

**From machine to patient:  
shifting the focus of care within a hospital haemodialysis unit.**

**By  
Shelley Tranter  
Clinical Nurse Consultant**

**A thesis submitted in fulfilment of the requirements  
for the degree of Professional Doctorate in Nursing**

**Faculty of Nursing, Midwifery and Health  
University of Technology, Sydney**

**June, 2005**

## **CERTIFICATE OF AUTHORSHIP/ORIGINALITY**

I certify that this thesis has not been previously submitted for a degree nor has it been submitted as part of requirements for a degree. I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of this thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Signature of Candidate

Production Note:  
Signature removed prior to publication.

---

## ACKNOWLEDGMENTS

This research would not have been possible without the support of the patients and nurses within the hospital haemodialysis unit of the participating hospital. I wish to express my special gratitude to the nurses, doctors and allied health staff involved in the care of patients with end stage renal failure especially those on hospital haemodialysis.

The thesis could only have been completed with the assistance of my committed supervisors. My special thanks to Judith Donoghue who has been extremely supportive throughout my journey as a doctoral candidate from thesis inception to completion. I would also like to acknowledge my co-supervisors Mary Chiarella and Jacqueline Baker who have been tireless in their comments and advice.

I would also like to acknowledge the support of Professor Judy Lumby from the College of Nursing who assisted in my plea for financial support. My successful application for the inaugural Vivian Bullwinkle Scholarship provided me with time out of my busy work commitments to conduct the data collection component of the study. Acknowledgement must also go to the NSW Nursing and Midwifery Board for granting me a Category 6 Scholarship for the completion of the thesis. Last but not least I would like to thank my family and friends for their enduring support for my endeavours throughout my doctoral candidature.

## TABLE OF CONTENTS

CONTENTS	PAGE
<b>ABSTRACT</b>	
<b>CHAPTER ONE - INTRODUCTION</b>	
1.1 Presentation of the thesis	1
1.2 Situating myself in the thesis	3
1.3 Impetus for the thesis	3
1.4 The ethnographic study	7
1.5 Practice development	8
1.6 The CNC framework	9
1.7 Chapter summary	10
<b>PART A - LITERATURE REVIEW</b>	
<b>CHAPTER TWO - THE PATIENT REQUIRING HAEMODIALYSIS</b>	
2.1 Introduction	11
2.2 The treatment of end stage renal failure	11
2.2.1 Kidney transplantation	11
2.2.2 Dialysis	12
2.2.3 Peritoneal dialysis	12
2.2.4 Haemodialysis	13
2.3 The management of ESRF in Australia	15
2.4 The patient requiring haemodialysis	18
2.4.1 The problems	18
2.4.2 The older patient requiring haemodialysis	21
2.5 Chapter summary	22
<b>CHAPTER THREE - HAEMODIALYSIS NURSING</b>	
3.1 Introduction	24
3.2 The evolution of haemodialysis nursing	24
3.3 Haemodialysis nurse education	28
3.4 The role of the haemodialysis nurse	29
3.5 Technology and nursing in the haemodialysis unit	33
3.6 What attracts nurses to haemodialysis nursing?	35
3.7 The CNC role	37
3.8 Research aims	41
3.9 Chapter summary	41
<b>PART B – THE ETHNOGRAPHY</b>	
<b>CHAPTER FOUR – THE STUDY METHOD</b>	
4.1 Introduction	43
4.2 Ethnography	43
4.2.1 Methods of data collection	45
4.2.2 Ethnography in nursing	47
4.2.3 Data analysis	48
4.2.4 Why ethnography?	50
4.3 Conducting the research	50
4.3.1 Study aims	51
4.3.2 The setting	51
4.3.3 Participants	51
4.3.4 Ethical considerations	51

