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**The experience of hospitalization first time for
an acute medical illness**

by

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Abstract

This research focused on exploring and describing patients' experience of their first hospitalization for an acute medical illness. Twelve participants who had experienced their first hospitalization within the last two years were involved. Unstructured, open-ended interviews were employed to obtain data. Thematic analysis (Burnard, 1991) was used to provide a detailed systematic description of issues addressed in the interviews.

Six main themes emerged from the participants' stories. Waiting was the predominant theme that emerged from the participants' experiences in the accident and emergency department. Once admitted to the ward, the need to know, support, environmental issues (which included the physical environment, privacy and safety issues) are the themes that emerged from the data. On discharge and post discharge, lack of information was a theme that had significance for the majority of the participants.

The implications of these findings for practitioners who work in an acute hospital setting, especially with patients who have not previously experienced an acute hospitalization, are explored.

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1.0 Introduction

1.1 Orientation to the study

The purpose of this study is to describe patients' experience of their first hospitalization for an acute medical illness. The impetus for this study came from both professional and personal experience. As a nurse educator I work predominantly in the acute clinical environment. Many patients, especially those admitted suddenly, appear to be working very hard on several different levels. They attempt to maintain socially competent behaviour, to manage severe emotional and bodily discomforts, to continue to run their family and work affairs, and to find some meaning in the entire experience.

On one level nurses should be aware of this dimension of patient experience, but it is particularly difficult to understand and articulate unless one has experienced hospitalization as a patient. My first experience of being hospitalized for an acute illness reinforced for me the importance of health professionals being aware of how people experience hospitalization. Reflecting on this time I was able to identify several responses that influenced my experience of hospitalization. At times I felt helpless, vulnerable and out of control. I wanted to know what was happening to me, but I was afraid to ask, firstly because I wasn't sure I really wanted to know the truth and secondly because I didn't want to bother everyone when they appeared to be so busy and preoccupied. I became curious as to how others experienced hospitalization.

Most people regard hospitalization with considerable apprehension. For patients, the act of hospitalization implies the presence of illness too severe to be treated in a doctor's office. This fact alone can be terrifying. It means the patient may need to abandon their role in society and perhaps even face the reality of their own mortality. People do not usually live with this anxiety in the forefront of their consciousness. It is hard to do otherwise in the hospital where one is surrounded by serious illness and death twenty-four hours a day.

My experiences raised many questions.

- What do patients experiencing sudden hospitalization for the first time have to say?
- How does the hospital environment affect the individual patient in their struggle with this anxiety-provoking situation?
- What are patients' concerns with and experiences of hospitalization?

It is these questions that this qualitative study seeks to address. The method of thematic content analysis was chosen because of the systematic method of analysing data (Burnard, 1991). I wanted to represent the thoughts, feelings and key issues of patients, in a systematic but honest way about their first experience of hospitalization in an acute medical setting.

1.2 The structure of the thesis.

In the introduction I have begun with an explanation of why and how I, as the writer, researcher and nurse have become interested in the patients' first time experience of acute hospitalization and why I subsequently chose a qualitative method and thematic content analysis as the research approach.

The literature review, chapter two will look at the broad array of literature available on the wider perspective of illness experience and specific experiences of hospitalization. The following themes emerged from the literature; physical well being, the nurse-patient relationship, information sharing, family and others' support and ways of coping. The above themes provide the structure for the literature chapter.

Chapter three outlines the qualitative research design and why this was chosen for this study. The method of thematic content analysis employed during the study is explained and ethical considerations

shared. A critique of the method of thematic content analysis is presented. The chapter ends with discussion on issues of rigour for qualitative research.

Chapters four, five and six are the data chapters. In chapter four I begin by discussing the preadmission to the ward experience. This involves firstly preadmission to hospital and then the experience in accident and emergency. Although I clearly stated in the information given to participants that I was interested in their experiences of first time hospitalization for an acute illness (see appendix 1), all participants commenced their discussion of their experiences of first time hospitalization with their experiences prior to admission to the accident and emergency department. The predominant theme that arose from participants' discussion of the accident and emergency experience is *waiting*.

Chapter five discusses participants' experiences in the ward. Several themes became apparent following examination of the data related to the participants' experiences in the ward. Firstly was the need for *information*. Participants needed to know what was happening to them. Secondly was *support*; that is support from health professionals and also support from family, friends and other patients. *Environmental issues* is the third theme explored. The first subtheme within environmental issues entitled the physical environment, included factors which contributed to participants' discomfort such as sleep and noise, hygiene, the temperature and lack of choice with food. The second subtheme within environmental issues was privacy, an issue for most but not all the participants. The issue of safety which included feeling unsafe due to effects of the participants' condition was the third subtheme explored in chapter five 'The Ward.'

Chapter six describes the discharge experience and also the post discharge experience. The importance to the participants of these

two aspects of the whole experience of hospitalization becomes apparent. *Information* (or the lack of it) is the main theme throughout this chapter.

Chapter seven entitled, 'Implications for nursing' moves from the participants to the larger context. I discuss implications for nursing practice as well as for health professionals in general. This chapter concludes the study. It will bring through the key points made throughout the study. I conclude by identifying areas for future study.

2.0 Literature Review

2.1 Background

This chapter provides a review of the literature from the late 1950s through to early 2000, predominantly using the cumulative index to nursing and allied health literature (Cinahl) data base. I found a significant amount of literature about the experience of illness and literature about aspects of the experience of hospitalization. However, there appears to be a gap in the literature about adult patients' first experience of hospitalization. I found no literature specific to the New Zealand context. Literature written by patients about their own experience of illness is common, for example by Allbrook (1997), Cousins (1979) and Young-Mason (1997). There is also a body of literature written by health professionals on the patient's experience of illness (Fife, 1994; Kleinman, 1988; Radley, 1994). Hospitalization can form part of the illness experience and indeed the impact of hospitalization has been shown to be significant for a number of groups of people. For example there is literature about the impact of hospitalization on children (Audit Commission, 1993; Bowlby, 1965; Sheldon, 1997), and the experience of institutionalization from the elderly patient's perspective (Ford, 1995; Sarton, 1973). There is also literature relating to how people with chronic conditions learn to adapt to their disabilities and manage hospitalization over time (McLennan, Anderson & Pain, 1996; Tickle, 1993).

The initial experience of hospitalization may be qualitatively different from subsequent admissions. I found no literature about the patient's first experience of hospitalization in an acute medical area and no New Zealand literature on the experience of hospitalization from the adult patient's perspective. Studies of hospitalization in adult patients tend to focus on particular aspects of the hospital experience including their perception of support from nurses (Gardner & Wheeler, 1987; Holliday, 1961), their emotional reaction

to hospitalization (Irurita, 1996; Taylor, 1979; Wilson-Barnett, 1976), and their experience of care (Brown, 1986; Johnston Reiman, 1986). The experience of patients in specific hospital environments such as isolation units, intensive care units (Connelly, 1992; Gaskill, Henderson & Fraser, 1997; Green, 1996; Knowles, 1993), and patients receiving technically complex care have been studied (Chappell & Case, 1997; Henschel, 1997). There is also a body of quantitative studies that measure patient satisfaction by assessing aspects of the patient's experience of hospitalization (Astedt-Kurki & Haggman-Laitila, 1992; Fosbinder, 1994; Harper Peterson 1989; Oberst, 1984; Taylor, Hudson & Keeling, 1991).

2.2 Themes:

In this review, common themes in the literature about the adult's experience of hospitalization are identified. These broad themes are physical needs, the nurse-patient relationship, information sharing, the support of family and others and ways of coping.

2.2.1 Physical needs

Under normal circumstances, most people can take care of themselves, however illness, medical treatment and hospital confinement often create physical dependency and discomfort. A number of studies have identified that attention to basic physical needs for example personal hygiene, relief from pain and attention to comfort, is a priority for patients (Marks & Sachar, 1973; Southwell & Wistow, 1995; Ward, 1992).

Patients rely on their caregivers to recognize and alleviate their physical discomfort (Cameron, 1993; Fajemilehin & Fabayo, 1991; Walker, 1993). Controlling acute pain is considered to be most important in maintaining physical comfort (Walker, 1993). While it is not desirable to eliminate all pain (since it can often aid in diagnosis or in monitoring a patient's condition), the most basic element of the caring function of nursing is the relief of pain, and aggressive pain

management is essential to patient centred care. Pain continues to be one of the most feared and debilitating aspects of illness and medical treatment (Walker, 1993). However Marks and Sachar (1973) found that seventy three percent of medical patients reported enduring moderate to severe distress in spite of their pain control regimes. More than a decade later, Donovan, Dillon and McGuire (1987) found that 58 percent of randomly selected medical and surgical patients who had pain at some time during their hospitalization, reported having 'horrible' or 'excruciating' pain at some point, and only one third of patients with pain reported obtaining total relief at any time.

When hospitalized for a serious illness, some patients feel almost disorientated, isolated and very dependent on others for basic needs (Boeing & Mongera, 1989; Irurita, 1996). Given their state of dependency, hospital patients are acutely aware of their physical needs and how they are respected and attended to (or otherwise). It is what they notice first about their nursing care (Ahmadi, 1985; Brown, 1986). Relying on others for their most personal care, patients are also sensitive to their caregiver's manner in tending them. *'One nurse was washing me up, and oh, she was so rough! Just like she was washing a doll and not a human being.'* (Johnston Riemen, 1986, p. 30).

One basic physical need that appears to receive little attention from hospital staff is the need for sleep. Patients often complain of not being able to sleep in the hospital (Closs, 1988; Southwell and Wistow, 1995; Ward, 1992). The most common reasons for this, according to Southwell & Wistow's (1995) quantitative study, is the noise of other patients, the noise of the nurses, telephones, lights and emergencies on the ward.

When nurses choose to focus on the psychosocial aspects of comfort, compassion and concern, and ignore the patient's physical

needs, nursing care is unsafe (Gorham, 1962; Holliday, 1961; Morse, 1991). In a study of elderly patients aged 64 to 81 years who were labelled 'difficult' by the nursing staff, English and Morse (1988) found that the key variable preceding the onset of difficult behaviour was unmet physical needs. In a time of crisis the ill person needs not simply presence but skill, not just personal concern but highly disciplined services targeted at specific needs. However according to the literature, psychosocial skills such as listening and talking are more highly valued by nurses (Cameron, 1993; Dunlop, 1986; Fleming, Scanlon & Scannel, 1987). Explorations of the literature revealed a lot of studies relating to psychosocial aspects of care in comparison to the few on physical aspects of care despite the fact that patients articulate that attention to their physical needs is a priority for them.

Many of the studies that focused on the physical needs of hospitalized patients who were cared for by skilled nurses, were rich in their depth but they did not look at the wider picture incorporating other dimensions of what it is like to be hospitalized suddenly for the first time.

2.2.2 The nurse-patient relationship.

Many studies focus on the establishment of a good nurse-patient relationship. It has been suggested that at best patients feel that they are the centre of all activity and that adding to their personal wellbeing is the goal of health care (Astedt-Kurki & Haggman-Laitila, 1992; Gardner, 1985; Jarrett & Payne, 1995; Williams & Irurita, 1998). In contrast to the studies where the patients' identified that meeting their physical needs was the priority, the studies focusing on the nurse-patient relationship identified the ability of the nurse to be with the patient as the essential characteristic of the experience of care (Gilje, 1992; Freeman, 1995; Fosbinder, 1994; Gardner & Wheeler, 1987; Samarel, 1990). The nurses did not have to be physically next to the patients; the fact that they were accessible or

available was enough to convey a sense of security and of feeling reassured. The expression of non-verbal skills such as touch and the tone of the voice were identified as important ways of showing concern or that someone cared.

It's the tone of the voice... quiet warm tone is obviously the best; and if you've got someone who is a little stern faced and perhaps a little brisk on the tone, that can automatically make you think – 'Oh, I am bothering him.' (Fareed, 1996, p. 275).

However personal qualities of the nurse, including genuine concern for the wellbeing of the patient, must be combined with the competent actions taken in the interest of the patient for the experience of care to occur (Gerteis, 1993; Gorham, 1962; Holliday, 1961; Morse, 1991). A comment mentioned most frequently by patients in the above studies was the importance of feeling that they were in competent hands. If they had that feeling, then they could relax, at least as much as their circumstances would allow. If not, they were worried, fearful, tense, on guard, or else they relied on their family and friends to be on guard for them. One patient described the nurse you could rely on by stating, *'Just her air of competence, when she was going around doing, asking, watching, and coming right back, promptness.'* (Fosbinder, 1994, p. 1089). The importance of promptness in relation to the nurse-patient relationship was mentioned in other studies (Astedt-Kurki & Haggman-Laitila, 1992; Johnston Reimen, 1986; Hildman & Ferguson, 1990).

The frequency of staff turnover was identified as an issue for some patients with regard to their relationship with the nurse. Inconsistencies of care between staff and just getting used to one nurse when she or he disappeared never to be seen again were mentioned in the literature (Allbrook, 1997; Cousins, 1979; Irurita, 1999). Nursing is the only caregiving profession that subscribes to

the notion that the identity of the caregiver is insignificant. Indeed if a patient prefers one nurse over another, this fact is not considered as a mark of excellence, but rather as a nuisance by the remaining staff (Morse, 1991).

Patients in Dewar and Morse's (1995) grounded theory study about unbearable incidents, identified that many of the unbearable aspects of their experience of illness were attributed to interactions with staff. For example, being treated as an object, being made to feel a burden, not being listened to, and not being believed. This article detailed interviews with patients about their experience of illness, and was not specifically about unbearable incidents that had occurred during their hospitalization.

It appears from the literature on nurse-patient communication that the nurse's role has been over-emphasized and the patient's role has largely been ignored (Gulino, 1982; Jarrett, 1995; Lawlor, 1991). The studies and books of people's experiences relating to the nurse-patient relationship fueled my interest in further discovering what the patients' first experience of hospitalization for an acute illness was like from the patients' perspective.

The third theme apparent in the literature was the need for information. There was a lot of literature about information and health care, most of it specific to information sharing and thus not in the context of the wider experience of hospitalization.

2.2.3 Information sharing

According to a focus group study by Ellers (1993), patients need information, skills and support in order to handle the experience of hospitalization and adjust to the rigors of treatment. They need to know what to expect. They want to know how their illness will affect their daily lives and how to improve the quality of their lives. If they are to maintain or improve their health in the future, they may need

to learn new behaviours and unlearn old ones. *'When I left the hospital, I left understanding what took place, what I could expect, what the prognosis was, how I could help myself, which was the really big thing—what I have to do now.'* (Ellers, 1993, p. 96).

Other studies identified the following specific information needs; understanding the medical condition with its related medical terms, treatments, drugs, symptom management and useful products (Gorham, 1962; McLennan, Anderson, & Pain, 1996). In contrast however, it appears that when patients are suffering and hanging onto threads of hope, they want to protect themselves from potentially serious information that may destroy the hope that all was going to be well (Cameron, 1993; Freeman, 1995).

Exploration of the literature relating to patients' needs for information suggests that patients in general, seek more information than they get, although individual needs vary significantly with age, gender and other socioeconomic factors (Bruster, Jarman, Bosanquet, Weston, Erens & Delbanco 1994; Cleary, Edgman-Levitan, McMullen, & Delbanco, 1992). Informational needs also change over the course of an illness and as a function of the patient's perceived health status (Cameron, 1993; Garret & Drossman, 1990). Patients need time to hear, assimilate and process the information they are given. They also want to talk about their individual goals and preferences (Chappell, & Case, 1997; Fareed 1996). Patients receive information from many different sources, compare it, and learn by trial and error whom they can trust for accurate information that is relevant to their circumstances (Dennis, 1990; Volicer, Isenber & Burns, 1977). Irurita (1996) found in her study that there was overwhelming consensus among the twenty three participants regarding the importance of being well-informed about their medical/surgical condition, all aspects of care, the hospital routine, and preparation for discharge; yet there was a general agreement that they had, in most instances been inadequately informed.

Findings from past studies demonstrate a strong relationship between adequacy of information and overall satisfaction with care (Ellers & Walker, 1993; Fosbinder, 1994). Patients are often not given important information about the hospital and its routine, their condition or treatment, and particularly about tests or operations they have had. Often when patients are given this information it is given in an upsetting way or with little respect for privacy. It appears that many patients are discharged without having been given information about returning home and how to help their recovery. An appreciable number of patients have problems getting home (Bruster et al, 1994; Oberst, 1984). *'Patient satisfaction may be an important predictor of compliance with treatment, and the psychological happiness of the patient is an important part of recovery.'* (Bruster et al, 1994, p. 1542). Bruster et al (1994) employed direct questions of patients about their experience in hospital, the objective of which was to produce data that would help managers and doctors to identify and solve problems.

One study of two hundred medical patients found that one quarter of the sample mentioned feelings of unease about not having information regarding their progress and with regard to their role and what was expected of them in certain situations. With regard to diagnostic tests they mentioned feelings of 'fear of the unknown' (Wilson-Barnett, 1976). A sense of control plays an important role in decreasing stressful reactions to invasive medical procedures. Previous research demonstrates that providing patients with procedural and sensory information enhances cognitive control, while facilitating active participation in the procedures enhances behavioural control (Dennis, 1990; Tagliacozzo, 1965; Volicer, Isenber & Burns, 1977).

Patients perceive nurses as having extra information (Jarrett & Payne, 1995). Some patients are experts on their particular condition

and treatment regimes and nurses may not be able to achieve this level of expertise for every patient. Nurses however, occupy a key position in fostering a flow of information, even though they may not be 'keepers' of the specific information which patients seek. Not only are nurses available as immediate sources of information and feedback, but also by understanding the patient and the healthcare system they can activate multiple resources. Nurses can question other health team members on behalf of patients who want information but may be reticent to speak up, remind patients who may forget to ask questions on rounds and support patients in their quest for information and the right to know (Ellers, 1993; Gerteis, 1993).

