

NURSES AS PATIENTS:

**The stories of two woman nurse educators as recipients of nursing
care**

By

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ABSTRACT

In this research two nurse-patients have engaged in a conversation about their experience of 'being nursed'. The project sets out to address the following questions: How might our experiences as nurses who have been hospitalised be drawn upon to influence positive changes in nursing practice? What effect might our experiences of hospitalisation have on us as nurses and on our nursing practice?

The study utilises narrative as inquiry and the method of story telling and auto/biography to tell the stories of Maria (a pseudonym) and myself, the researcher. This interpretive research has been informed by the feminist process and sits within a postmodern framework. Maria's stories were audio taped and transcribed before being prepared for analysis using 'core story creation', and the process of 'emplotment' (Emden, 1998b). My reflective topical autobiographical narrative was constructed through the processes described by Johnstone (1999).

Three distinct qualities emerged from both of our experiences. The first, 'knowing as nurse-patient' contains the three sub themes of 'having knowledge', 'expectations of being nursed', and 'knowledge gained'. The second distinct quality 'being nursed' contains the two sub themes of 'feeling safe and cared for' and 'presencing'; and the third 'not being nursed' contains the four sub themes 'feeling vulnerable', 'invisibility of nurses', 'getting out' and 'feeling let down'. The sub theme 'getting out' includes three additional sub themes of 'wanting to get out and not wanting to be there', 'leaving and the need for closure' and 'not wanting to go back',

This study on nurse-patients receiving nursing care will be useful for nurse educators, students of nursing, and nurse clinicians. Nursing does make a difference to patient care. For patients to receive therapeutic care new graduate nurses must be preceptored/mentored by experienced nurses in supportive programmes. Suggestions for further research have been identified.

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CHAPTER ONE: The Focus & Context of this Research

Introduction

This thesis is about nursing practice, and in particular about nurses as patients receiving nursing care. At the beginning of this thesis, it was exploring new territory, as there was little evidence of recent research on this topic. However, since this project began, two Australian studies on nurses as patients receiving nursing care when hospitalised have become available (Williams, 1998a; Zeitz, 1999). The primary intent of this qualitative research project is to contribute to the existing knowledge on patient perceptions of nursing care, and in particular the perspective of 'nurse as patient'. The most likely immediate significance of this study will be in the explication of the experiences of two nurse educators admitted to hospital with life threatening illnesses in the New Zealand health setting and their insights on account of being 'knowing' consumers.

Background to the study

My research began with an event that made me very disillusioned and disheartened with nursing. I had given much time and thought to what it meant to be a good nurse and to how I could teach the important domains of caring in my education practice. The literature cites several writings on caring as a central component of nursing (Benner & Wrubel, 1989; Watson, 1995), and in my own studies I had begun to explore the meaning of caring in nursing. Yet I was not prepared for what I was to experience during the second of two hospital admissions. The first admission had been for elective surgery; the second occurred four days after discharge from the first and occurred because of complications from the surgical procedure. It was my experiences of being a patient in hospital on these two occasions that gave me the opportunity to explore the meaning of caring in nursing. In particular, the second hospitalisation gave me an inside look at nursing practice from the perspective of a sick person.

I was admitted to hospital having been on the waiting list for six months. I underwent what was described as straightforward surgery. My hospital stay was relatively uneventful and I was discharged after four days. I felt satisfied with the nursing care I received and gave the ward staff a box of chocolates in appreciation. Over the next 48 hours at home, I became ill and was eventually readmitted to hospital with complications of the surgery. It was this second hospitalisation, as a very sick person requiring intensive medical and nursing care over a fourteen-day period, which provided me with the impetus to do something with my experiences of being a nurse-patient. Throughout this admission, it was evident to me that the nursing care was not providing me with what I believed nursing to be, and what I thought I had worked hard in my practice to extol. I felt that my experience was misunderstood by nurses and even trivialised by some. I felt I was not nursed.

I considered myself to be a good nurse. I believed that I was able to provide patients with the care they needed. I have been a registered nurse for over twenty-five years, and for the last fourteen years I have worked as a nurse educator in two polytechnic nursing programmes and as a marker within a university undergraduate-nursing programme. My initial pre-registration nursing preparation was undertaken during the 1970s in a hospital setting. Further educational preparation occurred as a student in hospital and polytechnic programmes and university. My practice experience includes a variety of placements in acute medical-surgical nursing and practice nursing. I have taught on topics related to medical-surgical nursing, ethical-legal issues in nursing practice, nursing knowledge and research. I have held administrative positions in nursing education, firstly, as a research co-ordinator, and more recently as a clinical co-ordinator in a tertiary education institute. In recent years my philosophy and perspective of nursing has been simultaneously stimulated by being a nurse working 'outside' the work on the ward, but 'inside' nursing practice as an educator-clinician.

During my early years in nursing education when I worked alongside students in the clinical area, I felt I was able to role model some of the attributes of being a 'good nurse'. In latter years, as the role and expectations of the nurse educator has

changed, this aspect of our role is more difficult to achieve. Role modelling has now become the domain of the nurse practitioners with whom the students work more closely. However, over the past ten years in New Zealand, particularly since the health reforms of the 1990s, experienced nurses have been leaving the acute care setting to seek other work opportunities. From my observation and experience, and dialogue with colleagues, nursing students of the 1990-2000 era have only limited opportunity with experienced nurses as their role models. This task has now been left to the more recent nursing graduates who are finding their own place in nursing, and the health care system.

Like most people, when I became ill and ended up in a hospital bed, I felt as if I had been invaded by some alien thing with little relation to the real me. I was shocked when serious illness reached into me, just 48 hours after discharge from straightforward elective surgery. I had contemplated a comfortable convalescence period before returning to my position as a nurse educator. Life threatening complications of the surgery seemed to plunge me into an altered state, a separate reality that despite my years of nursing, was as unfamiliar as anything I had come across. My reality at the time, as I shared my illness with colleagues, was that of a nurse recounting someone else's story.

At the time, I considered myself knowledgeable about the realms of nursing, and the requirements of hospitalised patients. As an experienced nurse educator and family member of health consumers, I could teach the holistic elements of nursing practice. I understood - or thought I did - what was required for students to know about nursing patients undergoing surgical procedures. But now that I was a patient, I began to question my own practices as a nurse, and as an educator. Now that I was a sick patient requiring nursing care, such knowledge was less evident in those involved in my care.

It took me many months to actually begin to write my story. Some time later I made notes and mapped out a framework on paper to recollect my thoughts. An initial literature search provided several descriptive accounts of nurses-patients'

experiences (Harrison, 1990; Ruiz, 1993; Sherrard, 1988). However, on reading the article by Ruiz on her experience as a nurse-patient, I realised why this process had taken so long. Ruiz (1993, p. 28) writes:

“The will to relate my experiences has been blocked for years by an intense feeling of shame, the possibility of being accused of exhibitionism, narcissism...”

As a nurse and nurse educator I am aware that through my experiences I would at times be exposing aspects of 'not being nursed'. I am saddened by my inability to recollect the positive experiences of 'being nursed' from my personal and family experiences. Why then do I feel the impulse to make this effort? It is because I have had time to reflect on my experiences. I now realise more than ever, that we must share what it is we do as nurses that makes a difference to patients. We must also listen to the stories of our patients. That is why I am choosing to tell my story of being a nurse-patient. I have chosen to give 'voice' to my story and the story of one other nurse-patient Maria so that the perspectives of patients and in particular nurse-patients receiving nursing care are told. I want to put a case forward, which will support the adage of 'nurses do make a difference to their patient's care'.

Patients' perceptions of care are often different from those of the nurses involved in their care; this has been demonstrated in the context of studies in pain, anxiety and comfort (Williamson, 1992). Nurses appear to have most difficulty when they have no area of shared experience while caring for patients in distress (Kapnoullas, 1988). While I am not suggesting nurses need to be patients to understand the experience of illness, research is necessary into the experience and perception of illness as felt by patients that can then be shared with nurses and students. Research that presents the stories of hospitalised nurses' meanings and understandings of being a patient may be a catalyst for more sensitive awareness of what 'being nursed' really means.

Aims of the study

At the time of my surgery, I was enrolled as a MA student at Victoria University of Wellington. After I was discharged from hospital I began to think about my final assignment, a research proposal. The topic evolved from my experiences as a nurse-patient. I began to consider how my experiences as a nurse-patient might be beneficial to the discipline and profession of nursing. I began to ask the following questions: How might my experiences and the experiences of other nurses who have been hospitalised be drawn upon to influence positive changes in nursing practice? What effect might our experiences of hospitalisation have on us as nurses and on our nursing practice? It is these questions that are addressed in my thesis.

Given the above, this research sets out to tell the stories of two nurse educators' experiences of receiving nursing care when admitted to hospital with a life threatening illness. This research incorporates my story as researcher-participant and that of Maria (a pseudonym). I will explicate these stories in relation to nursing practice in the mid 1990s in two different geographical areas in New Zealand. By telling our stories, I hope it will not only contribute to the existing knowledge on patients' perceptions of nursing care, but also add to the dearth of literature on nurses' stories of receiving nursing care. But first, I will discuss the context of New Zealand nursing and nursing education at the time that Maria and I were nurse-patients.

The context of nursing in New Zealand in the mid 1990s

Although human needs remain relatively stable, the context for the delivery of health services does not (Joel, 1985). During the 1990s when Maria and I were nurse-patients, major shifts occurred in the New Zealand health system due to the health reforms, budget cuts and changes in management ethos (NZNO, 1998). At this time nursing leadership was removed from positions of authority at the management level and thus the 'voice' of nurses became invisible. The disestablishment of nursing departments within our major hospitals meant that ongoing nursing education and training for nurses was limited.

The Employment Contracts Act (ECA) introduced in 1991, changed the terms and conditions of employment for many groups of workers, including nurses. The reality has been a greater casualisation of the nursing workforce and a lower morale in the workplace. There is no longer a national set of employment conditions, and pay rates for the same job differ according to where a nurse works. Many nurses lost leave provisions and weekend penal rates. In light of these changes the nursing profession has faced enormous barriers to the provision of a high standard of nursing service. Nurses continue to function in a system where the focus appears to be no longer on the patient as a person, but on the outcome to be achieved or the number of beds to be utilised. There is evidence to suggest that nurses are still feeling a sense of frustration at their inability to provide quality care to their patients because of the constraints they work within (Fletcher, 1997; Longdin, 2000). With the change of government late 1999 the ECA has now been repealed and replaced with the new Employment Relations Act 2000. The Act is said to provide a fairer industrial relations environment for workers. Time will tell whether it enables better pay and conditions for nurses.

Nursing education in New Zealand in the mid 1990s

Over the past 30 years the pre-registration education programme for nurses has undergone significant change. It has gone from a specialised hospital based course to a nursing degree taught in Polytechnics and Universities. The Education Amendment Act 1990 set down legislation that permitted degrees to be awarded by polytechnics. By 1995 all fifteen New Zealand polytechnics with nursing programmes were offering bachelor degrees in either nursing or health sciences.

Despite the changes in education there are still some unresolved issues regarding the preparedness of new graduates for the workplace (Ministry of Health, 1998). Clinical areas are faced with shortages of experienced nurses who, in turn, are having to deal with an increasing acuity of their own work with patients being discharged earlier. In an attempt to address some of these issues some hospitals now run orientation programmes with or without mentors or preceptors. New graduates as

well as nursing staff new to an area need such programmes to lessen the stress on the novice nurse and the ward staff.

The first formal evaluation of undergraduate nursing education since the mid 1980s is currently taking place in New Zealand (Nursing Council of New Zealand, 2000). While the focus of this project is on undergraduate nursing education that meets the health sector requirements in the future, it will not necessarily ensure that the caring needs of patients have priority. Three discussion papers have been circulated to stimulate debate and elicit feedback from nurses. The first two papers background trends and influences in the education and health sectors, and the third paper raise issues on the definition of the future nurse. The discussion papers suggest that as the context of nursing practice continues to change, nurses will need to be flexible and develop further business and technological skills. Caring is stated as being important, but it is suggested that the concept of caring may need to be redefined and enacted differently by the nurse of the future. The question is asked “Will nurses still be seen as the caring profession, or will a more generic health care worker assume this role in the future?” I believe that in Discussion paper 3 the project team have already reduced the concept of caring to mean aspects of personal care or the “hands on care” (Nursing Council of New Zealand, 2000, p. 16).

The three discussion papers reiterate that the nurse of the future will require advanced knowledge and practice skills in their chosen speciality area, and they will require a commitment to ongoing education and personal and professional development. However, nurses will need adequate funding and support to do this while maintaining work and family commitments and responsibilities. Discussion paper 2 outlines some of the challenges for the preparation of nurses in the future. It suggests that: nursing will need nurses who have the capacity to be proactive and critical thinkers, educators will be challenged further with the broadening scope of practice, and employers may take over learning with apprenticeship programmes (Nursing Council of New Zealand, 2000). However, the final discussion paper on ‘The preparation of the nurse of the future’ is not due to be released until late October 2000.

Overview of the study

I have organised the thesis into nine chapters. This first chapter provides the introduction and background. The literature on nurse-patients' perspectives of receiving nursing care is explored in chapter two. I begin by describing my search for anecdotal and research literature that reports the experiences of nurse-patients, and in particular that of nurses as recipients of nursing care. To consider this issue the findings from the literature have been organised into the following sections: what nurses learn from such experiences, whether nurses receive special treatment, and, nurses' experience of receiving nursing care.

In chapter three the non-nurse patients' perspective of receiving nursing care is examined. My initial search illuminated stories from both non-nurse patients and nurse-patients. I contemplated whether my stories as a nurse-patient could be different from that of a non-nurse patient. I made the decision to examine the perspectives of both the nurse-patient and the non-nurse patient receiving nursing care. The anecdotal and empirical evidence will be reviewed and critiqued. This chapter will focus on: hearing the patients' voice, factors involved in the nurse-patient relationship, patients' perceptions of their role, and the role of the nurse, caring nursing practice, and non-caring nursing practice.

In chapter four I begin with a critique of the traditional research paradigms. I then discuss this postmodern research project, which is informed by a feminist process. Secondly, I discuss narrative inquiry as a valuable qualitative research method. Central to narrative inquiry, is the potential for stories and narratives to understand the meanings people attribute to their lives. I include a discussion on how story telling has become an important part of my nursing and education practice. Thirdly, I discuss the suitability of narrative as inquiry in nursing research. As this research includes the weaving of the biographical story of one participant, and the autobiographical story of the researcher as participant, I then discuss auto/biography as a research method. Fourthly, I discuss issues of rigour in narrative as inquiry.

In chapter five I discuss how the various components of the methodology have come together to inform the research method for my thesis. I then discuss the issues involved with being a researcher-participant and the selection and relationship between Maria, the other participant and myself. Issues concerned with the right to be fully informed, and the right to the protection of identity and confidentiality will be presented next. My initial plan to use electronic mail (e-mail) as a data collection method will be discussed; and the subsequent method of collecting Maria's stories by audiotape is addressed. Last, I describe the process of weaving together the biographical narrative of Maria, and my reflective topical autobiography.

In chapter six and seven I present our biographical and autobiographical narratives. In chapter six, Maria's biographical narrative of being a nurse-patient receiving nursing care will be told in two parts. In the first part, I present her story of undergoing elective surgery that resulted in major complications and an extended hospital admission. In the second part, I present her story of receiving nursing care during this re-admission to hospital. Maria describes these experiences, which took place over a six-week period, as "shaking her perceptions of therapeutic care". In chapter seven, I present my reflective topical autobiographical narrative of receiving nursing care during my initial admission to hospital for elective surgery and subsequent admission with a life threatening illness.

In chapter eight, the biographical narrative of Maria, and my autobiographical narrative will be represented as one narrative on nurse-patients receiving nursing care. When our narratives, and the literature on nurse-patients and non-nurse patients are compared, three distinct qualities of our experience emerge. The first quality 'knowing as nurse-patient' contains three sub themes; 'having knowledge', 'expectations of being nursed', and 'knowledge gained'. The second distinct quality, 'being nursed', contains two sub themes; 'feeling safe and cared for', and 'presencing', and the third distinct quality, 'not being nursed' contains four sub themes; 'feeling vulnerable', 'invisibility of nurses', 'getting out' which contains three further sub themes of 'wanting to get out and not wanting to be there', 'leaving

the hospital and the need for closure’, and ‘not wanting to go back to hospital’. The final sub theme within the distinct quality ‘not being nursed’ is ‘feeling let down’.

And finally, in chapter nine I revisit the questions posed at the beginning: How might my experience and the experiences of one other nurse who has been hospitalised be drawn upon to influence positive changes in nursing practice? What effect might our experiences of hospitalisation have on us as nurses and on our nursing practice? In the discussion, I also reflect on narrative as my choice of research methodology, and I suggest some implications for nursing, and nursing education. I also suggest ideas for further research on the topic of nurse-patients. But to begin, what does the literature have to say about nurse-patients receiving nursing care?

CHAPTER TWO: The Nurse as Patient

Introduction

The aim of this chapter is to review the literature available on nurses as patients, and in particular, on nurses receiving nursing care. In 1996, I had the opportunity to view the health care system from the patient's perspective. Suddenly, becoming a patient with a life threatening illness made me reflect and analyse nursing practice differently. Prior to my initial admission for elective surgery and subsequent admission as a sick person, I would not have contemplated the disillusionment and despair I would have to work through in relation to my life's work of nursing. Being the 'nurse-patient' and a recipient of nursing care in an acute care setting stimulated my curiosity in this topic.

I conducted several literature searches over an eighteen month period primarily using the electronic database CINAHL (Cumulative Index to Nursing & Allied Health Literature) which revealed that the topic of 'nurses as patients' has received some attention from the international nursing community in the form of anecdotal reports (A. Allen, 1995; C. Allen, 1993; Edwards, 1994; Evans, 1995; Jaffray, 1995; LaBorde, 1996; McKenna, 1995; Ruiz, 1993; Shriver, 1995). However, at the time of searching, only one New Zealand anecdotal report was located (Sherrard, 1988). In her article titled: *Care that wasn't given*, Sherrard, a nurse academic, comments on the experience of her daughter, a newly registered nurse, who became permanently disabled after a tragic accident.

In addition to these searches, my research topic was posted on two Internet nursing bulletin boards in 1997 - NZNURSE, and the Nursing Resource homepage. Of the three responses received, all expressed an interest in my topic but did not offer any further information. In 1998 following these limited responses, I posted my topic on two further international bulletin boards on the Internet - Nursenet and Nurseres. This search revealed much more interest in the topic of nurses as patients at an anecdotal level, and supported my earlier contention that the topic has received some

attention from the international nursing community. However, one response indicated that the topic of 'nurses as patients' has recently been studied by an Australian nurse and presented at a conference. I subsequently made contact with her and was sent the abstract for the conference, and a paper she had submitted for publication (Zeitz, 1999). Her hermeneutic-phenomenological study exploring the experiences of nurses receiving nursing care was completed for a Masters in Nursing. I shall refer to this study in more detail later in the chapter.

Two reports on American surveys focusing on nurses as patients (Gillies, Child, & Biordi, 1993; Morris & Mendias, 1985) were also located and have contributed to this review. More recently I came across a research report by another Australian nurse (Williams, 1997). Her qualitative study, informed by critical theory, explored the experiences of female nurses as patients, and in particular how they viewed their bodies. When I made contact with her, I was referred to further work from this study that focuses on power relations between the nurse-patient and the nurse providing care (Williams, 1998a; 1998b). Her work has also contributed to this review of the literature.

A collection of literature was found reporting the narratives of non-nurse patients and their experiences of being in hospital (Edelstein & Baider, 1982; Irurita, 1996; Jacobs, 1998; Parkes, 1993; Sacks, 1993). They have been published in nursing, medical and consumer journals. These will be discussed in the next chapter. However, I will begin with a review of the literature that reports the experiences of nurses as patients, and in particular that of nurses as recipients of nursing care. To consider this issue, the findings from the literature are organised into the following sections: what nurses learn from such experiences, whether nurses receive special treatment, and, nurses' experience of receiving nursing care.

Learning from the experience

It is not always easy for nurses to put out for public scrutiny their experiences of being a nurse and patient at the same time, especially if the experiences are not positive. As previously mentioned, Ruiz (1993, p. 28), a nurse academic, writes that

“The will to relate my experiences has been blocked for many years by an intense feeling of shame, the possibility of being accused of exhibitionism...”. Nursing is our profession, and we do not want to see it demeaned in any way. Yet, we also want our colleagues to know what it is really like to be a patient.

Despite this, several of the anecdotal reports comment on how much the nurse-patient has gained both personally and professionally from going through an experience of being a hospitalised patient (Edwards, 1994; Haybach, 1993; Jaffray, 1995; Ruiz, 1993; Sherrard, 1988). In an American survey by Gillies et al. (1993), 1,500 nurses were surveyed and asked two questions relating to personal experiences with hospitalisation. Many of the 494 respondents indicated firstly, that a hospital experience for themselves or a family member had influenced their practice in a positive way. Secondly, the experience caused some respondents to evaluate nursing roles and practices with respect, while others in Gillies et al. (1993) study were negatively critical of the care delivered with respect to ‘incompetent’ nurses.

Before becoming a patient, nurses often consider themselves to be a good nurse and able to provide patients with the care they need, yet an experience as a patient can make nurses reconsider this (Haybach, 1993; Jaffray, 1995). It is not until nurses are exposed to an illness experience that they realise that nurses have little idea of what being a patient is really like (Gillies et al., 1993; Jaffray, 1995). One nurse in the Gillies et al. study said, “I learned that being a patient is as difficult as being a staff member” (1993, p. 71).

Nurses learn about nursing and how to nurse in classrooms, from textbooks and journals, and from working in the field of nursing practice. Yet, Jaffray (1995, p. 51) states, “My week in hospital has given me an education that a classroom could never provide”. She suggests that her experience of being a patient made her realise that she “had no idea of what being a patient was really like” (1995, p. 51); it gave her insight into the life of a patient. A few authors suggest that all students and nurses would learn much from being a hospitalised patient to understand what it is really like (Allen, 1993; Johnson, 1992; Mitchell, 1994).

Telling and sharing stories is a strong part of nursing culture; each nurse has many stories to tell. In recent years, nurses have been encouraged to tell the positive stories about nursing practice (Darbyshire, 1994). However, the stories of nurses who have been patients suggest that their perceptions of the quality of care delivered may be different from the perceptions of the nurse providing the care (Brown, 1986; Coleman, 1995; Prentice, 1995; Riemen, 1986; Zeitz, 1999). My own experiences as a patient, and as a nurse educator listening to the stories of nurses, suggests this could be true and worthy of further scrutiny. While Coleman (1995, p. 329) makes the statement that the stories of nurses as patients is “one tale that we disregard consistently”.

Buckalew (1982, p. 435), in describing her experiences during chemotherapy, states that her “perspectives were differentiated from a layman's point of view”. She infers that this is because she is not a registered comprehensive nurse, but a child psychiatric-mental health nurse, however she does not discuss this further. Stories and narratives from patients and their families are as important as those from the nurses providing the care. Patricia Benner tells us we have much to learn from the best and worst of nursing practice (Benner & Wrubel, 1989), and we can learn much from the stories of nurses as patients.

Zeitz (1999) used a hermeneutic-phenomenological approach to gather data from four nurses who had received nursing care during an uncomplicated surgical procedure. The stories were generated from a shared conversation that Zeitz says began as an unstructured interview. They were then transcribed, and the transcripts became the text for interpretation. Her process of analysis was influenced by the work of Colaizzi (as cited in Zeitz, 1999). Through her interpretation of the text generated by the four nurse-patients, Zeitz identified the following ten themes to exemplify the experiences of nurses receiving nursing care: ‘finding a balance’, ‘acknowledging me’, ‘spirit of caring’, ‘being in control’, ‘the little touches’, ‘I’ll be back’, ‘expressing feelings’, ‘I’d done wrong’, ‘therapeutic environment’, and, ‘being comfortable’.

Several anecdotal reports discuss the desire of the 'nurse as patient' to share their new insights on nursing practice with nursing colleagues (Lissenden, 1985; McKenna, 1995; Messina, 1989; Prentice, 1995; Shriver, 1995). Reflecting on their experiences as patients has caused the nurses to empathise with, and be sensitive to the importance of patients' basic needs. Like Zeitz (1999), McKenna suggests it is "those little things that mean so much" (1995, p. 28). One of the roles of a health professional is to provide the patient with information, yet Messina (1989), a nurse who lived with a central line (peripheral central venous line) for over five years, reminds us that patients can also provide nurses with a wealth of information.

Ruiz (1993) describes her experiences as a nurse-patient with severe status asthmaticus in an intensive care unit. She writes, "living data provided by the patient cannot be substituted" (1993, p. 33). Shriver (1995, p. 9) writes of the need for nurses to listen to their patients. She describes an "unnecessary terrifying experience" she had as a post-operative patient when at 5am, she awoke with chest discomfort that radiated down her arms. Feeling frightened, she alerted the nurse who did not take any recordings but kept reassuring her that she was all right. The following day after her doctor ordered an electrocardiogram that revealed post-operative changes, she was sent to a unit for cardiac monitoring. Williams (1998a) reports a similar incident when a disbelieving nurse effectively denied the experience of a nurse-patient who fainted and vomited each time she stood up.

Often, nurses who have been patients want to make changes to their nursing practice on return to the workplace. While most of these anecdotal reports provide the reader with accounts of events in the day of a patient, they are worthwhile for nurses to read and reflect on. However, Ruiz (1993) in her analytic and reflective account of receiving nursing care while hospitalised, suggests that we must do more with these individual stories if they are to be of value to us as a growing profession. In the New Zealand report, Sherrard suggests that from her experience as a nurse and family member, we do provide care well in acute situations and for the terminally ill, particularly at the "physical level" (1988, p. 23). However, she suggests that nurses need; accurate knowledge, to use humour appropriately, to recognise that patient's

are vulnerable and need “reliable, consistent and competent care”, and, that nurses must provide family centred care if we are to improve the experience for patients who become disabled, and for their families (Sherrard, 1988, p. 23).

The two recent Australian studies of Williams (1998a) and Zeitz (1999), which explore the experiences of nurses as patients, and as recipients of nursing care, will make a significant contribution to this discussion. The anecdotal accounts and research from nurse-patients, suggest that nurses who are patients may get different treatment to the non-nurse patient (Coleman, 1995). The literature on this aspect is reviewed in the next section.

Special treatment?

In the research report titled *Do nurses get special treatment when they're patients?* (Morris & Mendias, 1985), nurses said yes, even though they do not expect extra care. There are many difficulties inherent in the change of role for both the patient and the nurse caring for them when a nurse is admitted to hospital as a patient (Easton, 1995; Williams, 1998a; Zeitz, 1999). From my experiences with nurse colleagues they have at times approached caring for a colleague with trepidation. From her personal experiences Coleman (1995) supports this stance and suggests that there would be few of us who have not been present when the status of a nurse-patient is discussed during handover using some negative exclamation, such as ‘she's a nurse’. Nursing and medical notes will often be labelled ‘patient is a nurse’. Health care professionals often expect nurses to be model patients. They are expected to know about their illness, to be more compliant, and perhaps even to recover faster than non-nurse patients (Morris & Mendias, 1985).

In the study by Williams (1997; 1998a; 1998b), semi-structured interviews were used with six female registered nurses to elicit their experiences of being nurse-patients during an acute hospitalisation within the past five years. Each nurse was interviewed separately for 45 minutes duration. This qualitative research was informed by a critical approach, to expose some of the invisible forces that have shaped nursing practice and its location within the wider socio-political context. The

interviews were recorded and transcribed for thematic and deconstructive analysis. Williams (1998a) suggests that the six nurse-patients in this study were subjugated and marginalised. The data reveals several incidents where the nurse-patients perceived themselves to be of secondary importance to the actions of the nurses that focused on the medical and technological aspects of their care. The nurse-patients cite many occasions where the actions of the nurses made them feel powerless.

Cotter (1990) suggests that nurse-patients are often perceived as being unpopular: their peers frequently stereotype them as tending to be neurotic, as potential troublemakers, and they are more prone to develop complications. The nurse-patient may also be viewed as unpopular because they are able to scrutinise and complain about the care given by nurse colleagues to other peers. Estrellado (1983) and Buckalew (1982) support this; they generalise that doctors and nurses make the worst patients. When hospitalised, nurses could be considered to be more vulnerable than non-nurse patients because they have knowledge and experience, they are aware of the system and the environment, and they are aware of problems that can arise (Ruiz, 1993; Williams, 1997; Zeitz, 1999). Perhaps it is because of these issues that Coleman (1995) writes that nurses allege amongst themselves, that they experience illness differently.

In the American study by Morris & Mendias (1985), 131 registered nurses were surveyed about the care they gave to health professionals and the care they received themselves as nurses. Results suggest that nurse-patients are treated differently, 43% of the surveyed nurses reporting that they received preferential treatment. This was described as treatment that may or may not be better. Other results suggest that colleague-patients were perceived to be different from other patients, for example nurse-patients ask for more scientific information. Edler (1985) in describing her experiences, comments that if you are hospitalised where you work the staff treat you like a nurse. She goes on to say that nurses who are admitted to hospital need support and nursing care just like any other patient.

Caring for colleagues can be daunting for a number of different reasons (Johnson, 1992; Zeitz, 1999). There may be the desire to provide extra care, while there is also the fear of caring for a colleague, because you feel less experienced. In her account of being a patient, Johnson describes an instance when the new young house doctor whom she had not met visited her. She states, “He knew I was a staff nurse and I think he did not know how exactly to proceed...” (1992, p. 9).

In the survey by Morris & Mendias (1985) nurses reported that they were more cautious when caring for doctors than when caring for nurses. However, a number of nurses admitted losing confidence when caring for nurses who could expertly evaluate their work. In contrast to this Buckalew (1982), in her account of being a patient describes a lack of confidence in the knowledge of the nurses involved in her care as causing her much anxiety. The anecdotal and empirical information found suggests that there are inherent difficulties in being a nurse-patient, and in caring for a nurse colleague, and that nurse-patients may receive different treatment.

Nurses receiving nursing care

The terms ‘care’ and ‘caring’ have been used throughout the history of modern day nursing, yet it has only been in the past 25 years that nurses have studied the meaning of caring in nursing (Harrison, 1990). There is much debate in the literature about the nature and meaning of care and caring in the context of the nurse's role. Authors such as Benner & Wrubel (1989) and Watson (1995) have identified caring as the central phenomenon in nursing practice. Newman, Sime, & Cocoran-Perry (1991, p. 3) suggest that “nursing is caring in the human health experience”.