<b>CONTENTS cont.</b>	<b>PAGE</b>
4.4 Data collection	52
4.4.1 Observation	52
4.4.2 Field work schedule	53
4.4.3 Interviews	54
4.4.4 Documents	58
4.5 Issues arising from the research	59
4.6 Data analysis	61
4.7 Rigour	62
4.7 Chapter summary	67
<b>CHAPTER FIVE – ETHNOGRAPHY RESULTS - A BROAD OVERVIEW</b>	
5.1 Introduction	68
5.2 Historical development of the HHU	69
5.3 The HHU	70
5.4 The haemodialysis machine	73
5.5 The haemodialysis schedule	75
5.6 The people in the HHU	76
5.6.1 The patients	76
5.6.2 The nurses	83
5.6.3 The doctors	95
5.6.4 The other health care and hospital workers	97
5.6.5 The patients' visitors	101
5.7 Chapter summary	102
<b>CHAPTER SIX – ETHNOGRAPHY RESULTS – RELATIONSHIPS IN THE HHU</b>	
6.1 Introduction	104
6.2 The nurse - patient relationship	105
6.2.1 Rules and sanctions	106
6.2.2 Patterns of communication	114
6.2.3 Section summary	117
6.3 The nurse - nurse relationship	117
6.3.1 Rules and sanctions	117
6.3.2 Patterns of communication	120
6.3.3 Section summary	122
6.4 The nurse – doctor relationship	122
6.4.1 Rules and sanctions	122
6.4.2 Patterns of communication	123
6.4.3 Section summary	125
6.5 The nurse – visitor/carer relationship	126
6.5.1 Rules and sanctions	126
6.5.2 Patterns of communication	127
6.5.3 Section summary	128
6.6 Chapter summary	128
<b>CHAPTER SEVEN - ETHNOGRAPHY RESULTS - CULTURAL THEMES</b>	
7.1 Introduction	130
7.2 Doing more with less	130
7.3 Who gets a machine?	133
7.4 Technological creep	135

<b>CONTENTS cont.</b>	<b>PAGE</b>
7.5 Dialysis centred care	137
7.6 The bottom line	144
7.7 Chapter summary	149
<b>CHAPTER EIGHT - ETHNOGRAPHY DISCUSSION</b>	
8.1 Introduction	151
8.2 Doing more with less	151
8.3 Who gets a machine?	157
8.4 Technological creep	164
8.5 Dialysis centred care	166
8.6 The bottom line	174
8.7 Ethnography summary and conclusion	176
<b>PART C – PRACTICE DEVELOPMENT</b>	
<b>CHAPTER NINE - THE KEY TO SUSTAINABLE CULTURAL CHANGE</b>	
9.1 Introduction	178
9.2 Practice development	178
9.3 Facilitating practice development	180
9.4 Preparation of the NCNC for the PD facilitation role	182
9.5 The setting and participants	183
9.6 Preparation for practice development	183
9.7 Practice development study aims	184
9.8 The process	185
9.9 Practice development activities	185
9.10 The outcomes	189
9.11 PD summary and conclusion	190
<b>CHAPTER TEN - CONCLUSION</b>	
10.1 Thesis summary	192
10.2 The evolving NCNC role	193
10.3 Limitations of research	197
10.4 Recommendations for further research	198
<b>VOLUME TWO</b>	
<b>GLOSSARY OF TERMS</b>	1
<b>APPENDICES</b>	
Appendix A - An outline of the Australian Health care System	4
Appendix B	
Appendix B.1 - Study information sheet – patients and their families	6
Appendix B.2 - Study information sheet - staff	7
Appendix B.3 - Patient subject information sheet and consent form	8
Appendix B.4 – Staff subject information sheet and consent form	10
Appendix C	
Appendix C.1 - Interview questions - nurses	12
Appendix C.2 - Interview questions - patients	13
Appendix D – Domain analysis	
Appendix D.1 – The people in the HHU	14
Appendix D.2 – The relationships in the HHU	19
Appendix D.3 – Cultural themes	21