The majority of the studies about information sharing were quantitative and came from patient satisfaction questionnaires (Ahmadi, 1985; Bruster et al 1994; Cleary et al, 1992; Hildman & Ferguson, 1990). The results of the studies suggest that the patients do not receive the information that they need and desire.

The fourth theme that emerged from the literature was support. Whilst most of the available literature examined family support in particular, it became apparent that all support, even the support of other patients was important to patients.

2.2.4 Family and others support

Family involvement is critical to patient centred care. Yet the serious illness of a loved one which requires hospitalization makes it hard for families to carry on as usual, much less provide the extraordinary help and support a sick person requires. Health care institutions can often create barriers between patients and their families that make it even more difficult for families to offer their support (Allbrook, 1997; Ahmadi, 1985; Edgman-Levitan, 1993; Ellers, 1993; Stern and Pascale, 1979).

Patients depend on their families to look out for their interests and to serve as proxy decision makers and advocates, which may at times put family members in an adversarial role with health care providers. In one study of family interactions with providers in emergency rooms, nearly one half of the nurses viewed families as *'potentially troublesome, that is demanding, meddlesome and over reactive'* (Darbyshire, 1987, p.24). Health care providers often act on such perceptions by restricting family access, limiting visitation hours, or withholding information, justifying these actions on the grounds that visitors interfere with staff routines and disturb the patient's rest (Darbyshire, 1987). Flexibility with visiting hours was identified as very important for some patients, especially if family or friends worked shifts, and on special occasions like New Year's Eve (Allbrook, 1997).

This theme includes the importance of the support of other patients and in some cases being able to be there for other patients. At a time when one feels that they are always the receiver of care, being able to be useful to others became significant. McIntosh (1977) and Ahmadi (1985) have alluded to the presence of an informal patient support system that was found during their patient studies. These patients were in close proximity to each other. All intimate bodily functions were shared. Every cough, moan of pain, every conversation with peers, staff and family was heard by all. The very nature of the close physical presence bonded patients to each other and they began to work to build each other up (Ahmadi, 1985, p. 138). All one hundred patients in Ahmadi's (1985) study had had previous admissions to hospital. Whether relationships among patients, stress, social support and satisfaction can be studied using the quantitative approach is questionable. Supporting Ahmadi's (1985) and McIntosh's (1977) study, Weiss (1976) suggests that patients need to have available to them a temporary community of others in the same situation, for whom, their experiences will have meaning and who can fully accept them.

Taylor, Hudson and Keeling (1991) state in the results of their study of patient satisfaction with nursing care that *quality* nursing care was described as taking time to listen to the patient, involving family members in individualizing the patient's care and providing emotional support to both the patient and family. In Gorman's (1962) quantitative study of staff nursing behaviours that contribute to patient care and improvement, mention was made of the nurses' role in regulating visitors when, because of their medical state, the patients were unable to do this. Because it is often a goal of nursing intervention to have patients feel supported, patients' perceptions of what is supportive to them is critical. Addressing patients' emotional needs can also be cost effective. Patients who have such support leave hospital earlier (Mumford, Schlesinger & Glass, 1982), require less medication, and begin walking again more quickly (Lawlis, Selby, Hinnant & McCoy, 1985). When patients feel supported, whether this is from the health professionals, friends and or family, they are more likely to show a corresponding increase in their satisfaction with health care, which has been linked to health care utilization and effective health care behaviours (Gardner & Wheeler, 1987). The results of Gardner & Wheeler's (1987) work are tentative because the study was a preliminary one with a small non-randomized sample.

Like the theme of information sharing, the theme relating to family and others' support was focused on the specific aspects of hospitalization and not on the wider experience of hospitalization from the patient's perspective. The final theme about ways of coping was more generalist in nature, however much of the literature was not research based, but in story form about individuals' experiences of illness in which hospitalization was a part, and this made very interesting reading.

Ways of coping

The individuality of the experience of hospitalization includes a variety of ways of coping. What becomes apparent in reading the literature is how widely people interpret their experience. On the one hand some people have great difficulty coping with hospitalization and fortunately this appeared to be the minority of patients. At the other end of the scale some patients reported that their hospitalization was a 'turning point' in their lives. One patient in Allbrook's book describes her experience.

I noticed some people are unable for whatever reason, to handle their illness. They seem to fall apart. I watched one woman who was undoubtedly ill and feeling rotten complain continuously. She wasn't capable of making any effort, but it sort of feeds off itself and then the staff become negative. I always thought that the staff would do their best for me, so it is up to me to do the best for myself. I would keep it light. A few times I went under. I had my moments when I absolutely plunged but I always tried to do that in my own time when there was nobody else around. In my own bed, quietly sinking into this black abyss. (Allbrook, 1997, p. 168).

Cameron's 1993 study on the nature of comfort found 'enduring' as a theme of patients' experiences of hospitalization. Enduring was described as a self-comforting activity. The thought that '*given time, this situation would improve*' consoled the patients during the worst phases of their hospitalization (p.429). Enduring also involved delving deeply within one's self, reviewing the past, grieving, revising, hoping and eventually integrating this experience into their lives. Inherent in this stage was the recognition that each patient had to go through this particular situation no matter how much they fervently wished to return to a prior state. Gulino (1982) refers to this as each patient having a special task of being that can only be fulfilled by the person. The patients in Cameron's 1993 study were

described as discovering exactly what resources they had within themselves. Frankl (1962) and Tillich (1984) describe both constructive forces for growth and destructive forces for disintegration occurring in individuals under stress. Frankl (1962) insists that people have both potentials within themselves; which one is actualized depends on decisions not on conditions.

Researchers who focus on stress describe what they call problem-focused and emotion-focused styles of coping with stress. Problem-focused behaviours entail confronting the problem, seeking information about how to manage it, and devising strategies to deal with it. Emotion-focused strategies often entail denial and escape or avoidance, or reconfiguring the problem to make it more positive. Most people use both strategies to deal with stress, but one style usually predominates. Several studies have shown that patients who use problem-focused techniques make better adjustments and have better outcomes than those who use avoidance and denial (Dakof & Taylor, 1990; Kneier & Temoshok, 1984; Solomon, Temoshok, O'Leary & Zich, 1987).

Patients also vary a great deal in their perception of how much control they have over their lives. People with a strong internal locus of control feel the need to exert influence over what happens to them. They believe they are responsible for what happens to them through their own efforts to control the situation. Those with an external locus of control tend on the other hand, to hold outside institutions, other people or fate responsible for what happens to them (Dennis, 1990).

Lying in a hospital bed, many people find it hard to imagine coping with the normal activities of life at home or at work. Fears abound about the unknown course of illness and the permanent impairment it may cause. As Sacks (1983) describes,

The terrors of suffering, sickness and death, of losing ourselves and losing the world are the most elemental and intense we know; and so too are our dreams of recovery and rebirth, of being wonderfully restored to ourselves and the world (p. 202).

Patients differ in what they find the most difficult aspect of hospitalization to cope with. In Lonergan's (1980) report on a group study of medical in-and-outpatients, one woman who was admired by the staff for her stoicism said that one thing she could not handle was an elderly roommate who was in pain. She felt upset and helpless when confronted by such a person, much more so than in the face of the severe pain of her own chronic illness. Medical patients' coping mechanisms that were repeatedly observed by staff in this study were hope, fight for life, interpersonal skill, denial, anger, autonomy, narcissistic defences (grandiosity and idealization), faith and existential resolve (p. 60). This impressive list of coping mechanisms indicates the significant amount of resources patients need in order to cope with the stress of hospitalization and or illness.

In Tagliacozzo's (1965) study over 90% of the patient's in the sample, observed that nurses and physicians were overworked and rushed, which caused patients to be reluctant to take up their time, *'For anything but the most urgent matter'* (p.221). The number of participants in this study is not mentioned. All had been hospitalized previously. Lorber (1975) notes that as well as the sick-role prescription of cooperation and motivation to get well, the hospital patient role adds the obligations to submit to hospital routines without protest. Hospitalized patients frequently resent the passivity and submission expected by doctors and nurses, yet they tend to conform. There is evidence that patients believe this is the proper way to act in hospital; moreover, they are afraid that if they do not keep quiet and do as they are told, they may not get adequate care

(Lorber, 1975). Lorber's study used questionnaires before elective surgery on one hundred and three participants.

In the studies that used questionnaires, results showed that far more patients had positive responses to long lists of items relating to their stay in hospital (Hildman & Ferguson, 1990; Hogan Miller, Nordquist, Doran, Ahern, & Cariveau Karsten, 1998; Wilson-Barnett, 1976). Harper Peterson (1989) states that research shows that as many as 90% of respondents to patient satisfaction questionnaires indicate positive feedback. Wilson-Barnett (1976) found in her study of two hundred participants that generally females gave more negative responses than males, and younger people were more prone to give negative responses of feeling and appraisal than older patients were. However in a study of fifty-five subjects which focused on prompt service, males related nursing service significantly lower than females (Hildman & Ferguson, 1990). There was not enough information in this study to indicate why males related nursing services significantly lower than females. Gardner & Wheeler (1987) found that there was a difference in patients' perceptions of support between specialty areas. For example, medical patients perceived the most important support item to be a friendly nurse, whilst surgical patients perceived the most important item to be feeling confident that adequate care was being given. As mentioned earlier, Gardner & Wheeler's study was a preliminary study with a small non-randomized sample. The use of questionnaires is a valuable way of finding a lot of information about a wide subject area, but they do not allow the patient to explain the reasons why they answered questions the way they did.

A significant amount of the information about 'ways of coping' came from quantitative studies. Furthermore much of the information relating to the theme 'ways of coping' was not research based, but derived from books about individuals' experiences of illness and stress (Allbrook, 1997; Frankl, 1962; Sacks, 1982; Tillich, 1984).

2.3 Summary of the review.

In this review I have identified commonalities in the literature about the patient's experience of hospitalization by way of the following themes; physical needs, the nurse-patient relationship, information sharing, family and others support and ways of coping. There are many gaps in this literature. All of the literature identifies certain aspects of hospitalization as a focus for the study such as the experience of support, good nursing practice, the incidence and characteristics of pain, emotional reactions to hospitalization, sleep in the hospital setting or the patient's experience of reassurance. The specific nature of these studies is their strength in that they give a lot of information about a targeted aspect of hospitalization. However their strength is also a weakness in that it is difficult to gain an overall impression of the hospital experience from the patient's perspective. None of the literature is specific to New Zealand and none of the literature is specific to first time hospitalization for an acute illness. As identified many of the studies are quantitative and none use Burnard's (1991) thematic analysis as a methodology. The present study intends to give adult patients who have experienced hospitalization for the first time for an acute illness, the freedom to explore their experience from their own perspective.

3.0 Research design and Method

3.1 Introduction

The purpose of conducting this qualitative, descriptive study was to explore and describe the patient's experience of their first hospitalization for an acute illness. In this chapter qualitative, descriptive research as a study design is outlined, along with a justification for the method chosen for this study. I discuss participant selection and ethical considerations before outlining data collection. Data analysis using the approach of thematic analysis is described followed by trustworthiness, which includes issues such as transferability, dependability and confirmability.

3.2 Research design

As identified in the previous chapter, several quantitative studies have been undertaken that measure patient satisfaction by assessing aspects of the patient's experience of hospitalization (Astedt-Kurki & Haggman-Laitila, 1992; Fosbinder, 1994; Harper Peterson, 1989; Oberst, 1984; Taylor, Hudson & Keeling, 1991). In order to explore and describe patients' experience of first time hospitalization for an acute illness, a qualitative, descriptive research design was chosen.

3.2.1 Qualitative descriptive research design.

Qualitative research methods have been widely recommended for collecting data about people's perceptions of their subjective experiences (Munhall & Oiler, 1986; Morse, 1991). Denzin and Lincoln (1994), suggest that qualitative research offers the opportunity to focus on finding answers to questions that centre on social experience, how it is created, and how it gives meaning to human life. Rice and Ezzy, (1999) state in regard to the aims of qualitative research,

Qualitative research aims to elicit the contextualized nature of experience and action, and attempts to generate analyses that are detailed, 'thick' and integrative (in the sense of relating individual events and interpretations to larger meaning systems and patterns) (p.1).

Qualitative research allows the participants to tell their story. Individual meaning and understanding from the participants' perspective is emphasized. Field and Morse (1985) say that in a qualitative research approach, *'the underlying assumptions and attitudes are examined, and the rationale for these are also elicited, within the context in which they occur.'* (p.11). The descriptive approach allows the researcher to ask, What is the individual's experience here? Artinian (1988) states that the descriptive approach, *'is used to present a detailed description of what is happening in some settings with a particular group of subjects, so that the point of view of the subjects can be understood'* (p. 138). It is necessary for the researcher to interpret participants' stories in order to make sense of the data as a whole.

3.3 Participant selection

3.3.1 Recruitment of Participants:

The participants were recruited in two ways. Firstly from an acute medical ward at a large teaching hospital in a metropolitan area. Notices (appendix 1), informing patients of the study and inviting them to contact me if they met the inclusion criteria and were interested in participating, were given to patients on discharge by the ward receptionist. Permission to give the notices to patients was obtained from the general manager. When this method of recruitment provided only six participants a second method of recruitment was employed after consultation with the Otago Ethics committee and Massey University Human Ethics committee. An advertisement for people who had experienced a recent first time

hospitalization for an acute illness was placed in a local daily newspaper (Appendix 2). I interviewed individually the first twelve patients who met the inclusion criteria and consented to participate in this study.

3.3.2 Inclusion criteria

The people involved in this study had all met the following criteria as outlined in the information sheet (Appendix 3).

- They had all been patients for the first time in an acute medical ward not more than two years ago.
- They could all speak English and were able to cooperate with the requirements of this study, including giving informed consent.
- They all lived within the city boundaries.

3.4 Ethical Considerations

Anonymity, confidentiality and participant consent were issues considered important in the planning and conduct of this study. An ethics application was submitted to both the Massey University Human Ethics Committee and the Otago Ethics Committee on October 30th 1998. On 18th November 1998, the ethics committee at Massey University gave full approval for the research to go ahead and on 14th December 1998, the Otago Ethics Committee also gave full approval. The letters of approval are included in (Appendixes 4, 5 and 6).

3.4.1 Privacy, Anonymity and Confidentiality

Anonymity of the participants was ensured by using pseudonyms, which were chosen by the participants before the interview and were used by the participants and myself throughout the interview. Where participants make reference to any other person or place, pseudonyms are also used. Where the gender of any participant or persons referred to could have identified that person, it was changed. If a patient had a particularly rare illness that may identify them, an alternative diagnosis was used while trying to retain the

essential character of the disorder. Health professionals are referred to only by their profession.

As soon as possible after I received each transcribed interview I listened to each tape whilst reading the transcription, corrected any mistakes, and deleted identifying information, which included times when participants had inadvertently referred to themselves, others or places without using pseudonyms.

All details of the interviews, the tapes and transcriptions have been kept in a locked filing cabinet. The only people who had access to the tapes and interview transcripts were the transcriber, the supervisors and myself. I did not offer to return the transcripts to the participants. The audiotapes and transcripts will be retained for audit purposes and destroyed after five years.

3.4.3 Consent of participants

The availability of willing participants and the time constraints of the study in terms of an academic exercise determined the actual number of participants. All patients who contacted me for more information about participating in the study were given further information over the phone and invited to meet me to discuss the study. Reasons for doing the study and what it involved for them as outlined in the information sheet (Appendix 3) were discussed. These potential participants were then given a period of two weeks to decide whether they wished to participate in the study. Consent of interested participants was obtained using a written consent form (Appendix 7), which was sent to the interested participants with the information sheet when they confirmed their interest in the study. Most of the people who contacted me for more information decided to participate in the study and did not require two weeks to decide. The signed consent form was either sent to me by the patients once they had agreed to participate in the study and we had agreed on a

suitable time for the interview, or written consent was obtained directly before the data collection interview was commenced.

3.5 Data collection

Data from the twelve participants were collected by means of unstructured interviews. The interview process and a brief description of the participants is presented.

3.5.1 The interviews

Unstructured interviews, which are consistent with a qualitative research design, were used as a way of collecting data. Unstructured interviews are useful when the researcher is trying to explore, in some depth, a variety of points of view and does not want to be constrained by a particular interview schedule. In the unstructured approach, the interviewer is free to take up leads, explore issues raised by the participant and to uncover layers of meanings and perceptions (Burnard, 1994).

Prior to my interviewing participants, I conducted a pilot interview with a colleague. This gave me an opportunity to familiarize myself with setting up and testing the recording equipment and to experience the process of beginning an interview, developing the conversations and ending the interview.

Appointments to conduct the interviews were made for times and places convenient to the participants and myself. Eleven of the interviews were conducted at the participants' homes and for one participant at my place of work due to the fact that her home was inconvenient because she had small children. Privacy and confidentiality were maintained in these settings by choosing a room where the participant and I could be uninterrupted and not overheard.

3.5.2 The interview process

The period before the interview began was a time where participants had the opportunity to ask me any questions about the study. Brief demographic information such as age, whether married or single, ethnicity, occupation and medical condition, was then obtained as a way of getting to know the participants.

Of the twelve participants five were men and seven were women aged from between twenty-two to eighty-six, the mean age being sixty years. All but two participants were in long term relationships. Eleven participants identified as European and one as Maori. Participants had been admitted for a wide range of medical conditions including a brain tumour, myocardial infarction, campylobacter and suspected meningitis.

In the interview I asked each participant to share his or her experience of being hospitalized for the first time for an acute illness using the following question, "Tell me what your time in hospital was like for you?" The interviews were intended to yield a conversation about the patient's experience not a question and answer session. The questions employed by the researcher flowed from the course of the dialogue and not from a predetermined path and aimed to explore the experience to the fullest. Interviews ranged from between 45 minutes to an hour and a half in duration. All interviews were audio taped and transcribed by a typist who signed a confidentiality agreement. Participants were reminded that the tape recorder could be turned off at any time. At one point during an interview the participant became upset and I offered to turn the recorder off, but he declined and the interview continued. I made notes of my observations of body language while interviewing and again after the participant or myself had left and these notes provided further data to supplement the transcripts which were analysed using thematic analysis.

