult if the family home is some 300 km away, and the daily process of vigilance becomes lonely if other family members have had to return home, leaving the spouse to contemplate the future prospects alone in the non-local tertiary centre.

2.3.2 Spouses' Involvement In Rehabilitation.

Most articles on the families' responses to illness (Keizer, 1992; Kettunen et al., 1999; Minicucci, 1998) contend that nurses need to be active in including the family during both the acute phase of illness and the rehabilitation process. Failure to involve supporting spouses in rehabilitation programmes result in these spouses not adjusting to the change in lifestyle or supporting compliance with treatment were findings that emerged from a study undertaken by Miller & Wikoff (1989). Stewart et al. (2000) concluded from their research that reliable information about rehabilitative processes was identified as the main strategy that wives used to cope with their husband's myocardial infarction.

How that information is provided also influences how effective the supportive processes are for the spouse of one who is hospitalised. Medland and Estwing Ferrans (1998) conducted research to test whether a structured communication programme for family members would increase family members' satisfaction with care and improve meeting their needs for communication. These researchers conducted a quasi-experimental study with 15 family members in each of the control and experimental groups. A structured communication programme was offered to the members of the experimental group. The programme consisted of a discussion with the nurse 24 hours post admission, an information pamphlet, and a daily telephone call from the nurse caring for the patient. Those that received the structured communication programme made less incoming calls to the unit, and expressed satisfaction with the care the family member received. Less experienced nurses find it difficult to keep the family informed, as their energies are concentrated on caring for the critically ill person, rather than extending their care to incorporate the family (Kosco & Warren, 2000). Anecdotally this tension becomes more apparent as there is pressure to reduce the length of hospital stay.

Length of patient stay is one measurement of resource utilisation that demonstrates service effectiveness and efficiency (Poutasi, 2000). Therefore, one advantage of innovations of colorectal surgery in New Zealand is that patients are discharged one to two days post-operatively (Connolly et al.,

2002). Furthermore, innovations in heart valve surgery have decreased the post-operative patient acuity. In New Zealand the average length of stay in the critical care units following cardiac bypass graft surgery is only four days (McKay, Bunton, Galvin, Shaw, & Singh, 2002). However, the average length of hospital stay from diagnosis until discharge is 30 days (McKay et al., 2002); potentially a long time for those who, unless they are residents of the two centres that offer cardiothoracic surgery, would be required to travel out-of-town. Ironically, none of these research articles identified the social cost to families during the time of hospitalisation and rehabilitation.

Patients also wish to be actively involved in rehabilitation. For example, while an understanding of the individual's perspective of rehabilitation is essential, little qualitative research addresses this, and this lack of research results in poor understanding of the rehabilitative process (Griffiths & Jordan, 1998; Nolan & Nolan, 1998). Griffiths and Jordan (1998) concluded from their grounded theory study based in Britain that when patients suffer acute lower limb trauma they feel a sense of uncertainty that persists throughout the recovery in both the hospital and home. To compensate for this, patients tended to overestimate their ability or under-estimate the pain they actually experienced (Griffiths & Jordan, 1998). The reason the patient's perspective is included in this discussion is because of speculation about whether those who are hospitalised in non-local tertiary settings face both external and internal pressure to rehabilitate more quickly in order to go home.

Patients also over-estimate their ability to manage once they are discharged from a hospital setting (Clark, Steinberg, & Bischoff, 1997). Patients within the age-range of 60-86 years and with a variety of medical diagnoses took part in this Australian research undertaken by Clark et al. The majority of the patients identified that they did not cope as well as they had anticipated on discharge. Of greater concern is the fact that nearly half the patients reported deterioration in their health status and over half required readmission to hospital within three months. In addition the patient's carer rated the patient as requiring considerable assistance to maintain activities of daily living

(Clark et al., 1997). This leads to speculation that patients minimise their illness as they attempt to preserve self-image and locus of control (Nolan & Nolan, 1998). The need to maintain locus of control when dealing with personal illness is supported by Polaschek (2003) who found that New Zealand men on home dialysis adjusted their lives to accommodate dialysis treatment and retain control of their weekly schedule. These men also identified and managed their own ideal weight levels, diet, treatment regimes and on occasion, their medication in order to retain locus of control (Polaschek, 2003).

As noted previously, fear of dependency is reported to affect the patient's health (Koivula et al., 2002). This fear of dependency on care is supported by research conducted by Strandberg, Norberg, and Jansson (2001), who used hermeneutic phenomenology to determine the experiences of a patient who was dependent on others to meet personal care. In this instance, the researchers found it was a fine balance to differentiate between being dependent on care and becoming dependent on the caregivers themselves. This struggle is supported by research conducted by Strandberg et al. (2002) which concluded that nurses rely on the patient to request care, while the patient is reluctant to request assistance for fear of being a nuisance. Ironically Strandberg et al. (2002) report that the nursing staff did not view the role of the patient's wife in providing care as significant. Therefore, the need of the patient's wife to have social support is not recognised.

2.3.3 Social Support For The Family.

The social support provided by family members is vital to successful rehabilitation (Kettunen et al., 1999; Rantanen et al., 2004; Stewart et al., 2000). Baider et al. (2004) claimed that patients appraise their perception of family support on how well their partners participated in their rehabilitation. As the patients were more likely to identify that their social support comes from their spouse, health professionals need to ensure that the spouse is able to cope in this supportive role (Rantanen et al., 2004). Turton (1998) determined the relevance of the information provided during post-myocardial

rehabilitation. The spouses of post-myocardial patients, who took part in this British quasi-experimental study, expressed greater need for education as they adopted the role of provider of social support. The supporting spouse's level of anxiety expressed during the immediate post-myocardial infarction period (Turton, 1998) increased the need to maintain vigilance, which can result in the patient feeling stifled (Stewart et al., 2000). Social support for the family is also crucial for the spouses who spend energy in supporting the sick spouse (Rantanen et al., 2004).

Supporting spouses also assume responsibility to oversee patients' compliance with the taking of medication, and to follow modified diet and exercise regimes (Miller & Wikoff, 1989). The nature of supporting spouses' educative needs change with time, and these spouses require more in-depth education about mortality and morbidity two years after their partner's stroke than at the time of stroke (Hanger et al., 1998). However, informing the supporting spouses and relieving their anxiety by providing education programmes can only be possible if the spouses have on-going access to the providers of such information. Despite the fact that all supporting spouses received both written and verbal reports from nurses on several occasions, supporting spouses report a lack of understanding and consequent anxiety about management of the patient at home (Thompson & Cordle, 1988).

It is also important to consider the assistance provided to supporting spouses during the early period after discharge. For example, a questionnaire developed by Thompson and Cordle (1988) was used to research the support given to the wives of patients who suffered a myocardial infarction. According to these British researchers, the wives reported that during their husband's illness the major source of support came from relatives or friends. What is of concern is that nearly a quarter of the respondents in this research claimed that their support needs, in the form of advice from health professionals, or the opportunity to ask questions during the early stages of rehabilitation, had not been met (Thompson & Cordle, 1988). Miller and Wikoff (1989), who contended that health professionals provide little

supportive information to the spouses of those admitted with cardiomyopathy, confirm Thompson and Cordle's findings. Miller and Wikoff found that supporting spouses' needs included being informed of changes to be expected discharge. This is especially pertinent if the family have limited opportunity to access on-going professional advice.

Houstra and Mallon (1999) conducted a comparative study on those from rural Canadian areas compromised by spinal cord injury. They found that the transition from hospital to rural communities led to isolation and both patients and their families reported feeling overwhelmed (Houstra & Mallon, 1999). The research centre serviced a large rural population where distance from the centre resulted in difficulties in travelling to support group meetings. These authors suggest that technological advances in telecommunications could be used to enhance patient rehabilitation and promote group support during the early discharge period. To support this, they conducted a descriptive study to evaluate a programme designed to reach rural patients and their families after discharge. The researchers concluded that the teleconference support group did assist to manage the isolation and enormity of rehabilitative care.

2.3.4 Does social support become a burden of care?

In the stages of rehabilitation both the supporting and sick spouses need to adjust to the effect of the illness on their personal activities of daily living and life satisfaction (Blake, Lincoln, & Clarke, 2003; Broström, Strömberg, Dahlström, & Fridlund, 2003; Forsberg-Wärleby et al., 2002). It is during this time that supporting spouses once again face fear of an unknown future (Forsberg-Wärleby et al., 2002), exhaustion from maintaining watch (Broström et al., 2003; Schulz & Beach, 2000), and possibly social distress (DiBartolo & Soeken, 2003). The supporting spouse's ability to cope with a patient following Cerebral Vascular Accident (CVA) is dependent on both internal and external resources available to them (Forsberg-Wärleby et al., 2002). The internal resources are linked to the degree of disability and sensorimotor impairment or dysphasia. The degree of disability is also identified as a key factor in coping with the spouses suffering from congestive

heart failure (Broström et al., 2003), and myocardial infarction (Figueiras & Weinman, 2003). In their descriptive study, Swedish researchers Broström et al. found that the supporting spouses reported feelings of being left to cope alone, and difficulty in getting other members of the family to understand their levels of fear and anxiety. In addition, as Hunsucker, Frank, and Flannery (1999) pointed out, the uniqueness of a rural community and resultant cultural needs of various geographical populations does not change when patients are transferred to specialised metropolitan areas. The recommendations from their quantitative study are that nurses recognise and alter their nursing care to accommodate those needs. Simple strategies such as accommodating late visiting, or enabling the pastor from the home church admission to the unit with the family would ensure that cultural needs of these patients is included into the plan of care (Hunsucker et al., 1999).

Those with supportive social support networks report a higher degree of self-perceived coping and hardiness in caring for persons with dementia (DiBartolo & Soeken, 2003). Although patients may not need transfer to non-local tertiary hospitals for management of strokes, congestive heart failure or dementia, it is likely that a patient with one of these conditions would be treated at a regional centre before being discharged home. Certainly McNaughton, Weatherall, McPherson, Taylor, and Harwood (2002) found that it is more likely that Māori patients with CVA are likely to be transferred to inpatient rehabilitation, but less likely to be discharged to institutionalised care. What link to health professionals and support services do the spouses of these patients have?

A high proportion of those whose spouses had survived a myocardial infarction report feeling anxious, depressed and have trouble sleeping for the immediate period of time after the event (Kettunen et al., 1999; Thompson & Cordle, 1988). Providing long-term caregiving may require the caregiver to change sleeping arrangements (Broström et al., 2003) or result in changes to social lives and social support (Colvez, Joël, Ponton-Sanchez, & Royer, 2002; Thomas et al., 2004). As the patient becomes more debilitated, the spouses

move from the role of spouse to that of caregiver (DiBartolo & Soeken, 2003; Thomas et al., 2004), leading to the relationship becoming a burden of care (Ekelund, Westman, & Andersson, 2004). However, the changed roles are learned. For example, Strandberg et al. (2002) reported that although the patient himself had a 30 year history of a degenerative disease, with the probable outcome of needing residential care, his tired, distressed wife “has not learned to be in this situation when her husband is ill...She has reflected on her situation as a relative and asked herself how much strength she has” (p. 48-49). While Strandberg et al. (2002) note that it is a learned behaviour, they do not discuss how spouses of the chronically ill learn the changed role. Speculations are that the role is individualised, and the role changes over time with increased disability. However, nurses could support spouses by preparing them for the anticipated grief associated with the changed role.

2.3.5 Actual And Anticipatory Grief.

If one’s spouse is ill enough to warrant out-of-town hospitalisation, the family could also be facing the possibility of the sick spouse dying. Hainsworth (1998) and Duke (1998) both explored the relatives’ feelings of coping with anticipatory grief when visiting loved ones that had poor prospects of recovery. Furthermore, the loss of a spouse also means the loss of a social role as husband or wife (Waskowic & Chartier, 2003). This loss of social role requires adjustment. It is important to remember that grief is not necessarily associated with death of the spouse. As the spouse’s role changes, caregiver role strain causes pre-bereavement anxiety and depression (Bernard & Guarnaccia, 2003). Spouses of those with chronic mental illness report a sense of emotional loss as they adjust to death of the relationship that was (Hainsworth, Busch, Eakes, & Burke, 1995). Families of the neurologically impaired report a lack of personal connection with the nursing staff, as the physical presence of nursing staff and hospital surroundings provide a constant reminder to family members of the tragic circumstances (Hainsworth, 1998).

In New Zealand, intermittent respite care is available to relieve those who are caring for debilitated elderly at home. Gilmour (2002) found from her New Zealand study that those who utilise respite systems experience senses of guilt that they are unable to cope, and ambivalence that the caregiving staff may not maintain the same level of care that the family have been providing. Those living in rural centres have additional challenges in order to access respite care. Wilkes, White, and O'Riordan (2000) determined through a cross-sectional research conducted in Australia that the support requirements of families providing palliative care and found that the majority of rural women who support a sick relative were not in full-time paid employment. These women had to give up work or take long service leave in order to provide care to their sick relative. A lack of access to respite care emphasises the distance from service and limited treatment options.

2.4 The Balancing Act Of Distance And Treatment Options.

Location and distance from services influence treatment options. For example, geographical location determines whether rural women with osteoporosis participate in formal exercise programmes to preserve bone integrity (Roberto & Reynolds, 2001). The articles reviewed in this section were selected because of the effect that distance from regional centres seems to have on treatment choices.

Davis, Girgis, Williams, and Beeney (1998) used telephone surveys to assess the needs of rural Australian women travelling distances for treatment of breast cancer. They suggested that rural women are significantly more likely to undergo mastectomy than have breast-conserving therapy. The higher usage of the mastectomy treatment option is directly related to the increased burden placed on rural women and their families undergoing breast-conserving treatment options if they have to travel to urban centres for adjuvant therapy (Davis et al., 1998). The majority of women in this study spent an average of over six weeks away from home causing disruptions to family life and work. In addition, the majority of women participating in their study reported problems with a lack of social support and limited assistance

with their travel and accommodation needs. Women with breast cancer who are required to travel for treatment express concern about the effect of the absences on their children and doubts about their partner's ability to cope during those absences (McGrath et al., 1999). McGrath et al. used a thematic analysis to determine the needs of these rural Australian women. Strickland and Strickland (1995) found from their content analysis research that poor American minority groups prefer to treat themselves at home, rather than face travel to health services.

It is interesting to note however, that as medical technology increases, the likelihood of out of town transfer increases. For example, Frizelle, Emanuel, Keating, and Dobbs (2002) proposed that surgeons who specialise in the larger New Zealand centres prefer to perform colo-anal anastomosis, rather than traditional abdomino-perineal resection undertaken by general surgeons. Further specialisation of colorectal cancers has resulted in the surgical technique of utilising a specialised operating sigmoidoscope that enables laproscopic excision of rectal cancers (Connolly et al., 2002); a procedure only available in specialised units. As noted previously, the majority of those that require valve replacement in the South Island of New Zealand are treated in two cardiothoracic units (McKay et al., 2002); more complicated surgery requires transfer to Auckland.

Transfer for specialised medical care is relatively common in New Zealand, especially for children (Tan & Simmonds, 1998). However, the desire to have the best treatment available needs to be balanced with concerns about distance from the treatment areas (Magilvy & Congdon, 2000; Weeks, O'Rourke, Ryder, & Straw, 2002). While the New Zealand Ministry of Health Travel and Accommodation policies provide assistance if a child is admitted to a regional hospital for treatment, there is little, if any, recognition of the emotional and social costs to the parents of these children, and of forced separation of parents during the time of crisis with a sick child (Tan & Simmonds, 1998).

Agazio et al. (2003) conducted research in America to determine the effects on parents who are separated by non-localised hospitalisation of a child. In addition to accommodation needs, Agazio et al. found that the parents who accompany the child report issues with meeting personal needs of eating and stress from being at the bedside for long hours. The parents also experience difficulty in meeting the needs of other children who are still at home and maintaining the household (Agazio et al., 2003). The authors also speculate that couples are equally affected by an adult's hospitalisation in similar circumstances, but argue there is no literature to support their speculation. Rukholm et al. (1992) obtained data about the distance of subjects' residence from the site of hospitalisation when researching the needs of family members. Unfortunately this information is not discussed in the findings. Does this group of people have different needs than those whose spouse is hospitalised in the local centre?

Financial situations determine treatment options (Davis et al., 1998; Strickland & Strickland, 1995). It is reported that in America, families have the option of travelling 300km every two weeks in order to receive treatment, or paying for access to closer hospitals (Strickland & Strickland, 1995). In one instance, the research participants did not have transport to access the 'free service', but were sued for non-payment of the service they did access. Other patients in this American study, who did not have insurance cover, were routinely transferred to a particular hospital that treated indigent people. The hospital was three hours away from the area in which the participants of this study usually resided (Strickland & Strickland, 1995). There is no discussion about how this affects the patients' treatment options. Australians report additional costs for rural women seeking treatment for cancer include paying for someone to take their place in managing the farm and household (McGrath et al., 1999). The implications for New Zealanders are that increasingly people are moving to rural areas to access affordable housing, but that same life-style choice may affect their ability to access appropriate health options (Blakely et al., 2002).

While Arnesen, Erikssen, and Stavem (2002) disagree that there is international bias against people in lower socio-economic groups in terms of access to health care, there are inequities in the availability of treatment for New Zealanders. For example, while the risk factors of coronary heart disease are higher among Māori and Pacific Islanders, and this group has a higher hospitalisation rate when compared to other New Zealanders, this same group is less likely to receive coronary artery revascularisation intervention (Tukuitonga & Bindman, 2002). Furthermore, because of the non-likelihood of vascular surgery, Māori have a higher level of hospitalisation for heart failure (Westbrooke, Baxter, & Hogan, 2001). This is despite the fact that treatment for heart failure is rated as one of the most expensive procedures with over \$17 million dollars being spent on heart failure and a further \$21.2 million dollars on coronary bypasses during the 1999 financial year (Westbrooke et al., 2001). Westbrooke et al. further claimed that although socio-economic data was not included in the demographic data about each patient admitted for treatment, if the patient's usual place of residence were compared with deprivation indices, higher scores of deprivation indicate increased rate of heart failure and decreased rates of surgical intervention. The link between deprivation and varying intervention for heart disease has resulted in the fact that not only are Māori less likely to be referred for specialist screening, but because Māori are less likely to have health insurance, they cannot access privately funded echocardiography or cardiology specialists (Carr, Robson, Reid, Purdie, & Workman, 2002).

Insurance status and estimated out of pocket expenses became the determinants that rural American retirees used in deciding whether to utilise the regional hospital centre, or a closer private provider (Weeks et al., 2002). In instances where the retirees were insured, they chose to have treatment closer to home. Weeks et al. do not provide demographic information regarding the marital status of this population group, and the effect on the spouse is not explored, leaving further gaps in the literature.

Living in an American rural community also means those with illnesses struggle to maintain their environment and minimise dependency on others (Roberto & Reynolds, 2001). Australian rural women with breast cancer also have an increased sense of isolation, and may be reluctant to seek help (Sullivan, Weinert, & Fulton, 1993). The reluctance of rural women to seek assistance following mastectomy leads to increased social isolation and emotional turmoil (McGrath et al., 1999). Girgis, Boyes, Sanson-Fisher, and Burrows (2000) found from an exploratory study that Australian women who live in rural communities have greater psychological needs such as dealing with depression, stress and anxiety after they have had a mastectomy. Unfortunately, Girgis et al. conducted their research three years after the women had treatment for breast cancer, and acknowledged that a limitation of the research was that they did not focus on the disruption to family life, especially for the women from rural areas.

The findings by Girgis et al. (2000) that rural women's health needs are connected to the distance from service is supported by an American study undertaken by Koopman et al. (2001). This quantitative study revealed that rural women's usage of the oncologist or surgeon for information and emotional support are directly related to the distance between the medical treatment centre and home (Koopman et al.). In contrast, Wilkes et al. (2000) found from their thematic analysis that information was the key to empowerment and making decisions about treatment options that enabled supporting spouses to provide support to those requiring palliative care. This enabled the families to co-ordinate the sick relative's treatment and the household management, especially if they were away from home. Families need the information to gain a sense of having made the right treatment option decisions (Wilkes et al.). Goodman et al. (1997) expressed surprise that residents who lived farther from the hospital were less likely to be admitted for medical illness. This is not surprising however, if the consequence of this hospitalisation is a loss of family support.

2.5 Chapter Review.

This literature review highlights the paucity of research that focuses on the needs of those whose spouse is hospitalised in a non-local tertiary centre. Of the 89 articles that were reviewed about relatives' or spouses' involvement in care, only one was written from a New Zealand perspective. Spouses of those who are acutely ill face their own distress and sense of uncertainty as they maintain a vigil. At times the burden of providing a vigil is alleviated if the family feel they can be useful in assisting with personal cares. However, this means that relatives need to have the opportunity to be with the sick relative. It is also apparent that the distance from hospital centre and the home town affect treatment options and recovery after medical intervention. Despite the health reforms within New Zealand, and consequential centralisation of services, there is little literature that explores the effects of non-local tertiary hospitalisation on the supporting spouse.

In the next chapter the philosophical underpinnings that guide this research to address the questions about these experiences are discussed.

CHAPTER THREE PHILOSOPHICAL UNDERPINNINGS.

3.1 Introduction.

The purpose of this chapter is to explore the philosophical underpinnings that guide this study. To understand the experience of having a spouse hospitalised in a non-local tertiary centre, it is necessary to explore the reality of the experience. What is known about this, and how can the experiences that are shared generate wisdom among others? A Heideggerian perspective reveals understanding of the meaning of being. This understanding can facilitate interpretations of new experiences. Therefore, having explored the background and literature related to hospitalisation, it is logical to use phenomenology to aid interpretation of the experiences of non-local tertiary hospitalisation. Sharing these interpretations will also facilitate learning among health professionals who care for this patient group. Before phenomenology can be applied as a means of exploring the phenomenon under study, it is necessary to outline what phenomenology means and define some of the terminology associated with the philosophy.

This chapter opens with an overview of early philosophers, and their influence on the development of phenomenology. Husserl's ideas of transcendental phenomenology are compared to those of Heidegger's phenomenology, which initiated the use of hermeneutic phenomenology further developed by Gadamer. In order to understand the world, Heidegger (1962) argued that it was crucial to return to individual's interpretations of living within the world; to understand what it means to be. Hence the concept of *Being* is detailed so that the relationship between the world and knowledge about being human is fully explored.

3.2 Philosophy – A science of logic

Philosophy, defined by Heidegger (1982) as the science of world-views and reason, was initiated some 2500 years ago in fourth-century Greece, by philosophers who questioned the meaning of life and who struggled to balance understanding of worldly and cosmic matters. Plato intermingled questions such as “Why is there anything at all and not nothing?” and “Why are things the way they are?” while questioning the right way to live (Gadamer, 1975). Gadamer

(1981) explained that Socrates, and later, Plato and Aristotle, believed that philosophy is a process of thoughts and debates that one has in order to achieve harmony between logos (spoken and unspoken thoughts) and ergon (the way one is). Heidegger (1958b) explained that the word philosophy originated from the Greek meaning of path. The path lies before us but it comes from somewhere (has a history) and is going somewhere (has a future). To gain understanding, we are required to examine the phenomenon that shows itself on this path. The path (or journey to understand the meaning of life) is lost unless the history and the future is incorporated into the present (Heidegger, 1958b). In essence, philosophy is a science that addresses the understanding of one's life-world that leads to logical reasoning.

The founding of modern philosophy has been attributed to Descartes (1596-1650), who spent much of his life seeking a foundation from which he could balance the existence of God, proper scientific methodology, and the material world. Understanding of the relationship between God, the world, and humankind poses questions that cannot be answered by traditional foundations (the myths and legends) of culture (Gadamer, 1981). Descartes believed that the key to philosophical understanding was an individual human's certainty of his/her own existence that was differentiated from all other worldly matters and from other minds. Descartes' musings were amid a world of dramatic change for the European world. During the fifteenth century there were voyages of discovery; the Protestant Reformation dominated sixteenth century understanding of the world; and the seventeenth century was overwhelmed with scientific exploration. This led to Descartes concluding that subjectivity was the centre of philosophy (Cahoone, 1996).

In contrast to questioning the meaning of life and the right way to live, or subjectivity as the centre of philosophy, Kant (1724-1804) argued that humans had the freedom to determine the understanding of life, and failure to use that understanding demonstrated immaturity, compounded by cowardice or laziness. Kant contended that to remain immature resulted in humans relying on others to guide them, leading to a lack of reflective thinking (Cahoone, 1996).

Furthermore, in his writings *An answer to the Question: What is enlightenment?*

Kant (1996) contended that social structures such as religion and bureaucracy prevented reflective thinking; only political and religious leaders had the freedom to understand the meaning of life by exploring the meaning of God. While the opportunities to explore were accessible to few, such exploration would lead to truth and logical reasoning.

Despite the intentions to generate environments of reasoning, philosophers such as Husserl (1859-1938) struggled to explain theories of knowledge acquisition and philosophical knowing (Bell, 1990). Husserl's early writings reflected thinking that knowledge became logical and sound when it could be based on concrete notions such as arithmetic, because such knowledge could be traced back to the original notion, or objective knowledge (Bell, 1990). Therefore, the aim of philosophy was to make intelligible how humankind grew to possess notions or perceptions such as arithmetic, based on reflections that are grounded in current understanding (Bell, 1990). Husserl argued that such approaches satisfied the reductionist's call for a systematic and comprehensive articulation of knowledge (Gadamer, 1981).

Although philosophy is a science, because it focuses on the relationship between human beings, and life-worlds¹, it is not a positivist science (Gadamer, 1981). Philosophy, according to Heidegger (1962) is distinguished by the fact that understanding life is not gained by other scientific methods, it is bound up with understanding tradition, and traditional knowledge. Heidegger (2000, p.1) reverted to Plato's original question and asked "Why are there beings at all instead of nothing?" In order to answer this, Heidegger contended that rather than determine incidents that lead to knowledge, it is necessary to understand happenings that lead to understanding *being*. Such scientific exploration is phenomenology. By making the distinction between *being* and *beings* in general, it is possible to reason and to determine the things that are. In other words while traditional scientific approaches (ontical inquiry) focus on generating general knowledge, or knowledge that occurs from everyday knowing, hermeneutics

¹ Life-world refers to the everyday surroundings (world) that surround human beings, and exploration of life-world forms the foundation of investigation of human sciences (Dahlberg, Drew, & Nyström, 2001).

focuses on the study of the meaning of *being* (ontology) and generates understanding of the nature of existence (Dahlberg et al., 2001). All ontological knowledge comes from worldly knowledge and what is already known; it is *a priori*.

3.2.1 *A priori*

In order to determine the things that are, Heidegger (1982) claimed that phenomenology must not be confined to positivist methodologies; it is necessary to determine the characteristics and sources of knowledge. Knowledge about basic concepts determines and guides any additional scientific enquiry; not only extending knowledge, but also reinforcing what is already known (Heidegger, 1962). For example any study into disease causality, such as cancer, is based on the current knowledge about cancer. Positivist scientific methods demonstrate logic by revealing the results and describing the pathway that led to the findings (Heidegger, 1962).

Heidegger believed that since the original works of Socrates and Aristotle, studies of the attributes of living in a certain way and gaining knowledge of philosophical truths, precede any explorations of life (Heidegger, 1982). Such philosophical truths are termed *a priori*. *A priori* knowledge is given knowledge embedded in the world in which we live. Husserl himself, struggled to acknowledge the influence of intuition on self, in his desire to depend upon experience alone as a teacher (Bell, 1990). Therefore, the source of *a priori* knowledge needs to be explored in order to understand being human (Heidegger, 1962). Phenomenology will not answer the development of knowledge between life and humankind unless there is an exploration of the relationship between humankind and worldly knowledge. Phenomenology is an exploration of *a priori* understanding, or a standpoint of the phenomena that constitute humanity (Heidegger, 1982).

3.3 Phenomenology: An overview of philosophical stances

The Greek term that expresses a phenomenon is *phainomenon*, derived from the word *phainesthai* (Dahlberg et al., 2001), which translates as “to show itself” (Heidegger, 1962, p.51). Phenomenology aims to hold the researcher’s gaze on the phenomenon itself; that is to explore the experience of some activity that describes human knowledge (Willis, 1999). An explication of this knowledge

begins with an exploration of the relationship between humans and the world. This relationship cannot totally be captured by language, but is understood through the sharing of experiences (Dahlberg et al., 2001). Such sharing and interpretation of the experience and the relationship is termed hermeneutic. Phenomenology and hermeneutics form the foundations of theoretical knowledge of human science research; they are not single philosophies (Dahlberg et al.). While phenomenology provides a description of the phenomenon, and avoids interpretation or constructions, hermeneutic phenomenology interprets the situations (Dahlberg et al., 2001; Leonard, 1994).

Although phenomenology has been further developed since it re-appeared as a philosophical concept during the 18th century, there are two major streams of understanding: Husserl's transcendental phenomenology, and hermeneutic phenomenology initiated by Heidegger and further developed by Gadamer.

3.3.1 Husserl

Husserl (1859-1938) is considered to be the founder of modern-day phenomenology. He began his academic life as a mathematician, and although he had studied philosophy, he did not demonstrate an interest in philosophy until he worked in Berlin. He returned to Vienna and studied under the tuition of Brentano who was influential in modelling Husserl's beliefs about intuition, judgement, consciousness, intentionality, logic, and truth (Bell, 1990). Husserl believed that understanding about intuition, judgement, and thus logic and truth emerged as a result of reflecting upon the experiences of life (Dahlberg et al., 2001). At this time Husserl contended that all concepts are dependent upon concrete intuition; that is, viewing the experience in its entirety (Bell, 1990). This is done by reflecting upon the experiences of living (Dahlberg et al., 2001). A concrete phenomenon is one that comprises the whole, while an abstract phenomenon is one that comprises of the parts (Bell, 1990). Just as material things such as the newspaper or a book constitute part and the whole, so do mental concepts such as pain and despair. Through reflecting upon the concrete experience of pain, knowing about self becomes "knowledge of self-as-knower-of-the-world" (Grumet, 1992, p.33). In other words, having had the experience, the person is able to understand others in similar situations.

Husserl called the thoughts and ideas that direct our mode of *being*, consciousness. The result of consciousness and understanding he called intentionality. Intentionality refers to the relationship between individuals and their experiences of objects or events (Dahlberg et al., 2001). However, Husserl further wished to distinguish between sensory awareness gained through experience (intuition), and mental concepts, which are non-sensory but which require analysis (Bell, 1990). Reflecting on experiences explicates the mental concepts into thoughts. Phenomenology means the study of phenomena; a term Husserl uses to describe thoughts and ideas that come from intuition and mental analysis of the concepts (Bell, 1990). Husserl's works make truth available by encapsulating human consciousness that leads to understanding actions; understanding that only emerges when we distance ourselves from the experience (Grumet, 1992).

Beliefs, thoughts, or judgements, and consequently intentionality are rational if the individual judgements are well-formed. Beliefs are strengthened if the significance of the judgements can be categorised, and the object of the judgement is identified (Bell, 1990). For example, utilising Husserl's philosophical approach, when a person is facing the prospect of their spouse having surgery in the non-local tertiary centre, their decision to accompany the sick spouse to the centre would be rational if they could conceptualise their spouse being alone in the out-of-town centre, the spouse valued the couple's relationship, and outcomes of the treatment were an unknown state of affairs. Similar reasoning would also justify why the spouse should remain at home to manage work and the household. Through this examination, humans develop theories about conscious actions and gain an understanding of living. Husserl (1973) proposed that human beings do this by reflecting upon a new phenomenon and because of the reflection, they stand aside from their current way of knowing and question how they came about that knowledge. In order to reflect upon living, the world cannot be reduced to single entities that occurred in isolation; rather living is experiences (Husserl, 1996). Through living, humans develop attitudes (Dahlberg et al., 2001), and view the subjective and objective worlds epistemologically.

In a simplified version, Husserl's approach to understanding the phenomenon of living is that human beings have lived experiences, and through reflection on those experiences, understand the theory of living. Therefore, Husserl claimed, humans make judgements and develop theories before they can use the things before them (Dreyfus, 1991). They need an overview of life. The focus of experience is the things that are apparent. That is, Husserl's phenomenological approach is to question how we know what we know (Leonard, 1994). Once humans question how they have gained knowledge from experiences they move themselves beyond the experience; an expression that Husserl calls transcendence. In other words, by understanding the structure of life experiences, people transcend the experience or stand outside of the experience (Cohen, 2000); this transcendence leads to development of understanding existence, and hopes to generate universal truth about being human.

Husserl's focus on generating universal truth led him to believe that philosophy and religion were antithetical, a doctrine he stressed to his students. Heidegger had studied under the tuition of Husserl, and it was assumed that he would continue Husserl's teaching and works on phenomenology (Dahlberg et al., 2001). As Heidegger's philosophical musings became more sophisticated, not only had Heidegger begun to question the doctrine of Catholicism (Cooper, 1996), he also began to question the logic that knowledge came from living (Dahlberg et al., 2001).

3.3.2 Heidegger

Heidegger (1889 – 1976) was raised by pious Roman Catholic parents. He had originally attended university in preparation for the priesthood, but turned to philosophy when it was discovered that he had heart disease (Cooper, 1996). Husserl's philosophical stance caused Heidegger to question the role of doctrine on individual interpretations of life (*Being*). It could also be speculated that his questioning was reinforced, as Heidegger came to terms with his own personal health issues, and the fact that the Catholic teachings did not provide him with the answers about the meaning of life and death. Heidegger argued that in order to understand knowledge, it was imperative to gain an understanding about life itself. While epistemological knowledge and consciousness is reliant upon reflecting on

the subject of living, Heidegger believed that human understanding is hermeneutic, that is interpreting the everyday world in which we live (Dahlberg et al., 2001). In addition, the totality of the individual's worlds cannot be determined, because individual worlds are just that, individual, and because they change with time.

Heidegger's approach to phenomenology is to provide insights into being human by unconcealing the effects of experiences on understanding. Understanding does not occur in everyday experience; incidences that Heidegger coined as everydayness (Heidegger, 1962). Everyday experiences remain in the background and do not add to the understanding about being human. Hermeneutic exploration facilitates the self-understanding that emerges when everydayness is disrupted. Such exploration enhances the meaning of *being* (ontology). What does it mean to be? Does it mean to live, or to exist? Humans do not understand living and then transcend; they become engrossed in the world (Heidegger, 1962). Living means being involved in and attuned to something. Humans are not simultaneously aware of involvement and attunement; awareness only occurs with a rupture of the taken for granted associated with living (Segal, 1999). Self-reflection occurs by the disruption to the everyday, and knowledge about self is disclosed through interpreting the experience. Analysing what it means to live in the world leads to ontological understanding (Cooper, 1996). However, rather than disclosing self-reflection through language, Gadamer contended that self-understanding is embedded in language.

3.3.3 Gadamer

Gadamer (1900-2002), who was instrumental in developing the science of hermeneutic phenomenology also accidentally embarked on a career in philosophy. He explained that he had been raised in a household where it was stressed that research into the natural sciences generated knowledge. He was surrounded by beliefs that any study of theoretical knowledge would not withstand the rigour demanded of scientific enquiry (Gadamer, 1997). Gadamer had been introduced to Heidegger's work prior to spending a short time studying under Heidegger's tuition. During this introductory time, the possibilities of using Heidegger's approach to philosophical thinking excited him. As Gadamer stated

We lived in an expectation of a new philosophical orientation... tied to the dark, magical word, "phenomenology". But when Husserl... had envisioned a no better philosophical support than a Neo-Kantian transcendental idealism, where was help for thinking to come from? Heidegger brought it... What was it that so attracted me and others to Heidegger?... In Heidegger the development of thought in the philosophical tradition came to life because it was understood as answers to real questions... And questions that are understood cannot simply pass into one's stock of knowledge. They become one's own questions (Gadamer, 1997, p. 7 & 8).

Gadamer was inspired by Heidegger to return to the traditional Greek values that philosophy was based on a desire to know. He contended that the Greeks would view current sciences as "knowledge on the basis of which an act of making or producing is possible" (Gadamer, 1981, p.6). In *Truth and Method* Gadamer (1975) used a theatrical play to illustrate how self-understanding is embedded in language. The characters in the play are given lines to speak. Individuals in the audience are drawn into the story-line and the characters in the play, and are required to make their own interpretations of reality and existence. So it is with real life. Humans are familiarised with what is already known, and in that process of refamiliarisation, the imitations (or roles of the actors) fade into the background, and true meanings of life emerge; humankind celebrates this reconciliation and interpretation of itself (Gadamer, 1981; Gadamer, 1975). In other words, humans need to first live, rather than develop theories about living.

The word theory originates from the Greek word *theoria*, to participate in a delegation sent to honour the gods. *Theoria* intimates participation in divine proceedings, not the development of a neutral state of being. Through participation and living, humans interpret the world (Gadamer, 1981).

The past also has a truly pervasive influence on the phenomenon under study. Gadamer's stance is that the past defines the ground on which the current interpretations are founded (Linge, 1976). Interpretation must not point to a finitude of human knowing, rather to interpretations of humanity at that time. Understanding is embedded in language, and stimulates imagination to question experiences to determine what causes continuity of the familiar (Gadamer, 1975).

Hermeneutics enables an expansion and mastery of knowledge through articulation of the world which is lived in at any one time.

The picture of someone using an exercise machine illustrates how these three approaches to phenomenology discover and reveal the meaning of life. Those adopting Husserl's phenomenological stance would contend that the person using the exercise machine reflects upon others using similar machines, and is familiar with the notion that exercise is beneficial to health. The positive effects of the exercise reinforce this theory of living. Heidegger would claim that using the exercise machine becomes routine; it is the way that one ought to behave, and the experience of getting up each morning to exercise fades into the normality of everyday living. Within this interpretive framework, the positive effects of the exercise awaken an awareness of the effort that goes into exerting oneself every morning, and reinforces the drive to continue. This awakening is disclosed through conversations either with others or oneself, because the exercise caused weight loss and the individual's clothing is now too loose. Gadamer would explain the phenomenon of exercising by proposing that a discussion with others is the driving force to awaken our awareness of the benefits to exercise. In all cases the benefits to exercise are already known, but how individuals apply that knowledge becomes apparent through phenomenology. Phenomenology is the way to access "what one has in mind as that which shows itself is the Being of entities, its meanings, its modifications, and derivatives" (Heidegger, 1962, p.60).

3.3.4 Engagement with and justification of phenomenological stance

In the current study I have engaged with Heidegger's work to facilitate an understanding of the phenomenon of having one's spouse hospitalised in a non-local hospital setting. Heidegger's framework is that the experiences will reveal an understanding of humankind, because the disruption of these people's worlds caused them to question their understanding about *being* itself. In contrast, Husserl's framework is reliant upon studying phenomena as they appear through life-world experiences, and to critique the theories that guided actions. The phenomenon of having one's spouse hospitalised in a non-local tertiary setting is not an everyday occurrence. Therefore, there are no founding theories that guide the actions. Husserl also argued that phenomenology should study what is fully

evident, but Heidegger's stance is that our understanding of *being* is so pervasive that we can never move beyond it (Dreyfus, 1991). In order to explore an understanding of life using Heidegger's phenomenology, it is necessary to begin by returning to understanding humankind, or as Heidegger (1962) expressed it understanding *Being*². Heidegger termed this kind of *Being* as *Da-sein*³, which literally means 'there being' (Dreyfus, 1991), and the world in which *Da-sein*, or everyday *being* lives, as *being-in-the-world*⁴. Throughout this thesis familiar understanding of *being* is written as *being-in-the-world* with *being* in lower case. Awareness of self, or *there Being* is written as *Da-sein* or using upper case.

3.4 The world

As identified previously, *a priori* knowledge is that which is embedded in the world in which we live. The world, according to Heidegger is *a priori*, constituted by and of oneself within the world (Leonard, 1994). The world is the shared skills and practices, the language and culture from which humans develop understanding. In order to fully understand the concept of *Being* it is necessary to explore the impact of *a priori* or the world, on living.

3.4.1 *Being-ready-to-hand and present-at-hand*

Within the world we are surrounded by equipment that supports our everyday existence, and which we take for granted. The availability of equipment or concepts is *ready-to-hand* (Heidegger, 1962). Equipment is not a single entity of an equipment; equipment is used as part of everyday living. In everyday *being-in-the-world*, our concern with availability of instruments, or equipment is an extension of the activities of daily living. An often-cited example of Heidegger's

² Throughout Macquarrie and Robinson's translation '*being*' is given a proper noun '*Being*'. Fried and Polt (2000) discuss the controversy of using both upper and lower casing to describe *Being* and *being*. The problem arises because in German all nouns are written with upper casing, whilst in English, only proper nouns are capitalised. Heidegger expressed concern that English translations of *Being* might intimate a Supreme Being (Fried & Polt, 2000). Therefore, in this work I have used '*Being*' to mean the essence of the person, and '*being*' to mean the everyday person. Explanations of *Being* are threaded throughout this chapter.