<b>CONTENTS cont.</b>	<b>PAGE</b>
Appendix E – Job descriptions	
Appendix E.1- CNC	23
Appendix E.2 - NUM	28
Appendix E.3 - Clinical Co-ordinator	33
Appendix E.4 - RN	36
Appendix E.5 - Orderly	40
Appendix E.6 - Dietitian	44
Appendix E.7 – Social worker	47
<b>PORTFOLIO</b>	
Portfolio A - Practice development conference	52
Portfolio B - Practice development summer school	53
Portfolio C - Philosophy and objectives	54
Portfolio D - Brochure	55
Portfolio E - Focus group discussion paper – the role of the RN	57
Portfolio F - Draft job description for haemodialysis RN	60
Portfolio G - Article for ANJ	64
<b>REFERENCES</b>	65

## FIGURES AND TABLES

<b>TABLES</b>	<b>Description</b>	<b>PAGE</b>
<b>Table 1</b>	Summary of thesis presentation in volumes, sections and chapters.	2
<b>Table 2</b>	The number of people on the different renal replacement therapies 1999 – 2003 (ANZDATA, 2004).	17
<b>Table 3</b>	Age in years, years since graduation and years of haemodialysis nursing experience for ten nurses interviewed.	56
<b>Table 4</b>	Age and time on dialysis in months of all patients interviewed.	57
<b>Table 5</b>	Supportive relationships for patients.	58
<b>Table 6</b>	Domain analysis of people in the HHU.	62
<b>FIGURES</b>		
<b>Figure 1</b>	Patient receiving a haemodialysis treatment.	14
<b>Figure 2</b>	A patient with cannulae inserted into an A V fistula for haemodialysis.	14
<b>Figure 3</b>	A specially designed central line or vascath used to gain access to the blood stream for haemodialysis.	15
<b>Figure 4</b>	Basic floor plan of the HHU.	72
<b>Figure 5</b>	A haemodialysis machine showing major features.	74
<b>Figure 6</b>	Organisational chart for doctors “renal team” in the HHU	96
<b>Figure 7</b>	My evolving role as CNC.	196



## ABSTRACT

The thesis describes the process and findings of research conducted in an Australian hospital haemodialysis unit (HHU). The thesis consists of three parts. The first part is an in-depth review of the literature in relation to patients requiring haemodialysis treatments and haemodialysis nursing practice. The second component is an ethnography conducted within the HHU. The final component reports on practice development (PD) work performed with nurses within the HHU.

Patients receiving haemodialysis face a myriad of physical and lifestyle adjustments. In many instances, suffering and discomfort are an integral part of patients' illness and treatment experiences and a significant component of their everyday lives. Some patients who attended the HHU for haemodialysis treatments were suffering. I believed that patient centred care would be essential for the recognition and support of patients who were suffering or experiencing pain or discomfort from their treatment. As the Nephrology clinical nurse consultant (NCNC), I had experienced a number of interactions with patients that intimated that the nurses within the HHU did not provide patient centred care.

Impetus for the ethnography arose out of my efforts to support or refute my assumption that nurses in the HHU did not provide patient centred care. The findings would be presented to the nurses. The main research aims were to study the culture of the HHU to acquire a comprehensive understanding of how nursing care was conducted and to identify the structural and cultural enablers and barriers to the provision of patient centred care within the HHU. The ethnography was undertaken over twelve months and involved participant observations and interviews with patients and nurses. Five major themes were identified. These themes were "doing more with less", "who gets a machine?", "technological creep", "dialysis centred care" and "the bottom line".

The ethnography provided evidence for my initial assumption that the nurses did not provide patient centred care. The findings from the ethnography

became the basis for practice development work with nurses in the HHU. PD work began before final analysis of the ethnographic data, as there were findings I needed to address urgently. The PD work is ongoing but the outcome has been a slow shift in nursing work within the HHU from machine centred to patient centred care.

The journey with the nurses in the HHU and personally within the doctoral program has enabled me to develop within the role of NCNC and an account of the evolution of my NCNC role is also outlined within the thesis.