3.6 Data analysis

Qualitative research designs draw on a variety of theoretical perspectives and practical techniques in order to analyze the data. Thematic analysis is one such technique or process for encoding qualitative information.

3.6.1 Thematic analysis.

Thematic analysis was particularly appropriate for this research as I wanted to offer a description of what it is like to be hospitalized for the first time for an acute illness. I chose to use Burnard's (1991) method of thematic content analysis. He describes the aim of thematic content analysis as being, '*to produce a detailed and systematic recording of the themes and issues addressed in the interviews and to link the themes and interviews under a reasonably exhaustive category system*' (p.461-462). The category system represents the thoughts and feelings of others in a systematic but honest way. The main contribution of thematic analysis is to provide descriptions of prevalent concerns and experiences from the participants' viewpoints. Thematic analysis aims to identify and describe the content of an individual's perceptions (Luborsky, 1994).

There are problems associated with the thematic analysis. For example is it reasonable and accurate to compare the utterances of one person with those of another? Are the common themes in the interviews really common? Can we link one person's world view with that of another person? Burnard suggests that this is a reasonable thing to do. Therefore, it is necessary for the researcher to stay open to the complications involved in the process.

3.6.2 Using thematic analysis

The process of thematic analysis according to Burnard (1991) involves several stages which were followed in order to elicit themes for this study.

- Notes were made directly after the interview indicating impressions of what the participant was endeavouring to portray. Throughout the course of the research project, notes were also written to record ideas that I had as I worked with the data.
- Transcripts were read through and notes made on general themes found within the transcript. The aim at this stage was to become immersed in the data in order to become more fully aware of the participants' realities.
- Each transcript was carefully worked through again and as many broad themes as necessary were written down to describe all aspects of the content. According to Burnard (1991), the themes should account for almost all of the interview data; should remain true to the text that is being analysed and should emerge out of the data. In this way the themes would offer a clear and true representation of what was talked about in the interviews.
- Each transcript was worked through, along with the list of themes and subthemes developed and colour coded with highlighter pens to identify their similarities and differences. Each piece of transcript was allotted a theme or subtheme. The corresponding coded sections were cut and pasted into separate files on the computer. Care was taken to retain a complete 'clean' transcript so the context was not lost.
- Similar themes were grouped together under main headings. The new list of themes was worked through and repetitious or very similar headings removed. A variety of subthemes grouped together in this way meant that I could look for patterns in the data and thus offer explanations for them. Why do the data fall into these patterns? What is the significance of these formations? At this stage it was important that I stayed close to the original text so that I did not over

speculate about what participants might have meant during their interviews.

- During this time I was concerned about my ability to be certain that the themes I identified were an accurate reflection of what the participants had presented. To provide an element of validity I did not refer back to the final thematic groupings for a number of weeks. I reflected on the themes in my mind and through journalling. Each time I did this I felt a degree of certainty that what I had decided on as the themes were an accurate reflection of the participants' stories. I felt the same sense of certainty when I returned to the transcripts some weeks later.
- My supervisors were then invited to read through two transcripts and identify themes independently, without seeing my list. Following this the lists of themes were discussed and adjustments made as necessary. The aim of this stage was to attempt to enhance the validity of the method and to guard against researcher bias (Burnard, 1991).
- Transcripts were re-read alongside the finally agreed upon list of themes in order to ensure that all aspects of the interview data had been covered.
- Once all of the transcripts were sorted in this way, I was left with twelve analyzed interviews, divided into five main themes which described the experience of first time hospitalization for an acute illness with a range of subthemes within each theme. The themes and subthemes are identified and presented in chapters 4, 5, and 6.
- Copies of the complete transcripts and the original tape recordings were kept close at hand for reference during the writing up stage. If

anything was not clear, I referred directly to the complete transcript or tape recording.

- The writing up process commenced with the preadmission experience as articulated by the participants. Various examples of the data under that section were selected and lists of these examples were made. Following the preadmission experience, writing up continued systematically working through the ward experience, discharge and the post discharge experiences. Reference to the original interviews was necessary in order to stay true to the original meanings and contexts. I wrote up the findings using verbatim quotes from the interviews to illustrate various sections.
- Burnard (1991) states, *'the researcher must decide whether or not to link data examples and the commentary to the literature. Two options are available'* (p.464). The researcher may write up the findings using examples from the interviews while simultaneously referring to the literature concerning previous work. This is often more practical and readable (Burnard, 1991). The second option is to write up the findings and then separately link the findings to previous work in the literature to compare and contrast. I chose to write up the findings using the first option, that is linking participants' verbatim comments directly to the previous literature.

3.7 Rigour

Koch (1994) argues that the rigour of a study may be established if the reader is able to audit the events, influences and actions of the researcher (p.976). In the previous section on data collection and data analysis I have described the careful systematic audit trail that was maintained during the research process. In the next section trustworthiness, transferability, dependability and confirmability are discussed followed by a discussion on researcher bias and the place of my journal in the study.

3.7.1 Trustworthiness

Trustworthy data are that which are reliable, valid and have addressed the potential for bias. Drawing on her own research Koch (1994), discusses the importance of documenting the decisions made whilst undertaking qualitative research, in order for rigour to be maintained. In this manner the reason decisions are made can be audited which helps establish trustworthiness.

Trustworthiness is a term used by Lincoln and Guba (1985) to assess the criteria of transferability, dependability and confirmability of the research data. Each of these criteria are presented in the following sections.

3.7.1.1 Transferability

Transferability is about how the findings from one group of people can be transferred to another comparable group of people. (Lincoln & Guba, 1985). This thesis is a description of the experiences of twelve participants' first time hospitalization for an acute illness. It is in a large part their stories, their experiences that I as a nurse and researcher have the honour to write. These experiences are similar to those I have heard from friends, family and other patients I have cared for.

Generalization from descriptive and qualitative studies such as this can only be of a speculative nature. The whole point of studies of this sort is not to generalize but to offer examples and illustrations of particular situations and particular views at particular points in history. Thus, this study offers glimpses of how patients experienced hospitalization for the first time with an acute illness, in a particular part of New Zealand, at a particular point in their life. It would be dangerous to make more general claims than this.

To minimize my voice as researcher, data from which the five main themes of waiting, the need to know, support, environmental issues and lack of information were identified, are presented as direct quotations from interview transcripts. I wanted readers to decide if what these participants were saying about their experiences of hospitalization held true for others also.

The transferability of the findings from this study will be determined in the future as these findings are compared to the experiences of other first time patients hospitalized in an acute setting.

3.7.4 Dependability

Dependability refers to the stability of data over time and over conditions. In this research dependability was demonstrated by the use of what Polit and Hungler (1997) refer to as an inquiry audit which consists of a scrutiny of the data by an external reviewer. This approach also has a bearing on the confirmability of the data (see next section). There was a consistency of themes identified by my supervisors and myself.

3.7.5 Confirmability

Confirmability assumes there would be agreement between the researcher and another person who analyzed the same data (Polit and Hungler, 1997). Burnard (1991) identifies two ways that confirmability can be maintained in the process of analysis. The first method concerns the researcher asking colleagues familiar with the process of analysis to read through transcripts and develop themes. These themes are then compared with those developed by the researcher. The second check for confirmability is with the participants, allowing several of them to read their own transcripts and note what they see as the main points in the interview. These main points can then be compared with the researcher's list of headings. I chose the first method that Burnard described to ensure confirmability in the process of analysis of the data collection. In

order to check for confirmability, my two supervisors were asked to develop their own themes from three interview transcripts. Burnard (1994) states that ideally, there should be a reasonable match between at least two people reviewing the themes in this way. However, in practice two people nearly always generate slightly different themes and some degree of negotiation is necessary. The process of negotiation between my supervisors and myself was a lengthy one, with a positive outcome where all agreed that the proposed themes fairly represented the participants' experiences of first time hospitalization. This process also helped to address, to some extent, the issue of researcher bias.

3.7.1 Researcher bias.

The researcher in qualitative research is the primary research tool, therefore personal aspects of the researcher impinge on the interview relationship (Holloway & Wheeler, 1996; Roberts & Ogden Burke, 1989). Holloway and Wheeler argue that the researcher's own subjectivity becomes an analytical tool and consequently becomes part of the research. Bias is possible in an insider position and cannot be eliminated. It is therefore important for the researcher to recognize and acknowledge her subjectivity. Although bias cannot be eliminated in an insider position it can be monitored and accounted for. In this study frequent supervisor involvement to ensure confirmability and the use of a reflective journal were means used for monitoring researcher bias.

3.7.2 Researcher's Journal

Ongoing reflection in the form of journal keeping has taken place throughout the study and writing period. It has provided an outlet for my thoughts, feelings, hunches, a dialogue with the work itself and an integration of all aspects of the study. For example some of the stories from the participants aroused considerable anger and frustration when I heard of predicaments that should not have happened, such as situations where the nurse could have made a

difference and didn't. An example of such stories is of one of the participants who experienced having to wash herself and change her nightgown unaided with an intravenous line insitu following an episode of incontinence. The participant was stiff and sore from her arthritis. She had no idea how to thread the line through the gown, and ended up lying the intravenous drip and the stand on the floor.

Keeping a journal has also kept me focused on the research aim, and helped me in my decision making in regard to the appropriate themes and subthemes. I have shared the development of my thinking with my supervisors and my peers on a regular basis.

3.8 Summary

In this chapter I have outlined qualitative research as a study design. Participant selection was outlined followed by ethical considerations and the data collection process. The research methodology of thematic analysis, which was used as a tool for the analysis of the data, has been presented. Issues of rigour, which included trustworthiness, incorporating transferability, dependability and confirmability, were discussed. The chapter concluded with discussion on researcher bias and the importance of journalling as a means to address researcher bias when analysing the data. The themes and subthemes identified from the data are presented in the following three chapters.

4.0 Preadmission to hospital

4.1 Introduction

In this chapter I begin by discussing the preadmission to the ward experience. This involves firstly preadmission to hospital and then the experience in accident and emergency. As I mentioned in the introductory chapter, I clearly stated in the information given to participants that I was interested in their experiences of first time hospitalization for an acute illness (see appendix 3). Despite knowing that I was interested in their experiences of hospitalization, all participants commenced their discussion with their experiences prior to admission to the accident and emergency department. Obviously the preadmission experience was a significant part of the overall hospitalization experience.

4.2 Evaluating and Acting

Prior to admission all participants had a clear recognition that they were not well, but they were not always sure what exactly was wrong. Based on previous knowledge of themselves, or knowledge gained from past experience which included reading from books, participants made decisions about possible explanations for their symptoms and when to get help from the doctor or call an ambulance.

Yvonne had been an active elderly woman, involved in several community activities. She knew something was wrong when she was unable to find her way to her friend's house, something she had done many times before. Yvonne didn't know what was wrong, '*... and I thought, "What on earth's gone wrong with me?" I didn't know what had gone wrong with me.*' (Yvonne, lines 62-64). Because she was feeling dizzy and noticed that she was unsteady on her feet, Yvonne tested herself by performing a simple task and following this took action to reduce her activity.

...I was just a bit woozy you know. So Saturday morning I did my washing and when I went to put it on the line I was swaying and I thought, "Ah definitely something the matter with you." So I thought, "I'll see if I can walk in a straight line with one foot in front of the other." Well I couldn't. So I thought, "Well cancel everything." I was going out for dinner, so I canceled everything and had a very quiet weekend and rang up Dr. Garden first thing Monday morning. (Yvonne, lines 97-103).

When she woke paralyzed on the Tuesday morning, based on previous symptoms she had experienced, she thought that she had had a stroke.

So I went to bed that night and in the night I became paralyzed down the left side and didn't like the idea at all but I'd had that happen to me four years ago. But four years ago I had had heart pain as well so I knew what it was, but I thought this time I'd taken a stroke. (Yvonne, lines 113-116).

Unlike Yvonne, James had no previous symptoms. Although he had experienced pain the day before his heart attack, he dismissed it. Although a paramedic in his younger days he did not associate the pains with a heart attack; his expectation of a heart attack was different. Once he began to sweat profusely he rang an ambulance.

Never had them [the pains] before. I didn't really relate it to a heart attack because I expected that sort of thing gave you excruciating pain and all that sort of thing. But it wasn't that bad and oh after about an hour and a half I was sweating profusely I decided to call the ambulance and that was probably the best thing I ever did. (James, lines 29-33).

James remembers the feelings of relief that he wasn't on his own once the ambulance arrived. *'You know something's going to happen, that I'm not on my own anymore. You know even at my age being new to this whole, well the whole situation was new to me.'* (James, lines 37-39). James admits to being frightened in a situation new to him.

And I suppose it's quite scary and there's quite a feeling of apprehension. What's going to happen? What are they going to do? and all this sort of thing. I was prepared to a certain extent, I had twenty years paramedic experience you know. (James, lines 43-46).

Despite past experience it is different when you are the patient. *'Believe me it's different to someone else. [Experience] doesn't mean a thing. But nothing from that past experience influenced [me]. I was thinking about what was happening [to me]'*. (James, lines 50-52).

Unlike the sudden onset of James symptoms, Alan's experience was more insidious, thus a significant part of Allan's illness experience was prior to his admission to hospital. Allan experienced a clear beginning to his problems of nausea and unsteadiness.

Well I started off in July '97 I took ill. I'd been out in the morning with a walking group, we'd been down at Waihola and had about a 12 k. walk down there and went to the hotel for our lunch. We came home and it was a lovely day as I recall. I thought I'd get the roses pruned and I got about half way through them and I just conked out. My head wasn't spinning but it was sort of woozy and I could stand but I wasn't steady on my feet. (Allan, lines 12-18).

A previously active man he had suddenly become unable to do what he normally did. *'Just ran out of go, just couldn't do anything. And if my memory's right, I did vomit I think which was unusual for me and [I] didn't want any tea, wasn't hungry.'* (Allan, lines 27-29). From the beginning of Alan's period of ill health he was making decisions and evaluating what was happening to him.

And by this time I was getting a little shaky and I couldn't look at things, anything going, a car going past me on the street, and I couldn't just focus my eyes on it. So I carried on for awhile and I was getting worse and worse, I was not eating and I was losing weight. I couldn't eat and if I did eat or drink I vomited. (Allan, lines 45-49).

Allan was very persistent in his endeavors to gain an explanation for his symptoms. *'So I visited the doctor again and again and again and I was tested.'* (Allan, lines 53-54). The doctor decided that his symptoms of nausea and dizziness were indicative of depression and so Alan had been prescribed two different anti-depressants, which had made no difference to his symptoms. All the while his condition was deteriorating and he knew there was something physically wrong in his head. Finally when Allan asked for a second opinion he was sent to a psychiatrist, who on the second visit decided to send Allan immediately to the neurological ward at the hospital. Although Allan's diagnosis of a brain tumour was seriously life threatening, he will never forget the feelings of relief when he was told that he needed to go straight to hospital. *'It was a relief. It was really. That was the main feeling that something was going to be sorted out.'* (Allan, lines 190-191). When asked whether he had lots of questions about his condition, Allan replied,

No not really. I don't think I did at that time. I was so pleased that something was going to be done because I said to my wife quite a lot in the period before that that I wished they

would bung me in, put me in a scan or something and find out what was there. (Allan, lines 195-198).

Although Allan did not know what was wrong with him, he knew that his ill health was not due to depression. Kyle however formulated a diagnosis, weighing up his symptoms against prior knowledge.

What happened was I had just gone to bed and I had this really severe pain across my chest like a cramp and I couldn't breathe and I said to John, "I think I'm having a heart attack. Can you call an ambulance?" (Kyle, lines 11-13).

As did Yvonne, James and Allan, Kyle evaluated what was happening to him, and made a clear decision when to seek help.

Well during the time I was preparing for bed I was sitting on the toilet and the pain came on then, but I'd had this before and denied it basically. But it had never been anything like as severe or as prolonged and it never affected my breathing before and when you can't breathe that's really scary. So yes, so it was much more severe. I honestly did think it was a heart attack. (Kyle, lines 29-34).

Jacqueline was very specific about her initial symptoms. In hindsight she was aware that the pain in her arm was connected to the heart, however she was not aware at the time of the seriousness of the pain.

On the Thursday night I had a strange pain right down from the top of my arm right down to half way down my hand and I had no idea what it was and we all know that pain there can be connected to the heart, but I didn't think that. (Jacqueline, lines 18-21).

Jacqueline discovered that she also could no longer do something that she had been doing for many years and that is play eighteen holes of golf.

And we played nine holes, coming up the ninth hole was a gradual rise and I had a bit of pain in my left arm and then finished that hole, went down to number ten and it was a bit painful. Then I said to the two women that I was playing with, "I don't think I can hit over the hill, to hit the next hole," I said. (Jacqueline, lines 32-35).

In contrast to the previous participants who actively sought help themselves, Jacqueline was just going to drive home. However, once at the clubrooms, her two friends rang the doctor and he told them to take Jacqueline to accident and emergency.

Jack also didn't realize what was wrong with him. He thought that his breathlessness was natural in the context of a chronic illness.

Well I haven't been able to get air. I've only got one lung, and a quarter of a lung. And I've got emphysema in the good lung so that makes breathing very difficult. I've been like this for about three or four years. Now when it got near, round about Christmas time, I was having difficulty in breathing. I was hardly getting a breath. It was harder to get a breath than before. But I didn't realize what was happening to me. I thought it only natural, so I carried on... (Jack, lines 20-26).

Jack's wife called the doctor for her own symptoms of unwellness as she had a severe rash. However when the doctor arrived and noticed how unwell Jack was, the ambulance was called and Jack was taken straight to hospital. He was diagnosed with pneumonia.

Danny had been unwell with a high temperature and extreme weakness. Her husband called the doctor who suggested that she needed to go hospital.

I'd been sick the night before and the following day my husband rang up and made me an appointment to go to the doctor. I was quite determined I was fine. Went up there, I had a rash he wasn't happy with it, my temperature was very high and he didn't like the way I looked so he said, "Well I'll give the registrar a ring." And so he rung him and he said to go into A & E. (Danny, lines 23-27).