³ Macquarrie and Robinson translated Heidegger's original edition of *Being and Time*, but retained Heidegger's word *Dasein* to refer to one's individual understanding of self and the world. In a later translation of *Being and Time*, Heidegger requested any future translations should hyphenate *Da-sein*. Heidegger wanted it written in this way to differentiate it from *Dasein* as *existence* (Stambaugh, 1996). Therefore throughout this work, unless a direct quote is taken, the 'being-there' of *Being* is written as *Da-sein*, and the everyday *dasein* is *being*, which exists by *being-in-the-world*. More in-depth explanations of *Da-sein* and the world are embedded in this chapter.

⁴ *Being-in-the-world* is pivotal to understanding the relationship between the world and *Da-sein*. The term will be fully explored in Section 3.5.1.

ready-to-hand is related to a hammer. A hammer is visualised not only as an object (the hammer itself), but also as a purpose (of hammering in the nail). These are taken for granted until it is necessary to notice them because it is drawn to our attention. For example, being married to a builder, I do not use a hammer with the same confidence that my husband does, and visualise the hammer hitting my thumb. Hammering becomes a phenomenon because I picture how hitting the nail (both thumb and steel) could affect me. I become anxious. Hermeneutic phenomenology gives both access, and an ability to interpret experiences of living in everydayness, revealing an understanding of living in that world.

It is not merely the *readiness-to-hand* of equipment or concepts that exposes *Da-sein*, the ideas or equipment also need to work. Heidegger (1962) described the workability of the equipment as *present-at-hand*. The equipment is still there, but if it does not work, it lies useless. For example, although the hammer does not have left or right handed characteristics, the hammer cannot be used effectively in the 'wrong' hand of a left or right handed person (Heidegger, 1962). Such *presence-at-hand*, gives *being* to the *readiness-to-hand* of the equipment. Again, to cite my husband, he may go to use his electric saw only to find that it is not working. Although he has the option of using a handsaw, the fact that the electric saw is not working troubles him, and he cannot settle to complete the building task at hand. Finally, he abandons his project and takes the saw apart, repairs it, and solves his problem. Alternatively, if he were to lend the saw to a neighbour, but then forget about it until he suddenly finds some activity that requires him to need the saw for himself, by being not *ready-to-hand*, the saw becomes 'missing' (*un-ready-to-hand*). As illustrated it is not until the equipment is missing or unusable that its value becomes apparent. So it is with our everyday activities, which we take for granted.

Everyday practices stay in the background because they are just that, everyday practices. It is when the taken for granted become obvious that a vague understanding of what it means to be human becomes an understanding of oneself within the world. Hermeneutic understanding is based on our interpretations of the situations that surround us, and the availability and workability of the everyday surroundings. If aspects or entities of the world are not available and

workable, we cannot anticipate the immediate future. The *readiness-to-hand* does not become explicit in an ontological sense until the equipment that surrounds us becomes apparent in its entirety; that is its worth. The surroundings themselves become noted.

Although Heidegger used material entities to describe the everydayness of the world, I believe that *presence-at-hand* and *readiness-to-hand* can be applied to worldly concepts such as relationships, or health. The concepts are not material, but health itself is part of an individual's everyday world until it is disrupted or becomes 'missing'. When this occurs, individuals pay attention to its recovery. The workability and nature (*presence-at-hand*) of relationships changes with the *unreadiness-to-hand* of health. The material and conceptual nature of the world fades into the background.

3.4.2 Spatiality

Existing in the world that has been described, means more than occupying a space in the world; it means engagement with the world. However, space and distance also have their own *being*. For example, a stone's throw is relative to *Da-sein*; that is, the distance is relative to *being-in-the-world* and the world itself (Heidegger, 1962). *Da-sein* is not a physical body occupying space; rather space and distance are related to *Da-sein*'s concern with surrounding things. In the case of the current study, the geographical distance between home and the tertiary hospital may be perceived in different ways in different circumstances. For example, I was told of a gentleman whose wife had been transferred from a country town to a tertiary centre for treatment of cancer. He drove down to be by her side, a distance of 300 km, only to find that she had been transferred to another regional hospital, 150 km closer to the town in which they lived. She was transferred because her condition was so poor, that the cancer could not be treated. Although this man's wife was moved closer to home, her condition meant that she was further away.

That which is presumably 'closest' is by no means that which is at the smallest distance 'from us'. It lies in that which is *desevered*⁵ to an average extent when we reach for it, grasp it, or look at it (Heidegger, 1962, p.141).

⁵ This term to bring something closer, is explained in detail in Section 6.3.2.

If accessibility becomes problematic, distance and space are noticed.

Accessibility also causes the totality of the *ready-to-hand* and *presence-at-hand* to be noticed. “With this totality...the world announces itself” (Heidegger, 1962, p.105). However, because the things that surround us change, so too does our knowledge of the world change. Understanding of self is based on understanding the world at that time.

3.4.3 Temporality-of-understanding the world

In his earlier writings, Heidegger proposed that time, as an entity, has no characteristics. “It persists merely as a consequence of the events taking place in it” (Heidegger, 1989, p.3E). Our governance by time is both chronologically and culturally driven. For example ten minutes before the bank closes could mean a hasty dash into town, finding a park that is close to the bank and whipping in through the doors with seconds to spare. The same length of time waiting for the bus after a long day at work could seem like a lifetime. Furthermore, in reference to an earlier example, imagine the person undertaking the daily ritual on the exercise machine for thirty minutes. Time on the machine will pass with the ticking of the clock. The time will travel no more quickly whether the person is hastening to do the exercises before going off to do some other activity, or whether the exercises are undertaken as part of time spent meditating. In either situation, the person on the exercise machine looks forward to the time that the exercises are effective.

Because the world is temporary, *Da-sein* always adjusts its understanding of the world as it is at that time, in order to ‘be there’, thus *be-in-the-world*. How will time be perceived when one’s spouse is hospitalised out-of-town? Will the last precious moments with the dying spouse fly by so quickly that the research participant feels cheated of time? On the other hand, will the minutes tick by as the research participant is waiting around to hear some positive news, or to know that the spouse is coming home? Families in Plowfield’s (1999) research into the experiences of waiting following a neurological crisis, expressed that the waiting time has different meaning for those providing care and those waiting to see a loved one. One of Plowfield’s research participants is quoted as saying:

...they'll say give me 5 minutes. So I look at my watch and time passes so slowly then, but I give them 10 or 15 minutes...[and the nurses had still not finished the procedure and wanted longer]...They shouldn't tell you it's only going to be 5 or 10 minutes because that's when you watch the time, and it's always longer. That's when time passes so slowly (Plowfield, 1999, p.233).

Understanding of the world means to anticipate as *Da-sein* views the future ahead of itself. Anticipation is the authentic⁶ state of *Da-sein* because in anticipation *Da-sein* can let “itself come towards itself as its ownmost potentiality-for-Being⁷ – that the future itself must first win itself, not from a Present, but from the inauthentic future” (Heidegger, 1962, p.386). In the instances described above, the relative and the nursing staff had different perceptions of, and abilities to anticipate the waiting time.

Anticipation occurs when *Da-sein* understands the possibilities in relation to the concerns, and makes the future present. Because *Da-sein* is awaiting in anticipation of the concern, it expects the matter of concern. Expectations “are founded on awaiting, and [expecting] is a mode of that future which temporizes itself authentically as anticipation” (Heidegger, 1962, p. 387). In contrast, waiting for something discloses the horizon and range from which something must be expected; an awaiting (Heidegger, 1962). It seems to me that the authentic states of anticipation and expectation are because *Da-sein* understands the world. On the other hand, although the horizons from which the world can be circumscribed are identified, awaiting describes waiting with uncertainty.

Furthermore, the adjustments that need to be made when one's spouse is hospitalised in a non-local tertiary centre are time orientated. Whenever new situations occur, *Da-sein* determines ways of coping based on previous experiences (Heidegger, 1989), and what the phenomenon means to the future. It would be expected that knowledge about the world would change for the research participants as a result of the out-of-town hospitalisation, and any previous analysis about living and the world would change. If it were possible for things to

⁶ The terms authentic (self-interpretation) and inauthentic (social interpretation) are more fully explained in Section 3.5.5.

⁷ This term is explained in Section 3.5.3.

be revealed in an unchanging world, the past would remain vivid within the present (Vail, 1972), and we would understand what it means 'to be'.

3.5 Being/*Da-sein*,

Just as the nervous sensation in the little finger cannot be explained without referring to the overall central nervous system, human existence cannot be categorised into little separated boxes. Furthermore, Heidegger stressed that *Da-sein* is individual, and should always be spoken of in a personal pronoun; 'I am' 'you are'. However, this is challenging to practice in scholarly works. Whenever the word *Da-sein* is used, readers should think, 'I am, as an individual', or 'we are, as society'. To understand *Da-sein* it will be 'looked at' from different angles, and the fundamental structures are discussed under the next five sub-headings.

3.5.1 *Being-in-the-world*

Individuals exist and understand their actions in terms of the world in which they live. Heidegger (1962) coined this phrase as *being-in-the-world*. *Being-in-the-world* means to be surrounded by the familiar. As illustrated with the discussion about equipment, such familiarity is embedded in, and forms *a priori* knowledge. But this knowledge hides what it means to be human, because that too becomes familiar. In colloquial German, *da-sein* can be interpreted as 'everyday human existence' (Dreyfus, 1991). *Da-sein*, on the other hand, has a distinctiveness in that it does not occur among other entities, but describes ontological existence and the relationship between *Da-sein* and *being-in-the-world* (Heidegger, 1962). In other words, how life experiences affect a human being, shape and mould the individual human, as well as the human being shaping and moulding the experience itself. Rather than existence, *Da-sein* means we exist; we are.

Da-sein does not normally show itself, because it is surrounded by the familiarity of the world. The everydayness of *being* becomes so grounded in the right way to act, that its foundation becomes forgotten and no question arises about it or about its meaning. The shared everyday activities, in which we engage, assist us to make sense of the world in which we live, through interpretation of those shared activities so that analysis of the interpretation becomes invisible (Dreyfus, 1991). *Da-sein* is revealed when a situation occurs that awakens an awareness of, or

causes one to question the meaning of life. For example, picture a young man dating a girl for the first time. Although he is apprehensive, the young man is familiar with the world that he is in at that moment. If, however, the man realises that he is homosexual, how he deals with this revelation is *Da-sein*, the essence of him as a person. This state remains until he resolves the internal conflict caused by the awakening of his sexual orientation. Interpretation comes about because of our experiences with our surroundings.

Because *being-in-the-world* means being surrounded by the familiar, *Da-sein* becomes influenced by those with whom we deal and by activities of daily working and living. The world and the people surrounding us are familiar; an expression Heidegger (1962) called *being-alongside*. Rather than living side by side in a disinterested fashion, *being-alongside* means being absorbed into the world. For example, we stand next to somebody at the bus stop or on a train, but our very everydayness means that we are immersed within our own world and become 'no different' to the person next to us. The world-view is an interpretation of the sense of humanity (Heidegger, 1982). The way *Da-sein* understands the world is "reflected back ontologically upon the way in which Dasein itself gets interpreted" (Heidegger, 1962, p.37). *Being* cannot be analysed by interpreting *being-in-the-world*, as *Da-sein* is immersed in the 'they', an expression that Heidegger (1962) called *being-with-others*.

3.5.2 *Being-with-others*

No one exists within the world alone. In fact, in our everyday *being-in-the-world*, we live alongside others, and our actions are principally a reflection of what society expects of us. The average person becomes so involved in the day-to-day existence, and in what 'they' will say, that the reality of one's own existence (*Da-sein*) is overlooked. Our everyday actions are projected on society's authoritative way of being. While we learn how to behave from a cultural perspective, the cultural beliefs and values do not consist of a list of the ways to behave, but rather the interpretation of living (Kaelin, 1987). This interpretation includes understanding oneself as reflected in others, an expression that Heidegger (1962,) called *they-self*.

If Dasein is familiar with itself as they-self, this means at the same time that the “they” itself prescribes that way of interpreting the world and Being-in-the-world which lies closest. Dasein is for the sake of the “they” in an everyday manner, and the “they” itself articulates the referential context of significance (p.167).

Heidegger termed the absorption into the world, and society’s way of thinking as *falling*. Absorption into the world is the key to understanding *Da-sein*’s degree of *fallenness*; not a descent, but rather *Da-sein* falls away from individual self and has fallen into ‘their’ way (Heidegger, 1962). Just as *Da-sein* knows itself when surrounded by the familiarity of equipment, so too does it know itself when living in the world with others or general society. Constant measurement of ‘other’s’ way of *being* provides *Da-sein* with an insight into one’s own and others’ character by measuring how far from the dominant culture one may be compared to others. Anxiety is one of the fundamental modes of *Da-sein*, as *Da-sein* constantly is cognisant of the ‘they’, and anxieties of any differences between *Da-sein* and society cause disturbances. Fear of nothingness disturbs *Da-sein* because the interpretive frameworks of the world are no longer familiar, and *Da-sein* becomes unsure of the immediate future. In other words *Da-sein* becomes fearful⁸, and not at home, an expression that Heidegger called uncanniness because *Da-sein*’s future is surrounded by uncertainty.

3.5.3 Potentiality-for-being

Heidegger described *Da-sein* as undifferentiated from *da-sein*, when it exists in the background, as it does most of the time. *Da-sein* understands the world, that is *da-sein* is surrounded by the familiar and is what Heidegger termed *being-possible*. This *being-possible* is an integral part of the relationship of *Da-sein* to the surroundings; the world and others in the world. When encountering a phenomenon, *Da-sein* determines how it will address the phenomenon in terms of possibilities. This analysis is a *potentiality-for-being* (Heidegger, 1962). The *potentiality-for-being* is linked to the *readiness-to-hand* and the *presence-at-hand* of the world. If *Da-sein* encounters a phenomenon, the “possibility signifies what is *not yet* actual and what is *not at any time* necessary. It characterizes the *merely possible*” (Heidegger, 1962, p.183). This relationship to the possibilities enables *Da-sein* to understand itself. As *Da-sein* contemplates each possibility, it does so

⁸ The terms *anxiety*, *fear* and *uncanniness* are explored further in Section 3.7.

in terms of the *potentiality-for-being*, and its understanding of the past, the world and society. In other words, as individuals encounter new situations, they draw on the past to predict the future. *Da-sein* needs to discover, understand, or describe the phenomenon before it can resolve this discovery, and any issues that stand out from others' interpretations.

However, unlike Husserl's philosophical framework that people rely on theories about living to guide actions, *Da-sein* only does this when its everyday understanding of the world is disrupted. When *Da-sein* determines the *being* of an entity *present-at-hand*, it does so based on "its ownmost possibility" (Heidegger, 1962, p.68). In other words, *Da-sein* understands in advance what the *potentiality-for-being* is capable of. *Da-sein* makes decisions about how it will react to the lack of the *present-at-hand*, the changes to its world, or to the demands of others. Its reaction depends on how fallen it is into the way of others.

Understanding the new, because the phenomenon has raised awareness of something new, always pertains to the world as a whole. *Da-sein*'s rapport with the *readiness-to-hand* and the *present-at-hand* means that *Da-sein* must decide the possibilities, a phenomenon Heidegger described as projection. Understanding the past, the current world, and the possibilities projects *Da-sein* into a state of *potentiality-for-being*, into a new 'there'. This projection is not the projection of free-floating objects in space, but projection into a world of knowledge and understanding. As noted earlier, this understanding is based on previous experience and the possibilities that *Da-sein* can foresee from this situation. The loss of health that causes one's spouse to be hospitalised out-of-town could mean that the future is uncertain for these couples. To demonstrate how a new phenomenon disturbs *Da-sein* and *being-in-the-world*, a reporter writes of her experiences of hearing that her husband had prostatic cancer, and of determining the possibilities and adjusting to the lack of the present-at-hand:

My first reaction when John phoned to tell me he had cancer was panic. I ran through all the scenarios in my head, including the one in which he died. The word 'cancer' is still synonymous with death for most of us...At work I told only those closest to me...I wanted to preserve a state of normality and avoid pitying looks and people tiptoeing around me (Sherson, 2004, p.94).

Sherson goes on to write that other women reported to her that their husbands felt paralysed by the thought of the disease, particularly the prospect of being impotent. Critical reflection only occurs if awareness of the *ready-to-hand* and *present-at-hand* shifts from the background and becomes transparent. The *potentiality-for-being* impotent does not fit into New Zealanders' perceptions of health, and it certainly is not something that is talked about when *being-with-others*.

Phenomena such as grief and guilt highlight *Da-sein's potentiality-for-being*. In contrast, familiarity with the world gives possibility to *Da-sein's* understanding and interpretation, expressed by Heidegger (1962) as *for-the-sake-of*. This *for-the-sake-of* directs *Da-sein's* behaviour as it looks to the future in the *potentiality-for-being*. In anticipating our response to a phenomenon, *Da-sein* determines the possibility of itself *for-the-sake-of* its involvement. In order to make sense of the experiences that couples had when one's spouse is hospitalised, how they acted and the expectations of how they ought to have acted need to be expressed in order to foster understanding. The analysis of the experiences, presented in the current study, will provide an insight not so much into what the research participants did during this time, but what interpretations of their life-world resulted in them responding to the situation in the way that they did.

3.5.4 Da-sein shows its understanding through language(ing)⁹

An individual's world is a world of meaning radiating from *Da-sein's* ability to group, relate, and use things (Langan, 1959), which leads to understanding and disclosure of *Da-sein* to itself. *Da-sein's* sense of the world is exposed through sharing experiences (Heidegger, 1962). Experiences are situations, which have been interpreted, projected and which disclose an understanding of life (Kahn, 2000; van Manen, 1990).

According to Heidegger (1958a) language is more than words; it consists of both spoken and unspoken expressions that form part of the whole. Those who find it relatively easy to find words that explain the concrete (ontic) things of life may

⁹ Language(ing) means usage of language to express both the spoken and unspoken (McBride-Henry, 2004).

struggle to express the ontological (Heidegger, 1958b). Everything that is talked about, or visualised is understood in terms of the way *being* is accessed and interpreted, and the way the world is understood reflects the way *Da-sein* interprets itself. Through speaking *Da-sein* shows how it understands self. For example if someone enquires, “How are you?”, *Da-sein* recognises the truth of how it really is. Furthermore in recognising the truth *Da-sein* ‘moves’ from *potentiality-for-being* (an unknown) to ‘being-there’. However, *Da-sein* also recognises that the question is a polite greeting, and the enquirer may not really want to know the truth. While *Da-sein* would say to itself “I feel sad”, *da-sein* or everyday *being* would say “fine, thank you”.

Heidegger (1989) explained that

Dasein cannot be proven as an entity, it cannot even be pointed out. The primary relation to Dasein is not that of contemplation, but ‘being it’. Experiencing oneself, like speaking about oneself, self-interpretation is only one particular distinctive way in which Dasein has itself in each specific case. On average, the interpretation of Dasein is governed by everydayness, by what one traditionally says about *Da-sein* and human life (p.9E).

For example, a nursing student was expressing distress that her father-in-law had been newly diagnosed with cancer, and was facing a transfer out-of-town. She was not only distressed about the diagnosis, but also how the diagnosis disrupted her world of assignments, study and exams at that time, and the guilt she felt at expressing this disruption. ‘They’ would say that she needed to concentrate on her family’s needs. However it needed careful listening to hear *Da-sein* saying “what about me?” In a second example, I was discussing my research with someone whom I knew had accompanied his partner out-of-town. He listened to some of the stories that the research participants told me, and vividly recollected his impressions of the nurses’ home. He described the echoing of the footsteps up and down the corridor, until they seemed to boom outside his bedroom door. What he didn’t describe, but what I speculate was part of his anxiety, was the fear that the footsteps belonged to the security guards who could be coming to get him, because his partner’s condition had deteriorated. To describe the significance of the footsteps discloses true feelings at that time.

3.5.5 Authentic and inauthentic being.

In describing experiences, it is possible for disclosure of *Da-sein* to closely resemble something that it is not, a showing Heidegger (1962) called *seeming* [*Scheinen*]. Heidegger elaborated on the difference between *Da-sein*'s disclosure, and a *seeming* by explaining that when one talks of disease symptoms, not all symptoms are visible. The diagnostician needs to note what is visible and what is described. As some symptoms are apparent, they indicate other occurrences. For example, we cannot see the fluid behind an eardrum. What we do see is the bulging of the tympanic membrane. So, too, it is with *Da-sein*. The deep characteristics of *Da-sein* are veiled in everyday *being* as it is. In other words, we may believe we understand the words 'to be', until we try and explain them to others. Phenomenology lies in the interpretation of the basic structures of *Being*, which are made known to, and disclose *Da-sein*.

Choosing ownership of response to situations is authentic, while the seeming is inauthentic (Heidegger, 1962). It is the response to the *potentiality-for-being* that leads to authenticity (belonging to itself) or inauthenticity. The authentic present is a moment, when insight into the situation gives explanation (Vail, 1972). In contrast, the inauthentic *Da-sein* is so absorbed in the day-to-day living that self becomes a reflection of what others might think, or ignores the implications of other possibilities. Each authentic and inauthentic state complements and balances the other. In choosing whether to be authentic or inauthentic, *Da-sein* does not say to itself, "I am going to have an authentic day", rather the moment, others, and *Da-sein*'s own knowledge of the immediate world is evaluated when *Da-sein* is awakened to make different interpretations because its previous understanding has been disrupted. For each approach "toward the things that are – discovery of self as already in the world (*Befindlichkeit*), understanding (*Verstehen*) and discourse (*Rede*), there exists a corresponding inauthentic form: ambiguity (*Zweideutigkeit*), curiosity (*Neugier*) and prattle (*Geerede*)" (Langan, 1959, p.23). For example when talking about the experiences of having one's spouse hospitalised in a non-local tertiary centre there may be times when society expects the research participants to manage, and they may therefore prattle that they managed the house and let the hospital provide the expert care. Other times the research participants may express feelings such as guilt because they had

resolved that they were not able to 'be there' to provide care, but society thought that they ought to accompany the sick spouse. The emotions that expose *Da-sein* are moods (Heidegger, 1962).

3.6 Moods and thrownness

Human beings are constantly affected by moods, which Heidegger called *states-of-mind*. By moods I am referring to outlook, and how understanding of the world changes for the *potentiality-for-being*. As Heidegger (1962) explained, even a lack of mood is not that there is no mood, but rather that *Da-sein* is at peace within the world. Feeling a mood ontologically means understanding our true feelings of *being-in-the-world* as it is at that time (Kaelin, 1987). Disturbances to the *state-of-mind* or moods disclose *Da-sein*. Mood disturbance is a mechanism through which the background of familiarity becomes explicit. It functions like a gestalt switch that suddenly, and without warning transforms concern from one of being absorbed in things to an awareness of the absorption itself. From a Heideggerian perspective there are three different kinds of disturbance and concern: Breakdown of equipment leads us to awareness of the equipment; anxiety leads to the sightings of our own practices or forms of *being-in-the-world*; and moods detach us from our involvement in such a way that we become aware of the world itself (Segal, 1999).

Through moods *Da-sein* is projected into a *potentiality-for-being* manifesting the "how one is, and how one is faring" (Heidegger, 1962, p.173). In this projection, *Da-sein* is brought to its 'there' and *Da-sein* is disclosed as it evades the 'there'. For example, a previous illustration discussed the person trying to sleep in a nurses' home with footsteps going up and down the corridor. The *state-of-mind* of the person listening to the footsteps is anticipation. *Da-sein* acknowledged that the footsteps really belonged to others staying in the nurses' home and going about their activities of daily living. However, the *potentiality-for-being* understood what the footsteps could mean. The facts become distorted and the reality of the situation also needs to consider the possibilities as well.

When individual anxiety and thinking is different from 'their' thinking, *Da-sein* and authenticity come to the fore. Because *Da-sein* is no longer absorbed in the world everyday familiarity collapses leading initially to chaos. Heidegger called

this understanding, or disclosure of self through our moods, as thrownness. Thrownness causes turbulence, which intrudes on *Da-sein's* state-of-mind, resulting in movement and change. Thrownness does not mean being tossed around as a free-floating entity, but means self-revelation of this situation at this time (Heidegger, 1962).

“Thrownness is neither a ‘fact that is finished’ nor a Fact that is settled. Dasein’s facticity is such that *as long as* it is what it is, Dasein remains in the throw, and is sucked into the turbulence of the “they’s” inauthenticity (Heidegger, 1962, p.223).

Self-revelation through moods occurs through three processes. The first is an awakening through being thrown. When such an event occurs *Da-sein* suddenly realises that its way of thinking does not reflect ‘their’ thinking, that *da-sein* (or everyday being) becomes conscious and concerned, leading to the third process of *Da-sein* feeling threatened. When one is thrown, understanding what *being-in-the-world* means evaporates, and *Da-sein* needs to self-interpret how to re-enter the familiar world (Brock, 1968). We examine, as if for the first time, the norms of society. In its moods *Da-sein* feels, and delivers itself over from the present into the *potentiality-for-being*, until it can make sense of the world again. It is not the thrownness that disrupts *Da-sein*, but rather *Da-sein* becomes anxious about the *potentiality-for-being*. As discussed, the possibilities for authentic *potentiality-for-being* depend on the degree of fallenness into and *being-alongside* the world or *the being-with-others*. *Da-sein's* states-of-mind, along with the possibilities that disclose *Da-sein* to itself, explicate *Da-sein's* essence; or as explained “Dasein’s Being reveals itself as care” (Heidegger, 1962, p. 227).

3.7 *Da-sein* and care

A foundation of understanding what it means to be is to appreciate that *Da-sein* is disclosed through its thrownness when the *potentiality-for-being* becomes an issue (Heidegger, 1962). The world becomes unfamiliar and *Da-sein* becomes uncanny; not at home. In uncanniness, *Da-sein* compares itself with ‘what it is’, and ‘what it could become’. This constant comparison between *being-in-the-world* and Dasein’s *potentiality-for-being* means that *Da-sein* is always ahead of itself. *Da-sein* is disclosed because the possibilities cause it to project into the ‘being there’. However, Heidegger stressed that being ahead of oneself is an integral component of *being-in-the-world*. In other words, *Da-sein* cannot

evaluate the possibilities if it does not draw on past experience, *a priori* or worldly knowledge, and the reaction of others. When *Da-sein* deliberates on fears that cause it to question life, in *being-ahead* of something already disclosed, the circumscription of the possibilities for the *potentiality-for-being* leads to care.

In contrast, the entities themselves do not concern *Da-sein*, but are objects of solicitude. Heidegger used the word solicitude to describe concern that one human has for another, and is founded on *Da-sein*'s relationship with and absorption into the world. "For example "welfare work"¹⁰ ... is based on the constitution of the Being of *Da-sein* as being-with. Its factual urgency is motivated by the fact that *Da-sein* initially and, for the most part, lives in the deficient modes of concern" (Heidegger, 1996, p.115).

Da-sein can demonstrate solicitude in two ways. Firstly, *Da-sein* can remove the other's care by taking it over for self; an expression called leaping in (Heidegger, 1996). Solicitude in this way removes the burden of care from the other person so that once the situation is resolved the other may take the matter over as completed, or may not become concerned in the matter at all. In contrast *Da-sein* may become concerned about the essence of another, and give care back to the other person, a phenomenon called leaping ahead (Heidegger, 1996). In leaping ahead *Da-sein* cares for another by generating self-understanding of one's own abilities, thus relieving the other of anxieties of the unknown. When *Da-sein* leaps ahead, it does so because of concern for the other's well-being.

Da-sein as care is already in the world in *being-in-the-world*, ahead of itself in its *potentiality-for-being* as it circumspects the horizons as they appear at that time (Dreyfus, 1991; Heidegger, 1962). The essence of care is the notion that *Da-sein* makes an issue of its *potentiality-for-being*, especially in an instance such as having one's spouse hospitalised out-of-town, as presuppositions become distorted. For example, when facing the diagnosis of cancer, Sherson (2004), referred to on page 65, struggled to "*preserve a state of normality*". Normality in

¹⁰ Although this text is cited from Strambaugh's translation of *Being and Time* (Heidegger, 1996), Macquarrie and Robinson stress that *Fürsorge* is best translated as parental care of children as well

this instance meant daily concern in a world in which her husband did not have this diagnosis. In contrast, Sherson now cares about the uncertain future, and others' reactions to the diagnosis.

Care, or *Da-sein's* Being is revealed when *Da-sein* interprets itself in the face of the unknown, or anticipated thrownness. Caring for other entities within the world differs from *Da-sein's* care (Heidegger, 1962). The fact that things need to be taken care of is resultant from anticipation that the people or objects need attention. Heidegger termed this attention as concern. Concern brings attention to aspects of the world that *Da-sein* can manipulate or use; the items that *Da-sein* takes care of (Heidegger, 1962). In other words, anticipation of entities in the world causes *Da-sein* to become concerned with those entities.

In contrast to care as the totality of *Da-sein's* Being, concern focuses on entities within the world that *Da-sein* contextualises based on the *ready-to-hand* and *present-at-hand* of the world. In other words, concerns are not cause for alarm, but everyday entities of the world, in *Da-sein's* state of *being-alongside* the world. As previously explained in everyday concern with the world *Da-sein's* projections are made within a world that is understood, or dis-covered¹¹. *Da-sein* uses this understanding to circumspect 'their' possibilities. However, *da-sein* restricts the *potentiality-for-being* because only 'their' possibilities of what is fitting and proper are considered. Although *da-sein* is aware of the possibilities, 'their' vision of reality blinds *Da-sein's* ability to view the world.

Everyday *being* involves *being-with-others*, irrespective of the significance of others surrounding *Da-sein* (Heidegger, 1962). Care is disclosed when *Being* itself becomes the issue. In caring, we can 'care for' (solicitude) and 'care about' (concern) entities in the world. Solicitude is defined as an authentic mode of care, founded on *being-with-others* in terms of the things that cause concern. When *Da-sein* understands others' concerns, it bridges solicitous concern with empathetic understanding. Solicitude of knowing what is occurring in another's

as the care administered by welfare agencies. Care based on welfare could be used to describe nursing.

¹¹ I use the word dis-discovery to express "taking the lid off" of knowing that occurs in disclosedness.

mind (empathy) is possible only on the basis of *being-with-others* (Dreyfus, 1991; Heidegger, 1962).

3.7.1 Anxiety and fear as states-of-mind

Most of the time *Da-sein* is anxious in an everyday world as a state of comparing *being* with its understanding of the world. When a situation occurs that causes *Da-sein* to compare the degree of thrownness with its understanding of the world, *Da-sein* fears the unknown. It is not the anxiety itself that causes fear; it is that the source of the anxiety is unknown. Heidegger (1962) explained that *Da-sein* interprets fear in three integral ways. Initially, *Da-sein* determines the object or concept that we fear (the fearsome). Fearing this object or concept is based on entities within the world. *Da-sein* knows that it will be detrimental to become involved with the fearsome concept or object, because it will affect the possibilities open to the *potentiality-for-being*, and because the fearsome is coming close to us, it is threatening. Because it is not 'here yet', *Da-sein* feels powerless to confront the fearsome concept or object, and enters the second phase of interpretation; that of fearing. Through fearing *Da-sein* acknowledges the importance of the fearsome concept. *Da-sein* does not ascertain the threat as a future evil, and then fear it. Fearing occurs when *being-in-the-world* circumspects or contemplates the options. In recognising that this entity is fearsome, *Da-sein* also recognises that the feared concept threatens the *potentiality-for-being*, revealing "Dasein in the Being of its "there" ...Being-alongside is threatened" (Heidegger, 1962, p.180 & 181).

Da-sein can only be anxious of the familiar, no matter how vaguely we recognise the fearsome. On the other hand if the threat comes from the unfamiliar then the fear becomes dread, and turns to terror when suddenly encountered (Heidegger, 1962). *Da-sein* shrinks back in the face of the fearsome and flees towards the familiar. The experience changes *Da-sein*'s knowledge and understanding of the world. Therefore, how dreadful will the experience be when one's spouse is hospitalised in a non-local tertiary centre? Will the research participants who have had experience with hospitalisation in general dread the non-localised hospitalisation, or will this fear turn to terror because the spouse is now so sick

that the future cannot be contemplated? For example, supporting spouses experienced emotional distress and fear associated with their sick spouses' vulnerability when their partners were admitted following myocardial infarctions (Kettunen et al., 1999). Although couples found comfort in the knowledge that advanced technological medicine provided hope that the medical condition could be treated (Merz, 1998), does the lack of familiarity with transplant procedures accentuates the loss of familiarity of the world?

Contrary to fear, which threatens *Da-sein's* involvement with the world, anxieties are not entities from within the world; their origins are indefinable. Consequently, *Da-sein* struggles to overcome the anxieties, because it does not know which direction the anxiety is coming from. For example, when the couples are aware that the spouse is ill, but do not have a diagnosis, or prognosis, they are anxious. Anxieties cause a disruption to *Da-sein's* comfort (*being-in-the-world*), because the world itself is the cause of the anxiety. The *ready-to-hand* and *present-at-hand* are no longer comforting in their familiarity. The future holds nothing, freeing *Da-sein* to 'choose' the *potentiality-for-being* as the world is disclosed.

In anxiety one feels uncanny. Here the peculiar indefiniteness of that which *Dasein* finds itself alongside in anxiety, comes proximally to expression: the "nothing and nowhere". But here "uncanniness" also means "not-being-at-home" (Heidegger, 1962, p.233).

In this instance Heidegger's 'not-being-at-home' means not being comfortable and familiar with the situation. This unfamiliarity leads to an inability to interpret the situation, which is the basis of the anxiety. Talking about life experiences highlights the horizons through which the world is viewed (*Da-sein's* circumspection of the past and the future, or the *potentiality-for-being*), enabling phenomenologists to interpret *Da-sein's* revelation (Kaelin, 1987; Langan, 1959). For example, darkness leads to anxiety because it is difficult to see the surroundings; the world. The surroundings, which have not changed, become more obvious because they are not clearly visible (Heidegger, 1962). Furthermore, this concept could be applied to research that addresses the concerns of those who stay with sick loved ones during hospitalisation. Although it is not specified by researchers (Carr & Clarke, 1997; Plowfield, 1999), interpretations

could be made that the relatives' unfamiliarity with the hospital environs led to discomfort. By staying over they are literally not at home.

Anxiety itself may not necessarily reveal *Da-sein*, but rather the degree to which *Da-sein* can see beyond the state of anxiety to project a *potentiality-for-being*. This projection is based on the facts before *Da-sein*, the current state of the world, and the degree to which *Da-sein* is *with-others*, and *alongside-the-world* (Heidegger, 1962). These three aspects cannot be separated and put together again, but are deeply interwoven to form a totality of the phenomenon about which *Da-sein* cares. Anxieties come with a 'not yet'. These 'not yet' moments may never eventuate, but the way *Da-sein* cares is based on expectations, because care is embedded in *a priori* knowing. To be expecting something possible is to understand it and to wait for the expected moment to happen (Heidegger, 1962). *Da-sein* circumspects the possibilities as it waits for and gains understanding of the anxiety, leading to resolution; *Da-sein's* understanding and disclosure of truth (Heidegger, 1962). Through resolution *Da-sein* understands its reactions to this phenomenon. "When Dasein "understands" uncanniness in the everyday manner it does so by turning away from it in falling; in this turning-away the "not-at-home" gets 'dimmed down'" (Heidegger, 1962, p.234). In other words, once *Da-sein* has made sense of the *potentiality-for-being*, *Da-sein* is already 'there' and interprets itself as *being-in-the-world*.

On the other hand, if we are forced to face our own death, we do so in anticipation, but dread of what the death will mean. *Da-sein's* attitude is one of expecting death, and through this expectation is waiting for it. But in waiting for it *Da-sein* fears the unknown end of the world, and questions whether there is life after death. As identified in care *Da-sein* is ahead of itself. However, we do not have past experiences on which to understand our own death. Furthermore, there is no opportunity in death to flee back to the familiar, or to be ahead of oneself to be there, as the future becomes a *potentiality-for-being* what? Care is not driven by desire or urgency, but rather by concerns with living.

...the totality of Dasein's ontological structural whole must therefore be grasped in the following structure: the Being of Dasein means ahead-of-itself-Being-already-in-(the-world) as Being-alongside (entities encountered within-the-world). This Being fills in the

signification of the term “*care*”[*Sorge*], which is used in a purely ontological-existential manner (Heidegger, 1962, p.237).

3.7.2 Potentiality-for-being at life's end

Although we are aware that life is finite, and at some point we will die, we do not necessarily think about death everyday. The future is based on what it means to be in a *ready-at-hand* world, and thinking about death results in *Da-sein* questioning the meaning of life (Heidegger, 1962). Existence as a whole can only be understood if it is acknowledged that dying is part of living (Langan, 1959); the ultimate *potentiality-for-being* of *Da-sein* is death (Heidegger, 1962). The *potentiality-for-being* of one's own death cannot be projected, since as long as there is life, humans project themselves forward (Kaelin, 1987). While *being-in-the-world* avoids facing death closely, *Da-sein* broods on thoughts of death. However, *Da-sein* most often treats death as a possibility, rather than probability, which Heidegger (1962) called *being-toward-death*. In *being-toward-death*, *Da-sein* is unable to circumscribe the possibilities as *Da-sein* questions whether death means that our *potentiality-for-being* will result in nothing; we no longer exist (Vail, 1972). The more that *Da-sein* faces death as a possibility, the more it begins to anticipate it and expect it (Heidegger, 1962).

As noted, care is a basic state in which *Da-sein* exists ahead of itself in the world alongside others (Heidegger, 1962). The possibility of death disrupts *Da-sein's* being ahead of itself, or care. When we face the possibility of death in an everyday manner, *Da-sein* ‘hides’ from this *potentiality-for-being*. Although *being-in-the-world* may mean having encountered death, it is ‘others’ who die. Death is faced inauthentically as a ‘not yet’ occurrence. In addition, we cannot reflect upon or disclose a personal experience of dying, as it is something that we experience only once.

3.7.3 Call to understanding

Through disclosedness, *Da-sein* identifies its possibilities of being there. *Being-in-the-world* causes *Da-sein* to abandon itself to the possibilities, but is thrown by moods as outlined in the previous section. Moods are counter-balanced by understanding both the possibilities and the implications of each possibility (Heidegger, 1962). Only limited identification of the possibilities occur, because

Da-sein listens to others in idle talk and closes itself off from authentic discourse. "Losing itself in the publicness and the idle talk of the "they", it *fails to hear*...its own Self in listening to the they-self" (Heidegger, 1962, p.315). *Da-sein* needs to dis-cover itself and its *potentiality-for-being* when it hears its own conscience. The ability to hear its own conscience occurs when *Da-sein* is aroused by a call that quietens any ambiguity or curiosity about the possibilities, clearly enabling *Da-sein* to understand the *potentiality-for-being*.

The call to care is solely absorbed in summoning *Da-sein* from *being-in-the-world* so that *Da-sein* understands itself. The call does not come from an alien power that dominates *Da-sein* but just the opposite; the call empowers *Da-sein* to dominate itself. It comes from *Da-sein*'s uncanniness (Heidegger, 1962). As previously discussed, *being-in-the-world* means being surrounded by the *ready-to-hand* and *present-at-hand* of the world. In calling, *Da-sein* is called away from its previous understanding, and the framework on which that understanding of the world is based begins to collapse. Furthermore, the call does not make suggestions, or debate with *Da-sein* about what ought to be. Rather the call says nothing, which enables *Da-sein* to conceive the *potentiality-for-being* in caring for this situation. Understanding becomes an "attestation of Dasein's ownmost *potentiality-for-being*...which lies in Dasein itself" (Heidegger, 1962, p.324). The call points a way forward away from uncanniness, but not back into the 'their' world; *Da-sein* cannot 'unknow' something from past experiences or callings. Heidegger (1962) stressed that unlike Husserl's claim that consciousness provides understanding of humankind, the call to consciousness is not one that is universal; its appeal individualises understanding for the current situation. The call leads *Da-sein* to interpret the new phenomenon with greater understanding. "In interpreting, understanding does not become something different. It becomes itself" (Heidegger, 1962, p.188).