## CHAPTER ONE - INTRODUCTION

### 1.1 Presentation of the thesis

I have compiled the thesis for submission for the award of Professional Doctorate in Nursing. The thesis is presented as an ethnography and the practice development (PD) as the subsequent change in practice that is a requirement for this award. The basis of a professional doctorate is a practice concern and hence the thesis presents the work I have undertaken in relation to this concern. Study during the Professional Doctorate program includes coursework subjects in the area of leadership, policy and international frame of professional practice. These subjects have helped to inform this work.

Presentation of the thesis is in two volumes. Volume one provides the major thesis work presented in three parts. Part A provides an in-depth review of the substantive literature on the patient requiring haemodialysis treatments and haemodialysis nursing practice. Part B presents information related to the ethnographic study conducted in the HHU. I have presented the study method, results and discussion in five chapters within part B. Part C presents the PD method and the process and activities related to the PD conducted with the nurses in the HHU. The thesis conclusion draws the three parts together and provides an overview of the evolution of my role as Clinical Nurse Consultant (CNC) within the HHU.

Volume two includes the glossary, appendices, references and an additional section titled portfolio. Within the portfolio are a number of personal achievements and exemplars of activities arising from the PD work with the nurses.

Table I presents a brief overview of the thesis layout including the volumes, parts and chapters.

Table1. Summary of thesis presentation in volumes, sections and chapters

Section	Content	Chapters
<b>VOLUME ONE</b>		
Introduction	Overview of thesis	One
Part A - Literature review	The patient requiring haemodialysis	Two
	Haemodialysis nursing	Three
Part B - The ethnography	Method	Four,
	Results	Five, six, seven
	Discussion	Eight
Part C - Practice development	PD method, process and activities	Nine
Thesis conclusion		Ten
<b>VOLUME TWO</b>		
Glossary		
Appendices		
Portfolio		
References		

This introduction sets the scene and assists by situating myself within the thesis. I will introduce myself and provide an overview of the role and definition of the CNC within the Australian health care context. I will introduce the practice concern that became the impetus for conducting the ethnography and PD with the nurses in the HHU. A brief overview of ethnography and PD is included with a more comprehensive explanation within the subsequent parts of the thesis. Finally, the introduction will conclude with a presentation and discussion of the framework used to analyse the evolution of my role as Nephrology CNC (NCNC) since commencing Professional Doctorate studies.

## **1.2 Situating myself in the thesis**

I am the clinical nurse consultant for an Australian renal service and I have fulfilled the role in the unit since the inception of this position in 1999. I have over 25 years experience in different positions within nephrology nursing including the provision of clinical care to nephrology, dialysis and kidney transplant recipients. In addition, I have held nurse education and consultancy positions in various hospitals.

Within New South Wales (NSW), the CNC is an advanced practice position. There are three grades of CNC under the Public Hospitals Nurses State Award. I am a level three CNC, which is described as:

A registered nurse appointed to a position approved by the Area Health Service, who has at least seven years full time equivalent post registration experience, with at least five years' full time equivalent experience in the specialty field. In addition, the nurse must have approved postgraduate nursing qualifications relevant to the field in which s/he is appointed or such other qualifications or experiences deemed appropriate by the Area Health Service. An employer may also require a higher qualification in the specialist nursing field where such a qualification is considered essential for the performance of the individual position (2000 p1).

The CNC functions within five domains: clinical service and consultancy, clinical leadership, research, education and clinical services planning and management. The emphasis in each domain is dependent on the needs of the organisation and the particular position. More discussion on the role of the CNC will be presented at the end of the introduction and within chapters three and ten.

## **1.3 Impetus for the thesis**

Impetus for the thesis arose from my wealth of experience as a nurse caring for patients in end stage renal failure (ESRF). During the course of my time as a renal nurse, I had identified that in many instances suffering and discomfort

are an integral part of patients' illness experiences and a significant component of their everyday lives. This suffering and discomfort was evident in some of the patients who attended the HHU for their treatments. The following example from my reflective work journal highlights the major concerns, which pre-empted me to embark on this study.