Caring could be described as whatever the individual patient feels is caring, or as the recognition of a need for nursing care and nurses meeting that need. Research by Brown (1986), Riemen (1986), and Zeitz (1999) found that perceptions of caring and non-caring behaviours were quite different depending on whether it was the view of the giver or receiver of care. The relationship between the nurse and

the patient is contextual and relational (Lawler, 1991). It is formed when the patient is vulnerable and when they may be dependent on the nurse for help with tasks that the patient would usually do for themselves. Lawler (1991a) wrote that patients' perceptions of care are related to the immediacy of their situation, and the capacity of the nurse to be caringly responsive to the situation. The anecdotal and research literature on 'nurses as patients' provides evidence in which nurses received both caring nursing practice (Evans, 1995; Gleeson, 1992; Prentice, 1995; Zeitz, 1999), and uncaring nursing practice (Bailey, 1985; Gillies et al., 1993; Harrison, 1990; Shriver, 1995; Williams, 1997; Zeitz, 1999).

Further to the earlier comment made by Allen (1993), Johnson (1992), and Mitchell (1994), that all students and nurses should be patients, Mitchell (1994, p. 104) describes an experience where she states her nurse was "wonderful - she too had undergone major surgery and understood my fears". Like Jaffray (1995), many of the respondents in the study by Gillies et al. (1993) also said that they were better nurses for having been a patient in hospital. Most of the anecdotal reports suggest that the experience of being a patient has changed them (Coleman, 1995).

In recognising good nursing care, Gleeson (1992) identifies the change in emphasis from a task-based approach in nursing to a patient-centred approach. While Prentice (1995) comments that the care she received was good, her anecdote in places perhaps suggests the opposite and provides a task-focused approach to nursing. However, in describing that the way in which the tea round was delivered was as important as the quality of the tea itself, Prentice could perhaps be understood to mean that 'nurses as patients' are readily able to differentiate task-oriented practice from the caring aspects of care. Zeitz (1999, p. 70) concluded, "Nurse-patients are able to discriminate appropriate and skilful nursing care".

Several of the themes identified in Zeitz's (1999) study reveal aspects of caring nursing practice. They include: the spirit of caring; the little touches; therapeutic environment; being comfortable; and, 'acknowledging me'. Kathryn Zeitz is able to provide some positive aspects with regards to the attitudes of nurses,

and Ruiz (1993) discusses the immeasurable value of having an understanding attitude. However, Ruiz suggests that the negative attitudes of some health professionals, for example denial, impatience, and not knowing what to do at a given moment, can ruin an experience. The notion of acknowledging the person as an individual, is evident in the theme of 'acknowledging me' in Zeitz's (1999) study. Although recognised as an important factor in holistic nursing care, this does not always happen. Both Coleman (1995) and Williams (1998a) describe instances where nurses appear to avoid and isolate their nurse-patients. Being acknowledged as an individual would include treating the nurse-patient as a colleague.

Being a nurse-patient can be an advantage, in terms of having knowledge, but this can also be a disadvantage in that you are expected to know 'everything'. Nurse-patients are able to establish communication through discussing shared nursing experiences (Williams, 1998b; Zeitz, 1999). Nurse-patients may not be as overwhelmed by the health care system and are therefore able to be more assertive and manipulate the environment to meet their needs (Coleman, 1995).

While the rhetoric of holism has been espoused in the nursing literature, the study by Williams (1998b), found "that nurses continue to carry out medical orders and prioritise technological expertise over the caring work of nursing". She describes this as task-orientated nursing, which has been mentioned previously (Prentice, 1995; Zeitz, 1999). 'Being in control', and 'I'll be back', two other themes identified in Zeitz's (1999) study describe the locus of control and power relations in nursing practice. She gives examples of nurses, who while providing nursing care with participants in her study, say, "I'll be back in a moment" and they leave the patient to fend for themselves, often at difficult times. While Williams (1998b) cites comments from some of the participants in her study, they constantly had to ask permission to do things. One of the most pervasive factors about hospitalisation is an individuals' loss of control over aspects of their care, particularly over the physical environment (Coleman, 1995). Nurses often assume the control (Coleman, 1995; Williams, 1997; 1998a; 1998b; Zeitz, 1999).

It is evident from the literature, that nurses do make a difference to the experiences of patients in hospital. Two authors (Ruiz, 1993; Zeitz, 1999) specifically acknowledge this in their writings, while Ruiz writes that her experiences as a patient strengthened her nursing identity. She goes on to say that, “I had felt for myself what it is to ‘need looking after’ (not medical help...)” (1993, p. 36). While most of the work on nurses as patients is American (Gillies et al., 1993; Morris & Mendias, 1985; Ruiz, 1993), two Australian studies (Williams, 1998a; Zeitz, 1999), and the work of Coleman (1995) have contributed to this section. Only one New Zealand anecdotal report was located (Sherrard, 1988). We therefore need to be careful in transposing this work into the New Zealand context because there are cultural differences in health care systems.

Conclusion

The literature suggests that nurses who are hospitalised as patients gain both personally and professionally from the experience. Nurses who, prior to becoming a patient, consider themselves to be good nurses learn what it is like to be a patient and receive nursing care. The stories of nurses as patients suggest that the perspective of the patient and the nurse may not be the same. However, there is no empirical evidence to be found which studies both the nurses’ and the patients’ perspective of the shared hospital experience. The anecdotal and empirical evidence indicates that nurses who have been patients are keen to share their stories with colleagues so that insights that may enhance nursing practice will be gained.

There are difficulties inherent in the change of roles from nurse to patient, for both the nurse-patient and the nurses caring for them. Nurse-patients, like all patients, must be acknowledged as individuals and provided with the appropriate support and nursing care. It is evident from the literature that nurses do make a difference to the experience of nurse-patients in hospital. The literature suggests that nurse-patients have widely differing experiences. It appears that some nurse-patients are very satisfied with the nursing care they receive while others feel let down and experience a sense of frustration when the nursing care is not at the standard they expect. More studies that reflect nurse-patients' experiences of receiving nursing care

are necessary to add to the research located. That is why this study seeks to explicate the stories of two nurse-patients' experiences of receiving nursing care. In the next chapter I shall review the literature on the perspectives of the non-nurse as patient.

CHAPTER THREE: The Non-Nurse as Patient

Introduction

As I began to search the literature for writings on ‘nurses as patients’, I was also reflecting on my own experiences of being a hospitalised patient. The two quite different experiences of receiving nursing care gave me much to think about. It was after the second hospital experience I realised more than ever that every hospital experience could be quite different and unique. My initial search illuminated stories from both non-nurse patients and nurses who had been patients in hospital. As I was a nurse and a nurse educator, I contemplated whether my stories as a nurse-patient could be different from that of the non-nurse patient. I therefore made the decision to examine the perspectives of nurse-patients receiving nursing care, and those of non-nurse patients.

This chapter presents a review of the literature on non-nurses as patients and their experiences of receiving nursing care. In the past patient satisfaction surveys have been the main source of identifying patients' perspectives of receiving care. Their use in reflecting an accurate account of patients' perspectives has been limited. Since 1986, several nursing research studies that reflect patients' experiences of receiving nursing care have been completed (Brown, 1986; Drew, 1986; Gillies et al., 1993; Harrison & Cameron-Traub, 1991; Irurita, 1996; Kralik, Koch, & Wotton, 1997; Riemen, 1986; Webb & Hope, 1995). At the time of searching, only one New Zealand study on the non-nurse patient's perception of nurses' practice was identified (Parkes, 1993). Jocelyn Parkes, a nurse academic, conducted a phenomenological study with five adult patients who experienced a period of hospitalisation within a surgical setting.

Non-nurse patients' personal narratives of their health experiences provide a rich source of description and are sometimes published as anecdotal reports in weekly magazines, nursing and medical journals (Heywood, 1999; Jacobs, 1998; Julian-Allen, 1993; Kelly, 1988). The narrators are writing generally to express their

thanks, anxiety or dissatisfaction with the care provided. One New Zealand anecdotal report has been located (Jacobs, 1998). Susan Jacobs, a nurse academic, provides the introduction for the narrative of a woman who was hospitalised and received nursing care. Other narratives have been published as autobiographical accounts (Frame, 1984; Opie, 1996; Sacks, 1993).

In her autobiography *An Angel At My Table*, Janet Frame, an award-winning New Zealand author, describes her experiences as a patient in two psychiatric hospitals in the late 1940s-1950s. While a young student at university she was originally diagnosed as suffering from schizophrenia. Frame describes the six weeks she spent at Seacliff Hospital as a concentrated course in the horrors of insanity. Her autobiography tells the story of her personal nightmare and experiences as a patient while in Seacliff Hospital and Sunnyside Hospital in Christchurch (Frame, 1984).

June Opie, the famous New Zealand author of *Over My Dead Body* records her biographical narrative as a polio survivor. In 1943 while sailing to England, she became ill and was admitted to St Mary's Hospital in London, she spent ten weeks in an iron lung. The biography tells the story of her two-year battle at St Mary's to regain control of her body (Opie, 1996). The third autobiographical account located was that by Oliver Sacks, a neurologist, who wrote *A Leg To Stand On*. This book is his story of being hospitalised after he suffered a severe knee injury. He tells how his immobilised leg became an alien thing that did not seem to belong to him. He describes the nurses and doctors as being unsympathetic to him (Sacks, 1993).

The anecdotal and empirical evidence mentioned above on non-nurse patients will be reviewed and critiqued. To do this, the chapter will focus on; hearing the patients' voice, factors involved in the nurse-patient relationship, patients' perceptions of their role, and the role of the nurse, caring nursing practice, and non-caring nursing practice.

Hearing the patient's voice

The literature suggests that it is only in the last ten years that patients have shared their stories publicly. This could be because in the past patients were not asked for their opinions and experiences of receiving health care. Professionals believed that they knew what was best, while patients were seen as not able to judge the standard of their care and had to accept it as the right health care. However, in more recent years, advocacy services and patients'/consumer rights groups have ensured that the voice of the 'patient', 'client' or 'consumer' is now being heard. Patients' participation groups were started in some English general hospitals back in 1972, while Patient Councils and other ad hoc groups were in place from 1986, (Williamson, 1992). Julian-Allen (1993) suggests that 'consumerism' and 'the patient's charter' have become popular in Britain.

In New Zealand, patient advocacy has been more publicly recognised since the Cervical Cancer Inquiry (Cartwright, 1988). The Cervical Cancer Inquiry surfaced the fact that many New Zealand women who were under the care of gynaecologists at National Women's Hospital in Auckland, had been exposed to an abuse of patients' rights. The women were unknowingly part of a research project that sought to examine the invasive potential of carcinoma of the cervix. As a result of being a part of this 'unfortunate experiment', some women received inadequate treatment and follow-up care that eventuated in progression of the disease. The inquiry subsequently resulted in advocacy services and patients' rights groups becoming more prolific in New Zealand. This was followed eventually in 1994, by the introduction of the Health & Disability Commissioner's Act, which included the recognition of patients' rights, and advocacy issues in health care ethics and research.

Quality assurance programmes and accreditation programmes in some health care agencies in New Zealand, have also contributed to patients' comments being obtained. However, these are generally obtained through a survey, and Williamson (1992) suggests that surveys are limited in enabling consumers to share their experiences of care because of the types of questions asked. She does however cite an earlier English study, where the clinical experiences of women having inductions

in pregnancy were obtained (Kitzinger, 1975, as cited in Williamson, 1992, p. 46-47). Williamson suggests that this study helped change clinical practises for English women having an induction, although how this occurred is not evident.

One other point to note in discussing narratives is the timing of when stories are shared. While people's perspectives and opinions do change over time, stories are shared at a particular stage during hospitalisation or after discharge. An Australian study by Harrison & Cameron-Traub (1991), which sought stories from 26 patients on their perceptions of their nursing needs and expectations, suggests that the time at which the patient's experience is shared might influence the stories that are told. They suggest that patients' perceptions may be different when they are unwell, or later when they have time to reflect on their experiences. The effect of time on people's recall and memory was also discussed in a patient satisfaction study conducted by Pontin & Webb (1995). While Larson & Ferketich's (1993) descriptive co-relational study to refine and develop a tool to measure patient satisfaction of nursing care, found that "near-discharge patients can objectively respond to questions about the care dimensions of their nursing care" (p. 701). In more recent years patients have been discharged earlier. It would be interesting to discover whether their higher level of acuity would alter this finding.

The delivery of quality health care is acknowledged as being important, and in an attempt to study the meaning of quality nursing care; Irurita (1996) describes two separate grounded theory studies. Both concurrent studies that incorporated patients' and nurses' perspectives were undertaken in an Australian acute hospital setting. In exploring the patient's perspectives, data were obtained from 23 patients in total; these were collected over a 12-month period. These studies found that there were similarities and dissimilarities in the perceptions held by both patients and nurses on some of the elements of quality nursing care. It is interesting to note that Irurita (1996, p. 335) comments that a problem identified in the nurse data were the nurses' "inability to consistently provide high quality care". It was stated that nurses "dealt with this by a process of prioritising nursing care". Further findings from this study will be discussed under appropriate sections of this chapter.

Nurse-patient relationship

For most nurses, activities are centred on working directly with patients and so the nurse-patient relationship is of the greatest importance. A considerable range and number of papers concerned with 'nurse-patient' relationships can be found when searching CINAHL. A variety of factors such as the individual characteristics of both the nurse and the patient, have been identified in the literature that might affect the nurse-patient relationship. The following four issues have arisen from the literature on non-nurses as patients: the changing relationship; communication; reciprocity; and, the issue of power. These will now be addressed briefly.

Firstly, the nature of the relationship between health care professionals and consumers of health care is changing (Harrison & Cameron-Traub, 1991; Webb & Hope, 1995). This changing relationship is due partly to the changes in the health care system itself, and also because consumer groups have been calling for a more informed public, who are more able to be involved in decisions about their own care (Harrison & Cameron-Traub, 1991). Budget cuts in the health care system have had a profound effect on the way care is organised in hospitals. The nursing profession has faced enormous barriers to providing a high standard of nursing services. Nurses have been functioning in a system where the focus appears to be no longer on the patient as a person, but on the outcome to be achieved. In recent years, a more holistic approach to care has been espoused and consumers have been encouraged to actively participate in their care. The traditional relationship between nurses and patients is being challenged (Harrison & Cameron-Traub, 1991; Webb & Hope, 1995).

Secondly, the importance of communication in caring for patients has been extensively researched and written about in recent years. Kelly (1988, p. 17) reminds nurses to "Listen to the voice of the consumer" when she cites comments made by friends after their hospitalisation experiences. However, in a review of the literature undertaken on nurse-patient communication by Jarrett & Payne (1995), they argue that the patient's contribution to the topic has been largely ignored in the research.

In the Australian qualitative research study by Harrison & Cameron-Traub (1991), it was found that patients and nurses rarely communicate, other than conversing on general topics while physical care is carried out. Once patients are able to look after themselves, they are left alone. There are also some contradictory comments made by patients with regard to their need to talk with nurses about issues other than physical care. While Julian-Allen (1993) in his account of being a patient titled *Scarred by nurses*, provides two instances where nurses failed to communicate with the patient.

In attempting to find out more about what patients want from nurse-patient relationships, Webb & Hope (1995) investigated how nurses should address patients. In this study, five nursing students interviewed 103 patients on specific questions designed to elicit their opinions on certain aspects of nursing practice. The patients' responses were recorded on a structured interview schedule and subsequently analysed using a statistical package. Many patients do not consider it appropriate for the nurse to address them by their first names, especially when the patient is older. Julian-Allen (1993) in presenting his critical account of nurses' actions supports this view. He describes an elderly woman being summoned several times over the loudspeaker by her first name, and suggests that this is inappropriate for someone who has probably never been called by her first name by a stranger. Webb & Hope (1995) suggest that even when nurses do ask patients how they would like to be addressed, difficulties may arise. For example, if patients detect a climate where a certain form of address is used, they may feel reluctant to go against this.

Thirdly, in more recent years, the relationship that exists between the nurse and the patient is described as involving 'reciprocity', particularly in the ethic of care literature (Cooper, 1988; Gadow, 1988). In the study by Harrison & Cameron-Traub (1991), it was found that from the patient's perspective, it is clear that the relationship is reciprocal with obligations on both sides. Julian-Allen (1993) in his anecdotal account suggests that there needs to be more reciprocity in the nurse-patient relationship.

Finally, the traditional role of the health care professional has created an imbalance of power and authority between the patient and the nurse. It is characterised by: being in possession of the truth at all times, always being right, and knowing what is best for the patient. This is particularly evident when the patient is hospitalised in an unknown institution. The person who is dependent is particularly vulnerable to the actions of the other. There is evidence in both the anecdotal and empirical literature, of instances where nurses assert their power and authority over the patient by their actions (Drew, 1986; Julian-Allen, 1993).

Patients' perceptions of their role

One study was located that explicitly asked patients about their expectations and perceptions of their role as a patient while in hospital (Harrison & Cameron-Traub, 1991). The study found that people enter hospital with similar and strong expectations about their role as a patient. Patients learn their role through talking with and watching other patients, and through the media. Because of their perceptions of the patient role, the participants in Harrison & Cameron-Traub's (1991) study identified that patients must co-operate by not bothering the nurses unless it was really necessary. All the patients required extensive nursing care at the beginning of their hospitalisation. The following quotation from one patient helps illustrate the patients' perspective of their role:

...I've always strived to be a model patient in the sense that I only ask for what I need and I'm always polite and co-operative and willing to do whatever the nurses want me to... (Harrison & Cameron-Traub, 1991, p. 149).

The study also identified that this group of patients adopted a passive, compliant and accepting role and trusted in the judgments of the health care professionals. They did not see themselves as partners in the decision-making process, nor did they know what was expected of them. However, Salvage (1990) in reviewing patient's opinions, concluded that patients do wish to have enough information so that they can make decisions about their care.

Patients' perceptions of the nurse's role

To examine patients' expectations of the nurses involved in their care, two studies (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Webb & Hope, 1995) used structured interviews, while the grounded theory study by Irurita (1996) and the study by Harrison & Cameron-Traub (1991) used a semi-structured approach. The study by Brown (1986) used an unstructured approach in that participants were asked to describe their experience of feeling cared for. Participants in these studies appear to have similar characteristics in terms of their age and reasons for being in hospital. It is evident in the literature that there is no consensus on what patients think the role of nurses should be. Two of the studies (Gerteis et al., 1993; Harrison & Cameron-Traub, 1991) clearly identify nursing practice as the provision of care to meet the physical needs of patients, and patient's expectations of nurses are consistent with this definition. While in the Webb & Hope (1995) study, and the study by Irurita (1996), the psychosocial aspects of the nursing role are seen as more important than the physical aspects. It is interesting to note that, while the studies by Gerteis et al. (1993) and Brown (1986) found that physical care rates higher in importance to the patients, nurses often rate it lower in favour of technical and intellectually challenging nursing actions. Webb & Hope (1995) suggest that this might also be the same for the nurses in their study.

Pontin & Webb (1995; 1996) conducted an action research project in one English health authority that included assessing patient satisfaction about their experiences of nursing care. Patients in this study considered the role of nurses was focused on "observing and monitoring their progress from a dependent state in which physical care was needed, towards self-care" (Pontin & Webb, 1996, p. 35). While attending to physical care, it is evident that the patients also considered that nurses promoted their psychological and emotional well being by their presence. Patients in both Pontin & Webb's and Harrison & Cameron-Traub's (1991) studies perceived nurses as being busy, having a heavy workload, and so they tried not to bother them.

The traditional handmaiden role of nurses was evident in Harrison & Cameron-Traub's study (1991). Two-thirds of the patients did not believe that nurses

made decisions about their nursing care. The study found that patients thought nurses were there to carry out the doctor's instructions. While the findings of Webb & Hope's (1995) study found that the patients see nurses as having a distinct and independent role, it was interesting to note that they did not consider it a nursing role to either help the doctor, or to be responsible for co-coordinating the work of other members of the multidisciplinary team.

In the studies by Gerteis et al (1993), Harrison (1991), and Webb (1995) patients identified the personal qualities of the nurse as important. Qualities such as friendliness, kindness, approachability, and being mentally present (Gerteis et al., 1993) are mentioned. However, in the study by Harrison & Cameron-Traub (1991), a comment from one patient suggests that cheerfulness in nurses does not always equate to quality nursing care. Participants in the New Zealand study (Parkes, 1993) revealed that they valued the importance of competent care by nurses who were also sensitive and caring. Julian-Allen (1993) summarises his experience of being a patient and suggests that patients' are also entitled to respect by caring nurses.

Caring nursing practice

Several of the anecdotal narratives and the empirical evidence related to caring nursing practice indicate instances of caring nursing actions (Brown, 1986; Harrison & Cameron-Traub, 1991; Jacobs, 1998; Kralik et al., 1997; Pontin & Webb, 1996; Riemen, 1986; Webb & Hope, 1995). Patients notice and appreciate efforts to make them more physically comfortable, and it matters to patients that care is individualised, and that nurses are present for them (Gerteis et al., 1993). An earlier study by Brown (1986) asked fifty patients to describe an experience in which they felt cared for by a nurse. Eight care themes were identified which Brown states represent the common elements fundamental to the experience of care. They are: recognition of individual qualities and needs, reassuring presence, provision of information, demonstration of professional knowledge and skill, assistance with pain, amount of time spent, promotion of autonomy, and, surveillance. These themes are evident in all the stories by patients when they describe the 'good nursing care' they receive (Gerteis et al., 1993; Harrison & Cameron-Traub, 1991; Pontin & Webb,

1996; Webb & Hope, 1995). However, the study by Parkes (1993) reveals that participants found it difficult to articulate what they meant by caring nursing practice. One participant summed it up by saying: "... It's the way they do things, just the fact that they are there, being there, it's important (1993, p. 64). Jocelyn Parkes study does reveal a range of perceptions about nurses' practice, yet despite this, nurses' practice is recognised as central and pivotal to the participant's recovery (1993).

Non-caring nursing practice

It is also apparent from the literature that when patients are asked about their experiences of nursing care, a range of responses is offered. If the story of the experience is being sought while people are still requiring care, it appears that they voice their criticisms in a different way (Pontin & Webb, 1995). Several articles were located which described non-caring nursing practices (Brown, 1986; Drew, 1986; Harrison & Cameron-Traub, 1991; Jacobs, 1998; Kralik et al., 1997; Parkes, 1993; Pontin & Webb, 1996; Riemen, 1986; Webb & Hope, 1995).

A phenomenological study by Riemen (1986) sought ten patients' perceptions of non-caring interactions with nurses. Significant statements from patient's descriptions are grouped under the five headings of; 'being in a hurry and efficient', 'doing a job', 'being rough and belittling patients', 'not responding', and, 'treating patients as objects'. When the patients' descriptions were analysed, Riemen (1986) revealed three themes that help show a picture of non-caring interactions. These interactions are: the nurse's presence, the client's response, and, the consequences of the nurse's lack of concern for the client. The theme 'the nurse's presence' represents the nurse's physical presence, rather than their emotional presence. Nurses are viewed as being there because it is their job rather than because the patient needs assistance. When nurses do not respond to patients' requests, they are seen as being non-caring. This theme is represented in the literature as being a caring behaviour when it represents the nurses being truly present (Gerteis et al., 1993; Pontin & Webb, 1996). As a consequence of the nurses' lack of concern, the patient's needs

are not met; the patient then feels frustration, fear, anger and anxiety (Riemen, 1986), emotional states that may affect their recovery.

Participants in the study by Parkes (1993) were more easily able to express instances of non-caring nursing practice. Her study reveals a number of occasions when the post-operative patients felt powerless when they were not progressing as expected by the nurses. When patients' needs were not met they felt devalued, for example, when technological care was given at the expense of emotional care. Parkes suggests that when technology becomes dominant experiences of caring practice are less visible. In the New Zealand anecdotal report, the female patient describes a variation in nursing care, and suggests that she did not have confidence in the nurses. She said, "There seems to be some things missing in terms of what I needed..." (Jacobs, 1998, p. 9). Her account reflects instances where nurses were either engaged or detached (Kralik et al., 1997) in their relationship with her as a patient.

Julian-Allen (1993), an educational consultant, wrote a straightforward account of his dissatisfaction with nursing care some months after he left hospital. There is no evidence of good nursing care in his published story. While the editorial by Kelly (1988) in the nursing journal *Nursing Outlook* provides several instances of uncaring nursing. Kelly asks 'has the ethic of care been discarded?' She suggests that if those of us who do care about patients and about nursing don't accept the challenge to change the situation, we too will be responsible for discarding the ethic of caring. The study by Harrison & Cameron-Traub (1991) also highlights uncaring nursing practice. A number of patients acknowledged a gap in nursing care, their physical needs were met, but psychological, emotional and spiritual needs were not.

While the research and anecdotal narratives share the patients' perspective of their health care experience, there is also a suggestion in the literature that patients' perspective of care is often different from that of healthcare professionals (Kapnoullas, 1988; Larson & Ferketich, 1993; Love, 1996; Webb & Hope, 1995).

Conclusion

Research and anecdotal evidence on non-nurses' perspectives of being a patient have been reviewed. Patient satisfaction surveys have been the main source of patients' perspectives in the past, but Williamson (1992) suggests that these are limited because of the closed nature of the questions used. Since 1986, several nursing research studies have been undertaken which explore non-nurse patients' perceptions of receiving nursing care.

It is acknowledged that the relationship between the nurse and consumer of health care has changed, along with changes in the health care system itself. Generally, the patient of today expects to be involved in decision-making related to their care, and wants to be treated with respect and acknowledged for having insight into their own condition.

The literature suggests that there are wide variations in the perspectives of patients' stories of nursing care. It appears, that while some patients still expect the nurse to be the traditional handmaiden and to work according to the doctor's instructions, the majority of anecdotal and research literature suggests that nurses are seen as having a distinct and independent role. Many instances of caring nursing practices were located in the literature from the non-nurses' perspective. However, there still remain many anecdotal accounts and empirical evidence to suggest that non-caring nursing practice occurs. I would suggest that more research is necessary to gain both the nurse's and the patient's perspective of the shared experience. Maybe then, nurses will gain the additional insight into what it means to truly nurse and to be nursed.

This then completes the theoretical and empirical underpinning of this thesis. Much has been written about patients' perspectives of receiving nursing care. Less has been written about nurse-patients' perspectives of receiving nursing care. This thesis attempts to add to that literature. In chapter six the story of Maria, a nurse-patient will be told, and, in chapter seven I will tell my story of receiving nursing care. But first, I will justify the use of narrative as inquiry.

CHAPTER FOUR: Narrative as Inquiry

*This is a both exciting and dizzying time in which to do social inquiry
(Lather, 1991, p. 14).*

Introduction

In this thesis I wish to explicate the stories of two nurse-patients' experience of receiving nursing care in two New Zealand hospitals in the mid to late 1990s. The thesis sets out to address the following questions: How might my experience and the experience of one other nurse who has been hospitalised bring about changes in nursing practice? What effect might our hospitalisation have on us as a nurse and on our nursing practice? In order to do this, my methodology involves weaving together the theoretical and empirical perspectives of the literature review related to patients who have been admitted to hospital, and the personal narratives of two nurse-patients.

The first literature review is related to the nurse-patient receiving nursing care as outlined in chapter two; and the second literature review is related to the non-nurse patient receiving nursing care, as outlined in chapter three. The two narratives involve a participant (Maria) narrating her stories of receiving nursing care while hospitalised during two admissions, and myself as researcher and participant, narrating my story of being a nurse-patient receiving nursing care when hospitalised for elective surgery, and my subsequent readmission to hospital as a sick dependent patient. Maria's narrative is presented in chapter six and my narrative is presented in chapter seven.

In this chapter, I begin firstly by presenting a critique of traditional research paradigms, and a discussion on doing research, which is informed by a feminist process, within a postmodern/post-positivist era. Secondly, I discuss narrative inquiry as a valuable qualitative research method. Central to narrative inquiry, is the potential for stories and narratives to give meaning to people's lives. I include a

discussion on how story telling has become an important part of my nursing and education practice. Thirdly, I discuss the suitability of narrative as inquiry in nursing research. As this research includes the weaving of the biographical story of one participant, and the autobiographical story of the researcher as participant, I then discuss autobiography as a research method. Fourthly, I discuss issues of rigour in narrative as inquiry. To explain why nurse researchers are seeking new approaches to inquiry, I shall begin with a critique of traditional research paradigms.

Critique of traditional research paradigms

In 1986, Allen, Benner, & Diekelmann wrote that three major paradigms have been used predominantly in nursing research, they are: the empirical-analytic paradigm, Heideggerian phenomenology, and critical social theory. Nursing studies have used methods from the positivist and post-positivist paradigms to identify patient's perspectives on nursing practice. However, in more recent years, there has been a significant shift in the theoretical and philosophical positions that inform nursing research (Glass & Davis, 1998; Lather, 1991; Watson, 1995). Nurse researchers are now using and searching for different possibilities of making sense of human life.

We live in a period of dramatic change in our understanding of scientific inquiry, a time that has learned much about the nature of science, its attributes and its limitations (Lather, 1991). Many different approaches to generating and legitimating knowledge have arisen out of the possibilities created by the development of the post-positivist and postmodern era. All question the basic assumptions of what it means to do science. There are fundamental differences between the positivist/post-positivist paradigms and the postmodern paradigm. I shall address these based on the ontological and epistemological assumptions rather than from a methodological stance (Guba & Lincoln, 1994).

In the positivist paradigm the ontological assumption is that there is only one truth, one reality that is out there - somewhere. This reality is independent of the context and can be studied independently. The epistemological assumption is that

knowledge is developed through value-free observations of the reality. The researcher and the researched are independent identities, and objective methods of inquiry are used. From this perspective, findings from representative samples are considered generalisable, that is, inferences can be made from the data to other population groups. The major goal of positivism is to discover causal relationships.

The post-positivist paradigm is characterised by the ontological assumption that reality is complex, holistic, and context dependent. The focus of the inquiry is on human experience, thus subjectivity rather than objectivity is emphasised. Because there are multiple realities and human experience is variable, multiple ways of knowing are valued in the post-positivist paradigm. The researcher is involved in the process and there is sustained contact with the research participants or the 'objects of our inquiry'. Generalisability is not considered possible by post-positivists, but the notion of transferability, which refers to how information gained in one setting might be useful in another setting, is considered. However, post-positivism remains in the broad tradition of positivism. It retains the positivistic features of objectivity, validity and generalisability, but in a less attenuated form (Crotty, 1998).