Danny however believed that she was over the worst of her symptoms. Despite the doctors querying that she had meningitis, she did not believe that she did. Danny also evaluated her symptoms and reached a decision about her symptoms based on her prior knowledge.

...I knew at that stage that I didn't have, well you know it was unlikely to be meningitis because it had been over twenty-four hours and definitely wasn't getting progressively worse. It [the temperature and the rash] was sort of easing out and obviously they [the doctors] weren't so keen to let me go at that stage. (Danny, lines 47-50).

Preadmission to hospital was an active period where participants evaluated their symptoms, formulated a diagnosis based on their symptoms and knowledge of themselves, and then took action. Participants either sought assistance from their doctor or called the ambulance themselves or someone sought assistance on their behalf. Once participants reached the hospital however, the situation changed as becomes apparent in the next section.

4.3 Accident and Emergency

In contrast to the time immediately before coming to hospital where participants actively sought assistance; participants became passive recipients of care once they arrived in the accident and emergency department prior to their admission to the ward. The predominant theme that arose from participants' discussion of the Accident and Emergency experience is waiting.

Jack articulated his experience of Accident and Emergency. *'They take x-rays, they prod you and they push you and they poke you, they put needles in your hand, they do all sorts of things and all for your own benefit as I realized.'* (Jack, lines 60-62).

James described the experience of passive acceptance. *'Some things you know you brush off. But as I said what actually happened in A & E with the hours I was there is I think figuratively and physically I closed my eyes to it.'* (James, lines 76-79).

Jacqueline had a similar experience.

I can remember hearing them say, "she's very restless," and I knew it because of this arm [the pain] and next thing I heard them say, "Mrs. Moore! Mrs. Moore!" But you know you see this on television, half a dozen faces all around you... (Jacqueline, lines 63-66).

One participant described herself just lying there, "drifting off" with both her mother and her partner present; in a situation which would normally have caused her stress.

I was facing away from them actually because it was on this side and I just felt less nauseous and my legs were curled up and I was facing away from them, so I just drifted off for what seemed like forever, [would] occasionally wake up and hear

them talking which was quite weird because I normally stress out when they're interacting with one another because they're quite different kinds of people but I was totally incapable of... (Frances, lines 108-114).

When asked by the interviewer if being totally incapable meant that she was beyond caring Frances confirmed this. Perhaps she was too sick to care.

In contrast to the participants' passive role in this acute and busy environment, their partners took a more active stance. Frances' partner stood at the doorway in order to be seen which had a positive outcome. *'Well actually Jimmy was getting fed up so he went and stood at the door of my little cubicle and just kind of looked around. That worked a couple of times actually. The doctors were reappearing quite suddenly.'* (Frances, lines 166-168).

John's partner who also participated in the interview, felt that the time spent waiting in accident and emergency was unacceptable. He commented,

My impression of A & E was that it was hopelessly overcrowded. There were hordes of people waiting which was why we were put into a children's room and they were very apologetic about it but it was actually a room designated for child patients but it was the only one available and that explained the delay. They were just rushed off their feet. And I was just sort of thinking, well everybody's doing their best but it's not really very acceptable. This was just an ordinary day. I mean it wasn't as if there'd been a major disaster or something.' (John, lines 656-662).

John's partner became increasingly annoyed as he continued. *'And it was just, it was something ridiculous like three hours or something*

from when you got to the hospital to when you were finally taken up to the wards, I think it was.' (John, lines 666-668). John quietly agreed, *'Yes, yes, I know it was a long time.'* (Line 670).

Participants spent a lot of time waiting in the Accident and Emergency department. However they were not always clear about what they were waiting for. One third of the twelve participants experienced long periods waiting in accident and emergency. They appeared to accept this passively as part of a patient's lot. Jack commented about his experience of accident and emergency. *'I was down there for two hours mind you.'* (Jack, line 77). When asked whether it was busy Jack said, *'No. I don't know why it took so long...'* (Line 81). *'It took all that time before they got me organized and sent me upstairs, by the time they took x-rays and everything.'* (Jack, lines 86-87).

Frances explained how she had to wait for a doctor. She also had to have tests repeated because the results of the prior tests had been mislaid, but the wait was much longer than expected and she was not clear why.

It took a long time in A & E that night actually, probably about five hours.' (Lines 104-105). *'The reason I had to be in there so long was it took him (the doctor) another hour or so to arrive and then although I'd had blood tests done that day...'* (Lines 131-133). *'...for some reason the results hadn't appeared at A & E or at the GP's so I had to get more blood tests sent to the hospital labs. So I was told by the doctor that that would take about another half hour to get done but it ended up being more like two hours I think, so I was just sort of lying there in the meantime.'* (Lines 137-141).

John found it difficult to remember why he had to wait so long.

And there we sat and then somebody came and saw us briefly, a nurse or something, I think she, did she take a blood test or something at that stage? Anyway she probably did temperature and blood pressure I think and then vanished and there we sat for a very long time didn't we? (John, lines 101-105).

John gave the following explanation as to why he experienced the long wait.

... so we sat there in this little room and that was rather off putting I must say, but obviously again they were, as my partner says, they were understaffed and over pushed. But eventually I think a female nurse turned up... (John, lines 120-123).

When asked how he was feeling at this stage John responded,

Oh yes I wasn't feeling very wonderful and so this was going... You could go mad you know; the leg was swelling up and breaking out and all very nasty and anyway then somebody turned up I think apologetically, and I was then taken off up to a ward and admitted properly. (Lines, 127-130).

Kyle also had a long wait during his time in Accident and Emergency. He was in an anxious state because he didn't know what was causing his chest pain and dyspnea. He gave his explanation as to why the wait, but like John and Frances he was not clear about the real reason for the delay.

I remember I was in a cubicle, just a wee cubicle with a curtain. I was just sort of abandoned for ages but I think that might have been because they had to allow twenty minutes or

half an hour or something to monitor. They do a series of tests, there has to be a time delay in between and so it's necessary though that wasn't explained. I mean I just thought I'd been abandoned. (Kyle, lines 85-90).

Participants appear to be passively self-focused as they wait to be attended to in the Accident and Emergency department. Even whilst being treated, participants hand themselves over to the medical and nursing staff in a resigned manner perhaps because they are just too sick to do otherwise at this stage. Participants are not always certain what it is they are waiting for whilst in the Accident and Emergency department, but waiting has been identified as the predominant theme of this experience.

4.3 Summary

Chapter four has described the participants' experiences from the time of noticing that something was wrong with them to before they were admitted to the ward. The next section, which is the largest chapter, focuses on the ward experience. Participants assume a more active role once in the ward setting than was apparent in the Accident and Emergency department.

5.0 The Ward

5.1 Introduction

Despite participants assuming a more active role once in the ward setting they remain vulnerable beings, at the mercy of the health professionals involved in their care. My expectations were that participants would discuss their physical symptoms such as pain or breathlessness even if briefly. Instead they all focused on the experience of being a patient in a foreign environment and what that meant for them. The reason for admission was rarely alluded to. The experience of being hospitalized first time for an acute illness obviously has left a deep and lasting impression on all of them.

After being admitted to the ward, most participants wanted to know what was happening to them. They rang the bell if assistance was required and asked questions. The need for information is the first theme relevant to the ward experience. All participants discussed in the interviews matters that related to their physical and emotional support and well being. I have addressed these issues under the theme of support, firstly support (or the lack of support) from health professionals and then support from family and friends. The third theme relevant to the ward experience was environmental issues and these have been addressed under the subthemes of the physical environment, privacy and safety.

5.2 The need for information.

Most participants were happy with the information given. Their comments indicated that they were receptive to learning what was happening and that they were keen to be considered in a participatory role.

James was very impressed, after he was admitted following a heart attack, when the consultant described what they (meaning the staff and James) were going to do in order to promote a full recovery.

James said he felt included and also responsible and he liked that. James describes the way his consultant came across,

He managed to put answers across in ways that were searching enough without sounding too serious you know. He was able to explain things without, well I'd say to the ordinary person without causing any alarm what-so-ever. This was the state of the thing at the moment, this is what happened, this is what we're going to do. (James, lines 192-197). James stresses this again to reinforce his point (line 200). "And this is what we are going to do," he said, not I, we.'

Knowledge and information were important to James. He was also impressed with the explanation the "physio-terrorist," as he called her, gave him about his condition.

She explained the working of the heart, lungs and the body and everything else [as] clearly and concisely as she possibly could. You know I didn't have the heart to tell her that I used to teach basic anatomy. That would be unkind. (James, lines 487-489).

Colleen was not only impressed, but she was very grateful to the pharmacists. She had been taking methotrexate to treat her arthritis for some time and wasn't aware of one of the potential side effects. Although she had been hospitalized for an unrelated condition, one of the pharmacists took the trouble to educate her about her current medications.

I was very impressed with the pharmacological staff because they were very thorough. Not only in checking up and making you aware of all the complications that methotrexate can give one; I had been told such by my doctor, but he [the pharmacist] even went to the trouble of getting me a print out

of different side-effects and things that I could take and should not take on the day I had taken the methotrexate. For instance I wasn't aware that taking vitamin C greatly increased the toxicity of methotrexate on a given day. I didn't know that. (Colleen, lines 257-264).

Colleen wasn't only impressed with the pharmacy staff. Later in the interview she described how well the nursing staff and allied health professionals explained what they were about to do. Colleen's comments indicate that being informed about procedures was not an expectation for her.

They explain everything they're going to do to you, they explain when they're putting things on your chest for the ECG, when they're taking your temperature, when they're taking a blood test, why they're doing it, why they have to do it. They're very thorough in that respect and as honest as they can be at answering your questions with the facts as you present them to them. (Colleen, lines 733-738.)

It was not only health professionals that met the need for information. The other three patients in Kyle's room provided him with information that both relieved and comforted him. They had been in hospital several times and all had experienced angina. According to Kyle the patients said, '*Don't panic, because angina can be managed and once they know what it is and they're on to it, there are things they can do to control it.*' (Kyle, lines 203-205).

A study by Mumford, Schlesinger and Glass (1982), demonstrated that on average patients who are provided information to help them master the medical crisis, do better than patients who are not informed. Mumford et al's study is supported by other studies (Irurita, 1998; Seeman & Evans, 1962; Taylor, 1979; Warren, Holloway & Smith, 2000) that demonstrate that when information is

not provided, suffering is increased which contributes to patient vulnerability and lack of control. Indeed in New Zealand under the Health and Disability Act (1994) patients have a right (Right 6) to receive knowledge and be fully informed.

Although most participants were satisfied with the information they received whilst in the ward, some participants described circumstances where they weren't told what was happening. However unlike their experience in the Accident and Emergency department where they accepted passively what was happening to them, without asking questions or commenting, in the ward setting it appears that they were actively able discover what was going on.

Jack indicated by the following comment that although he needed to inquire as to what was going on, he wasn't afraid to ask. *'If I'm not too sure what they're doing and who's doing it I want to know why and how they're doing it. So I find out all I can about it and they cooperate by telling me.'* (Jack, lines 745-748).

Although unable to ask, Jacqueline was able to investigate. She asked to see her hospital records as she attempted to discover what had happened to her. An unexplained misadventure had occurred to her in the Accident and Emergency department that caused the consultant to make the comment that Jacqueline was an embarrassment to the staff.

I did have a most unfortunate experience. It happened I think when I was down in A and E and I presume it was because I was tossing backwards and forwards. It was never, ever... I wasn't told for sure what had happened, but I'm pretty sure... they kept asking me if I remembered what had happened. (Jacqueline, lines 472-476). I finished up with a bruise spread from here to there. They put a pencil round it

and then it still spread and still spread and they put another pencil around, so every single person that came into the ward wanted to know what had happened. They were aghast that that would happen. It was severe it really was. I never did think to ask the doctor because when they came around to say for sure that I could go home he looked at me and said, "You're an embarrassment to us." (Jacqueline, lines 486-497).

Elaborating further about the bruise Jacqueline continues, *'It sure spread. It was disgusting. Everybody was shocked when they saw it. I suppose the doctor meant... I presume that it shouldn't have happened and people would be wondering what they did to me.'* (Jacqueline, lines 531-541). Although Jacqueline felt she couldn't ask anyone what had happened not only to her arm, but what had occurred in the Accident and Emergency department when she had a cardiac arrest, she was able to ask to see her notes. She needed to know what had happened to her and the information wasn't forthcoming.

I decided to test the establishment. I asked to read my notes. I'd heard, well you're entitled to know whatever, it's your information so they did get a bit of a surprise. It was a nurse I asked for them. And she said, "Oh well, I'll see the doctor. And I thought, "Oh." I said to her, "Seventy one years old and you've got to ask if I can read my information." Anyhow I got it and read my notes. Of course it didn't make any sense. I really wanted to know when I had had the attack and what happened you know. Did I lose consciousness or was I just...? I didn't pick any of that up. I didn't ask them. I was satisfied that I was able to read information about myself. (Jacqueline, lines 341-368).

Although Jacqueline didn't understand what she had read about herself, she was content that she had been able to at least try to make sense of the situation.

Danny expressed that the nurses provided good clear information. *'...and they were, yes they were really good that way, doing blood pressure they would tell me what my blood pressure was and yes they were excellent.'* (Danny, lines 301-303). However she emphasized that some of the doctors either talked over her or about her, but not to her.

The other doctor I think he must have been quite high up, I wasn't too keen on him because he talked around me. He talked directly to the registrar, you know he was saying this and that and I could only pick up a few bits and pieces here and there. (Danny, lines, 115-122).

Two of the participants were whisked away for a procedure without knowing where they were going or why. Both participants questioned this however. When Elinor objected she was returned to the ward without having had the x-ray. *'Oh yes, [I] was taken nolins bolins¹ for an x-ray after a rather pointless discussion with an eager young male doctor to conclude which I said, "I wish to see the patient advocate," and then I was returned to the ward.'* (Elinor, lines 74-77).

Despite feeling unwell and not being steady on his feet, Allan was taken to the Maternity wing to have a scan. He still doesn't know what for, nor what the results were.

A porter arrived out of the blue one day, said, "Hop in, we're going down to the Maternity Hospital. So I said, "What the

¹ Nolins bolins is colloquial terminology for suddenly without warning.

hell are we going there for?" They had a sonic... And I hadn't heard anything about it at all and nobody seemed to know anything about it. I was sitting there in all my glory in my dressing gown with all the pregnant mums for a while. The guy that did it came with the wheelchair and said, "Righto over here can you walk?" and I said, "Not very well." I said, "What's going on here?" He says, "Haven't you been told?" and I said, "No I haven't. " I don't know to this day what it was all about because before I was sent home I meant to ask the lasses [nurses] about it and I never. But it just seemed to be one of these things that happened and I know somebody's got to make these things happen, but nobody seemed to know who made it happen. (Allan, lines 602-632).

Elinor was the only participant who commented on the following situation where she wanted information that wasn't forthcoming from the staff. Perhaps not all patients would want to know as Elinor did. In a ward setting, a difficult issue for the staff that occasionally presents is when a patient dies. Is it appropriate to tell the other patients who have been close to this person? Elinor indicated by the following quote, how upset she was not to be told that one of the patients who had been in the four bedder with her and with whom she had made friends had died. *'No one said anything about it. I was astonished! Not a thing, not the other patients, not the nurses!'* (Elinor, line 113-114). Elinor happened to read the death notice in the paper. Elinor's comments indicate that she felt that it was very important to be told that her roommate had died.

Although most participants demonstrated a more active role once they were in the ward setting some were very open and ready to accept whatever they were told blindly. James displayed an awareness of his unquestioning acceptance of the correct nature of information given to him by staff with the following comments.

'Sometimes when you ask people particularly nurses questions you tend to take it for granted that they're right. Because you want an answer and whoever gives it to you you'll believe them.' (James, lines 137-138.) When his doctor told James how he rated his heart attack, what had happened and what was still happening, the scar tissue and the possibility of an aneurysm James said, *'It leaves you wide open to obedience. Whatever they say to do, you do it.'* (James, line 290).

Having been hospitalized acutely, participants were plucked out of their comfortable and familiar home environment where they were in control and able to meet their own needs and placed in a foreign situation with other strangers when they were at their most vulnerable. Participants were faced with not only a need for information but also with a need for support and assistance both emotionally and physically. Unfortunately support and assistance was not always forthcoming.

5.3 Support

Every participant made comments that related to their need for support at a time of great stress, not only for them but also for their loved ones. While space age electronic gadgetry has dramatised and accentuated the stress of hospitalization, the hospital has probably always been a frightening place for patients and their families. Certainly on one level, patients can appreciate hospital as a reassuring place. Modern medicine is now able to perform 'miracles,' but that big building with its special sights, sounds and smells, remains for most people, a very frightening place.

All patients are in need of support during the stressful time of hospitalization. This theme has been addressed under the subthemes of support from health professionals and support from friends and family.

5.3.1 Support from health professionals

Lawlor (1991) described the relationship that a nurse has with a hospitalized patient in acute settings as one based on the mutual recognition of the patient's vulnerability, and the patient's partial or complete dependence on the nurse for help with events which, in their everyday lives, people do for themselves (p. 156). Many of the comments of the participants in the present study, indicate how embarrassed they were about needing assistance with tasks that they normally would take care of themselves unaided were they well.

In Lawlor's chapter on social rules and body care she discusses the fact that experienced patients know the rules of what is acceptable and expected behaviour as far as body exposure and the performance of 'private' bodily functions goes. However patients experiencing their first time hospitalization don't know these rules. Therefore embarrassment can be problematic for the first time patient. There are added difficulties when patients lose control of bodily functions as Colleen, Carrie and Frances did. Some participants were not only embarrassed, but they were also frightened in a situation in which they felt out of control. Despite feeling this way participants were reluctant to bother the nursing staff because they were acutely aware of the busyness of the ward and they did not want to be a nuisance.