In disclosedness, *Da-sein* already understands the relationship of self in the new situation. That is, *Da-sein*, in care, leaps ahead of itself so that it is already there in the *potentiality-for-being*. The world is also understood in terms of *Da-sein*'s *being-in-the-world*. However, interpretation is founded on advanced interpretation of the *readiness-to-hand* of the world, a term Heidegger called *fore-*

having. In *fore-having*, the usability of items in the world is understood. Humans know how to use the hammer for example. Interpretation is also grounded in what is seen in advance, or as Heidegger expressed it a *fore-sight*. The *fore-sight* is not a premonition, but rather a view of the possibilities of the *fore-having*. In order to understand it is also necessary to be able to grasp the phenomenon, or hold a *fore-conception*. These three processes *fore-having*, *fore-sight* and *fore-conception* lead to *Da-sein* hearing the call, circumscribing the horizons, and interpreting the phenomenon (Heidegger, 1962).

3.8 Application of phenomenology to the situation at hand

As noted earlier, Heidegger explained that while the experiences of self cannot be proven, the experiences are shared through speaking about self. How those experiences are interpreted is governed by *Da-sein*'s reaction, and analysis of the words, or assertions made. In order to do this one must engage with phenomenology, not as a scientific technique, but as a fluid method to capture the moment of understanding (Heidegger, 1982). In other words phenomenology is a philosophy that enables one to un-cover *Being* deeply embedded in the world.

Heidegger called this first step in phenomenology phenomenological reduction. Reduction means leading "phenomenological vision back from the apprehension of a being, whatever may be the character of that apprehension, to the understanding of the being of this being" (Heidegger, 1982, p.21). Husserl also used the term phenomenological reduction. But Heidegger argues Husserl's reduction "is the method of leading phenomenological vision from the natural attitude of the human being...back to the transcendental life of consciousness (Heidegger, 1982, p.21). In contrast Heidegger believed that phenomenological reduction leads to understanding *Being* through examining the *potentiality-for-being* on the 'not-yet' moments. For example, if the spouse of one who is being transferred out-of-town has the opportunity to speak at that time, that person may well reveal the anxieties are facing the unknown of the outcome of the treatment, and the potential loneliness of not having anyone to talk things over with.

As previously discussed, *Da-sein* is not disclosed until a phenomenon causes disturbance to *being-in-the-world*. *Da-sein* is brought to view through

phenomenological construction, the reflection of *Being* on the *potentiality-for-being* and the world-view. In other words the articulation of the possibilities and projections that *Da-sein* states is care. However, because *Being* is so influenced by tradition, it is impossible to determine whether such exposure of *Da-sein* has “arisen originally and genuinely from the domain of being and the constitution of being they claim to comprehend” (Heidegger, 1982, p.22). Therefore, the investigative method needs to lead to destruction of the traditional concepts “down to the source from which they are drawn” (Heidegger, 1982, p.23). Destruction does not mean to destroy but rather free ourselves from previous interpretations, so that what is now being said is being heard (Heidegger, 1958b). The traditional ideas that are constructed are now de-structured¹².

Cooper (1996) elaborated on this process by explaining that when we encounter a new phenomenon we cannot ignore our past understandings and view the phenomenon with fresh eyes. Our thoughts and interpretations are based on our traditions and unarticulated understanding. In order to capture true understanding, the traditional ideas must be reconfigured, so that understanding forms truths through construction of alternative thoughts of understanding (Cooper, 1996). In other words, the impact of the non-local tertiary hospitalisation on the supporting spouse needs to be differentiated from the expectations that hospitalisation may have on any couple.

3.8.1 Da-sein and a circle of understanding

Through judging a phenomenon, *Da-sein* is exposed. It is the judgements derived from assertions made by *Da-sein* that point out the entity itself (Heidegger, 1962). This pointing out does not attempt to interpret the entity, but to raise an awareness of it within the world. In raising this awareness *Da-sein* predicts the impact of the assertion on *being-in-the-world*. However, because it has been noted, the assertion is communicated, and shared with others. Furthermore, the assertions should not be looked upon as explanations of the world, but rather the entities that reveal *Da-sein*. Heidegger (1962) explained

...phenomenological access to the entities which we encounter, consists rather of thrusting aside our interpretative tendencies, which

¹² I have written de-structured this way to stress that the breakdown of the cultural structures of knowing, not destruction of society in general.

keep thrusting themselves upon us and running along with us, and which conceal not only the phenomenon of 'such concern', but even more those entities themselves *as* encountered of their own accord *in* our concern with them (p.96).

Understanding and dis-covery of the world is embedded in a prior interpretation of the world. Haugeland (1992) provided a very good example of *Da-sein*'s disclosedness based on prior interpretations of the world by asking readers to visualise a game of chess. As chess players scrutinise the board, they also scrutinise their opponent's weaknesses and potential strategies to overcome their opponent. This scrutiny takes place within preconceived understanding of how the game is played, and the rules and reasons behind each move. It is the dis-covery of the other player's ability that directs the next moves. Before chess was invented, the rules for playing the game would not make sense (Haugeland, 1992). Such is the world of those whose spouse is hospitalised with critical illness. In the same way, recovery from critical illness is not a phenomenon that occurs without understanding the impact of illness on life (Hanger et al., 1998; Miller & Wikoff, 1989).

Gadamer (1981) took Heidegger's process of reduction, construction and de-struction further by proposing that while realisation of self occurs in the circle of understanding, it is expressed in a hermeneutic circle. In the hermeneutic circle the phenomenologist must not only examine the language that the story-teller uses to describe the dis-covery of *Da-sein*, but also the phenomenologist's personal world and understanding. Self understanding does not emerge from transparency of oneself, but from throwing light onto the motivations and tendencies that are exposed in speaking (Gadamer, 1981). Reduction, construction and de-struction can only be made possible as *Da-sein* is given the opportunity to speak about the projected *potentiality-for-being*. Within the hermeneutic circle, interpretations and understandings are made because there is shared background with the members of the circle (Plager, 1994). For example, although the effects of having a spouse/partner hospitalised out of town have not been explored before, nurses have some understanding of the effects of hospitalisation in general. This enables them to conceptualise the scene described by each participant. It is my responsibility to present the stories from each research participant in such a way

that the experience is described and linked back to the analysis. This way readers will also be able to interpret the significance of having one's spouse hospitalised in the out-of-town setting. This framework is supported by Leonard (1994) who stressed that there is a mandate for the researcher to "stay true to the text" (p.57), in order to systematically analyse and gain insights into the experiences in this way for this time. By sharing experiences of the research participants with others who have experienced this phenomenon, the concepts are validated and truths emerge. Because language is how *Da-sein* is revealed, it is necessary to listen to what this group is saying, and whether they are describing everydayness, or truly revealing 'being there'.

Furthermore, the seeming of a phenomenon can be explained by the use of the word 'events'. Events happen, but two people may not necessarily experience the same event in the same way. It is the impact of the event on the individual that transforms it into a phenomenon. If there is to be an understanding of the phenomenon, it is necessary not only to differentiate between the phenomenon that shows itself and the phenomenon that resembles the self, but also demonstrate the connections between the two (Heidegger, 1962). A phenomenological study of a spouse being hospitalised out-of-town will not identify one meaning of *being*, but will provide insight into the experiences, so that others caring for this patient group can be there in a meaningful manner for the couples during this time.

3.9 Chapter review

In conclusion, phenomenology is a philosophical approach that gives attempts to understand the meaning to life. The meaning of life has intrigued and plagued philosophers since Greek times. Although Husserl believed that the answer would lie in discovering the source of knowledge, Heidegger believed that understanding *Being* is the essence to understanding life experiences. Therefore, his thesis sets out to prove that *being* can and must be defined in order to analyse *Da-sein*'s reaction to a changing world. This interpretation is based on understanding the world, which has already been discovered.

Using Heidegger's phenomenological approach means to grasp *Da-sein* so that everything about the phenomenon can be exposed and described. Everydayness

occurs in an ever-changing world. As *Da-sein* struggles to come to terms with changes in the world, *Being* oscillates between *being-in-the-world*, *potentiality-for-being* and *being-there*. How *Da-sein* adjusts to the world depends upon past experiences, and the ability to anticipate and make sense of the phenomenon. This adjustment is affected by experiences of *being-with-others*, and does not become apparent until affected by moods, or death of the world as it is now, occurs.

On the surface, Heidegger's thesis does not automatically provide guidance about the content and methodology required to ascertain truths. Because the very nature of the inquiry is actions behind everydayness, it could be easy to lose interpretations in the language used. It is the analysis of language that leads to an understanding of *Da-sein*. To Heidegger, phenomenology and hermeneutics are one and the same. Gadamer explained that dis-covery of life is embedded in language and revealed through the hermeneutic circle.

Phenomenology is an approach to research that challenges nurses to not only validate the experiences of others, but also to reflect upon the lessons learned from those experiences. At the times when individuals are feeling vulnerable or apprehensive, it is often the unspoken that portrays far more than the spoken word. The value of hermeneutic phenomenology is that it enables those working with people to move beyond the superficial message, and examine the understanding of the message (Walton & Madjar, 1999). How hermeneutic phenomenology is used to facilitate an understanding of having one's spouse hospitalised in non-local tertiary settings is presented in the next chapter.

CHAPTER FOUR RESEARCH METHOD.

4.1 Introduction.

The basis of hermeneutic phenomenology is that phenomena are studied within the context of *a priori* understanding of living in the world. Hermeneutic phenomenology “encompasses both the alien world that we strive to understand and the familiar world that we already understand” (Linge, 1976, p.xii). In the case of the current study, the research participants’ familiar world had already changed as a result of the illness. The purpose of this chapter is to discuss the engagement of phenomenological enquiry that brings “to light of day” (Heidegger, 1962, p.51) the experiences of having one’s spouse hospitalised in a non-local tertiary setting. In addition, I explain the processes that were used to conduct this study.

The chapter begins with a justification of why phenomenology guides understanding of the experiences of having one’s spouse hospitalised out-of-town. The ethical issues related to participant recruitment and selection are discussed before readers of this thesis are introduced to the research participants and their spouses. Although I have engaged with Heidegger’s work to gain and understand *being*, I have been guided by the works of Benner (1994) and Dahlberg et al. (2001) for the analysis of the data. The philosophical underpinnings of Heidegger’s framework are presented in Chapter Three, but it is also necessary to present some of the debate that has occurred between writers about phenomenology and how that debate influenced my thinking in undertaking the current study, and in presenting the findings. This debate focussed around usage of words such as ‘phenomenology’, and ‘interpretive phenomenology’ and the challenge issued by Crotty (1996) to nurses when he contends that nurses use phenomenology to foster caring and nurturing, while Heidegger’s philosophy is to understand *being*, not foster caring. An additional challenge for those using humanistic sciences is to fulfil traditional scientific expectations of presenting absolute truths. Therefore, strategies to foster rigour and truths need to be considered in analysing and presenting the findings.

4.2 Why Phenomenology?

As noted in Chapter Three, phenomenology is a philosophy that explores realities of *being-in-the-world* and the foundation of Heidegger's hermeneutic phenomenology is that understanding *being* is the key to the essence of interpreting how experiences change individual interpretations of life.

Hermeneutic phenomenology is a philosophical framework that has captured nurses' imagination as it enables a deeper understanding of how to treat those whose experiences change their understanding and interpretation of the world (Johnson, 2000). Anecdotally hospitalisation in a non-local tertiary centre is now becoming relatively common both nationally and internationally.

However, the effects of this phenomenon could be minimised by others (in this instance, health professionals). The minimisation by others could result in the supporting spouses' perceptions becoming reflections of *being-with-others* (they-self), and lead to an expectation that the experiences do not generate ontological deliberations. Through careful listening, the authentic self will have the opportunity to express the reality of this experience.

Interpretive phenomenology, developed by nurses such as Benner, provides nurses with a theoretical basis to explore human concerns within frameworks that do not reduce such concerns to levels of cause and effect (Plager, 1994). However, as identified, Crotty (1996) is very critical of Benner's theory proposing that because Heideggerian phenomenology is to reveal the meaning of Being, nurses' usage of phenomenology to foster general understanding and caring misinterprets Heidegger's purpose. Crotty's argument is based on his belief that Heidegger was obsessed with understanding Being and the actions behind Being.

The critique of nurses' use of Heidegger's work is not new, and the criticism arises from attempts to generate the commonalities of interpretations in culturally-grounded meanings, rather than interpretations that are private and individual (Paley, 2002). The issue arises when studying a phenomenon such as the experience of non-local hospitalisation because the stories can become descriptive, not critical, especially if the intent of the stories is not to explicate the phenomenon (Barkway, 2001; Crotty, 1996). It has been argued that

because nurses who use Benner's approach to interpretive phenomenology focus on extracting meanings from the phenomenon, that is highlighting a focus on the subjective experience, they do not return to the phenomenon (understanding Being) itself (Crotty, 1996; Paley 1998).

Barkway (2001) contends that unless caution is taken when analysing the data, a subjective experience will provide meaning, but will not reveal a Heideggerian perspective of individual understandings of being. As outlined in Chapter Three understanding being occurs when the world as we know it is disrupted. Furthermore, Heidegger stressed that individual interpretations are bound in an understanding of the world as it is at that time; each new experience changes interpretations of the lifeworld. Having one's spouse hospitalised in a non-local setting is not an everyday occurrence; therefore there is no everyday interpretive framework on which to base the experience. Each experience brings new meaning.

Meanings that emerge from the text cannot be presented as arbitrary interpretations according to Gadamer (1975), who goes on to argue that just as misinterpretation of a word causes misinterpretation of the whole, continued dependency on previous understandings blinds interpretations of the new. Although Heidegger's hermeneutic perspectives provide insight into the nature of being, interpretations that emerge from the text enlighten understanding of similar situations (Gadamer, 1975).

Hermeneutic phenomenology explores the disclosure of *Da-sein* when the taken-for-granted is disrupted; disclosure that reveals how *Da-sein* would make sense of the world. My role is to glean understanding of having one's spouse hospitalised in a non-local tertiary centre from the research participants' stories about their experiences, and share that understanding with others. Interpretive phenomenology enables meanings to be pointed out (van Manen, 1990). Phenomenological descriptions echo experiences that others have had, or can relate to, as the researcher reflects upon the descriptions of the situations and other's life-worlds (Benner, 1994; van Manen, 1990). In other words, the research participants may not have necessarily reflected upon

the impact of having their spouse hospitalised in a non-local tertiary centre had they not taken part in this study. However, having been asked the question, they were able to reflect and disclose their understanding of the impact that the experience had on them. Although others' life-world can never be completely revealed (Benner, 1994), connections between individual experiences that facilitate other's understanding are "good phenomenological descriptions" (van Manen, 1990, p.27).

4.3 Meanings, Interpreting And Hermeneutics.

As described in Chapter Three when Heidegger used the term phenomenology, he describes the process of *Da-sein* interpreting the world based on its understanding of *being-in-world*; that is the past, the present and *potentiality-for-being*. He further explains that perception "is consummated when one addresses oneself to something as something and discusses it as such. This amounts to interpretation in the broadest sense" (Heidegger, 1962, p.62). Gadamer added to this understanding of the word interpretation, by differentiating between interpretations as pointing to something and pointing out something. The aim of pointing to is not to read something into the phenomenon, but to reveal the phenomenon itself (Gadamer, 1986). Interpretation is not the acquisition of "information about what is understood; it is rather the working-out of possibilities projected in understanding" (Heidegger, 1962, p.198). The interpretive nature of phenomenology enables the researcher to weave between the participants' worlds, expressed through dialogue (Benner, 1994). Benner further argues that the interpretive researcher needs to move back and forth between the situations to contextualise the worlds. However, it is not the general world, but individual world of non-local hospitalisation that is the focus of inquiry. The purpose of this study was to describe the phenomenon of having one's spouse hospitalised in a non-local tertiary centre following hermeneutic phenomenological processes to interpret *being-in-the-world* as it became for the research participants at that time.

4.4 Phenomenological Processes.

One of the challenges of conducting research is that readers need assurances that the processes and findings are credible. Heidegger did not envisage that hermeneutic phenomenology would become a research method. Therefore, he did not clearly provide guidance for employing phenomenology as a process of enquiry. To uncover the structure of being Heidegger analysed being's world, and how entities within the world were understood. As explained earlier when the understanding of the world is disrupted, aspects of self are revealed. However, understanding disruptions to the world can be difficult when making interpretations based on others' stories, unless the focus is on the phenomenon itself. Nurses are familiar with the hospital world, but in cases such as presented in this current study, not all patients or family members are familiar with the hospital environs. It is the presentation of the unfamiliar, and uncanniness that reveals the research participants' understanding that is the focus of this study. Although similar research could be replicated, similar interpretations are not necessary to validate their understanding of the situation at that time.

4.4.1 Addressing Suppositions And Learning From The Data.

Of interest, is van Manen's (1990) claim that the research process aims at being "presuppositionless" (p.29) in that the researcher aims to avoid "constructing a predetermined set of fixed procedures, techniques and concepts that would rule-govern the research process" (van Manen, 1990, p.29). While this is sound advice, he further argued that those engaging in phenomenological approaches should identify their suppositions and preconceived ideas in order to avoid shaping the text to reflect those suppositions. Indeed Heidegger advised that access to understanding is achieved by "thrusting aside our interpretive tendencies, which keep thrusting themselves upon us" (Heidegger, 1962, p.96). However, how can one put aside the suppositions? If there are no suppositions, why is there a question? Heideggerian philosophy is that assumptions cannot be put aside because they underpin understanding or intelligibility (Burke Draucker, 1999).

Heidegger (1962) explained that the hermeneutic circle is:

...a positive possibility of the most primordial kind of knowing. To be sure, we genuinely take hold of this possibility only when, in our interpretation, we have understood that our first, last and constant task is never to allow our fore-having, fore-sight, and fore-conceptions to be presented to us by fancies and popular conceptions, but rather to make the scientific theme secure by working out these fore-structures in terms of the things themselves (p.153).

Gadamer (1975) adds to the need to gain understanding from the experiences themselves by arguing that passing on understanding does not emerge from the practice of hermeneutics, but rather from describing the way the interpretations have been made. Individual understanding can be distracted by anticipation of the concepts, not the portrayal of the concepts themselves. Therefore the interpreter must remain open to others' meaning embedded in the language (Gadamer, 1975). "The important thing is to be aware of one's own bias, so that the text itself may present itself in all its newness and thus be able to assert its own truth against one's own fore-meanings" (Gadamer, 1975, p.238). Preventing presumptions is founded upon focussing on the text to extricate the interpretations that emerge and remaining open to the meanings (Gadamer, 1975).

My suppositions are that the phenomenon of non-local hospitalisation may cause disruption to daily living, fear of the unknown and possibly a sense of being overwhelmed by the experiences. My question about the experiences of non-local hospitalisation remains from the initial concern expressed in Chapter One. As a clinical nurse, I probably nursed people who were not residents of the area in which I worked, something I did not take note of this at the time. As a nurse-educator, I may only look at the patient notes by invitation, usually from the student nurse that I am supervising. I am dependent upon them to identify that the patient is from an out-of-town centre, or is to be transferred to a tertiary centre. Therefore, my suppositions about the impact of this experience are not derived from a professional or personal perspective, but rather from that of an on-looker, as a nurse educator, and member of the world.

Despite this, in interpreting the experiences shared by those who have had their spouse hospitalised in a non-local tertiary centre, it is important that my mind is focussed on understanding the experiences through listening to and interpreting the stories of those who experienced out-of-town hospitalisation, not through what I think they would experience. In other words, understanding *Being* does not occur through story-telling, but through the conception of *Da-sein*'s interaction with the *present-at-hand* and the *potentiality-for-being*. In order to make a connection, the hermeneutic phenomenologist needs to look at the world-horizon through the storyteller's eyes, to allow understandings to emerge. This understanding occurs within the hermeneutic circle where existence is understood in reference to the world as a whole, and vice versa (Heidegger, 1962). To enable others to understand the experiences of having one's spouse hospitalised in a non-local tertiary centre, I needed to collect the stories of those who have had this experience, and share my interpretations of those stories with others. While having one's spouse hospitalised in a non-local tertiary centre may be overlooked if one views it as an event, the phenomenon of this experience is understood through attentive listening and reflection. Should the experience be viewed as an event, the impact on the individual's understanding of *being* could be lost.

During the first interview conducted for this study, I discovered that Melanie (pseudonym) had been hospitalised in an out-of-town centre for only three days. I speculated whether that would be easier to cope with, and started looking for participants whose spouse/partner had been away for longer. However, later, I also interviewed Andrea, where I discovered that Eric had been transferred to a non-local tertiary centre for only two three-day episodes. He had been transferred to the out-of-town centre, transferred back 72 hours later, but had complications and later needed to be transferred back again. These three-day blocks were more difficult for her to cope with than earlier episodes when he had been treated out of town and had been hospitalised for two weeks. As noted in Section 3.4.3, time itself has no characteristics; time is an entity within the world that continues to pass irrespective of whether or not it is considered in our everyday deliberations (Heidegger, 1989). Andrea's experiences are a very good example of how *Da-sein* became

apparent to itself as it anticipated disruption to the world as it existed, and how *being* manipulated the time and the taken-for-granted surroundings. Although Yoland and Andrea both had their spouses hospitalised in the non-local tertiary centres for the same length of time, their interpretations of the situation were individual, not thematic.

A major criticism of Benner's interpretive phenomenology is that she encourages nurses to search the data for themes, not enabling the data to speak (Crotty, 1996). However, during the time of undertaking this research, I had the privilege of listening to Nancy and John Diekelmann when I attended a workshop in Wellington (hosted by Victoria University, 25 February, 2004). They seemed to be able to differentiate for me processes of searching for themes versus letting the data speak. Letting the data speak involves reading the text, and determining my interpretation of the story by seeking partnership with the story-tellers. The Diekelmanns stressed that it is essential when using hermeneutic phenomenology not to use the stories to provide examples of what you want to say, rather to allow the phenomena to emerge. As the researcher reads the stories some aspect of the experience comes to the fore and generates understanding. While the researcher focuses on part of the story other components of the story may momentarily recede. These components get addressed in turn, temporarily fading other aspects of the story as themes come forth. The extent to which there is convergence between the individual and others stories generates validity (Burke Draucker, 1999).

By reflecting upon and through hearing similar stories I analysed the experiences, which validated others' similar experiences, thus bridging the gap of individual stories in order to generate understanding (Walton & Madjar, 1999). Instead of searching for themes, I looked behind the words of the stories, and could see that issues, such as living with the illness, or coping with life-changing emergencies, were part of the experience of having a spouse hospitalised in a non-local tertiary setting. Such issues seemed to influence how these research participants reacted to the necessary hospitalisation. The themes that are presented in subsequent chapters of this

thesis are the result of scrutiny and critical analysis of the words used; that is the themes are the result of analysis, they have not generated the analysis.

4.4.2 How Did I Select My Research Participants?

In my original proposal to the ethics committees, I had indicated that I would use two approaches to seeking research candidates. I had ready access to patients, and therefore potential research participants whilst supervising students during their practicum experiences. However, this had the potential to place these people under pressure to participate. I therefore intended to seek permission to advertise the research in places such as hospital critical care units to capture potential research candidates, and to ask case co-ordinators or senior nurses at the local District Health Board if they would approach likely candidates for me.

After receiving ethics approval (See Section 4.4.3), I approached nurses who worked within the transport team, as well as those who worked in areas such as emergency departments and critical care units at the local District Health Board. However, despite the fact that people are transferred to tertiary centres very regularly, initially, it was surprisingly difficult to get participants. Some of the nurses willingly gave flyers to potential research participants.

However, those who had a spouse being transferred did not readily contact me, and on reflection, it could be assumed that they had other things on their mind, and would have put the flyers to one side. Furthermore, phenomenological reflection must be retrospective as reflection upon the here and now is impossible; the phenomenon has already changed (van Manen, 1990). For this reason, I abandoned the idea of seeking potential research participants from places where they were living the experience and relied on working with appropriate nursing personnel, such as flight nurses, case co-ordinators and nursing contacts to identify and contact people whom they knew had their spouse transferred to non-local centres.

Until these intermediaries became engaged in the idea of this research, they did not value their role in approaching potential research participants. It was not until some intermediaries had an opportunity to hear about the research

that they became interested and identified potential research participants. Other potential research participants approached me themselves. Snowballing is a very effective process of having research participants approach the researcher, or identify other potential participants (Dempsey & Dempsey, 2000; Nieswiadomy, 1998).

It was intended that I interview 12-15 people for this study. Of the 15 people who either approached me, or whose name I was given as a potential participant, 14 took part in this research. Their stories and my interpretations of their experiences are presented in Chapters Five, Six, and Seven. After initially agreeing to take part, the fifteenth candidate declined at the time of the pre-arranged interview, as she “*had no time*”. At this point I felt I was beginning to identify patterns in the stories I had heard, so accepted her decision, rather than arranging another time that might suit her.

4.4.3 Ethical Issues.

Ethics approval for undertaking this study was acquired through Massey University Human Ethics Committee and the Hawke’s Bay Ethics Committee. Although none of the spouses were to be current in-patients in the non-local tertiary centres, the Hawke’s Bay Ethics Committee requested that I notify them prior to conducting initial interviews. This was so that the areas in which the spouse had been treated could be identified, enabling the local ethics committee to notify the relevant area ethics committee that the research was being conducted.

However it became apparent during the first interview that I was not able to become privy to the site of the non-local tertiary hospitalisation until the interview was in progress. In addition, the site of the hospitalisation would not form part of the findings. On further correspondence with the local ethics committee it was suggested that I formally inform the regional ethics committees in the four areas that the spouses would likely be hospitalised in, of the research. Having complied with this requirement, I continued with the interviews.

After some initial interviews, I became concerned that I would be unable to maintain confidentiality for two reasons. Early research participants lived in one particular province, and if they had been treated at the local hospital prior to the transfer, there was a danger that their situation could be recognised. The participants had been transferred to Palmerston North, Wellington and Auckland for treatment. I became concerned that it may be easy to identify them if I discussed the length of stay, or the specific medical condition that caused hospitalisation. On the other hand, I did not want their stories to become so vague that they became meaningless. Therefore, after additional correspondence with the Hawke's Bay Ethics Committee, they forwarded approval for me to interview participants from two other District Health Boards.

Of the 14 individuals or couples affected by a transfer to a non-local tertiary centre, and who took part in this research, six of the spouses had cancer, five had heart conditions, while the remaining three had other conditions that required treatment in non-local tertiary hospitals. In all, these research participants were from six different geographical areas, and the spouses had been transferred to five centres, including some being transferred to more than one centre for the same illness. Although the spouses of the research participants had differing medical conditions, aspects of their stories that they shared were similar.

All research participants had the opportunity of having a support person present during the time of interview. It was a coincidence, rather than for support, that eight of the research participants had their spouse there for either one or two interviews. This privileged me to hear things from both perspectives, but there were times when I also wanted to hear things from the research participant's perspective only, and had to negotiate a time to revisit, or explore the experiences with the research participant alone.

I had also arranged access to counselling should the research participants find that recalling their experiences of having their spouse hospitalised in the non-local tertiary setting caused distress. After my second interview I did not

emphasise this, as that second participant became apprehensive that she was going to be questioned until she became upset and traumatised. When approaching people, most did not think that they would need a counsellor, as they felt they “had nothing to say”; they “just got on with it”.

Each interview was begun with the same question “*Tell me about the events to [your spouse] needing out-of-town hospitalisation*”. Despite the claims that they had little to contribute to the research, the transcripts reflected that I would often ask the opening question, and apart from using facilitative communication techniques, would not ask another question for some two or three pages. There is obviously comfort in having someone who wanted to hear the experiences of hospitalisation from the supporting spouse’s perspective. After some initial surprise that someone was interested, the research participants told their stories in the hope that others may learn from the experience.

After I had presented some of my research findings at a seminar, two people approached me and asked me if they could take part. Both talked about the experiences of having a spouse hospitalised in a non-local tertiary setting. However although she was interviewed about her husband’s non-local hospitalisation, this second person wanted to talk more about her experiences of supporting her daughter who was currently undergoing treatment. This research participant had felt in control when her husband had been hospitalised in a non-local tertiary centre. In contrast, she felt quite powerless in dealing with her daughter’s illness, and providing support from a distance, and said, “it is nice to talk to someone who is interested”. Her need to tell me about her daughter also made me realise that there are commonalities in having loved ones hospitalised in non-local tertiary centres, and the stories I was hearing were not unique to spouses. As identified this research participant’s sense of control that had sustained her during the time her husband was hospitalized non-locally, but not during the time that her daughter was hospitalized out-of-town.

4.4.4 The Research Participants.

Let me introduce the research participants to you. All names used have been changed. I had initially intended that the research participants would select a name for themselves. Prior to the interviews, I decided against that, as I did not want the participants to adopt a role in a play that they had written, but to talk about their real experiences as they occurred for them. Making up pseudonyms after I had met each research participant initially caused me problems as the names I gave them were so removed from the people who so generously shared their stories, I felt I was giving them personalities that they did not have. While I could easily go to any piece of the individual transcripts and remember passages of the stories word for word, I had difficulty remembering the names I had randomly assigned to the participants. To counteract this, I interwove their pseudonyms into each of the transcripts, and used them in any reference I made to their stories. Once I immersed myself in their stories, I forgot the research participants' real names, and began to think of them by their pseudonyms. These pseudonyms citations are used in the thesis rather than interviews numbers from one to 14.

Of the couples affected by having the spouse hospitalised in non-local tertiary centres, four wives and ten husbands required transfer to another centre. It may be a coincidence, but of these couples, only one man accompanied his wife for a short period of time. On the other hand, six of the wives accompanied their husbands for the entire time that they were in the non-local tertiary centre; only two of the wives stayed at home. One of the women spent some time in the out-of-town centre with her husband before returning home. Traditionally, it has been seen that women have the role of caring during times of sickness (Koivula et al., 2002), and the role of men as carers is often overlooked (Maughan et al., 2002). Certainly, it was not in the scope of my research to determine the role of men as carers. However, it seemed that the male participants of the current study were content to leave the specialist nursing to the health professionals and wanted to reassure their wives that they could manage the household without them for a while.

The estimated age-range of the research participants was mid-thirties to mid-seventies. At the time of interview their age did not appear important. What was important was that six of the couples had young children at some stages during the illness that required non-local tertiary hospitalisation, which affected their freedom to accompany their spouse. Five of the research participants were business people, and the non-local tertiary hospitalisation resulted in them making alternative arrangements to maintain that business, or influenced their ability to accompany their spouse. Six of the participants were in paid employment, and availability of sick leave influenced the decision of staying at home, or accompanying the spouse out-of-town. The remaining three were retired, in which case it was finances and support that influenced their decision to stay at home, or accompany the spouse.

Although some of the spouses took part in primary health activities such as monitoring cholesterol levels and cancer screening, eight couples had no warning of the life-changing occurrences that were about to occur. Of the fourteen spouses who required hospitalisation in a non-local tertiary centre, only three patients were suddenly transferred. However, the medical condition of five of the remaining eleven spouses did deteriorate suddenly, hastening the need for transfer to the tertiary setting. Two of those five were transferred from local hospitals to the tertiary settings. In addition, although the couples had little warning of the life-threatening illness, most of them had to wait for the treatment at the tertiary centre. Some of the spouses were transferred directly from the local hospital, while others were discharged and put on a waiting list.

The research participants had to make several adjustments to the world as it became when their spouse's health was compromised. Some of these adjustments had been made several years before. For example, although one of the research participants had a driver's licence, this person never really used it. They lived 140 km from the regional hospital. Her husband needed to have renal dialysis three times a week and he was too sick to drive himself to the centre of treatment. They had to rely on friends, until after some time this research participant realised that she could no longer ask others for

assistance, and had to learn how to drive. Furthermore this research participant also realised that her husband's wages (their only source of income) were in an account in his own name. (Although this aspect of the story centres on events thirty years ago, and might not occur in this day, it could occur with de facto couples maintaining their independence.) Her husband at that point was desperately ill, but she had no access to money to maintain the house. Once he was discharged from hospital, the bank account was put into joint names. She also wondered what other adjustments to the world she would have to make.

The length of time that the spouses were hospitalised in non-local tertiary centres varied from three days to eighteen weeks. My concerns about how to compare such different lengths of time are addressed in this chapter, as it became apparent that it was not the length of time that was the issue, but rather the experience during that time of having one's spouse hospitalised in a non-local setting.

Winifred was married to Robert who had long-term complications from a medical condition he acquired some years before. Therefore she was used to him being in hospital, and as she said "*I don't panic about it now, 'cos I think 'oh well, he is in the right place'*" (p.1).

Andrea also had lots of experience with her husband being hospitalised out-of-town. Eight years prior to the current study he had been transferred to a non-local tertiary centre for elective surgery. She had accompanied him on that occasion and, with her daughters, turned the trip into a type of holiday. His condition had deteriorated over the years and at times he had gone to stay with their children "*to give me a break*" (p.1). Unfortunately he required hospitalisation during some of these times. On one occasion, Andrea chose not to go and see him for the first few days. She had been looking forward to a break from single-handedly caring for her husband and the household, and although she did not express it, there was a feeling of resentment that he required out-of-town hospitalisation during times when he had gone to stay with other people.

Yoland had been worried about Melanie's well-being for six years prior to her needing hospitalisation out-of-town. He was unable to accompany her to have treatment, something that Melanie was still upset about. Meanwhile, Yoland was so relieved that Melanie was to receive treatment, he felt timely treatment was more vital than it being delayed until he could get time off work.

Carol had a long period of time accompanying her husband to the non-local tertiary centre. He had been waiting for some time to have surgery in the out-of-town centre, but had little warning of the actual transfer.

Time away became part of a continuum of living for Nancy. William had received out-of-town treatment about five years before the time of the interview. Nancy simply said of her role at that time "*I went with him* [to the initial specialist appointment when the treatment plan was developed] *and I went with him for every treatment after that*" (p.1).

Zoë was fortunate that she was able to accompany her husband when he was transferred out-of-town. Zoë's husband, Trevor, was going to be transferred to a non-local tertiary centre for elective surgery. However his condition deteriorated, so his transfer was initially delayed for a few days until he was stabilised, prior to the transfer. Because it was initially planned that Trevor would have the surgery, Zoë had already arranged to have time off from her place of employment. The altered timing of the out-of-town hospitalisation resulted in Zoë having to change the travel arrangements, and paying full price for the airfare to the tertiary centre; a financial cost they had not planned on.

Financial costs also challenged Warren and Alice. Warren has had several trips to non-local tertiary centres for treatment, and each time Alice juggled her time and commitments to support Warren and the children at home. As well as meeting financial commitments, Alice has been fortunate that family support also sustained her and Warren during the times of treatment.

Paul found juggling their business and home life, including looking after two young children, a challenge during the time that Glenys was hospitalised in another centre. Like Warren and Alice, Paul and Glenys decided that he would not accompany her, as they wanted to create as much normality for the children as possible. Paul later identified that their two-year-old daughter was very confused by her mother's absence, and they speculated whether their decision was the correct one to make.

Edward and Trudie also tried to determine the best options for the entire family when Trudie required out-of-town hospitalisation. In addition, Edward, was reluctant to jeopardise his work, and struggled to balance his commitments to Trudie, and his work. He accompanied Trudie to the non-local tertiary centre for some time, but also had to leave her there in the centre while he returned to paid employment.

Queenie found solace in her work when Gerry needed transfer to a tertiary hospital. However, her work was not in the town that she lived in, so she needed to return home and make hasty preparations so that she could support her husband. The next few weeks resulted in her travelling between hospital, home and work.

Victoria and Don also needed to change arrangements when Don was suddenly hospitalised for a longer period of time than anticipated in the non-local tertiary centre. Don was expecting to undergo pre-admission screening tests in the tertiary centre; an expectation of being in the centre overnight only. The couple were unprepared for his extended admission.

Jan and Euan were on holiday when he identified the symptoms that resulted in a transfer to a non-local tertiary centre. Not only was their holiday ruined, the tertiary centre would not treat Euan at that time. Therefore, they needed to return home and in the subsequent period of time waited for treatment. Jan found herself watching her husband for signs of exacerbation of this medical condition until his condition deteriorated to the point where they returned to the out-of-town centre for surgery. Furthermore, Jan felt that Euan was

cheated as he had taken particular lifestyle precautions, but still developed the same condition that caused his father to die at a young age. Jan was relieved when Euan was finally treated; relief that sustained her during the days that he was away.

Owen chose not to accompany his wife Fiona when she was transferred to a non-local tertiary centre. He had a seasonal business to run, and felt that it would not be fair to ask anybody else to run this during a particularly busy time. In addition, he knew that his wife was surrounded by support in the tertiary centre.

The last couple, Therese and Ernie had long ago adjusted to the illness that resulted in Ernie requiring out-of-town hospitalisations. Despite having had long periods of time to make the adjustments, Ernie's condition suddenly deteriorated. Therese was uncertain whether he would survive the transfer. At the time of Ernie's original illness, they had young children.

4.4.5 Gathering The Data.

The aim of the research was to provide opportunities for the research participants to tell their stories. Therefore, I did not have standard questions that I asked apart from always beginning with "*tell me about the events leading up to [your spouse] getting sick and needing out-of-town hospitalisation*". After an early presentation at Massey University Doctoral School, it was suggested that I also determine what sustained the spouses during this time of out-of-town hospitalisation. At that point I had met with four of the research participants, and found it was implied in their stories. However, knowing what kept people going during this period of time was pivotal to understanding the experience of non-local hospitalisation. Consequently I included a question around that subject for subsequent interviews.

When retrospective data is gathered, the participants need to be re-focussed on the experience at that time (Kahn, 2000). How did I do this? I began by asking participants to recall the events leading up to their spouse's illness in

general, and then focus on finding out that their spouse was to be hospitalised in the non-local centre. From this beginning reflection, the research participants were then able to tell me what it was like for them. Once they moved past the “I have nothing to say, because I got on with it” stage, they revealed the moments of hope, despair, boredom, and carrying on with life that they encountered during this time.

I initially questioned whether there would be problems interviewing people who had a long period of time between the non-local hospitalisations and the recollection. However, I had mentioned my intention to research this with a friend, whom I knew had been through this experience some many years earlier. The moment we started discussing it, I could see that she had transferred herself back to that time. This happened frequently throughout the interviews, and as Zoë said during the second interview “*That was what [I was doing]...going right back*”. The “*going right back*” (p.12) also connected with other people during presentations about this research.

When conducting research using hermeneutic phenomenology, it is essential that the researcher does not view participants in terms of individual characteristics that can be seen as variables, but as people who illustrate what it is like to be themselves (Steeves, 2000). The key words here are ‘being themselves’. When I first began the research, I went back to see the participants for a second time. On the second visit I would take the transcript, which the research participant would read and we would use this as a trigger for further discussion. However, it seemed that I had gleaned the majority of information during the first visit, and the second one produced little additional information. I had experienced this during the first visit with Andrea and Eric. Every time I asked Andrea a question she would supply the answer, and then say, “*what else do you want to know?*” Consequently, I made the decision that if I felt I had as much information as I was going to get, I would not revisit.

The decision whether or not to go back and see the participants was difficult to resolve. I had read Elizabeth Smythe’s (1998) PhD thesis *Being Safe in*

Childbirth where she expressed sentiments that she had felt as a research participant when the researcher came back to see her, and she felt she had nothing left to say. On the other hand Jo Walton (1995) made several visits to her research participants when she undertook her PhD thesis *Living with Schizophrenia*. Was I doing an injustice to my research participants by only visiting some of them once? I don't think so. As I have identified, there was general surprise that there was interest in how they coped with the out-of-town hospitalisation as their focus was on the spouse who required treatment. Therefore, a second visit to them would only exacerbate their surprise, and could lead to frustration that their story was not heard in the first place. On the other hand there was benefit in going back to some places, particularly if both the spouse and the research participant were there for the initial interview. During the second meeting, and without the spouse, the research participants were able to express their reality of the experiences, without feeling that they were being disloyal.

When I reflected upon the subject of Jo Walton's PhD thesis, she wanted to explore living *with* a condition (in this case Schizophrenia), whilst Elizabeth Smythe's PhD wanted to explore a single phenomenon (safety in childbirth) that occurred in the continuum of living. I felt that I too was exploring a phenomenon that occurred within living. Although it transpired that the spouse was also 'living with' this condition, the point of interest was the experiences of having a spouse hospitalised in a non-local tertiary centre, a single phenomenon.