Research in a postmodern era

Early in this project a senior nurse academic mentioned that my research was 'very postmodernist'. At the time we discussed the idea of locating myself the researcher, as participant in the research process, and the dissonances between my practice as a nurse educator and my experience of being a nurse-patient. She suggested that I was saying 'that nursing is not nursing', that there is a discrepancy between the idealism and realism of nursing practice. However, I found it difficult to explicate the meaning of this term from my readings. Since the 1950s, the presence of postmodernism has impacted on a variety of disciplines such as philosophy, architecture, literature, and the arts in many varied and often contradictory ways. Sociologist, Laurel Richardson wrote, "We are fortunate to be working in a postmodernist climate" (1994, p. 517). But what does it mean? To take the words of Crotty (1998, p. 183), "postmodernism is the most slippery of terms," and I note that

there are different definitions and interpretations surrounding postmodernism (Dickson, 1990; Lister, 1991; Reed 1995; Watson, 1995).

The major tenets on what has come to be called 'postmodernism' include the need to deconstruct knowledge and reality, and to recognize personal experience as a truth of its own (Crotty, 1998; Lister, 1991; Reed, 1995; Tierney & Lincoln, 1997; Watson, 1995). These tenets are congruent with issues of concern to both nursing and the feminist process. The underlying values and assumptions associated with feminism include the reciprocity involved in the relationship between nurse and patient, the ethic of care, and the importance of the experiences of women's social and personal worlds (Glass & Davis, 1998). This kind of information usually remains hidden when only quantitative methods are used. I concur with Glass & Davis (1998, p. 44) when they state that "postmodernism is a philosophy that supports and values the social contextual experiences and differences of unique individuals and rejects generalisation of those experiences." Among other things, postmodernism constitutes a set of ideas concerning 'the self'. The self is positioned in relation to situated knowledges and presentations, as contextually and temporally specific rather than as static and unitary (Stanley, 1993a).

Referring back to the earlier work of Richardson (1994), I came to understand what it is that has come to be called postmodernism. She wrote:

The core of postmodernism is the doubt that any method or theory, discourse or genre, tradition or novelty, has a universal and general claim as the "right" or the privileged form of authoritative knowledge. Postmodernism suspects all truth claims of masking and serving particular interests in local, cultural, and political struggles. But postmodernism does not automatically reject conventional methods of knowing and telling as false or archaic. Rather, it opens those standard methods to inquiry and introduces new methods, which are also, then subject to critique.

The postmodernist context of doubt distrusts all methods equally. No method has a privileged status. The superiority of 'science' over 'literature' - or, from another vantage point, 'literature' over 'science' - is challenged...

Qualitative writers.....still have plenty to say as situated speakers, subjectivities engaged in knowing/telling about the world as they perceive it (Richardson, 1994, p. 517-518).

The postmodern perspective is relevant to this piece of research in that it acknowledges the relationship between the context in which the object of inquiry, i.e., the participant, is located and who the 'self' is in relation to that location. Therefore others who locate themselves differently may not share what is perceived to be true by one person. From a feminist and postmodernist perspective, the self/researcher is inevitably in the text. It is therefore appropriate that this thesis is written in the first person. A postmodern approach will also challenge the status quo, which this project is ultimately doing by exposing different realities of nursing practice from the perspective of Maria and myself as nurse-patients. Both nursing and feminism refute the traditional positivistic view, that research and science must be objective, and both value the subjective experience.

Epistemological issues underpin a feminist research methodology. Women's experience is a legitimate source of knowledge and women are knowers of their experiences (Olesen, 1994; Sigsworth, 1995). Many studies have been done utilising women's subjectivity and experiences (Olesen, 1994). Subjective knowledge is valid and the women themselves are the best informants about their own lives. Research using a feminist methodology needs to incorporate the underlying values and assumptions associated with feminism as described earlier (Glass & Davis, 1998). Researchers following a feminist methodology will combine a variety of collaborative methods and approaches. Research methods most commonly used include in-depth interviewing, life histories, story telling, and participant observation (MacPherson, 1983; Shields & Dervin, 1993). To use research which is informed by feminism involves a new epistemology, in that it constitutes a way of being in the

world that challenges the traditional scientific/positivist paradigm (Sigsworth, 1995). The merging of feminism and postmodernism appears to be contentious in the literature (Carryer, 1997; Glass & Davis, 1998) because of the diverse opinions within each. Both are discourses that are changing, however, it is argued that there is a degree of shared epistemological and ontological issues that can have implications for nursing research (Glass & Davis, 1998). Manifestations of a postmodern paradigm are already reflected in the knowledge development of nursing.

Nursing's ways of knowing, its epistemology, and its ontology are being explored in many different ways. These ways of knowing do not always fit comfortably with the traditional sciences, nor fit comfortably into any other category. Meleis (1991) suggests that since the development of schools of nursing by Florence Nightingale, her followers have failed to differentiate the focus and goals of nursing and medicine. Somehow, the medical domain of practice, which was better developed and more powerful, replaced what was becoming a nursing domain of practice (Meleis, 1991). Because of this close alliance with medicine, the dualism of subject and object has been a traditional model for nursing knowledge. Nurses are influenced by the philosophical underpinnings of the time.

Some of nursing's knowledge has been based on personal and group experiences and passed on through the oral tradition of nursing's work. Accounts of individual experiences have been published over the years in nursing journals (Jacobs, 1998; Julian-Allen, 1993). These accounts have been useful for nurses but ignored by traditional scientists who have claimed that a scientific discipline has no place for experiential knowledge.

However, there are other ways of knowing that are integral to nursing practice, the aims of which are congruent with the engagement that marks nursing practice. More creative ways of knowing are required. Carper (1978) in her seminal article *Fundamental patterns of knowing in nursing* identified four ways of knowing, only one of which is empirical; she described this as the science of nursing. The others are aesthetic – the art of nursing; the component of personal knowledge; and

ethics – the moral component. Jacobs-Kramer & Chinn (1988) and White (1995) further developed this model with the intent of facilitating the integration of these patterns of knowing in nursing into clinical practice and nursing inquiry. I have used this framework in my work with nursing students to provide a pathway through which nursing knowledge can be further developed.

I believe that nurses may wish to use the traditional science of the positivist and post-positivist paradigms to gather knowledge about the issues they encounter in nursing. Some issues will necessitate using the methods that fit with these theoretical perspectives. However, when I consider my concern for the focus of the discipline of nursing “...the study of caring in the human health experience” as defined by Newman, Sime, & Cocoran-Perry (1991, p. 3), I require a different approach to gathering knowledge about the lived experience of the nurse-as-patient. So it is appropriate for me to use narrative inquiry to tell the stories of two nurse-patients receiving nursing care. Using narrative as inquiry for this nursing research project will contribute to the development of nursing knowledge.

Narrative inquiry

There is much written in the literature on the precise definition of narrative. The terms 'story' and 'narrative' are widely used in publications. Clandinin & Connelly (1994, p. 416) describe narrative as both phenomenon and method, and they say: “Narrative names the structured quality of experience to be studied, and it names the patterns of inquiry for its study.” They call the phenomenon ‘story’ and the inquiry ‘narrative’. Narratives are generally understood as stories that illustrate and explain human experience. Polkinghorne (1988) describes narrative as the most appropriate discourse for describing human action. The term ‘narrative’ embraces the stories of people's experiences and narrates them into order and meaning (Sandelowski, 1991). This view is supported by Stanley (1993a, p. 213) who wrote, “A narrative is a story told by structural and rhetorical means...” Polkinghorne (1988) refers to narrative as “a kind of organizational scheme expressed in story form” (p. 13) or “a meaning structure that organizes events and human actions into a whole”

(p. 18). Narrative is a way of knowing, because through narrative we share our experience with each other (Gadow, 1995).

People lead storied lives and tell stories of their lives. Narrative researchers describe these lives as they collect and tell the stories and write narratives of experience (Clandinin & Connelly, 1994). The methods we use in telling our stories of experiences are similar to the ones used in other qualitative research methods, of which there are many. Narrative approaches in qualitative research include life histories, oral history, biographies, autobiographies, ethnography, phenomenology, grounded theory, and research interviews. Story is, however, central to each. There is increasing interest in the use of narrative in current qualitative research (Mishler, 1995; Polkinghorne, 1997).

Story telling

Story telling is an intrinsic part of most cultures. Nurses have always told stories - about their patients, themselves, and their profession. Story telling is a natural and powerful means of communication between nurses. We first use it to listen to a person's story before recording it in some way. In nursing practice, Judith Lumby (1993) suggests that the transmission of the real story occurs as the nurse hands over the care of the patient to another nurse, the original story being transformed as it is retold. When nurses tell their clinical stories they invite others into their practice world; a world that is easily recognised by other nurses, even when there are different histories and different experiences.

My interest in the use of story telling arose from my readings during the early 1990s on the use of reflection in nursing education and practice (Boud, Keogh, & Walker, 1985; Mezirow, 1981; Schon, 1991). I was keen to work with nursing students and assist them to develop critical reflective skills for practice. The literature on the use of story telling, journal writing, and sharing examples from practice in the form of written exemplars, was becoming more prolific. New Zealand and British nurses were also being invited to submit their stories of nursing practice for publication in journals (Darbyshire, 1992; Editor, 1993).

The work that came out of the United States of America in the early 1990s, especially that of Diekelmann (1989; 1991), was also influential on my practice as a nurse working in education. In 1994, Diekelmann a proponent of the use of stories in nursing practice came to New Zealand and I attended one of her workshops. Stories enable us to share our practices, to evolve new thinking and understanding. The experience of the narrative can bring us to a place where the meanings and understandings of another can be made visible (Baker & Diekelmann, 1994).

Over the next six years I continued to formalise the use of story telling in nursing by structuring it as part of a course I coordinated. Students would return to the classroom after having spent time in clinical practice. An environment was created which enabled students to reflect on their practice, and with the aid of their journals, we shared stories from our nursing practice (Heinrich, 1992). The use of story telling as a formal activity enables students to preserve the integrity of nursing knowledge and to enhance their understanding and knowing in nursing. While sharing stories of nurses' practice is useful to nurses and students, it also helps make the work of nursing more visible (Koch, 1998), especially if these stories are published. However, if we are to strive for holistic nursing care which meets the needs of the/our clients, then as nurses we also need to hear stories from the perspectives of the/our patients and their families (Bradshaw, 1994).

A number of authors distinguish between the term story, storying, and story telling. Livo (1986. p. 108) describes story as "a way of knowing and remembering information", thus experience is restructured in order to be saved. Story is a method of organising, recreating and communicating a situation in order to share with others (Boykin & Schoenhofer, 1991). Story has emerged as an important way of understanding in nursing practice and education (Baker & Diekelmann, 1994; Koch, 1998; Parker, 1990). Meanwhile, storying is what we do to information when we transform it into a story (Livo & Rietz, 1986). In her seminal research on the development of expertise in nursing practice, Benner (1984) used narrative story telling as a method, to study skill acquisition in nursing practice. Other authors have suggested the relevance of story telling as a legitimate method of inquiry in nursing

(Gadow, 1995; Koch, 1998; Moss, 1991; Reason & Hawkins, 1988; Sandelowski, 1991).

Story telling is a means by which knowledge embedded in nursing practice can be uncovered and examined. In this thesis, the ontology or what it means to be a nurse, is discovered through the use of story telling by two nurse-patients. The use of narrative or story provides rich data sources for research that is truly nursing inquiry. As this study will include the method of utilising the personal experience of Maria the participant, and myself as the researcher and participant, a starting point will be our narratives of our experience. To use 'narrative as inquiry' in nursing research seems a natural choice of methodology for me, as it has become an important aspect of my nursing and education practice since the 1990s.

Narrative as inquiry in nursing

Nursing is experience, an engagement with people negotiating pathways through health and illness. The narrative of experience offers nursing a research method congruent with its practice of engagement (Gadow, 1995). Scholars across the disciplines are re-discovering the narrative nature of human beings suggests Sandelowski (1991). Likewise, she considers that the narrative provides a framework for understanding the person as the subject of nursing inquiry. This view is also supported by Boykin & Schoenhofer (1991, p. 245), who state the significance of narrative "lies in its potential for illuminating rather than obscuring the uniqueness, subtlety and depth of nursing knowledge". As mentioned earlier, Koch (1998) and Diekelmann (1993), proponents of the use of the narrative, advocate story telling as a method for interpretive inquiry. Telling stories, or narratives is a way of developing, interpreting and making visible our practical knowledge.

The focus of this work is to look within the stories of the two recipients of nursing care as they experienced it at a particular time. Our meanings and understandings are sought so that nursing might develop more awareness of what 'care' in nursing is concerned with. The stories were collected using narrative as

inquiry and the research method involved the biographical story of Maria and the autobiographical story of myself.

Autobiography as a research method

From the beginning of this project, I knew that my story - the story of the researcher - was important to this thesis, but just how it was going to be included was not clear to me at that stage. I grappled with the issues of how to incorporate and integrate the personal with professional and public ways of knowing. Much of the literature I was reading spoke of the need to position 'ourselves' inside our research, to be both the 'subject' and 'object' of our inquiry (Lather, 1991). Through the feminist literature, I came to understand that this study would involve the 'weaving' of biographies of both myself the researcher, and the researched, and our significant others (Cotterill & Letherby, 1993). Some authors claim that all research, whether acknowledged or not, involves elements of biography or autobiographies of all the participants involved (Cotterill & Letherby, 1993; Smith, 1994).

Life writing comes with many labels. Biography and autobiography are just two forms of the life history/story method. Conventional understandings of biography and autobiography as a research method have a longstanding tradition within sociology dating back to the 1920s (Ribbens, 1993). Nevertheless, its use as a research method declined in the following years because of the concerns about improving 'scientific credibility' in social inquiry (Denzin, 1989). However, in more recent years, auto/biography has received attention and acknowledgement as a rich, but unexploited form of inquiry (Ribbens, 1993; Smith, 1994). Stanley (1993b) presents an argument for the label 'auto/biography'. This is an attempt to reflect and redirect inquiry in life writing. Cotterill & Letherby (1993) appear to support this concept of 'auto/biographical' in their work on the weaving of the stories of both the researcher and their respondents. My work also includes the biographical account of Maria, the participant's experience of being a nurse-patient.

Midway through this project, I was introduced to the recently published work of Johnstone (1999), on the use of autobiography as a research method in nursing.

Documenting and analysing one's own life history is being utilised by a variety of researchers in other human disciplines. Yet, according to Johnstone (1999) and my search of the literature, the autobiography method is relatively unknown in nursing research domains. While Polkinghorne (1997) provides evidence of an early example of a narrative report by Moustakas in 1961, Johnstone (1999, p. 25) describes this same piece of work as "an important example of a reflective topical autobiography (although not generally recognized as such)". As I read Johnstone's (1999) article, I found myself becoming excited, for it seemed to label and validate the research method of autobiography that I was embarking on with my thesis.

When used as a research method, the aim of autobiography is not to represent a 'true' account of the self as those subscribing to the philosophy of positivistic research expect. The aim of autobiography, is rather to present "an account of the lived experience of the self that advances shareable understanding of common human experiences" (Johnstone, 1999, p. 25). The measure of this for my thesis will be in whether readers (that is, nurses and students of nursing) are able to find something in common with the accounts given of nursing practice from a nurse-patient perspective. This might help nurses and nursing students expand their insight and understanding about the lived experiences of their patients, and the meanings they attribute to them.

There is often a tension expressed between the treatments of personal experience narratives as an essentially 'objective' or 'subjective' account. I would suggest that it is more important to explore what auto/biography can tell us about our own 'subjectivities'. Auto/biographical writing is described as a particular reconstruction of an individual's narrative, and other reconstructions are possible (Clandinin & Connelly, 1994, p. 421.). From this point of view, while the auto/biography aims to re-count actual lived events – that may or may not be remembered 'truthfully' – its purpose is to guide insights into and understandings of the individual's lived subjective experience, not to construct as 'fact' historical life-events per se (Ribbens, 1993). Johnstone (1999) cites the work of several authors in

describing autobiographical memory as comprising a variety of embodied verbal, visual and felt memories.

Autobiography can take different forms, however, for this thesis I have utilised the reflective topical autobiography research method (Johnstone, 1999), as I understand it, to present my narrative. Reflective topical autobiography encompasses introspection of the subjective self and its interpretive responses to a 'snap shot' or a 'fragment' of the lived experience of my story, that of a nurse-patient receiving nursing care while hospitalised with a life threatening illness (Johnstone, 1999). The story is written from my deep involvement as the storyteller, the researcher, and from my own whole state of being in a particular experience. Reflective topical autobiography is located within the post-positivist interpretive research domain and adapts aspects of the research approaches of heuristics and phenomenology (Johnstone, 1999). It has the ability to advance nursing inquiry and knowledge by enabling the actual production of postmodern narratives (Johnstone, 1999).

In choosing to use auto/biographical narratives, I have at times felt a sense of unease in that the research text created involves 'real' people; it is about Maria the participant, and myself as researcher-participant. Clandinin & Connelly (1994) suggest that as personal experience researchers we must consider how our research texts may shape our participants lives. As the researcher and a participant, my identity is revealed, but I have endeavoured to protect the identity and confidentiality of Maria. In some sections of the research text aspects of our stories have been fictionalised as suggested by Clandinin & Connelly (1994). Ethical issues are further discussed in the next chapter.

This study will therefore present the biographical account of Maria's experience, and a reflective topical autobiography of my experience as a nurse-patient. Denzin (1989, as cited in Smith, 1994) describes these types of experiences as an 'epiphany' or 'turning point' which to date has been the most important personal-professional learning experience of my life. In the next chapter, I describe

the relevant steps involved in writing our auto/biographical narratives for this project.

Issues of rigour in narrative inquiry

In an effort to satisfy demand for validity or rigour, as it is referred to in qualitative research, researchers initially used criteria from quantitative research (Koch, 1998). However, more recently, researchers have adapted the criteria of credibility, transferability and dependability (Guba & Lincoln, 1994), for ensuring rigour in qualitative research. Credibility is said to be present when the research reports the perspectives of the participants as clearly as possible. Transferability refers to the probability that the research findings have meaning to others in similar situations, and the term dependability is used to encompass the processes of establishing that the research is credible. In this thesis, I have endeavoured to use 'reflexivity' as described by Koch & Harrington (1998) as a way of ensuring rigour in my research approach. Throughout this thesis my own position as a researcher has been revealed, and there has been ongoing self-critique. I have endeavoured to ensure that the reader knows what is going on throughout the research process. Readers will then be able to travel easily through the experiences of the participants and the researcher, and decide for themselves whether the text is believable or plausible.

Conclusion

In this chapter the methodological underpinnings of this research have been discussed. A research methodology that will generate knowledge of relevance to nursing practice is utilised. Narrative as inquiry has been chosen for this project as it offers nursing a research method that is congruent with the practice of engagement. Story telling is a natural means of communicating between nurses and has emerged as an important way of understanding within the nursing practice and education realms. This study using narrative as inquiry will embrace the use of stories and the biographical narrative of Maria, and the reflective topical autobiography of myself the researcher. The feminist process informs this postmodern project. In the next

chapter I discuss how the various components of the methodology have come together as the research process for this thesis.

CHAPTER FIVE: The Research Process

Introduction

The previous chapter discusses what it means to do research in a post-positivist/postmodern era. As I elected to use Maria's and my stories of our experiences as hospitalised patients receiving nursing care, it is appropriate that the methodology for this work is narrative inquiry. In particular, the reflective topical autobiographical method was selected to tell my story for the opportunity it offers to advance nursing inquiry and in "teaching students the art of investigating subjectivity" (Johnstone, 1999, p. 29).

This chapter begins by articulating the presence of the researcher as participant within autobiographical narrative research. A brief discussion on the relationship between the researcher and the participant is provided, followed by the process of selecting and accessing Maria, the other participant. Ethical issues concerned with the right to be fully informed, and the right to protection of identity and confidentiality are also specifically addressed in this chapter.

The proposed method of using email as a data collection tool is discussed briefly, followed by the actual process of linking with the participant to collect her stories and narrative by audiotape. As the researcher-participant, the process of writing my stories using reflective topical autobiography for this thesis is discussed. The chapter concludes with a discussion on the narrative analysis processes utilised for this study, and the final weaving together of Maria's biographical narrative and my topical autobiographical account. As mentioned in chapter four, I have attempted to incorporate a reflexive account into this project by signposting to readers 'what is going on' to ensure the text is believable and plausible (Koch & Harrington, 1998). Other authors suggest similar methods are necessary. Polkinghorne (1988, p. 177) wrote that narrative studies rely on "the details of their procedures" to achieve trustworthiness, while Sandelowski (1993) supports this, in her discussion on the issue of rigour in qualitative research.

Researcher as participant

Early in the preliminary discussions for this project when I first recognised what my thesis topic was to be, a supervisor at the time suggested that I write 'my story' as the thesis. She guided me to a collection of qualitative genres that could provide 'maps' for my narrative study (Barasch, 1995; Gaut & Boykin, 1994). My education and training in research methodologies had not prepared me for doing research in this manner. It was only after much reading and further discussions with my supervisors that the idea of using my story and that of another participant/s became a reality.

Having made the decision to use my own story as part of this thesis, I then had to consider how I might go about doing this in a safe and academically acceptable way. In discussions with my critical friends, many ideas were put forward. The idea of having a conversation with another nurse or perhaps several nurses who had been in hospital with life threatening conditions and who would be keen to share their stories about receiving nursing care was of interest to me. Oakley (1981) was one of the first to argue that the researcher should share her personal knowledge and experiences with the person she was interviewing as a way of encouraging women to speak openly about their lives. Finch (1984, as cited in Cotterill & Letherby, 1993) describes the need to place the researcher within the project as it results in a more honest and accurate account. While Cotterill & Letherby (1993) also assert that there is a place for autobiography within the feminist research process. In using the autobiography research method, and being a researcher-participant, I am taking a risk in rendering myself vulnerable, in that an honest self-disclosure of being a nurse-patient receiving nursing care is required (Cotterill & Letherby, 1993; Johnstone, 1999). To counter this, several critical friends have supported me throughout the project.

In the past, the personal voice has all but been silenced in academic writing. When the education institution where I worked first began to offer a degree in nursing in the mid 1990s, I read Webb's (1992) paper on using the first person in academic writing. Nursing as a relatively young academic discipline, has imitated

other longer-established disciplines and insisted on the tradition of objectivity and the use of the third person in written work. In my education practice, I advocate that it is acceptable for students to write in the first person when giving a personal opinion or when one has played a crucial role in shaping the ideas presented. The New Zealand feminist educationalist Jones (1992) supports this postmodernist standpoint when she wrote about her reflections of her own research writing in the book *Women and education in Aotearoa*. By using the autobiographical method to tell my story, it is appropriate for me to use the first person in this piece of work. In the discussion to follow, the relationship between the researcher and the participant is explored briefly.

Researcher - participant relationship

As part of the research process, the participant and I, share experiences and perceptions of receiving nursing care. Exposing ourself to another in the research process involved issues of trust, truth telling, respect, and commitment. As a nurse educator and a researcher whose practice is informed by a feminist process, it is important for me to work with people in a way that reflects reciprocity in the relationship. Reciprocity implies notions of trust and mutuality (Lather, 1991). The feminist aim of being an involved participant rather than an impartial or objective observer is also favoured. Narrative approaches are person centred, and unapologetically subjective (Hatch & Wisniewski, 1995).

Respondents to a survey conducted by Hatch & Wisniewski (1995) identified some of the major issues connected with narrative work; they include authorship, ownership and voice. At times throughout this project, Maria and I discussed these issues. Our discussions reflect shared concern for establishing a mutually beneficial relationship between us as participants and myself as researcher. Throughout this journey, I have been concerned with issues of 'giving voice' to Maria while working through issues of privacy, power and control within the researcher-participant relationship. It is argued, that the balance of power favours the researcher, for they walk away with the data and write and publish the research (Cotterill & Letherby, 1993). In the next section, I shall discuss how I was introduced to Maria.

Participant selection

On hearing of my intended research, several women expressed an interest in participating in the project, either to myself or to friends. However, when I first met Maria and heard aspects of her story of receiving nursing care, the idea of our two stories alone contributing to this thesis appealed. At the time of beginning this piece of work, my hospitalisation had occurred within the last six months, so I decided it was appropriate to work with someone who had also been hospitalised with a life threatening illness within a similar time period. I believe that my many years of nursing and education practice have a strong influence on my story of being a nurse, receiving nursing care. Therefore, I decided it would be appropriate to find a participant of similar age and cultural values, who was a registered nurse and also worked in nursing education. My nursing practice had occurred predominantly up to this point in the field of acute medical-surgical nursing. It also seemed relevant that the other participant in the study would have a similar background in nursing practice, and would have cared for patients in this area for a period of more than three years.

Access to participant

I approached a woman who agreed to act as a mentor, and to ask her friend (Maria) if she would be interested in becoming involved in my project. The mentor's role was limited to ensuring that there was no coercion to participate in the research project. She indicated that the potential participant was interested in discussing my research proposal with me.

Once ethical approval had been gained from the Victoria University of Wellington Ethics Committee, I began to contemplate my initial contact with Maria. I duly left a message for Maria on her answer phone, and went on with other aspects of my work. Finally, we made contact. I was able to introduce my project to Maria and discuss what it might mean for her to become a participant in my research project. Maria identified the present pressures in her life, but also stated her interest in being involved. I shall now discuss our subsequent contact with each other.

Meeting with the participant

While still in the initial stages of establishing rapport with Maria and discussing what might be required of her as a participant, I was planning a visit to her city for a work-related meeting. We arranged for our first meeting to be at her home and to carry on with our discussions about the project. I took a small micro cassette audiotape recorder with me because on each of my phone calls to her, she began to share aspects of being a patient and her experiences of receiving nursing care.

As I journeyed to Maria's place, I contemplated my initial meeting with her and how it would take shape. I was greeted warmly on my arrival. The formalities over, we sat down to talk and to continue discussions on how we could work together on my project. Maria began to share aspects of her story of being a hospitalised patient. I waited for the right moment and asked if she was happy for me to turn the audiotape on, which she agreed to. The evening passed quickly as our conversation moved from some of her stories on her experiences of being a patient, to our lives, our practice and families. My first rather impromptu attempt at audio taping our discussion was not entirely successful. However, as I travelled home, I reflected on Maria's story and made field notes. I was later able to refer to these field notes when I listened to the more formal audio taped story telling sessions.

Over the next six weeks we made several phone calls to each other as I continued to map out the process of how it was going to work. Some three weeks later when I attended a conference out of town Maria was also present. Neither of us had mentioned the fact that we would be attending the conference. So we met on several occasions. This enabled us to get to know each other further and to continue our conversations about the research process. Maria mentioned that she would be in my town over a holiday period. We decided to meet and to formally begin our conversations together on audiotape.

Our meetings and telephone conversations were important in developing a mutual understanding as we came to share stories of our personal experiences. On each occasion, I reflected on our conversations and made field notes. Hatch &

Wisniewski (1995) describe narrative research as being distinctive from other qualitative approaches in that it has a focus on understanding individual stories. Related to this emphasis on the individual, the process of doing narrative work is therefore more personal than other types of qualitative research. The researcher and participant work closely together to come to a shared understanding of the participant's story. From my experience of research I agree with this. I discussed with Maria the dilemma that I felt in being the researcher and our growing friendship, and the fact that it was important that she felt no coercion to be involved. Undertaking a research project places certain requirements on the researcher to ensure ethical standards are maintained. These will now be addressed in the following section.

Ethical issues

Prior to this study commencing, the application for ethical approval was presented to, and discussed with my thesis supervisor. Amendments were made before it was submitted to the Victoria University of Wellington Human Ethics Committee for subsequent approval. As a staff member at Christchurch Polytechnic, the proposal was also submitted and subsequently approved by the Christchurch Polytechnic Academic Board: Academic Research Committee. Issues concerned with the right to be fully informed, and the right to the protection of identity and confidentiality will now be specifically addressed.

The right to be fully informed

As a researcher I wanted to ensure that the participant would feel in control of the research process as much as possible. I also wanted to ensure that the research would not only be beneficial to myself in terms of gaining a Masters degree, but also to Maria the participant, and to nursing. As stated earlier, my initial contact with Maria was by telephone. At this time, the purpose of the study and the methods involved in collecting the data were explained to her. Following verbal interest being ascertained, I sent her the written information sheet (Appendix 1) and two copies of the written consent form (Appendix 11). Maria was encouraged to contact my supervisor or me if she had further questions that needed answering.

The two consent forms were signed by both of us at the time of our first formal audio taping session; Maria kept one copy of the consent form. I explained to her that she was free to withdraw from the study at any time and any information obtained from her would either be returned or included in the study as she wished. I also offered her the opportunity to read my written work prior to the completion of the project. At this stage, we also decided that a separate informed consent would be negotiated if I chose to use information collected in the research for published papers and conference presentations. The need to protect the identity and confidentiality of all concerned in the research process is discussed next.

The protection of identity and confidentiality

It is important that the identity and confidentiality of Maria the participant is protected at all times. This has been ensured by not revealing her name and geographical area. She chose a pseudonym that was used to identify all audiotapes and transcripts. Her residential area and the hospital where she was a patient have not been identified. Maria was sent a copy of her transcripts and the draft of the eventual core story created, to enable her to read and request any deletion or change of the material, which on reflection she preferred not to include. Further access to the data was restricted to the researcher, the transcriber, and the thesis supervisors. The need for complete confidentiality was explained to the person who word processed transcripts, and he signed a contract agreeing to protect the confidentiality of the participant. While all possible identifiers have been removed to ensure that Maria and other people involved in our stories will not be recognisable, identifiability cannot be guaranteed, as the participant's words and direct quotations have been included in this final written report of the study. Pseudonyms have also been used for the staff involved in our care, and for family and friends mentioned in our stories to protect their identifiability. However, as Maria and I do mention our mothers, and I include my husbands name in this work, we both obtained their permission for this.

Due to the nature of the topic that I researched and my personal involvement and commitment as one of the participants, my identity is revealed. Potentially this could make me more vulnerable after publication of the thesis, in that my

commitment to an honest account of my autobiography includes my criticisms of my life's work of nursing practice and nursing education. This is a problem that 'traditional' researchers do not face because they reveal less about themselves, and participants do not face because their identity is protected (Cotterill & Letherby, 1993). However, as with the other participant, I have been able to be selective and decide what I wish to disclose. The method of collecting the stories will now be discussed.