It was my usual practice as the nephrology clinical nurse consultant (NCNC) to visit the HHU each morning to discuss clinical issues with the staff and to assist where required.

The day at this stage was like any other but perhaps I was feeling more vulnerable than usual because the week had been a long one with lots of unresolved patient issues.

A new nurse to the unit had requested assistance from a more senior staff member to supervise her whilst she connected a patient to the haemodialysis machine. As was usual the other nurses were all busy connecting their own patients so I decided to assist her.

I sat next to the patient so that I would have a clear vision of the nurse and her activities. "Where do you think I should go?" she asked regarding the best position for needle placement.

"Just up from your finger" I replied "Not too close to that part of the arm where the tattoo is".

"The tattoo" exclaimed the patient.

"It's a fine one" I replied.

"It has a lot of meaning or perhaps no meaning at all" the patient went on. "I was in the navy and I got this tattoo the day I proposed to my lovely wife. See the heart in the middle? Look at us now. All those years together and now we are apart. She is at home without me and I am in a home without her. I cannot do anything for myself anymore and I have to come here all the time. I wish it would all end".

"You wish what would all end?" I asked.

"You know all this coming to the hospital and stuff" he replied.

"What would happen if you stopped coming?" I asked.

"I would be better off because I would be dead" he explained.

“Have you ever talked to the nurses about these thoughts?” I asked.

“No, they are far too busy to talk to me. They have all the machines to run,” he said sighing.

“There you are” said the nurse. “Both needles are in and working fine”.

“Fine” I said. “Well done” and an alarm sounded in the other room. I wanted to talk with the patient some more but no one was answering the alarm.

“I must get that,” I said to the patient.

He replied “thanks for listening”.

The machine in the next room was “alarming”. I found the patient, Henry unresponsive, with a weak pulse. I responded immediately, placing his chair flat and infusing a bolus of normal saline. The colour returned to Henry’s face and his pulse became stronger. He opened he eyes and said, “Why did you do that?”

”Why did I do what” I replied.

“Why did you bring me back? I could have just gone and everything would be over. Just let me go next time” He ordered angrily.

“Why do you want to go?” I asked.

“There is nothing here. This is not living. I have not lived since I started coming and I have not lived since my wife died”.

“Have you discussed these things with your family or the nurses?” I asked.

“No” he replied. “My family is pushing me to be here and that is why I am here. The nurses do not ask me about how I am so I do not think I want to tell them. They do not have time to talk with me anyway.”

I told Henry that I would return following his dialysis and that we would talk further about these issues (Abstract personal work diary November 10<sup>th</sup>, 2000).

I met with Henry privately and he talked at length about his concerns. He had never had any help with his unresolved grief since the death of his wife. His family had wanted him to have dialysis because they had just lost their mother and did not want to lose their father. He had commenced dialysis soon after her death and this compounded the problem as he was also grieving for the

loss of his normal life. Henry continued on dialysis but met with the hospital's grief counsellor and myself regularly. He seemed much happier at further meetings and expressed his gratitude for my time and the fact that someone was willing to listen.

This scenario highlighted again to me the issues faced by patients with ESRF on hospital haemodialysis. The process of attending the HHU is endured week in, week out, for the rest of the patient's life. Consequently, a significant aspect of treatment with haemodialysis is the need to conform to the interminable monotony of dialysis regimens. Furthermore, limited unit resources lead to tight schedules and the patient has little choice in the allocation of days or times for dialysis.