All interviews bar one were conducted at the research participants' homes. The Massey University Human Ethics Committee had expressed concern about my personal safety when I was conducting these interviews, and had suggested that I develop safety strategies. Consequently my husband always drove me to the place of interview, and sat in the car. After a few interviews, I became quite blasé about my safety, and did not think that I needed being accompanied to individual people's homes. This false sense of security remained until one day when I knocked on the door of one house and, in response to asking if I was at the correct address, was told, "*it depends on*

what you want". On that occasion I was very grateful that at least someone, sitting outside in the car, knew where I was. Of course, my husband always had the dilemma of never knowing whether the interview was progressing, or whether I was in need of his help, while he sat unaware, outside.

In the meantime each research participant made me feel very welcome, and in instances when they became aware that my husband was sitting in the car outside, wanted to welcome him in to the house too. I declined this invitation on my husband's behalf, in order to maintain the research participants' anonymity and confidentiality.

I was always cautious about where they would want me to place the audiotape machine, so sought permission before I invariably placed it on the dining room table. This was the place that the interview participants wanted to share not only a cup of tea or coffee, but also their stories.

In addition to recording each interview via audiotape, during the first few interviews I made field notes. I stopped making these after the first three interviews, as it appeared to stop the flow of conversation, although my contribution to most conversations was facilitative communication as the research participants told their stories. Interviews lasted any length from 35 minutes to approximately three hours; most lasted about an hour and a half to two hours.

Each tape was then transcribed. Although I had originally intended to arrange for the tapes to be transcribed, I chose to transcribe them myself. Despite the fact that it was time-consuming, I found this very valuable as I engaged in the dialogue, heard the nuances, and could visualise the interview. In all, I gathered over 150 pages of data from the interviews.

4.4.6 Data Analysis.

The aim of hermeneutic analysis is to generate greater understanding by taking note of specific meanings within the text (Benner, 1994), bringing something "to speech" (van Manen, 1990, p.32). This approach requires

readers to read individual texts to determine what new interpretations emerge (Benner, 1994; Dahlberg et al., 2001). While phenomenology provides a description of the phenomenon, and avoids interpretations or constructions, hermeneutic phenomenology interprets the understanding of life that emerges from the experience (Dahlberg et al., 2001; Leonard, 1994). Unlike quantitative methods that begin analysis processes once all data is collected, when using hermeneutic phenomenology, analysis begins before data collection is completed. This is because analysis requires the researcher to engage in critical dialogue with the text, drawing on key aspects, impressions and interpretations (Benner, 1994; Dahlberg et al., 2001; Leonard, 1994). Heidegger's process of data analysis is more obscure, as one does not 'do' phenomenology. He suggests that if the causality between two events is interpreted, the phenomenon is only interpreted as *being-alongside Da-sein*. By this he means that this kind of knowing identifies a "kind of Being which belongs to Being-in-the-world" (Heidegger, 1962, p.88). On the other hand, the way *Da-sein's potentiality-for-being* is projected discloses its significance to the world. Through this projection *being* is understood, but the "meaning of this understanding of Being cannot be satisfactorily clarified...except on the basis of the Temporal Interpretation of Being" (Heidegger, 1962, p.188). The process of data analysis is difficult to explain because it is not sequential (Walton, 1995). Furthermore words do not describe the moments when suddenly the significance of something becomes so apparent that you wonder at it being there all the time, yet being so invisible. For example, in the busy activities of living in the natural world, understanding of that world is not reflected upon (Dahlberg et al., 2001). In contrast, it was not an everyday occurrence to have one's spouse hospitalised in a tertiary centre. Once the research participants began to describe their experiences, they revealed their interpretations of the situations. The research participants' familiar worlds no longer provided interpretive frameworks to make sense of life as it had now become.

Early during the analysis, it seemed to me that most of my research participants who had been affected by having their spouse hospitalised in non-local tertiary settings were living with the illness and in fact were pleased that

the condition was being treated, rather than worrying about where it was being treated. I consistently questioned, “so what?” “What would be the difference if one’s spouse were hospitalised locally?” It could be thought that there is a difference if these research participants do not have regular support systems during this time. If you go and visit your spouse in the local hospital, you can return to your own home at night. Although it may be lonely, the familiar surrounds you. However, those who did not accompany their spouse out-of-town were surrounded by the familiar, but without the comfort of the spouse to visit every day. In contrast those who had the comfort of visiting their spouse sacrificed the comfort of having familiar environs.

Extricating the meaning from the texts requires the researcher to examine each part in terms of the whole and vice versa until there is harmony between both the parts and the whole (Gadamer, 1975). During this stage the interpreter moves back and forth between the worlds that the participants describe, the world that the researcher understands, and the history, culture, and other parts that make up the whole of those worlds (Benner, 1994). Hermeneutic analysis also requires the listener to actively listen to what has been described (Benner, 1994; Walton & Madjar, 1999). By actively listening the interpreter seeks to make sense of the spoken, innuendoes, and aspects of the story that facilitate understanding. The usage of language(ing) facilitates description of the subjective world, thus creating “greater access and understanding of the text in its own terms, allowing the reader to notice meanings and qualitative distinctions within the text” (Benner, 1994, p.101).

In presenting the text, at times it was necessary to insert words to make grammatical sense of the research participants’ stories, and for ease of reading. Insertion of my words is indicated by usage of square parentheses. The research participants’ stories are referenced by their pseudonyms that were woven into the transcript, and providing the page numbers of their interview transcript. In addition, I have used round parentheses when I asked the research participants a question and included that in order to contextualise, or raise awareness of their responses to the time of having their spouse hospitalised in the non-local tertiary setting.

Central to hermeneutic phenomenology is an appreciation that understanding is tested and recorded by writing, and further re-writing (Benner, 1994; Dahlberg et al., 2001). During this process, ideas are set down so that they can be reflected upon, revealing the underlying components of the experience. The process of continued writing and reflecting upon the writings relates to Heidegger's (1982) processes of *re*-duction (or leading back), reconstruction (projecting not only the phenomenon into view, but also its structures of *being*) and de-struction (during which the concepts are de-structed down to their original source). The key to data analysis, according to Gadamer (1975), is that of openness. Such openness leads to the hermeneutic '*as*'. The hermeneutic '*as*' contextualises understanding (Dahlberg et al., 2001), such as in the case of the current study, living with a specific illness.

Each transcript was read several times as I attempted to understand the world of those who had their spouse hospitalised in a non-local tertiary centre. I made notes down the side of each transcript, and frequently noted similar comments made of experiences by other research participants. However, I resisted searching for meanings as interpretations of the experiences, and focussed instead on the descriptions that were before me. Furthermore, as I made note of some ideas that were emerging from the data, I talked these over with colleagues in clinical practice. Through this reflection, the connection between *Da-sein* and the world is revealed in moods disclosing ontological understanding (Heidegger, 1968; Kaelin, 1987). Through writing and rewriting, it was possible to reflect upon the first ideas and determine the temporary interpretations of *being* as the research participants recalled this time of *being-in-the-world*.

I found that as I was conducting the research, participants were interested to find out that other people had had similar experiences, or made similar observations. They found comfort in knowing that they were not alone. However, the significance of others' experiences did not dominate each current interview that I conducted. After I had conducted interviews with 13 research participants either alone, or with their spouse, I was beginning to hear the same stories. Once the researcher begins to identify patterns in the story,

there is enough data that the researcher can present the findings in such a way that the text answers the original concern (Leonard, 1994). I reached this point, but wanted to conduct two more interviews, the first because one of the couples had young children at the time of the transfer, and the second because of the adaptations the couple made as a result of the ill health. Unfortunately, I was only able to interview one of the volunteers. During the initial time of questioning, this participant also felt she did not have much to say. I began by reading out sections of my research findings, and was not surprised to have her engage with some of the stories she was hearing. Furthermore, I found that when I was talking to student nurses about my initial findings they could relate my presentation to their personal experiences, and to experiences when they had arranged for the transfer of patients. I discovered that engaging listeners or readers of the study in this process of data analysis not only validates the understanding, but also strengthens the data findings of 'being there' at this time.

Having one's spouse hospitalised in a non-local tertiary centre was an individual journey. This was not a journey about how major the operations were, or for how long the spouse was having radiotherapy. It was rather determining how the individual research participant predicted a future over which they perceived they had no control. The unpredictability of the future was exacerbated because these participants were required to make life-changing decisions without the social support of familiar people if they accompanied their spouse, or from a distance when the supporting spouse was unable to physically be with the sick spouse at that time.

Hermeneutic phenomenologists are interested in both the tradition from which the individual interprets the experience and the specific way the experience is interpreted. According to Gadamer (1975) the tradition is language; the way people talk about the world in which the experience occurred. I needed to be mindful of the language used by those who have their spouse hospitalised in non-local tertiary centres. If I consider the world of a hospital, with which I am relatively familiar, the language used by nurses is quite different from the language used by people entering the environment for the first time.

Therefore, is it the hospital world that can become overwhelming, or is it the hospital world out-of-town? Does someone, whose spouse has a life-threatening condition, such as cancer, and who is facing the possibility of death, express a language similar to the language used by those who have more hope? Hermeneutic phenomenology challenges us to discover truth by disclosing *Da-sein*. Through understanding individual stories, I will be able to answer these and the original research questions. It is not an assertion of the facts that they were hospitalised in non-local tertiary centres for such and such a period of time, but rather ‘this meant this’ to these spouses.

4.5 Chapter Review.

The purpose of hermeneutic phenomenology is for the researcher to interpret and communicate life-world experiences to others, enabling others to understand the experiences. Therefore, hermeneutic phenomenology is a logical approach to explore the realities of having one’s spouse hospitalised in non-local tertiary settings

Although Heidegger detailed an explanation of hermeneutic phenomenology, he intended this to form the basis of philosophical enquiry, not a research methodology. Therefore, in his writings Heidegger did not detail processes of data analysis. Other writers such as Benner (1994), Dahlberg et al. (2001), and van Manen (2000) proposed that the researcher becomes immersed in each text, drawing on the patterns that describe life-worlds. Unlike traditional processes of data collection followed by data analysis, those who use hermeneutic phenomenology appreciate that analysis begins at the moment of collection. Through this process, themes emerge. While Crotty (1996) criticised nurses’ usage of phenomenology claiming that they focus on exploring the text for commonalities, I contend that the themes presented in the next three chapters emerged from the data; that is, I did not search through the data to validate pre-determined themes.

A background introduction to the 14 participants of this study has been presented. Interpretations of their stories are presented over the next three chapters. Chapter Five tells of the times when the research participants

waited, and because the familiarity of their world dissolved, and *a priori* understanding did not provide a foundation for the future, the research participants found themselves in a state of suspension.

CHAPTER FIVE BEING-IN-SUSPENSE.

5.1 Introduction.

This chapter is the first of three chapters that present the findings that emerged from the research participants' experiences of having their spouses hospitalised in non-local tertiary hospitals. The impact of thrownness caused by the experiences is discussed as the research participants came to terms with the ramifications of the spouse's medical condition that could not be treated at the regional hospital. Research participants talked about the periods of waiting either for diagnosis or treatment, and waiting to see whether the treatment was successful. Overarching all states of waiting was that of facing death.

Chapters Six and Seven examine the state of thrownness as the research participants fitted into being in the world of out-of-town hospitalisation, and finally, how they negotiated *being-with-others* in a world with which they were unfamiliar.

5.2 Disturbing The Presence-At-Hand.

Prior to the experience of one of them being hospitalised, most of the couples had taken their health for granted. Although it was a shock to get the diagnosis, the participants also felt that they should have realised that something significant was happening, and used expressions such as "*I would never have thought he was as sick as he was*" (Nancy, p.2). Another research participant felt guilty that she had not recognised the warning signs that her husband had, as there was a family history of this illness. The concept of *unreadiness-to-hand* was presented in Chapter Three. In the case of the current study, it was the *unreadiness-to-hand* of the spouse's health that caused the state of thrownness. One research participant summarised the thrownness of the situation:

And through that whole winter he was getting the flu a lot. And he has never, ever got the flu. He just...even now, never gets colds, or sore throats or anything. But he was all winter getting it. And we just thought, because I was getting them as well; catching them off him, and the children, because we all had colds that winter, we didn't really think anything of it. But then we

went to the doctor, and our GP was away, and they just sent him home and said "look it is just [minor], don't worry about it. He's probably just caught something"...A couple of weeks later he was actually getting the spins. I rang a friend, we didn't go to a GP, and I said, because he almost collapsed, and it was at night, and I said "could you take him over to the hospital, to A&E". [He] went to the doctor with just 'flu symptoms and [an aching leg]. We just didn't think anything of it. It was just a sore leg. It was a huge shock.

...[Later, when they decided to transfer him to the non-local tertiary centre, it was] just terrible [having to suddenly go with him, and leave the children]. I just felt terrible that I couldn't see them [before we left for the non-local centre]. I was going to see them, but I thought if they see me in such a mess, it would make it worse. [I] hated it. And it was the first time I had ever left [our youngest]. That was hard...Yeah it was horrific to drop everything and go [to that out-of-town city] (Alice, p.2).

As illustrated not all research participants had warning of the impending adjustments to their life-world. In the previous exemplar, although Alice's husband was unwell enough to go to the emergency department during the night, they had not anticipated that he had a life-threatening illness. Not only was her husband ill, but also the couple had to adjust their lives to manage the non-localised hospitalisation. The couple's immediate adjustments required them to arrange care for their children while Alice accompanied Warren to the non-local tertiary centre 400km from home. Another couple faced the possibility of sudden death, resulting in admission to one hospital before being transferred to the non-local tertiary centre. They had to adjust to being the spouse of 'someone who was sick', facing an uncertain future.

The shock of the illness that requires non-localised hospitalisation, affects the ability to be able to interpret any information that is provided. As identified in Chapter Two, sudden admission results in confusion and uncertainty (Stewart et al., 2000; Thompson & Cordle, 1988). Other research findings suggest that information given at this time of stress is not retained or fully understood (Hanger et al., 1998; Stewart et al., 2000). Findings of the current study are that confusion, uncertainty, and an inability to fully appreciate the information were exacerbated if the spouse was transferred to the non-local tertiary setting. Not only were their previous interpretive frameworks of life disturbed, the

couple were receiving the information alone in the non-localised tertiary setting. The couples were trying to make sense of the information unsupported by other family members. In addition, the research participants also had a responsibility to accurately remember the information for family members waiting at the other end of the telephone.

It was just so overwhelming that you...well I could never remember everything that the doctor would say in every detail, so I would just write everything down. Because people always asked of course, "what is happening"? The family would get in contact and would ask, "what's what" and "well, what else did he say?" (Therese, p.4).

While some research participants were uncertain of the cause of the ill health, other research participants had been concerned about their spouse's well-being for some time. These participants talked about the period of time knowing that something was wrong with their spouse, but not having a firm diagnosis to deal with. For example, Trevor had been back to the doctor several times with complaints of the same symptoms. Each time he went back, Trevor was told "*there is nothing wrong with you*" (p.2), until finally Zoë was not going to rest until referral was made to see a specialist. Another participant thought that she might be the cause of her husband's problems so "*I had said to him one day "Well I've gone and got myself checked, so I think that the least you could do is for you to do that"*" (Nancy, p.1).

In the fear¹ that resulted from the *unreadiness-to-hand* of health, the research participants struggled to anticipate the implications of the unknown. *Da-sein* anticipates that previously held interpretations of *being-in-the-world* are crumbling, and faces the future with uncertainty as the interpretive horizons are blurred (Fell, 1992).

5.3 Temporality Of The Presence-At-Hand Of Health And Dis-Ease².

As I analysed the data, it became apparent that during the time when the research participants' spouses were hospitalised in non-local tertiary settings,

¹ Refer to Section 3.7.1 for the differentiation between anxiety, fear and dread.

² I have written dis-ease this way to differentiate it from an illness or disease that can be medically treated. Dis-ease is the reaction to the illness, not the illness itself.

they all had a period of *being-in-suspense*. What do I mean by this expression? I mean putting life 'on hold' until the situation could be managed. The process of coming to terms with the dis-ease and the need for out-of-town transfer means that the *potentiality-for-being* hangs in suspense, as there is no past experience to drive the future, and the world, as the research participants knew it, became confused and bewildering.

Findings from this research were that the research participants had limited interpretive frameworks that enabled them to understand the experiences, and fear of the unknown added to *being-in-suspense*. As explained in Chapter Three, when facing something for which there are no interpretive frameworks *Da-sein* fears the unknown, and attempts to flee back to the familiarity of *being-in-the-world*. Findings of this research are that there was limited familiarity on which to base understanding. It also seemed that each time the research participants 'arrived' at a familiar comfortable world, a new phenomenon would cause them to be projected forward into a state of *being-in-suspense* again.

Being-in-suspense began prior to the period of time of having their spouses hospitalised in the non-local tertiary centre, and for some research participants continued long after this. In fact, for those whose spouse had complications and who required hospitalisation after they had been treated out-of-town, the period of *being-in-suspense* did not become apparent until the complications developed. *Being-in-the-world* and the *potentiality-for-being* is grounded in a world that it is at a given time. That is, the research participants' understanding of the world changed as they experienced their spouses' initial ill health and the subsequent hospitalisation in a non-local tertiary setting.

We just didn't know when he was going to be sick again. Then he'd be in hospital for ten days... 12 days (Winifred, p.3).

We didn't know what the hell was going on, and I was worried about her (Yoland, p.3)

5.3.1 *Being-In-Suspense For Treatment.*

Being-in-suspense was exacerbated when the research participants felt that treatment was required, but they could not get the health professionals to take any notice. Although Melanie and Yoland spent six years returning to the doctor before Melanie was finally diagnosed, Zoë and Trevor were not going to be so patient with the health professionals. Zoë was frantic with worry, which gave her the drive to be determined that the GP would make a specialist referral:

[He] *kept going back. And he [the doctor] did [tests]...and said "There is nothing wrong..." and then finally you [Trevor] said to me "there is something really wrong". And I said, " Right. I'm coming with you this time, because I think that you have got [this] problem. And that is when we saw the doctors. And I said to him "I think there is something wrong". And he said "Well his [tests] show there is nothing up". And I said "but he has got [disease] history, history of [these] problems in his family. And I am not leaving here until you refer him [to a specialist]". And he said "I am telling you there is nothing wrong". [We got the referral and saw the specialist; Trevor did have this condition] (Zoë, p.2).*

While projecting forward to a future of supporting a sick spouse occurred at all stages on the disease continuum, *being-in-suspense* was intensified by the uncertainty of when the spouse would be transferred to the non-local tertiary centre. The lack of knowing the time of treatment, or waiting for the condition to deteriorate, resulted in some of the research participants perceiving that they were unable to hand over the care of their loved one to the health professionals, and they needed to maintain watch. It was not the medical disease that caused this need to maintain watch; it was the dis-ease that led to the constant *being-in-suspense* and *being-in-a-state-of-not-knowing*:

[The non-local tertiary hospital discharged him and said], *"let's just see how you go on your medications". And they put him on the usual medications. But he kept getting [continued signs and symptoms]. He would wake up in the middle of the night in pain. I kept a little graph of what was happening... (Jan, p.1).*

It was not only the inability to convince the health professionals that the spouse was unwell, the uncertainty of the timeframe for treatment added to the sense of *being-in-suspense*. It was discussed in Chapter Two that there is

literature that indicates waiting for surgery has a negative effect on couples' well-being (Jónsdóttir & Baldursdóttir, 1998; Mulgan & Logan, 1990), with those waiting for surgery reporting that life is put on hold as couples struggle with a faceless bureaucracy (Sjöling, Ågren, Olofsson, Hellzén, & Asplund, 2005). The findings of the current study identified that not having any control over the timeframe for the operations or treatment in the non-local tertiary centre affected ten of the couples who waited each day for their spouses to be sick enough to warrant transfer and additional treatment. Each day the couples measured time until treatment was offered, with the couples wondering whether this would be the day of transfer. Not only did awaiting³ transfer compromise the immediate and long-term future, the couples also had to prepare work, children, and the household for the possibility of transfer that could occur at any time. The unknown associated with awaiting added to the anxiety and distress. Furthermore, they could not envisage how their world would be as a result of the out-of-town hospitalisation. The research participants spent this time in anticipation and wondering what else would be occurring in the world as it was becoming for them.

The couples also adjusted their lives to minimise the effects of the medical condition, and to gain some control over their world. One couple, who had a long waiting-time before treatment was offered, did not tell their children that their father required treatment for cancer. The spouse wanted to have all information before he informed anybody else. Life, for these research participants, alternated between *being-in-suspense*, and falling back into *being-in-the-world* as they continued with living.

And I think then we actually had to wait ...I suppose for the [test results] to come back which took a wee while. That was quite stressful...This was March/April when we first found out about it, so we had about a six-month wait (Nancy, p.1).

Although Nancy knew that treatment was to be offered, and other research participants, such as Jan, waited for the spouse's medical condition to worsen, health professionals and research participants had different ideas about how

³ I have used the expression awaiting, rather than waiting, as awaiting better describes the waiting for...(diagnosis, treatment, transfer, positive or negative outcomes of the disease, or

urgently this treatment should be provided; couples being told that treatment was required “*but there is a long waiting list*” (Jan, p.1). It has been acknowledged in the literature that distance from service (Cass et al., 2001b; McDonald & Russ, 2003), and funding systems (Cass et al., 2001b; Degeling et al., 1999; MacCormick & Parry, 2003; McDonald & Russ, 2003) add to the burden of managing illness and can delay referral and treatment options (Arnesen et al., 2002; Cass et al., 2002). None of this literature discusses the correlation between distance from service and stress as each research participant waited for treatment. As two of the research participants said:

...We were told that she was on the urgent list, and they said it would be quick; she would be in the hospital real quick. And I think she had to wait a couple of months...it was quite a long time. I remember them talking about urgent, and for me urgent meant the next day...When I questioned the surgeon, he said, “oh in actual fact that was pretty quick”. So my idea of urgent was the next day, and their idea of urgent was in the next couple of months...We really didn't know quite what was going on at that stage (Paul, p.2).

Well he was diagnosed about four months earlier, and that he would need [this surgery]. But we waited and waited... [About two years earlier, he was visiting family and developed symptoms. The regional hospital he was admitted to] had wanted him to go to [a tertiary centre], but [the centre] didn't want him because they were busy, and because of the funding (Andrea, p.4).

Waiting leads to a loss of situational control (Merz, 1998). In the context of the current study, situational control refers to opportunities the couples had to anticipate treatment in the non-local tertiary setting, and expectations of the transfer. In contrast, awaiting occurred when the couples not only faced uncertainty, but perceived that they had minimal control over the situation. Awaiting the outcomes added to the state of *being-in-suspense*. *Being-in-suspense* oscillated between stages of awaiting, anticipation and expectation, as the research participants and their spouses entered stages of the unknown throughout this time.

The relationship between *being-in-the-world* and the *potentiality-for-being* underpins the sense of powerlessness in awaiting treatment and the outcome

death).

of the non-local tertiary hospitalisation. *Being-in-the-world* means *Da-sein* closes off from the *potentiality-for-being*, because there is no conflict between what one is doing and what one ought to do (Heidegger, 1962). In the case of the current study the couples' anticipation and expectations of the non-local hospitalisation were also closed off to the *potentiality-for-being*. However, in contrast to Heidegger's explanation that *Da-sein* is closed off because self-understanding is congruent with *being-in-the-world*, the research participants were closed off because the world, and therefore the *potentiality-for-being*, was surrounded by uncertainty.

The transfer to the out-of-town centre did not guarantee treatment, thus prolonging the state of *being-in-suspense*. Not only was there a loss of situational control, the couples also wanted to minimise what they saw as unnecessary delays that would cause the spouse to have prolonged periods of time in the non-local tertiary centre. As one research participant said:

And we had to hang around [the tertiary centre] probably for about a good week before they decided what they were going to do, which was hard; not knowing whether they were going to operate (Alice, p.1).

This time was particularly difficult for the research participants if the delay in surgical intervention was not to stabilise the spouse's medical condition, but a wait for the opportunity to operate, or for treatment such as radiotherapy. Any delay in treatment resulted in the research participants awaiting and not being in harmony with others' concepts of time. Not only did the delay in treatment cause them to fear the long-term ramifications of cancer, heart disease, or the other conditions that caused the non-local hospitalisation, the delay also resulted in extending the length of time that the spouse was hospitalised in the non-local tertiary centre. The research participants' perceptions were that the medical conditions were severe enough that transfer was required. However, if there was no immediate action in the tertiary centres, the couples questioned why the centre had accepted the patient at that time. The participants of the current study tried to maintain control of the situation by comparing their spouse's medical condition to other patients in the ward, to ensure that no one 'jumped the queue'.

[My husband] seemed to be getting further and further down the list...So I went and spoke and said, "I am going to be really upset if that man goes before my husband. We have been here for five days" (Zoë, p.6).

Because the spouses had medical conditions that could not be treated at the area hospitals, they were reliant on technology available in the non-local centres for their treatment. Two of the spouses found, however, that their treatment was delayed because the radiotherapy machines had broken down. Not knowing whether the radiotherapy machine would be operational in time for her treatment stressed one research participant's spouse, and consequently the research participant as well. Their world, that was already chaotic, became a continual state of suspense:

...once the day is out, they can't reschedule, you just have to go back a week [in the schedule of treatment]. And you got all this, "well I'm sorry, what else can we do?" And it didn't just happen once, there were two or three times, where an appointment [was broken because the equipment was not working]. And [her] point quite often was "You know they tell you that you have got to relax and keep calm. But you always...There is always something to get me". There was always something that kept you anxious. And you didn't, you couldn't rely on the fact that this was going to happen...You sort of went hoping each time that this is what it was going to be (Edward, p.6).

The *potentiality-for-being* was constantly oscillating between anticipating the further unknown, and adapting to the everyday in a strange environment. The research participants were in a state of suspension within the world as it was at that time, and closed off from a *potentiality-for-being*. As two participants said of this time in their lives:

It was just the waiting. And the fear of the unknown. You are going into a phase, if you like, of something you had never experienced before...It is always the unknown of what's going to come ahead. Of whether the operation is going to be successful. Is there going to be some after effect that we are going to have to deal with, or...? Is it not going to be successful or...? I suppose, yeah, it is all those things really. But I tried not to think about them too much because I kept making day-by-day conversations. And we just lived day by day...(Zoë, p.16).

But you didn't know from day to day exactly what was happening. You would tell the family one thing, and the next day it would all change again. It was a lot of work (Andrea, p.3).

The research participants were in a state of *being-in-suspense* of the present, because their previously understood interpretive frameworks did not enable them to make sense of *being-in-the-world*; they could not be there, as they did not know which direction the future would take them, or what would be the outcome of having a spouse with the specific medical condition.

5.3.2 Anticipating The Effects Of Dis-Ease.

During the time of waiting the research participants were reliant on the expertise of others but aware that procedures also carried risks. For example, coronary artery operations carry a high risk of complications such as peri-operative stroke (Koivula et al., 2002). Waiting was particularly difficult during times of surgery as was waiting for the opportunity to see the spouse for the first time post-operatively. The research participants' sense of powerlessness to prevent harm to their spouses added to the time of awaiting. One participant described her distress during this time as she sat waiting in the accommodation, adapted from what had previously been the nurses' home. Her *being-in-suspense* was exacerbated by not knowing whether the surgery had been successful, or even completed.

I found it difficult waiting for that whole period of the day, and it wasn't until about 7 o'clock that night that I was actually allowed in to see him. That was a long time to wait for any results, for anyone to [contact me]...They had my cell phone number to ring me to say, "he's fine, he's out of surgery, he's doing well, he's in recovery". But I never knew any of that. Every time I pushed the button, in, [the hospital] you know, it was "no he hasn't arrived yet, hasn't arrived, hasn't arrived. No, we have no news" (Zoë, p.6).

In living day by day in the world that it had now become for the research participants, and despite not wanting to be in the non-local setting, the research participants were not prepared for the responsibilities of discharge from the tertiary setting. A large proportion of those having cardiac surgery are afraid to return home (Koivula et al., 2002), because they feel frightened that the disease will recur without the health professionals available to treat them. Such fear results in a discord between the expectations and the reality of early discharge (Clark et al., 1997). In New Zealand, many centres are

using clinical pathways that set standards of care and identify expected outcomes, including the expected number of hospitalised days. While the clinical pathways predict the length of hospitalisation, and early discharge is normal for nurses, it was unexpected by the relatives. Research participants in this study claimed that their spouse had been sent home too soon, and had there not been the early discharge, the treatment would have been more successful. For example, one research participant was very fearful of taking her spouse to a motel rather than him staying in the hospital. The spouse wanted to be discharged from the hospital as he could not sleep and found the environs were not conducive to healing. He was required to return to the hospital for monitoring of his vital signs and to see the doctors on a daily basis. However, the research participant was fearful of having to monitor her husband's progress and stated, "*I was not confident that I could handle anything that was going to happen; not being a nurse or anything*" (Zoë, p.10). If he was well enough to be discharged to a motel, she wondered why they could not come back to the regional centre.

Although they anticipated and expected the spouse to regain health, the perceived absence of support from the tertiary centre caused *Da-sein* to again become anxious in awaiting the unknown. Another research participant claimed:

It was only seven days. To me for someone who had had such a major surgery, seven days isn't long enough. And they said "oh no, no, no. He is fine. He can go home"...And then there was, from then on there was a saga. I thought "ok, I'll take him home". I wasn't happy about taking him home, but we will just go...(Victoria, p.4).

It emerged from conducting this research that eight of the 14 research participants and their spouses that I interviewed experienced complications of the condition. These complications resulted in either prolonged hospitalisation in the non-local tertiary centre or readmission to the local hospital. Whichever the place, it was the complications that caused more stress for the couples, and added to the fear of dying, especially when they were in the non-local centre. Facing the possibility of death reminded them of

the temporality and fragility of life. One of the spouses provided a personal perspective of facing death:

I read the report on me... "Is now in remission" and it just hit me. It was like someone had smacked me between the eyes. I came back home and I said, "You won't believe what was on that report ... And then I cried. I'm only in remission. The lying bastards ... Why can't they tell me the truth? Why do they say you are cured, when you're not bloody well cured? ... Why don't they just say, "you are in a remission"? In a remission ... and five minutes later I'll need further treatment. [Now] I know in my head logically that one day it is going to turn up somewhere else, and hopefully next time I might be able to knock it again who knows, but it might be the end of me. But who knows? (Melanie, p.16).

5.4 Facing Death.

As discussed in Chapter Three *Da-sein* flees from the possibility of one's own death, reflecting upon the notion that death happens to 'others'. In the case of this research, however, it was not un-named others who might die; death was nearby. Prior to the diagnostic stage, Melanie and Yoland were very frightened about the future. For six years Melanie had been complaining of the condition that eventually resulted in her transfer out-of-town. During this stage Melanie and Yoland found the uncertainty of the future difficult to address. As Yoland said:

I didn't know what the hell was happening. Was she going to be here next month, next week, next year or not...? (p.2).

While Yoland faced the possibility-of-death before Melanie was transferred out-of-town, and saw the treatment as "*like the cream on the pudding sort of thing*" (p.6), Melanie claimed that preparation for the hospitalisation in a non-local centre included preparation for the prospect of not coming home again. Although she laughed about this during the interview, she also revealed the underlying fear of this potentiality.

And I had heaps of meals and stuff in the freezer for him. I don't know why, because he is quite capable of managing. Just in case, just in case...I had so many meals for him, so much in the freezer...It is quite funny because I know why I did it. I kept thinking, "Shit if I die when I'm down there, Yoland won't have any food". I cooked all these meals and put them into containers. Really, honestly. Because, the first time, I thought I was going to

die, but I don't know what I thought cooking all these meals was going to do (Melanie, p.12).

Feelings of uncertainty about the future were also very strong during the time of transfer. At this time it was very apparent that the research participants were not able to keep watch over their spouse, and they faced the uncertainty of the immediate future on arriving at the centre for treatment. This possibility occurred for some of the research participants if they were separated at the time of transfer. The *potentiality-for-being* in the face of death could mean returning home alone. During this time of separation the sense of uncertainty about the future was very acute, as Zoë identified:

When I got in the plane [the commercial flight to the tertiary centre], it was the first time I had been away from [Trevor, after treatment at the regional hospital]. He was getting on that air ambulance, and I was wondering all the way up [during my flight] whether I would get there and find that he had died. And I was going to have to turn around and come back and I was going to have to come back on my own. That's what I was worried about. And I think the biggest joy was to see [Trevor] coming down that corridor in that wheelchair. Yeah, I do vividly remember that now. I was on the plane and I got to [the city] and if he'd died, I would have to come back...It is not like coming home and being recalled and turning around and coming back ten minutes later. I mean, you're an hour or so, or you are up in the air and you've got no communication whatsoever (p.19).

5.4.1 Hope And Hopelessness In The Face Of Waiting-For-Death.

Often it was the health professionals providing treatment for the spouses who gave the research participants the lead in the *potentiality-of-death*. As discussed in Chapter Seven, *Being With and Being Without Others*, the research participants relied on health professionals to fulfil certain roles. The lead from the health professionals in *being-in-suspense* included keeping the couple informed about the possibility of death. For example one research participant was grateful that the surgeon talked about the severity of the spouse's condition. This couple could prepare for the worst, and any positive outcomes were a bonus.

In fulfilling the expected role of others, the research participants felt they could not *be-in-the-world* of dealing with the illness when the health

professionals did not fulfil expected roles, including accurate prediction of disease outcomes. On one occasion, a research participant had believed the positive message she had received from the health professional, only to face the possibility of her husband's death a short time later. This participant was told there was no chance of her husband having a heart attack as a result of his heart disease. Two weeks later he was admitted with a myocardial infarction, something for which she was totally unprepared. It was not only facing death that distressed Victoria, it was the realisation that the health professional who reassured her did not have sufficient expertise to provide the reassurance. Furthermore, Victoria reflected that she was mistaken in not only asking the 'wrong person' the question, but also believing the answer. Victoria felt she 'ought to have known' not to rely on this mis-information, but she did not want to be exposed to a 'realistic' possibility of death. In sharing her narrative Victoria said:

[I am] furious. To think that they had told me that. And actually the person who told us that had no right to tell us that anyway, because she didn't have the knowledge to be telling me that. And I don't even know what made me ask that. I just said to her "Could he have a heart attack?" And she said "oh, no, no, no" (Victoria, p.9).

In contrast, when the medical personnel express despair, the spouses believe that all hope is lost. For example, Paul described the time when he and Glenys realised that she had a life-threatening condition. He said:

...we both went to see the doctor. [Glenys] came out very upset. And the doctor lost it a bit. [The doctor] painted a gloomy picture and said there was less than a 50% chance...Then we went to see the surgeon. He was a lot more positive. He felt there was a good chance that they could [successfully operate]. So we went from doom and gloom from the GP to feeling quite positive...(p.1)

Paul and Glenys were overwhelmed by the GP's reaction, but the surgeon restored the hope of life. Therefore, the research participants' understanding of the probability/possibility of death was surrounded by uncertainty. During the time of treatment, the possibility of death was also a constant companion and the sense of powerlessness to predict death in the non-local tertiary setting exacerbated the research participants' sense of loneliness and isolation from their normal support.

While it is acknowledged in the literature that parents separated by out-of-town transfer have to make crisis decisions alone (Agazio et al., 2003; Tan & Simmonds, 1998), there is no literature that acknowledges adults facing the same crises. Findings of the current study are that the couples made life and death decisions without the support of familiar physical surroundings or interpersonal support. For example, Alice and Warren had to face the possibility that Warren's medical condition could result in death during surgery. Having been warned that this was a possibility, they then had minimal time to decide whether the surgery should be undertaken. They were alone in the centre with no other available social support:

...we had been told [earlier] that they were going to operate and [the operation] was going to [be successful]. And then that night we were told otherwise "...that it looks like [the operation might not be successful]. They don't really know until they go in..." So we had to make a decision whether they [should proceed] and there was a fifty per cent chance or even more that he would probably die on the operating table (Alice, p.2).

The night before Warren went to theatre Alice had said goodnight, not knowing whether, in fact, she was saying goodbye. Although the research participants were reliant on the health professionals to indicate the likelihood of death, *Da-sein* also alternated between the *potentiality-for-being-toward-death*, and *being-in-the-world*. These research participants were awaiting death rather than anticipating death. Death could not be anticipated or expected as a known; it could only be awaited as an unknown. Such awaiting exacerbated the state of suspense.

In addition to making the life and death decisions in unfamiliar surroundings, facing an unknown future resulted in some research participants being constantly alert. Each time they went to the ward, they were not sure what they would find, adding to the sense of awaiting during this time. Being powerless to prevent death was a constant thought that accompanied them everyday. For example, Victoria, whose father had died recently, vividly recalled going to the ward, and finding Don's bed empty:

...I got there and Don wasn't in his bed, and of course you freak out when you see that he wasn't in his bed. And I went to the nurse and I said "where's Don?...I don't know if I was paranoid, maybe I was...I think it is because you have in your mind that you almost lost them, so you smother them a bit. I knew what I was doing, but I couldn't help it, it was just the way it was. I had lost a father and I wasn't going to lose a husband (p.4, & p.10).

5.5 Buffering The Impact On The Spouse Of Being-In-Suspense.

Findings of the current study are that research participants attempted to buffer at every possible opportunity to protect the spouses from the unknown.

Buffering is the term Carr and Clarke (1997) used to describe the protection that supporting spouses use as a process of being there and supporting in order to minimise the effects of the unknown.

Well, I spent a lot of time by his bedside. He is a bit nervous when it comes to injections or anything like that, and being in hospital is a bit [nerve-wracking if you are not familiar with the environment]...It was all a big shock to him. I spent as much time as I could with him [to protect him] (Jan, p.3).

Buffering, however, could not minimise the state of suspension. The fear of the unknown and "hard work" keeping the family informed (See Andrea's narrative in Section 5.3.1), were intensified because once the spouse was hospitalised in the non-local tertiary centre, there was often no-one else who could ring other family members, and any discussion about the spouse's progress was done over the phone. Having one's spouse out-of-town at this time deepened the research participants' sense of *being-in-suspense* alone. Those who were unable to accompany their spouse to the tertiary centre could not buffer by being by the bedside, so would try and substitute the physical presence with mental visions of the future. However, this accentuated the loneliness that the couples experienced during this time. Paul, for example, who was unable to accompany Glenys to the tertiary centre, felt that it was most beneficial to Glenys' return to health if he maintained a positive outlook. Therefore, he was not only in suspense for the outcome of the treatment, but both he and Glenys spent this awaiting time alone; separated from each other. Paul put aside his fears and supported Glenys via the telephone. He perceived that his supportive role was to keep Glenys focussed on the future, as she anticipated treatment and possibly death:

[I] found quite a lot of time having to keep Glenys positive. It got at her quite a few times. Sometimes that would be a bit difficult, and probably that's the area where I feel I was probably the most benefit to her. You know, I could keep her on the straight and narrow; keep her looking forward. And keep her thinking about spending the rest of her life with the kids and me... We spoke on the phone a lot. And those were probably some of the hardest times because there was a lot of time when she was there on her own and she just wanted to come home (p.5).

The research participants not only faced the possibility of the spouse's death, the spouses themselves were also fearful about their own future. The spouses' perceptions about life's fragility resulted in the research participants not only having to address their own fears, but also listen as their spouses expressed their personal fears.

I sat and talked to Trevor, because he was feeling quite apprehensive about everything. The more he kept thinking about things [the more he dwelt on them]. He is quite obsessive; he gets quite nervous about the unknown, which you do. And he kept having to reconcile [what was happening with the possibility of death. He kept saying to me] "don't worry, you are alright"... And when we talked about death, and what happened if he died, and what we are all supposed to do... Talked all about those things, all about those sort of things. I had obviously gone away, and he must have thought about it, because when I came back he talked to me about it, you know "If something happens to me and I die, if I die, this is how you are to carry on". He kept on talking about it, you know. So we went through all those emotional type things, and what sort of burial he wanted if something happened. The only thing, and it is difficult being in a public hospital, you don't get that privacy. You have only got the curtains drawn across. People, you can hear conversations that are going on, and you can hear what is happening with the, you know, the poor person that's next door, and what they are going to be doing to him, and yeah. There is no privacy and that, you know. But I think he had got to the stage where well ...you have got to talk about it. You have got to now, there is no other place to do it. You have to do it now. So that is what we did talk about. Yeah, talked about what we were going to do, what was going to happen (Zoë, p.15).

It was not until other spouses began to recover that they addressed their own personal possibility of death. For example, when Christopher expressed the thought that he might die, Carol was shocked. Although she had faced the possibility of Christopher's death on her own before, she had gained strength

from the fact that Christopher had not expressed a fear of dying. His articulation that he might die caused additional fear.