Collection of research material

From early discussions with one of my thesis supervisors and her suggestion to use my story with that of one other participant, the idea of writing letters using electronic mail (e-mail) was considered. My intention was to use electronic mail as the primary data collection tool. I had become conversant with the computer over the past few years and as I was writing the initial research proposal I obtained access to the Internet. I also envisaged that other data sources such as written narratives; journal entries; letters; and personal documents would contribute to the project. As a person who valued relationships with others, I also envisaged that some face-to-face contact would occur wherever and whenever possible.

As this project began to evolve, and it became evident that my potential participant did not live in my town, the idea of using e-mail was appealing. In my initial plans I had considered that the participant and I would be working together, sharing our stories via e-mail over an approximate period of six to eight weeks. As my discussions with Maria evolved during this preparatory phase, it became evident to me that this time frame would be too short and a longer period of time would be necessary to suit both our work and family commitments. In the following discussion, I present a brief overview on the possibility of using e-mail as a data collection tool.

E-mail as a data collection tool

Nurses within the clinical area, education, management, administration and research, are increasingly using computer technology. Although personal computers have traditionally been used by nurses as word processors, they are now being used more widely as nursing information systems, for example, creating and searching databases, searching the Internet, and for storing patient information (Bowles, 1997). Two reports were located outlining the use of the Internet and electronic mail as a data collection method (Fawcett & Buhle, 1995; Murray, 1995). Both articles mention that there is little literature related to this method. Fawcett (1995) and Murray (1995) outline the many advantages and fewer disadvantages of using electronic mail, and both comment that it has potential for researchers with access to online facilities.

One of the primary advantages of using e-mail is that electronic data collection occurs at the user's convenience. As a busy woman, wife, mother and nurse educator, I consider this an ideal way of linking with a participant who would possibly be equally as busy and who lived in another part of the country. E-mail also appealed as a cost-effective method for collecting data. Another important aspect and added bonus of using email is that there would be no need to transcribe the data. All data would be copied onto a computer disc.

However, after discussing my intentions with Maria, she was not keen to use the e-mail method as a means of communicating her story. She did not have easy access to a computer with Internet services and she was currently spending much time with her own writings on the computer. To share her story with me by writing it as e-mail felt like another constraint on her precious time. Maria constantly said she was happy to talk with me and for us to audiotape her story. The idea of using e-mail as a data collection tool on this occasion became less appealing. In the following section I will discuss the process involved in the audio taping sessions.

The Audiotapes

As noted in the previous chapter, narrative inquiry is used for this project. The technique I used in obtaining Maria's biographical story is influenced by the work of Minichiello, Aroni, Timewell, & Alexander (1990). They suggest the choice of interview strategies are dependent on the perspective the researcher holds and that:

“Interviewers rarely ask directly for a story. However, in the case of a life history, this is very often what is called for” (Minichiello et al., 1990, p. 118).

Minichiello et al. (1990) also describe story telling as paralleling the social interaction of a normal conversation. This best describes the technique utilised for audiotape one in this study.

Audiotape one

Maria arrived at my home late one Saturday afternoon. We moved into my office and began informally by talking about her work and then my study. As we had met on two previous occasions I aimed to give Maria the opportunity to further discuss the project and to seek her written consent before we began taping the conversation. From my previous research experience, I understood the importance of creating the right environment when using interviews as a method for collecting data. We discussed both the information sheet and the consent forms before signing them. The right to be fully informed has been discussed earlier in this chapter.

At this first formal session together, I shared a comment with Maria that I hoped would enable her to recount her story. My intent was that rather than seeking an interview with her we would share our stories together. The interview with Maria more aptly resembled a story telling session - I was the active listener as she put her feelings into words that she felt encapsulated her experience. She was free to select aspects of her experience that she saw as pertinent, and to develop her ideas and feelings as she wished. In the later part of this session, by adding aspects of my own experience I was perhaps encouraging Maria to explore some of our shared

experiences. I felt pressured by the time constraints we had, and at times I had to resist the temptation to seek further information in an area that seemed of intense interest to me, but at this stage in the story telling it seemed of little relevance to Maria.

Unfortunately it was necessary to bring this story telling session to a close. We arranged to meet again while Maria was in town but due to her commitments this did not eventuate. However, Maria offered to share the rest of her story on an audiotape and post it to me. This first audio taped story-telling session thus recounts the story of Maria, a nurse-patient receiving nursing and medical care during a life threatening illness when admitted to hospital for elective surgery. The audiotape was later transcribed and subsequently returned to Maria for her comment. My own reflections on the taping session were recorded in field notes. Within a week of the first recorded session together I sent a blank audiotape and letter to Maria as she had suggested. In the next section, I discuss the process involved in preparing to record the story of Maria's second admission to hospital.

Audiotape two

As Maria had many pressures and commitments in her life, we renegotiated a fairly open time frame that would fit with the requirements and expectations on me to submit a Master's thesis. She frequently stated her commitment to my project. However, it was another three months before I received the second audiotape from Maria. At this point, we revisited the information sheet and the anticipated plan of using e-mail for this project. Maria again expressed her reservations and limitations in using e-mail, although she was happy to continue to dialogue our experiences as telephone conversations and for me to record them. I subsequently purchased the technology to do this. But unfortunately it did not happen due to her commitments and time availability. I am reminded at this point that things do not always work out the way the researcher originally intends. So as I wished to foster reciprocity and promote co-operation and collaboration within the research process I continued to negotiate with Maria as to the best way of gathering the stories.

Thus, Maria recorded the second audiotape in her own home. It records her story of what it was like to receive nursing and medical care when she was readmitted to hospital with a life threatening illness. As mentioned earlier in this chapter, I had envisaged that other data sources apart from e-mail would contribute to my project. However, I had not entirely anticipated that my project would evolve in this way, but I was happy that Maria had offered to share her story using an audiotape. As with the first audiotape, this second audiotape was also subsequently transcribed by a person who I had contracted for this purpose as mentioned earlier, and both transcripts were sent to Maria for her comments.

Returning the transcripts of the audio taped sessions to Maria was for me an essential part of ensuring accuracy of the stories. This enabled Maria to not only check the account of her experiences, but also to stimulate reflection for further dialogue. In keeping with the feminist underpinnings of this research, returning the transcripts helped maintain participant ownership of the data provided. The process of linking these two audiotapes which tell Maria's biographical story, and the subsequent creation of a core story as described by Emden (1998b) is fully described later in this chapter under the analysis section. In the section that follows, I shall explain the process involved in writing my story, that of the researcher as participant.

Collecting and writing autobiographical data

My experiences of being a nurse-patient have had a profound affect on my personal and professional life. I realised that it was important to make sense of my experiences in the context of nursing and nursing education as it was happening in one region of New Zealand in the mid 1990s. There is ample evidence as cited in the previous chapter, to suggest that autobiographical writing is relevant as a research method, and promises to make a significant contribution to nursing inquiry and nursing knowledge (Johnstone, 1999).

In her article espousing reflective topical autobiography, Johnstone (1999) outlines several steps that a researcher engaging in this process might follow. These include the steps of; immersion, incubation, illumination, and contemplation which I

will now discuss. As mentioned earlier, I came to this method after my topic was identified. My experiences were a 'turning point experience or epiphany' (Denzin, 1989). It seemed to fit the autobiographical approach that I had already begun. I felt I was already working within the immersion phase as described by Johnstone. Using the strategies of deep and systematic introspection and self-dialogue, I was able to explore and describe the perceptual, emotional and cognitive details of my experiences of being a nurse-patient. Once immersed in these experiences again, I returned to my earlier journalled notes and reflected on the key aspects of my experiences. I then began my narrative by writing a rich descriptive account of the events. This became the raw data for my reflective topical autobiography. At times during this early writing phase I included a self-dialogue on the events and provided some critical self-reflection. However, a more in-depth, critical self-reflection on what was happening at the time, and my thoughts and feelings associated with the experiences, followed in the re-draft of my writing.

Following the intense, concentrated focus that was required of me while writing my narratives, I was pleased to be able to enter the next step in the reflective topical autobiographical process. The 'incubation' phase as described by Johnstone (1999) enabled time for me to clarify and extend my knowledge and understanding of these 'turning point' experiences. During this time, I continued with my dialogue and the data collection process with Maria. Later in this chapter I discuss the further steps involved in uncovering the meanings from my narratives.

Initially, when I began to write my story, I felt a sense of self-indulgence. It seemed almost decadent to be sitting alone at my computer writing about my subjective experiences. Ribbens (1993) describes similar statements made by other autobiographical writers and suggests that there may be a parallel here with research interviewees being hesitant in talking about themselves. Riessman (1993) reminds readers that personal narratives are studies of subjectivity, and nursing research has sought to increase understanding of subjectivity and to make these subjective experiences, such as those of Maria and myself, more visible and intelligible through interpretive research (Johnstone, 1999).

The process of writing about my experiences of receiving nursing care, and in making those experiences public, has at times made me feel vulnerable amongst my peers in nursing. I have endeavoured to develop this piece of work in such a way that it does not act as a personal catharsis, but speaks to others in ways that are found to be acceptable and convincing.

Data sources in this study have included: Maria's audiotaped stories, my reflections and self-dialogues on my experience as a hospitalised patient, the literature on nurse-patients' perspectives, and non-nurse patients' perspectives of receiving nursing care, my journalled reflections throughout the thesis writing, and excerpts from my patient progress notes. Formal collection of data has involved only the material derived from Maria's audio taped sessions and my autobiographical writings. In the section to follow, I shall discuss the process involved in analysing these narrative stories.

Analysis of the research material

The process of collecting research material previously described resulted in a collection of stories and narratives. The goal of analysis is to uncover the common themes or plots in these narratives. I have not used a qualitative research analysis programme such as *ethnograph* or *NUDIST*, which assists in the data analysis process. Instead I have used manual analysis of the data in order to retain personal input and flexibility. An article by Australian nurse scholar (Emden, 1998b) on *Conducting a narrative analysis*, provided me with further clarity, along with the work on narrative analysis by Polkinghorne (1988), Mishler (1995), and Riessman (1993).

In the following section, I will begin with a discussion on the process involved in preparing Maria's stories for analysis using 'core story creation', and the subsequent process of 'emplotment' as described by Emden (1998b). As mentioned earlier in this chapter, my reflective topical autobiographical narrative was constructed through the processes described by Johnstone (1999). The next steps of

‘illumination’ and ‘contemplation’ will then be described. This section will conclude with a discussion on how the meanings of the two narratives are uncovered.

Analysis of the audiotapes

As previously mentioned, two tapes were obtained from Maria during the data collection phase and subsequently transcribed. Maria was sent both of these transcripts to read and make comment on. I then began the work of proof reading and correcting each transcript as I listened to the audio tape recording. As I became more accustomed to the sound and familiarity of Maria's voice and content, I was able to hear words and nuances that the transcriber had missed. This enabled me to revisit our first shared audiotaped session and to listen to Maria's second tape that she had audio taped in her own home. The corrected transcripts of these sessions were posted to Maria. I asked her to make any comments and corrections she felt necessary, and to consider the reading of the transcripts as a catalyst for further thought and dialogue between us.

Over a period of several months I re-read the full transcribed texts of Maria's audio taped stories many times, while simultaneously listening to the audio tapes. This enabled me to better understand the content. I favoured the narrative analysis strategies of ‘core story creation’ and ‘emplotment’ described by Emden (1998b) in her nursing study on scholars and scholarship, as it retains a feeling of the whole story. ‘Core story creation’ is a method of reducing the full-length story as shared by Maria to a shorter, concise story, to aid in the narrative analysis process. I shall begin with this process.

Emden (1998b) suggests that the main points or theme of a story are not always found neatly packaged by the narrator. I found this to be the case in Maria's stories. Using the steps of core story creation outlined by Emden (1998b), I removed all unnecessary duplications of words and sentences that detracted from the key ideas expressed by Maria. With repeated readings of this now shortened ‘core story’ and simultaneous listening to the full text on the audio tapes, I was satisfied that Maria's stories and narratives of being a hospitalised patient receiving nursing care, remained

intact. Mishler (1986, as cited in Polkinghorne, 1988, p. 176) describes this process of returning to the original audio recording, as a way of ensuring the trustworthiness and dependability of the data.

However, as the spoken story often moves between stories, the next step outlined by Emden (1998b), involved identifying 'fragments of themes' from the ideas expressed within the text and moving these ideas together to create coherent core stories. After several readings I began colour coding to identify groups of ideas or fragments of themes as I recognised them. Maria had identified that audiotape one represented her first admission to hospital and audiotape two represented her second admission to hospital. Other than knowing this, I did not read the transcripts with any sense of pre-set categories or themes, nor did I have any imposed framework in mind. These began to emerge as I read Maria's stories and became immersed in reflections on my stories, and the literature on patient's perspectives of receiving nursing care. The analytic process was interpretive, as I did not impose any theoretical framework on the project. This correlates with the method of reflective topical autobiography that belongs to the genre of interpretive research and rejects theoretical imposition (Johnstone, 1999).

The final step described by Emden (1998b) involved returning the core story to Maria, as I had promised to do this early in the project. During this project there was difficulty at times connecting with Maria on the telephone. Over a period of three weeks Maria and I left several phone messages on each other's answer phones as I attempted to make contact with her before I posted off a letter, and my core story creation from the corrected, transcribed audiotapes. The questions I asked Maria about my core story creation were:

...Does it ring true? Do you wish to correct/develop/delete any part? I would appreciate any comments or suggestions from you as you read the story, make comments.... I have endeavoured to protect your identity and maintain confidentiality, and have at times changed

things a little for this reason. But I believe it remains true to your original ideas expressed. What do you think?

By returning the core story to Maria and seeking clarification, I was enabling the participant to become a true narrator of her experience. Involving the participant in this manner may perhaps eliminate the dilemma described by Bruner (1987) who asks, 'by what criteria do you determine the rightness of a story?'

After almost four weeks of not hearing from Maria, I finally managed to get her on the telephone one evening. She had begun reading my creation of her story, and she said she would make some changes to make her feel '*less vulnerable*'. She said I had done '*a good job*'. She restated her commitment to my research, particularly now that she had started her own thesis and was having to seek people to interview. Maria now spoke from her own experience and understanding of the difficulty in getting research participants. She promised to phone me back.

Another ten days went by with no word from her. I phoned again and left a message on her answer phone. Despite the fact that Maria had on many occasions told me to keep phoning her, I did not enjoy having to always initiate the contact with a research participant. I was conscious that I was the researcher; I did not want to be seen to be coercing Maria. It was to be another three weeks before we would connect again. I was anxious to receive her chapter and to make the necessary changes that would then enable me to proceed with the next step in the analysis process.

On making contact with Maria, I was taken aback by her discussion with me. Despite saying she would get the chapter into the post the next day, Maria now stated she was '*feeling sensitive*' and was '*concerned about (her) voice*'. She was now openly expressing her vulnerability and hesitancy as a participant in the research process. Maria stated '*I feel better about the changes*', that she had made, but she said she was feeling '*confused*' about the truth of her story and what she could remember. She said she found it distasteful and was not interested in retelling or

rewriting her experience. From my readings and understanding of working from a postmodern perspective, I suddenly realized that Maria's concern was perhaps more to do with her understanding of the notion of truth in research. I mentioned that her story and narrative as originally told, did not need to be rewritten as with each presentation of our story we re-present the experiences (Polkinghorne, 1988). In the more recent work on postmodernist representation, Tierney (1997, p. 25) states it becomes "One version of reality rather than the only version".

The telephone line was not clear and I was having trouble hearing Maria. I also sensed that Maria was not her usual self. I said that it was difficult to know what the extent of the changes were without having her amended version of my 'core story creation' in front of me. As she had suggested earlier that she would post it the next day, I asked that she do this as long as she was comfortable with the changes she had made. I said I would phone her when I received it. I was extremely conscious that Maria's commitment to my project had taken a lot longer than both of us had anticipated. Her amended story arrived in the post within the next couple of days and was accompanied by a letter.

Maria wrote that she was now feeling easier with my core story creation. The requests received from Maria were for changes to statements that she felt might identify her, not so much about herself but about those of whom she spoke. Maria also suggested changes to where her memory of the events had changed, or as Polkinghorne (1988) contends, the events had been reshaped by later happenings. Sandelowski (1993) describes this issue of research participants changing their stories from one telling to the next, as the 'revisionist nature' of narratives. Over the next few days, I went through Maria's narrative and made the required changes. The strategy of using core story creation was effective in making Maria's narrative a coherent and concise story. The core story created from the two audio taped sessions used Maria's own words almost exclusively. The final step in the narrative analysis is to make sense of the narrative. This will now be described in relation to Maria's core story using the process of 'emplotment' (Emden, 1998b).

Emplotment of Maria's narrative

Emden (1998b) describes the term emplotment as the process involved in making sense of the story. It requires the identification of one or more plots (themes or main points) or 'plotting' as Polkinghorne (1988) suggests. The emplotment process of narrative analysis has some similarities to the thematic analysis proposed in phenomenology; the plot in narrative analysis is a similar concept to a theme (Emden, 1998a). Polkinghorne writes that emplotment, "can generate unique and novel configurations" (1988, p. 20). However, he does not specify a procedure for plotting and states that it is not a rule-governed activity. It remains for researchers to clarify and determine their own specific plans. However, Polkinghorne describes a 'tacking procedure' or moving back and forth between plots and the events in stories. Like Emden (1998b), the tacking procedure identified by Polkinghorne (1988) best describes the emplotment process I utilised with Maria's narratives.

Using the principle of 'best fit' and a pen and paper, a dialectical process took place between the events as described in Maria's narratives and the emergent plot or themes as identified by myself (Polkinghorne, 1988). This process of moving back and forth helped ensure that a preconceived plot structure was not imposed upon the events. The emplotment process began with the identification of four subplots within Maria's narrative and a searching back and forth for what was important. I was looking to see what distinguished them. I named these four subplots; *knowing as nurse-patient*, *caring nursing*, *uncaring nursing*, and *getting out*. Further searching back and forth across the stories to compare and contrast these distinguishing or important features was used to see if they were common to more than one story (Emden, 1998b). These are discussed fully in chapter eight. The next part of the narrative analysis process describes the examination of my autobiographical account.

Analysis of my reflective topical autobiography

During the 'incubation phase' as outlined by Johnstone (1999), I spent many weeks reading and clarifying my knowledge and understanding of my reflective topical autobiography. In the process I experienced a breakthrough into conscious awareness of the qualities and themes inherent in my research topic of 'nurse-patient'.

The illuminations I experienced enabled me as self-researcher to fully reflect and examine the meanings I was uncovering through the process of deep introspection or 'contemplation' (Johnstone, 1999). Emergent themes became evident to me throughout the steps of illumination and contemplation. These emergent themes include; *knowing as nurse-patient, being nursed, not being nursed, and not wanting to return*. These emergent themes are fully discussed in chapter eight.

Making sense of the narratives

My task as the narrative researcher has been to grasp the features of the individual stories of being a nurse-patient that are significant for Maria and myself, and to make sense of these events as one story (Polkinghorne, 1988). By referring to the plots (themes) identified during the emplotment phase described by (Emden, 1998b), and the emergent themes identified throughout the incubation, illumination and contemplation steps described by Johnstone (1999), I have brought these issues together as a further narrative. Three distinct qualities emerged from both of our experiences. The first, 'knowing as nurse-patient' contains the three sub themes: 'having knowledge', 'expectations of being nursed', and 'knowledge gained'. The second distinct quality 'being nursed' contains the two sub themes: 'feeling safe and cared for' and 'presencing'; and the third 'not being nursed' contains the four sub themes: 'feeling vulnerable', 'invisibility of nurses', 'getting out' and 'feeling let down'. The sub theme 'getting out' includes three additional sub themes: 'wanting to get out and not wanting to be there', 'leaving and the need for closure' and 'not wanting to go back', which are fully described in chapter eight. In the final section of this chapter I will present a brief discussion on two specific issues arising during the data collection process.

Issues arising in the process of data collection

As mentioned earlier, during the extended time of developing a rapport with Maria and collecting and transcribing her stories, we were in telephone contact. On one occasion Maria surprised me by asking, "*had I found someone else?*" But she added very quickly, "*I am committed, I am happy to dialogue*". Maria acknowledged

the many constraints on her time, and as the researcher I was mindful of these. There were times when I thought that perhaps she did not wish to continue, but she frequently stated she was committed to completing the process with me. As I have previously mentioned, the further dialogue and reflection that I had anticipated would occur between us, did not happen.

I believe the return of the transcripts was an integral part of the research process. I had also agreed to send my written story to Maria as a way of stimulating further discussion. However, on reading through Maria's full written transcript prior to doing this, I became concerned that my final written story was the result of much reflection and re-wording on my part. Maria's story was transcribed as it was reflected and spoken by her. Because of the limitations on her time, I made the decision not to send her my written story. I felt this academic piece of writing might cause her further distress. In consultation with my supervisor, I made the decision to utilise Maria's two transcribed stories along with my story and my field notes for the analysis part of the thesis. Further dialogue was limited to clarifying aspects of her story on the telephone. We discussed very little of my experiences as a nurse-patient receiving nursing care.

Conclusion

This chapter has outlined the practical aspects of carrying out the research and the issues involved with researcher as participant. The relationship between the researcher and the participant has been discussed, followed by the process of selecting and accessing Maria. Issues concerned with the right to be fully informed, and the right to the protection of identity and confidentiality have been presented. The proposed method of using e-mail as a data collection tool was discussed, and in particular, the method of collecting Maria's stories. The process of weaving together the biography of Maria, the autobiography of the researcher, and the analysis of this material was presented. Background information to this study is now complete; the next chapter introduces Maria, and it tells her story of being a nurse-patient receiving nursing care, when admitted to hospital with a life threatening illness.

CHAPTER SIX: Maria's Story

Introduction

In this chapter, I will share the story of Maria, a woman, nurse and nurse educator receiving nursing care while hospitalised with a life threatening illness. Maria's story of being a nurse-patient will be told in two parts. In the first part, the story begins with her experience of undergoing routine surgery that resulted in major complications and an extended hospital admission. In the second part, Maria shares her story and experience of being a nurse-patient receiving nursing care during her re-admission to hospital. Maria describes these experiences, which took place over a six-week period by stating “it shook my perceptions of therapeutic care. Until then, I had accepted it unconditionally as the essence of nursing practice”.

I will begin by providing a brief introduction to Maria that aims to protect her identity and maintain confidentiality. Maria has extensive experience as a registered nurse within medical speciality areas. She has worked in both secondary care institutions and the community. At the time of her surgery, Maria worked as a lecturer in nursing education. She was also enrolled as a postgraduate student in a nursing programme. She was admitted to a large city hospital for elective surgery.

“Terrible Nursing”: First admission to hospital

It was a lovely summer's afternoon when Maria came around for the first audio taping session. We adjourned to my office to begin our session together. After signing the consent forms, Maria asked me how we would start? What questions did I have? I replied that it was her story I was interested in, rather than seeking an interview with her. I suddenly became aware of the change in the proposed method of collecting data from using e-mail to now having face-to-face contact. I had not totally prepared myself for this. As a beginning, I adapted a comment I had heard a colleague use when discussing her research. I said:

I have this experience of being a nurse-patient in hospital, with a life threatening illness; I want to know what it was like for you, who has a similar background to me and how the sharing of these stories may contribute to nursing knowledge for educators/students and clinicians. I'm really interested in your story about being a nurse as a patient and what it was like for you. There are going to be lots of stories within that, and I suppose, if we just start with whatever you want to start with. I'll pick it up at different times.

Maria then began to share her story of being a nurse-patient receiving nursing care. She began by talking about her pre-operative care:

It's been some time now, but I think the thing that hits me about going into hospital, is that knowing, because I am a nurse, I actually had a right to question. When I was trying to decide, about going into hospital, I was thinking, did I really want this surgery? Knowing that I had been offered it four times. I had lots of problems, but I still had anxieties about it. Because I was a nurse, I felt like the other nurses actually listened to that anxiety and bypassed the house surgeon, but accessed the registrar, although I think he was a bit flippant. My first introduction to the nurse who admitted me was positive, in the fact that she advocated for me. I think that probably would have happened anyway but I feel like she made a point of letting me know that she was advocating for me. So that was my first introduction. The freedom of going out of the ward once I had been admitted and coming back late at night and being told how to access the hospital as well as the ward I was in.

The very next day when I was going to theatre, I remember being given a razor, and I presume it's that thing of, everyone expecting you to know what to do. It was, a sort of a razor that I had never seen before, I didn't know whether you used it wet or dry, or really how

much I needed to shave, because it was internal surgery anyway. So that was my first experience with ... you are meant to know this because you are a nurse, but perhaps I didn't know what I was expected to know.

And going on to theatre feeling incredibly alone, partly because I had no one there. I also realised that I was doing this on my own, I felt incredibly distressed. It was a feeling of vulnerability really. Then going to theatre, and my friend who was a nurse, being there to greet me, as a theatre nurse, her smiling, positive face, her bright lipstick, and her presence. I stayed focused on the fact that she was there for me. She stayed with me until I went under (the anaesthetic). Her presencing, as a nurse, was special, she was relaxed, yet confident, but it was also because she was a friend and she was a nurse in that position. She made herself available for that shift.

When I woke up post-surgery, I was just relieved it was all over. My positive way of thinking about things usually comes back to me. I think that I must have had incredible anxiety leading up to this surgery, although I dismissed it. Despite extreme pain, which I realised on reflection was the beginning of haemorrhaging internally; I was just relieved that it was all over. Going back to the ward and having friends there, from then on really, all the time I was in hospital, meant that I felt ok. I definitely felt like I was going to be out of there within a day or two because I can cope with pain. I was pretty horrified when things went a bit differently for me.

The first day, I think because I was a nurse, I was a bit cheeky about what I knew. I knew that if I drank I would vomit, but I knew that I wanted to drink because I had extreme thirst. On reflection, I realise that extreme thirst is related to haemorrhaging, it was extreme thirst. I talked a friend, who was also a nurse, into going and getting me

cans of Diet Coke, or Pepsi. Knowing that and being quite insistent for nurses that, I wanted ice. I think it was on the first day that I realised I was actually a bit resistant to using the PCA (patient controlled analgesia) because I felt I could cope with what I had to cope with. I didn't want to use a PCA. The nurses helped me sponge that night, I felt fresh, and I felt cared for.

I think, the next day when I woke up, I was starting to have abdominal bloating. That day for me, was the day that I felt really distressed about the level of nursing I received. Not because of people not being nice to me, but feeling and getting sicker, and realising that I was sort of asking questions. Asking why my underpants were wet when I had a supra pubic catheter? Asking why my stomach was blowing up? At the same time knowing that I was the nurse, I mean I was the patient not the nurse.

I remember one nurse in particular, and being aware of her distress while nursing me. Friends sort of recognised her anxiety in nursing me. Also the nurse who had advocated for me, when I said to her as things went wrong, 'why is my stomach blowing up?' She didn't really address it, although she came back to me later, a few days later and apologised for not addressing that. I think that reminds me of the learning that I have done in nursing, that actually sometimes you learn through your mistakes. Sometimes that is at the patient's expense. When I think of the patient that I nursed who had an anaphylaxis reaction, now I know how to deal with that. But until that happens, you don't know how to deal with it, and you are grateful that you managed it. I thought these nurses were a bit like that, with regards to managing my post-operative complications.

I was first on the theatre list, so that was quite a long day with lots of visitors. By that evening, I was getting into trouble with not passing

enough urine. I remember this pool nurse coming in, she was also a midwife, and that nurse, you could just see the expert knowledge and her actioning it quickly. I guess I went from routine surgery to someone who was having some problems. So having Haemacel (a colloid replacement fluid) put up and fluids pushed, and that nurse..., she was really confident and didn't bother with all the niceties and all the talking that some of the other nurses were doing. I felt really good about whom she was. She knew her stuff.

I'm getting my days mixed up here really, but I think, that the next day when I started to get a bit bloated, more bloated, I also had this quite bad pain, abdominal pain. I remember saying to the consultant about it. He ordered a blood test that never got done, which is why the factor didn't get picked up. At that stage, I remember friends coming in, lots of people visiting all the time, people being quite angry about the nursing. Friends that were nurses were quite horrified with the way I looked. They realised that I was quite sick. Friends who were I guess, really experienced nurses, being quite aggressive to one of the new graduate nurses that was looking after me. They were muttering under their breath that obviously I wasn't well and what's happening and why weren't things being sorted out.

That particular day, the consultant, this is two days on now, the consultant came back in and realised that the blood test hadn't been taken. I think what happened is that the doctors were changing over. By that day, which was a Friday, I was a mess. My blood pressure was low, I had the Haemacel and all that sort of thing (other intravenous fluids). But, by then, my blood count was in the fifties (haemoglobin level), I was incredibly oedematous and white. I remember looking at myself and thinking how shiny I was. By that stage, they were taking out the supra pubic catheter. I had changed my underpants twice and said to a nurse 'my pants are wet'. I smelt

them as a nurse but they didn't smell like urine. In retrospect, by that time I had quite a hole in my bladder from the supra pubic. I had an IDC (indwelling urinary catheter) put in and had constant urine measures. By that stage, my output was high because I had gone into a polyuric phase (a large volume of urine voided).

I remember at one stage having a sense of drifting in the room a bit. My friends were sitting there, and I was actually thinking that I was sitting with them, but I wasn't sitting with them. At that stage, some friends had rung my family, none of my family lived nearby. I was possibly going back to theatre, and I was having some scans that day. A friend was there; she went with me, which was really good. The scan showed that there was a lot of fluid in the tissue above the bladder and a hole. I don't think it actually showed the hole in the bladder. They worked that out because of the leakage of fluids into the tissue - I had an interstitial leak of urine. When I look back, I was incredibly oedematous and transparent. Friends that came and saw me that next day, still remember how I looked. When all the fluid went, I had actually lost quite a lot of weight, but my abdomen was bloated. At that stage I was being sponged in bed, the nurses were really quite attentive.

I had blood cross-matched that day and started a blood transfusion. It was incredible, because I had said quite clearly at my pre-assessment visit that I didn't want any blood with this surgery. There was quite a hoo haa about this when I was going to have three-four units of blood. I think I put that down to the imbalance of experience in nursing. I think my nurse had never given blood before. From my own nursing experience and the specialty area that I worked in, giving blood was actually no big deal with me. I remember having this blood, with nurses incredibly anxious about recordings, whereas in reality, it just seemed like their novice nursing came through to me. The doctors had

come to get the consent and were aware that I hadn't wanted to have blood. They said it would take a long time for my body to pick this level of blood count up. They also said that it would help the fluid shift and the extent of oedema that I had. Another nurse, the nurse who had advocated very well for me, and who hadn't listened when I had gone on about my abdominal distension, then talked about the risks of giving blood. It's a bit like with a drug, there is a hundred and one problems that can be caused by a drug, but you don't actually have to explain all of them. I felt like telling her to stop because it was a patient's choice. I had little choice with the amount of blood that I had lost, and I wouldn't have agreed to receiving blood if it was only one-two units that was needed. But, I wanted to get well and get home.