Colleen detailed an experience where she felt she needed more support, not just physical assistance, but emotional support. She had had a bad day and was feeling very poorly physically. *'I had occasion during the night to call the nurse several times because unfortunately the diarrhoea wasn't subsiding and I must have dozed off at one point and unfortunately soiled the bed which distressed me greatly.* (Colleen lines, 123-126). Colleen elaborated on this situation later in the interview and she explained how frightened the lack of support made her feel.

I think they must have had a lot of admissions that night when I was at my lowest. I'd had a very bad day and I was quite frightened and that was when I dozed off and they came to me quickly and brought me a clean top but no one stayed with me and no one helped me, because I had a drip up and I am very stiff as I hadn't had any medication [for arthritis] for three days and it took me about twenty minutes to get the top off and she changed the sheet but she didn't take anything away and I... (Colleen, lines 421-429).

When I queried why Colleen hadn't felt that she could ask for help from the nurses she quietly replied,

Well I could hear bells ringing all over the place and I thought well there's people just as bad as I am. I was a little angry that time, not angry but upset. I cried a lot during that time, trying to get things off and trying to get washed and in between having to change this, I wanted the toilet again and had to get out [of bed to go to the toilet]. I had the toilet next to my room but I had to go with nothing on apart from this thing [night-gown] hanging off the side that I couldn't get off. You see I had to lay the drip trolley down on the floor to get it off because I simply wasn't strong enough to do it all on my own. I'm one of the old school, I was embarrassed. I would have my bra on so of course this complicated the fact. And I was just standing there going, "Help!" with my hands in the air. (Colleen, lines 438-449.)

Colleen didn't tell anyone how distressed she had been even when the morning nurse acknowledged Colleen's depressed mood.

Irurita's (1996) study found that patients, especially experienced patients, perceived that they had certain obligations to contribute to

the quality (and amount) of care that they received. Some patients had learned strategies that helped them receive more or better attention. These strategies included;

- *Being a 'good patient,' unselfish, uncomplaining, undemanding and not ringing the bell too often.*
- *Trying to recover (or being seen trying to recover).*
- *Enhancing the development of the nurse-patient relationship* (p.275).

According to Lorber (1975), hospitalized patients frequently resent the passivity and submission expected by doctors and nurses, yet they tend to conform. *'There is evidence that patients believe this is the proper way to act in a hospital; moreover, they are afraid that if they do not keep quiet and do as they are told, they may not get adequate care'* (p.214). Cameron's (1993) study supports Irurita's (1996) and Lorber's (1975) findings. Cameron discusses the importance patients place on learning how to act appropriately as a patient. Patients felt that they could jeopardize their care if they annoyed the staff.

It appears from Colleen's experience that, although not an experienced patient she wanted to be a 'good patient' by not disturbing the obviously busy nurses.

When Frances was incontinent, she was so embarrassed that she didn't tell the nurses.

But what ended up happening was, well how do you describe it? I passed this horrible liquid bowel motion thing unexpectedly while I was lying in bed. Not to any great degree. I didn't tell the nurse because I felt, I was wearing underwear, so I sort of did this sort of covert

operation of taking off my underwear and feeling, (I was still lying down), and feeling around in my bag and stuff for another pair which I knew was there and stuffing those ones into there. (Frances, lines 628-635).

Two hours later Frances realized that she had got her period. She describes feeling very vulnerable, because she was dependent on someone else to help her with something she normally did herself.

She (the nurse) wheeled me into the bathroom and I discovered that I had my period and so she came and got me and I had to tell her that and got her to get my bag. And so that was the down time, the worse part of things really was that morning, just feeling like everything from here down was all sort of munted. I just felt yucky* really. I guess that was when I was feeling most vulnerable really because I wasn't in control of anything that was happening and you don't feel like you can get up and go to the toilet. (Frances, lines 658-667.)*

Carrie also felt as if she wasn't in control of anything that was happening when she had major problems with double incontinence following a brain haemorrhage. She remembers how angry she was when the consultant ordered the removal of the catheter. She knew that there would be problems because of her past experience as a health professional. *'God I could have strangled him when he took that out you know because I thought, "Oh now I've got to go through this whole big drama."' (Carrie, lines 978-980).* Carrie remembers comments made by the nurse when her wet bed was being changed. *'I used to hear them talk about me when they changed the bed... it felt so nice and warm and they'd come along and next thing all these blankets are gone. So you felt like you were*

* Munted is colloquial terminology for something useless.

* Yucky is colloquial terminology for something horrible

actually a nuisance.' (Carrie, lines 966-972). Although Carrie was most uncomfortable because of constipation, she felt unable to request an enema because she didn't want to cause problems.

And I was constipated and I used to (this is a laughing point), I used to get money from my visitors, and they would put it on the drawer and I said to them, "It's for a newspaper." But what it was really for is I was going to sneak out of the hospital and go to a Chemist and get some microlax.' (Carrie, lines 487-491).

Physiotherapy was torment for Carrie, because of the very real fear that her bowels would move suddenly, which they did on numerous occasions, yet she was unable to request assistance because she didn't want to be any trouble. *'Why didn't I tell the doctor to come and examine me? But if you did you were a nuisance anyway.'* (Carrie, lines 551-553).

Frances articulated two situations where she had no response to requests from the nursing staff for assistance. Firstly she was annoyed that on the fourth day of her admission her bed hadn't been changed and when she told the nurse, she said she'd be right back to do it, but she didn't come back. That made her feel totally powerless.

...because I was in there for three days and the next day my bed didn't actually get changed that whole day and I asked her (the nurse) about it in the afternoon and she said, "Oh has your bed not been changed today?" and that she'd come and do it but she just sort of didn't. And I just hate that feeling really, of just total powerlessness. (Frances lines 680-684).

This same situation happened again to Frances when she asked a nurse for a mobile drip stand so she could walk to the toilet. *'I can't remember which nurse it was or anything like that, but they went away and didn't come back and so you ring the bell and feel like a pain.'* (Frances, line 694).

Boeing & Mongera, (1989), list five hospital orientated factors that contribute to powerlessness as defined by the Fifth National Conference on Nursing Diagnoses (Kim, McFarland & McLane, 1984).

- *Relinquishing some control to others*
- *Lack of privacy*
- *Altered personal territory*
- *Lack of explanation from caregivers*
- *Not being consulted about decisions* (p.274-275).

I would like to add unfulfilled promises to that list. When a nurse says she'll be right back and does not return, not only is the patient left with their request uncompleted, but also trust is undermined. And trust is the basis of a good nurse-patient relationship. Irurita (1999), considers broken promises to be an abuse of the nurse's power as well as a lack of courtesy, and that these factors contribute to patients' sense of vulnerability.

Kyle was not impressed with the demeanour of two staff members who appeared to be most unsupportive.

There was one nurse who I felt was a bit, vicious is a nasty word but that's exaggerating, but who was a bit curt but otherwise with that one exception and she wasn't bad but she was a bit bossy really. (Kyle, lines 447-450).

Kyle had this to say about one of the doctors.

An Asian woman, I think she was very competent but she was very again sort of curt, very, what bossy. No smile, no anything. Abrupt yes that's right. She didn't seem to be at all friendly or warm or anything like that. I don't necessarily think she was nasty and I don't think incompetent or anything like that but she wasn't a person you could warm to, she was very sort of the cold, efficient type. (Kyle, lines 491-499.)

John experienced the incompetence of a young doctor attempting to replace his drip site and he wasn't impressed.

One was I think an oriental gentleman who was pretty young and he had to replace one of those drips, made a mess of it which I wasn't very happy about. It came out again in the morning too. He made a bad job of that. (John, lines 226-229.) He was very apologetic that he had made an absolute mess and in the end they had to change hands and I had a massive bruise on the back of my hand for about three weeks.' (John, lines 551-552).

Not all the comments participants had to make about the support they received whilst in the ward were unfavourable. Many of the participants spoke very highly of the staff and they were very quick to point out how busy they were.

Allan spoke highly of the support he received from staff. *'You know there was a lot of back up in there, a lot of support.'* (Allan, line 244-245). Allan couldn't identify anyone in particular. *'It was the system overall I think. The nursing staff were great, the chaplain was around, the house surgeon was round about...'* (Allan, lines 255-

256). Allan expressed his gratitude. '*So I knew I wasn't on my own. Oh they were very good.*' (Allan, line 279).

Danny was also impressed with the support and attention she received.

The nurses were there all the time. They were just in and out, in the middle of the night and all. There was a couple of times I pressed my button accidentally. I quickly flicked it off and they were just about there before I could cancel it again. So yes they were great. (Danny, lines 291-294).

When asked about her impressions of the ward, Danny is full of praise. Her comments indicate that she didn't expect the attention that she received.

Really very efficient and yes, I was surprised because I know how overworked the nurses are and everyone else. I was really surprised at how much time they found for everyone. I was just absolutely amazed at the, I mean quality time. Everything is done, it was done efficiently, everyone was really, really friendly and nice and approachable. (Danny, lines 601-605).

Despite his earlier comments about two staff in particular, Kyle was full of praise for the nursing staff in general, at the same time as he acknowledged how busy they were.

I think most people are so conscious of how overworked and under resourced they are and rushed off their feet. One often hears and reads tributes that when it gets down to the grass roots, the actual front line people doing the job, they're marvellous. They're very professional you know and we all know the political things going on with health but when

you're actually in there as a patient you don't notice it. (Kyle, lines 451-456.)

Despite the lack of assistance and support Colleen had which are detailed earlier, she had this to say.

I have no complaints about the medical staff and the nursing staff. They were run off their feet. They run, they don't walk. On the Monday night the day after I was admitted, I don't know whether there was some emergency somewhere, but they were running. There were people being admitted left right and centre. Bells were going, oh look, they are really dedicated up there. They are just magnificent. I can't stress too much how wonderful they were. (Colleen, lines 280-287).

Jack spoke highly of the nursing staff. *'They were excellent, the nurses on the ward. I don't have any complaints about them at all and I won't listen to anybody that has got complaints about them. I'll go damn crook about it. They're good girls.'* (Jack, lines 155-157). When asked if anything could have been better in relation to his experience in hospital Jack said firmly, *'Not as far as I'm concerned. I think everybody did everything they could have done.'* (Jack, lines 733-734).

Several of the patients commented on a person, usually a nurse, who stood out as being special in some way. This person was aware of how important the little things were. They went the extra mile, and nothing seemed too much trouble. The relationship aspect of the participant's hospitalization made a big difference to their overall wellbeing.

Elinor had difficulty finding the right words to describe her favourite nurse. *'There is that something extra...'* (line 700) *'Having the*

personal touch, just realizing that it isn't a patient necessarily but it's a person as well.' (Elinor, lines 704-705.)

Kyle said his favourite nurse's quality was her personality.

Just one of those warm sort of people, people that you warm to. I don't think it was a professional thing in the way she was doing her job or anything, but I think she was just a warm person that made you feel better. She told you what she was doing and that sort of thing. (Kyle, line 678-682).

For Colleen the nurse that she remembered in particular made her feel special.

There was just something really special about that girl. I had never met her before and we just hit it off straight away. On the day I was discharged she was way down the ward and she didn't know that I was going to go home and she came flying along and gave me a big hug and said, "It's been a pleasure nursing you." Yes she was quite special. I can't imagine her ever losing her cool or being cantankerous with anyone. She made me feel as though it was a one to one person. She was dealing with Colleen on that ward. Some nights when they're really busy they can have six patients but she was there just for me. (Colleen, lines 644-654.)

Colleen described a situation when she felt cold to illustrate how special this nurse was and the difference she made. She didn't even have to say she was cold. This nurse went away and got a blanket, put it in the drier to warm it through and then came back and wrapped it around her. *'Just with a wink she pulled back the cover and said, "This will keep you warm." And I thought, "How lovely."* (Colleen, lines 672-673.)

For Carrie the relationship that developed between a diet aid and herself was very important to her. This person made Carrie feel special. *'I guess that during that whole time I was in there the greatest thing for me was one day this Island lady gave me breakfast. I thought I was in heaven...'* (Carrie, lines 661-662).

And she used to really fuss over me you know. The tray, she used to put the tray down for me and she used to straighten the forks and knives and fold the napkin and, "Here's your porridge," and "Oh thankyou" and she said, "Do you want anymore? I can get you some cream if you like." (Carrie, lines 666-670).

Personal interactions between caregivers and patients have been shown to be the most important influence on patient satisfaction (Gorham, 1962; Peterson, 1989; Taylor, Hudson & Keeling, 1991). *'A satisfied patient is seen as participating more carefully and accurately in his or her treatment and therefore achieving a better clinical outcome than a dissatisfied patient.'* (Hildeman & Ferguson, 1990, p.26). Thus measures to increase patient satisfaction can contribute to a more positive health outcome for patients which must be the goal of all health care. Nurses, as the largest group of health professionals within the health sector, have a huge responsibility in achieving patient satisfaction. As Frances comments when asked about the atmosphere in the ward, it was the nurses who looked after her who determined how she felt. Her comments indicate how vulnerable patients are in hospital and the importance they place on support from the staff and from the nurses in particular.

I felt like there was a whole sense of well, predominantly the nurses because there was a feeling that the doctors did their round and that was cool. You would defer to them while they were there and they are very important but then they went

away again and life in the ward went on. So that's the vibe that I picked up from the nurses I guess, so you start thinking that yourself really. To a large extent how I was feeling in myself was determined by how I was feeling about the nurses I suppose really because you are so dependent on them. (Frances, lines 903-913).

The dependence on the staff that Frances alluded to is apparent also in the participants' comments they made in regard to their relationships with family and friends. Support from significant others was considered very important, especially given that the admission was sudden.

5.3.2 Support from family and friends.

All twelve participants considered that the support of family and friends was an important aspect of their hospitalization. The necessity of support has been identified in the literature as significant to other patients. Dakof & Taylor (1990) studied fifty-five cancer patients in all stages of their disease, to identify what, specifically, they found to be helpful or unhelpful, and from whom. Potential providers of support included spouses and other family members, friends, other cancer patients, nurses and physicians. From the patient's in Dakof & Taylor's study's perspective, the first and most important category of support was the expression of positive affect or bolstering of self-esteem. This included such actions as expressing concern and empathy, showing special understanding of the nature of the problem, calm acceptance of the problem, and the expression of optimism or hope. The majority of patients studied found expressions of love, and encouragement to talk about feelings to be the most helpful support given by all providers; but it was least helpful when it was done poorly or not at all.

When admitted for an acute illness most people are completely unprepared for a hospital stay and have only what they stand up in and this was the situation for all of the participants in this study. Having someone available to bring in things from home like toothpaste and pyjamas and take care of bits and pieces like the mail and the cat was identified as a huge support meaning that patients could put those things behind them and concentrate on the issues at hand. Kyle articulates his experience.

...and I found that it's really handy to have, well someone if only sort of to bring in toothpaste and that kind of thing because I mean in the circumstances I was in bed so just put a pair of underpants on and slippers, (I never go anywhere without my slippers), and a dressing gown. And at home I was assisted out to the ambulance and that was all I had and the hospital provided pyjamas and a face flannel and stuff but I didn't shave that day and then he [partner] brought in my toilet gear and I could have a decent shave and a shower the next day which I appreciated. So I think it is very important to have somebody as a go between, you know provide some practical support from the outside world, but also at an emotional level especially initially it was very hard. I think that any visitor if you're up to receiving, again it breaks the monotony. (Kyle, lines 609-621).

One patient mentioned that it didn't matter who it was that came to visit. There was comfort in knowing that someone cared.

It was the realization that you might have been lying there for hours just reading or doing nothing, thinking of something and someone turns up. It's the realization of the fact that these people are aware that you are there. You're not put

away in a corner and forgotten about. (James, lines 656-658).

Danny described herself as a calm, self assured and independent person. However her hospitalization made her feel very dependent on others.

It's probably the only time I actually get dependent on needing people around, is if I'm ill. It's quite a heart-wrenching thing, it's really hard to explain, like you just want them there and it's very needy but yes I do. "You've got to be here with me. You don't need to sit there and molly coddle me but just be there." (Danny, lines 636-641).

Some participants found that their visitors imposed more stress on them, particularly when they were in the acute stages of their illness. They just couldn't be bothered interacting and yet felt as if they couldn't very well ignore people who had been kind enough to go out of their way to come and see them. Family seemed to understand this or perhaps participants didn't feel as concerned about keeping up appearances with family as they did with their friends. James thought that hospital visitors should have to attend a course.

I sometimes think that visitors should have to go through a seminar before they're allowed in the hospital. They don't realize sometimes that a patient's just not up to coping with them for any length of time. It's difficult sometimes even to give an answer yes or no. (James, lines 532-535).

Colleen said the support of her husband was very, very important. On her very worse day, she had other visitors,

...but I couldn't be bothered to talk to them that day. I just wanted them to go. But they didn't stay long. I think they realized that. Barry, [husband] he was just happy to sit by the side of the bed. So he didn't tire me. I just knew he was there. (Colleen, lines 630-634.)

Although Jacqueline could say to her close family that she was tired she found it more difficult with friends. Jacqueline articulated her experience.

My sister and two brothers came in and that was fine because I said to one brother, "I'm sorry but I'm really tired and I can't keep my eyes open." So he just went away and that was fine. But I felt that some friends didn't really stop and think. I think they were told that I was tired but because I was inclined to respond to them they didn't realize that I was tired. (Jacqueline, lines 289-296)

Jacqueline also found it difficult to respond to phone calls from her children who live out of town. She didn't wish to concern them, so tried hard to reassure them, all the while just wanting to be left alone to rest.

Weiss (1976) points out that often people going through times of crisis and transition such as acute hospitalization, are isolated from their usual support network as their family and friends are unable to share the experience. Although the participants' family and friends were willing to be there for their loved one, it appears that they were unable, as Weiss states, to fully share in the experience. Neither were family and friends able to completely comprehend the impact of the environment on their loved ones. Nor were they able to protect them or make a significant difference to their experience of the hospital environment for example problems with sleep, noise, hygiene, privacy and safety.