The research participants also felt a sense of powerlessness when their spouses' fellow patients died. This reminded them that their spouses were vulnerable, and that death was not happening to nameless others, but was a constant companion. Because of the nature of the disease, and because those who accompanied their spouses to non-local hospitals were on their own, the research participants received and gave social support to other families in similar situations. For example, two of the research participants had to support families from the same geographical location when the sick family member died. In one instance, a research participant had befriended the wife of a patient who had the same surgery as the participant's spouse, and who subsequently died in the non-local tertiary setting. In a second instance another research participant had befriended the mother of a patient who was an unsuccessful transplant recipient, from the same donor of an organ that this research participant's spouse had received. The research participants were not only supportive of the other families, they also felt guilty as their partners had survived; but were not sure whether they too would become bereaved in the tertiary centre. *Da-sein* was 'being there' with those who suffered through death. As two of the research participants said:

There was another chap who ended up in the same ward.. I ended up realising that his wife was in the nurses' home, after a couple of days. And, we ended up becoming friends, and having tea, having breakfast and that together. But she was horrified at the way the doctors had come up and said, "there was no possibility of him getting [further treatment]". He had already had [a lot of treatment]...And they said there was no way they could [do any more]...In the end, his wife, she was just about in tears, and said, "well we will just have to take him back home. This has been a waste of time". And then I said, "Don't give up. There must be something, somebody, something that they can do". Something happened. I was not quite sure what it was the next day, but she said to me "a new doctor had come along and ... said 'oh yes we can do [something]'". So they did. But unfortunately, he did die...That was really, really sad...I sort of felt a bit guilty, because here was [my husband] beside me, and her husband had died (Zoë, p.13).

The other man...He died. That was really hard. [We] immediately bonded with him, because they were both in the same room, both getting prepared for [the operation]...It was about 10 days or two weeks. It was the saddest part. Christopher was in that room, the next bedroom, but he didn't know...About three or four days later I [felt I had to tell my husband]. He said "I had a feeling something was going on" he said. "I didn't know what". "Oh", he said "I'm so upset, Forty-one...[that is too young to die]". Then [there was] another man, I got to know him really, really well. He was an older man. I got to know him well, because Christopher was there in the ward, and this man was right next to him. He knew what Christopher had been through, and that [he] was having lots of trouble. Because Christopher was sedated so much, I'd sit and talk to him [the other man], you see. And [this man] said one day, "Carol, I want to talk to you". And I went over to him and said "What's the matter?" And he said, "I've just been told that I can't have any more treatment". I knew what that meant straight away. He never properly recovered, because he was away with the fairies all of the time. They kept him in the ward, which I thought was bad, because [we could all see him deteriorate]. They would have to put [cot sides on] his bed, which was way up high because he tried to get out and all sorts of things. Oh it was so sad. Christopher didn't know that this was going on. And [he] said to me about two weeks afterwards, "I haven't seen [the patient], what happened to me mate?" So, I had to tell him. He said, "I want out of here, because everyone's dying around me". There were about three or four who died...(Carol, p.15).

One of the biggest challenges facing the research participants in supporting their spouse during this time of facing death is that they are powerless to prevent death, and know it is impossible to die in order to save their lifelong partner. As another research participant said:

...and I haven't been [in the life and death situation]. I have been a spectator, a partner more than spectator. I have been involved in it, but it has never actually...I am not [living] a life and death situation. It has certainly changed my life, but life is the key word, whereas, you know, wondering whether you are going to have a life; whether you are going to see your kids grow up. I can't imagine, well, yeah I can imagine, but I can't ever put myself in that situation, because I don't really want to be in [it]. But I have some idea of the experience [that my spouse is] going through, because I now understand from a different perspective, what other people go through (Edward, p.11).

5.6 Re-Evaluation Of Life As A Result Of Facing Death.

In contrast, not all the research participants wanted to think about death as the potential outcome of this hospitalisation. Some believed that by not contemplating the possibility, death would not occur.

...there were a few times when I thought "oh what if she doesn't make it", but not very many. I was always confident the whole way through that she was going to get through...A few times I did wonder what it would be like if she wasn't, you know, if it were permanent. And I think it would have been different. To me it was always a temporary arrangement; it wasn't going to last forever (Paul, p.4, & p.7).

Although the research participants were in suspense, they were supported in the knowledge that the disruption could be temporised. "To me it was always a temporary arrangement...it [the hospitalisation out-of-town] wasn't going to last forever" (Paul, p.7). Furthermore, the prospect of dying was put into the context of life's developmental stages. Owen pointed out during the interview that:

...twenty-eight years ago, [Fiona] had been diagnosed [with the same problem]. I was more worried then, when I thought I was going to lose her. I think mainly because, and the kids were upset, because they were only young still. Her Mum and Dad were terribly upset, because they had already lost two sons. This time round the kids are all married...(p.4).

The *being* of the world belongs to the relationship of *Being* of the whole. In the case of the experiences under discussion, the illness that required a transfer to the non-local tertiary centre had to be considered in the context of the continuum of living. Although they did not think about it, each research participant contextualised the illness in order to make sense of the world. On reflecting over the interviews and listening to the tapes, I realised that I started off by asking much the same question... ("Tell me about the events leading up to [whoever] getting sick and finding out that s/he was being transferred out-of-town"). The non-local tertiary hospitalisation was not a phenomenon that occurred without the 'rules' of living with an illness.

In contrast, none of the research participants identified their spouses as 'being sick', both during the time that they were transferred out-of-town, or now.

They may have been unwell, and in the case of Warren, had only just come out of hospital, but no-body talked about chronic illness and they were not sick in comparison to others or what they could have been. During the interviews Don (the patient) was describing his first admission to hospital, and said “[It was a] *massive heart attack*”. However, Victoria interrupted by saying “*It wasn’t massive, because you were still sitting up*” (p.1). Victoria’s previous understanding of heart attacks was founded on the time when her father had collapsed following his heart attack. Although Don was unwell, he was not as sick as her father had been, because he was still sitting. Another research participant talked about her husband “*taking sick*” (Nancy, p.7) just days before he died. In disclosing the experience, research participants also disclosed their understanding of life. Until facing death, *Da-sein* takes the *ready-to-hand* of living for granted.

Having received treatment, and now returned home, the state of *being-in-suspense* is not resolved; it has become part of the research participants’ state of living:

...she’s been having regular checks and everything seems to be fine. I just prefer not to think about it, you know. ...As far as I am concerned she is well...and I’ll keep thinking that until I know otherwise (Paul, p.7).

Although their spouses were not sick, the research participants were aware that the problem may resurface. Research participants were still *being-in-suspense* knowing that while the treatment had been successful, most spouses of those who took part in the current study still had a medical condition that would eventually require further treatment. Some research participants were concerned that the disease would resurface after thinking that the problem had gone away, while others felt that the dis-ease was waiting to pounce at the earliest opportunity. In either situation, the research participants expect the dis-ease to resurface, but they acknowledge that the dis-ease is now part of living:

And [we were told during the consultation]...they think it is alright, but they can’t be sure. We just sat there and said “God, you know, when the hell can you actually relax with this thing?” And the thing is you can’t. You can only think positively but from

now on, she says "she is a time bomb" ...Daily life takes you away from that, but every so often something happens, and it brings you back to the fact that...Really, what are your priorities here? And we do revisit that quite often (Edward, p.9).

As identified earlier, when I set out to explore the experiences of having one's spouse hospitalised in a non-local tertiary centre, I was taking this hospitalisation out of the context of having a disease that required hospitalisation in the first place. Almost all the research participants used the word "luck" when describing their experiences. Research participants felt fortunate that their spouses found the diagnosis early enough to have treatment, or that the condition was not so severe. For example, one spouse with coronary heart disease could be treated with an angioplasty, rather than open heart surgery. Others felt that it was luck that the cancer had been diagnosed in an early stage, or that the children had left home, and they did not have to juggle children, the home, and support the spouse having treatment. As two research participants explained:

I guess there are other people who don't have that [future to hold on to]. They are very unlucky when it comes to things like this. We are grateful that we got onto it in time. That it was only a very small lump, very aggressive, it was one of the worst kinds. But we got it early, and touch wood, everything seems to have worked. So...it was, as I say it was something that we could have well done without, but I guess you learn from the experience (Paul, p.3).

We were unlucky that it happened ... but lucky that we were older. Basically, if you look at it, we have done our working life, come closer to the end than we were to the beginning (Yoland, p.15).

The state of uncertainty still remains in the *potentiality-for-being* as the research participants make sense of being in the world as it has become. Although the couples are focussing on living, they acknowledge that the disease remains in the background:

Nothing is guaranteed anymore. Before we probably felt a bit bulletproof. Now we are a little bit more careful about what we do, and how we do it, what we have got going for each other. Because nothing else is going to happen...but you never know. Everything is fine at the moment, and we just keep praying, finding the philosophy that until we know anything else we will keep doing what we are doing (Edward, p.9, & p.11).

In taking part in this study to explore the experiences of having one's spouse hospitalised in a non-local setting, the research participants disclosed their world that they had not deliberated about. As identified in Chapter Four, the research participants did not initially believe that they could contribute to others' understanding of having one's spouse hospitalised in non-local tertiary centres. In disclosing the experiences and associated anxieties, *Da-sein* understands the impact of it on the possibilities, and resolves the anxiety itself. Once the research participants were able to make sense of the world, *Da-sein* could flee back into the comfort of *being-in-the-world*. In other words, *Da-sein* can confront and disband the anxiety, because the immediate future no longer remains uncertain. "When the anxiety has subsided, then in our everyday of talking we are accustomed to say 'it was nothing'" (Heidegger, 1962, p.231); and *Da-sein* becomes resolute⁴ Because the worst possible fear (that of death) did not eventuate, the research participants' perceptions of the experiences were that they did become 'nothing'.

The onset of a life-threatening illness now presents a challenge for a couple to maintain the same pre-illness relationship. What was once routine has become unpredictable as the couple adjust to the world, which for them has included non-local tertiary hospitalisation. In learning from the experience, research participants re-evaluated their lives as a result of the out-of-town hospitalisation. It was not only the non-local hospitalisation that caused this re-evaluation of living, but the medical diagnosis itself. For example, one of the participants talked of cancer. "*It is such an awful word we would probably try and hide it. Ignore it*" (Alice, p.3). Therefore, the first process of evaluating lives is acknowledging time together, or celebrating small achievements.

You know we had a goal, and the goal was to have the treatment, and we would have a little celebration at that time, which is what we did, and that is what we were focussed on really (Paul, p.8).

We are having a party this weekend, just people for dinner that have really supported us. And [my husband] said "it is a staying

⁴ Refer to Section 3.7.1 for an explanation of resolution.

alive party". Yeah. He is making a bit of a joke about it. They haven't got me yet... (Alice, p.3).

The second process that the research participants and their spouses underwent in coming to terms with the illness was to make the most of living as examples from three research participants illustrate:

once the operation is over, you can relax a lot. You can, I think it is such a huge weight off your shoulder...It is like boy, I can do anything because there is life, so it didn't really matter. I didn't feel sorry for myself having to look after the children by myself or anything, because it had all gone so well that I thought we were really lucky (Alice, p.4).

...now, since she got sick, and I keep saying it to her too, "in the morning, if the sun comes up, make the most of it, because tomorrow it mightn't". And that's how I am now. And her getting sick has done that. I was always a little bit that way, but I am more so now. And I mean if the world falls over tomorrow, I am not going to be terribly concerned about it, because there is not a hell of a lot we can do about it (Owen, p.7).

And when you go through something like that it makes you re-evaluate your whole life. It makes you think that a lot of things that you thought were huge are not important anymore. Like you don't worry about things like you used to. You sort of think you know, it doesn't matter, we are still alive, we are still breathing, we will carry on...we are inclined to slip back into "you should be doing this and that", putting pressure on the person again. Then someone says something, and you think "yes, that's right. We're not going there again" (Victoria, p.7).

5.7 Chapter Review.

Having a condition that causes an episode of non-local tertiary hospitalisation results in times of uncertainty and fear of the unknown. This period of time of *being-in-suspense* occurred on the continuum of living. Research participants and their spouses experienced times of *being-in-suspense* at all stages, from being aware that their spouse was not well but not having a diagnosis, through to the time of having completed the treatment, and waiting for symptoms of the condition to become apparent again. Coupled with *being-in-suspense* while awaiting treatment, is the fear of death. Research participants came to terms with their personal fears of death of their spouse, but they also felt surrounded by death, and walked alongside other spouses who faced death on a daily basis. Such experiences encouraged the research participants and their

spouses to re-evaluate life and celebrate the elements of luck that had emerged from this out-of-town hospitalisation.

In the next chapter I address *Da-sein*'s state of resolution, and the strategies that the research participants utilised to adjust to *Being-in-the-world* as it had become when their spouses were transferred out-of-town for treatment.

CHAPTER SIX

FITTING BEING OUT-OF-TOWN INTO BEING-IN-THE-WORLD.

6.1 Introduction.

When people are transferred to a non-local tertiary setting, the known and taken-for-granted world rapidly changes. It was identified in the previous chapter that many research participants could not envisage what the future held for them and spent the time waiting for the worst, but at the same time hoping this worst would not happen. The previous chapter closed with the research participants minimising their concerns, because they could make sense of the world again, and the dis-ease became part of their world. The couples oscillated between *being-in-suspense*, to *being-in-the world* as they adjusted to living with the illness, until the next anxiety caused them to *be-in-suspense* again.

In this chapter the adjustments that the research participants made during the oscillation are explored. As the research participants adjusted to the *being-in-the-world* of having a spouse with a medical condition, the necessity of the out-of-town hospitalisation became part of everyday life.

The research participants had to make the decision whether to accompany their spouse to the non-local tertiary hospital or stay at home. Either decision required them to fill the long hours of waiting either by being by the bedside, or managing the house and home. It is intended that those reading this chapter will be able to conceptualise the research participants' experiences as they had times of wondering who was caring for them and they juggled their priorities, leading to times of feeling torn in two. Finally, readers of the chapter are introduced to the assertions that despite the challenges the research participants faced, these participants contended that they coped mainly because they needed to cope.

6.2 Being The Partner Of Someone Who Is Sick.

When I set out to understand the *Being* of having one's spouse hospitalised out-of-town, I had not anticipated the effect that being the partner of someone who is sick would have on each of these individuals. Research participants did not have the opportunity to fore-conceive the adjustments that *Da-sein* would make to re-

interpret their worlds. For example, Fiona and Owen had no idea that a routine screen would result in the diagnosis of cancer. As Owen said:

She went away from here...into town full of the joys of living, and an hour afterwards, we had all the worries in the world on our shoulders...our life changed completely (p.1).

The dis-ease resulted in the couples making changes to their previous relationships, and reminded them that the familiarity of the world they experienced had changed. As identified in the above excerpt, the illness not only caused the transfer to a non-local tertiary centre, their “*lives changed completely*”. To understand the impact of the transfer to the non-local tertiary centre, I also needed to understand the impact of the dis-ease. Having a dis-ease, or living with chronicity meant that the couples had to make adjustments to their lives while awaiting¹. During this time of awaiting, life seemed to revolve around the illness. While the adaptations were so much a part of living they became everyday, as demonstrated in the following extract. The illness was always in the back of their minds. This was particularly apparent in the following extract, which illustrates that Yoland did not fully agree that having this dis-ease had minimal effect on their daily lives:

Melanie *And ... I mean Yoland was really good, really good, but he was just sick of hearing me, listening to me again; all my aches and pains and “oh here we go”*

Yoland: *Yeah, We went for a few holidays overseas. But we sort of planned the holidays so that, we’d sort of do a bit of travelling and then have a few days set somewhere, so that if she got crook or anything, she’d have a few days to try to get over it or something. It sort of restricted us to a certain extent didn’t it?*

Melanie: *Yeah...And I had to be careful. Mind you it didn’t really stop me though did it?*

Yoland: *... Nooo ...Not really,*

Melanie: *Now and again it did a bit (p.2).*

Although the illness was part of everyday *being-in-the-world*, the couple also had to adjust activities of everyday living in order to accommodate the periods of time that Melanie was unwell. Another couple also accommodated illness of one family member so that treatment maintenance became a responsibility of the entire family:

¹ Refer to Section 5.3.1 for an explanation of usage of this term.

And I thought he can teach me [how to maintain the treatment] when he comes home. And that's exactly what happened...And it's been like that for three years. So it's all, it's part of my life too. It's part of the family's life as well (Carol, p.8).

However difficult the adaptations required to live with the illness were, they reminded the couples that they were different from others. In Chapter Three, I refer to the impact that cancer had on Sherson (2004) and her husband as she told her story in *Next*² magazine. In the article, Sherson stressed the effect of the disease on both her and her husband; it was not something that affected only one person, and being impotent is incongruent with New Zealanders' perceptions of health. Impotence also affected one couple in the current study. The research participant's husband struggled to make the necessary adaptation to a situation over which he had no control. Despite his wife trying to accept his impotence, and demonstrating continued love, the impediment created a barrier between them:

...that part of it actually bothered him a lot. And in the three years after [having had this operation], he was quite diffident with me. He did not really want me to come too close. I mean if I was in bed and I lay and put my arm around him, you could feel him tense up...I think that he thought that if he couldn't perform...and it wasn't like that (Nancy, p.3).

The couple's previous understanding of the world changed as a result of the disease, particularly the adjustments to life forced by the disease pathology. Although their spouses were facing out-of-town hospitalisation, *being-in-the-world* for both the research participant and their spouse now meant living day by day. In living day by day the couple anticipated the effects of the disease in an ontical sense. They could not anticipate it ontologically because the interpretive frameworks were unpredictable. The self-interpretative frameworks of the spouses could not make sense of the world amid the unknown. When self-understanding becomes sensitive to its own feelings, and concerned that inner feelings do not match 'their' emotions, *Da-sein* is called to care.

6.3 Answering The Call To Care.

The concepts of care, concern, solicitude and empathy are outlined in Chapter Three. As explained the call to care comes from *Da-sein*'s uncanniness with

² *Next* is a popular women's magazine in New Zealand.

being-in-the-world. The situation disturbs *Da-sein*'s comfort so that it is no longer at home and receives the call to care. In the context of the current study, the call to care pulled the research participants in two directions; whether to accompany the spouse, or to stay and manage the household. As well as the research participants having the sick spouse to support, they also had homes, children and work to manage.

6.3.1 Juggling Home And Family.

Although juggling home and family during the hospitalisation of one partner is a phenomenon that all couples must contend with, those whose spouse was hospitalised in a non-local tertiary setting had to either support the sick spouse from a distance, or manage the home and family from a distance. These research participants faced their own additional unique challenges at this time directly related to the fact that their spouse was hospitalised in a non-local tertiary centre. Of the individuals or couples that were interviewed, seven accompanied their spouse out of town. However, two of them also returned home shortly afterwards, as they were torn between their commitments to work or maintaining stability for the family. One of them talked about the effects that the challenges at this time had not only on her, but on the entire family:

...we had just had the baby, who was six weeks old. And [having this condition would result in] a major operation. And I went [with my husband and took] the baby down there. But I couldn't stay long, because the baby was quite unsettled and I had to stop breast-feeding, and yes...[it was] a bit hard (Alice, p.1).

Other research participants stayed at home to manage their business, provide stability for their children, and maintain some sense of normality for the remaining members of the household. Their call to care was to remain focussed on the household. However, in staying at home, these research participants faced the challenge of supporting the sick spouse from a distance. Although the research participants tried to reinforce their support through telephone contact with the spouse so far away from home, the loneliness that the spouses expressed during this time intensified the research participants' sense of powerlessness, that they could not physically be with the spouse, and dealing with the necessary separation in order that the spouse received the necessary treatment. The 'being

there' of these supporting spouses meant that their role was to manage the household or business, 'freeing' the sick spouse to recover from the disease.

So I kept going on, kept going back to that's what she needed to do to get well. And I would do whatever I could do to make sure that that happened. And sort of keep the emotion out of it, and look at the facts, you know... And those were probably some of the hardest times because there was a lot of times when she was there on her own, and she just wanted to come home, you know. And she would say, "I have had enough of this, I'm coming home". Those were probably the hardest times really to try and keep her going. And keep her positive about it... The worst was, the radiotherapy was boring really. It took five minutes a day for five days of the week. And for the rest of the time she had all this time to fill in, you know. So it was more about that. It wasn't painful, or she didn't feel that crook from the radiotherapy... (Paul, p.5).

She didn't want to be there on her own... and really what could I do? [Whenever we talked she would say] "I don't want to be here; I don't want to be here"... And that's when she wanted to come home, she wasn't going to stay... (Edward, p.10).

Furthermore, there were times when things occurred in the home that the research participants did not tell their spouse, as they did not want to add to the stress of the spouse being away from home at the time. Not wanting to tell the spouse added to the burden of care, and it was one more worry that exacerbated the other worries that the research participants were facing alone:

I remember where one night [my son] had a very high fever, and I had to rush him in with the other two [children], all of us went. We didn't get home until, I don't know, nine o'clock that night, and then I had to sleep with him, because it was touch and go whether he would go to hospital. I sort of kept that a bit quiet. That was a bit scary, of course having to do it all on your own, get them all inside. I suppose that is what solo mothers do, don't they... (Alice, p.4).

6.3.2 Keeping Watch.

The research participants who accompanied their spouse to the non-local tertiary centre described periods of time watching, which involved ensuring that the staff, especially nurses, monitored the patients for signs of a change in condition, and treated the patients accordingly. While families are aware that it is difficult to remain at the bedside, they also fear that something will happen while they are away (Carr & Clarke, 1997; Leske, 1991; Plowfield, 1999). This fear resulted in the research participants feeling that they needed to stay as much as possible,

even if there was little response from the spouse. *“He’d be out of it and didn’t know if I was there half the time or not”* (Carol, p.18).

In the case of this research, the research participants’ modes of care became focussed on the significant person in their life. *“I’d watch his graph. Hello, his temperature’s up, something’s happening here”* (Carol, p.4). In the meantime, however, the research participants had everyday concerns about the health professionals which are discussed in Chapter Seven. The everyday and average *being-with-one-another* concern is in modes of *passing-one-another-by*, or *not-mattering-to-one-another* in distant and indifferent modes. *Da-sein* distrusts the ‘other’ until there is awareness that *Da-sein* and ‘others’ are caring for the same cause (Heidegger, 1996). In the case of this research concern about the spouse became the opposite of the indifferent modes, that is states of not passing-by; and of mattering to one-another. In the context of the current chapter, the indifference existed because the research participants’ concern was the spouse, and nothing else in the world existed for them at this time. One couple provided the following example of how they distrusted that the ‘other’ and the supporting spouse did share the same concern. This distrust led to a need to watch, and if necessary intervene on behalf of the spouse.

Zoë And I went up to the nurse and said to him “I would like to congratulate you, ’cos you are the only person that has walked in here with a drug trolley and a chart, and checked them and signed them off properly. Everybody walked in with little pottles of pills. And he was the only person the whole time we were there who walked in, he actually walked in with the drug trolley and he had all the charts. He was the only one following the procedure...”

Trevor Some of them would come in and say what pills have you had today? Well I wouldn’t have a clue what pills I was having, would I?... And the guy next door, he had his drugs twice...

Zoë Yeah, asking a patient what drugs they’re on, rather than [checking what was prescribed]... When somebody is in that state...(p.1).

Because the research participants could not identify that a specific nurse was keeping watch, they adopted this role. Watching also resulted in the spouses’ perceptions that they were the only ones who were really aware of what was going on with the patient. This would be acceptable until something untoward occurred. During these times the research participants, who accompanied their spouse, expected appropriate interventions from the health professionals. If the

health professional did not implement interventions that the research participants perceived as essential, there was distrust in the ability of the health professionals to maintain professional watch. For example, one research participant recalled being horrified that a nurse stated, “*oh I don't have to deal with that now. I am off duty*” (Zoë, p.17) when the spouse's fellow patient had a cardiac arrest. Such comments affected the trust that the research participants could place in any of the staff to keep watch when they were not there. In the absence of trust that the health professionals were able to monitor their spouses, the research participants adopted this monitoring role.

Keeping watch was a role that research participants adopted before the spouses were hospitalised in the non-local tertiary centre and for a long time afterwards. What is more, the research participants who had accompanied their spouse had nothing else to do all day, but sit in the ward. Therefore, they became frustrated when the nursing staff failed to address the spouse's needs as promptly as the research participants thought they ought. The research participants acknowledged that their spouse was the centre of their world; while to the nurses they were one of many. Interpretations are that some research participants who had been on this journey with their spouses became very protective and concerned that their spouses needed instant interventions. For example, Victoria told a story about how waiting for action caused stress and added to a sense of powerlessness because the nurses did not intervene as the couple thought they ought:

Don said to me “I am going to be sick”, because of all the morphine he had after the operation. And I said “I will go and get someone to give you something”. [To which he replied that the doctor had just been around and prescribed something]. Anyway we sat there for a little bit. And [nothing happened, so my son] got up and stormed out. And I thought “oh where is he going?” Don was “I am going to be sick”, “I am going to be sick”. And I could hear this commotion out at the desk. And I went out there and there was [my son] saying “if you don't get in there and give my father something to stop him from being sick, he is going to spew all over the bed, and you are going to have to clean it up”. Within about 2 seconds someone was there. I mean you shouldn't have to do that (p.7).

When the patients were transferred to the ward from places like intensive care units where they were nursed one-to-one, research participants felt the need to

keep watch was intensified. In the wards the nurses had several patients, including the spouse to monitor. For example Zoë spoke of going to the ward to visit her husband who had been transferred from the critical care unit, and who had become one of many patients:

Trevor came down to the wards, which I was quite horrified at because, um... not that he wasn't ready but when they came to do the x-rays they actually got him up, made him go down and have the x-rays done. [He was put in a wheelchair and taken to the X-Ray Department]. But they left him down there.

Trevor... They left me down there for about three hours. I thought "I'm going back", you know because I had already had the x-rays, and nobody had come to pick me up. So then I got in the wrong lift, and I ended up going all over [the hospital]...

Zoë. He ended up in the basement. He was gone for ages... He came back with his pyjamas half down. I said "where the hell have you been?" "Oh, I've been everywhere" he says. But nobody knew he had gone. Nobody knew he was missing except for me. I just sat on the bed waiting for him, thinking "oh God, he's got to turn up shortly" (p.7).

The research participant perceived that her husband's absence was significant, and 'they' should have shared her concern too. Earlier it was identified that Victoria made incorrect suppositions when she found that Don was "missing" from the bed. (See Section 5.4.1.) Victoria's first assumptions were that Don's health had deteriorated, or he had died. There are two important aspects in identifying the significance of Trevor's absence: the *unreadiness-to-hand* of Trevor, and what his absence meant in terms of spatiality. *Readiness-to-hand* and *presence-at-hand* are discussed in Section 3.4.1. In that instance I discussed a piece of equipment that is 'missing', because it is on loan. "The more urgently we need what is missing...the more authentically it is encountered in its unreadiness-to-hand" (Heidegger, 1962, p.103). Although Heidegger refers to equipment, this concept can also be applied to the current research. Zoë did not 'need' Trevor; rather her urgency was a result of the need to know where he was. To be 'missing', means to be far away, because the research participant had no interpretive frameworks on which to understand the absence, from the bed, or delay in returning to the department.

The place, which the *ready-to-hand* occupied, becomes conspicuous only when the equipment is not occupying that space (Heidegger, 1962). Although Trevor was not a piece of equipment, the space normally occupied by his presence was

void; and as Heidegger explains, *Da-sein* strives to bring remote objects closer, characteristic of spatiality he calls *de-severance*. Remoteness is not related to measured distance, only accessibility. To bring something close-by, means to circumscribe the horizon and grasp the object as a fore-conception. Through *de-severance*, the objects are understood, quashing any distance between *Da-sein* and the object (Heidegger, 1962). Because only Zoë 'knew' her husband was missing, and she did not know where he was, she could not fore-have, fore-see or hold his *being* within her concerned gaze. As long as Trevor and Don were missing, accessibility to them was impaired. While Victoria was able to find her husband, all Zoë could do was watch the space where she had last seen him.

As identified earlier in this study³, concern is bound up in individual perceptions of the world and in *being-with-others* in the world. The research participants' worlds were their sick spouse, and for most of the time their energies were devoted to ensuring that everyday household matters did not detract from the spouse's sense of health or dis-ease. However, the research participants also needed to be nurtured, and this need accentuated the absence of their spouse at this time.

6.3.3 Who Cares For Me?

Many reports that discuss families' needs during time of medical crisis include strategies to address the personal needs of the family, and the relatives' requirements when planning waiting rooms in acute care settings (Coulter, 1989; Daley, 1984; Leske, 1991). The research participants in the current study reported that organisational consideration of their needs, such as accommodation, was not apparent at all. While they were appreciative of the specialist care provided, some of the research participants who accompanied their spouses would have welcomed acknowledgement from hospital staff that they were from out of town, and may have had personal needs too:

I never got a cup of tea or coffee or anything while I was in there. They never offered me anything. Never said would you like a cup of tea, or would you like a cup of coffee, or anything like that, no. No, not a thing (Zoë, p.7).

³ Refer to Section 3.7 for concepts of care and concern.

These sentiments are supported by findings in the literature, which report that the nurses make little comment about the patient's spouse, and imply that the wife was unimportant to the plan of care (Strandberg et al., 2002). Other literature that identifies that nurses fail to recognise the role of the spouse as future caregiver was discussed in Chapter Two⁴. The role of nurses engaging in partnership with research participants or the spouse is discussed in the next chapter. However, the narratives described by the research participants strengthened their perception that they were 'invisible and unimportant' to the 'others' in the hospital world.

These perceptions emerged from the research participants' underlying sentiments of "who was caring about me?" In contrast to those who visit the hospital in the town of residence, these research participants did not have a person waiting for them at home. The only person who knew what time they left the bedside at night was their spouse, who was frequently too ill to be cognisant of the fact. The research participants who accompanied their spouses were not only sleeping in strange surroundings; their personal safety was also threatened as they walked back to the accommodation late at night.

...It is a bit daunting being in a huge, huge hospital like that, and not having any...someone concerned about you. And, but mind you, they did have security guards that [would walk back with you. But I wasn't informed they were at hand]...The first night that I was there and I didn't know about that, I didn't know that you could have somebody walk you across the dark quad to your room. In actual fact it was two nights when I went back to the little room on my own that I actually ended up [going a different route from the one that I walked across earlier. I] didn't know that there was a shortcut across. I ended going up around the back of the building, by the swimming pools, and I was quite scared, you know. Because you don't know who's lurking around there, and I didn't even know where I was. But I actually came a long way round to the main entrance, until one night I happened to notice there was a security guard walking people across. I said "oh do you walk people across, over there?" He said "yes". I said "Oh that's great". So, they go backwards and forwards and they take people backwards and forwards going across late at night, so that was quite good. I felt a bit easier after that (Zoë, p.6).

The research participants were not informed that security guards could escort those who were staying in nearby hostels. Furthermore, having security guard

⁴ Refer to Section 2.3.4 for more detail.

services to escort relatives staying in the nurse's home was not available in all areas. It was not until one research participant, who had spent some time at the out-of-town centre, was recognised by the security guards and they provided escort:

[I met one of the security guards who] said to me "Are you going over to the house?" And this must have been about half past twelve in the morning. And I said, "yeah, I'm going now". And I had a little torch with me; I used to carry that. And I would sort of walk in the middle of the street; it was just straight down the hill and straight through like that. And two or three times there used to be someone sitting under the tree or something like that. But I used to take no notice. But anyway, he called one of the girls, one of the girls who was a security guard, she was a big girl, she was lovely. And she said to me "Come and sit in here" she said, "I'll take you down. I'm going out in the car, shortly." Twice actually that happened (Carol, p.18).

The responsibilities of providing professional care include caring for the entire family, not only for the acutely ill individual (Kosco & Warren, 2000; Minicucci, 1998). Nurses are aware that families' needs are not always met as nursing interventions focus on patient recovery (Daley, 1984; Kosco & Warren, 2000; Leske, 1991; Mendonca & Warren, 1998; Twibell, 1998). Although the previous examples illustrate that security services were available, the research participants discovered their availability by accident. The fact that they were uninformed accentuated the research participants' perceptions that other hospital personnel were not concerned about their well-being, and treated the out-of-town hospitalisation as an everyday occurrence:

Well it was a stress and strain on the rest of the family when he was in and out of hospital as often as he was. ...At that time I was a bit resentful because it seemed to me that he was being looked after, but nobody was looking after me, if you know what I mean. Handling the three littlies and managing the home...It is not only the patient who needs looking after (Winifred, p.1).

As explained previously, in everyday living, individuals dwell in indifferent modes of *being-with-others*. In the case of this research, most 'others' did not have their spouse hospitalised out-of-town, therefore the phenomenon was something only the research participants were living with on a daily basis. Their world was having their spouse hospitalised, but it was not the world of others. Although people asked about the spouse's well-being, not asking how they themselves were managing hurt some research participants. The following

extract is an example of how the key issues during the spouse's hospitalisation in the non-tertiary centre became part of the 'unspoken' as the research participants adjusted to *being-in-the-world*. It took quite a lot of encouragement from the researcher before Alice expressed her perceptions:

(So, having to be the strong one for Warren, and the strong one for the kids. Who looks after you?)
Alice *No-one, really. No, It's always been "How's Warren?" I sort of feel that everybody always asks you know, about him and how he is... (...and few ask how you are?)*
Alice *A few do...*
(Only a few do...)
Alice *mm hum. They do. But I mean they are probably thinking about me, but very few asked* (p.5).

Because they were out-of-town on their own, there were periods of time when they were lonely and fearful of what the future held for them. Furthermore, the uncertainty of the future resulted in the couples being unable to predict or grasp the possibility of future health. The more compromised the health status of the spouse who was hospitalised, the less the research participants could make sense of the experience. *Da-sein* is not disclosed when one is with others, because *Da-sein* is part of the world. It is, however, disclosed when one becomes aware of the differences between self and the surrounding world. In the circumstances of the current study, the social support (and thus ability to flee from the differences) could only come directly from their spouses, or via distance telephone, exacerbating the participant's sense of isolation during this time:

I didn't have, you know, a day-to-day companion...It was, pretty hard, pretty lonely, at the time...and you have got helicopters flying around all night. But you didn't sleep very well. There is no phone in the room. So you only had your cell phone...(Zoë, p.9).

I said to my daughter one day "Do you know, that that was the loneliest time of my life; that [time] down there. All those people in [that city] and it was the loneliest time of my life (Carol, p.20).

Despite the challenges associated with accompanying the spouse to the out-of-town centre, knowing that the spouse was to receive treatment brought a sense of relief for research participants. Some research participants had spent so many years looking after their spouses during episodes of ill-health that it was a bit of a relief to hand that care over to someone else. Treatment in the non-local tertiary centre could relieve the anxious time of waiting.

6.4 Measuring Time And Waiting Time.

As well as buffering the impact of the illness, the research participants measured time during which the dis-ease disrupted the household. Time and temporality is a fundamental aspect of *being-in-the-world*, because individual perceptions of the events are temporary. Heidegger (1982) described three modes of temporality: the future as that-which-is yet-to-come; the present as immediate; and the past as that-which-has-been. Time, like *being* is a concept that exists, but cannot be explained, and because the phenomenon cannot be explained, *Da-sein* cannot interpret it; furthermore, time is temporary. Our cognisance of the time, irrespective of whether it is recorded by the clock, forms part of everydayness (Heidegger, 1982). However, whenever *Da-sein* interprets and understands something, it does so within the framework of time; the past, present and future (Heidegger, 1962). The past is no longer current, and the future forms part of the 'not yet'. Moments of time are founded on a readiness to encounter the new, as well as restraint to being captivated by specific items (Vail, 1972). While we can control what we do with the time we have, we do not know when that time will run out.

During the interviews, I became very aware of the significance of times and dates that the phenomenon of being hospitalised out-of-town had for some research participants. For example research participants would be able to identify the specific date of events. Words such as "*he had his original [operation] on 16 March* (Therese, p.3), or "*it was the 9th, my grand-daughter's birthday*" (Carol, p.4) were interwoven into the stories. Andrea could tell me the date eight years earlier that her husband had his first episode of out-of-town hospitalisation, but the year was less significant. At the time, the future was bound to the awaiting, anticipation, and expectations outlined earlier in Chapter Five.

6.4.1 Measuring Time.

Although the effect of awaiting on *being-in-suspense* are detailed in Chapter Five, the couples in this research, affected by the out-of-town hospitalisation, measured time. This is illustrated in the following interaction:

Victoria *So we went home, I think it was after 7 days.*

Don. *No I went in on the Sunday. They let me out on the Monday, and on the Tuesday we went home...nine days, after ...*

(So how many days were you in before you had the operation?)

Don *I went in on the Tuesday and I had the operation the following Tuesday.*

(So you were in for a whole week...)

Victoria *A whole week before.*

(How long ago was it?)

Victoria *Six years.*

Don *It was on the 20th October, I know that (p.7).*

As identified in this passage, the number of days that the spouse was hospitalised out-of-town also had significance. In a second example Trevor had said he had treatment out-of-town for “*about two weeks*”. Zoë interrupted him with “*ten days*” (p.8). Although time becomes more precious amid limited quantity (Heidegger, 1962), the days waiting in the out-of-town area passed too slowly to be approximated. Another research participant was able to give exact dates or days of the week for each event that had occurred:

It started on the 17th March last year, which was a Sunday, which was St Patrick's Day...They flew him out of there, [my son] and I actually sat there and waited, 'til the helicopter got him, and took him four o'clock on the Sunday afternoon and he arrived at 5 o'clock. We [followed] in the car and they let us in...and we saw him at half past eight. [He had more surgery on] the 25th of March, that was the second operation...the fifth one was on my son's birthday, the 25th May. That was his fifth one⁵.

In these instances, time means the ‘moment that the world stood still’. Life was ‘on hold’ for the research participants. As Heidegger (1982) explained time and motion are interrelated. While time is not itself motion, it cannot exist without the movement of entities within the world. In addition, time lies before us in the world, but if one were to stand and watch a clock the time would lie behind that person as the minutes ticked away. Furthermore, although time stands before us it is not linked to a location but it is bound to *Da-sein*'s location (Heidegger, 1962). While the horizons of east and west can be used to determine times of the day, the horizons of earlier and later lead to understanding the meaning of life for that one moment. Through scanning the horizons, experiences of time become visible (Heidegger, 1982). Because the research participants of the current study were in a state of suspense awaiting the outcome of the out-of-town hospitalisation on the rest of their lives, there were no horizons to scan; the

⁵ I have not referenced this narrative, as the details could inadvertently reveal the research participant's identity. Specific references could be made available if required.

research participants did not have time-linked life-world frameworks that would guide their understanding of these experiences. Each moment of each day became precious time. In contrast, because they were also waiting for events to occur, the measurement of time distorted the waiting time.

6.4.2 Waiting Time.

Findings of this current study are that there were long periods of time during the out-of-town hospitalisation when, for the research participants, time became a blur. Research participants who had been so exact with the dates used expressions like:

They kept us there for...ah it would be about a fortnight I think. Yeah, 'cos he was in ICU, yes in ICU, yeah that's right he was in ICU for five days (Carol, p.4).

Despite the state of *being-in-suspense* whenever they were separated, the research participants who accompanied their spouse also admitted that the waiting meant that the hours sitting beside the bed were long, and occasionally boring, which exacerbated the sense of watching in the non-local tertiary centre during this time. The research participants' spouses were in hospital, but the research participants who accompanied them had no other activities of daily living to engage in.

Heidegger (1982) explains blurred passages of time by using travel as a simile. Travel is constituted by movement through a series of places, which if reflected upon with another, does not facilitate the experience of motion in either the storyteller or the listener. So it is with time. Time is counted in the:

“nows. We count a sequence of nows or of thens and at-the-times. The then is the not-yet-now [it will happen soon, but not now]; or the now-not-yet [because it didn't happen] the at-the-time is the now no-longer or the no-longer now. The then and the at-the-time both have a now-character” (Heidegger, 1982, p.246).

The research participants managed time by the mindfulness that the situation of the out-of-town hospitalisation was temporary. Furthermore, although the conditions that caused the transfer to the setting are likely to cause further hospitalisations this time also belongs to the 'then time'. In the interim, the research participants counted time in order to make sense of the current time

within the horizons of earlier and later. The immediate danger of surgery was over, and all the research participants could do was wait for the time that they could all go home counting a series of 'not-yet-now' times.

I had my son with me. He wanted to come and be with me. And then after [the day of surgery] everyday we went up there and spent all day up there. And we had our meals in the cafeteria...It was quite good having my son there because then I wasn't visiting by myself. Because it is very, very tiring, going backwards and forwards, sitting all day with someone who is not talking to you anyway. Well actually in the end my son got sick of it. He said "oh Mum. I just can't go anymore". So, he didn't go some days. He would stay back (Victoria, p.4).