I think by that time, I felt aware I had caused some problems. There had been some knuckles wrapped I think, about the fact that the blood hadn't been taken. There was a bit of debate as to the cause of the renal problems. There was some discussion about an ADH (anti diuretic hormone) thing, post surgery shock, or was it the Voltaren (anti-inflammatory drug) I had, that had caused these side effects? The consultant or someone said it was glomerular damage and had consulted with the renal team to come in. By then, I was producing excessive amounts of urine, and I was incredibly thirsty. I was drinking, like before seven o'clock in the morning, at least one litre of fluid, just to quench my thirst. It actually took several days for that to ease off.

The thing that did hit me was that I had this catheter, an IDC (an indwelling catheter) in, and had the lines in. I think I actually probably got the PCA taken out a bit prematurely, but to me it was important to have it out, as I was going home on the third day. I do remember saying very clearly to nurses that I had this pain on the

right hand side. When I said that to the consultant the following day, he did blood tests, he acknowledged that it was probably a bleed. Yet, none of the nurses seemed to acknowledge it when I talked about the pain. I had taken the PCA directly for pain on my right hand side; it was when I was haemorrhaging. It wasn't to do with normal surgery pain. I think when you haven't had the surgery yourself, you don't know what you are expected to have. However, you expect the nurses to, with knowledge or experience, to be able to tell what is normal or what is not normal.

I think the other thing is, that while I went in with a pulse (rate) lower than 60, although probably on my admission it was higher, that is what my resting pulse (rate) usually is. My BP (blood pressure) would be 100/60. Therefore, when I was haemorrhaging and getting quite dehydrated and things with shock, my pulse rate had gone up, the most up to 90. To most people that wouldn't actually be that shocking. I think people expect you to fit into that sort of textbook thing. I think this is why there was this discomfort a little bit about the management of me. I must admit from then on, that definitely medical-wise, it was the consultant who sort of made decisions. The nurses in a way, sort of seemed to advocate for me out of a bit of concern for what the consultant wanted.

I remember once I started getting up, I wanted to get dressed, and I had a shower. But I had to ask for things, I think it was again, it was (in) experience. Like thinking of things, like a leg-bag for the catheter so that I didn't have to carry a catheter bag around. I think I was my own worst enemy, because I remember asking for the leg bag and then walking through the hospital with this leg-bag on. I think this was my own determination really. I walked over to another ward, to where my friends were, walking up the stairs, not taking the lift, like proving that I was going to get there despite this catheter bag.

I wanted to get out, to go home for lots of reasons. After a while I got to the point where I felt like I had outstayed the normal patient stay. I was also aware that I had too many visitors and phone calls. I was using the phone a lot, organizing the grocery shopping and trying to do things, so I had to get out of there.

There were nurses that were really nice to me, and there were still nurses who I felt had a real concern for me. Maybe I was oversensitive but I actually remember there was one nurse in particular who I hated looking after me. She had no caring about her at all. That nurse could wreck your day, by just a comment in the morning. For me, things like "oh you've hardly made a mess of your bed", so actually, not stripping your bed, just pulling it up and not making it. Those sorts of things didn't appear to be caring to me. Maybe it was my training, as in many wards it is now not the nurses who make the beds anyway.

This particular nurse, who I think was really slack, the nurse who didn't pull my bed up and didn't sterilise the jug again or things like that. Things like to me, when someone has got a continuous catheter, urine measures are important. Even to the point of, on my last day, still having major trouble with my bowels, and asking for something. This nurse was quite rude about suppositories and basically querying whether I needed them. I don't know why she was nursing really, bringing in suppositories and me having to say 'could you help me', and her saying 'I thought you could do it yourself'. That was enough to make you feel broken. She didn't make me feel very comfortable about needing assistance with the suppositories, especially as I was pretty sick still. In reality, I have never stuck a suppository into myself, and despite years of nursing and doing it to other people, it is not something I felt that comfortable with.

I got really constipated. In the end, I managed that myself, by asking nurses from another ward to bring me Codalax (a laxative) because it was more effective than the medication I had. Friends were also bringing me in liquid food drinks, as I couldn't eat without my abdomen reacting. I think constipation is worse than haemorrhaging in hospital. The management of that with some nurses would be fine, so you wouldn't feel embarrassed about needing suppositories. Other nurses would presume that you could actually give them to yourself. They are the nurses that strip you of your confidence and ability to feel comfortable. I think for me, I had to get out of there. I think that nurses perhaps forget that when you are like that, I don't know what the word is really, but you are shattered by a health experience.

I am aware that I still had lots of people visiting. By this time, they had moved me around to another room, away from the nurse's station. I guess I'd passed the really sick phase, and people having new surgery were going to that room. But I didn't have a toilet. At that stage I still had a catheter, but then they took the catheter out. That was quite horrendous in a way because they woke me up every hour I think it was, to go to the toilet. The urine output was still a bit high, but it was getting to be a more normal level. I had been awake most of that night. They were concerned that the hole in the bladder might not have healed.

So when I look back, I think I probably was still quite sick, quite weak and was still unable to eat at that stage. I would get very bloated and uncomfortable and didn't seem to be able to digest; I actually did blow up quite visibly. Then talking myself into a bowel obstruction and saying to the surgeon that I was really concerned about that. I had had a bowel motion but I actually think that my bowel was really affected and in effect, it wasn't until my second admission that they

were looking at a bowel consultation for me. To this day my bowel is not the same.

Yeah, I remember being in that room, I enjoyed looking at the space outside. I remember a friend bringing a walk-man in for me, and using music to escape. I had an acquaintance, a friend F, who I had worked with a few years ago; she didn't ever look after me. It was obviously her choice not to look after me; she came and saw me often. You knew that she was a great nurse. She was an experienced woman and hadn't gone nursing until later in life. She had a sense of nurturing about her; it was just fantastic. I remember her coming to that room and perhaps restoring me at times. She was bringing me in spirulina drinks when I couldn't manage to eat anything.

I was very aware that, you know, being a patient you sometimes feel a bit awkward, on one hand, lots of people would be saying 'oh she's got so many neat friends', on another level, you felt like, when the ward receptionist came to you and rolled her eyes again looking for the phone. It's that sort of thing, when you know it's really time to go. A few doctors had come back and sort of said, how unfortunate it was that me of all people had had this happen. I guess with my concerns prior to surgery and the idea of blood. I didn't want friends upsetting the staff. I definitely needed my friends.

I remember feeling very much like I had to get out of there. I remember the day that I did get dressed; the first time that I went for a walk I had my shoes on. I lay back on the bed not wanting to take my shoes off. I really wanted to keep my shoes on and know that I could get out of there. The shoes were very symbolic I guess that was after about eleven days of being in hospital.

I remember sitting in a chair, in one of those old chairs with metal arms on, and a friend walked in and I am looking out. To me that was like protecting myself. I have to say that I was protecting myself from perhaps this one doctor. In some way I felt like it was my fault because I think he'd been rapped over the knuckles for things. He was never convinced that it was kidney damage. Obviously, it was reversible. Even when I went back to the specialist after my second admission, the specialist said again, despite some people's opinions, this is what happened.

I really worked towards getting discharged early, because by the time I left hospital, I felt like I'd overstayed my time. I didn't feel safe there. That was the time I definitely used my walk-man. I definitely felt from one nurse in particular, that I had overstayed my time in there and that I shouldn't be there. It seemed to me ignorance, because I didn't want to be there. I remember finally saying to the surgeon, that I wanted to go home very much. On reflection, I got out earlier and the consultant had said that I was perhaps leaving early, but I knew I had to get away.

The same slack nurse was the nurse who was with me the day I was going home. This same nurse, when it was time for me to go, gave me my scripts and stuff. They'd given me some prophylactic antibiotics for the bladder, after the IDC was removed. I still needed about three tablets to complete the course and I asked if I could have them from the ward supply. She said no that I couldn't. The nurse told me quite clearly that they weren't available in stock, or that they had run out. I just think that you know.... I appreciate I should have gone and got them from the chemist, but just some assistance or something like that would have made a difference. My friend F came in, she wasn't a friend as much as an acquaintance, popped into the room when we

were packing up. I said to her about these pills, so she went and got them for me.

It was embarrassing because the slack nurse didn't help me pack up my room. I had all these flowers in jugs and vases, and photos and presents all over the place. My room definitely looked different. This nurse hadn't offered any help to get down to the car; you had to go down quite a few levels to the car park. A friend B, came in, she was a nurse, and had trained overseas. She thought that it was just incredibly slack that my fluid levels hadn't been picked up and all this sort of stuff anyway. When this friend walked in, I was actually nearly in tears. She hadn't ever worked at this hospital and she had parked some distance away. I had to ask was there a trolley we could use? I was aware that there was no help. I was aware of the logistics, of me not being able to physically do very much, and having to get out. F got a trolley for my friend to take the gear down to the car, and assisted in taking it down, because I couldn't lift anything.

The other thing, it was a feeling like, that her connection, F would have done it for anyone, it wasn't just because she knew me. She was sensitive enough to know that. Just her presence, not as a friend, but as a nurse. There was just a sense of; she knew what she was doing. My feeling was, how do I do this, how do I get all this stuff out there.

I remember leaving that ward, and thinking 'I haven't bought them a present and I don't want to', and leaving, and just feeling like, I was in a way sneaking out of the place because I just wanted to get away. There was no one around when I was leaving anyway. I was very clear that I didn't leave a present. I did not want to leave a present for the nurses. I didn't want to thank the nurses by the time I left. I remember people saying to me that when you walk out of a ward, you feel like, even though it has been a big part of your life for the last few

weeks that no one is there to say goodbye. If it hadn't been for F to actually support me... I do think that there was a sense of embarrassment because I was a nursing tutor, as well as a nurse. I think that actually while a lot of the young nurses were really nice to me; I think there was a sense of distancing between, like the Charge Nurse I never met and different things. I think because there had been problems.

I remember coming home, just that sense of being driven home, and being absolutely exhausted, and having just had the catheter out the day before. Driving home; and walking up in a really shattered state into my house; and going straight to bed. I was actually getting weaker, not stronger. It was like I was cocooned coming home. I remember walking up to my door when I had hardly been able to walk, B helping me to get into home and going straight to bed. I was broken walking up into my own home. I just felt; get into my bed for my protection. I did not want to go back to that place. I was ready to be at home.

The next week or so I just got sicker and sicker. Mum had to bath me; I could only drink liquids because of my abdominal discomfort. Oh no, I wasn't actually that sick, oh I was, but at the same time I still remember J coming out and marking an assignment or moderating an assignment. I definitely felt cocooned. I got sicker again, and then I had severe pain again.

Side one of the audiotape is complete. I turn the audiotape over in the machine, we continue:

Dianne - You are starting to get into it, it is interesting and as you are talking my experiences are coming back. And there are so many similarities, yet quite different stories, it is about nursing.

Maria - Yeah, during my first admission I had at times, terrible nursing, but my second admission was fantastic nursing. It was terrible nursing (referring to first admission).

Dianne - Yeah, I don't know whether I would describe my experience as terrible nursing, but I became disillusioned, I didn't say terrible nursing; I just wasn't nursed.

Maria - Well my problem is that they didn't pick up through their assessment the initial problems that then lead to other problems. I mean, I'd never had a haemorrhage before, they'd seen post-surgical problems I presume.

Dianne - Yeah, then I think myself, as a surgical nurse we have no idea what it is like really, it's not until you've actually been through it yourself.

Maria - But I do think that you have a sense, like I've never had chemotherapy but I can be empathetic to the nausea and the anxiety, and the, I just think that level of nursing....

Dianne - you weren't even experiencing?

Maria - Oh I think that personality wise, there were nurses that liked me and liked my friends. I had people around me like that, but they didn't have the knowledge. I wrote about that in a paper on caring. They didn't have the mentoring. It took that one nurse to come in who knew what she was looking for, to make me safe, but the damage was done.

Dianne - I am aware that there are lots of stories there that I would like to pick up on.

Maria - yeah

Dianne - It is your story of being the patient, being a nurse as a patient

Maria - I have to say that the second time (the second admission) it was (the nursing care) very different. It reaffirmed my belief in skilled nursing assessment.

Dianne - Yes, and that (the nursing care) is what I am interested to hear about.

The audiotape is stopped.

It was necessary to finish our session together. Maria suggested we make plans to link again in a few days, to record the story of her second hospital admission to hospital. Due to her commitments, Maria was unable to meet me again while she was in town. She suggested she would be willing to audiotape the story of her second admission to hospital, and post it to me. I agreed, as this would meet both our needs at this time. Therefore, Maria recorded this next story at her home.

“Fantastic Nursing”: Second admission to hospital

Maria began:

When I think back about this admission, I guess I have to go back to the stage that I came home from hospital. I really did find coming home pretty shattering. I spent a lot of time in bed over the next week. Friends were great and kept popping in. I couldn't eat anything without discomfort. My mother was here; she tried to get me to drink spirulina, I think I lived on milkshakes. Friends were coming in and out.

I thought that I had haemorrhaged again, as I had this severe pain, severe abdominal pain; the GP (general practitioner) arranged a blood test. Although my blood count had dropped, it hadn't dropped that much actually, but, by the time I got back into hospital, it had dropped about 20 counts (referring to haemoglobin level). And then, I was beginning to think 'oh it must all be in my head', but still getting weaker and weaker. By this stage, my mother had to manage things for me. That whole week I think I was getting weaker really with an infection, when the abscess was brewing. My mother spent time just looking after me, with my friends.

On reflection, one friend says that it should never have happened, she came and took my mother and I out. By that stage, I was starting to pass quite big clots, she took us to the after hours doctor who actually, was luckily my GP. He did an internal, and said that he thought that it was just the old clots from the hysterectomy. At home I'd passed something that looked to me like a bit of liver, and you know quite a large piece. I accepted that, and my temperature was only very low grade when he took it at that time.

So I went with my friend, we dropped my mother off to visit other family and we went to the supermarket. I remember just struggling to get around the supermarket. I had to do some banking, I wanted to catch up on things that I couldn't do. This friend, on reflection, said she realized that I was incredibly sick, but because of the way I directed people they were all doing what I wanted. In reality, I don't know how I made it anywhere.

By the Sunday night, the pain was getting worse and I started rigoring with temperatures. The GP came around and arranged some blood tests, and also some oral antibiotics that took the temperature down. I

was still perhaps rigoring but not as much, and I still had a low-grade temperature.

Anyway, by this stage, a friend who is a nurse, had been in contact with another friend who was a gynaecologist. She rang me to say that what I was going through wasn't normal and to ring the GP back. By the time I rang the GP back, he had spoken to a specialist again. They said to go straight into hospital. I had intended my mother to go home the next day, I was waiting for my mother to go so that I could just go to bed and stay in bed. I actually think that I was pretty much ready to just go to sleep.

And so, I went back into hospital. It was interesting; my friend took me back. I was dreading going back, thinking that it would be the same. It just seemed very different, it was as if.... I was expecting it to be, not to be welcomed, but I think also I had a sense of.... a sense of. I think I realised actually that if it had been better in hospital, I would have gone back earlier. So I went back and was admitted. The house surgeon came to do an internal, I refused to have an internal and said that no, that the specialist would be doing it again. I queried about the registrar that was going to be on and had also heard from some other people about a particular incident. So I knew that I wasn't going to have an internal from that person. And anyway, IV (intravenous) antibiotics were started that night, I was still fairly crook, with a temperature and I was rigoring. A friend brought my mother in the next day on the way to the airport. By that time I had seen the consultant and was going to have a scan arranged. I think actually, I was pretty sick. I didn't want anything brought from home that I didn't need, unlike my first admission. I wouldn't really have cared if I had visitors or not. Whereas the previous time, I think that I was entertaining them really.

Anyway, I was just looked after by different nurses. I didn't get, even though some of the younger nurses had been really good to me, I didn't seem to get, All of a sudden I had what appeared to be a lot of the part-time nurses. I felt safe. I felt like I was being assessed properly and I felt safe. And I felt people weren't embarrassed, as if it was their mistake, so I think that perhaps that had changed from the first admission.

They moved me to a really nice room. It had a toilet near it that was just wonderful because I was passing revolting smelling clots all the time. I went and had a scan, a CT (computed tomography) scan that showed that I had a big.... It was put down to another bleed, and quite a large abscess, theatre was then booked.

But all the time, I just felt very protected by the nurses; I just know that I had really good nurses. I had experienced nurses who knew what they were doing. They listened to my symptoms; they listened to me when anything was a bit peculiar. That listening hadn't happened in the same way before. I think that, I was listened to. The fact that my abdomen swelled when I tried to eat anything was noted, and previously it hadn't been actioned. One nurse apologized to me about not doing anything about that earlier. I think that I was just surviving really. I definitely felt safer. I felt part of the ward. I actually felt safe.

I remember going to theatre and not wanting to bother ringing family, a phone call came to my room from them. I actually think that I did really wonder at one stage what this all meant, whether I was actually going to make it. Which in retrospect is probably not so silly, but I wasn't in the ICU (intensive care unit). I had a sense that I had to get something from home; I had a letter written from when I had been quite distressed. I didn't want to send it as I'd written it as a way of

resolving my distress; I wanted to get rid of it. I just had a sense that if things didn't go right I didn't want it to be around.

I remember I was in incredible pain, post theatre, in my abdomen for probably a good two or three days. And being given Acupan (analgesic) and things I think. Then the consultant coming in to see me, saying that they had really pressed on my stomach very heavily to expel the pus and things from the abscess, and saying that I had Pethidine (analgesic) charted, and so I should use it. Actually, I only used it for a few doses but I realized that I actually had needed that kind of pain relief. And actually I think that sometimes nurses perhaps need to direct. I know that I was a bit stoical, but the pain was excruciating, and basically, I wasn't sleeping because of the pain. But when I had just a couple of injections of Pethidine, I actually felt much better.

I was given Ondancetron (an anti-emetic) because of the nausea; it had been a bit of a problem for me. The problem there was, with the IV antibiotics was that my veins I think were quite difficult to find. I was very aware of the nurse that could make a decision and take an IV out, or the nurse who wanted it kept in because the house surgeon didn't want to try and put another one in. And saying that this is just so painful and actually pulling my legs up with pain having IV antibiotics pushed in. So there again, it was the nurse who could make a decision and take it out, that was valuable really. I definitely used my wheat pack in a way to help dilate my veins and those things. It made me realise that for all the times that I had pushed through and fixed IV's, how painful it must have been for patients. In reality as a nurse, I often was focussed on making a line (an intravenous line) work. I guess I felt like I was being paid back a little bit, in a funny sort of a way.

Anyway, I found that there were a fewer older nurses. I remember in particular, having dialogues with these nurses. I just remember feeling, like being positioned properly in bed, and being looked after really, really well. One nurse in particular who was just always looking out in case something was going wrong. That made me feel incredibly safe, because actually however much drainage or if I said that I was concerned about how much urine I was passing she would take note. I just felt that she had very good assessment skills.

Actually they were really good with that admission, I felt safe. Near the end, when I finally got my IV out, and was recovering from surgery, I wasn't discharged but I was given the freedom. I went and got my haircut one day from the ward, I remember, being out and came back and, just feeling like I was coming back to a safe place. I wasn't concerned about coming back. Which definitely was not the feeling I had the first time around. I think in that admission, I felt like my room was my room. I didn't need to feel embarrassed about anything and visitors weren't such a problem. I think in a way that the first time I felt a bit judged because of the stream of visitors I had. I don't know. But the second time, I know I was sick. I know that I was nursed properly; I know that I was assessed properly and I felt clean. I felt like there was time put aside for me, whether it was for my recordings or just to help me position myself in bed better, or whatever. During the admission, a haematologist who I had worked with saw me; he was trying to work out why I had haemorrhaged twice. The consultant kept visiting and friends kept visiting, he just popped in I suppose. You know, I can't really think of anything else done around that time. I guess by the time I left though I was ready to leave. I was going to have a consultation with a bowel specialist but then the specialist decided that he wouldn't at that stage. If I had any further problems when I came back to see him he'd do it then. But he felt that things would recover as my bowels started again to recover.

I felt very aware that I wanted to give the nurses a present, I wanted to say thank you. I arranged, I think actually that when they let me out of the ward one day, I caught a taxi and went and got a present. God knows how I did that now when I look back. I gave them the present. I felt like it was closure when I left the ward. If I had any problems I would have had no concern about ringing them and going back. I went home that time feeling, not violated, but having been cared for. One of the nurses even gave me a hug when I was leaving and wished me well; she acknowledged what I had been through. I don't know why, but the nurses I had were different. They weren't the same nurses, they were the older nurses, and the CNS (Clinical Nurse Specialist), who had never looked after me before, I had her on several shifts... Perhaps once or twice I had one of the nurses who wasn't straight out from her training, but was still reasonably new. She was the nurse who had apologized to me for not noticing things before, but she was never a nurse who I felt unsafe with. She was the nurse who had advocated for me on the first night I came in, she continued to look after me. But the bulk of the young nurses that I'd had, I say young when I mean a new graduate really, on the first admission, I didn't have them on the second, I don't know why that was. I don't know why all of a sudden I had these more experienced nurses and why I hadn't had them the first time. But for me it meant that I left the hospital feeling well and feeling ready to leave, and feeling safe and having felt cared for, as if they had a real interest in me as well as assessed and nursed properly. I think I was also on the road to recovery, partly because I was getting well. But also, I know that the nursing had an impact on that. In reality, I had very little to do with medical staff, besides the consultant.

That is about all I can say really. Maybe we'll get into dialogue one day and it might bring back something. I definitely know that there is a big difference between my first admission and my second. I think

that it relates to my first, I was an embarrassment because things kept going wrong and things were missed. Whereas, by my second admission, people were looking out for something to go wrong. I think they probably also picked up, a sense that they actually um ... that although I had lots of visitors I had withdrawn in many ways. I remember thinking back to my mother who had had a hysterectomy and cried when we'd been to see her as a child. I realised that actually I didn't have any energy, whereas on my first visit I did. I think that in some way the nurses picked that up because I was seen by a social worker. Support was given to me for when I went home; home help was arranged. I would be interested to read my notes really to see if my memory and perceptions of the admissions came through in my nursing notes.

Conclusion

This chapter has presented the stories of Maria, a nurse-patient, receiving nursing care while hospitalised with a life threatening illness. By reflecting on her own experiences as a woman, nurse and nurse educator, many experiences of receiving nursing that were previously invisible are explicated. In the next chapter, I will tell my story, that of another woman, nurse and nurse educator receiving nursing care while also hospitalised with a life threatening illness.

CHAPTER SEVEN: Dianne's Story

*"You cannot sit down to write about yourself
without rhetorical questions of the most tedious kind
demanding attention. Our old friend, the Truth, is first.
The truth ... how much of it to tell, how little?"*

Doris Lessing, *Under My Skin*, 1994, p11

Introduction

In the last chapter, the story of Maria a nurse-patient was made visible and intelligible. Her story provides a rich narrative of the reality of one nurse-patient's perspective of receiving nursing care. In this chapter, I will share my story of being a nurse-patient as a reflective topical autobiography (Johnstone, 1999). I was initially hospitalised for four days as a well person to undergo elective abdominal surgery that was subsequently described as 'uncomplicated surgery' by the surgeon in his operation notes. Within forty-eight hours of discharge I was readmitted to hospital as a sick person. This narrative will contribute to the intent of the thesis of explicating the stories of two woman nurse educators receiving nursing care. It will also contribute to the existing knowledge on patient's perceptions of nursing care (Ruiz, 1993; Williams, 1997; 1998a; 1998b; Zeitz, 1999).

Telling the truth about myself is one thing, if I am able to do that, but what about the other people involved? There have been times where I have had to leave out or change a name or two to protect the identity of those involved, but mostly very little. Pseudonyms have been used for all the staff involved in my hospital care. There are aspects of my own story I knowingly leave out and other aspects I unknowingly omit to tell. As Lessing (1994, p. 12) writes in her autobiography:

*Telling the truth or not telling it, and how much, is a lesser problem
than the one of shifting perspectives, for you see your life differently
at different stages....*

As I began to write my story of being a nurse-patient, I soon realised that the experiences I have had as a family member of a hospitalised patient have made an incredible impact on me as a nurse and nurse educator and more recently on me as a nurse-patient. I therefore begin this chapter by briefly reflecting on the stories of two family members who were hospitalised with life threatening illnesses. I shall describe how they have contributed to who I am, and my expectations of nursing and nurses. The journey of recounting all of these stories has at times been painful. I believe there are two reasons for this. Firstly, there is the issue of reliving traumatic personal experiences as a family member. And secondly, as a nurse and nurse educator, I am aware that through my experiences I am at times exposing aspects of 'not being nursed'. I am saddened by my inability to recollect the positive experiences of 'being nursed' from my personal and family experiences. However, through my experiences as a nurse, I believe that there are many positive experiences of nursing practice. Yet the literature suggests that the perception of care does differ, depending on whether it is the patient or the nurse telling the story (Prentice, 1995; Zeitz, 1999).

Reference to several documents and people has assisted my recollections of these personal and family events. My personal journal entries and notes have been supported by the medical notes we obtained for my husband and me. During the process of reflecting on the experiences, I have also had many discussions with both my husband Harry and my mother to help validate my recollections. They both read my writing as I was working on the thesis and both agreed to their experiences being shared as part of my story.

These are my stories as experienced and recalled by me, the intent of which is to capture some 'turning point experiences' or 'epiphanies' (Denzin, 1989, p. 14).

The beginning

I was only five years old when I was first admitted to the children's ward at the local hospital. It was from this early age that my desire to become a nurse arose. My memories of this childhood hospitalisation

are intertwined with my experiences from the early 1970s when as a junior student nurse I worked on this same children's ward.

Throughout my early schooling years, it was anticipated and possibly expected, that I would become a nurse. However, during my seventh form year, I decided to apply for both Teachers College and entry to Nursing School. I do not recall now what specifically made me apply for both, but as girls, we were socialised to choose occupations that were seen as feminine (Middleton, 1993). Teaching and nursing were seen as appropriate feminine occupations during the 1960's (Middleton, 1993), and like many others in those times, I applied and was accepted for both. I had no family connections with teaching, and my only connection with nursing as a career, other than my personal hospitalisation, was an older cousin. She had gone nursing some years earlier, but I had little contact with her. It seemed that I was destined to be a nurse. In 1971, I began my journey as a student nurse at the Christchurch Hospital School of Nursing.

Family encounters with nursing

Members of my close family and friends have been admitted to hospital over the years. It was during my early nurse training days when the first significant event of a family member requiring hospitalisation occurred. My father was admitted for investigations, to the hospital where I was working as a student nurse. I was able to visit him frequently; he referred to me as his 'own' private nurse. I remember doing things that made him more comfortable. I was caring for him, as my nurse training had taught me to do. I remember well, one particular nurse who was involved in my father's care. He often commented on her 'presence' and how she cared for him in comparison with some of the other nurses. In later years, I would recognise that my father was speaking of the nurses' 'engagement'

(Kralik, Koch, & Wotton, 1997) *and interpersonal skills in working with a patient.*

The next significant family illness was eleven years later, when my husband Harry was hospitalised with a life-threatening illness. It was during his hospitalisation that I realised I was beginning to examine nursing practice from a different perspective. Previously, it had been from the perspective of a nurse with fifteen years experience. Now, it was from that of a family member, the patient's wife, who was a registered nurse and nurse educator.

As a non-nurse patient, Harry was able to recognize nursing care that made a difference to him. He spoke of the difference between the nurses, he said:

...I saw more of the green ones (enrolled nurses), they talked more at a personal level and the blue ones (registered nurses) were detached, they didn't appear interested in me, I hardly ever saw them.

The visibility of the different nurses, and the amount of time individual nurses spent talking with Harry, was important to him. He also recognized what it was that made a difference to him, he said:

...That to make you feel good, the medical things need to be taken care of, as in drugs, but there is another side that needs to be perked up.... Mental well being can influence physical well-being.

Later that year, Harry underwent major surgery. It was from this point in the mid 1980s that I began my journey of critically examining nursing practice in New Zealand, especially in relation to my own

practice as a nurse educator, and as a recent clinician. It was during these next few weeks of Harry's hospitalisation, that I was to learn so much more about nursing, and about the involvement of the family in a loved one's care; possibly more than I had learnt in the past fifteen years of my nursing career. By observing the actions and comments of the nurses who provided nursing care to Harry, I realised what made him feel safe; he knew when he was 'being nursed'.

Since this time, I have frequently considered the knowledge and role of both medicine and nursing in different health contexts, and societies expectations of the people in these disciplines. My experience as a consumer of health services has made me more aware that each profession not only has a distinct part to play in health care, but that each discipline has a specific body of knowledge to contribute to the patient's experience.

As a nurse working in a surgical ward, my knowledge was limited to the precipitating illness and the surgical procedure that clients were admitted for. I knew, and was able to provide the care that was necessary for patients within those first few days post-operatively until they were discharged from hospital. Since going through these personal experiences, I have come to recognise that as a nurse, we need to hear the patient's perception of their experience of receiving nursing care. This has provided the impetus for me to share my experiences as a nurse-patient receiving nursing care.

The patients' experience of being nursed is of critical importance for nurses to understand. Nurses plan and implement care to meet the individual's needs, but in order to do this, nurses must ascertain what it is that patients perceive their needs to be. We must understand the way in which patients view nursing care. As health professionals, we must encourage and support patients and their families to share their

stories of receiving nursing care with us. Their stories would provide us with a much richer knowledge of illness and the realities of recovery from the patient's perspective. The quality of health care we are able to provide would then be truly holistic. And now, to my story of being a nurse-patient receiving nursing care.

The nurse-patient anticipating hospitalisation

I was not keen to personally undergo abdominal surgery and all that it required. I was hopeful that my discomfort would disappear, and that the surgery would not be needed. My biggest fear about having surgery was with being anaesthetised. I was afraid of losing consciousness, of losing control of my life. I had read Oliver Sacks (1993), 'A leg to stand on' in which he describes his experiences on becoming a physician-patient. He too, writes of the fear of undergoing a general anaesthesia. The similarity is that like him, my life as a nurse has also been directed towards awareness and observation. The thought of a general anaesthesia, of losing consciousness and control, would deny me the opportunity of remaining aware and making observation.