5.4 Environmental issues.

The hospital patient is sick and helpless and aspects of the physical environment which are relatively unimportant when well, can become important when one is confined to a hospital bed. The healthy person can make adjustments to their environment. They can arrange furniture, move about to avoid unpleasant smells or noises or lights. The hospital patient must, for the most part, accept the environment as given.

A significant aspect of most people's experience of hospitalization means sharing intimate space with strangers in an unfamiliar environment. In our home circumstances most people choose who they sleep with, what they eat and have some control over the bedding, noise, temperature and the cleanliness of their surroundings. This is unfortunately not the situation in an acute ward setting. Environmental issues are addressed here in the three subthemes which arose from the data; the physical environment, privacy and safety.

5.4.1 Physical environment

None of the patients commented specifically about the structure of the ward, but all of them had comments about the effects of the structure on their comfort and well being. Jacqueline had difficulty sleeping and hearing another patient's radio didn't help. This became quite distressing for her as she describes.

One thing that really did bug me and I did mention it the next day. I worded it quite well I think, was a radio and I said to the nurse, (I was nearly crying), I spoke quite calmly and she went and turned the one radio off because the woman was asleep. And then after she was gone there was still another radio on and I didn't... I thought she must have been listening to it and couldn't go to sleep so I just left it. (Jacqueline, lines 210-215).

The second night James was in hospital he ended up complaining to the nurses about the noise they were making which was preventing him from getting to sleep.

I quietly spoke to the nurse on the second night saying, "It's very difficult going to sleep when you're having a party out there." I don't think they realize it when they laugh loudly or talk loudly that their voices carry and it's a bit like an echo chamber in a way. (James, lines 734-738).

The findings of Southwell & Wistow's (1995) study show that many patients do not consider that they have sufficient sleep in hospital at night. It is my consideration that it is impossible to achieve silence in a ward full of sick people, however it is possible to reduce the level of unnecessary noise.

Also unacceptable to one patient was the level of hygiene in the ward she was admitted to. Yvonne and Danny had conflicting viewpoints about the cleanliness of the same ward environment. Perhaps this was because of the difference in the level of unwellness experienced by participants on admission to the ward. Perhaps there were different cleaners at the time of each participant's admission. It is difficult to understand how two people could interpret the ward so differently. Danny described her impression of the ward she was in. *'And the ward was yes, I mean from what I saw of it, just busy and clean and everything you want. You wouldn't want it run down and dirty or, you know I'd notice things like that. Yes it was great.'* (Danny, lines 610-612). However Yvonne who was in the same ward at a similar time had this to say about her impressions of the ward.

It was terribly dirty. And it was cold too. We all complained of the cold. The hospital is a cold place... (Yvonne, line 160).

The cleaners only do the middle of the floor. Also there was a lady in there and she had dysentery and they [the patients] went in and showered themselves. They [the patients] wouldn't pick up their towels and put them out in the bag and tidy the bathroom. (Yvonne, lines 181-185) No and the lockers and the wardrobes aren't kept clean either. I cleaned the locker and the wardrobe. Two of us used the wardrobe and it had broken coat hangers and dirt in the wardrobe. (Yvonne, lines 198-200). The hygiene for a hospital I thought it was disgraceful. (Line 228). If the patient's complain the only thing that I could see was the cleaning that's all you could complain about. (Lines 729-730). Yvonne continues, And I don't think it should be cold like it is, very cold. (Lines 734-735).

John mentioned that he found the pillow rather uncomfortable and because it was necessary for him to have a bed cradle, he too suffered from the cold.

I used to find some discomfort with these hard pillows and things and also of course I tended to get cold in bed because of the cage. You know because the bedding isn't close to you, it's kept off you and because a lovely draft can blow up through the damn thing like a tunnel. So that was a bit of a nuisance. So yes sleep was not as good as I normally sleep. (John, lines 387-396).

Danny found not being able to choose what she wanted to eat very difficult especially as she didn't feel very hungry. Although patients do get a limited choice, this usually occurs the previous day and often one doesn't feel like what one ordered by the time it arrives.

The other thing I didn't really like was being put in like that, (admitted acutely), I didn't get the chance to decide what to

eat. (Danny, lines 68-69). Well my husband bought me in some McDonald's but it just wasn't what I wanted. Anyway they brought in tea at the same time. I thought, "Oh it might be a sandwich or something." Can't remember what it was, but no it wasn't right. And then at breakfast I just thought there was nothing there that took my fancy, so yes it is quite a big issue. You really feel like, because when you are sick you feel like you know there's particular things you want to eat isn't there, and there's other things you can't look at. (Danny, lines 88-94).

Physical comfort is one of the most basic services a hospital offers patients, and it is an important need for a sick person. A patient's experience of hospitalization can be seriously affected by the physical environment of the hospital; its unfamiliarity, its institutional character, its frightening sights and sounds. Although not every aspect of the physical layout and equipment of a hospital can be changed, sensitivity to patient's perceptions and experiences can make it a more humane environment.

Many participants in this study also experienced a lack of choice and a lack of control in their physical environment that affected their privacy. This was an issue for most, but not all the participants.

5.4.2 Privacy

Privacy is a basic human need and right that allows people to maintain their individuality. It is important for the psychological well being of hospital patients that private domains are provided which are not open to public view or use. It is also important for health professionals to respect the right to privacy and not invade patients' privacy without permission (Barron, 1990). Respecting privacy is a fundamental principle of practice, and much of what nurses do when they help patients with the body is done in the context of the need to protect privacy (Lawlor, 1991, p.166). Lack of privacy was

accepted by participants as something one had to deal with and the phrase, *'leaving one's modesty or dignity at the door'* was mentioned by one participant when discussing this concern, (Danny, line 499). None of the participants commented about privacy when describing their experiences of their admission to Accident and Emergency. Either they were too acutely ill for this to be a consideration, or privacy was adequately provided. However once their conditions had been stabilized and they were settled in the ward, then the lack of privacy often became quite problematic. Unfortunately some of the participants had the experience of a nurse or doctor accentuating their discomfort and contributing to their vulnerability, either because they were rude or insensitive in some way.

Frances was amazed when one of the doctors just walked into her cubicle, and started examining her without telling her who he was.

The consultant just walked into my cubicle and pulled the curtains and started feeling around here and didn't tell me who he was or anything. Luckily the house surgeon was there as well so I knew it was all sort of... And he didn't tell me his name actually and the house surgeon had to come back into the cubicle and say, "Oh that's Mr. X the consultant," sort of apologizing for him. (Frances, lines 773-782).

Danny had a similar experience.

There were actually two older doctors at two different times and one of them in particular was coming in and poking me and feeling all my glands you know under my arms and in my groin and sort of it would have been nice to say, "Okay we're just going to check you," you know rather than just coming in and having a poke around. I mean after having

kids you get used to most things, but just a wee bit of courtesy you know is nice. For some people I can see them finding it, especially older women you know, I think a few older women in particular would find something like that quite horrendous, just so embarrassing they wouldn't know what to do with themselves. I don't know whether perhaps they think being younger it's something you're used to or I don't know but yes a wee bit of common courtesy would have been...(Danny, lines 207-225).

Indeed according to Barron (1990) the denial of privacy can erode rehabilitation prospects for elderly hospital patients (p.29). It seemed to Danny that it was the older doctors who had less consideration.

But the older ones, I gather they were more along the specialist lines, I don't know, they were not brash but perhaps not... maybe just... Yes they were doing their job... I mean they haven't got time for too much molly coddling, but a wee bit of just basic good manners, "Excuse me, I'm just going to do this because..." or "We're checking because..." or you know just a little bit thrown in here, would have been quite helpful. (Danny, lines 241-247).

Participants were not only concerned about their own lack of privacy, but they were aware of the lack of privacy of others and this, along with the inconsideration of some of the staff was a source of distress.

Elinor commented about her experiences in the Coronary Care Unit.

There was a lack of privacy. You sit there and the curtains are drawn, but they are only half curtains. I know that's

where they need to be but it still doesn't feel secure enough. And they walk out with a full pan, right through the crowd, with people coming and going through the hall and you just feel the most intimate things are being exposed. (Elinor, lines 602-607).

Whilst in the ward, Danny had several more rather unpleasant experiences relating to the lack of privacy which she would rather not have seen or heard.

Part of the reason I definitely didn't want to stay the next night as well was they brought a lady in who, an older lady who'd had a stroke, and she was really bad to look at anyway, and she had the gurgle and I couldn't ... My grandfather died of a stroke and I remember when I visited him in hospital he would gurgle and my grandmother would give him oddfellows and I used to think, "Oh they were so huge," and I would sit there waiting for him to choke and that's all I could think of with this lady. (Danny, lines 314-321).

Danny commented on how embarrassed and sorry she felt for the parents of the patient next to her in the four-bedded room. *'There was another young girl beside me who had obviously tried to commit suicide and it was like there was no privacy for them. I felt guilty sitting there with her parents trying to talk to her.'* (Danny, lines 333-335). A concern about the privacy of the other patients led her to feel guilty about her own condition. *'I was trying to worry about not disturbing other people who you felt should have been in rooms on their own and then also not being anywhere near as bad as them and you know... Funny situation really.'* (Lines 343-346). Danny was not only very aware of other patients in the four-bedded room she was sharing, but she was conscious of the visitors as well. She related a distressing experience where she woke during

visiting time needing to go to the toilet. She had come into hospital completely unprepared and had been given a hospital gown to wear.

I woke up and there were visitors around and other people so I thought, I couldn't get up and go to the toilet because I had this stupid gown on that did up at the back and they are relatively small anyway so I couldn't even get it to, it was just about off my shoulder and it was awful, and I had been sweating, so it was all stuck to me and I thought, "Oh." And then that's the other thing too as silly as it sounds, was the toilet or bathroom when there's visitors outside because I mean because you can hear people going to the toilet. It doesn't bug some people but it bugs the living daylights out of me and yes you're sort of thinking, "Oh." I mean you expect to lose a little bit [of privacy] but oh, there's nothing you can do about that. But visiting hours could actually be rather traumatic. (Danny, lines 451-464).

Danny elaborated on how the lack of privacy made her feel.

I felt more embarrassed for the people beside me like especially that young girl. I just felt that I didn't have a right to be hearing what I was hearing and if I had been in that situation or a parent of that child or something like that I couldn't think of anything worse. (Danny, line 506-511).

Danny's concerns about how others were coping relate to a woman in Lonergan's (1980) report on a group study of medical in and outpatients as mentioned in the literature chapter. One woman who was admired by the staff for her stoicism said that one thing she could not handle was an elderly roommate who was in pain. She felt upset and helpless when confronted by such a person, much more so than in the face of the severe pain of her own chronic illness. It is

difficult to be confronted with another's suffering and be powerless to affect change for that person.

Danny was so concerned about her privacy and the privacy of those about her that she tried to keep her curtains pulled around her. *'I tried to keep my curtains pulled a wee bit, just for, I mean not so much for my privacy, but I didn't want to be intruding on other people's but however someone would come by, whip the curtains back...'* (Danny, lines 564-566).

Although aware that the other patients could hear during doctor's rounds, Kyle felt that this wasn't an issue for him.

They closed the curtain so you can't see but you could still hear and I was conscious of that, but it wasn't an issue because I mean there was the common bond that we're all in there for something medical and the same sort of area, obviously the heart, and so there was that common thing and that's a uniting thing rather than a dividing thing. (Kyle, lines 242-247).

Despite the doctor's rounds not being an issue for Kyle, he did comment about the inconvenience of a common bathroom and the embarrassment this caused him.

The fact that it was a common bathroom was a bit more of a privacy issue because I tend to take a long time and somebody actually commented on that. This is just a hang up that I have generally because everybody knows where to go to the bathroom and of course when you're in there other people can't use it. (Kyle, lines 249-253).

Several participants mentioned how potentially intolerable it would be to be in very close proximity to another patient of the opposite

sex in the ward situation. Even though only Elinor experienced it, it was a very real fear for the other patients.

I think I was aware that there were rooms with both male and females but I would have a major problem with that in terms of you know not feeling comfortable and that the privacy would go right out the window both from women being aware of me and me being aware of women. (John, lines 560-563). John continues, 'I think it is unfortunate for all concerned, for the women and for the males. I mean there are female things and there are males things and yes, no it would not be good.' (John, lines 584-590).

Elinor did experience mixed rooming. *'It was only awful being stuck with those two men who were male bonding. (Elinor, line 579). When asked what it was like she comments, 'Exceedingly unpleasant, but at least they were courteous. They would always ask before they went to the bathroom for any reason, whether I wanted it.'* (Elinor, lines 593-594).

Some participants were appreciative of the respect afforded to them in situations that were potentially difficult. Allan was grateful to the doctor, when told the results of the scan he had indicating that he had a brain tumour.

When the doctor told me she [his wife] was there. He waited until she came in. He took us down to a wee anteroom down at the bottom of the ward. And he had a print of the scan and he showed me where it was. No he was very good. (Allan, lines 294-298).

Jacqueline was also appreciative of the consideration she received from a male nurse.

...there was a male nurse of course and I hadn't had a male nurse before and he washed my back for me and I was a bit concerned and then he just went away...left me to wash myself, so that was okay. (Jacqueline, lines 266-268).

It appears from the participants' stories, that some health professionals are very aware of patient privacy. However due to the physical construction of the ward setting with only curtains between each bed, privacy is difficult to maintain. This is particularly problematic as patients can't help but overhear private conversations.

Although the close proximity to other patients was a source of difficulty for some participants, for others fellow patients provided comfort and support. James found that everyone in the four bedder he was admitted to, came from the same area he was from, and so there was an instant rapport from which he gained support. *'I come from Central Otago and found that all the ward come from some place in Central Otago, so there was a rapport there which was for me to get support from...'* (James, lines 450-452).

Elinor commented, *'There was a surprising camaraderie between the patients. In fact when you don't get it, the patients who don't respond to it or one who just pulls the curtains and that, you miss it.'* (Elinor, lines 571-574).

Jack said the other men in his four-bedder were a *'happy combination.'* (Line 362). He did have the experience of people not responding however and he found it rather trying.

...twice while I was over there people would come into the room who just sat and didn't talk or say anything and it is extremely difficult. If you get people to say some little thing,

[like] *“Good morning,” it makes it so much easier, so much more pleasant.* (Jack, lines 367-371).

It seems that when people are living and experiencing life so intimately, getting on together is very important. The significance of other patients' support was a finding in McIntosh's (1977) and Ahmadi's (1985) studies as mentioned in the literature chapter. Weiss (1976) also suggests that patients need to have others in the same situation to relate to and who accept them as they are.

The close proximity to other patients was a source of frustration for some participants however. The sound of another patient constantly complaining upset Allan.

One of the guys in there was forever grizzling. Nothing was right. He pushed the buzzer every five minutes. And if nobody appeared more or less just as he pressed it nothing was right, “Where the hell are they? Why don't they come?” There was another guy there and we listened to this fellow every night for a while and we got a bit fed up with him. He got the message that there were busy people in there and sick people in there, but I don't think it registered somehow. (Allan, lines 332-339).

Unlike most of the other patients, Frances did not enjoy interacting with any of the other patients, mainly because she was much younger than they were. Frances and her mother became rather irritated with another patient in her room who kept trying to talk to them when Frances' mother was visiting.

I guess we didn't feel it was really appropriate that another patient should join in on our conversation. It's kind of one thing when you're just lying there and talking to one another

but we felt a bit invaded sometimes I guess. (Frances, lines 367-373).

This same patient used to talk to Frances about her annoyance with the other patients in the room, saying they should be in a geriatric ward and this upset Frances.

And then this poor other little old woman diagonally across from me who was very frail and very deaf, who [patient] was actually quite mean about because she kept saying things like she should be in a geriatric ward. She was actually quite old, you know really old and kind of didn't look very well and got confused in the middle of the night... and would get up and wander around and try to get back into [patient's] bed. (Frances, lines 378-385).

Frances philosophized about her reactions.

I guess I just couldn't be bothered. It's a weird thing when you're somewhere that you don't really want to be like in hospital. It's your choice about whether you kind of embrace it and decide to talk to and make friends with these people or whether you just kind of want to ignore and get out of there and back to your normal life. (Frances, lines 415-423).

Frances' comments not only contrast with most of the other participants experience as described above, but also contrast with a study by Coser (1962) which demonstrated that 83% of patients expressing satisfaction with ward life gave "liking to be with other patients" as the reason for their satisfaction (p. 90). Ahmadi (1985) speculated that the informal patient support group had potential to reduce the stress of hospitalization and Cameron, (1993) found in her study that the very nature of the close physical presence bonded patients to each other.

It appears from the interviews, that when consideration for one's privacy, and respect for one's need for space was met, then participants did not comment on the issue of privacy, indicating they did not feel this was an problem for them. In regard to the issue of safety there was a similar pattern. Participants only commented in regard to their safety if they did not feel safe.

5.4.3 Safety

The third and last subtheme relating to the theme of support was safety. There were mixed comments from participants when they commented about how safe they felt in an alien environment whilst unwell and dependent on others for all aspects of their physical care and safety.

Because of the nature of his condition, Alan was unsteady on his feet. He was grateful for the nurse's consideration of the fact that he wasn't feeling safe in himself when he required the toilet.

She took me in and sat me on the toilet. She said, "I'll just leave you. There are rails there to hang on to. Are you right? Comfortable? I'll just be outside the door. I'll leave it ajar so I can hear you if you want me." (Allan, lines 508-511).

Colleen however had problems with the nurses insisting that the door to her single room remain open. She wanted it shut because she didn't feel safe.

You were never allowed to close the door during the day and they didn't like you to close the door at night. But one night I did close the door because I wanted a little privacy. There was one occasion when I was a little scared. Further along the ward there was a schizophrenic who had a medical problem, and I was told they she had to be assessed there

before she could be taken to the psychiatric ward, and she during the course of the evening became very, very agitated and was coming along to my end with very abusive language. There was a staff nurse with her, but she wanted cigarettes. She wanted to smoke and of course they were trying to insist their rules and it was two o'clock in the morning. Now I was the last one along there in that ward and I felt once that she was on her own and I felt well I'm in bed here on my own with a drip up, if someone came in and started to harangue me, I couldn't, I was so weak, I couldn't fight back. That was the only time I was afraid and that was the time I closed the door. But they did come along later on and open it. (Colleen lines, 548-571).