I'd just sit around, read a book, something like that. He didn't seem to be with it a lot of time. He had his radio, and he was quite happy, you know. There wasn't a lot of conversation holding...I'd just go in, do the washing, sort things out, go and help shower if he hadn't done it, put his stockings on, you know all those little things that may not have been done. I would do that in the later part. But when you are in intensive care there is not much you can do. Just sit there and read a book, and I mean if I could have had other things to do, I would have just gone and done them, you know...(Queenie, p.3).

Whilst juggling to manage the home and family those who stayed at home also experienced loneliness, especially at the end of the day when they were tired. They too found the call to care had different, but equally taxing challenges as those who accompanied their spouses to the centre.

The hardest time was when she was in [the out-of-town centre], and [I had responsibilities for] having to cook the meals, get the kids and put them to bed. I did feel as though during that time I was rushing around like a chook with its head cut off at the end of the day...[The] only time when I was really stressed or when I felt out of control was when I was looking after the kids at the end of the day. I had done a day's work, or as much of a day's work that I could, and then cooking, cooking the meal, getting them bathed and ready for bed and all that sort of thing (Paul, p.7).

It was lonely, once you put the children all to bed, and sit and yeah, the house is all quiet. That is hard. It was hard. I couldn't stand that. And going to bed, and hoping you are going to get some sleep. It was hard work. I mean having to do, having to do all the dinner, just to do absolutely everything. It was hard work...I don't think people actually realised what I was going through (Alice, p.6).

While the research participants who accompanied their spouses out-of-town struggled to find activities to occupy them during the day, these research participants also spent the time waiting, counting the "at-the-time" moments.

Their only alternative to watching the clock tick by was to bury themselves in the comfort of familiar activities.

Most of the time it was get up, go to work, work all damned day, get a meal and...I didn't really get a lot of time to think... (Yoland, p.15).

6.4.3 Filling In The Long Hours By Myself.

It was not just sitting by the bed of those who were hospitalised out-of-town. After a while, the research participants who accompanied their spouses to the non-local tertiary centre also needed to inject some normality into their everyday lives. The best way of doing this was to develop a relationship with others in the ward, assist the spouse with personal cares, and do what domestic chores were possible. When they were not caring for their spouse by being at their bedside, this group of people walked for a little self-care, or to enable the sick spouse to rest. The research participants were still awaiting, but also were now anticipating and expecting that the spouse would get better, and come home; awaiting for life to get back to normal. *Da-sein*, as care, lives in advance of the present based on circumspection of the possibilities of the *potentiality-for-being*. However, in the case of this research, the research participants were not totally at home, as they were in a non-local tertiary setting, and they did not have sound interpretive frameworks to make sense of the experiences. Therefore the possibilities were restricted because they only had the choice of staying beside the spouse, or entertaining themselves to fill in time.

The following examples were how two participants spent their days. There were few alternatives to spending the long days waiting beside the bed in a city where their only contact with people they knew was by distant phone calls. In waiting, the research participants waited for changes in the spouse's condition, for the doctor to come around and for time to pass.

I didn't have a car. So I walked everywhere. Yeah. Quite often I spent time, a lot of time, just walking around the park. In the gardens, or going to the shop, or you know, doing something to have a break. But I spent most of the time walking around the parks, sitting outside, and just getting that odd break and having a cup of coffee. Making phone calls, I spent heaps of time on the phone. Lots of walking around the park. I wasn't worried. It was basically [to maintain] normality really. To get a break from the boredom was a lot of it. And to give Trevor a break, because he needed to rest and he would feel that he probably needed to keep awake to talk to me. He needed to get a break from me. You know

that they do...So that is why I went walking. Basically. Get the fresh air, find lunch, have a coffee...mm. Yep. I used to go back and forwards to the room. I used to go back and answer any calls on the cell phone, and then I used to go to the kitchen and make a cup of coffee. I didn't really stay there. I didn't know anybody while I was there. And, and the only contact I had with people I know was via the cell phone...(Zoë, p.9).

I used to go over to the hospital before 9 o'clock in the morning, so that I could see the doctors, 'cos I knew that they would come around anywhere between half past eight and whatever, which was twelve thirty, maybe... And then I stayed with Christopher for most of the day, and I would go and get something to eat at the cafeteria...then I'd go for a walk. I always went for a walk, just about every day, depending on how worried I was about him. But most days I went for a walk, well for an hour, or an hour and a half, or something like that, yeah. I think that is what actually saved my sanity. And I used to get on the bus sometimes, or walked into town and then catch the bus back. I used to do that too a lot. Went to the museum I don't know how many times. Walked all around. And I did that a lot (Carol, p.18).

Although Carol contended that she filled in the days by walking, or going into town, my interpretations are that her ability to walk was dependent on how worried she was about her spouse. The more worried she was, the shorter the time away from the bedside, and the greater the need to maintain watch.

However, despite spending time awaiting the outcomes, and closing off the *potentiality-for-being* from any negative future, Carol felt that she had been unwittingly pre-warned about the need to fill in the hours by herself, as she and Christopher had planned a holiday in the city where he was later hospitalised. Christopher had suggested that he would find some other activity to do while Carol visited the museum. Carol had 'fled back' to the familiar *being-in-the-world*, as she found little anticipatory pleasure in the future of taking part in activities in the city on her own. As she reflected on the experience of having Christopher hospitalised in the non-local tertiary centre, that future had become the present:

And the funniest part about the whole thing, now that I think about it, prior to this happening, we had been talking about going [there]. And all I wanted to do was to...have a look at the museum. Christopher wasn't that interested. We kind of planned it, thinking, well...But I don't know why, but I thought I would be on my own doing it, because we planned the holiday together. That's exactly how it worked out. Because I'd been walking around there, and I would think "My God, here I am,

I've got my pack on my back, I'm on my own", and I never dreamed this would be happening, Christopher's in hospital... (Carol, p.18).

Unlike those who are based in their own home, and are able to go back and forth to the hospital, for those staying in the nurses' home or nearby accommodation, walking to the park or around the shops was the only alternative to sitting by the bed. There was nowhere else to go, or no other way of filling in the time. If they did go off to see any display, such as a museum, there was always a sense of guilt and fear:

I went to the Trade Fair one day, before Trevor's operation. My daughter said "right. Come on. I'm taking you to the Trade Fair". We went shopping, that's right. We went shopping, to get some pyjamas. And then [my daughter] said to me "I am going to take you to the fair. Trevor will be fine". And she took me to the home show. I felt a bit guilty about that. Wandering around while he was sitting up there, and [my daughter] was trying to keep my mind off it. She was showing me around and I must admit I was feeling a bit guilty, but I was pleased I did it, as I saw some very nice things. And then the night after Trevor came out of surgery and I was able to get in to see him. The nurse said "he will be very comfortable, just leave him. And [my daughter] came out and said "come on, I'm going to take you out. You haven't been out for dinner at all the last ten days or so". So she took me to a little pizza place, and we sat together and had a pizza, and she bought me a drink, and I came back about ten o'clock and he had just woken up. I felt guilty about that, and [my daughter] knew I did. She said "come on, I am taking you back now, I can see that you are itchy" (Zoë, p.13).

The research participants experienced a sense of guilt and internal tension that life was going on. Zoë identified that it was acceptable to leave her husband to go and buy him some pyjamas. That was something that she was doing for him. On the other hand, she should not be out having dinner while her husband was requiring immediate post-operative care. Whenever Carol went for a walk, or did spend some time in the city, she always made sure that she would "*go straight [back] to the hospital to sit beside him for hours*" (p.6). As long as they could return to the bedside and sit for hours, their guilt was alleviated.

6.5 Being Guilty.

Heidegger (1962) uses guilt to demonstrate a deficient state of *Da-sein*. The reactions of everyday *being (da-sein)* to phenomena that generate guilty feelings are inauthentic. Inauthentic guilt becomes apparent when the cultural norms are broken and the interpretations of 'others' leave us feeling guilty. In contrast, *Da-sein* recognises authentic guilt when the call to care raises *Da-sein* into an

awareness of anxiety, but challenges it not to flee into the comfort of the world's moral values (Dreyfus, 1991; Heidegger, 1962). The research participants experienced both authentic and inauthentic guilt. In maintaining the everyday activities in the home, the research participants who were unable to accompany their spouse to the out-of-town centre experienced inauthentic guilt from the no-win situation that they were unable to physically 'be there' to support their spouse. These research participants were not only aware of the world's moral values, but also of the authentic guilt as they were comfortable with the decision, but needed to justify why they were unable to physically be there. They began to doubt whether the decisions were the right ones:

We didn't want to disrupt [the children] too much. [Our daughter] was two, just turned two, so...I think she didn't cope with her mother going away, either. That was something that we didn't realise at the time, but we realised after. She put some mechanisms in place to deal with her mother not being there. So I mean in hindsight it could have been something we should have done [travelled to the tertiary centre as a family, so that our daughter would see her mother everyday], but we didn't (Paul, p.5).

I was torn because I wanted to be there, but, because of my [job, I couldn't]. There were a few things that were happening that I tried to work through. And so, I tried to do everything at once. And yeah, I was pretty down...I was torn, very torn. I guess why I was really torn was, because no matter what I did [either stay here or go there], it wasn't enough (Edward, p.5).

To escape the uncanniness of the situation, the research participants withdrew into 'their' way of thinking, but privately they had their own thoughts:

It was an awkward situation because you are trying to please everybody but you can't please anybody sort of thing. What ever you do, you are damned if you do and damned if you don't (Yoland, p.5).

While the spouses did not express sentiments that generated guilt, the research participants were mindful of the tension between engaging in activities of everyday living, and the situation of the spouse in a non-local tertiary hospital surrounded by the unknown. Life remained static for their spouses. The spouses were not able to accept that life was going on, or that their supporting spouse was adjusting to life without them, resulting in tension between the couple and the research participants experiencing guilt. The research participants found that to attend to their own needs resulted in inauthentic guilt because they perceived that

society would believe they had failed to maintain the purpose of accompanying the spouse to the tertiary centre, by not being at the bedside all the time, or sheltering them from harm. The research participants became guilty (authentically) of coping.

6.6 Coping.

Most research participants talked about coping. Coping was an essential part of supporting the spouse who was hospitalised out-of-town. Unlike the psychiatric sense of ego-enhancing coping, action-oriented problem-solving strategies or defense mechanisms (Arnold & Underman Boggs, 2003; Horsfall, Stuhlmiller, & Champ, 2000), the research participants used the word as a strategy to deal with this strange physical and emotional environment in which they found themselves. The research participants felt that if they didn't cope, they would be adding to the distress of the spouse requiring treatment. Furthermore it was a case of having to cope (with activities of everyday living) because they had to retain some form of control over the world for the sake of the spouse who was hospitalised in a non-local tertiary centre. As the participants explained, there was no other choice than to cope. The ability to cope was founded on the predictability of the *potentiality-for-being*, temporality of the situation, and the expectations that 'others' had that the research participants would cope. These concepts are explored in the following sections.

6.6.1 Coping And The Presence-At-Hand.

People who have a spouse hospitalised in town may see their spouse on a daily basis, and still go home to the familiar environs. In contrast, the need to cope with the separation from home or the spouse (*unpresence-at-hand*) is unique for couples who are affected by non-local tertiary hospitalisation. As long as the spouse was hospitalised out-of-town the *presence-at-hand* was incomplete. Those who chose to stay at home had the *presence-at-hand* of home, familiar objects, and daily support systems, but did not have the spouse. Those who chose to accompany the spouse that required hospitalisation in the non-local centre, were together and made a couple, but were without the familiar surroundings of home and other daily support systems. Both groups were counting the time until they could be a family again. *Da-sein* does not reflect

upon the dealings with worldly things, and barely notices the concerns, or coping associated with everyday living (Dreyfus, 1991; Heidegger, 1962). When the everyday concerns become a source of care, *Da-sein* recognises that there is a need to cope with life.

Findings of the current study are that everyday coping require the research participants to determine how the *potentiality-for-being* that would enable *being* to 'fit' into the world that now involves health professionals, and a non-local tertiary hospital setting. It became apparent during the study that some research participants were not distressed when their spouses were hospitalised in the non-local tertiary centre. For example, the one research participant in my study who did not feel the nurses' home was depressing was a nurse who would have been familiar with such accommodation. She expressed gratitude because having such surroundings took away some of the worry for her:

I stayed in the nurses' home, which was lovely. But it was nice and handy...and living in the nurses' home, I didn't have to worry (Jan, p.2).

Not only did Jan express her gratitude that accommodation was available, and that she had ready access to the ward, because she was a nurse she was not surrounded by the unfamiliar. Her familiarity with medical treatment enabled her to foresee the outcomes.

6.6.2 Coping - Predictability And Temporality.

The degree of predictability determined how people managed the periods of time when their spouses were hospitalised out-of-town. Research participants found it easier to cope if they were aware of what was happening or had some past experience on which to base the current hospitalisation. For example as identified earlier in this chapter one of the research participants was a nurse.

Therefore:

It didn't worry me [that my husband was to be treated out-of-town] because I knew that he was going to be OK. Even if he had had [complicated] surgery, I knew that, it didn't worry me, because I knew what it was all about. I didn't worry about it. I just felt that he would come through. And if he didn't, well that would be another story, another day. But I just felt quite confident that everything would be OK (Jan, p.4).

The worry and uncertainty associated with predictability provides a good example of how interpretive frameworks are disclosed through language(ing). Fear can be described in numerous ways, such as alarm; dread which accompanies circumspection of the unfamiliar; terror or misgivings (Heidegger, 1962; Kaelin, 1987). Prediction can also be described in numerous ways. For example the word can be described as a forecast; a hint; prognosis; premonition, or omen. While an omen has negative connotations, a hint has a positive connotation. In either instance, findings of the current study are that the fore-conception of daily living while awaiting was the uncertainty of outcome.

If the length of time that the person was to be hospitalised was relatively predictable, the research participants could make arrangements to manage their respective businesses, or continue in their paid employment. If the research participants had experienced fear during the time that the spouse was hospitalised in the non-local tertiary centres, the *potentiality-for-being* was not only constantly adapting to *being-in-the-world*, but also oscillating between anticipating further unknown, and the everyday in a strange environment. These participants discovered that the length of stay out-of-town was unpredictable because they could not be assured that treatment was going to be offered, or that treatment would be successful. However, both the research participants and their spouses needed the research participants to cope despite not being sure of the future:

I got on fine, I think. I mean everybody says to you "How did you cope?" But you just do, you know. It was a little bit chaotic. To try and still be responsible for the business and looking after children... To me it was always a temporary arrangement, so we just got on with it and did whatever we had to do. I kept going on, kept going back to that's what she needed to do to get well. And I would do whatever I could do to make sure that that happened (Paul, p.3, & p.5).

Although the number of days in hospital was outside the control of health care professionals, nurses need to keep the spouses and the research participants informed about the likely length of stay. Furthermore, although some of the spouses were hospitalised in the non-local tertiary centre for a short period of time, the sense of thrownness is not time-orientated. Predictable and unpredictable lengths of stay link to Heidegger's concept of time. The ability to

control what they could do with their time was compromised when the research participants were unable to fore-conceive the *potentiality-for-being*; as they waited for the end of this phase in their lives. The research participants coped because they relied on the temporality of the situation and were sustained by the *potentiality-for-being* together again.

In addition, there were times when other catastrophes occurred for the participants, such as the spouse developed complications, or accidents occurred at home. On these occasions, the research participants found the catastrophe challenging to manage, and struggled to maintain the home as well as cope with their spouse's illness. As long as the spouse was hospitalised in a non-local tertiary centre, the research participants either stayed at home and focussed on the household and work, or accompanied their spouse out of town and focussed on that spouse. When complications occurred, the 'nightmare' began. It was as if another thing to cope with became the catalyst for the research participants to feel that the world had become chaotic again.

[The complications] *that was the hardest, that and the following six weeks was the hardest bit. Trying to cope with [the complications]...and trying to cope with [this on top of everything else]. I could cope with everything else, but I couldn't cope with [this]...I found it very difficult to cope with the fact that she was a completely changed person. And I found that very hard to cope with. But that's hard. But, you know, in between times, no problem at all. But that was, I found that extremely hard to, to cope with...That was the bit I was finding hard to cope with* (Owen, p.2).

This time of not *being-in-the-world* was temporary, but as soon as both members of the household were home again the couple moved from the thrownness of being hospitalised in a non-local tertiary centre to a state of living with an illness. Although research participants were surprised that I was interested in how they coped, they identified that there were times when 'others' expected them to cope, but the research participants could not fore-conceive how they would be able to cope, as the hurdles facing them were too high.

I could have coped with it if he wasn't as sick. I think you can cope with things if things are nice. But it knocks you right on your socks, doesn't it? It bowls you. If you felt if you could only cope with one thing at a time, you would be able to cope. But life is not like that (Nancy, p.10).

Nancy was guilty because she did not have the opportunity to address life one step at a time, causing her to question her self-resilience.

6.6.3 Coping And Self-Reliance.

As identified earlier, moods and thrownness disturb individual interpretation of *being-in-the-world*. Heidegger (1962) also uses the expression *for-the-sake-of* to describe the degree to which that self-interpretation is disturbed by phenomena. The ability to solve and cope with complex problems draws on the involvement of *being-in-the-world*, not as a disinterested spectator, but as one bound into the *for-the-sake-of-being-with-others-in-the-world* (Dreyfus, 1991; Heidegger, 1962). In other words, in a *for-the-sake-of* mode, *Da-sein* understands self in terms of the world and others in the world. This understanding of the world is revealed when the research participants explained why they coped.

You just do it, it is part of like going to work you know. You've got to do it, you just do it... You manage, you manage, you have to manage. It is something [that you have to do], and I have done that all my life (Queenie, p.1, & p.6).

In coping because they had to cope they were resolving the *potentiality-for-being-in-the-world*. In talking about the *potentiality-for-being* that they could fore-see, the research participants described circumspection of the situations and actions *for-the-sake-of* their spouse that moulded *being-in-the-world*. The world of those whose spouse was temporarily hospitalised in the non-local tertiary centre did not contain the *presence-at-hand* of their spouse's health, or the spouse in the role that was traditional to that household. Therefore, temporising the situation required *Da-sein* to consider the *for-the-sake of*, which resulted in self-determination of the possibilities for the *potentiality-for-being*. Because, in this instance the research participants were aware that the situation was temporary, they did cope.

All the research participants responded that having a sense of positive outcomes sustained them, and in fact it is apparent that having a sense of hope was the most vital factor in supporting their spouse during this time of out-of-town hospitalisation. Although there were times when the research participants were uncertain of the future themselves, they believed that the positive outlook they adopted in front of their spouse sustained their own ability to cope. Being aware

of their own coping reserves not only gave themselves confidence, but also assisted their spouse to maintain confidence, which in turn led to hardiness. The ability to maintain hardiness correlates with an individual's appraisal of the situation (DiBartolo & Soeken, 2003), and has a positive effect on quality of life, while hopelessness has a detrimental effect (Northouse et al., 2003). As one research participant summarised:

But, you just cope...At the time you just don't think about it. You just go on and on and on and on. But when it's over and you are back to some normality it kind of hits you then. And you think, "how have I coped?" But you know. I think you do. You find some inner strength...and you just do it. I don't know...But you keep everything together then after, it kind of hits you. You start to think of all the things that could have happened. But at the time you don't. Like, you just carry on and do the best that you can I guess. And you try and be strong for the person that is sick...And you just find an inner strength and carry on. Battle it out. But it is definitely not easy. I certainly would not like to go through that again (Victoria, p.6/7).

All research participants now believe it is vital to the family well-being that they move forward. Most of the research participants found that they were sustained by looking towards a positive future during the time of non-local tertiary hospitalisation, something that their spouses were not so positive about. However, as identified in the following extract from one research participant, in moving forward, the research participants were aware that the dis-ease remains in the background of daily life as it has now become:

But there are an ever-increasing number of days when you don't think about it, [this illness] but there is always something that brings you back to it, every so often... And I don't think that that will ever change now... (Edward, p.11).

6.7 Chapter Review.

Couples adjusted to *being-in-the-world* of having their spouse hospitalised out-of-town because they held on to the knowledge that it was a temporary arrangement. They had already found their world had changed as a result of their spouse having dis-ease. However, during the times that the spouse was hospitalised in the non-local tertiary centre, and they were with them, there were long hours of loneliness which the research participant filled by walking around the park, or doing whatever domestic chores they could. Those who stayed at

home found the evenings long and lonely, and once the children were in bed, and the house was quiet, the participants worried about their spouses and the future.

Worrying about the immediate future also resulted in the research participants wanting to maintain a watch over their spouses. The research participants felt that their watch was required because, while the spouses were the centre of the research participants' worlds, they were not the centre of the world of the health professionals. If the supporting spouse did not maintain watch, no-one would. The research participants reported that maintaining watch, and 'being there' was hard work, resulting in the spouses wondering if anyone was concerned for their personal well-being. All energies seemed to be focussed on the sick spouse, leaving little energy to focus on self, or the requirements of juggling home and family.

Despite feeling that they had no energy to focus on personal needs, the research participants contended that they coped; they coped because they had to cope. Although they all expressed that they coped during this time, they did not want to add to the spouse's stress, and needed to find other sources from which to draw on their own strength. In addition, the state of thrownness for the research participants was managed by an ability to generate a sense of coping with life-world activities. Coping meant that the research participants could 'be there' with their spouses during these turbulent times.

The next chapter focuses on the challenges that the research participants had to being there with their spouses. Some of these challenges are generated by bureaucracy, and by the health professionals who treat patients in tertiary centres, especially those for whom the tertiary centre is not in the region of residence.

CHAPTER SEVEN BEING-WITH AND BEING-WITHOUT-OTHERS.

7.1 Introduction.

This chapter, the last in the presentation of the findings, examines the times when the research participants felt that they were alone in the world. They may have been with their spouse during the time of out-of-town hospitalisation, but they were surrounded by unfamiliarity and because the health professionals did not recognise the impact that the non-local hospitalisation had on the participants and their spouses. Like other times when the research participants were affected by the out-of-town hospitalisation, the disruption to their interpretive frameworks occurred at times when the research participants felt that 'others' were not listening to either them or their spouse. Further times that 'others' made the research participants uncomfortable within the world occurred when the health professionals did not focus specifically on the spouse, or individualise the spouse's care. This treatment with indifference occurred prior to receiving the diagnosis, and during the time that they were in the out-of-town centre. There were times too when the research participants felt that their spouse's understanding and needs was removed from the research participants' understanding of the situation resulting in the participants being-alone-in-the-world.

Throughout this chapter I focus on the time that the research participants felt isolated, especially during the times that the spouse was in hospital out-of-town. During this time, the sick spouses were in a hospital environment, and although the nursing staff and other health professionals were there, the research participants perceived that the health professionals did not use processes to facilitate understanding of the hospital world. While the health professionals were familiar and at home in this world, the spouses were surrounded by the unfamiliar, and until the research participant and the spouse were transferred home there was no familiarity with any surroundings.

7.2 'The They' Of Solitude.

No-one exists in the world alone. As outlined in Chapter Three people exist in the world and give little thought to understanding living. During analysis of the

interviews, it became apparent that the research participants talked about ‘they say’. For example... *“they kept telling us that it was [the infection], but they never did grow anything. But that’s what they said it was”* (Winifred, p.1). Or, as another research participant’s spouse said, *“I had at least eight Giardia tests over that two-year period. They all kept coming back negative... They treated me for it with all the tablets... but I didn’t have it”* (Melanie, p.1). Furthermore, the research participants were perturbed that the health professionals did not pay full attention to the information presented by the spouse or the research participant. The health professionals were the experts; therefore ‘they’ gave answers to explain the symptoms. Because they were the experts, the health professionals did not have to justify their actions to the spouses or research participants, even if their actions were incorrect:

You know, you go to a doctor and you say “I’m crook and there is something wrong with me” and they just don’t seem to be interested. Well in her case they did not seem to be interested, and as she said, it was six years before they actually really did something, and that is a long time. I do think that if people go back with the same problem time and time again, I think it should be looked into (Yoland, p.1).

In these instances the research participants were reliant on the health professionals’ expertise to treat the disease symptoms; sometimes, as identified, for diseases that the spouses didn’t have. Heidegger’s phenomenological stance stressed that *being-with-others* means that we allow ourselves to become overwhelmed by ‘the they’, suppressing our individuality. We are ‘thrown’ into the world and situations of living with others, so we understand the ‘that-it-is’ of existence (Dreyfus, 1991; Heidegger, 1962; Leonard, 1994). In other words we are already situated in the world in which we interpret the ways of speaking and conducting ourselves. Our reactions to situations that do not concern *Da-sein* are reflections of the degree of our falling into ‘their’ way of thinking (Heidegger, 1962; Leonard, 1994). In contrast, situations that cause us to question societal norms raise awareness of *Da-sein*’s fallen state (Dreyfus, 1991; Heidegger, 1962). In the above examples, ‘the they’ became apparent as the research participants became aware of different interpretive understandings of the world. The research participants and their spouses were reliant on medical expertise to make the diagnosis, but they also felt their spouse’s awareness of their own health status was being disregarded. Although Heidegger (1962) reminded us that in order to

fully understand we need to thrust “aside our interpretative tendencies, which keep thrusting them-selves upon us” (p.96), findings of this research are that the health professionals overlooked the information that was presented. As the following extract demonstrates the research participants were disturbed that their life-worlds appeared different from the health professionals’ interpretations:

He [the GP] was not taking any particular interest or hadn't researched the history of his [my spouse's] family. And that was on file, on computer for him [the GP] to view. And anybody should have said, "perhaps we had better do a little more investigation into this". And he chose to ignore that. [My husband's apparent health status] was deceiving, but you [Others] don't know what's going on. You should never take appearances for granted (Zoë, p.17).

What are the interpretations that the research participants made from the health professionals’ reactions? Are they interpreting that as everyday people, they are not the experts, therefore they cannot ‘know’? Are the health professionals reliant on technology for diagnosis and symptom management, and if there is no physiological evidence, the symptoms do not exist? Are the frustrations expressed by both the spouses and the research participants a result of reliance on the health professionals’ medical knowledge, and disappointment if the health professionals don’t interpret the lay person’s actual symptoms?

It became apparent during analysis of the narratives that society has expectations about the specialist knowledge and associated roles and responsibilities of health professionals. When the health professionals did not do what the research participant expected should be done, individual, rather than general society expectations, had not been fulfilled. Because the dissatisfaction was not something that was talked about with others, the research participants felt isolated thinking this way. When the health professionals viewed the dis-ease with unconcerned circumspection, because they ‘knew’ the expected dis-ease outcomes, the research participants perceived that concern and solicitude were missing, and resulted in the research participants’ perceptions of *being-alone*. Situations when health specialists did not use expert knowledge added to the sense of *being-alone* and to the couple’s concern. Alice used an example to illustrate this:

... [Later Warren] had the CAT scan and the lump was as big as an egg, or an Easter Egg. It was an Easter Egg on the scan, but they

didn't pick it up...And now when you look at it, I mean the surgeons in [the centre], and our GP just can't believe whoever read that scan didn't pick it up (Alice, p.2).

Not only were the research participants reliant on the health professionals' expertise, 'others' moulded the research participants' response to any dissatisfaction with the health professional's actions. In everyday living, *Da-sein's* interpretations are grounded in its existence of *being-in-the-world* with others. Others in the world are encountered in an "unconcerned, uncircumspective tarrying alongside" existence (Heidegger, 1962, p.156). Our ordinary existence is inauthentic, falling into the way of the public, or 'the they'. *Being-alone* is not related to the number of people surrounding us, but to the relationship between interpreting self and others. Even in situations when no-one else is visible, others influence the *potentiality-for-being* (Heidegger, 1962). However, 'their' way also influences the way in which *Da-sein* views others. If a person were not immersed in 'their' way, it would be impossible for that person to foresee any possibilities (Cooper, 1996). It became apparent from this current study that 'others' did not fulfil the research participants' expectations by not being focussed on the information at hand. I call this time *Being-without-others*. By this expression I mean a time when the research participants felt isolated from familiar *being-in-the-world* interpretive frameworks.

Society had given the medical experts 'their' role. However, because 'they' were not listening to the research participants, the research participants were 'thrown' from *being-in-the-world* and those who surrounded them. The research participants did not feel they had the mandate to criticise the health professionals, because their criticism was challenging the 'their' expectations. For example, Alice had been warned that the resources in the tertiary centre were too great to challenge. Warren was going to require additional treatment in the future, and Alice was fearful of the unspoken, but real threats to his continued treatment if she did complain.

Our GP said that there are going to have to be a lot of questions answered about this. And...yeah, but I don't think anything will be done. But you feel like, I actually feel like writing a letter, because I know who it is. Because if she had noticed it, it would have been quite a simple operation... [But] I don't think anything will happen.

Because [the tertiary centre] told us, that it is probably not worth it, and...I don't really know how you start. I don't know (Alice, p.7).

Like all the other *Beings* described in the previous two chapters, *Being-without-others* occurred both before the out-of-town hospitalisation as well as during the time that the spouse was hospitalised.

7.2.1 *Being-Without-Others Because Others Are Not Listening.*

As identified earlier in this thesis, listening is one of the roles that patient groups expect health professionals to adopt. Listening does not mean hearing the words used, but interpreting them, and this interpretation can only be based on closing the gap between individual worlds (Gadamer, 1975). Everyday conversations occur when each player knows what the other is going to say in a shared world. In contrast, speaking means to actively seek and find the words used to describe an individual's reality (Gadamer, 1975). To converse in such a way means that both parties must listen. When the spouses and the research participants felt that they had not been heard, the *potentiality-for-being* was disconnected from *being-in-the-world*. The health professionals took part in everyday conversations, the research participants perceived that the health professionals did not need to listen, if they already 'knew' what was going to be spoken. To look deeper, or listen, required more work. Incidences of the research participants presenting the health professionals with the evidence, but not seeing any deliberations of the evidence occurred all too frequently. For example Nancy explained:

[Previously]...he must have made an appointment to get his eyes tested. That night [after his eye test, the optometrist told us that] we had to go and see the specialist the next morning. He went to [the eye specialist] and within a few weeks, out came his eye. The only way that we knew that it was melanoma was by reading it on the reports. [The specialist had] sent it to his doctor. And William always said then, "that if that's melanoma cancer, that's what I'm going to die of. He obviously knew what melanoma cancer meant. And nobody took any notice of it...And all this other cancer came up. We told them, but it was always in the initial consultation, and they [never referred to it again. This specialist that he had been seeing for this cancer] said, "You know, I'd clean forgotten about his eye" (p.4).

Because the research participants and their spouses did not know what to expect, the situation caused chaos. The world had become unpredictable to all but the health professionals who were surrounded by familiarity. It could be argued

that most couples would feel that they were surrounded by the unfamiliar during episodes of hospitalisation. However, in the case of the current research, the participants' total world was surrounded by a lack of familiarity. Those who accompanied their spouse out-of-town were unable to envisage the *potentiality-for-being* in the world in which they now found themselves existing, and they could not easily return to their own familiar surroundings on a daily basis. There was no place to *be-in-the-world*. Those who stayed at home were acutely aware that their partner was alone in this strange hospital environment. Although the research participants who stayed at home were in familiar surroundings of their own homes, they were unable to spend time with their spouse on a daily basis. They could not foresee the *potentiality-for-being* because they did not know exactly what the future held for their spouses.

In either situation, the research participants became alienated from *being-in-the-world*, which reduced their confidence in questioning the expert knowledge. The professionals did not fulfil the roles expected of them by the research participants and their spouses, but they were still fulfilling the roles that society gave them. The research participants were the ones who were disconcerted as the concern for the spouse resulted in them becoming totally absorbed in the spouse's world. In its basic state *Da-sein* lives alongside others, until care makes its possibilities for *being* become an issue (Dreyfus, 1991; Heidegger, 1962). When *Da-sein* becomes concerned about aspects of the world and *being-with-others*, it responds to the call to care (Heidegger, 1962).

7.3 Care And Solitude.

As long as the spouses were hospitalised out-of-town, the research participants' worlds were never everyday, and the research participant's absorption of the world (care) focussed on their spouse's well-being. This state of care resulted in the research participants watching the spouse's progress with good intent.

However, lack of acknowledgement of their intent caused resentment:

I found that the nurses were a bit arrogant. Because they think that they know the best. And they think that you know nothing... There was a couple of those infections, I said "look at the stitches, it is rather red". [However, the nurses' responses were] "there is nothing wrong". And look where it ended up? I mean another month in

hospital because of the infection, which would have come from those stitches...and it started from day one. And they [the nurses] just wouldn't swab him. They just think it is alright. They just think that you [don't know anything]. I wasn't impressed with one certain one. Wasn't impressed, because of the arrogance. No [saying] "We could do a swab", or "we could look into it". There was something from day one [that was giving signs of infection, but nobody would listen to me...] (Queenie, p.4).

In the previous example, the research participant's experience was that the health professionals were not attentive in her solicitous concern, because her knowledge was not expert. Other research participants also found that there were incidences when the health professionals would not act on symptoms that the research participants noticed:

[He had the operation on a Monday]...By the Wednesday, because I'd watch his graph, [I noticed the difference]. Hello, his temperature's up, something's happening here. So I said to the nurse, "something's happening, his temperature is going up". [The nurse responded by saying] "Oh it's not going up". I said, "it's going up; something is happening here". I said "there is a poison; something is happening". Anyway she didn't do much about it. And then I saw a doctor. I said "something is happening with [him]". He said "Yes we are a bit worried about it, his temperature is going up". And I said "Something is happening. You'd better do something". Anyway they let it go...(Carol, p.4).

Are these two narratives examples of nurses being in indifferent mode, because the situations constituted part of the nurses' everyday averageness? In order to understand another's concerns there needs to be connection between self and the other (Heidegger, 1962). "Solicitude dwells proximally and for the most part... in indifference of passing one another by" (Heidegger, 1962, p. 161). Solicitude is not normally apparent, as individuals pass each other in indifferent modes. Solicitous concern for others enables *Da-sein* to 'open oneself up', or 'close oneself off' to entities in the world in an empathetic manner. However, empathy can only occur in the foundations of a public world suppressing a genuine understanding of the other (Dreyfus, 1991; Heidegger, 1962). In the exemplar provided by Carol, the nurse may well have been aware of the temperature, and either the need to notify the medical personnel for further action, or the need to continue to monitor the patient. Had the nurse involved the research participants about the actions she was taking, Carol would have had more confidence that the nurse was caring.

7.3.1 Being Alone, But Surrounded By Nurses.

For over 20 years nurses have researched and written about meeting the needs of families during the acute stages of illness¹. The consensus of this literature is that the hospitals need flexible visiting hours that will enable family members to have access to the patient (Clarke, 2000; Plowfield, 1999), and both written and verbal information that is presented in terms that the relatives can understand (Miller & Wikoff, 1989; Stewart et al., 2000; Turton, 1998). It is also acknowledged in the literature that the needs of the family members might be considered a low priority if the health professionals' energies are focussed on treating acute life-threatening situations (Kosco & Warren, 2000; Leske, 1991; Medland & Estwing Ferrans, 1998; Mendonca & Warren, 1998). The overwhelming link that will meet the families' needs is nursing care.

When I set out to do this research, I had not anticipated that nursing care would be almost invisible and impersonal when it was portrayed in the stories I was hearing. Nurses or nursing care was described as “*just swallow this tablet please*”... *and they've got these big gloves, gauntlet things on and this mask thing and he's got this...an atomic bomb or something and he holds it out and drops it in your hand*” (Melanie, p.6). This invisibility and perceptions of aloofness identified a lack of partnership between the nurses and the research participants. An effective partnership with the patient and patient's family adds to perception of quality care (Fosbinder, 1994; Minicucci, 1998). Through interpersonal communication skills and taking an interest in the patients, nurses establish trust and nursing presence (Fosbinder, 1994). Minicucci (1998) explained that nursing presence is the therapeutic relationship that develops when the nurses demonstrate care for the patient and significant others; usage of Benner's concept of 'being there', rather than doing for (Benner, 1984). Trust and a sense of being there is dependent upon the nurses' helpfulness and ability to appreciate patient individuality and empathy with the patient's situation (Reynolds & Scott, 2000). Findings of the current study are that there were times when there seemed to be a lack of empathy for the couples and what they had to cope with during the out-of-town hospitalisation. This added to their perceptions that the nursing care was not apparent:

Never did the nurses come and said to me “are you alright? Have you been accommodated? Where are you staying? They never, they hardly ever spoke to me...(Zoë, p.1).

7.3.2 Other’s Perception Of The Impact Of Dis-Ease On Da-sein.

It was acknowledged earlier in this thesis that advances in technology have resulted in centralised care. However, the surgery and out-of-town hospitalisation has become everyday for those working in such centres. In contrast, it is not everyday for those affected by such surgery. At some point during the time of hospitalisation the research participants identified that they had priorities outside of the hospital’s four walls. At the same time the health professionals’ view of the spouse did not extend to *being-in-the-world* outside of the hospital. As one research participant said:

They sent him home too soon... They get them all in and shove them all out again as quickly as they can. They should have done more tests and found out that he [needed more surgery]...because his heartbeat was not what it might have been. He could have had the pacemaker then instead of having to come back and have another trip down. It was pretty traumatic (Andrea, p.2).

Findings of the current study are that those who do such surgery overlooked the effect of having to return to an out-of-town tertiary centre for the insertion of a pacemaker. This return is not a simple readmission to hospital, but a disruption of home-life. Furthermore, the outcome of the surgery is predictable for the health professionals who see such surgery every day.

Another couple travelled to the out-of-town centre for the beginning of a week’s radiotherapy, only to find that it would not be offered that day, and they would have to extend the number of weeks that radiotherapy was to be offered. The state of *being-in-suspense* that resulted from this is discussed in Chapter Five. However, the suspension of radiotherapy, because the machine was non-functional, not only resulted in concern that the delay in treatment could mean that the spouse’s health could deteriorate, but also that the delay prolonged the length of time that the spouse would be staying out-of-town:

That was one of the things, you know that, when they said “oh look I am sorry the machine has broken down, just come back next week for your appointment”. And, you say “well, huh, this was our last week”.

¹ Refer to Chapter Two for a complete discussion on this topic

...I mean [I don't know] how many times she turned up and they [gave us an appointment for later, saying] "Look we have got an appointment for you in here". And you are saying "I am glad that you can fit me in, but we've ...like we've actually turned our lives upside down for the last how ever many weeks... We planned our whole life [around the given time frame]" (Edward, p.6).

Empathy and the ability to see things from the patient's perspective was essential in determining both the research participant's and the spouse's ability to manoeuvre around the health system, both physically, and emotionally. For example one research participant felt that the doctors had little understanding of the reality of caring for her husband who was dying, and severely physically debilitated. They proposed further out-of-town treatment:

They were going to take him back [to this out-of-town centre] for palliative care. And that was only decided the day before he died. And I can remember saying to the doctor, I said, "where will he go?" and he said "to [the hostel]". And I said "Oh that's fine, we've been there before". But William wasn't walking, and I could remember from the time before that we had to walk across [to the hospital]. And I said to the doctor "Would you, this time would he be put into the hospital and you would treat him there?" "Oh, you wouldn't want him to go there", he said, "[the hostel] is much nicer. Don't you think you could manage?" And I said "if I had to I would", but I knew that he wasn't even [capable of assisting me]... He couldn't even sit up in bed, let alone walk at that stage...(Nancy, p.5).

Another described a sense of powerlessness that the specialists wanted her spouse to return to the out-of-town centre for elective surgery, and she was unsure that additional surgery was the correct option at this time. Carol's perception was that Christopher was not well enough to have the surgery, but the couple were persuaded by the specialist to proceed. Unfortunately, the elective surgical procedure was not successful, and Christopher had a second operation as an emergency. While they were reliant on the specialist's knowledge, they felt that the specialist did not understand the day-to-day reality of living with fragile health:

...the next thing they sent us an appointment for [further surgery]. And I got in contact with them, and said "I'm sorry it's too soon". I said, "he's not well enough...And I think it's too soon to go putting him through another operation." So they said "OK. How about you coming down and seeing us in October?" [So we travelled to have this October appointment. And the surgeon] said, "I'd like to do the operation in November"... So he had this operation on 4th November...And on the Saturday they came to me and they said we've

got to give him an emergency operation. [The doctor] said to me "I'm sorry, but things are not looking too good.... I said "Now you tell me. I said "I said to [the surgeon] when we came down for the consultancy that I felt, that it's a bit too soon". [Later in the day, the surgeon rang] me and said "My God, if I'd have known what was in there", he said "I would never have gone in". I said "don't you tell me about it". "Because you knew... You knew what he's been through..." (Carol, p.4).