The date for my elective surgery was scheduled. I spent time reorganising a busy teaching timetable and commitments with my colleagues. However, while I was in Wellington attending a course the week prior to my surgery, my husband phoned to say that my surgery had been postponed because of an urgent case. For a moment, I felt numb, my workload had been organised. I was ready for the surgery, yet I knew that, this was how the system operated. When I returned home from Wellington, the hospital waiting list clerk informed me that a woman with a cancerous growth required surgery. With this knowledge of the other woman's urgent need, I was able to return to work and begin the task of rescheduling my teaching commitments again. My own impending surgery was mirroring the

journey that Harry had had ten years earlier, when he underwent major surgery. Like him, I too, was prepared emotionally for the surgical experience to happen now.

I attended the pre-admission visit two weeks later. I was surprised when the anaesthetist, after listening to my earlier mentioned concerns regarding general anaesthesia asked, "Have you considered the options?" What options I thought. Despite working in the surgical area with nursing students, it had not occurred to me that 'other' forms of anaesthesia would be possible for my impending surgery. The doctor discussed the different options with me and suggested I go away and think about them. I was introduced to a woman, also a nurse, who had recently undergone similar surgery. She spoke enthusiastically about her spinal-epidural anaesthetic. Of course, this was the option for me, why had I not considered it? I then used my skills as a nurse researcher to locate information on the impending surgery and anaesthesia.

As a nurse educator, I supervised a student group working in the hospital. I understood well the difficulties in obtaining patient experiences for students to be involved with. Prior to my admission, I discussed the possibility of students being involved in my care with an education colleague. She supervised students in the ward that I was to be admitted to. I felt privileged in that I was able to say which student I would like to be involved in my nursing care. Jo was a mature student, in her third and final year of the programme. She had just completed the module of work that I taught; I had confidence in her clinical knowledge and nursing capabilities. She would be working alongside my education colleagues and a nurse practitioner from the surgical area. I felt satisfied with this plan.

Being admitted

I was admitted to the ward at seven o'clock on the morning of my operation. It was a cold, dark, winter's morning. Jo, the nursing student, greeted us on our arrival to the ward. She led me to the bed that I had been allocated, and she mentioned that I would be in a single room on my return to the ward. I was told later that this was usual for patients undergoing my particular surgery. There was much to be completed before my trip to the operating theatre, so I farewelled Harry and mum. I looked forward to their return later in the day. Jo and I then worked together to complete the pre-operative tasks that were required of the patient and the nurse. The anaesthetist made a brief visit; he was not the same person I had seen at my pre-admission visit. I informed him of my desire to have a spinal-epidural anaesthesia. Fortunately for me, this was agreeable to him.

I had not worked on this ward as a nurse, and had only visited once or twice as a nurse tutor. My room was situated at the entrance to the ward. The quietness of the early morning on a busy surgical ward struck me. As I lay on the bed awaiting the final preparations for my journey to the operating theatre, my solitude was distracted by the sound of noisy heels, of someone walking into the ward. My thoughts immediately returned to my early days as a nursing student, we had been told that the shoes a nurse wore were important. They must not only be comfortable and protective, but they must not have hard soles that would be noisy and disturbing to patients. I was later to recognise that the noisy shoes belonged to Sally, the ward clerk. I heard her shoes constantly during my stay in hospital. The sound of her feet irritated me for the three days that I was less mobile and confined to my room. I was pleased when Saturday came and she was not at work. I felt her strong presence in the ward. She appeared to be 'the boss', and I felt intimidated by her presence. I pondered on the

thought that if this is how I, a nurse tutor, who worked in the hospital was feeling, how did the non-nurse patient relate to her?

Within a couple of hours of arriving on the ward, I was on my way to the operating theatre. Jo, and my colleague Melissa were at my side. As I reflect back to the morning of Harry's surgery ten years earlier, it was important for Harry and I that I escorted him to the operating theatre. Yet, the role was reversed now, and I did not feel the need for him to accompany me on this excursion. He had not expressed any desire to come either. I believe the nature of my surgery and my knowledge of what was ahead allayed many of the anxieties.

The surgical experience

After a short pause in the anaesthetic room to have an intravenous cannula inserted, I was wheeled into the operating theatre room. There was a sense of the familiar, I had spent time working in the operating room as a student and as a registered nurse. However, the difference this time was, that it was I, the nurse-patient, lying flat on the theatre table, about to be operated on. It was not long before Desmond, the anaesthetist, began to site the spinal-epidural infusion in my lower back. At this point, I was sitting up with my legs over the side of the operating table. Desmond was having difficulty with the insertion when the supervising anaesthetist came in. I heard him mutter 'general anaesthesia'. I could feel my anxieties rise. Fortunately, Desmond was able to site the spinal-epidural needles and the anaesthetic was introduced. I was assisted with lying back onto the theatre table.

My lower body was now adjusting to the effects of the anaesthetic drugs. I could no longer feel my legs, when suddenly; I felt something happening beyond the green screen in front of me. I exclaimed, "What was that?" to be told that I had just been catheterised by the nurse. I

looked up at Jo, and commented that the nurse could have given me some warning. I was somewhat indignant. Had this theatre nurse forgotten and, or, lost the art of communicating with her conscious patients.

I was offered a set of headphones and some music of my choice to listen to. However, I was more interested in staying focused and keeping up with what was happening to me. I had taken my contact lenses out, and could not see well when Desmond suggested I use the theatre light above as a mirror to see what was happening. I was somewhat disappointed that my short-sightedness would not allow me to see that far. I remained awake throughout the procedure and Desmond or Jo, and at times the surgeon leaned over to explain what was going on.

Within an hour, the operation was completed. I was transferred onto my bed and moved to the recovery area. I felt amazingly well. The recovery room nursing staff continued with their observations of me for the next fifty minutes. This part of my hospitalisation had been a pleasant experience. I was then transferred back to the surgical ward just on midday.

Being nursed

Jo, the nursing student, remained at my side throughout most of this period. On my return to the ward, she worked alongside Melissa, my education colleague. Together, they provided me with the nursing care I required for the next three and a half hours of their duty. The spinal anaesthesia had numbed my left leg, and although I knew it was there, I could not feel it. This was an uncanny experience as I was now aware of and able to move my right leg. As I lay there, I began to think of an old school friend who had been paralysed from a car crash

many years earlier. I contemplated briefly what it might be like to have lower limbs but to have no feeling or use of them.

During the next couple of hours, I felt as if Jo and Melissa were constantly with me. They exercised my numb leg, encouraged me with deep breathing exercises, and were kept busy taking my observations, looking after the intravenous fluids, the urinary catheter, and the drain from the wound. Shortly after returning to the ward, I experienced three episodes of feeling light headed, I occasionally, felt nauseated. My blood pressure had dropped. The surgeon visited and increased my intravenous fluids. I also began to experience some pain on my right side. I wondered what was happening to me. The anaesthetist was contacted, but was unable to see me until he had finished in theatre, two hours later. When he finally arrived, he immediately increased the intravenous fluids, and the epidural infusion.

At about this time, I remember feeling a sudden sense of panic. My nursing experience told me that in order to prevent the occurrence of deep vein thrombosis, I would require hourly passive exercises to my numb left leg. Jo and Melissa had been able to give me the constant attention needed. I am grateful for their caring nursing practice. However, my mind was thinking ahead. What would happen when Jo and Melissa finished work for the day? Would there be someone available to exercise my numb left leg for me? I did not want to develop a deep vein thrombosis. I knew that this could have the potential to develop as a pulmonary embolus. As a nurse tutor, I knew that students in general, were able to spend more time with their patients. Would the oncoming nurse have time to spend with me and exercise my numb leg?

When Jo and Melissa finished their duty for the day, I awaited the arrival of 'my' afternoon nurse. When Shelley came into the room and introduced herself as my nurse for the afternoon, I felt even more anxious and apprehensive than I had already been. I remembered Shelley as a pleasant, but less than confident student of some years earlier. I was concerned not only about the potential of developing a deep vein thrombosis now that my 'passive' leg exercisers had gone home, but would Shelley be able to give me the time and nursing care I needed? My mind began to race as I considered some contingency plans to move that numb leg of mine, at least hourly! Although the doctor would have been happier with an effective bilateral epidural block, I was now feeling happy that I could feel one leg and at least be reminded that I needed someone to exercise the left leg for me. Perhaps, I would have been less anxious if the regional block was symmetrical.

It was a long anxious afternoon for me. I was just one of several patients to whom Shelley was responsible for providing nursing care. When she did get into see me, she was most apologetic for the lengthy times between her visits. I was pleased to see one of my education colleagues working with other nursing students in the ward that afternoon. I hastily invited Teresa into my room. I mentioned the concern about my numb leg. She promptly removed the bedclothes from the end of the bed and began to passively exercise my leg. I was reassured for a while. On subsequent visits to the ward, Teresa returned to exercise my leg. She would also provide other nursing cares that she either noticed I needed, or I asked of her. I was grateful for her time and attentiveness. She demonstrated those confident caring qualities that made me feel cared for. I felt nursed when she was around.

The feelings of light-headedness continued intermittently throughout the afternoon. I vomited once. The left leg remained numb, while I continued to feel the right one. This was despite the epidural and intravenous infusions being increased. During the latter part of the evening, the right sided abdominal pain that had appeared earlier in the day, began to bother me. I saw little of Shelley throughout the afternoon and early evening. My anxiety levels were rising. By ten o'clock, I was timing the frequency of my spasmodic abdominal pain. The clock on the wall enabled me to accurately record the frequency of the pain. It occurred every three minutes and caused me much discomfort.

I had a high pain threshold but this pain was quite something. The timing and frequency of the pain reminded me of women in labour. When Shelley came to see me, she initially appeared unfazed by my pain and distress. As her evening drew to an end, she appeared more concerned for me; she tried unsuccessfully to get the anaesthetist to visit me. I now sensed her frustrations at her inability to get medical assistance.

A restless night

My spasmodic pain continued every three minutes and showed no signs of relenting. It was just after midnight when the anaesthetist at last, returned to visit me. By this time, I had had this spasmodic pain for over two hours. I was feeling distraught. He prescribed a change in the epidural infusion drug and suggested intravenous morphine to be administered as necessary for the pain. I had a restless night with little sleep.

Patient's medical records are a legal document and provide a valuable source of information (Burgess, 1993). The hospital staffs who write in these records are professionals and experts in their

respective fields. They are well informed of the legal implications of writing in these documents. In the early stages of writing this thesis, I obtained copies of my confidential patient records, primarily to use as adjunct to my recollections and those of my husband, who was present during much of my hospitalisation. I assumed that my records would provide me with an accurate, objectively written account of my surgical experience from the expert's point of view.

I was sadly mistaken; my records were incomplete and even inaccurate in places. I was surprised to discover, that the distress I was in throughout this period, was not evident in the written documentation made by either nursing or medical staff. The following extract is taken from my nursing notes on that night. Although I have written it in paragraph form, the nurse caring for me wrote it up as a list, she wrote:

IV due 1000hrs. Epidural running @18mls/hr as per doctor's orders. now luered @ 0700 as per doctors orders. IV Morphine given x 3-4 overnight last given 2mg IV @ 0700. Observations stable. Catheter output good. Minimal from drain. IV anti-emetic given x1 for nausea. Wakeful night. (Nurses signature)

My emotional distress throughout this period was described in two words "wakeful night". This was recorded as the final point in the notes. As a nurse-patient, I expected my records to tell the story of my distress that night. A recent conference paper by Hardy (1999) supports my personal experiences of reading my medical records and the discovery that my notes were incomplete. Hardy (1999) identifies several reasons why there appears to be a problem with patient medical records and makes suggestions to improve this. She states that there is a problem, because 'client records are not viewed as an

important part of client care' (1999, p. 5), and secondly, they are not just an end of shift chore. Report writing is a skill and should be treated as such.

Recovering post-operatively

Jo and Melissa were on an afternoon duty this day. I had agreed to another student, Kate, being involved in my nursing care for the morning. My education colleague, Lyn, and Kate removed the urinary catheter. Like Jo, Kate demonstrated a professional, caring attitude towards me as a patient. The discomfort of the night continued for most of the morning. I required a variety of medications to settle my pain. I was at last on the way to recovering from my surgery. By the end of day one, I was up walking with some assistance, and able to have a light 'fluid' meal that evening.

During the afternoon, Sally, the ward clerk arrived at my doorway. She said, "Your sister is on the phone from Australia, what would you like me to tell her?" I remember thinking; well this is great that you are coming to ask me, I replied, "Could I please speak to her?" I knew that there was a mobile phone available. I was rather stunned when the Sally said, "No", and gave some reason to the effect that the mobile phone might be needed. This did nothing for my mental-emotional-spiritual and probably physical well-being. I was also thinking of my sister in Brisbane, who was unable to speak with me.

Keeping the family informed of your health status when a hospitalised patient is important to most people. However, there are often difficulties for patients in hospital when it comes to having access to a telephone. I had come to hospital with all my phone cards. When I eventually discovered a coin phone box, it would not accept my phone cards, or a 0800 number. It certainly would not accept a call to Australia. I plucked up the courage to ask one of the nursing staff on

the evening shift if I could use one of the office phones to make a call to my sister in Australia. By using this phone, I was able to use one of my phone cards to make a call and have the charges transferred to my home account. I felt uncomfortable asking to use 'their' phone. I felt as if I had been granted a special privilege to be able to use it. I returned to the office with some trepidation on the next two evenings to phone my sister in Australia.

I was fortunate to have a single room during my four days in hospital. I appreciated this immensely. I dreaded the thought of being moved into a room with other patients. I just wanted and needed my own space and privacy to recover from surgery. Over the next two days I made a quick, uneventful recovery. I required little care from the nursing staff and was independent in all my activities. I recall the nurses commenting on my well-being. I was keen to go home on Sunday - the fourth day after surgery. However, it was usual for patients after the type of abdominal surgery I had to be discharged on day five. My mother was due to fly out to Australia on the Monday afternoon. I wanted to be at home with her for one evening before she left. I hesitantly pleaded my case with the surgeon. Fortunately, he was agreeable to this plan if all remained well.

On the evening of the third day - the Saturday afternoon, I experienced lower back discomfort. Sarah, 'my nurse', offered me a hot water bottle. This provided me with some comfort and the ache in my back did not bother me again. Shortly after receiving the hot water bottle, I felt rather hot and flushed. My temperature was taken and found to be elevated. Both Sarah and I rationalised this as being due to the hot water bottle. Although I remember thinking at the time, that from my experience this seemed a little unusual. However, on checking my temperature a short time later, the reading had come down, it was now within the upper limits of normal. When I read

through my nursing notes, it is interesting to note that Sarah - the nurse, recorded the elevated temperature and stated: "? Due to hottie." Perhaps she was not convinced either? In hindsight, I believe it was more coincidental.

Going home

I awoke from a reasonable night's sleep, feeling good and keen to go home. I remember having a fleeting feeling of nausea early that morning. I rationalised this as due to the oral Voltaren (an anti-inflammatory medication) I had been commenced on the night before. By the time the surgeon appeared mid morning, I was showered and hopeful that he would be agreeable to my discharge. My discharge was duly planned for later in the afternoon. However, not long after the surgeon left my room, I began to feel rather hot. I found my nurse, Raewyn, and suggested we take my temperature. As I suspected, it was elevated. I did not want this to stop me from going home. We decided to contact the surgeon, who by this time had returned to his home. Fortunately, Raewyn, an experienced nurse, was able to contact him. I was subsequently discharged home with a prescription for an antibiotic. I felt happy and reassured with this.

By mid-afternoon, my family had arrived to take me home. I was dressed and my bags were packed. In appreciation of the nursing care I had received, I presented Raewyn with a card and box of chocolates for the nursing staff. At this stage I was not analysing, nor reflecting on my nursing care, but believe now, that what I was doing by giving the chocolates was what I felt I needed to do as a patient on discharge. It isn't that nurses expect this to be done. Yet I felt compelled to do this.

On arriving home, I contemplated the next few weeks off work convalescing from my surgery. It was time to heal the body in a

holistic sense, not just from the physical trauma of the surgery. However, my feeling of recovery was short-lived. The next morning I felt nauseated, I vomited and had a bout of diarrhoea. The nurse in me, again, began to rationalise these events, I must be reacting to the antibiotics I thought. The next day, I began to feel uncomfortable again. I was not interested in eating or drinking, the nausea had returned. I began to worry and ask myself, what was wrong with me? Was I developing a bowel obstruction?

As the evening went by, I felt no better. I had a restless night. By five o'clock in the morning, I knew that I needed medical assistance. I was dehydrated. I needed some fluids. As I did not want to phone a duty doctor who would not know me, I phoned the staff in the Accident & Emergency Department for advice. Fortunately, the night nurse was someone I knew from my professional practice. I told her my story. She suggested I come straight to the hospital. What a relief!

Re-admission to hospital

I was greeted at the Accident and Emergency department by familiar nursing staff; I worked here occasionally with nursing students. Throughout my experiences of being a patient, and a family member of a patient, I am aware how this familiarity with staff and the environment was beneficial to me. However, it did make me consider how daunting it must be to the 'uninitiated' patient, and family member. The nurses and a doctor quickly attended me to. I was then transferred back to the ward I had been discharged from, just forty-eight hours earlier.

It was seven o'clock in the morning. The night duty nursing staff that I did not know, greeted me warmly. They tended to my initial readmission requirements before heading off duty. I was then left in the care of the day nursing staff. I do not recall Harry arriving at my

hospital bed later that morning. I was too unwell. I was to spend the next fifteen days in hospital, the first four days of which I was a very sick person. I did not realise the seriousness of my condition at the time.

During these first four days as I lay in my hospital bed, I had deep, meaningful conversations with my education and clinical colleagues who visited. I became disappointed and disillusioned with nursing and nursing education. As a sick dependent patient, I did not feel that I was receiving the nursing care that I felt I had been teaching and practising for twenty-five years. It was much later when I realised, that as a well, independent patient, as I was on my first admission, the nursing care that I required and received, was quite different from the nursing care that I now required and was receiving, as a sick dependent patient.

So what was it about this experience of being a nurse-patient in hospital that at the time made me feel so disappointed and disillusioned with nursing and nursing education? It was not any particular incident, nor any particular nursing action. Rather, it was a collection of my experiences as a nurse-patient receiving nursing care. I felt that I wasn't being 'nursed' as I thought I had nursed, and was focusing my teaching practice on. I kept asking myself 'what is nursing? What am I expecting, now that I am a patient?' Nursing has a distinct and important role in working with hospitalised patients, alongside other members of the multidisciplinary health team.

I am able to recall many aspects of this second hospitalisation, however, I know that there are also other aspects I do not remember. For the purpose of this piece of work, I am focusing on the significant aspects of 'nurses as patients' that relate to the aim of the thesis,

which is to explicate the stories of two nurse-patients receiving nursing care and nursing practice.

During the first evening of my readmission, it was decided that a naso-gastric tube should be inserted. This is a procedure that I had performed many times on patients early in my nursing career. I had never experienced it myself. The thought of it always makes me gag and immediately clutch my throat. I agreed to one of the nursing students inserting the naso-gastric tube. However, It was an unpleasant and unsuccessful experience for me, and I would imagine for the student involved. A staff nurse later inserted the tube. I believe it was my fear that prevented the successful insertion on the first occasion, rather than anything the student did or did not do. I soon became accustomed to having the tube in my nostril, but I was pleased to have it removed on the fourth day by a staff nurse.

Late on the evening of my second night back in hospital, I was unwell, and being seen by many different doctors. I had become short of breath and was sitting upright in the bed. I watched, as an unknown doctor walked around my bed with a needle and syringe and a laboratory specimen bottle in his hand. He said little, but helped me sit forward, then promptly proceeded to take a sample of pleural fluid from my back. After this had happened, I remember feeling that I was rather oblivious to it all, that this wasn't actually happening to me. I was aware how compliant I was, but I had little energy to question and complain.

In the early hours of the morning, three different surgeons and their respective medical teams saw me. I became aware that there was a discrepancy over my proposed medical treatment. A discussion between the doctors took place at the foot of my bed as to whether I should be taken back to theatre for exploratory surgery. I thought to

myself, 'I'm not keen to return to the operating theatre'. I had recently read an article in the newspaper about a young woman who had died from a 'flesh eating' disease (necrotising fasciitis). She had earlier undergone abdominal surgery and had been taken back to theatre with complications. I was feeling quite scared. I remember the junior medical staff later telling me that they thought surgery was the best option. I was in no state of mind to agree or disagree. I was however, happy with the conservative treatment being offered by the senior surgeon. Some days later my surgeon mentioned that his concern in taking me back to surgery was related to the woman with necrotising fasciitis.

I am aware of the invisibility of the night nursing staff in my discussion of these last two incidents. The ward was a busy surgical unit that accommodated twenty-six patients. The two nurses on duty this night were both permanent night staff, I do not recall either nurse being present in my room during these events. I assume that they were busy with other patients.

During this same night, I required the commode and the two night nurses came in to my room. One was an enrolled nurse, and in my ill health, appeared to be a rather loud, jovial person. The other, a staff nurse who had worked the night shifts for many years. My physical condition was not good, I had been short of breath earlier and had a tense painful abdomen for which I was receiving intravenous Pethidine. The nurses assisted me out of bed and onto the commode.

At the time, I felt like I was sitting on the commode that had been placed on top of the bed. The memory is very vivid, both of the nurses are at my side, laughing and being rather noisy. I felt it was all rather inappropriate. On further reflection, I have realised that I was possibly experiencing some effects of the intravenous narcotics. My

visualisation of the event was quite absurd; I must have been on a high from the drugs. The commode would not have been placed on top of the bed. I then began to ponder 'How would the nurses have known that I was 'on a high' from the intravenous Pethidine?' I do not believe that at this stage there were any outward signs. Did I tell the nurses that I felt like I was sitting up high?

The next day Sarah cared for me again. She is an experienced, registered comprehensive nurse who has worked in the area for several years. In my early years of teaching she was a student in one of my classes. I remember one of my education colleagues describing her as 'a very caring nurse'. Sarah was involved in my nursing care on my first admission; she was pleasant and smiled a lot. It was Sarah who gave me the hot water bottle on the Saturday night when I had backache. It was now day three of my readmission. I was feeling miserable and Sarah gave me a lovely bed sponge. It left me feeling very relaxed and comfortable. I dozed on and off for the rest of the morning. I was unable to keep my eyes open. I felt like I was floating. Midmorning, Sarah came into my room to attend to the intravenous infusion. She apologised for giving me too much intravenous Pethidine. I was very dozy; I didn't have the energy to respond. However, I do recall feeling annoyed by this. Later, when I shared this episode with my colleagues I felt angry about the incident. There had been no further explanation from Sarah, and I did not question her about it. I felt too vulnerable; I would be questioning her practice as a nurse.

During the 1990s I taught the subject of 'ethical-legal' issues in nursing practice. I was therefore, interested in not only how Sarah dealt with the issue at the time, but also in her subsequent actions and documentation of the event. On reading my nursing notes, I am able to establish that my Pethidine infusion had inadvertently been set to

run faster than the prescribed dosage. I had received an overdose of Pethidine, a narcotic analgesic. Sarah documented this episode at the end of her report in my nursing notes as:

... IV Pethidine infusion in progress due 1715hrs. Bag is an 8 hr one but was inadvertently put up at a 6 hr rate. Dr notified - bag to continue at 8 hr rate in meantime. IV bolus of Pethidine x3.... (Signature of the nurse)

I was now able to understand why I was having trouble with my eyelids, and why I was feeling so relaxed. Since these two incidents, I have a clear idea in my mind of what it is like to be high on drugs. Hopefully, my experience with narcotic analgesics will perhaps enable me to detect the early warning signs in patients I am working with. There was however, no mention in the nursing notes that were written by Sarah, of how I was feeling in response to this overdose of narcotic analgesia. She had begun the shift report by stating:

*Miserable most of duty. Temp (temperature) 38-39.
Pulse (rate) and BP (blood pressure) satis....*

As mentioned earlier, patient's medical records should provide an accurate and complete account of the patient's stay in hospital. Patients' nursing notes provide a record of the patient's nursing care and health state during hospitalisation. They are also an essential communication tool between nurses and other health team members. Nurses use both oral and written communication to achieve this transfer of patient information to colleagues. Research shows that at the collective intershift handover, nurses talk about their practice, they constitute the patient as a person through their everyday talk (Parker, 1995; Parker, Gardner, & Wiltshire, 1992). While some

patient information is considered important enough to share verbally at handover, the same information is often omitted from written nursing notes. Research by Parker & Gardner (1992) revealed that nurses only document a minute proportion of their care, and this documented portion usually reflects medical and highly visible tasks. There is very little focus on the patient as a person, or their feelings and reactions to being ill (Parker, 1995; Parker & Gardner, 1992). This is what I found as I read through my patient notes.

I was also concerned that there was no mention in Sarah's nursing notes of an incident form having been written. Incident reporting is part of a hospital's quality and risk management system. They have been used in nursing practice in New Zealand for several years. Serious incidents, (especially those involving intravenous drugs), should be followed up to prevent recurrences (Duffy, 1998). New Zealand Health and Disability Commissioner Robyn Stent, stated in her report on patient safety at Canterbury Health that "Staff who fail to complete incident reporting forms act in an unprofessional and unethical way" (Stent, 1998).

Later that afternoon, I was pleased to have five of my colleagues visit me. They looked pale and drawn as they stood and sat around the end of the bed and chatted with me. I wondered what was happening at work for them to look as they did. I remember giving them an afternoon report on the patient. It was very matter of fact and analytical. I was telling them about a patient that they had come to see. However, I was telling them a story about me, the nurse-patient. I was not a well patient. I was lying in bed, naso-gastric tube in my nostril; both arms had intravenous lines connected up to a pump system, one on each side of the bed. I was short of breath and my colour was grey. The doctors were now treating me for a pleural effusion and pulmonary embolus. I was unable to conceptualise the

seriousness of my own health at the time. I was telling my colleagues a story about someone else.

By my fourth day back in hospital, I was being treated for every textbook complication of surgery. I found it rather irksome when health professional colleagues said to me 'trust you to get complications, typical nurse'. This was not something I had considered in my nursing practice, and I did not appreciate hearing these comments when I was unwell. It was therefore interesting to find an English study by Cotter (as cited in Williams, 1997), who found peers of nurses frequently stereotype nurse patients as being more prone than lay patients to complications. No evidence was located to suggest why this may be so.

As a nurse I always enjoyed working in the wards on a Saturday and Sunday. There was generally less hustle and bustle. Many members of the multidisciplinary team are not present. Nurses provide the twenty-four hour essential co-ordination and patient management role (Coleman, 1995). As a patient, the ward felt serene, it was quiet and restful. The nurses appeared more relaxed. I was able to sit up in a chair for the first time in four days. I longed to wash my hair, but the shower would have to wait until tomorrow when I was feeling better.

Lying in the darkness of the room after I was settled for the night, I listened to the voices of the nurses as they completed their duty. Just before eleven o'clock, I was startled by a popping noise coming from the infusion pump on the right side of my bed. I felt the tingling sensation of an electric shock running down my arms. It reminded me of the feeling I once had from an electric jug cord. I called out in surprise. Several nurses appeared at my door. They removed the infusion pump from the power point and replugged it into another point in the room. As the afternoon shift of nurses was due to go

home, I was left alone to try and go to sleep. I was left feeling anxious by this incident.

A short time later a similar event occurred, I called out again. New faces appeared at my door, the night staff were on duty. I remember well one nurse in particular. Kathy made me feel like I was imagining this experience. She was a senior night nurse whom I recognised. She attempted to reassure me, and said "Dianne, you just need to go to sleep". I replied that I felt unsafe. Eventually, I was moved, I felt rather reluctantly, to a room two doors away. The night was initially, an uneasy one for me; I drifted off to sleep for short periods. At times when I awoke, I recall having discussions with this experienced night nurse. She had been a charge nurse when I first worked in the hospital. I had been feeling 'down' earlier in the day and enjoyed talking with someone I knew. Kathy provided reassurance and offered to take my temperature and oxygen saturation (O₂ sats) recordings.

However, on reading my medical file and the nursing notes written by Kathy for this night, I was again, surprised by the nursing documentation. This experienced nurse began her notes by stating:

*Reasonable night, sleeping well between cares. Up to
commode. Passing flatus freely. N/G (nasogastric
tube) drainage scant and tube irritating throat.
Lozenge helped this. Heparin infusion OK. IV additives
given. Pethidine infusion 8 hourly due 1200hrs.
Rather anxious about herself, wanting temp and O₂
sats checked etc. O₂ sats 94% at 0600hrs. Not on O₂ at
present. HPU (has passed urine) approx 400 ml
overnight. (Signature of the nurse)*

This documentation by the nurse included her objective data and provided her subjective assessment of me. However, my response to the night that I had encountered was not evident. And then, as if she may have just remembered my distress, Kathy added:

Early in duty experienced electric shocks from ?power point in Room 6. Got shocks in both arms and heard popping noises, shifted to another room and no further problems noted.

I was pleased to read that this incident, which caused me much anxiety and sleeplessness, had finally been recorded in my nursing notes. However, there was again, no mention of an incident form being written. In terms of legal accountability, it is essential that patient records reflect the total care that has been provided (Burgess, 1993). The incident was however, reported in some way. An electrician came to speak with me in the morning after he had checked the room. No obvious technical problem was identified. From my teaching practice, I knew that this employer had an incident report book. It included clear guidelines on when an incident form should be written. Good nursing documentation will state that an incident form has been written. Duffy (1998) writes "all incidents not consistent with the routine delivery of service and 'near misses' or potential incidents should be reported". This incident and the earlier mentioned narcotic overdose were not consistent with the routine delivery of a nursing service. They were very frightening and distressing to me - the nurse-patient.

The day had arrived for my first shower and that longed for hair wash. Sarah pushed me down the corridor on a mobile shower chair to the bathroom. After being in bed for so long the shower was lovely. On one of the following days, I recall a nurse took me to the shower

and asked me to ring the bell when I was ready for assistance. As I wanted to wash my hair again, I asked her to stay and help, she replied, "Dianne you have to be able to do your own activities of daily living". I was dumbfounded and speechless by this response; I still had intravenous cannulas in both of my arms (antecubital fossa). I had been having problems with the lines tissing and having to be resited. I did not want to dislodge one of the needles as I showered and washed my hair. Somehow, I managed to attend to my own 'activities of daily living' and keep the intravenous lines intact. A subsequent entry in my nursing notes by this nurse read:

...Needs encouragement +++....