Colleen was not given an explanation as to why the door needed to remain open.

Carrie had difficulties feeling the difference between hot and cold temperature on her skin following a brain haemorrhage. The nurses would leave her in the shower and then would reprimand her for having the water too hot. Carrie considers that she should have been helped more as she wasn't safe.

And I tell you when I did feel scared, the one whole time, was when they weren't there when I was showering because I knew from my experience that you could fall over and one of them asked me one day, "Is somebody there the whole time that you shower?" I said, "No," and of course they used to say, "Don't turn the water on so hot!" Well I didn't know it was bloody hot. (Carrie, lines 1008-1012). And I thought, "You bitch." I almost burnt myself and I don't know how many times were they actually there? (Lines 1030-1031).

According to Irurita's 1996 study on hospitalized patients, preserving integrity was the core process identified for dealing with patient vulnerability. Preserving integrity means in the context of hospitalization, conserving, protecting and restoring the patient's integrity by minimizing risks, such as keeping safe, protecting, defending, guarding or shielding the patient from injury or harm. The examples Colleen and Carrie have given where their integrity was not preserved, leaving them feeling more vulnerable and unsafe relates to Irurita's definition of 'rough-hand care' (p.277). Irurita states that not only is vulnerability increased when patients do not feel safe, but they are dehumanized, they experience despair, frustration, fear and anger as a consequence (p.277).

Carrie philosophized about some of the reasons for the inadequacies in her experience of acute illness.

I guess you've got to look at the big picture. If they're cutting staffing how do the paper pushers up the top expect to have a healthy society, because people's needs aren't being met and it's not because of the staff, it's because of those people on the board and the money and what it does. It affects people like me right down to the bed. God you write letters but I never post them in. (Carrie, lines 1113-1119.)

Safety is an important issue, without which people's physical and emotional well being is jeopardized as is apparent from the participants' stories.

5.5 Summary

When participants speak overall about their experiences in the ward in general, they speak very highly of the care and attention they received. However on closer examination, most participants discuss experiences that suggest their experiences of acute hospitalization were much less than desirable. Many of the

situations described are incidents where a nurse could have made a difference and didn't. Participants are mostly ready to make excuses for the care (or lack of care) they experienced. Perhaps the reason for this was the fact that they all knew I was a nurse educator. Maybe participants made excuses and accepted the less than desirable experiences because they were aware of the shortages of staff and the under resourcing of the hospitals in New Zealand at this time.

The first theme discussed in relation to the ward experience, was the need for information. Comments made by the participants about their experience of being hospitalized suddenly and the need to be informed indicate that being informed is an important consideration when a patient. The second theme of support was discussed within the subthemes of support from health professionals and support from family and friends. All participants had issues to relate relevant to the theme of support. Environmental issues were discussed under the three subthemes of the physical environment, privacy and safety. It is apparent how these issues impact on the participants' physical and emotional wellbeing.

Once people had recovered enough to leave the ward, the desire to get back to normal everyday life was apparent, with most of the participants expressing an eagerness to go home. Needing to know became more of an issue on discharge than it did in the ward.

6.0 Discharge

6.1 Introduction

Studies have shown that both hospitals and patients benefit from facilitating the transition out of hospital (Cunningham, 1981; Kennedy, Neidlinger & Scroggins, 1987; Schwatz, Blumfield & Simon, 1990). The evidence suggests that such benefits include the following: Improved patient outcomes (Kennedy, Neidlinger & Scroggins, 1987), increased patient satisfaction (Schwatz, Blumfield & Simon, 1990), decreased length of hospital stay (Cunningham, 1981), fewer hospital readmissions (Naylor, 1990), enhanced cost effectiveness (Safran & Phillips, 1989; Weinberger, Smith, Katz & Moore, 1988) and lower mortality (Ellers & Walker, 1993). Despite the evidence of the benefits of discharge planning, there were issues surrounding discharge that affected some participants in the present study, that would suggest the need for greater facilitation with the transition out of hospital.

Information (or the lack of it) is the predominant theme surrounding the time when participants were getting ready to go home. Most expressed satisfaction at the amount of information given before discharge, but several issues became apparent on closer investigation. Frances received conflicting information and was still unclear about the cause of her medical problem. Two participants considered they were ready to go home before being given the okay and this caused some anxiety for Danny because she had a young family depending on her. An omission in his medication on discharge meant a second acute hospitalization for James. Lack of information has been shown to be the most influencing factor in communication breakdown and patients' dissatisfaction in hospital (Fareed, 1996).

6.2 Lack of information

Frances was confused about the information she was given prior to discharge because the information she was given was conflicting. She states that initially she was well informed.

I felt like I was well informed though because the guy who'd seen me at A & E originally, the surgical registrar, came and told me before I got discharged, he drew a little diagram and showed me what was going on and talked about this idea of a functional obstruction. So he was cool, I really liked him and I felt like I went home with all the knowledge effectively. (Frances, lines 790-795).

However Frances then described two different situations where she wasn't informed. Firstly Frances described how upset she was to learn that she was to wear a bag home which would collect her urine. The nurse looking after her annoyed her by telling her that the bag was normal and lots of people have them. Wearing a bag, which collected her urine, wasn't normal for Frances.

See what was happening was that I had a wedding to go to that Saturday afternoon and actually that was another of the reasons why I was so upset earlier on was because this nurse said, "Oh no I don't think you'll be out of here by then." I was really annoyed. I didn't even know then that I was still going to have this bag when I left. Because the nurse said, "They're very normal, people go home with them" and I said, "Yeah, that's not going to happen to me." (Frances, lines 814-820).

Frances articulated the confusion she experienced over being told one thing by one doctor and something quite different by another. The physician said the blockage in her kidney was caused by inflammation and then when she was referred to the surgical team,

they said the problem was congenital. In the end she still doesn't know whom to believe nor what caused her illness. *'I'm still getting told different things.'* (Frances, line 474).

Well it annoys me a little bit that I still don't really know the situation because continually throughout the whole time I was getting told one thing by the house surgeon and another by the consultant. So I wasn't very happy about that actually. (Frances, lines 949-959).

Jack was transferred to one of the assessment and rehabilitation areas before discharge, but was not told why or what to expect.

And this part I went to was the rehabilitation, and when they get you down there they don't look after you. They're trying to make you do as much as you can for yourself including if you're able to walk up to the tea room and have your lunch and walk back again so they... because I went crook about the bloody place... I reckon they didn't do enough... So they sent a nurse along to explain it to me and when she explained it to me I understood then what they did. They're not there to look after and fuss over you, they're there to see what you can do and get you to do it on your own if possible. (Jack, lines 607-618).

Jack felt that he was ready and would have liked to have gone home earlier than he did, but he accepted the doctors' suggestion.

Oh I could have come home, I could have come home two days before I did. I told them that but they wouldn't let me go home in the weekend but I said to them, "You can't do any more for me," because I know they can't. So, "No" they said, "You're staying here over the weekend till we have another

look at you on Monday.” So that was okay. (Jack, lines 635-639).

Danny however became very frustrated because she wanted to go home to her family and was expected to wait for the results of the investigations she had had before being given the all clear to go. Expecting to be discharged, she was upset to learn when she asked one of the nurses later that evening after waiting all day, that the doctor wanted her to stay in. No one had told her.

... and they asked me when I wanted to go home and I said, “Well as soon as possible” and they said, “Okay, well when your blood tests come we’ll let you know.” And so I was presuming that they would send me out, get me out as fast as they could so I sort of spent the rest of the day wandering around and came back in, oh went out for a smoke, came back in about 5.30 and asked the nurse if the discharge forms had come yet and she goes, “No actually he’s asked for you to stay for another night.” I went, “No I can’t do that, I’ve got kids,” and it’s just too stressful when you’re not really, really ill. All I wanted to do was get home and go to my bed. (Danny, lines 125-133).

Not all participants were as eager as Danny to go home. When asked how he felt when he was told he could go home following hospitalization due to a myocardial infarction, James says,

Well it’s funny you should ask that, initially when the doctor said, “We’ll discharge you tomorrow,” you know and I can’t understand why and I never tried to fathom it out either, I felt a small tinge of regret. I think it’s because you feel safe in there. (James, lines 327-330).

Information was scarce at a time when participants needed to be given clear information so they had confidence in their ability to cope at home following a period of significant ill-health. It is significant that almost half of the twelve participants were readmitted within a few weeks of their first admission, all with conditions that directly related to their first admission. Readmissions to hospital account for a significant number of all hospital admissions. Early discharge and inadequate care both during and after hospitalization are among the causes cited by Kee & Borchers (1998) for readmissions. According to Astedt-Kurki & Haggman-Laitila (1992) patients expect to be informed and prepared for caring for themselves at home. This was not the experience of some of the participants in this study.

6.3 Post discharge

As they did with the preadmission experience, some participants continued to detail their experiences once home from hospital, despite the fact that I had explained to them that I was interested in their first time experience of hospitalization for an acute illness. It is not clear to me why participants continued to describe what their experiences post discharge were. It is possible that they consider these experiences part of the whole experience of hospitalization. Considering that almost half of the participants in this study were readmitted shortly after their first admission, it appears that the experience of ill health did continue after discharge.

James was readmitted within two weeks of discharge and found this experience more disturbing than the first because of the possibility that ill health requiring hospitalization was going to reoccur. James was happy about the amount and content of the information he received when he was discharged. *'Oh yes, yes. Verbal, pamphlets and what have you.'* (James, line 335). However he developed congestive heart failure shortly after discharge. He believes this was because of an omission on his discharge

prescription meaning that he didn't receive all the medication he should have.

Yes the doctor was quite honest about that, he's not saying that's why I was admitted but he certainly, it went a long way towards causing what happened. And the second time [admission] I think was more frightening than the first because I was starting to think, "Is this going to go on every two weeks?" (James, lines 353-356).

Colleen actively sought further information from the Public Health Department post discharge in order to gain more information about her diagnosis. Whilst Colleen received adequate information about what to do and what to avoid on discharge, she received no information about what had caused the campylobacter that necessitated her sudden admission to hospital.

The Public Health Department were of course notified and they in turn sent me several forms which I had to fill in, and when I felt a little better I was given another week off work by the doctor at the hospital, and during the course of that week I went down to the Public Health Department myself because I knew staff there and he explained a little more about it. (Colleen, lines 350-354).

The two oldest participants, Yvonne and Jack, were both discharged with very little ongoing support. Yvonne lived alone and couldn't manage at home because she was unable to walk. Apparently the district nurses and home help were available, but she also had to have someone to be with her constantly because she couldn't manage.

I didn't get the home help for about a week later or the meals on wheels till a few days later but I had some good friends. I

had to get Bonnie to come and stay with me at night and Marlene, she came during the day and so did Jill because I couldn't be left, I was so ill. (Yvonne, lines 352-356).

Yvonne ended up being readmitted to hospital because she couldn't manage at home alone despite the support of her friends.

Jack, frail and with a severely compromised respiratory system, had an elderly wife who had been unwell whilst he was in hospital. He was discharged without any community support services in place. Jack's wife was concerned and mentioned that she wouldn't be able to cope with his hygiene cares on her own. *'I don't know how we're going to do that because I couldn't manage to shower Jack.'* (Jack, lines 495-496). Neither Jack nor his wife were aware that the district nursing service was available to them.

Danny remained unclear as to her diagnosis, despite endless blood tests and examinations. She gathered that even the doctors weren't sure, but she would just like them to tell her something, even if it was what they were looking for. In hindsight, Danny declared that if there was a next time she would be doing a lot more questioning of the doctors. *'I'd say, "Okay what's wrong this time, tell me, I want to know everything?"'* (Danny, line 763.)

Whilst Kyle was in hospital he believed that he had angina caused by a blocked artery secondary to high cholesterol. However it wasn't until Kyle had a cardiac catheterization two weeks post discharge that he was told that his arteries were clear. He had gone home armed with facts on a correct diet, prepared to make lifestyle changes, when in fact his underlying problem was apparently pericarditis.

After the catheterization showed there was no significant blockage of the arteries the consultant cardiologist said,

"We've eliminated everything else, therefore it must be pericarditis." And that is not a confidence inspiring way to deliver a diagnosis. But by default that's the official version. (Kyle, lines 357-360).

Kyle received no information at all about pericarditis.

I didn't know anything at all about pericarditis. It was a case of consulting books but whenever you get something you've never heard of and start talking about it you always find people who've had it or know someone who has. (Kyle, lines 372-375).

It wasn't until Kyle met up with someone from his work that he became more informed. What Kyle wanted to know was how long it would be before he would feel one hundred percent again. He needed to know when he would feel up to returning to work, what effect this pericarditis would have on his lifestyle, whether his heart would be damaged and what the chances were of this debilitating illness returning. None of this was forthcoming. Kyle still doesn't know.

But here we are seven months and while definitely better than I was, I'm definitely not right and last time I saw my general practitioner he said, "I would like to know more about the reasons which led to this diagnosis," which in my opinion means he was being discreetly professional and saying, "I don't think he (the cardiologist) knew what the hell he was talking about." That's how it came across to me. (Kyle, lines 380-384).

Hospitalization can precipitate an emotional crisis for patients and their families (Ellers & Walker, 1993). Returning home may result in concerns about one's illness, disability, loss of control and

dependency. Patients may fear that they may have difficulty resuming a “normal” life-style. Because of the nature of the illness, which precipitated their admission to hospital, some of the participants in this study will not be able to resume a “normal” life-style. This is the reality of many patients admitted to hospital with acute conditions that have long term effects.

6.4 Summary

The time of discharge appeared to be a time of conflict for some of the participants. There was the conflict that James expressed about being pleased that he was well enough to go home, and yet not really wanting to go because he felt safe in the hospital. Jack and Danny however both felt they were ready to go home before the doctor said they could be discharged. Frances wasn't clear as to the reason for her illness because of the conflicting opinions of the consultants.

Whilst discharge appeared to be a time of conflict for some of the participants, post discharge appeared to be a time of confusion. Neither Colleen, Yvonne, Danny or Kyle were clear about their diagnoses. Yvonne and Jack were not wholly clear as to whether ongoing support for them had been arranged. Danny had been told she could go home earlier in the day by the doctor and was then told by a nurse later that day that she couldn't go home.

It appears that whilst in hospital participants are mostly contented with the support and the information they receive from health professionals. However on discharge and then post discharge, support and information are obviously lacking.

In the next section I will conclude by summarizing the experiences of the twelve participants involved in this study.

7.0 Implications for nursing

7.1 Introduction

The final chapter of this thesis summarizes the twelve participants' experiences of first time hospitalization for an acute illness. Following an introduction to the next section, I outline the implications for nursing under the subheadings of practice, education and research. A conclusion will finish this chapter.

7.2 Summary of experience

In concluding this thesis I wish to bring to some closure the questions posed in the introductory chapter and addressed in the subsequent chapters. These questions evolved over the course of the two and a half years that the study took to complete.

- What do patients experiencing hospitalization for the first time for an acute illness have to say?
- How does the hospital environment affect the individual patient in their struggle with the anxiety-provoking situation that first time hospitalization for an acute illness creates?
- What are their concerns with and experiences of hospitalization?
- How should the knowledge of the participants' experiences of hospitalization influence professional practice?

While the experiences of Jack, Frances, Danny, Carrie, John, Kyle, James, Alan, Elinor, Jacqueline, Yvonne and Colleen are the unique stories of each individual, and must be respected as such, they could also potentially represent examples of the experiences of thousands of New Zealand men and women experiencing their first time hospitalization for an acute illness. Understanding what the participants were going through at the time is essential to understanding the process. Three major circumstances affect their experience. Firstly their health was so compromised that they needed specialist treatment in a hospital. Second they were

separated from familiar lives and life-styles. And thirdly, they were faced with adjusting to hospitalization with its frightening connotations at a time when they did not have all their personal resources intact to aid them in this adjustment. Being a patient can mean being vulnerable, experiencing disturbed sleep, discomfort, lack of privacy, loneliness, fear, being confined or restricted, being in unfamiliar surroundings, feeling powerless and or being deprived of choices in many aspects of daily living. These experiences have all been demonstrated in this study.

The themes that developed from the participants' stories are common, to a greater or lesser degree, for all people who have experienced hospitalization for an acute illness. Some of the impressions that these patients had of the hospital may have developed long before their admission. If they read the paper or listened to the news on television they would have learned about the high cost of hospitalization, the shortage of skilled nursing personnel and widely publicized errors in care and cure procedures. Some of their friends may have exposed them to stories about their more traumatic experiences during hospitalization. Some may have experienced supporting a family member through their first hospitalization.

By reflecting on Jack, Frances, Danny, Carrie, John, Kyle, James, Alan, Elinor, Jacqueline, Yvonne and Colleen's experiences, this chapter summarizes briefly how these patients experienced their first hospitalization. I then address the bigger question of where to from here? What can we learn from these examples?

7.2.1 Preadmission and accident and emergency.

The time leading up to admission was an active period where participants knew something was wrong with their health, but they weren't always certain what it was that was wrong. Some participants actively sought help from their doctor, or their friends or

a family member rang for an ambulance. This active time demonstrated in chapter four, contrasted with the passively self-focused time spent waiting in the Accident and Emergency department.

7.2.2 The Ward

There were a variety of experiences described by the participants once they reached the ward setting. It is interesting that participants speak highly of the *overall* care and attention they receive, but when they describe their experiences in *detail*, most participants (but not all) had less than satisfactory care and attention. Some experiences in the ward I would describe as traumatic. According to Dewar (1995), there is immense social pressure on the individual to bear the profound life changes that result from disease, injury and the ordeal of treatments. Most individuals find that there is a limit to their endurance. Colleen in particular articulated a situation where she was unable to cope any longer and could have done with the support and assistance of the nursing staff.