Other professionals could not seem to understand the impact that out-of-town hospitalisation was having on the entire family, and how bureaucracy added to the difficulty of negotiating the future prospects for these couples. One participant talked about her battle with Work and Income New Zealand² (WINZ) as they asked for financial assistance, and her husband applied for a sickness benefit. This battle was the final straw for this couple who were juggling an unknown future as well as maintaining the day-to-day:

It was a huge problem because they wanted to see [him]. And I came back [home] for a couple of days... And went to apply for it, had the appointment and everything, and she wanted to see [my husband]. It was no good seeing me. And I was trying to tell her, "that you are not going to be able to for a long time. [He was in hospital in that place] and he was not going to be well enough after the operation... to [come home and] to see you". In the end, [he] ended up having to... he came home for a weekend, that's right, because he was having the operation on the Tuesday, and he came home on a Friday, and we did it all that day. It took the whole day of doing. Yeah. They wouldn't take it from me. Even the letter from the GP. They had to see him, which was just hopeless (Alice, p.3).

Another talked about the difficulty she had in receiving an accommodation allowance when her husband was hospitalised in the tertiary centre for a second time. In this instance the research participant became caught in the bureaucracy of which cost centre within two District Health Boards was going to pay for accommodation:

...I had a fight with the [service people]. At first, up to the point where [my husband had been first treated in the tertiary centre, before he] was flown home, they paid. No worries. When I went back for [his operation], they weren't going to pay. And I had a fight with them... This time, they [at the first cost centre] had nothing to do with it, because it was [another health problem]. So, I tried to get some assistance through [the area hospital]. And they absolutely refused.

² Work and Income New Zealand is a government department that provides welfare services for those needing financial support for low income, unemployment or long-term sickness.

Their policy is, if they're flown down with a nurse, and flown back with a nurse, well that's it. There is really no need for anyone to be there. But they are hard-hearted really, because my husband would not have survived if I wasn't there. And I'd like to get in front of a panel, and just tell them that... (Carol, p.9).

Although the *National Travel Assistance Policy* had not been approved at the time of this research, Carol may still not have received financial assistance. Assistance for the spouse to travel to the non-local centre is dependent upon recommendations of the referring specialist. If the current policy of the regional District Health Board is “*if they're flown down with a nurse, and flown back with a nurse, well that's it. There is really no need for anyone to be there*”, the referring specialist may still not challenge the local policy, and endorse assistance for the accompanying spouse. Transfers to non-local tertiary centres are everyday for referring health professionals.

7.3.3 Health Professionals' Everyday Solicitude And Empathy.

One strategy that enhances a sense of trust and minimises fear of the unknown is the personal provision of information (Coulter, 1989; Dewar & Morse, 1995; Fareed, 1996; Medland & Estwing Ferrans, 1998; Stewart et al., 2000). Being informed about what is going on is essential to retaining control and providing support when family members are critically ill (Mendonca & Warren, 1998; Minicucci, 1998). One major contributing factor of distress expressed by spouses of those having coronary bypass surgery is the lack of information related to the expectations of rehabilitation and projected progress after surgery (Miller & Wikoff, 1989; Thompson & Cordle, 1988; Turton, 1998).

As discussed in Section 2.3.2, information, both verbal and written is essential to foster adherence to treatment on discharge, and to relieve the supporting spouse's anxiety (Turton, 1998). There are arguments that written information is necessary because there is too much information for the couples to absorb during times of stress (Azoulay et al., 2002). In contrast, in situations where family members are given information leaflets alone, nearly a quarter of the research population did not fully understand the implications of the diagnosis (Mahler & Kulik, 2002). This is despite the leaflet being prepared by the professionals who worked in that environment. Mahler & Kulik (2002) argued strongly that video-tape preparation

informs family members and subsequently benefits the patient's rehabilitation processes as videotaped information is more informative than written information. Ironically, Trevor and Zoë felt that the books and information video they were given to view were a substitute for information from the nurses. Having information via videos meant that the information was not personalised. Trevor and Zoë had limited opportunities to have their own questions addressed. This added to their sense of *Being-without-others*:

A lot of the time we were left alone. We were given the booklet to read, a video to watch [but no nurses spent time with us telling us what would happen]...(Zoë, p.5).

Another couple, who felt that they had not been given sufficient information to prepare them for discharge, also experienced a lack of information. That lack led to perceptions that there was no care at all:

...And there was a long weekend in the middle of his stay, so he had not seen any physios; nobody over that length of time. They didn't tell us anything about what he should be doing, exercises or that. Nothing, we were told nothing (Victoria, p.4).

Participants did not always find that the health professionals focussed on them during time of consultation, which reinforced that they were one of many. In empathetic states *Da-sein* must connect with others' *Da-sein*; empathy is also dependent upon understanding oneself (Heidegger, 1962). However, nurses report that, because of overwhelming workloads and time, they are unable to get close to their patients (Strandberg et al., 2002). The New Zealand health reforms have also resulted in increased casualisation of staff and fewer permanent nurses struggling to manage increasing workloads (Brinkman, 2002), leading to situations where nurses question if there is time to attend to the patient as an individual (Melnechenko, 2003). In the current study, participants reported that the nurses did not have the time to make that connection with the individual or focus on one patient who was ready for discharge. For example, one research participant reported that she had to make her own arrangements to return home when her husband was ready for discharge. The nurse refused to let her use the ward phone, as the nurse was fearful that the research participant wanted the District Health Board to fund the travel. Instead of listening to what the research participant really wanted, the nurse called in the social worker.

A lack of individual focus was also apparent when medical consultants monitored patients' progress in the wards. The individual patient and supporting spouse wanted progress reports. If the research participants could not be present during the consultant's visit, they had difficulty getting this information, or ascertaining what progress had been made. The research participants believed their needs for information, and individuality were minimised:

If I was there and the surgeon was doing his rounds, it was almost...I mean it probably wasn't looming large in his mind, but in our mind it did loom large...That kind of a feeling really. Unless you were on the spot when the surgeon did his rounds, you didn't see him, and didn't get that kind of information. Nurses quite often were reluctant to say what the doctor said. I do think that it's a small, well it's not small...It's an important aspect, making sure that wife or partner is kept up-to-date with all the information, and be prepared to answer the same questions again. That was a problem. I'd ask him, "now what did the doctor say?" He'd tell me, and down the track, we'd maybe talk about it again and I'd say, "I can't remember you saying that" or he'd say the same thing. And then we were not sure what had been said at all. I think everybody takes what they know and understand from a conversation and it is only when you are down the track that you start questioning each other and you think, "oh, maybe I didn't understand, or didn't hear that bit" ... (Winifred, p.2).

Another research participant explained that a health professional's lack of concern, added to the sense of isolation in the hospital-world that the research participants were experiencing during this time:

I can remember the kids being there then, and there was a young doctor on, and they did not...there was something about this young guy that they did not like, did not like him at all. They said "Mum, he is not...He is just a smart arse". They were really upset with him. And I was telling them, "sh." They were not happy with him at all. And we were told that he [my husband] was to see [a specialist]. And of course I was a receptionist at the local doctor's surgery, and I knew [this specialist] usually assessed really old people...Why is he [my husband] seeing this doctor? I couldn't believe that he was going to see a geriatrician. But it was to assess how we were going, and how we were coping with things. That was just prior, just before he was flown [on to the second centre] (Therese, p.4).

Had the house surgeon³ explained to the family the likelihood of treatment at the tertiary centre, and the rationale for the geriatrician referral, they may have felt cared for as a family unit, rather than confused, and subsequently angry.

³ A new graduate doctor completing practical experience in the public hospital.

Knowing, or not knowing, what to expect also influenced the degree to which the research participants or their spouses felt that they were *with-others* and were able to control the situation. One research participant's spouse spoke of how the lack of knowledge lessened the locus of control in overcoming cancer:

...if I was going to die of cancer next week, I would rather them tell me, because I can deal with it. I mightn't like it, but I can deal with it. It's when we don't know. Like when I had [original cancer] and my lung is not working properly at the moment and...nobody will bloody give me any answers and so it makes me angry and frustrated. Whereas if they just do everything that needs doing and tell me, I'd go, "Oh OK, that's fine". Now I know I've got to do this, or do that or whatever, but, yeah I didn't know what would be going on [when I first had radiotherapy]. I thought [when I knew that I was going there to have it], "oh well". I mean [a friend, who was coming with me] and I even talked about it... "Once they've done your bit of treatment for the day, we will just go uptown and do a bit of shopping and we have a look around the shops". I didn't know that I was going to be stuck in a tiny little room on my own, and that nobody was allowed over the threshold, and that when anyone came to the door, I would have to be over that side of the room. I didn't know that... (Melanie, p.4).

7.3.4 The Spouse's Reality Of Dis-Ease Adding To Being-Without-Others.

Having one's spouse hospitalised out-of-town strained marital relationships, adding to a sense of *being-alone* in the world. Not all research participants were able to accompany their spouse to the out-of-town hospital centre as they had family, work, and business commitments to meet. For example, one research participant felt that the stress of trying to juggle home and family was too much, as he could not please anybody. His wife was also resentful that he was unable to travel with her for the period of time that she was hospitalised out-of-town. He knew his wife was not managing the hospitalisation alone, which added to his sense of guilt that home was coping without her. To add to the tension, whenever this research participant travelled to spend time with his wife, they would argue about the situation. His sense of *being-without-others* came from a dread of seeing her, knowing that they would argue, but also knowing that she needed him, which added to his sense of helplessness and isolation:

I tried to do everything at once. And yeah, I was pretty down...I was torn, very torn. I guess why I was really torn was, because I knew I could cope, but I knew she wasn't, and that was the hardest thing. And no matter what I did, it wasn't enough...[As well as my wife's illness] my mind had to be focussed on other things [home and work]. And that is a bit of a chore too, because you think, you sort of feel

guilty for that as well...I can by and large switch off if I have to from what ever I am doing. But I found I couldn't do that. The whole thing was all getting mixed up, and I guess when that starts to happen, I guess you start to question your own ability, what to think, and what you are doing, and why are you doing it, and what your actual values are. I hated it because I knew where I had to be. But even when I went there it was never enough...It was almost better to be away, because as soon as you go down there, you know that you are going to get bombarded, and you don't really want to be. Of course, you went anyway. I wanted to be there, but I also knew what was in store for me...⁴.

These research participants were under the impression that they were alone in not being with their spouse at this time, a further indication of feeling isolated and in a no-win situation:

He absolutely hated it...He was the youngest one, and...feeling a bit nauseous, and was just lonely. Yeah. And everyone else has their husband or wife, partner with them. And I hated that; thinking that he was down there on his own...(Alice, p.5).

At the time they did not realise that they were not the only ones who had not been able to accompany their spouses. Another research participant wanted to point out that other patients did not have a spouse with them at the hospital, and that he was not the only one in the world who was unable to be there with his wife:

[When she was going to be hospitalised out-of-town] we agreed that it was best that the kids had the stability and not just be farmed out in fact. And the other thing was that most of the other husbands and wives that were there, although in saying that most of them didn't have kids, or the kids had left home, so they were able to be there together the whole time. But that was brought up quite often. [She] was one of the only ones. But what I noticed was that, yes it's true but, it wasn't the spouse that was with them, the other ones in most of the cases, it was an older daughter or other family member that was there with them. And we, even though [she] had that, with her sister and other people, I mean on occasion, my eldest daughter [spent time there with her], I mean we took [our daughter] out of school for a week, and my youngest one for another time. Um we tried to do the best we could⁵.

Family support is essential so the couples can maintain the household (Maughan et al., 2002). However, men are less likely to fully confide the effect of a shared

⁴ This quote is not cited to maintain the confidentiality of this research participant. Specific citation details can be supplied if required.

⁵ This quote is also not cited to maintain the confidentiality of this research participant. Specific citation details can be supplied if required

life crisis especially to people other than their wives, as such disclosure is a sign of weakness (Edwards, Nazroo, & Brown, 1998). If these claims, made by Edwards et al., were applied to the men in the current research, the one person that could support them during the time of non-local tertiary hospitalisation would be unable to do so because her own health status was compromised. This inability to confide the effect of a shared life crisis added to a sense of *being-alone* and isolated, especially when the couple were physically separated by the out-of-town hospitalisation.

Sometimes, I just wanted to get away, and just get away from it. I just wanted to go. I did say...on one or two occasions "I've just had enough. I really just, I need to get away from here. I just feel like getting on a plane and getting away from everyone" ...It was just too much for me, in my head at times (Edward, p.6).

The research participants felt isolated from the spouse that they were fretting about, and found that their role as wife or husband within the partnership, changed to one of being both parents, having to keep watch over the sick spouse, or having to be the peacemaker.

7.3.5 Leaping In And Leaping Ahead.

One reason that the participants in the previous section felt isolated from their spouse was because that spouse was making decisions about what they expected the research participant to do during the non-localised hospitalisation. Because those who were transferred became critically ill, the research participants who accompanied their spouses also had to adopt more of an advocacy role during this time. The spouses could not always speak for themselves as illustrated by one of the research participants: "*He didn't know, he was so sick that he didn't know his date of birth or where he was or anything like that*" (Therese, p.9). The research participants found it very frightening that sometimes they were asked to give consent, or make decisions that would affect the spouse's future; decisions that they could not discuss with the spouse because that person was too ill. As identified in the next three quotes, making these decisions without social support added to the enormity of the situation, and the sense of isolation from others:

And because he was so confused, and I had to make decisions, and things like that for him... That had sort of quite an effect...(Therese, p.2).

...I got a ring at half past nine, quarter to ten that night to say, "We are going to have to get the team to look at [him]". And I thought, "Oh my God, here we go". Then they rang us back, the nurse rang us back a little bit later, to say, "The team's been in. They don't want to operate, but he's got a bleed. They don't want to take him back to theatre, but they are going to have to. Would you like to come over and see him before he goes?" I said, "Just get him back in that bloody theatre. Don't worry about me coming to see him" (Carol, p.7).

Well the same thing happened when he started haemorrhaging, they rang me at 6 o'clock in the morning and said, "oh we have got to go back in because he is haemorrhaging, we don't know where it is coming from. Can we have your permission?" [My reply was] "For God's sake, just do it" (Therese, p.3).

Authentic solicitude is demonstrated when one 'leaps in' to remove another's concerns (Heidegger, 1962). Heidegger stressed that 'leaping in' can result in dependency of 'the other' and domination of self. In the case of this research, however, the research participants justified 'leaping in', because there was an absence of trust that others (health professionals) would provide the care in their absence.

Feeling that the health professionals were not listening was a key factor to hindering trust that the spouse was being appropriately cared for, and that they would 'be there' with the patients at this time. The need to maintain watch was identified in Chapter Six, and the participants of this research reported that they adopted this role in the absence of this care. The research participants needed the health professionals in general, and the nurses specifically, to indicate that whilst they were attending to the spouse, they were focussing specifically on the needs of the spouse at that time:

...They only do their job. When I went in there, [I would find things hadn't been done]...I mean sometimes Gerry didn't even have his stockings on, and I had to put those on him. I said, "you should have asked the nurse". I mean, that is what they are here for, to make sure that you have got that equipment that you need to have, you know. It's that, just little things I think that, you know...I mean I know it's still medical treatment that he had to wear those stockings. They needed to be there, and they should have seen that they were there; that they were on him. But it wasn't there. And he said, "I can't get them on" and I said, "ask the nurses. That's what they're there for". But that's what they should have been doing in the first place...I don't feel that they [anticipate]. I've done some nursing too. I have been in

resthomes, and I have been in hospital. And I don't think, I think there is not enough one-to-one patient [contact]. It's just do the job, get out, and yeah. It's not there anymore...but you still need that one-on-one patient [care]. He's quite happy [to be sitting in bed without his stockings on]; wouldn't know any different. But for stockings and things like that [he should not have to ask]. And it wasn't until another nurse said "Oh I will get another pair for you". So she went and got another pair, because the other ones needed washing. They didn't do any of that either. You know, they didn't rinse out any, and I mean he wasn't really capable. So I mean, yeah, they are not thinking that way. I mean, you know, he wouldn't have minded, or anything like that. He never said two words to them. They just asked him if he had any pain before he'd say, "yes", or "no". He never told them anything. But I feel sometimes they weren't thinking [that he needed more than pain relief] (Queenie, p.5).

Research participants' narratives identified that providing their spouse's personal care failed to provide the participants with a sense of purpose, or promote independence in preparation for discharge. Ironically, Coulter (1989) and Appleyard et al. (2000) proposed that the ability to provide personal cares for sick relatives generates a sense of purpose and hope for the relatives. Furthermore, Minicucci (1998) suggested that nurses should actively encourage the family to be involved in a partnership of care, which includes enabling them to provide personal care. In contrast, as noted in Chapter Two, other research findings contended that nurses are reliant on the patients to initiate the need for care (Strandberg et al., 2002), because nurses wish to generate independence (Strandberg et al., 2001). Perceptions that providing assistance with personal care was not undertaken in a nursing partnership model of care is demonstrated in the next passage where Victoria sensed she was providing the care instead of them:

[That morning when I got there and found Don wasn't in his bed] I went to the nurse and I said "where's Don?" And she said, "he's in the shower". And I said "by himself?" (This is like the second day.) And she said, "I suppose yeah. He said he was alright". I said, "I beg your pardon. He said he was alright?" And she said, "yeah". "He's had [a major operation]", I said, "you don't need to be a rocket scientist to know how bad he is, and you have left him in the shower on his own". I couldn't believe it. And I said, "Where is he?" And she said "Oh this one here". And she said, "Oh I'm sure he will be alright". And I went in there and here he was sitting on the chair like this. [He was slumped forward with his elbows on his knees and the water from the shower cascading down on him]. And I said, "are you alright?" and he said, "no I can't wash myself". Wow, that just blew me away. I just couldn't believe it; that they would leave him there, you know. He could have drowned...He could have passed out, fallen

off the chair. From then on I said, "look. I'll come up every morning and shower him. Leave it and I will do it when I get here". I used to go up every morning and shower him. That wasn't my job. I shouldn't have had to do that...I did a lot of things that I felt the nurses should have done, but you know it is just... [something I needed do] (Victoria, p.8).

The research participants wondered who would assist the patient had they not been there with the spouse. Because the nurses failed to involve the couples in the plan to promote independence, the research participants' trust in the nurses was threatened:

No, I couldn't trust them. I couldn't entrust my husband's life in their hands. I didn't feel confident that they were going to look after him. And then you try and think, "Is this just because he is my husband, and I'm worried about him being looked after 100%, or are they not doing their job?" I don't know (Victoria, p.9).

7.4 'Being There' And Understanding.

Understanding the new is dependent upon grasping the totality of the situation; a fore-having of the tangible; a fore-seeing of vision; and the ability to hold the impression in our grasp, a fore-conception (Heidegger, 1962). All understanding is bound in not only what has been said, but also, and more importantly, in the reactions of others (Gadamer, 1997; Heidegger, 1962). Interestingly, when the research participants became informed, perceptions were that it was the medical specialists who provided the information. It was not only that the information enabled the couples to make an informed choice, it was provided in language that the research participants could understand:

The surgeon was really good though. He explained everything...And even after the operation when I first went up. He got them to tell him when I arrived. He came and saw me, and explained to me what they had done. And he had a paper weight with a valve like they put in, in it. And he showed me what they had done and that sort of thing (Victoria, p.4).

[The surgeon] sort of explained it like being a weed, and the surgery gets rid of the weed and the root, but it may have dropped seeds in the ground you know. And the seeds are so small that they can't be picked up. That's what the chemotherapy was for; to kill off those seeds that may still be there. That made a lot of sense to me... (Paul, p.5).

There were a few times when you were not sure what the heck was going on. It was overwhelming. You sit there and listen to them all,

and [wonder what they were really saying].. I actually found that the [the specialist at that hospital] was fantastic. He had all his registrars and things around him when he first diagnosed [my husband]. [The specialist] was talking all this jargon, and I was thinking "oh God". Then he said "right. Now I will tell you what is happening". And he spoke to us in just everyday common language that we could understand, which I thought was absolutely wonderful (Therese, p.4).

The research participants' perceptions that the medical consultants were the ones that provided information strengthens the claim that nurses' educational role is supplementary to that of doctors', rather than as a substitute for it (Marsland & Logan, 1984). Although this article is dated, a perceived lack of information from nurses also occurred in the current study. The research participants' perceptions were that there was no information about discharge, and the nurses gave them videos to watch, or leaflets to read, rather than directly addressing any questions.

Despite the focus on *being-alone-without-others*, not all the research participants' experiences were that there was a lack of acknowledgement that their spouses were distant patients who needed to travel for treatment. Some of the spouses, who had to travel out-of-town for radiotherapy, found that the staff rearranged the appointments as much as possible to accommodate the fact that they travelled:

...they did try to accommodate her in her appointment times because she was out-of-town. So they would try and give her a Monday afternoon appointment, so she didn't have to get down there, or leave here early in the morning to get [there] And they did try and give her, whenever possible, an earlier time on the Friday morning, so that she could take her time to get home. That didn't always work out. There was one time when she had quite a late appointment and did not get back until seven or eight o'clock at night (Paul, p.6).

7.4.1 'Being There' In Alliance With Social Support.

It was identified earlier in this study that there were times when the research participants were required to pay for their own travel to accompany, or visit the spouse in the out-of-town centre. During the time of the interviews, the income levels were not determined because they appeared irrelevant. However, participants of the current study made comments such as, "*My parents paid for the airfares. They are fairly well-off*" (Warren, p.4), or "*I could afford it, but I might have been somebody who couldn't have*" (Jan, p.7). Two of the couples sought private treatment in order to hasten the treatment in the tertiary centre, and

one other spouse had received surgery in a private hospital in a tertiary centre earlier during the illness continuum. Therefore, although they would not describe themselves as affluent, these research participants were not of low socio-economic status. In addition, their employment roles indicated that they had education levels that enabled them to question the health professionals and command health goods and services if those answers were not satisfactory.

What is the link between social mobility and acting as an advocate for one's spouse? Despite the difficulties expressed by the research participants in convincing the medical specialists of the severity of the disease, or coping with the incorrect diagnoses, the research participants remained committed to maintaining responsibility for the spouse's welfare. This commitment, and the couple's socio-economic status, gave them the confidence to deal with the health professionals, and to insist on the best options. Their ability to question the health professionals also developed as they gained experience with the health system. This confidence is founded upon reflection on life which leads to anticipation of phenomena that we encounter as part of living (Heidegger, 1993). Through such anticipation we calculate the options that present themselves. However, to calculate the options, we must link the familiar to the unknown. This is only possible if one is familiar enough with the world of 'others' (in this case the world of health professionals) to know that such calculations are possible.

All the participants who took part in this research had had long dealings with the health professionals, and through those dealings came to understand both the spouse's health, and the health systems. This understanding enabled them to start questioning the system and the specialists:

I mean you just have to be onto it, on their backs the whole time. I was always ringing up to get results, and" when are they going to do the biopsy". Yes, I'm quite good at it now. But we know that we have to be on their backs to get results; find out what is going on (Alice, p.7).

Furthermore, research participants became included in exploring treatment options. Contrary to the findings of Maughan et al. (2002) that health professionals can exclude men when the man's partner is diagnosed with a gynaecological disease, one research participant felt very included by the health

professionals. He attributed this to his own attitude at the time of diagnosis, and felt that his inclusion sustained them both during this time:

...From my own point of view, whenever we went to see the surgeon, or the breast nurse, or the radiology people, they always included me, which I felt very grateful for. They always talked to me as well as talk to Glenys. I always felt ...I wasn't just there, surplus to requirements. I tried to involve myself as well, you know. I wanted to make sure that I knew what was going on. That is why I went whenever I could. Yes. Well I sort of made that decision pretty early on that I would do whatever it took [to make sure my wife got better]. So I wanted to know what it was that I could do, you know...what was going to happen. And I think...I mean maybe, I don't have anything to compare it with, but maybe I could ask the questions...wanting to know...And I guess when you show that you are interested and you are wanting to know, then people will include you (Paul, p.6).

Whether it was because they learned that they were able to control the situation with the health professionals, and were aware that they were able to command health services, the research participants did not find all aspects of the out-of-town hospitalisation unmanageable. They realised that they could cope with the out-of-town hospitalisation, and answered the call to care by recognising that they were coping with living day by day, and that there were possibilities that would assist them to master the situation. This authentic state is that of resoluteness. Through resoluteness the entire 'being there' of *Da-sein* is revealed; 'being there' means self-interpretation of this situation at this time (Heidegger, 1962).

The research participants recognised that they could not have coped with the experience of having their spouse hospitalised out-of-town had it not been for the support from family members that they received during the time. Members of the family stepped in to maintain the home, to mind the children, to provide some companionship when the research participants accompanied their spouses, or to help the spouse who stayed at home to manage the household so that they could go to work:

... I don't think I would have coped without my family...my sister as well as my mother. They both, they were like rocks. And I don't know how people cope without family. To go through what we went through without family support would be just unbearable. You couldn't do it. Well I'd admire someone that could. I couldn't have got through without them (Victoria, p.8).

Another research participant also acknowledged that the support she received at this time assisted her to cope with the loneliness she experienced:

[It was fantastic that I had my mother-in-law with me]. *I would have hated it on my own. She was great. I don't know what people do without it. There are plenty out there though. The first time he was there was just hideous because I was there by myself through the operation. Just had no-one. But this time Warren's Mum went there with me, which was good. She stayed with me; she didn't want me to be on my own* (Alice, p.8).

As identified in Chapter Five, some research participants formed quite a close relationship with other patients who were having similar surgery, or with the other patients' families who accompanied their relatives during the out-of-town treatment. This bond also helped both research participants and the spouses navigate their way around the strange environment. Knowing that others were in the same situation gave the research participants strength that they were not alone and limited the perceptions of *being-without-others* during this time:

There were a couple of other women there, you know, we would natter about what we were there for, or our husbands were, and that was very supportive (Jan, p.3).

In this instance Jan was *being-with-others* in the same world as she was. Jan and the other women would compare notes in a common language. In contrast, the language that Jan used with the other women would differ from that she would use in the conversations that she would have had with the health professionals; they were not in the same world.

7.5 Chapter Review.

The findings in this chapter present occasions when the research participants became isolated from the health professionals and often their spouses during the time of out-of-town hospitalisation. *Being-without-others* is a time when the research participants believed that the health professionals were not fulfilling the roles bestowed on them by society. However, because the experiences 'threw' the research participants' perceptions of *being-in-the-world*, they believed that they were the ones who were not in harmony, leading to this sense of *being-without-others*. The health professionals perpetuated this isolation by not listening to the spouse, or dismissing the couples' understanding. Because the research participants were separated from their spouse (if they stayed at home to manage

the household) or home (if they accompanied their spouse out of town), they were disconnected from their everyday support systems. This disconnection resulted in the research participants doubting themselves and added to their sense of isolation.

Furthermore, this self-doubt and isolation was exacerbated if the research participants and the spouses did not seem to be talking the same language. This occurred when the spouse wanted, for example, the research participant to have accompanied them to the out-of-town hospital, but this was not possible for the research participant. Although the spouses knew that this was not possible, they added to the sense of isolation by questioning the research participant about their role in the relationship. People fulfil roles that others have given them, and when that role is questioned, the thrownness adds to the sense of *being-without-others*.

During the interviews, the research participants focussed on *being-in-the-world*; the world as it was at that time, and as it had become. Their world, as it was at the time, was different than if the spouse were hospitalised locally. For example, while they acknowledged that the service was good, radiotherapy treatment occurs for a short period of time every day, but because it was not offered locally, it resulted in the spouses being hospitalised in out-of-town centres for long periods of time. The long hours of waiting for treatment on a daily basis, surrounded by others in a similar predicament, added to the sense of isolation and grief for changes to the life that was.

In contrast, other research participants also reported instances of being involved in the treatment plans and a sense of 'being there' aided by support received from family members, and alliance with health services. All research participants acknowledged that they could not have managed the out-of-town hospitalisation had it not been for family members and friends that assisted them throughout this time. The out-of-town hospitalisation affected not only the research participants, but also all members of the family, and sometimes the dis-ease, and the hospitalisation in the non-local tertiary centre also affected the couple's relationship.

The implications of the findings presented in the last three chapters are discussed in the next chapter, and the ramifications of *being* and *being-in-the-world* when one's spouse is hospitalised out-of-town are explored.

CHAPTER EIGHT DISCUSSION.

8.1 Introduction.

The purpose of this chapter is to discuss the findings outlined in Chapters Five, Six and Seven, and to determine models of care for all health professionals, and suggest the implications for nursing practice, nursing education and nursing research. The uniqueness of having one's spouse hospitalised in a non-local tertiary centre, which has been portrayed throughout this thesis, is discussed in this chapter. However, before the unique issues can be discussed, it is necessary to provide a brief synopsis of Heidegger's hermeneutic stance that facilitates an understanding of 'being there' in the world at this time.

The three major themes that emerged from the research are discussed in this chapter. First, readers are led through the periods of *being-in-suspense* while the couples waited for diagnosis, treatment, recovery, and, at times, death. The second theme revolves around the periods of time where the supporting spouse tried to make adjustments to their constantly changing world. The final period of time that is summarised explores times when the supporting spouse felt that they were in the world by themselves, and surrounded by strangers; even their spouse did not appreciate the research participants' perception of *being-in-the-world*.

Although it was originally intended to explore the time that the spouse was hospitalised in a non-local tertiary centre, it became apparent that this experience did not occur in isolation, as the couples' worlds became that of living with disease. These adjustments also continued after the sick spouse had received interventions in the non-local tertiary centre, and subsequently developed complications that required readmission to either a non-local hospital or to the local hospitals.

The participants' ability to cope is linked to the perceived quality of nursing care. As was introduced in Chapter Three, the meaning of nurses' care differs from Heidegger's concept of *Da-sein's* care. Analysis of this meaning leads to recommendations for nurses and other health professionals as appropriate, before the limitations of the study are discussed.

8.2 Heideggerian Phenomenology: A Summary.

Hermeneutic phenomenology means to analyse the experiences and lay open the meaning of *being* amid a background of one's individual familiar world. Living in an everyday manner hides the meaning of *being*. Heidegger described this as *being-in-the-world*, explained by *da-sein* (as in existence) and *Da-sein* (as in being there). In existing, *Da-sein* is overshadowed by *da-sein*. It is *da-sein* that faces the activities of daily living and *Da-sein* exists in the background.

Da-sein lives in the background because humans' behaviour is culturally moulded. Heidegger (1962) explained this moulding as *being-with-others*. *Being-in-the-world* is not separated from *being-with-others*, as we are part of the world. The degree to which we are immersed in the world, Heidegger called a *falling*. As individual worlds change so does *being-in-the-world*, and *Da-sein's* adjustments are dependent on how far one has fallen into 'their' world.

When one's conscience is disturbed, *Da-sein* is called to interpret the situation, and determine whether previous understanding guides *Da-sein's* interpretive frameworks to address the phenomenon inauthentically ('their' way) or authentically (*Da-sein's* way). Authentic frameworks disclose *Da-sein's being*. The interpretations are based on understanding of past experiences and conceptualised projection into the future; the *potentiality-for-being* (Heidegger, 1962).

Da-sein expresses this interpretation through speaking. However, speaking does not mean talking out loud; but rather refers to usage of language, silence, and assertions to make disclosures about the situation. The science of hermeneutic phenomenology is to listen to, and interpret what is expressed, to hear what is really being said. This interpretation occurs in the hermeneutic circle, in which others can experience 'being there' with the interpretations of individual narratives. The obligation of those using phenomenology is to portray the narratives and link the ideas in such a way that others can learn from the experience and also 'be there' in similar situations as in the case of the current study.

8.3 Summary Of The Study Aims And Outcomes.

The aim of this study, identified in Chapter One, has been to explore the experiences of those whose spouse is hospitalised in a non-local tertiary centre, and to increase understanding so that health professionals can learn from those experiences. The thesis that emerged from this study is that those whose spouse was hospitalised in a non-local tertiary centre lived day by day, with little or no social support, awaiting outcomes over which they had limited control. The worst potential outcome for these individuals would be that of the spouses' death in the non-local centre. When the outcomes could be predicted, the time that the spouse was hospitalised in the non-local tertiary centre was manageable on the continuum of living. It also emerged from conducting this study that in living day by day, the supporting spouse coped by focussing on the temporality of the present and a vision of a positive future, but the sick spouse was not always able to conceive the future in such a positive way.

The research participants in the current study shared their experiences, in order that they might enrich understanding among health professionals who are actively involved in transferring patients between hospitals.

8.4 The Unreadiness-At-Hand Of A Dis-Ease That Cannot Be Treated Locally And Being-In-Suspense.

The transfer to non-local hospitals is no longer an uncommon phenomenon in New Zealand. There are five tertiary hospitals in New Zealand, where increased technology and specialisation of services are available. As New Zealand medical specialists gain increasing expertise in surgical techniques, what were once news-breaking procedures, such as heart transplants, are now becoming everyday occurrences. Although they are everyday occurrences for the health professionals, they are not everyday for those requiring transfer to the specialist centres.

Anxiety is a state-of-mind that leads to fear when *Da-sein* becomes concerned about the unknown. Because the cause of the anxiety is unknown, *Da-sein* cannot overcome the concern. The research participants feared the unknown (*being-in-suspense*), uncertain when their spouse would be hospitalised in the non-local tertiary centre. *Being-in-suspense* was exacerbated because the couples and the

health professionals had different expectations of the availability of surgery as they waited to have biopsies, waited for the results of the biopsies or screenings, and waited for surgery or radiotherapy. Most people hear the word cancer as a death sentence, irrespective of the potential outcome (Maughan et al., 2002; Mellon & Northouse, 2001). This is despite claims made by MacCormick and Parry (2003) that a six-month waiting time for some malignancies is appropriate. Waiting until all the test results had been collated, or the wait between diagnosis, surgical intervention, and radiotherapy added to the research participants' sense of *being-in-suspense*. Because they did not know when the transfer would occur, the time of waiting had a negative effect on the research participants' perspective of their spouse's well-being, and indirectly on their own health.

While there is some literature that acknowledges that the emotional impact of illness on relatives is related to the degree of warning of illness (Leske, 2000; Thompson & Cordle, 1988), there are unique issues when one's spouse is to be hospitalised out-of-town. For example, only those whose spouse is hospitalised in non-local hospital centres need to make arrangements for children, work, or managing the household on the basis that there is distance between the place of work and the place where the spouse is to be hospitalised. Having to make such arrangements adds to the stress for couples without support networks, who are then forced to choose between being with the sick spouse, or staying at home with the children. Waiting for the outcome of the disease accentuated the sense of *being-in-suspense*.

Furthermore *being-in-suspense* is timeless. Timelessness acknowledges that the world still continues and time moves forward, but in recounting their stories, the research participants' minds kept going back to the incidences of having their spouses hospitalised in the non-local hospital setting. In projecting forward, *Da-sein* anticipates, waits for, and expects the outcome (Heidegger, 1962). The couples could not project forward because there were long periods of time 'waiting for'.

8.4.1 Awaiting, Anticipation, And Expectations Of Dis-Ease.

The concepts of awaiting, anticipation and expectations are outlined in Chapter Three. While expectations are projections into the future, in anticipation *Da-sein* can foresee the *potentiality-for-being*. In contrast, circumspection of the possibilities leads to awaiting. Heidegger claimed that awaiting is inauthentic, and anticipation is an authentic state of *being*. Awaiting occurs because the source of the concern is unclear. To apply these concepts to the current study, the research participants were in a state of awaiting because they were uncertain of the diagnosis, the outcome of the diagnosis, and what treatment would occur. In contrast, expectations occurred when the research participants were aware that the transfer to the out-of-town setting was likely in the future, but 'not yet'. In anticipation, the research participants waited for their spouses to become ill enough to warrant the transfer. While Heidegger (1962) focussed on the expectation of *being-toward-death*¹, findings of the current study are that such expectations were also reflected when the research participants became aware of the imminence of treatment in the out-of-town centre, and understood the outcomes. However, at the same time they were powerless to prevent the dis-ease complications or death, and therefore awaited nature to 'take its course'. It was not the possible outcome (death) that they feared, it was the powerlessness to prevent their spouse from dying, and the reliance on others who did not view the illness within the same interpretive framework. The research participants tried to manage the uncertainty of outcomes by focussing on the positive aspects of treatment.

However, their purpose in focussing on positive aspects of treatment, and in handling one step at a time was not to enable themselves to cope; a strategy proposed by Hunsucker et al. (2000). Their positiveness was to reassure either the spouse or others affected by the non-local hospitalisation, rather than themselves. The research participants used expressions such as... "[I] found quite a lot of time having to keep Glenys positive" (Paul, p.4), or as another frequently said to her family, "it's OK, everything's going to be OK" (Jan, p.5). The research

¹ *Being-toward-death* was explored in Chapter Five. In *being-toward-death Da-sein* anticipates death but cannot determine the *potentiality-for-being* dead as this indicates the end of *Da-sein*.

participants would not think of any negative outcomes, as their spouse relied on them for support during this time.

8.4.2 Facing Death.

The underlying nature of *being-in-suspense* revolved around the possibility that the spouses might die during the time that they were hospitalised in the non-local tertiary centre. While anticipatory fear of the unknown is identified in the literature (Duke, 1998; Hainsworth, 1998), the potential of becoming bereaved without social support or familiar surroundings is unique for those whose spouse is hospitalised in a non-local tertiary centre. The research participants who accompanied their spouse out-of-town faced the possibility of coming home alone. Those who could not accompany their spouse feared that their spouse would die in the non-local centre, and arrangements would have to be made to bring the body home.

Research participants also faced the possibility of death during the time of transfer to the non-local tertiary setting. This was a particularly difficult time if there was insufficient room for the accompanying spouse in the air ambulance, or the research participant was not accompanying the spouse. The research participants also had to wait on the day of surgery, being fully aware that there was a real possibility that the spouse might die during the operative procedures. Furthermore, the research participants were mindful that should interventions not be offered to the spouse in the non-local tertiary centre that they would have to return home, and then await death. The research participants struggled with the concept that despite their care the spouse might die.

Care is a basic state in which *Da-sein* exists ahead of itself in the world alongside others. The possibility of death disrupts *Da-sein*'s being ahead of itself or care (Heidegger, 1962). In encountering death so closely, the research participants experienced what Heidegger referred to as a projection of *being-toward-death*. Although Heidegger claimed that individuals face others' deaths inauthentically, some of these research participants got as close as it is possible to an authentic *being-toward-death*; it was not their own death they feared, but that of the ones closest to them. The research participants were concerned that death may occur;

they were awaiting death. These research participants were awaiting and dreading death without the social support, and familiar surroundings. The awaiting added to the state of *being-in-suspense*. In contrast, should they have anticipated death they would have felt that it was imminent. In these circumstances *Da-sein* faces death as a 'not yet' occurrence, but it was a matter of when the spouse would die.

It is recommended that when anticipating death of a spouse individuals plan changes so that the transition of bereavement occurs over time (Carr & Clarke, 1997; Duke, 1998; Keizer, 1992), and couples facing death should reminisce in order to have memories once the spouse has died (Duke, 1998; Waskowic & Chartier, 2003). However, although the participants were facing the possibility of their spouse's death, their spouse was not dying, and despite living with the possibility of death, only one couple planned what should happen should the spouse die in that centre. Those who accompanied their spouse were reluctant to predict the *potentiality-for-being* widowed without the immediate *presence-at-hand* of social support. Those who stayed at home to manage the household were reluctant to predict becoming widowed without the chance of being with their spouse at that time. It was more important that the research participants supported their spouse to have a future; they felt it would be defeatist to reminisce. Rather than gather memories for future coping, the research participants placed their energy into sustaining life. As each day passed, and the spouse did not die, the research participants began to count the days until they could be together at home again.

8.5 Living Day By Day Amid The Unknown.

The research participants who accompanied their spouses who were transferred to a tertiary centre faced periods of time when they were lonely, and tried to fill in the long hours of waiting by sitting at the spouse's bedside. The need to have ready access and close proximity to the patient is well documented in the literature, as presented in Chapter Two, especially during the time of acute critical illness. While nurses also recognise that relatives cannot maintain a vigil for endless hours (Appleyard et al., 2000; Carr & Clarke, 1997), the only activities away from maintaining vigilance that those who accompanied their spouse out-of-town could undertake, was to walk in the park, go to the museum, or wander

around town. The purpose of such activities was to fill in time, as there was nothing else to do but measure time.