The nursing staff were always friendly to me. Many had been students in the programme I taught in, others were familiar to me as staff members I had worked alongside in other areas within the hospital. There were others, whom I had not met in my professional practice. Because of my role as a nurse tutor, and my experiences as a nurse, I was aware that some of the staff might feel anxious about being involved with my nursing care. However, I did not foresee this as a problem. Since the early 1990's, my role as a polytechnic nurse tutor in clinical practice had changed due to the increasing demands of the institution. I recognised that the clinicians were the experts in clinical practice, and the nurse educator was the facilitator of student learning.

One day, a young staff nurse, Lara, who had been a student in the programme I taught in, came in and sat on my bed. She said, "I am not involved in your care, but how are you? This all must be horrible for you." This was the first time a member of the nursing staff had openly acknowledged my experience of illness. I remember feeling a little overwhelmed by it, but was able to thank her for asking. On

subsequent days when Lara was on duty, she would stop by to say hello and talk about her impending overseas trip.

Lara was soon to leave the ward, and, as I remember happening from my early nursing days, the antics and farewells began. One evening, I was feeling alone and emotionally down. Harry had visited earlier, but had since biked home. I was alone in my room when I heard much yelling and screaming coming from out in the ward. I soon recognised the noise as the voices of the nursing staff. Lara, who was fully dressed in her uniform, had been put into a bath. I was not against nursing staff having some fun while on duty, but my interests in nursing being seen as a profession were paramount. One of the teaching subjects that I taught was 'Professional issues' in nursing. As a nurse-patient, my needs were not being met; I did not consider this frivolity in the ward as acceptable professional nursing behaviour. This was not an isolated incident, a similar event happened on one other occasion during my fortnight in the ward. Another nurse, who was leaving the ward, was taken into a shower amongst much laughter and frivolity. I was aware that there were many unwell patients in the ward. I found the noise distressing, especially as I felt my needs were not being met.

Janice, a registered nurse, was often involved in my nursing care. She was very diligent in providing the technical aspects of nursing practice. She would literally run into my room, attend to the intravenous infusion pump, and run out again. Janice was pleasant and friendly. However, as a patient, I felt there was something missing with her nursing care. I felt that she did not 'engage' with me, she made little time to be with me. When I am working with students, I am reminded that as we learn a skill or task, we are only able to focus on the task in hand. Perhaps this incident indicated where Janice was at in terms of her nursing practice.

In my early nursing career as a staff nurse, I spent a lot of time working the night shift on acute medical and surgical wards. I enjoyed the autonomy and flexibility that this shift gave. I enjoyed being involved with all the patients and their nursing cares, and was able to chat with patients who were unable to sleep. However, as a patient I did not enjoy the long, lonely nights of this hospitalisation. My single room was situated opposite the entrance to the utility room, the nurses were moving in and out of here all night. Despite half closing my door, I found the lights and noise annoying. The sound of voices in the distance, and the banging of the utility room door and bedpans were frustrating. I only saw the nurses briefly during the night when they came to administer my intravenous antibiotics. I remember feeling quite lonely at times.

I remained connected to an infusion pump through to the day of my discharge. Once I was able to be up and about, I made frequent trips to the toilet; it was some distance away from my room. It was an effort to get myself up and out of bed while connected to the pump. I was slow to mobilise, my abdomen was distended and uncomfortable. Occasionally, I would ring the bell for assistance, and often the nurses would not respond. I would heave myself out of bed, bend down to disconnect the power source, wind the cord and tubing around the pole and walk slowly to the toilet clutching my abdomen with my free hand. After toileting, I would walk slowly back to bed, bend down to reconnect the power source, unwind the cord and tubing taking care not to catch it while I clambered back to bed unaided. The nurses rarely assisted me. At times, I would see them in the office; they were sitting down chatting to each other. I felt neglected and frustrated that the nurses did not make an effort to assist me. I would lie back in bed and reflect on my previous role as a staff nurse on night duty. I remember the regular rounds we made, and that we would respond to any noise we heard from the office.

On the Sunday morning of the last weekend I was in hospital, and after a disturbed night, I recall getting out of bed and sitting in a chair by the door to wait for breakfast. I felt miserable and began to sob. I noticed one of the experienced nurses walking towards my door with my breakfast tray. I immediately felt safe that she would be able to nurse me. However, she was unable to deal with my tears, she exclaimed 'oh dear' and walked out of the room. I felt let down, yet again. On reading her nursing notes for the morning, she wrote:

Satis. Showered. Mobilising freely. Feels much better now. Heparin Infusion continues. (Signature of the nurse)

As my abdomen was very tender and rigid, I knew it was important for me to be up walking rather than lying on my bed for long periods. However, I would not have contemplated the energy and effort required to mobilise. As a nurse-patient, I did not conceptualise the seriousness or significance of my post-operative complications. I also recall little discussion with the nurses related to my condition.

The hospital routine can become monotonous for patients as they recuperate from their illness. I looked forward to my visitors each day and to the visits and discussions I had from nurse colleagues who were not directly involved in my care. As my health and appetite improved meal times became the focus of the day. It was not a matter of thinking 'what will I cook tonight' but, 'what will be on the menu today?' Nurses often discuss amongst themselves and at handover time patient's obsessions when they are in hospital. I am now able to better understand why patients may focus on specific aspects, for example, their meals, during their hospitalisation.

Harry was my main family support while I was in hospital, he would visit once or twice every day. As he did not drive, he would either walk, bike or travel the eight-kilometre journey in a taxi. As a consequence of his earlier surgery, Harry's health was determined by him getting adequate rest and eating sufficiently to sustain his mental and physical activity. He would often arrive at the hospital with a supply of food for himself. Harry would sit with me for several hours, reading, watching the television or nodding in the chair as I rested. He was my constant caregiver at times. He noticed the little things that made me more comfortable. As he arrived on the ward each day, he would go into the kitchen and bring me a fresh glass full of ice. I never had to ask him, he knew what I needed. He knew that I did not like the warm water from the jug on the locker. At times, Harry felt as if the nurses scorned him for getting me ice from the fridge, or for making me a milkshake. He said most of the nurses did not speak to him, they did not acknowledge him in any way.

Over the past twenty years nursing practice has espoused the rhetoric of providing holistic care. For me, this means caring for patients as a complete identity, not just as an objective part that needs treating. I considered the emphasis in my teaching to be on the holistic concerns of the patient and their family, or significant others. I was therefore, surprised when I read my patient file to discover that Harry was not mentioned once in my nursing progress notes. I recall very few nurses asking about him or how he was. As a patient, his presence was vital to my well-being and he spent many hours at my bedside.

Getting out

I still had the intravenous heparin infusion running, but had now been commenced on warfarin (anticoagulant medication) in preparation for my discharge. The surgeon came into my room one morning, and after a brief discussion said I could go home. Although I had been

desperate to go home and get out of the ward, I was not prepared for discharge. I was short of breath at times, and still had abdominal discomfort. Although I was independent with my hygiene needs, I found it difficult to mobilise freely. I phoned Harry at home, but there was no reply, he was already cycling up to the hospital. Fortunately, Elizabeth, a work colleague arrived shortly after this and offered to take me home. Harry arrived at the hospital, on his bike, as I was gathering up my personal belongings.

My departure from the ward, after being a patient for fifteen days, appeared to me to be insignificant for the nursing staff. I felt like I just slipped out. I asked Harry to find a wheelchair that we could use to carry out the television set. We bundled my things together and walked out the ward with the wheelchair laden high. I recall no farewells or any acknowledgment from the nursing staff, other than being given a prescription and discharge letter at some stage earlier in the day. No nurse assisted me with my belongings or escorted me to the car. After my first admission, I had given the staff a box of chocolates, but on this occasion, I did not feel the inclination or necessity to do this. I just wanted to get out of there. The final report in my nursing notes reads:

*↑→ independently. Heparin discontinued. S/B Mr
Marshall - discharged home with medical and
Marshall follow-up. (Signature of the nurse)*

Since my discharge from hospital, I have a real fear of having to return to hospital as a patient. It is not something I look forward to. I began to question further my own past practices as a nurse working in a surgical ward. Did I really meet the needs of my patients? I thought I did. As mentioned in an earlier chapter, recent literature suggests that the perception of nursing care does differ, depending on whether

it is the nurse's story, or the patient's story, you are hearing (Prentice, 1995; Zeitz, 1999). I often think about what might the stories of the nurses involved in my care tell. How different might they be from my story - that of the nurse-patient receiving nursing care?

Conclusion

In this chapter I have shared some significant moments of my personal and professional life. I have told my story of being a nurse-patient who was hospitalised for elective surgery, and subsequent readmission to hospital within forty-eight hours of discharge with a life threatening illness. I have shared my story of being a nurse-patient requiring nursing care. By sharing my reflective topical autobiography of one aspect of my personal and professional life in this thesis, it invites comparison with the account of Maria from the last chapter (Johnstone, 1999). As is the aim of this thesis, the next chapter will present an analysis of these two stories, in that some shareable understanding of the experiences of two woman nurse educators as nurse-patients is explicated in relation to nursing practice.

CHAPTER EIGHT: Receiving Nursing Care

Introduction

In this chapter I begin by providing an overview of the journeys of Maria and myself as nurse-patients. Then I identify and discuss the themes that emerge from our stories. The core story created from Maria's biographical narrative was analysed for underlying patterns or themes using the emplotment process described earlier (Emden, 1998b). My autobiographical narrative was analysed in a similar way to generate emergent themes. When our narratives and the literature on nurse-patients and non-nurse patients were compared, three distinct qualities of our experience emerged. The first, 'knowing as nurse-patient' contains the three sub themes of 'having knowledge', 'expectations of being nursed', and 'knowledge gained'. The second distinct quality 'being nursed' contains the two sub themes of 'feeling safe and cared for' and 'presencing', and the third 'not being nursed' contains the four sub themes 'feeling vulnerable', 'invisibility of nurses', 'getting out' and 'feeling let down'. The sub theme 'getting out' includes three additional sub themes of 'wanting to get out and not wanting to be there', 'leaving and the need for closure' and 'not wanting to go back'. As I describe the emergent themes, I shall also provide an interpretive discussion with themes identified from the literature review.

The journeys

Maria and myself are two nurse-educators who were admitted to hospital rather reluctantly, for elective surgery. Our journeys over the next days and weeks were unique, but some commonalities are evident. Our experiences had us both reflecting on our practice as nurses and nurse educators. We were both admitted as well independent persons who required nursing care as part of our surgical interventions. Maria became unwell after surgery requiring intensive nursing care before her health improved; she was subsequently discharged and then later readmitted as a sick person. Maria clearly differentiates these two experiences of receiving nursing care. In summarising the story of her first admission, she said:

...I had at times terrible nursing, but my second admission was fantastic nursing. It was terrible nursing (referring to first admission)...

Later, in summarising her second admission, Maria describes the difference between her two admissions and said:

... Things kept going wrong and things were missed (referring to first admission).... the second time it was very different, it reaffirmed my belief in skilled nursing assessment.

Whereas my first hospitalisation was relatively straightforward; I was dependent on nursing care for a very short period and I left hospital feeling well after four days as a patient. I was pleased my hospitalisation was over and that I was going home. At this time I had not analysed my experience of receiving nursing care. However, I returned to hospital within forty-eight hours of being discharged, and during the next four days when I was a sick person requiring nursing care, I said:

I became disappointed and disillusioned with nursing and nursing education.

After reflecting on the experiences of both Maria and myself, it is evident that we both felt disappointed and disillusioned with the nursing care that we received. I also began to consider what it meant 'to be nursed' as a well, independent patient compared with that of being a sick, dependent patient. As a sick dependent patient I felt that:

I just wasn't nursed.

As mentioned in chapter two, the anecdotal accounts and research on the topic of nurse-patients offer contrasting experiences of nurses receiving nursing care. The literature found on nurse-patients did not identify a nurse-patient who required

readmission to hospital, nor did it identify sick dependent nurse-patients. The study by Williams (1998a) interviewed nurses regarding their recollections of their acute hospitalised experience and although it is evident that some of the nurse-patients underwent major surgery, their dependence on nursing care is not stated. Zeitz (1999) however, does state that her participants had undergone an uncomplicated surgical procedure and I assume from this that the nurse-patients would probably have been dependent on nursing care for only a short period. The anecdotal evidence found in both of these studies provides valuable insight into the experience of nurses as patients.

Our narratives tell much more than the stories of two nurse-patients receiving nursing care. They tell about the roles and expectations of being a patient and about the role and responsibilities of the patient who is also a nurse and nurse educator. They also speak much about medical care. Our narratives provide valuable insights into the meaning of illness and the experience of hospitalisation for the individual. However, as the intent of this thesis is to explicate the stories of nurse-patients receiving nursing care, chapter eight will present the analysis of this aspect only.

The following key qualities emerge from our narratives as nurse-patients receiving nursing care, and the literature located. The first I name '*knowing as nurse-patient*' which includes the three sub themes; 'having knowledge', 'expectations of being nursed', and 'knowledge gained'. The second distinct quality to emerge, I identify as '*being nursed*' and includes the two sub themes; 'feeling safe and cared for', and 'presencing'. The third distinct quality I name '*not being nursed*' which includes the four sub themes; 'feeling vulnerable', 'invisibility of nurses', 'getting out' and 'feeling let down'. The sub theme 'getting out' also contains three further sub themes; 'wanting to get out and not wanting to be there', 'leaving and the need for closure' and 'not wanting to go back'. The distinct qualities of our experience and the sub themes describe the essential components of what it means to be nursed, and could contribute to a model for nursing practice. They are summarised overleaf in Table 1: Key qualities and sub themes emerging from the narratives of nurse-

patients. I will now describe each of the distinct qualities and emergent sub themes in more detail.

Table 1: Key qualities and sub themes emerging from the narratives of nurse-patients

1. Knowing as nurse-patient

- 1.1 Having knowledge
- 1.2 Expectations of being nursed
- 1.3 Knowledge gained

2. Being nursed

- 2.1 Feeling safe and cared for
- 2.2 Presencing

3. Not being nursed

- 3.1 Feeling vulnerable
- 3.2 Invisibility of nurses
- 3.3 Getting out
 - 3.31 Wanting to get out and not wanting to be there
 - 3.32 Leaving and the need for closure
 - 3.33 Not wanting to go back
- 3.4 Feeling let down

Knowing as nurse-patient

The importance of knowing and having knowledge emerges throughout our narratives. The significance of the knowledge nurse-patients have, or think they should or might have, or are expected to have, would appear to be multifaceted (Coleman, 1995). The knowledge with which nurses enter the realm of being a patient is different from that of non-nurse patients. Our educational preparation and experience in caring for people empowers us with certain information. As nurse-patients we have knowledge, particularly within our own field of nursing practice, and we know much of what will and/or might happen. However, as nurse-patients we may also have limited knowledge in other areas. The knowledge that we have as a nurse-patient can therefore be an advantage or disadvantage to us and will be

discussed as the first sub theme of 'having knowledge'. Two further sub themes: 'expectations of being nursed', and 'knowledge gained', will then be discussed.

Having knowledge

Our nursing knowledge can give us the opportunity to prepare ourselves for the experience and hospitalisation. In my case I was able to read up on the options for anaesthesia and discuss this with a nursing colleague who had been through the procedure. Our knowledge can be reassuring when various events occur because we have some understanding of what is involved. This was evident in both of our narratives. On speaking about her first post-operative day, Maria said:

... Because I was a nurse, I was a bit cheeky about what I knew...

We were also able to be actively involved in the recovery process by doing things without having to be reminded by the nurses. Our knowledge of the environment and of the nursing staff may have ensured that as nurse-patients we were "not overwhelmed by the system" (Coleman, 1995, p. 335). Maria and I were both admitted to hospitals that we had worked in so there was much about the environment that was familiar. We both knew many of the nursing staff at a personal and/or professional level. However, this knowledge may also have been a disadvantage to us as nurse-patients. It may have contributed to the nurses making the assumption that we knew everything. This was evident in Maria's comments when she discussed her preparation for surgery. She said:

I remember being given a razor, and I presume it's that thing of everyone expecting you to know what to do. It was, a sort of a razor that I had never seen before, I didn't know whether you used it wet or dry, or really how much I needed to shave.... You are meant to know this because you are a nurse, but perhaps I didn't know what I was expected to know.

This aspect of knowing relates to what is perceived as an expectation by nurses that nurse-patients are informed and understand what to do for themselves. The resulting implication is that this assumed knowledge often results in less explanation being provided by the nurse and/or the patient being left to fend for themselves, as evident in Maria's case. This has been found in the anecdotal reports and research relating to nurse-patients (Gleeson, 1992; Hodgkinson, 1993; Johnson, 1992; Ruiz, 1993; Williams, 1998a; Zeitz, 1999). A lack of information was perceived to be a problem for non-nurse patients in the study by Irurita (1999), and although this can be related to many factors, patients were left feeling vulnerable. As the issue of vulnerability is evident throughout the narratives, I have discussed it further as an emerging sub theme later in this chapter.

By having knowledge, the nurse-patient may be more vulnerable than the non-nurse-patient because we know what might go wrong. The anxiety level of the nurse-patient may thus be increased (Buckalew, 1982; Williams, 1998a). When the regional anaesthetic block was asymmetrical after my initial surgery, I was concerned about the complications that could happen if my leg was not exercised. My anxieties and distress were evident when I said:

I remember feeling a sudden sense of panic.

And later on a second occasion when the doctors were talking about taking me back for exploratory surgery, I stated:

I was feeling quite scared.

I had knowledge of a woman who had recently died following her return to the operating theatre with complications. The knowledge that Maria had was also evident when she expressed her anxieties and distress two days after her surgery. Maria felt things were going wrong; she felt that she was getting sicker, she said:

I felt really distressed about the level of nursing I received.... I was asking the questions.... I was the patient not the nurse.

In our narratives, Maria and I both speak of our frustrations and distress with the nursing care that we received during our hospitalisations. The above example highlights not only the knowledge that we have as nurse-patients, but also demonstrates our expectations of what it means to be nursed. In the next section I discuss the second sub theme - 'expectations of being nursed'.

Expectations of being nursed

Maria and I both came to hospital with expectations regarding the nursing care that we would require and receive based on our knowledge and experience. Whether these expectations were met during our experience is how we evaluated the nursing care provided. Our narratives reveal that while we both recognise and describe incidents of 'being nursed' and 'not being nursed', we are also able to identify a difference between the care given by a novice nurse and an expert nurse, as identified by Benner (1984) in her work *From novice to expert: excellence and power in clinical nursing practice*. Zeitz (1999, p. 70) suggests that nurse-patients "are able to discriminate appropriate and skilful nursing care...".

During Maria's first admission to hospital, she states that many of the nurses involved in her care were new graduate nurses. Throughout this part of the narrative when she felt she received terrible nursing, Maria makes reference to nurses' knowledge, to their apparent lack of knowledge and assessment skills, and to their inability to relate clinical practice to theoretical knowledge. She talks about receiving a blood transfusion that she had previously said she did not want. The nurse did not appear to have administered a blood transfusion before, and there appeared to be some anxieties about the recordings necessary during this procedure. Maria, an experienced nurse who had been accustomed to giving blood transfusions in her nursing practice, described this incident as:

... The imbalance of experience in nursing.... It just seemed like their novice nursing came through to me.

As experienced nurses, as nurse educators, and now as nurse-patients, Maria and I may have been expecting expert nursing from those involved in our care. Zeitz (1999), in summarising the specific implications of her study to nursing practice, suggests that although nurse-patients are aware of the humanity of nurses, they acknowledge that perfect situations are not always possible. However, this does not necessarily make us more accepting if problems occur. Nurse-patients can still experience frustration when their expectations about nursing practice are not provided. In both of our narratives there are excerpts to illustrate this. For example and as previously mentioned, when I felt *I wasn't being nursed* as I had expected to be early in my second admission, I expressed my *disappointment and disillusionment with nursing and nursing education*. Maria also expresses her frustration on several occasions when the nursing care was not meeting her expectations, as illustrated in the following quotes:

I had to ask for things.... None of the nurses acknowledged it (the pain).... You expect the nurses to....

This frustration and perceived lack of care can also lead to the unpopularity of nurse-patients, who can scrutinise and complain about their colleagues' care to other peers (Morris & Mendias, 1985; Williams, 1998a). Both of our narratives reveal instances where we share our frustrations with our visiting nurse colleagues. However, we both also recognise that we gained knowledge from the experience.

Knowledge gained

The practice of nurses who have been the recipients of nursing care while hospitalised, can be positively influenced by the experience (Gillies et al., 1993; McKenna, 1995). Nurse-patients learn much about their own practice (Edwards, 1994; Haybach, 1993; Jaffray, 1995; Ruiz, 1993; Sherrard, 1988). Maria reveals what it felt like as a patient to receive intravenous drugs when the intravenous line

was not working effectively. This caused her to reflect on her own nursing practice and to consider that her focus then was on getting the intravenous line to work. She said:

It made me realise.... I felt like I was being paid back a little bit.

Likewise, throughout my narrative I provide several accounts that made me reflect on my practice as a nurse. I now discuss some of my knowledge gained with the nursing students I am privileged to work with in the acute hospital setting. For example, I discuss with the students what it meant for me as a patient 'to be nursed'. I ask them to consider what this means for them in their nursing practice. As I read and reread our narratives, the distress, the disappointment and the disillusionment that Maria and I felt as nurse-patients are evident from this distinct quality of 'knowing as nurse-patient' and the sub themes of 'having knowledge', 'expectations of being nursed', and 'knowledge gained'. The second distinct quality of 'being nursed' will now be discussed.

Being nursed

'Being nursed' encompasses the incidents of receiving nursing care when Maria and I felt nursed. We recognised caring nursing practice as nursing care that made a positive difference to our well being. Waterworth (1995) describes this concept of care as 'therapeutic care'. While caring is described as a central phenomenon in nursing practice (Benner & Wrubel, 1989; Watson, 1995), much debate exists in the literature about the nature and meaning of care and caring in the context of the nurses' role (Coleman, 1995). Both of our narratives reveal incidents where at times we felt that we were cared for and were 'being nursed'. I shall describe this distinct quality of what 'being nursed' meant for us by discussing two sub themes; 'feeling safe and cared for', and 'presencing'.

Feeling safe and cared for

As sick nurse-patients requiring and receiving nursing care, Maria and I both recognised nursing care that made a difference to us. Maria's narrative of her second

admission suggests that this was more evident when experienced nurses were involved in her nursing care. She said:

...I had these more experienced nurses.... I hadn't had them the first time.... It meant that I left hospital feeling well.... feeling safe and having felt cared for.... they had a real interest in me, as well as assessed and nursed properly.... they knew what they were doing, they could make a decision.... they reaffirmed my belief in skilled nursing assessment.

Throughout Maria's narrative she describes these experienced nurses as nurses who made a difference to her experience as a patient. They were nurses who listened to her and acknowledged what she had been through - they were attentive and took an interest in her; she said:

They had a real concern for me.

During the first three days of my first admission when I was dependent on nursing care, an experienced nurse-educator and the nursing student she was working with provided me with safe, caring nursing practice. At other times, another experienced education colleague provided aspects of my care. When she was involved, I said:

She demonstrated those confident caring qualities that made me feel cared for. I felt nursed when she was around.

Benner (1984) in her seminal work on skill acquisition and the development of expertise in nursing practice; identified five levels of clinical proficiency in nurses (novice, advanced beginner, competent, proficient, and expert). According to Benner's model, a novice nurse has little practical experience and therefore must rely heavily on prescriptive rules to aid in decision-making. In this process, a novice nurse may not comprehend the context of a particular situation and thus is unable to

be discretionary when there is an exception to a rule. Benner (1984) suggests that an expert nurse develops a way of approaching complex situations and makes clinical decisions or judgements through the use of past experiences and education.

We both describe incidents where the confidence of the experienced nurse impacted positively on our nursing care. In one particular incident, Maria describes a nurse who made a difference to her care, she said:

She was really confident and didn't bother with all the niceties and all the talking.... I felt good about who she was, she knew her stuff....

As previously mentioned, I describe the *confident caring qualities* of a nurse colleague who visited me. However, I am less able to find excerpts from my narrative that illustrate my confidence in the nurse caring for me. Fortunately as the above excerpts demonstrate there were examples in both of our narratives where expert nurses provided us with nursing care that made us feel safe and cared for. Nurses do make a difference to the experience the patient encounters (Ruiz, 1993; Zeitz, 1999).

Presencing

Throughout our narratives, it is evident that Maria and I perceived the 'presence' of the nurse as a positive aspect of being nursed. These nurses were able to acknowledge the physical, emotional, spiritual and environmental dimensions for us, they provided expert holistic nursing care that assisted in our recovery from surgery. Maria describes these nurses as being the older, more experienced nurses. She describes one nurse who she knew had not gone nursing until later in life by saying:

She had a sense of nurturing about her, it was just fantastic.... The nurses had a presence about them, they restored me.

This sub theme of ‘presencing’ or being present, which represents not only the nurse’s physical presence but also her mental presence, has been found in the literature (Brown, 1986; Brown, Masters, & Smith, 1997; Gerteis et al., 1993; Pontin & Webb, 1996; Riemen, 1986). It also describes the ‘engagement’ of the nurse as revealed in their attitudes and the way they deliver nursing care. Kralik et al. (1997) identify and describe the concept of ‘engagement’ that emerged from their study. It encompasses the ideas expressed by Maria and myself as aspects of being nursed. Another example from Maria’s narrative was when she arrived at the operating theatre and was greeted by a nurse:

...Her smiling positive face.... her presencing as a nurse was special....

The current study reveals that the nurse ‘being there’ was important to both Maria and myself. In the study by Kralik et al. (1997) the concept of ‘presencing’ was evident in the minor theme of ‘always available’, and they also report that ‘being with’ is important to patients. While this theme was not explicitly stated in previous studies, Irurita (1996) revealed it under one of the themes identified in her study. When nurses made frequent contact with Maria and myself, we felt safe and cared for, we felt that we were ‘being nursed’.

Zeitz (1999) identified the emerging theme of ‘acknowledging me’, to refer to this connectedness between the nurse and the patient and the sense of being recognised as an individual. I recall completing a personal details form at my pre-admission visit; it asked if there was anything particular the staff should know. I wrote: ‘I wish to be treated as an individual’. Other nurse researchers have found similar themes in their studies (Brown, 1986; Drew, 1986; Riemen, 1986).

Other factors also affect the quality of the nurse-patient relationship. This can be influenced by the attitude of the nurse and is revealed by the way in which the patient feels the nursing care is delivered. Maria and I both discuss times when nurses were nice to us, they were pleasant and friendly while providing nursing care.

Maria identifies the influence of attitudes in nursing practice when preparing to leave the hospital after her first admission. A nurse friend arrived and offered to help her, Maria said:

... It was a feeling, her connection...her presence...she knew what she was doing.

Zeitz (1999) identifies these same aspects in several of the themes that emerged from her data. Our stories of receiving safe, caring nursing practice and 'being nursed' reveal the same important characteristics and behaviours of the role of nurses as that found in the literature (Brown, 1986; Gerteis et al., 1993; Kralik et al., 1997; Riemen, 1986; Ruiz, 1993; Zeitz, 1999). They include: the engagement and presencing of the nurse, acknowledging the individual, being there, listening, and, the attitude and manner in which the nurse delivers care. However, as mentioned in chapter 2, research by Brown (1986) and Riemen (1986) identifies that the perceptions of caring and non-caring practice are very different depending on whether the view is that of the giver or receiver of care.

Not being nursed

It is evident from our narratives that Maria and I value the 'engagement', the 'presencing', and the 'being there' of the nurse. Therefore, when we received nursing care by nurses who lacked a 'presence' or who were 'not there' for us, we perceived this to be uncaring nursing practice. We felt we were 'not being nursed'. An example from my narrative highlights this when a nurse ran into my room, attended to the intravenous infusion pump, and literally ran out again:

She was very diligent in providing the technical aspects of nursing practice...however, I felt there was something missing with her nursing care.

I believe that what I was experiencing was a nurse who was present in the physical sense, she came in to attend to the infusion pump. However, she did not have a mental presence about her. The concept of 'being present' represents a physical and mental presence (Brown, 1986; Gerteis et al., 1993; Pontin & Webb, 1996; Riemen, 1986). The study by Kralik et al. (1997, p. 404) identifies that "all physical care was provided in a hurried manner with minimal verbal communication". This was also found in the study by Riemen (1986), and is congruent with my example. Both studies suggest that patients' perceived nurses as too busy to attend to them; they were not available to 'be with' the patient (Kralik et al., 1997). While in a study by Drew (1986), it was found that male and female patients from a surgical and obstetrical/gynaecological unit felt their caregivers had not cared about them as they lacked emotional warmth.

As previously mentioned, the attitude of the nurse can affect the quality of the nurse-patient relationship and is revealed by the way in which the nursing care is delivered. There are several examples in both of our narratives where this is evident. In my narrative I refer to an incident one night when I felt as if I had received an electric shock from the infusion pump. After calling out to the nurses, a senior nurse came into my room and her actions and words:

...Made me feel like I was imagining this experience

She finished her discussion with me by saying:

Dianne, you just need to go to sleep.

This disbelieving nurse effectively denied my experience and may have enhanced my feelings of powerlessness. As a sick dependent patient who was attached to two infusion pumps, I felt very aware of the power and control that this nurse had over me. Williams (1998a) and Zeitz (1999) report similar incidents from their studies where participants sensed a loss of control. Likewise, Maria speaks about a particular nurse whom she:

Hated (her) looking after me. She had no caring about her at all.

Maria refers to the (in) actions and comments of this nurse that made her feel this way. The nurse was rude; she did not make Maria feel comfortable. Maria obviously felt strongly about this nurse as she also stated:

This nurse was really slack.... I don't know why she was nursing...

The description of a 'slack' nurse is identified in the study by Harrison & Cameron-Traub (1991). They found that some patients did criticise the nursing care they received. The non-nurse patients related 'slack' incidents to the perceived heavy workload of the nurses and blamed the hospital organisation. The workload of the nurses is not evident in our narratives. However, other nurses that were involved in our care made Maria and I feel less confident and unsafe by their actions and comments.

As sick hospitalised nurse-patients, Maria and I had expectations of what nursing care we would require. Our narratives provide several incidents where we were encouraged to do things for ourselves even though we felt unwell or unable to do so. As nurse-patients we were both eager to do things that would help our recovery. However, on one occasion when I asked for assistance to wash my hair in the shower, the nurse replied:

Dianne, you have to be able to do your own activities of daily living....