Chapter five 'The Ward' describes a more active time when participants felt able to ask questions because they needed to know what was going on. What patients want to know, is not necessarily what they're told. According to Gadow (1995), when patients lack explanation, illness becomes a situation of 'limitless vulnerability' (p. 27). The need for information was the first theme considered in chapter five. The second theme considered was support. Firstly support from health professionals and secondly support from family and friends. Several times participants articulated their awareness of how busy the nurses were which meant that they were more than a little reluctant to bother them with their discomfort in situations where a nurse could have easily made a difference. The importance of support from health professionals was strongly emphasized by all the participants. This support was not always easy to access and

some situations that participants found themselves in, which were due to the inconsideration of a staff member, left them feeling vulnerable and powerless.

There were varying comments about the support of family and friends, most of the participants acknowledging their importance at a time of extreme stress. However some of the participants also felt that some visitors (usually friends) imposed more stress when they (the participants) were acutely unwell.

Environmental issues was the third theme apparent from the participants' stories of the time they experienced in the ward. This was addressed within three subthemes; the physical environment, privacy and safety. Participants described problems with sleeping because of the noise, concerns about the lack of hygiene and a cold environment temperature wise. The lack of privacy participants experienced was an issue for some but not all the participants. Often the concern wasn't only for themselves, it was for the other patients in the room they were in. It must be acknowledged that with only curtains between each bed, privacy, especially auditory privacy, is very difficult to maintain. Not feeling safe was an issue for three of the participants and this is the last subtheme within the theme of environmental issues.

7.2.3 Discharge and post discharge

It cannot be cost effective practice if people are readmitted because they were not ready to be discharged in the first instance. According to Kee & Borchers (1998), hospital readmissions account for 22% to 37% of all hospital admissions for older people. Whilst not all the participants in this study who required a second admission were elderly, five out of twelve readmissions are significant. Discharge planning involves the coordination of services and resources, patient education, provision of care, consultation with other disciplines and with the patient, family and friends. It is

easy for the experiences of one individual presenting with a problem to be discounted.

As discussed in chapter six, patients may not know what to expect and are reliant upon health professionals to take their problem seriously and to provide the necessary information. They may be in a very vulnerable and dependent position. This was certainly the experience of some of the participants on discharge and post discharge. It appears for those five participants who required a second admission, that support and information are just as important on first admission as it is on subsequent admissions.

7.3 Implications for practice, education and research.

In undertaking this study I wanted to hear some of the stories of people experiencing their first hospitalization. I do not need to refer to my journal to remember how shocked and disturbed I was at some of the information I received and how disappointed I felt as a health professional for the large gaps in the care that people received. For example Yvonne was appalled at the dirty state of the ward she was in. She even had to wash out her locker and wardrobe before she used it, because it was grubby. She felt the hospital was a cold place. I have heard these comments before. Danny and Frances' terrible experience when their consultants marched into their room, pulled the curtains and examined them without a word being said, accentuated how vulnerable patients really are. Common courtesy would indicate that one should at the very least greet the patient. Respecting privacy is a fundamental principle of practice and much of what all health professionals do when they help patients is done in the context of the need to protect privacy among other things. No one should be examined in any context by a person or persons when they have no idea who that person is. If health professionals developed and practiced a philosophy of practice of 'doing unto others as they would have done unto them' many of these problems of practice might better be

avoided. I felt for Alan as he struggled with the frustrating memories of those preadmission days trying to make himself heard. Knowing that he had something physical going on in his head, he was instead diagnosed with depression and sent to a psychiatrist.

I did also however experience some moments of pride and satisfaction. It was a nurse who helped turn Colleen's fear and depression at her lack of progress around. All the nurse did was acknowledge quietly that Colleen was low today. Danny admitted that despite being run off their feet, the nurses were always there. All these patients had potentially life threatening conditions and they all except Jack (who passed away at home in April 2000) have survived.

7.3.1 Practice

Research findings indicate that the patient's perception of quality care is related to interpersonal relationships and suggest that personal interaction between caregivers and patients significantly influence patient satisfaction (Cleary, Edgman-Levitan, McMullen & Delbanco, 1989; Fosbinder, 1994; Irurita, 1999). The relationship that health professionals have with a hospitalized patient is context related and situational. It is unlike a 'normal' social relationship because it is formed during a time when the patient is undergoing, what Newman (1986) has described as, one of the most stressful personal experiences in technological society. In acute care settings it is the health professional-patient relationship based upon two things; the patient's vulnerability, and the patient's partial or complete dependence on someone for help with events which in everyday lives, people do for themselves. Nurses know that patients are vulnerable, that they are in unfamiliar surroundings, and that they may know little of what lies ahead for them especially when the admission is for the first time. Nurses understand patients may be facing an uncertain or unwanted diagnosis, or that they may be ignorant of what hospitalization means for them. Nurses

need to be better able to advocate for the patient when the patient is unable to advocate for him or herself for whatever reason.

Many of the participants in this study commented about the busyness of the nurses in particular. Tagliacozzo (1965) found in her study, that the willingness of the patient to be 'good' was motivated partly by gratitude and admiration for the 'overworked and rushed' nurse and physician. These attitudes express the insecurity that restrains the uninitiated lay person in their relationships with health professional personnel (p.223).

Williams & Irurita (1998) demonstrate in their study that the overriding contextual condition needed for relationship development between nurses and patients is the availability of adequate time. Reductions in the time available for nursing care delivery may adversely influence the development of nurse-patient relationships. Within the current health environment it is important that skills be imparted to nurses to promote relationship development within the context of limited time, and that strategies be implemented that facilitate continuity of contact between specific nurses and specific patients in order to provide continuity of care.

Patients' experiences can best be appreciated through a changing mindset of health professionals who are willing to meet patients as partners. Such partnerships recognize peoples as individuals with individual needs and problems.

7.3.2. Education

Patient's wishes for information and teaching have frequently been identified and lack of information is a common source of complaints (Ellers, 1993; Webb, 1995; Wilson-Barnett, 1983). According to English & Morse (1988), the greater the amount of information communicated to the patient, the greater is the patient's power to control his or her own care. Irurita (1999) suggests that when

patients perceive or actually have control over their experience that this helps them interpret their situation as less threatening.

Educating patients from the moment of admission as to what to expect from hospitalization must be seen as important. Patients often assume that the nursing staff are too busy to answer their 'foolish questions.' The participants in this study mostly reported a satisfaction with the explanations they received when they asked questions in the ward setting, but information has been identified as lacking particularly at the time of discharge. This is a time in a busy acute setting where another patient is often waiting for the bed and therefore patients feel they need to leave as quickly as possible. Danny articulated well how much of a fraud she felt because the nurses were so busy. She just wanted to go home to her family. Unless patients have been carefully told what to expect, medications explained and written out clearly, adequate and appropriate support put in place and when to get help should they have any concerns specified, then patients are not properly prepared for going home after an acute first time admission and may end up being readmitted.

In regard to the implications of this study for the education of nurses, I see it as essential that nurse educators facilitate student nurses' understanding not only of the patients' perception of the meaning of the experience of illness, but also of hospitalization. Hospitalization for an acute illness is a very significant event in anyone's life and first time hospitalization is so much more so. The importance of discharge planning as a necessary part of patient care also needs to be focused on in nurse education.

7.3.3 Research

As well as providing a basis for further research, these findings should increase our understanding of the experience of being a patient. Furthermore they could prove to be useful for assessing the

nursing needs of patients with the view of reducing their vulnerability and improving the quality of nursing care. One specific future research need is for a comparative study between first and subsequent admissions in order to further explicate the specialized needs of first time patients. Another future research need is in regard to discharge planning, especially for the elderly patient. What is it that patients want and need to have in place before they go home? How can the transition period between hospital and home be facilitated in order to avoid future readmissions?

7.5 Conclusion

Having personally been hospitalized for an acute illness, I was more than aware of the profound affect of first time hospitalization on one. However not all health professionals experience hospitalization. Health professionals in general need to listen very carefully to the patient's perspective of every aspect of their hospitalization. I believe nurses are often well placed to be advocates on behalf of patients. Often nurses are more accessible and approachable and have a field of vision that includes the importance of the whole person and quality of life issues. All nurses need to be good role models of the nurse as advocate to our future nurses, our nursing students.

The response from the participants in this study suggest that they expect nurses to be responsible for seeing that their needs are met not only during hospitalization but also in preparation for resuming their lives outside the hospital. In addition, they also expect nurses to have personal qualities that enable them to be caring as well as proficient and professional.

Very little nursing literature has been written from the patient's perspective, about the experience of hospitalization for an acute illness and none from the perspective of the *first time* patient admitted for an acute illness. This study will contribute to nurses'

understanding of the acute hospitalization experience. Hopefully a deeper understanding of the experience of hospitalization will better enable nurses to journey with and support their patients during this often stressful time. As patients clarify their perceptions of their situation they are hopefully deemed better placed to select courses of action to enhance their future lives. Aware of this, nurses will then be able to better assist individuals towards meeting their goals.

**Invitation to take part in a study of
patients' experience of first hospitalization for an acute illness.**

Dear

You have been given this letter on your discharge from Ward 8a at Dunedin Hospital because you now know what it is like to be hospitalized for the first time with a sudden illness. I would like to invite you to consider taking part in some research I am doing that aims to describe patients' experience of their first hospitalization for an acute illness.

This research is part of my studies for a Masters Degree in Nursing from the School of Health Sciences at Massey University. I am a Registered Nurse employed as a lecturer at Otago Polytechnic. The study should help nurses and other health professionals understand and meet patient's needs.

The research would involve taking part in an audio taped interview with me about your first experience of being in hospital. The interview would take between an hour and an hour and a half. I may also have to contact you a second time to clarify information from the first interview. The results of this study may help health professional learn about the needs of people in hospital.

If you think you might want to take part in this research and would some more information, please contact me at home (03) 456-2411.

Yours sincerely,

Colette Blockley RGON BA (Nursing)
Masters Student
School of Health Science
Massey University

244 South Road
Caversham
DUNEDIN

17 February 1999

Ethics Committee Otago
PO Box 5849
DUNEDIN

Re: 98/11/089. An exploratory descriptive study of patient's experience of their first hospitalisation for an acute illness.

Dear Committee members

Due to a number of difficulties in dissemination of the letter of invitation to potential participants, I am requesting approval of a change in the method of recruiting participants.

Initially I had intended that the ward receptionist would give the letter of invitation to patients on discharge and she was quite happy to do this. Unfortunately she forgot for the first two weeks. She is now on annual leave for four weeks. I am due to recommence work as a nursing lecturer on 23 February in the identified ward and am concerned that there may be a conflict of interest once I am in the ward again.

In order to overcome this, I seek approval to place an advertisement in the local newspaper, inviting people who have been hospitalised in an acute medical ward to contact me in order to share their 'experiences of first time hospitalisation.'

The advertisement would read as follows:

Do you now know what it is like to be hospitalised for the first time with a sudden illness. Colette Blockley would like to invite you to consider taking part in some research she is doing that aims to describe patients' experience of their first hospitalisation for an acute illness.

This research is part of Colette's studies for a Masters Degree in Nursing from the School of Health Sciences at Massey University. Colette is a Registered Nurse employed as a lecturer at Otago Polytechnic. The study should help nurses and other health professionals understand and meet the patient's needs.

The research would involve taking part in an audio taped interview with Colette about your first experience of being in hospital. The interview would take between an hour and an hour and a half. She may also have to contact you a second time to clarify information from the first interview. The results of this study may help health professionals learn about the needs of people in hospital.

If you think you might want to take part in this research and would like some more information, please contact Colette at home (03) 456 2411 or at work (03) 479 6135.

I hope you will consider this request at your earliest convenience.

Yours sincerely

Colette Blockley

Information Sheet

Patients' experience of their first hospitalization for an acute illness.

Principal Investigator:

Colette Blockley, Lecturer, Otago Polytechnic, Dunedin. Phone: (03) 456-2411

Supervisors:

Professor Julie Boddy, Head of School, School of Health Sciences, Massey University, Palmerston North. Phone: (06) 350-4334

Paul Watson, Nursing Lecturer, School of Health Sciences, Massey University, Palmerston North. Phone: (06) 350-4326

Introduction:

You are invited to take part in this research that aims to describe patients' experience of their first hospitalization for an acute illness. The information in this sheet is designed to enable you to make an informed choice about whether you would like to take part in this study. You do not have to take part and if you choose not to this will not affect any future care or treatment.

About the study:

The study involves being interviewed about your experience of your first hospitalization for an acute illness. The interview will be organised at a place and time convenient to you. The interview will not follow set questions. The opening question will ask you to describe your experience of your first hospitalization. Any other questions will aim at exploring your experience further. You do not have to answer any question you do not want to. The interview will probably take between an hour and an hour and a half. A second shorter interview may be requested if the investigator needs to clarify any points from the

Information Sheet

Patients' experience of their first hospitalization for an acute illness.

first interview. The interview(s) will be recorded on a tape recorder. You have the right to ask for the tape to be turned off at any time during the interview. The recordings will be transcribed and then analysed for themes that describe the range and variety of the participant's experience. You will be given the opportunity to have a copy of the recording of your interview. You may wish to add or delete any information before the information is analysed.

Confidentiality:

No material that could personally identify you or anybody you mention in the interview will be used in any reports on this study. The only people that will have access to the interview tapes and transcripts are the principal investigator, her supervisors and a typist who will sign a confidentiality agreement. The investigator will keep the recording of the interview and the typed transcript in a locked filing cabinet for five years and then they will be destroyed.

What are the risks or inconveniences of the study?

There should be no risks involved in participating in this study, unless your experience of being in hospital was disturbing, in which case you might find talking about it difficult. You may also find talking about your experience beneficial. Taking part in the study will take up to two hours of your time. There should be no cost to you associated with taking part in the study and you will not receive any reimbursement.

What will happen after my interview?

If you would like a summary of the results of the study they will be made available to you. There will be a delay of at least twelve months between your interview and the completion of the study.

Information Sheet

3.

Patients' experience of their first hospitalization for an acute illness.

This study has received ethical approval from the Massey University Human Ethics Committee and the Otago Ethics Committee. If you have any queries or concerns about your rights as a participant in this study please don't hesitate to discuss these with the researcher, or her supervisors. You may wish to contact a Health and Disability Services Consumer Advocate in Otago; Phone (03) 479-0265.

If you wish to take part in this research, or would like more information, please contact me at work (03) 479-6135 or at home (03) 456-2411. You may also contact either of my supervisors regarding this research.

Dr. Julie Boddy, School of Health Sciences, Massey University.

Phone: (06) 350-4334

Paul Watson, School of Health Sciences, Massey University.

Phone: (06) 350-4326

Thank you for your interest in this project and for taking the time to read this information.

Yours sincerely

Colette Blockley

18 November 1998

Ms Colette BLOCKLEY
244 South Road
Caversham
DUNEDIN

Dear Colette

**Re: Human Ethics Application – MUHEC 98/201
"Patient's Experience of their first Hospitalisation for an Acute Illness"**

Thank you for your letter of 11 December 1998 and the amended Information Sheet and Consent Form.

The information you have given and the explanations you have provided now meet the requirements of the Massey University Human Ethics Committee and the ethics of your application are approved.

Yours sincerely



Professor Philip Dewe
Chairperson
Turitea, Palmerston North Campus
Massey University Human Ethics Committee

cc Professor Julie Boddy, Mr Paul Watson, School of Health Sciences - Turitea, Massey University

ETHICS COMMITTEE OTAGO

South Office
229 Moray Place
PO Box 5849
DUNEDIN
New Zealand
Telephone 03 477 4222
Facsimile 03 474 0080

14 December 1998

Ms C E Blockley
244 South Road
Caversham
DUNEDIN

Dear Ms Blockley

An exploratory descriptive study of patients' experience of their first hospitalisation for an acute illness

Investigators: CE Blockley, J Boddy

Protocol Number: 98/11/089

Thank you for your letter of 11 December 1998 enclosing amended Consent and Information forms and responding to the Committee's queries. The study has now been approved in full.

Approvals granted to protocols are for 12 months. If, after 12 months the study is not completed, it will be necessary to forward to the Committee a brief report on progress made to date and a request for an extension. Please quote the above protocol number in all correspondence relating to this study.

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

Please advise the Committee on the completion of the study or if, for any reason, you decide not to complete it. On completion of the study a brief report should be forwarded to the Committee.

Yours sincerely



Carol Algie
Ethics Committee Administrator

22 February 1999

Ms Colette BLOCKLEY
244 South Road
Caversham
DUNEDIN

Dear Colette

Re: Human Ethics Application – MUHEC 98/201
"Patient's Experience of their first Hospitalisation for an Acute Illness"

Thank you for your letter of 17 February 1999 regarding the change you wish to make to your already approved MUHEC application.

Attracting potential participants via an advertisement would meet the requirements of the MUHEC and this amendment to your application has been placed on your file.

Yours sincerely



Professor Philip J Dewe
Chairperson
Turitea, Palmerston North Campus
Massey University Human Ethics Committee

cc Professor Julie Boddy, Mr Paul Watson, School of Health Sciences - Turitea, Massey University

Consent Form

Study of patients' experience of their first hospitalization for an acute illness.

STATEMENT BY THE PARTICIPANT:

* I have read and I understand the information sheet dated.....for volunteers taking part in this study designed to describe the first time experience of being a patient in an acute medical ward. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

* I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my continuing or future health care.

* I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

* I understand that I have the right to ask for the tape recorder to be turned off at any time during the interview.

* I understand that I am free to decline to answer any question in the study.

* I have had time to consider whether to take part.

* I know whom to contact if I have any questions or concerns about this study.

* I would like the researcher to discuss the outcomes of the study with me. Yes / no

* I understand that this study has been approved by the Southern Regional Health Authority Ethics Committee (Otago) and the Massey University Human Ethics Committee.

* I(full name) hereby consent to take part in this study under the conditions set out on the information sheet, of which I have a copy.

Signed (Participant).....Date.....

Signed (Researcher).....Date.....

Project explained by researcher:

Colette Blockley, MA student Massey University, Palmerston North.

Contact phone number: work (03) 479-6135.

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