It is also identified in the literature that family members need to address their own needs of daily living, and eventually return to work (Carr & Clarke, 1997; Leske, 1991; Plowfield, 1999). Participants of the current study who accompanied their sick spouse to the non-local tertiary centre had no opportunities to spend part of the day sitting by the bed, and then to return home for work and to meet their own needs. Because these supporting spouses did not have ready access to their own homes, they could not undertake the activities of daily living that are associated with being at home, and visiting a sick spouse in a local hospital.

The research participants who stayed at home did not have ready access to their spouse. Those who chose to stay at home struggled because, although they could attend to their own needs and return to work, they were well aware that their spouse was alone in the tertiary centre. This awareness resulted in these research participants being torn between supporting their spouse and managing the household. These research participants were challenged to support their spouse via long-distance telephone conversations, particularly when they were mindful of the fact that their spouse was miserable, and wanted to come home. The separation affected the entire household. For example, the absence of one parent through hospitalisation had unanticipated effects on the children, who for a long time afterwards suffered from sleep disturbances and demonstrated signs of depression. The only people who could empathise with the situation are those who have had children hospitalised out-of-town, a situation which also strains familial relationships (Agazio et al., 2003).

As identified earlier in this chapter, the process of 'being there', supporting one's spouse during this time is exceptional for those whose spouse is hospitalised in non-local tertiary centres. The requirements of having to make a choice whether to accompany the spouse, and spend long hours waiting by the bed, or having to juggle home and family is unique to those who have their spouse hospitalised in a tertiary setting. *Being-in-the-world* for the research participants meant either seeing their spouse daily, but living away from home, or not seeing the spouse for

periods of time. In both instances the distance between home and the place of hospitalisation was one that the spouse needed to de-sever². Those who accompanied their spouse needed to adapt to the 'being there' in a strange environment in order to protect the spouse from harm. Those who could not physically 'be there' were challenged to breach the space between home and the hospital as they too tried to protect their spouse from harm.

8.5.1. 'Being There' And Spatiality.

Space and distance relate to accessibility of things. When distance is not problematic, *Da-sein* is not perturbed. Distance and space also relate to the hopefulness of the outcomes, and in the case of the current study, the physical distance between home and the hospital centre reminded the research participants that their world was in chaos.

In the current study, most of those who stayed in the converted nurses' homes reported that although the accommodation was adequate, it was only a space to sleep. They were fazed by having to share showering facilities with strangers, and few of them were provided with cooking facilities. Research participants also made comments about cleanliness; something that Agazio et al. (2003) reported their research participants noted because they spent long hours sitting in the ward with few other activities to occupy their time. In all instances, the research participants of the current study could not return to their normal daily activity of employment, and addressing personal needs, such as bathing, took minimal time out of the day.

The research participants, who did not accompany their spouse to the non-local tertiary centre, found the space of home very lonely, especially in the evenings. The house was very quiet and there was a large void in the marital bed. Because of the emptiness, the space itself becomes transparent (Heidegger, 1962).

In Chapter Three I refer to a gentleman whose wife was transferred from one hospital to another closer to home, but she became further away as she was dying. Similar findings emerged from the current study, as the distance from home

² Refer to Section 6.3.2 for an explanation of this term

related to the well-being of the spouse. For example, Nancy perceived that admission to the tertiary centre, although geographically further away, would result in William receiving treatment. Andrea was distressed that Eric was discharged to the local centre, but subsequently transferred to the non-local tertiary centre again. Research participants would rather that the spouses were away from home for longer, but fully treated, than geographically closer to home, but further away in health; the distance between home and the tertiary hospital was insignificant if the spouses could be treated. These research participants endeavoured to close the distance between the treatment centre and home “in the sense of procuring it, putting it to readiness, having it to hand” (Heidegger, 1962, p.140). The distance between home and the tertiary centre was manageable if the journey included a time when “*a trip in the car with your mate is no problem*” (Nancy, p.8). In contrast if the trip with the spouse was problematic, the distance from home and the dis-ease became insurmountable. As long as the spouse was well enough, treatment that means quality of life enabled them to literally journey through this part of their life together.

8.5.2 Barriers To ‘Being There’.

The decision to accompany the sick spouse was one of the most difficult decisions facing the research participants. The supporting spouse needed to determine whether to accompany the sick spouse, or to remain at home. In this research there were two main reasons why the spouse decided to remain at home: they had young children and did not want to disrupt the household too much; or their work or business commitments resulted in them staying in the centre of residence. Having to make this decision added to the stress of supporting a spouse who was ill at the time.

There is an unexpected additional burden to having one’s spouse hospitalised in non-local tertiary centres, and that is financial cost. The choice to accompany their spouse resulted in the research participants having to take sick leave if they were in paid employment, or alternatively making arrangements for someone to run their businesses. This placed additional financial strain on the couples, especially when the non-local hospitalisation was for an extended time, such as for one couple who were out-of-town for four and a half months.

Sadly, the research participants, who accompanied their spouses, faced additional costs of paying for transportation and accommodation. Furthermore, there were inequities in the way financial support was provided to the supporting spouses. Such inequities had the potential of adding to the burden of care. For example, three of the research participants who accompanied their spouses to the tertiary centre were forced to pay for their own transportation costs during the time of transfer. One of the research participants was upset that the arrangements for her to travel with her husband in the air ambulance were suddenly changed as there was no longer any room for her. Another participant was not even offered the option. Because there was an inability to plan the time that the spouse would be transferred to the non-local tertiary centres, these participants paid full-priced airfares.

As pointed out in Chapter One, in 2000, the Health Funding Authority drafted guidelines to address the different levels of financial assistance available for those who are required to travel for treatment. These guidelines were not approved until August 2005, for implementation from 2006. Despite the guidelines only just being approved, the draft recommendations should have resulted in all of the research participants who accompanied their spouses receiving financial support for both travel and accommodation. However, only two of the research participants received financial assistance for accommodation during this time. In addition, one research participant received financial assistance when her husband was transferred to the tertiary centre for one medical condition, but had to pay for her own accommodation when it became apparent that he had a second medical condition that required specialist treatment.

Significantly, most research participants were not informed that they could be eligible for assistance with transportation and accommodation. Others who had been referred from the private to public health systems had been informed that the private care resulted in a forfeiture of eligibility. Such inequities and interpretation of the draft policies added to the stress that couples faced during this time. In the absence of a national policy, the District Health Boards used the

Community Services Card as the criterion for eligibility, adding to the disparity in support.

There were also additional meal and telephone costs for the participants of the current study. Because they were from regional centres, keeping in touch with home resulted in expensive telephone costs. The only access to telephones was in phone booths, or by cell-phones, adding to the cost of calling home. Furthermore, meals became expensive as not all accommodation enabled participants to cater for themselves, or to get a drink during the day. *I went downstairs to the café...I never got a cup of tea or coffee or anything while I was there [with Trevor in the non-local tertiary hospital ward] (Zoë, p.9).*

It is acknowledged that many hospitals have converted the nurses' home into accommodation for those who accompany relatives. However, such accommodation has resulted in accompanying relatives having to provide their own linen. *You bring your own linen, or your own sleeping bag. I brought my own sleeping bag and pillow (Zoë, p.9).* When patients are being transferred to a non-local tertiary setting, the last thing on the accompanying relative's mind is remembering to take sufficient numbers of towels, and personal clothing to accommodate their own needs. If items such as pillows and sleeping bags are overlooked, these have to be purchased, as it is impossible to return home and collect them. The additional financial costs, as well as the lack of facilities added to the sense that the research participants were 'visitors' in someone else's world.

8.5.3 Being-In-The-World – Whose World, And Who Is Caring For Me In The World?

In his book *At Home in the World*, Jackson (1995) described how Warlpiri Aborigines are not at home when surrounded by buildings and items that Westernised Australians value so dearly. Jackson found that the Aborigines moved through life as they moved through the desert, never taking a direct route, and always circumnavigating the landscape to determine the best path to follow. The Warlpiri acknowledge that this is not the way of others, particularly white Australians, but it is their way. Jackson argued that he was fortunate to spend such time with these people that he entered a world he never knew existed.

Furthermore, the Appalachian people of America have cultural values that result in Americans, who are not of the area, being viewed as outsiders to the extent that they could be foreigners (Hunsucker et al., 1999).

What is the significance of these two different cultural views for the current study? In the current research, the participants and their spouses were thrown into a strange world that resulted in some of them being far from home, both spiritually and geographically. The nurses who work in the tertiary settings are familiar with that world. However, unlike the world of the Warlpiri, which is visibly different from mainstream Australia, the world of having one's spouse hospitalised out-of-town is not necessarily visible. In fact, there are no visible effects of having one's spouse hospitalised in non-local centres, compared to having one's spouse hospitalised. Therefore, the effects can be overlooked and the supporting spouse left to flounder alone.

During the time that the spouse was hospitalised in non-local tertiary centres, the research participants were thrown into a constant state of chaos and uncanniness. Through thrownness *Da-sein* becomes uncanny as it recognises that it is not in harmony with *being-in-the-world*. The degree of thrownness, and a sense of not *being-in-the-world* and not *being-with-others* were dependent on the support that the research participants received themselves. The research participants reported that while they were looking after the spouse who was hospitalised in the tertiary centre, they sometimes wondered who was looking after them. This sentiment was expressed irrespective of whether the research participant accompanied their spouse or stayed at home to manage the household. Although they all expressed that they coped during this time, they did not want to add to the spouse's stress, and needed to find other sources for their own strength.

Much of the literature, presented in Chapter Two, discusses social support required by the supporting spouse during time of critical illness. Coulter (1989) claimed that few people face critical incidences of ill health alone. However, in incidences such as those referred to in this current study, when one's spouse is hospitalised in an out-of-town centre, social support is compromised. For example, some of the spouses had expressed fear of dying, and had not "*expected*

to come out of there" [the hospital] (Don, p.5). Therefore, the spouses were reliant on the research participants for strength during this time. In turn, the research participants had limited possibilities of having someone they could turn to for support, because if they accompanied their spouse, they were physically separated from their sources of social support. The sick spouse was too ill to provide it, and the research participants were often staying in the centre by themselves. While some members of the family were able to be with the research participants for isolated periods of time, most day by day support for this group of people came from other couples who were in similar situations. The reality for these research participants was that they were isolated, and if the spouse was too ill to contribute to the social support, the research participant was very alone. This led them to say such things as "*this was the loneliest time of my life...all those people there and it was the loneliest time*" (Carol, p.20).

8.6 Being-Alone.

In this research, some supporting spouses believed that they needed to accompany their spouse in order to advocate on behalf of their sick spouse. Others stayed at home to honour commitments to work or the children. Because the environment was unfamiliar, the research participants felt isolated from the world and others, especially the health professionals, within the world.

8.6.1 Being-Alone In Advocacy.

The research participants' reasoning was that because the health professionals were the experts, they had the mandate from society for those roles ('their' roles). When the health professionals did not fulfil those roles of expert, the research participants' worlds (*Da-sein*) became chaotic, and not *da-sein's* world. The research participants' interpretive frameworks, as they had known them, crashed around their heads. However, although the world as they knew it had changed dramatically, the horizons of new understanding were unclear, especially as at times the medical opinions differed from their own opinion.

The research participants or their spouses perceived that they had provided the health professionals with information that enabled them to accurately diagnose the condition. Perceptions that the health professionals did not make use of the information, led to the research participants and their spouses perceiving that they

were surrounded by chaos and the sense of *being-alone*. The health professionals not only paid superficial attention to the information on offer, but also having made their own judgements, did not explore non-authoritative knowing any further. However, only one of the research participants made a formal complaint and that was after her husband had died. *Da-sein* did not feel in a position to question the expert knowledge. In addition, the research participants were also made aware that the organisations were more powerful than the individuals, and that any complaint might compromise further treatment. While they could, and did, change GPs if appropriate, the research participants could not change the centre of referral. Despite their reluctance to make formal complaints when 'others' were not listening, the research participants could advocate on behalf of their spouse.

While acting as an advocate for one's spouse is not unique, acting as an advocate alone exacerbated the loneliness of having one's spouse hospitalised in a non-local tertiary centre if the research participants had to make life-changing decisions on behalf of the spouse. Again, the only other people who make such decisions in similar circumstances are those who accompany their children to the tertiary centre. Parents become compelled to advocate, ensuring that their children receive the best possible care (Agazio et al., 2002; Tan & Simmonds, 1998). The findings of the current study were that the participants found that their confidence as advocates grew with experience. "*Yes, I'm quite good at it [advocacy] now. I mean you just have to be onto it, on their backs the whole time*" (Alice, p.7). Advocacy resulted in the research participants determining where possible whether their spouse was 'ready' to be informed about their own condition, or the progress of other patients with whom the spouses shared life experiences. However, the research participants also argued that their spouse had been discharged too quickly. They could not advocate that the spouse stay in hospital for longer and cared about the dis-ease outcomes. They care about their loved ones by worrying about the implications of the illness for both themselves and their partner. Caring about is worrying about (Cheung & Hocking, 2004). In contrast, nurses describe care as offering a guarantee of well-being (Dunlop, 1994).

8.7 Nurses' And Supporting Spouses' Care And Concern.

Care is a word that is used by both those with an interest in the patient, and professionally by groups such as nurses to describe nursing care. Heidegger used the word care to describe the totality of *Da-sein*'s involvement in a phenomenon. If a situation does not draw *Da-sein* away from *being-in-the-world*, *Da-sein* will not hear the call to care, or disclose itself. *Da-sein* will remain fallen into 'their' way of dealing with the situation, and the status quo remains. Conversely, *Da-sein* will answer the call to care when disturbed by the unfamiliar. In identifying the significance of having their spouses hospitalised in non-local tertiary centres, the research participants (lay people) had different definitions of care than the nurses (professionals) who provided the care. Because there were different perspectives of care, and because the research participants that accompanied their spouses were at the bedside for long periods of time, they had a chance to reflect upon care. Sadly, because there were different definitions, the research participants' expectations of care were often not met.

In the situation of having one's spouse hospitalised in non-local tertiary centres, the research participant's role was that of working toward minimising the effects of the dis-ease on both the spouse and the rest of the household. Research participants used phrases such as, "*She didn't have to really worry about anything back here. That was, she was the focus*" (Yoland, p.12). The totality of their world (care) was that of the sick spouse. Therefore, the research participants expressed frustration that nurses did not respond to the spouse's needs as quickly as they thought the nurses ought. The fear of death also meant that the research participants felt diffident at handing over the care of their loved one to the health professionals. The participants identified that while they identified the spouses as the centre of their world, they also acknowledged that to the nurses the spouse was one of many. However, research participants' world centred on their spouses, there were feelings of resentment to find that they were not the centre of the nurses' worlds.

Nurses deal with sick patients every day. To them, sickness is *being-in-the-world*. Therefore, there is no disturbance to force the nurses' *Da-seins* to 'be there', because they already are 'there'; *being-alongside* the patients. By *being-*

alongside, the patients' worlds become invisible, because they are everyday. Everyday care becomes concern, as *Da-sein* lives alongside others in the world (Heidegger, 1962). "The average everydayness of concern becomes blind to its [*Da-sein's*] possibilities, and tranquillizes itself with that which is merely 'actual'" (Heidegger, 1962, p.195). The *potentiality-for-being* is modified to 'see' only what is at its disposal. For example, because nurses see ill people in an everyday manner, the recovery from illness does not generate a *potentiality-for-being* but rather is an expected situation. In contrast, the situations are not everyday to the patients and their social support.

A model of caring is dependent on a model of listening to, and understanding other's reality (Dahlberg et al., 2001). In this instance, the research participants' perceptions were that their realities were immaterial to the care that the health professionals proffered. The research participants had different expectations of solicitude. For example, feeling compelled to assist the spouse with personal cares added to the research participants' sense that the help may not be provided if they were not there to assist. The participants of the current study merely saw the nurses busy caring for other patients. This was compounded if the patients or the research participants did not have an identifiable nurse. Those who were unable to accompany their spouse to the out-of-town centre required information from the nurse, rather than from a nurse. If the totality of *Da-sein's* involvement is care, and concern is *Being-alongside being-in-the-world*, nurses have concern for the sick, while the supporting spouses care. The two differing perceptions led to an invisibility of nursing care.

These findings support claims that nursing care is not always visible, with patients often thanking medical personnel for saving their lives, and minimising the role that nurses have in continual monitoring and assessment of the patient's condition (Buresh & Gordon, 2000). If the monitoring that occurs in hospitals is reduced to the task of recording vital signs, the continuous nursing assessment undertaken while someone is a patient in the ward becomes invisible. For example, one of the spouses was discharged to a nearby motel on the proviso that they return to the ward on a daily basis so that the vital signs could be recorded. Recording vital signs this way reduces assessment and monitoring to a task. Had nurses caring for

those in the current study recognised that the illness that required the tertiary hospitalisation was not an everyday happening for the individuals that had been transferred, nursing care would have been apparent.

Sadly it is also reported that nurses do not approach significant others as they do not want to intrude on time that the patient is spending with their support persons (Kettunen et al., 1999; Rantanen et al., 2004). Ironically, the findings of the current research are that those supporting their spouse during the period of hospitalisation wanted the nurses to spend more time with them, and would not have viewed this time as an intrusion.

Ward-based nurses are the only health professionals who stay in the department for their entire working day; every other health professional acts in a consultancy role, and attends to the patient for a brief period of time. Ward-based nurses become part of the *readiness-to-hand* and *presence-at-hand* of the hospital world. Because other health professionals come and go, they become visible. Furthermore, when other health professionals record in the notes or discuss patients, it is seen as leading case reviews. When nurses do this, it is seen as idling away the time, as described by one research participant. “[The nurse said] ‘*Oh we are very busy*’. He said ‘*you look very busy all sitting around there having a chat*’” (Victoria, p.7). Ironically, one consultant nurse must have spent quite some time with one research participant and her husband, but the research participant did not recognise her as a nurse, instead saying...“*the lady came and taught me what to do*” (Carol, p.3).

Nursing care is also anticipatory, in that nurses anticipate patients’ needs, and because they intervene early, the needs do not always become apparent to patients (Benner, 1994). In anticipating those needs nurses ‘leap ahead’. However, nurses’ leaping ahead is not Heidegger’s authentic care. Anticipatory care is undertaking care within a professional framework, not disturbance of *Da-sein* because it is uncanny; not being at home. Nurses demonstrate care for and concern about their patients when they have leapt ahead to anticipate the patients’ needs. In contrast, when the nurses cannot manage the situation, they become concerned. If concern about the patients’ condition results in the nurses referring

to other health professionals because they are no longer able to manage the situation, they 'leap in' (become concerned about). The spouses, on the other hand care about their sick partner, because that is their world, and become concerned for them when they cannot foresee the *potentiality-for-being*. Interpretations from this research are that nurses *care for* and are *concerned about* their patients, while the research participants *care about* and are *concerned for* their spouse.

8.8 Implications For Health Professionals And Nursing Practice.

The likelihood of treatment in non-local tertiary centres is only likely to increase as services and technology become more sophisticated. Such medical specialisation has social implications when families are affected by the requirements to travel to specialist centres. As medical care becomes specialised, so must nursing care specialise in treating the family unit affected by such requirements. There is much that nurses and other health professionals can learn from the research participants' experiences.

The first factor that must be considered is of nursing the entire family unit, rather than the individuals who occupy the hospital bed. A simple strategy to ensure this is to note whether the couple is from a non-local centre. The research participants reported that while their spouses acknowledged that there were valid reasons for not being accompanied to the non-local tertiary centre, the spouses in the out-of-town centre were lonely, frightened and homesick. However, few nurses demonstrated much empathy for the situation. A simple enquiry about the accommodation needs of the supporting spouse, or the welfare of the supporting spouse and family at home would individualise the plan of care, and ensure that nurses practice holistically, and not fall into the trap of a bio-medical model of specific treatment for specific diseases (Madjar, 1992). Nurse educators need to emphasise family care, rather than only individual patient care when discussing hospital treatment in nursing education programmes.

Through effective communication, and demonstration of interpersonal skills nurses will generate a presence, and raise the visibility of nursing care. Presence does not demand that nurses spend more time with the patients (Melnechenko,

2003), rather nurses need to focus on 'being there' and becoming involved with their patients. At a minimum to ensure the well-being of this population group, nurses must acknowledge that what is common and worldly for the nurses in that tertiary setting is frightening for those who have been transferred from their home town. A sense of trust in care can be generated when the couples are informed of potential outcomes by the nurses providing care.

The findings of the current study have confirmed that the supporting spouse needs acknowledgement for the role they play in patient recovery. However, when the spouses believed that they were providing care that the nurses ought to have provided, nursing care itself became invisible. As nurses strive to foster independence in preparation for discharge, they need to communicate the plan of care to the family unit. While the maintenance of personal cares can be delegated, nurses need to be sure that the patient and the spouse are aware of the rationale behind that delegated activity, and be visible in assessing the patient in other ways.

In addition, nurses need to continue their assessment and monitoring during the times that patients have visitors, rather than withdrawing for fear of intruding on private times. While it is acknowledged that it is difficult to become involved if they have too many patients to care for, nurses need to make the most of the opportunities they have for patient contact. Furthermore, the sense of trust is dependent on the nurse having a manageable workload, highlighting the need for additional research on nursing workloads.

A fifth recommendation from this research is that nurses raise their visibility by detailing the education that they provide to patients. It was identified in Chapter Seven that one couple reported that the information was not presented personally by the nurses; rather they were given videos to watch. Although they did not discuss the value of the video in informing them of the surgical procedures, they perceived they had been given a video instead of receiving the information from nursing staff. Whether it is societal expectations that information comes from the medical personnel, the current research reinforces perceptions that nurses are losing the opportunities to provide patient education, and thus raise their

professional profile. Contrary to leaving informative education to the medical personnel, nurses need to use the time that they are there with the patients to inform them about the likely treatment outcomes, and potential future health needs, thus involving the spouses in a partnership of care. Instead of using videos and written material as a substitute for information, nurses should use these media to supplement such information.

Nurses also need to be identified as the responsible nurse clinician. By this expression I mean that the relatives and the patients need to be fully aware of the nurse's name. When the research participants knew whom to contact, they felt supported and secure in the knowledge that their spouse was cared for. Conversely, when the research participant did not know who was caring for their spouse, whether they accompanied the spouse to the non-local tertiary centre or not, the couple did not have a sense of care. The sense of trust could only be developed if the research participants could clearly identify that someone was taking responsibility for the spouse's care. Sadly, few of the research participants identified that they had a nurse who took that responsibility. Instead they reported "*we had not seen anyone over that period of time...we were told nothing*" (Victoria, p.4).

Furthermore, the research participants also struggled to determine the patient's progress, especially if the supporting spouse was unable to be present during the medical rounds. Being present during these rounds presents a challenge if the supporting spouse is at home, maintaining the household, and the sick spouse is too ill to remember every detail. Findings from the current research are that those whose spouses were hospitalised in the non-local tertiary centre and involved in the plan of care perceived that information was pivotal to maintaining a locus of control. Therefore, medical personnel need to become more available for those who are supporting their spouse in hospital. One research participant reported that she went to the ward "*at nine o'clock to try and see the doctors who could come any time between 8.30 and midday*" (Carol, p.6). While literature claims that the role of families is to wait (Plowfield, 1999), such waiting reinforced the power structures that do not consider any other obligation that the supporting spouse may have. If doctors want to be actively involved in educating the patients (Marsland

& Logan, 1984), they also are obliged to keep the supporting spouse informed as well. Nurses need to be cognisant of the needs of this patient group, and if they are unable to be the providers of information about the patient's progress, they need to facilitate processes that ensure access to medical personnel.

Another recommendation that emerges from this research is that there is a degree of urgency to adopt the recommendations from the Government's *National Travel Assistance Policy* into local District Health Board policies, to ensure equity for what is becoming a common phenomenon. As noted, too many research participants were required to pay for their own travel and accommodation. While they contended that they could afford this, this requirement did financially challenge them, and added to the burden of care at this time. Nurses need to become cognisant of the national policy, and facilitate processes, so that patients have access to appropriate financial support.

In addition, administrative assistants in organisations need to be aware of the ramifications of non-local tertiary hospitalisations. Some simple strategies could demonstrate acknowledgement that these couples need to travel. For example, radiotherapy staff could make late Monday and early Friday appointments to allow couples to travel on the day of therapy. Importantly, couples need to be informed before they leave home that the machinery is not operational, so that extra travel or unnecessary time in the out-of-town centre is avoided. Alternatively, staff could arrange the schedule so that local people, who can access their local centre for treatment, are the ones who are deferred.

Other bureaucracies, such as WINZ need to acknowledge the reality of having a spouse hospitalised in a non-local tertiary centre, and utilise social workers in those centres if they require applications from the sick spouses themselves. Again the possibility of couples being affected by non-local tertiary hospitalisations, and requiring financial assistance for daily living is likely to increase, and strategies need to be implemented to ease the process.

8.9 Research Limitations.

This study is reliant on the representations of the research participants, and the findings are unique to those who took part in the study. The reliability, validity, rigour and objectivity that foster generalisation apparent from quantitative studies are not presented in qualitative studies (Nieswiadomy, 1998). Instead researchers focus on the disclosure of the philosophical underpinnings (Beanland, Schneider, LoBiondo-Wood, & Haber, 1999), the relevance of the study (Dempsey & Dempsey, 2000; Nieswiadomy, 1998), and an audit trail that enables readers to follow the researcher's decisions and conclusions (Beanland et al., 1999). The experiences of 14 individuals or couples affected by the non-local tertiary hospitalisation have been presented in this thesis. The experiences of 'being there' at the time are individual, although themes did emerge from their stories. However, the individual stories carry lessons, and sharing the individual stories with others who have been in similar situations strengthens the findings. Credibility has been maintained by weaving the individual stories into the data analysis.

Aspects of the research participants' stories have been presented, and the interpretations linked back to their stories. This has enabled the writer, and readers of the study to share in the experiences and interpret the impact of the non-local tertiary hospitalisation on couples. This approach does lead to a limitation of the thesis in that while it describes the experiences of those whose spouse was hospitalised in a non-local tertiary centre, the intent of the thesis is to generate understanding of the experiences, not be emancipatory and facilitative of changes to practice. However, it is anticipated that nurses reading this research will be able to 'be there' with couples in similar circumstances in the future, and incorporate the interpretations that emerged from the current study into their practice.

The research processes for this study enabled individuals to self-select as research participants. One major limitation of this research is that no Māori nominated to take part in this study. As identified in Chapter Four, case managers were asked to approach potential research participants. Despite this, nobody appeared to be interested in the study. It was originally intended to advertise the research in

centres such as doctor's surgeries and out-patient departments. On reflection, this seemed to be an impersonal and culturally inappropriate method to approach people, so the advertisements were not placed. Furthermore, when the local iwi³ were asked to comment on the research proposal, the Kaumatua⁴ and Kuia asked local rununga⁵ to identify potential research candidates, but no-one volunteered. Does this mean that the research findings are not applicable to Māori? Māori may place different interpretations in similar circumstances, but they may also be able to identify with aspects of the findings. Such identification with the situation enables their own interpretations to be made.

Further limitations of the research are that at times the couples discussed the period of time when the spouse was hospitalised, rather than focus on the out-of-town hospitalisation. This is because it was the reaction to the illness, such as complications, that caused the problems, not the place where the spouse was hospitalised. Such commonalities between the out-of-town hospitalisation and the local hospitalisation add strength to the research, as it enhances understanding of the spouse's need to 'be there' during this time. The research participants' lifeworlds were living with dis-ease, and to remove the dis-ease continuum from their stories, and focus on one aspect of that continuum would be to distort their interpretations of the experiences at that time.

8.10 Future Directions For Research.

This study did not specifically target particular ethnic groups, and, as previously identified the participants did not identify themselves of specific ethnic origin. Additional research that ascertains the experiences of non-local hospitalisations among those from Māori background is needed. However, Māori not only need to determine whether the research is necessary, they must also be able to direct the research processes.

No other New Zealand research has explored this common phenomenon. A concern about the international lack of research on the effects of non-local hospitalisation on adults has been noted (Agazio et al., 2003; Mercer, 2002).

³ Iwi means tribe, based where the original Maori landed in New Zealand.

⁴ Kaumatua and Kuia are senior members of the Maori community. Kaumatua are male, Kuia, senior female.

⁵ Rununga means local health provider.

While this lack of international and national research has resulted in limited literature with which the current thesis can be compared, the findings of the current study form a foundation for further research and scholarly debate. Further research that examines the impact of non-local hospitalisation on families based on differing theoretical perspectives would enable comparison between the current and future findings.

Finally, it has been proposed that nursing care is inauthentic in Heideggerian terms. Further research about nursing lifeworlds, workloads and caring is required, but is beyond the scope of the current study that focussed on the supporting spouses' ability to 'be there' during times of non-local tertiary hospitalisation.

8.11 Chapter Review.

All couples who participated in this research were affected by the hospitalisation of their spouse in a non-local tertiary setting. Although in some cases the transfer was implemented quickly, there were always periods of waiting. This included times of waiting for the results to be returned, the transfer to be organised, and the treatment to begin once the patient had been transferred. Throughout these times of waiting, the research participants were constantly in suspense. Their unspoken, but largest proportion of time was spent awaiting death. However, because they did not want to face death, the research participants did not want to engage in activities such as gathering memories in preparation for their spouse's death.

In order to maintain some sense of normality during the time of waiting, the research participants became involved in care as much as they could. This care resulted in them 'leaping in'. In contrast, nurses 'leapt ahead' in anticipation of the patients' needs. In providing the care that they could (leaping in), the research participants did not see nursing care (leaping ahead), and did not perceive the nurses as being informative, or the care provided by the nurses as visible. Rather than be reluctant to provide care when the family are visiting, as it is seen as intrusive, nurses need to include the spouses in plans of care and raise the profile of anticipatory nursing care. By demonstrating a presence, nurses can 'be there'

with their patient group when patients' perceptions of *being-in-the-world* are compromised.

CHAPTER NINE CONCLUSIONS.

9.1 Introduction.

Having one's spouse hospitalised out-of-town has an impact on the entire family unit, reflected in this research by three major themes. These three themes: *being-in-suspense*; fitting being out-of-town into *being-in-the-world*; and *being-with* and *being-without* others were presented and discussed in the thesis.

Chapter Five focussed on the times that the research participants and their spouses were waiting for diagnosis, and then for treatment to be offered. The research participants and their spouses also spent time waiting for the outcome of the treatment, and to know whether the treatment had been successful. I have called this time *being-in-suspense*. The times of *being-in-suspense* occurred for periods of time before the spouse was transferred to non-local tertiary settings, and also afterwards. This state of suspension for those whose spouse is transferred out-of-town differs for those who live in the bigger cities, and therefore whose spouse with the same medical condition would be treated at that tertiary centre. While technology has increased treatment options for those with complex health needs, the specialisation has resulted in an increase in the need for treatment in tertiary or specialist centres. In Chapter Five, two themes of lifeworlds are presented: *being-in-suspense* as the participants waited, and *being-in-suspense* in facing death.

In Chapter Six I discussed the time when the couples made the necessary adjustments until they could *be-in-the-world* again. Five themes reflect the adjustments that the couples had to make during this tertiary hospitalisation: Filling in the long hours while the spouse was in hospital; keeping watch over their partner; wondering who was caring for themselves while they were caring for the spouse and family; struggling to juggle home and family during the time that the spouse was hospitalised in the tertiary centre; and coping during this time.

Chapter Seven focuses on the time when the research participants felt their worlds were different from those of the health professionals, as well as often their own spouses. This sense of being different that led to a time of *being-without-others* came about because the research participants perceived they were not being listened to, and their perceptions of the situation were not acknowledged. An invisibility of nursing care added to the sense of *being-without-others*, which was compounded if other professionals could not perceive the reality of having one's spouse hospitalised in a non-local tertiary centre. Sadly, the spouses often added to the sense of *being-without-others* as the research participants and their spouse had different perceptions of the support needed at this time. On the other hand, the actions of some family members or health professionals generated a sense of *being-with-others* for some research participants because they were able to discuss issues, and could work in partnership with their spouse and the health professionals to facilitate positive outcomes.

9.2 Having One's Spouse Hospitalised In A Tertiary Centre.

The findings of this research are that having one's spouse hospitalised in a non-local tertiary centre affects the entire family. Furthermore, the time that the spouse was hospitalised out-of-town occurred on a continuum of living with a medical condition. Periods of hospitalisation in the local hospital, and in the non-local tertiary centre were seen in the context of the original illness and of living. The dis-ease, rather than this episode of illness that required the transfer to the out-of-town centre, was part of *being-in-the-world*. *Being-in-the-world* of having their spouse hospitalised out-of-town meant that the research participants' worlds initially were that of being the spouse of someone who was sick. Some couples had difficulty convincing the medical practitioners that there was a health problem. Other couples knew that the health problem existed, but that it was not severe enough to warrant further action. These couples spent each day waiting for additional signs so that their spouse would have treatment, thereby beginning a time of *being-in-suspense*.

It was a coincidence that the participants of this current study did have a period of time to adjust to the non-local hospital transfer, in that most of them had a condition that had been treated locally prior to the transfer. Although the dis-ease would result in an out-

of-town hospitalisation, the research participants made the necessary adjustments to life. During this time the research participants entered into a period of watchful waiting; a phenomenon that became part of the dis-ease process. The unknown implications of the illness itself caused more consternation than transfer did, continuing the state of *being-in-suspense* as the research participants were uncertain what the future would hold for them.

The time of *being-in-suspense* was exacerbated when couples were uncertain whether treatment would be offered, often sitting at the tertiary centre for periods of time prior to having surgery. In addition, waiting during the day of surgery, often alone, added to the state of suspension. Awaiting outcomes resulted in the research participants adjusting to having their spouse in the hospital, and to the world as it was now becoming. But their over-riding fear was that the spouse might die during this time.

9.3 Fear Of Death And Dying.

The unknown caused such a strain for the research participants, that having treatment became a relief. However, the need for hospitalisation brought reality to the possibility that the spouse might die. At times the research participants could not distance the fear of dying in the non-local tertiary centre from the connotations of the actual condition. Research participants were particularly fearful of the spouse's death during the time of transportation to the tertiary centre, especially if they were unable to accompany their spouse. In addition, waiting for surgery to be offered also exacerbated the fear and sense of powerlessness that the research participants experienced during this time. The sick spouses were transferred to a tertiary centre because the regional centre did not have the expertise and technology to treat the condition. However, these conditions were so commonplace to those in the tertiary centre, that they were not seen as out of the ordinary, and did not warrant immediate treatment. This was particularly difficult for couples who were uncertain whether the treatment was going to be offered, either because of the nature of the illness, or because the equipment was not working. The couples were fearful of the unpredictable ramification of delays to treatment, and whether this would hasten death.

Other research participants had to make decisions that would affect the spouse's future. However, because the spouse was too ill to participate in the discussion, the research participants were forced to make these decisions on their own. Making such decisions added to their fear of the spouse's death, and a sense of loneliness that occurred during this time.

In addition, at times the research participants felt they were surrounded by death. They were aware that fellow-patients of their spouses were dying, or died suddenly, yet their spouse still lived. This added to the understanding that life was fragile, and to the apprehension that their spouse was not immune to dying of similar conditions. However, despite not using the terms 'sickness' and 'chronic illness', most participants and their spouses realised that life is finite. The possibility of death was before these participants, but having faced death, they oscillated between living and dying.

9.4 Being-Alone In The World But Making Adjustments To Being-In-The-World.

Those who accompanied their spouses out-of-town had personal challenges of long days and sleeping in strange environments to manage. The only alternative to spending the long days sitting by the bedside was to walk around the park, visit the museum, zoos, and any shopping trips were to fill in time, rather than explore the city in a holiday mood. The activities of daily living associated with filling in time also had the potential to financially compromise these couples.

9.4.1 Financial.

There are major financial implications to having one's spouse hospitalised out-of-town, as couples need to determine implications of the transfer on employment, accommodation, and transport. When an individual requires hospitalisation, they also need to consider their place of work or make alternative arrangements if they are running a business. Furthermore, when one's spouse is hospitalised in a local setting, the supporting spouse is usually able to continue their employment. The findings of this research were that those who had businesses, or who were in paid employment, and who accompanied their sick spouse, were required to take sick leave, or to employ other people to maintain the business for them in their absence. Whether the employer would

hold a position open for a long period of time if one were accompanying a spouse, would be dependent on the goodwill of the employer, and places a couple in a vulnerable position for loss of income adding to the financial burden.

In addition, the findings of this research were that many of those who accompanied their spouses to the tertiary centre were required to arrange their own transport and accommodation. As a result, this study accentuated that there is a fine balance between caring for the individual and family nursing care. Fortunately, the nurses at the regional hospital told Zoë that accommodation was available for the public in the nurses' home. However, other research participants were not informed of accommodation options, and nurses at the tertiary centres did not ascertain that the research participants had been accommodated. This added to the research participants' sense that care was not provided. Having to make one's own travel and accommodation arrangements highlighted the inequities in care provision.

The final financial implication of having one's spouse hospitalised in non-local tertiary centres is that of telephone contact to supporting family who have remained at home, and money for sundries such as meals and personal items. Again, while it is not the place of the District Health Boards to provide free tea and coffee for all relatives, having to pay for every drink and every meal also becomes an added expense.

9.5 Implications For Nursing Practice, Education And Research.

What can we as nurses learn from the research participants' experiences? The first factor that must be considered is of nursing the entire family unit, rather than the individuals who occupy the hospital bed. This research has confirmed that the supporting spouse needs acknowledgement of their supportive role. The literature identifies that nurses are reluctant to attend to patients when the relatives are visiting, for fear of intruding (Kettunen et al., 1999; Rantanen et al., 2004). Tragically, the findings of this current study are that the couples wanted the nurses to attend to them, and the lack of attendance led the research participants to believe that there was a lack of care. This was especially difficult when the spouses were transferred from the critical care units to the general wards, and the supporting spouses were sitting by the bedside with nothing else to do but wait for nurses to attend to their spouse.

In addition, nurses need to note whether couples are from a non-local centre. A simple enquiry about the accommodation needs of the supporting spouse, or the welfare of the supporting spouse and family at home would individualise the plan of care, and ensure that nurses practice holistically. Through effective communication, and demonstration of interpersonal skills, nurses will generate a presence and raise the visibility of nursing care. The very least that nurses can do to ensure the well-being of this population group is to acknowledge that what is common and worldly for the nurses in that tertiary setting is frightening for couples affected by out-of-town hospitalisation. Findings of the research have led me to conclude that nursing care is based on nurses *being-in-the-world*. When the nurses cannot manage the situation, they become concerned. The supporting spouses, on the other hand, care about their sick partner, because that is their world, and become concerned for them when they cannot foresee the *potentiality-for-being*.

Nurse educators must reinforce the need for family nursing, not individual patient care in nursing education programmes. Nurses in the clinical setting can apply the theory to practice, supported by theoretical underpinnings.

Further research undertaken by differing ethnic groups who are affected by non-local hospitalisation would enhance and strengthen understanding of this phenomenon. Other research that explores nurses' workloads and ability to provide care for their clients would provide a framework to increase understanding of nurses' lifeworlds. Finally research that used differing methodologies would enable comparisons between the interpretations of the experiences that emerged from the current study.

9.6 Chapter Review.

In this chapter, a summary of the research findings and discussion is presented. This study has determined that, while there are some commonalities of having one's spouse hospitalised, there are also unique aspects to the phenomenon. During this time, the supporting spouses experienced periods of *being-in-suspense* as they feared the outcome of treatment and possibility of death. However, these research participants faced these

times alone, in centres where they had no social support. In addition, the research participants were challenged to fill in the long days while their spouse was in hospital, by burying themselves in work, or by waiting by their spouse's bedside.

The thesis that emerged from this study is that those whose spouse was hospitalised in a non-local tertiary centre lived day by day, with little or no social support, awaiting outcomes over which they had limited control. The worst potential outcome for these individuals would be that of the spouses' death in the non-local centre. When the outcomes could be predicted, the time that the spouse was hospitalised in the non-local tertiary centre was manageable on the continuum of living. It also emerged from conducting this study that in living day by day, the supporting spouse coped by focussing on the temporality of the present and the vision of a positive future, but their spouses were not always able to conceive the future in such a positive way.

Whether they stayed at home, or accompanied their spouse, at times the research participants struggled to juggle work, home, and family. In addition, there are financial implications of travel and accommodation costs, and sundry costs of telephone contact and meals that can place additional burdens on the families during this time. Nurses already have the strategies to care for this population group. It is timely that the specialisation of medical care results in nurses accepting the challenge to provide specialist nursing care that is family centred.

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