I was concerned about the intravenous lines in the crook of both of my arms; I did not want to dislodge the needles. I was left feeling dumbfounded and speechless by the nurse's response. Isn't it the role of the nurse to assist the patient with their care? Maria also knew what she felt comfortable with when she required suppositories. When she asked the nurse for help, the nurse replied:

...I thought you could do it yourself.

Maria said:

That was enough to make you feel broken.... I was pretty sick...

These two examples demonstrate the powerlessness that Maria and I felt at times as nurse-patients. We were made to feel that we must be able to perform self-cares and cope, despite recognising that we needed assistance. The power and control that the nurse had over us is evident in our narratives. There were many occasions when we tried to minimise our feelings of powerlessness by being a 'good patient', by not demanding care, and by conforming to acceptable patient behaviour as described by Lawler (1991). My narrative reveals times when I was especially compliant during the night shift. On several occasions when I was encumbered with two intravenous pumps and rang the bell for assistance to go to the toilet, help was not forthcoming. Rather than interrupt the nurses from their routine, I would heave myself up out of the bed and unplug the machines from the wall sockets before taking myself to the toilet. Similar examples of nurse-patients feeling powerless were evident in the study by Williams (1998a).

Kralik et al. (1997) and Zeitz (1999) found similar incidents in the stories of the women they interviewed. More examples of nurse-patients being left to fend for themselves have been found in the studies by Williams (1998a), Hodgkinson (1993) and Ruiz (1993). The feelings of exclusion by these patients suggest they felt vulnerable. Riemen (1986) described non-nurse patients' perceptions of similar uncaring behaviour and attitudes of the nurses that were found to increase patient vulnerability. The feeling of vulnerability that emerged is now discussed as the next sub theme.

Feeling vulnerable

The narratives of Maria and myself do not explicitly state our feelings of vulnerability. However, they do reveal a feeling of vulnerability and insecurity as a

result of the nursing care we received. This is particularly evident when we were sick and dependent on nursing care. On several occasions it was because we felt the nurses attending to us lacked confidence and knowledge, and on other occasions it was because they were not available to be with us. We both knew what to expect with respect to some events which were to take place, but our sense of vulnerability came also from our fears about the unknown and from known persons in whom we would have to place a great deal of trust. Post-operative women in the Kralik et al. (1997) study suggested that the detached nurse promoted a feeling of vulnerability and insecurity in them. For the patient who is also a nurse it is a double-edged sword; we are more vulnerable than the non-nurse patient because we have nursing knowledge and experience (Buckalew, 1982; Williams, 1998a), and our expectations as a patient may not be fulfilled.

Our narratives reveal many incidents where both Maria and I felt we were not nursed. My narrative explicitly states my disappointment and disillusionment with nursing and nursing education. I recognised early in my second admission to hospital, that as a sick dependent person I was not receiving the nursing care that I required and expected. Maria clearly states her views on the nursing care she received as mentioned at the beginning of this chapter. Much of this nursing care has been described in this section. As a result of this uncaring nursing practice, Maria and I felt uncomfortable and unsafe at times. We were left feeling vulnerable and we often felt the nurses were not there for us. This emerged as the next sub theme, which I have named the invisibility of nurses.

Invisibility of nurses

On several occasions throughout my narrative, I comment on the invisibility of the nurses. This was especially apparent to me when family and friends were not present, and on two occasions when I was attended to by doctors during the night shift. The nurses often did not respond when I rang the bell for assistance, nor did they acknowledge it later. I felt that the nurses were invisible by their absence, and as a result of this I felt that they were not meeting my needs. I did not enjoy the long

dark wintry nights when I was a sick dependent patient; this is captured in my comment:

I felt lonely at times.

A participant in the study by Kralik et al. (1997) describes a similar experience where the night shift nurses did not meet her needs. In a more recent study, it was found that when nurse-patients recognised their need for assistance they felt frustrated when it was not forthcoming (Zeitz, 1999). While patients in Riemen's study (1986) describe the interaction with a nurse who did not respond to their request as non-caring. Similarly, the participants in the study by Kralik et al. (1997) found that the 'detached' nurse who avoided personal contact with their patients, compounded this by not communicating their unavailability.

As a result of feeling as if the nurses were not always available for us, we felt that we were 'not being nursed'. Maria and I wanted to get out of hospital and we expressed concerns about having to return again. This will be discussed in the next sub theme 'getting out'.

Getting out

As a nurse, I have often said that hospital is a good place to be when you are ill. However, the narratives of Maria and myself reveal that our experiences as nurse-patients suggest otherwise. This theme emerged from both our narratives and refers to the feelings evoked and expressed while in hospital. In particular 'getting out' describes the feelings of: wanting to get out and not wanting to be there; leaving the hospital and the need for closure; and, not wanting to go back to hospital.

Wanting to get out and not wanting to be there

On several occasions throughout Maria's stories of her first experience of receiving nursing care, she describes feelings of 'wanting to get out and not wanting to be there'. It portrays what she felt when she recognised the inexperience of the nursing staff and her need to have to ask for things. The stories describe various

experiences where the nurses were not meeting Maria's needs and they did not make her feel comfortable, in particular being constipated and requiring suppositories. She felt she had too many visitors and phone calls and that she had:

... Outstayed the normal patient stay.

She also describes the first time she got dressed and went for a walk after being in hospital for eleven days, she said:

I really wanted to keep my shoes on and know that I could get out of there. The shoes were very symbolic...

Maria's narrative describes the strategies she used to cope with these feelings of 'not wanting to be there'. She enjoyed looking out the window into the open space and using music to escape. My narrative reveals a similar feeling. At the end of my fourteen days back in hospital, I said:

I just wanted to get out of there.

The literature located on nurse-patients and non-nurse patients did not reveal this aspect of 'getting out' as discussed in this section.

Leaving and the need for closure

'Leaving and the need for closure' refers to that time when the nurse-patient is able to go home from the hospital, and the feeling of needing to close the experience of being a patient. The narratives of Maria and myself describe that after being patients for eleven-fourteen days, we did not feel that our departure from the ward was satisfactory. We describe the lack of involvement of the nursing staff at this time. The nurses were not there to help us pack our belongings, nor did they escort us to our means of transport. Maria said:

I was in a way sneaking out of the place because I just wanted to get away. There was no one around when I was leaving anyway.

I describe my sadness on leaving the ward and how I felt that it was insignificant for the nursing staff. I said:

I felt like I just slipped out.... I recall no farewells or any acknowledgment from the nursing staff.... No nurse escorted me with my belongings or escorted me to the car.

As part of the closure to the experience of being a patient, we both describe the issue of buying a present for the nursing staff. Maria reveals how after her first 'terrible nursing' experience she did not want to leave a present nor thank the nurses when she left. However, after her second 'fantastic nursing' experience she was determined to say thank you. Prior to her discharge, Maria went out from the hospital in a taxi to purchase a present for the nursing staff. This time she said:

I felt like it was closure when I left the ward.

Likewise, I presented the nursing staff with a present after my first admission when I perceived the nursing care to be satisfactory. However, on leaving hospital after my second admission, I felt unable to express my thanks to the nursing staff by giving a present. Two participants in the study by Zeitz (1999) also identify this feeling of needing to close the experience of being a patient. One expressed a similar sentiment to that of Maria and myself, in that she felt it was not finalised in a satisfactory way. The other participant was saddened by not being able to say goodbye to the nursing staff because they appeared too busy. Although Maria and I do not mention the nursing staff 'being too busy' to be involved in our care at the time we left the ward, it may have been a reason for our feeling a lack of closure. The notion of the nurse being 'too efficient/busy', and not being available (Kralik et al., 1997), and 'being in a hurry' (Riemen, 1986) is identified in the literature. However, neither of these studies makes reference to the time of discharge for the participants.

Not wanting to go back

As a result of our experiences, Maria and I describe a fear of having to return to hospital as patients. When Maria arrived home from hospital after her first admission, she said:

I did not want to go back to that place.

And when it was necessary for Maria to return to hospital, she said:

I was dreading going back, thinking it would be the same.

Maria's narrative describes how she was expecting not to be made welcome because of her first experience; yet she also acknowledges that if the experience had been better, she would have returned to hospital sooner. Likewise, I felt disappointed and disillusioned with nursing during my second admission and I also describe a fear of having to return to hospital as a patient. Maria felt the nursing care was much better when she did return the second time and she left the hospital with no concerns about having to return as a patient. Both of us felt 'let down' or betrayed by the experience as nurse-patients. This will now be discussed as the final sub theme 'feeling let down'.

Feeling let down

The narratives reveal that as experienced nurses with advanced nursing knowledge, the expectations that Maria and I hold of the values and beliefs and the possibilities of the profession of nursing, have not been fulfilled. On occasions we felt let down by our nurse colleagues, we felt a sense of betrayal. This is reflected in the description I give when feeling miserable one morning towards the end of my second hospitalisation:

...Began to sob. I noticed one of the experienced nurses walking towards my door... I immediately felt safe that she would be able to nurse me. However, she was unable to deal with my tears, she

exclaimed 'oh dear and walked out of the room. I felt let down, yet again.

And for Maria, it was during her first account of receiving nursing care that she states:

... I felt really distressed about the level of nursing I received...

The knowledge and experience of nurses involved in our care is reflected in the nursing care given. As nurse-patients, our expectation of what constitutes nursing care is based on our own caring practice and knowledge. Our expectations may have been that we would receive expert nursing as defined by Benner (1984). However, on many occasions it is evident from the narratives that the perceived nursing care received by Maria and myself was less than this. Benner's model (1984) suggests that the ability of the nurse to provide therapeutic care is influenced by the complexity of the patients' needs and the nurses experience. The nursing staff utilised their knowledge and skills in providing our nursing care, yet Maria and I did not always feel safe or confident with the care we received. We were also able to recognise a difference in the care given between novice nurses and the more experienced nurses. The issue of feeling 'let down' or betrayed has not been identified in the literature located on nurse-patients or non-nurses as patients.

The experience of receiving unsafe nursing care and 'not being nursed' was of concern to Maria and myself. Such experiences can be detrimental to the emotional and physical well being of patients (Kralik et al., 1997). For two nurse-patients who may be more vulnerable than the non-nurse patient (Williams, 1998a), this lack of nursing care or feeling of 'not being nursed' is therefore two fold. The narratives of Maria and I reveal that we are committed to and loyal to the ideals of the nursing profession in the face of betrayal. However, we still felt 'let down'.

Conclusion

In this chapter the stories of two nurse-patients were examined and compared with the anecdotal literature and research located on nurse-patients and non-nurse patients. Three key distinct qualities and subsequent sub themes were revealed and discussed. Our narratives identified that 'knowing as nurse-patient' is an important component for the nurse who becomes a patient and is a recipient of nursing care. Nurse-patients have expectations of what it means to receive nursing care based on their knowledge and experience. They are able to discriminate between caring and uncaring nursing practice. This study has revealed that we felt unsafe and uncomfortable with the nursing care we received at times. We were often left feeling vulnerable and we felt that the nurses were not available for us. The nurses were invisible at times. Our narratives reveal that we wanted to get out of hospital, and that when it came to leave the hospital; there was a need for us to close the experience. Both of us expressed our fear at having to return to hospital as nurse-patients. For both Maria and myself, who are committed to the ideals and values of the nursing profession, there is a sense of feeling betrayed or let down by our nurse colleagues. It appears from the literature located on nurse-patients that the experiences of Maria and myself of 'not being nursed' are not isolated instances. In the final chapter I will discuss the significance of this to the nursing profession.

CHAPTER NINE: Discussion & Conclusions

Introduction

Throughout this thesis I have endeavoured to address the questions: How might my experiences and the experiences of other nurses who have been hospitalised be drawn upon to influence positive changes in nursing practice? What effect might our experiences of hospitalisation have on us as nurses and on our nursing practice? Using the literature and the stories of two nurse educators who received nursing care when hospitalised with a life-threatening illness, I have identified what these two nurse-patients experienced when they were recipients of nursing care. In this chapter I discuss these experiences as they took place within the context of nursing and nursing education as it was during the mid to late 1990s in New Zealand. While providing insight into aspects of the patient experience for Maria and myself, it is also important to consider what this means for the nursing profession. A discussion follows on some of the implications of this insight, of being a nurse-patient; in an attempt to highlight aspects of nursing care that Maria and I believe contributes to being nursed. Further implications for nursing, nursing education and nursing research are discussed.

Providing and receiving nursing care

After examining our narratives of being nurse-patients, it is evident that the concept of caring is an important component of what it means 'to be nursed'. Caring in our practice is reflected by our connectedness with patients and their significant others (Maria, personal communication, 1998), and with the students we work alongside. 'Nurses care' is a phrase used commonly to describe the essence of nursing practice. What does the concept of 'caring' really mean, and what does it mean to be a nurse, and to be nursed? At the time of our hospitalisation and experience of receiving nursing care, Maria and I both worked in nursing education. We were both experienced nurses who had worked in a variety of clinical areas before becoming nurse educators. Our expectations of what it is to be a nurse and to be nursed comes from our own unique backgrounds, our nursing knowledge and

experience, and our advanced nursing education. We both understand how the relationship between the nurse and patient is crucial in the illness experience. Expert nurses understand it very well (Benner & Wrubel, 1989).

As mentioned in chapter 2, the terms ‘care’ and ‘caring’ have been used throughout the history of modern day nursing. However, it is only since the mid 1970s that nurses have studied the phenomenon of caring, and various models of caring and caring constructs have been developed and espoused (Harrison, 1990). I believe that a model of caring, which derived from an early study in a neonatal intensive care unit (Hutchinson, 1984), is relevant to other areas of nursing and provides a useful framework to examine caring in nursing practice. Hutchinson (1984) suggests that nurses create meaning (*or provide care*) in three ways: emotionally, technically, and rationally.

Nurses ‘care’ by investing emotion in the patients and families with whom they work; this is characterised by personalising behaviours. Nurses create meaning (care) emotionally by attaching and separating, as is the case when the patient goes home. Our narratives do provide some examples where nurses connected with us as individuals; however, there are other examples where as nurse-patients we felt that there was no ‘engagement’ by the nurses (Kralik et al., 1997). Nurses create meaning technically by providing sophisticated technical care. They derive satisfaction from the ability to use extensive technical knowledge, skill and judgment. Our narratives reveal incidents where technical care was provided with knowledge and skill, for example, *the nurse ran in to my room to attend to the intravenous line and pump*. However, the emotional aspect or the communication between nurse and patient was missing from this episode of care.

Nurses create meaning rationally by justifying and accepting their actions in order to make sense of the situation. Hutchinson (1984) suggests that nurses must integrate and balance these three ways of creating meaning. She states: “If a nurse becomes a technician, devoting all energies to learning about new techniques and new equipment, other processes of meaning will remain elusive” (p. 90). The nurse

will be capable of giving only technical care, and will lack the humanness necessary for relating to patients, as was evident in the above example.

Situations where technological innovations have effectively intervened between nurse and patient, have been located elsewhere in the literature. Fletcher (1997, p. 45) reports on a study in which nurses comment that the amount of technical care to be given provides an obstacle to psychosocial contact; however, it is also noted, that there are “instances when the technology was used as a convenient barrier by nurses, to evade such contacts”. In another study, patients using patient controlled analgesia (PCA) regimes report that nurses focused their attention on the technology rather than on their social needs (Fletcher, 1997). From my experience, I would concur with Williams (1998a) who suggests that the authority of technological knowledge has usurped the value of subjectivity in nursing practice.

If nursing is to achieve its aim and commitment to caring, the nursing profession will continue to require a foundation to support this. As mentioned in chapter four, knowledge in nursing comes from shared and distinct bodies of knowledge. Hutchinson's (1984) model of caring outlined above is closely linked to the *Fundamental patterns of knowing in nursing* as represented by Carper (1978), Jacobs-Kramer & Chinn (1988) and White (1995). These models highlight the important balance between the personal, empirical, aesthetic and ethical knowledge that is necessary to enable caring nursing practice, and are influenced by the socio-political context. Patients may then feel as if they are ‘being nursed’.

‘Caring’ nursing practice has beneficial effects on both the recipient and the giver of care, while ‘uncaring’ nursing may “repair the body, but crush the soul” (Kelly, 1988, p. 17). During our experiences of receiving nursing care, Maria and I felt that we were often ‘not being nursed’. Fortunately, the genuine caring of some nurses compensated for the ‘uncaring’ of others. When we felt as if we were ‘being nursed’, these caring nurses shared a number of characteristics: they were experienced nurses; often the older nurse, who engaged or connected with us as an individual; they had a presence about them; they displayed confidence in what they

were doing; they had a sense of nurturing about them; and they made us feel safe and cared for.

As sick nurse-patients receiving nursing care, Maria and I were able to recognise therapeutic nursing care that made a positive difference to our well being (Waterworth, 1995); primarily the experienced nurses give it. In discussion with Maria, she suggests “therapeutic care is a tall order for the novice and beginner nurse, yet expected in all nursing practice” (Maria, personal communication, 1998). As nurse-patients, I believe that Maria and I expected that the nursing care we would receive would make a difference to us. This is what it meant for us ‘to be nursed’. The ability of the nurse to provide therapeutic care is influenced by the complexity of the patient’s needs and the nurse’s experience (Benner, 1984). When nurses who are experienced and expert at their work look after people, they do so in a way that considers the personality and particular circumstances of the individual patient.

In contrast, when we felt we were ‘not being nursed’, the nurses: were often the less experienced nurse, the novice nurse or new graduate nurse; were detached and seemed only interested in completing a task; and, lacked a ‘presence’ which left us feeling vulnerable and unsafe. These less experienced nurses had limited ability to provide us with therapeutic care in the context of our illness and post-operative care.

Despite the increased emphasis on caring in nursing (Benner, 1984; Benner & Wrubel, 1989; Newman et al., 1991; Watson, 1995), a review of the anecdotal reports and recent research undertaken in a number of countries, suggests that nursing as practised rather than as theorised, fails to fulfil its caring rhetoric. Harrison (1990, p. 125) suggests that “the public image of nursing reflects a profession that has lost its ethic of caring”. A more recent study by Kralik et al. (1997) reveals that the nursing profession has much to learn from the recipients of nursing care. It is also evident that there is a growing concern that today’s changing social and technological context is limiting nurses’ caring abilities (Fletcher, 1997; Harrison, 1990; Kralik et al., 1997; NZNO, 1998; Zeitz, 1999). However, this

dilemma facing nursing has been reported in the international nursing literature for almost 20 years (Harrison, 1990).

Implications for nursing

As nurse-patients Maria and I felt that at times we were ‘not being nursed’, we felt ‘let down’ or betrayed by our nurse colleagues. Our narratives reveal that the experience and knowledge of the nurse is important in providing therapeutic care. If nursing does not have experienced nurses as ‘role models’ to work alongside the new nursing graduates or novice nurses, how can we expect these new graduate nurses to learn the important caring role of nursing and build on their knowledge and clinical skills? For nurses to be able to provide therapeutic care, they themselves must feel valued and respected by colleagues and management. The re-establishment of nursing departments within our large hospitals might assist in this process. Nurses must be responsible for and be involved in the decision-making, planning and delivery of nursing services.

In order to ensure high quality nursing care, the skill-mix of the nursing workforce must meet the acuity of patients for nursing expertise. However, it is of concern to me that nurses do not appear to be able to dictate the number of nurses needed for a particular clinical area, nor the number and type of other health workers to assist them. The third discussion paper titled *Defining the nurse of the future* (Nursing Council of New Zealand, 2000) suggests that a more generic health care worker may assume some aspects of the caring role of the nurse. At a recent meeting called by the Ministry of Health chief nursing adviser, nursing representatives agreed on the need for a second level of nurse/health worker to be trained and regulated through the Nursing Council of New Zealand. However, division continues amongst nurses over what to call this worker (NZNO, 2000).

New Zealand has no formal requirement for structuring a nursing graduate’s first year of practice, as is the case in some other professions such as teaching and accountancy (Ministry of Health, 1998). Many employers and nurse colleagues, especially in the acute hospital settings, expect these new novice nurses to take up a

high workload and a high level of responsibility with little structured help or support. Formal programmes to support new graduates into their first year of practice, such as preceptorship, mentoring and orientation programmes, need to be well developed and structured, to enable novice nurses to consolidate their knowledge and clinical skills. Registered nurses who take on this preceptor/mentor role need to receive preparation and continual support for this important aspect of their nursing practice. The workload/patient allocation of these nurses could be reduced and staffing levels within the particular area could be compensated to account for this. I would recommend that these preceptor/mentor registered nurses meet at regular intervals with experienced facilitators, and as a group, individually and with the preceptee to reflect and share stories of nursing practice. However, as there is evidence to suggest that the stories may differ depending on who the teller is (Prentice, 1995; Zeitz, 1999), it would also be necessary for these nurses to examine the anecdotal and research literature available from the perspective of patients and nurse-patients.

Implications for nursing education

As the health sector continues to change at a rapid pace, there are huge challenges and pressures facing nurse educators to ensure that the education of nurses keeps up with it, despite the funding squeeze on tertiary education institutes since the 1990s. From my experience of working in two undergraduate nursing programmes since 1986, I believe that nursing education in New Zealand has endeavoured to engender the personal, aesthetic, ethical, and empirical knowledge that is necessary to enable caring nursing practice within a changing socio-political context. Many degree programmes are producing graduates with a comprehensive knowledge base who are able to provide safe care (Ministry of Health, 1998).

As nurse educators we can role model 'caring nursing practice' when working with nursing students in the practice settings. However, with our changing role throughout the 1990s and into 2000, this has become more difficult due to higher student-clinical tutor ratios, reduced clinical tutor hours, and demands of our educational institutes. This research has utilised narrative inquiry and story telling as its methodology. Nurse educators could continue to encourage story telling as a

medium for teaching/learning about caring in nursing practice. This research and that of Zeitz (1999) and Williams (1998a) might also be used by nurse educators in teaching students what it means to nurse and be nursed.

There is an expectation by many nurses and employers that new graduates will come out of polytechnics 'ready to work' in any setting. The differing aims and expectations of new graduates should be communicated not only between nurse clinicians and nurse educators, but also between employers and education institutions. The aim of the present undergraduate-nursing programme is to prepare a multi-skilled beginning practitioner for nursing within a full range of safe and autonomous practice. They are then ready for further education, mentoring and preceptorship, and consolidation of their nursing knowledge in a chosen speciality area. New graduates need a supportive work environment during their first year of practice after gaining registration.

If nursing is to keep its commitment to caring and address the issues raised in this thesis, nursing education should continue to be scientifically based and founded on the core values and fundamental elements of knowledge and practice. The success of nursing in the future will lie in our ability as nurses to combine the demands and knowledge of technological nursing care with that of the personal, aesthetic, ethical, empirical and socio-political ways of knowing. The final discussion paper in the review of undergraduate nursing education in New Zealand titled *The preparation of the nurse of the future* is not due to be released until late October 2000 (Nursing Council of New Zealand, 2000). I believe that unless we continue to use these models of knowledge as the basis for nursing practice, we will continue to hear the voices of patients who believe they were not nursed.

Implications for nursing research

Although several anecdotal reports on nurse-patients were located, it is only more recently that research has been undertaken with nurse-patients who have been recipients of nursing care. While these studies (Williams, 1998a; Zeitz, 1999) and Maria's and my narratives reveal some commonalities in the experiences of nurse-

patients, the nurse-patients in Williams and Zeitz's research had uncomplicated admissions to hospital. It would be worthwhile to undertake further research with sick dependent nurse-patients admitted to hospital with life threatening illnesses to gain further insights and understanding of the 'knowing' consumer.

Our narratives reveal that as experienced nurses with advanced nursing knowledge, our expectations of the values and beliefs and the possibilities of the profession of nursing were not fulfilled. The issue of feeling 'let down' or betrayed was not identified in the literature located on nurse-patients or non-nurses as patients. A subsequent search of the wider nursing literature revealed little information on the topic. One anecdotal account was located of a patient who was left feeling vulnerable by the nurses' lack of support and advocacy skills during his hospitalisation (Carter, 1999). He wrote that the experience hindered his recovery, and that he still feels 'let down', eight years after the experience. Johnstone (2000) suggests that patients' rights have been betrayed when nurses do not fulfil their responsibility and take action in regard to the issue of informed consent. Wright (1993), in discussing the ethical-legal issues in helping someone to die, asks 'is it a betrayal of nursing values?' This brief analysis of the available literature on the use of 'betrayal' or feeling 'let down' in nursing, suggests that these words are used to describe the feelings experienced when expectations are not met. It would be worthwhile to undertake further research with nurse-patients and non-nurses as patients on the concept of patients feeling 'betrayed or let down' to gain further insight and understanding on being a recipient of nursing care.

As the researcher and a participant, my story as a nurse-patient receiving nursing care has been told using a similar approach to the reflective topical autobiographical method described by Johnstone (1999). This interpretive research method, although not often used by nurse researchers, offers much to both new and experienced nurse researchers with regard to advancing nursing inquiry and generating new nursing knowledge, and teaching students the art of investigating subjectivity (Johnstone, 1999). However, it is as demanding as any other method and

it requires an honest self-disclosure by the self-researcher that may be a threatening experience for some people.

Perceptions of care are dependent on whether they are the perspectives of the 'carer' or the 'cared for'. A congruent perception of need must be attended to if the experience of care is a goal of nursing practice. The nurse must not assume that all nursing acts delivered with good intentions will be experienced by the patient as 'care'. Research, in which the voices of both the nurse and the patient are heard from the same moment of caring nursing practice, would provide further insight and understanding into perceptions of care.

Conclusion

This study has assisted me to examine my own practice as a nurse, nurse clinician, and nurse educator, and to reflect on future strategies for practising and teaching caring nursing practice. I have used story telling in my teaching practice. Therefore, to use narrative inquiry that is informed by a feminist process as the methodology for this project was an acceptable approach for me. The choice of using auto/biography as the method of telling our stories was initially somewhat overwhelming due to the sense of self-indulgence of writing about our subjective experiences (Ribbens, 1993), and the self-disclosure required (Johnstone, 1999).

Both Maria and I felt that at times we were 'being nursed', however, there were other times when we felt we were 'not being nursed'. Our knowledge and experience as nurse-patients may have led us to expect that we would be nursed in an expert way at all times, although as nurse educators, we knew that this is not always possible. The theme I report as 'getting out' was not found described as explicitly in the nursing literature. As a result of 'not being nursed' I named the final theme 'feeling let down'. Maria and I felt 'let down' or betrayed by our nursing colleagues. Again, there was little evident in the nursing literature on this concept.

This study on nurse-patients receiving nursing care will I hope be useful for nurse educators, students of nursing, and nurse clinicians. Further suggestions for

research have been identified. This study presents my interpretations as the researcher. For the reader, there will be different interpretations of the two narratives of nurse-patients receiving nursing care.

APPENDIX I: INFORMATION SHEET

Becoming a patient: the experience of two woman nurse educators' admitted to hospital with life threatening illnesses.

Researcher

I am a New Zealand Registered Nurse working as a Nurse Educator at Christchurch Polytechnic. This research project is the thesis for a MA (Part 2) that I am undertaking through Victoria University of Wellington.

Purpose

The purpose of this study is to examine the stories of two woman nurse educators' hospitalised with life threatening illnesses, and to explicate these stories in relation to nursing practice. Narrative inquiry will be used and will involve the weaving of the stories of both the researcher and the researched.

Benefits

Participating in this study may be beneficial to you as a nurse, and as a nurse educator. The knowledge gained from the study will be useful in expanding the body of nursing knowledge. The knowledge will be beneficial for all nurses and health care workers.

Procedures / Risks

For this research project, the intention is to use electronic mail (email) as the primary data collection method. You would need to be able to communicate with the researcher with a computer and e-mail. Electronic mail is a cost-effective way in which to collect data. Specific software programmes are available which would protect the privacy of electronic mail. In this study the researcher and researched will become co-researcher/s.

The process of collecting and making meaning of the data will follow through various phases, over a period of weeks. You will be asked to begin by telling your story of being a hospitalised patient with life threatening illnesses. Other data sources may be utilised as considered appropriate by the co-researchers. During the process, co-researchers will re-read their written stories (electronic mail) and converse and question each other as they seek to understand the issues involved.

The electronic mail texts will be copied onto a computer disk. These disks will only be seen by the researcher and her supervisors. Once electronic mail data is transferred to computer discs, the participant/s will only be known by their pseudonyms. All computer discs and other data collected will be kept for five years following the completion of the research, and then the researcher will destroy it.

A copy of the final report, which may contain anonymous quotations, will be available to you at the end of the study if you wish. A copy of the research project will be held at the Victoria University Library and also in the Department of Nursing and Midwifery, Victoria University.

You may find that reflecting and analysing your hospital experience/s surfaces unresolved issues for you. I will endeavour to be sensitive to your needs. However, you may find that you need further help and I will assist you to find the appropriate service for your needs. This would be at your initiation.

Costs / Reimbursement

There will be no financial cost to you, and you will not be paid for your participation. Any expenses encountered, as part of the project will be reimbursed to you.

Voluntary Participation / Confidentiality

Your participation in this research is completely voluntary, and you may withdraw at any time. If you wish to withdraw, any information provided will be returned to you if you wish.

The Ethics Committee of Victoria University of Wellington, Wellington, has approved this research project.

If you have any further questions, or would like to receive further information, please contact me at home on Ph: 03-343-5574 or via email on: freese@es.co.nz, or my supervisor, Joy Bickley, Lecturer, Department of Nursing and Midwifery, Victoria University of Wellington on Ph: 04 471-5363, or via email on: Joy.Bickley@vuw.ac.nz

Dianne Harker

APPENDIX II: CONSENT FORM

Becoming a patient: the experience of two woman nurse educators' admitted to hospital with life threatening illnesses.

The research has been explained to me and I voluntarily consent to participate. I have read the information sheet and I have had the opportunity to ask questions.

I have the right to withdraw from the project at any time, and/or to withdraw any information that I have provided for this project.

I understand that any information I provide will be kept confidential to the researcher and her supervisor and will only be used in the published thesis document. I understand that my name will not be used and that a pseudonym will be used in any publications.

I understand that the data I provide will not be used for any other purpose without my informed consent.

I would like to receive a copy of the final report of this research when it is completed.

I agree to take part in this study.

Signature of participant

Date

Signature of researcher

Date

Copies to:
Participant
Researcher

If you have any further questions, or would like to receive further information, please contact me at home on Ph: 03-343-5574 or via email on: freese@es.co.nz, or my supervisor, Joy Bickley, Lecturer, Department of Nursing and Midwifery, Victoria University of Wellington on Ph: 04 471-5363, or via email on: Joy.Bickley@vuw.ac.nz

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