In addition to dialysis, there are numerous other restrictive aspects to life as a patient in ESRF. The dialysis process is not capable of performing all of the functions assigned to normal kidney function. The patient must conform to rigid dietary and fluid restrictions to control symptoms. Multiple medications are required to subsidise the shortfalls of dialysis and to treat several of the side effects of kidney failure. Additionally, the relationships and family roles of the patient are often challenged resulting in social and psychological dilemmas for these patients. These are some of the many stressors identified in patients requiring haemodialysis who attend HHUs (Welch & Austin, 2001; Lok, 1996; Gurkis & Menke, 1988; Baldree, Murphy, & Powers, 1982). The issues faced by patients requiring haemodialysis are discussed in detail in chapter two.

The scenario also suggested that there were issues regarding the delivery of nursing care within the HHU. I was confused as to why the patients were unable or unwilling to speak to nurses about problems which were causing them major concern. Nurses are the major health care professionals within the HHU and consequently spend a lot of time with patients providing dialysis treatments. I had always believed that the nurse, as the primary carer, is the best-placed health care professional to offer support to patients suffering or



feeling discomfort due to their treatment. This support should be based on an understanding of the patient as an individual and encompass the physical need for dialysis and the requirement to function as an individual with an acceptable quality of life. An in-depth review and discussion of the literature pertaining to haemodialysis nursing is provided in chapter three. I considered that nurses in the HHU did not seem to provide patient centred care. The lack of patient centred care in the HHU provided me with a practice concern that has become the foundation for my Professional Doctorate program.

I identified the problem of nurses not seeming to provide patient centred care as an issue that the HHU nurses must address. The nurses did not perceive the lack of patient centred care as a problem. I decided that the problem could be approached using a PD framework. However, there could be no meaningful PD until an investigation of the practice issue was undertaken. An ethnography was selected to provide a comprehensive understanding of nursing care provision within the HHU.

#### **1.4 The ethnographic study**

The second component of the thesis is the ethnography. Simply, ethnography is the study of culture. There are various definitions of ethnography in the literature. In a broad sense ethnography:

“involves the ethnographer participating, overtly or covertly, in people’s daily lives for an extended period of time, watching what happens, listening to what is said, asking questions – in fact collecting whatever data are available to throw light on the issues that are the focus of the research” (Hammersley & Atkinson, 1995 p.1).

Prior to commencing the study there had been little literature exploring the work of nurses in HHUs (Bevan, 2000a, 1998; Wellard, 1992) and little understanding of the culture of a HHU. Subsequent to commencing the research, a study of the culture of haemodialysis units in England was published (Aswanden, 2002). Within chapter four, further discussion on this study is presented. Arguably, findings of the English study may not necessarily

be generalised to every HHU. This has been reinforced by the different themes identified in this study.

The ethnography was undertaken within the HHU between February 2002 and February 2003. The major data collection methods included both participant observation and interviews. Participant observations were carried out within the HHU over a nine-month period. Formal interviews were conducted with patients and nurses following the observation period. The study focused on the interactions and relationships between nurses and patients to provide a comprehensive understanding of nursing care provision. The study also aimed to identify the barriers and enablers to the provision of patient centred care within the HHU. I have provided an in-depth discussion of the study method in chapter four.

The ethnography results are provided in chapters five, six and seven. Discussion of the findings is provided in chapter eight. The ethnography established a number of critical practice issues requiring attention. In order to ensure more effective care provision, it was necessary to address these issues immediately following data analysis. The ethnographic findings were utilised to engage the nurses employed in the HHU in reshaping their clinical work through the process of practice development.

### **1.5 Practice development**

PD has become widely accepted as an effective initiative in change in health care and it was the second method used to effect change within the HHU. A concept analysis of PD undertaken by Garbett and McCormack (2002) has established the following comprehensive definition of PD:

“Practice development is a continuous process of improvement towards increased effectiveness in patient centred care. This is brought about by helping health care teams to develop their knowledge and skills and to transform the culture and context of care. It is enabled and supported by facilitators committed to systematic, rigorous continuous process of

emancipatory change that reflects the perspectives of service users” (Garbett & McCormack, 2002 p.88).

The success of PD hinges on the abilities of the facilitator. Simply the facilitator role is about supporting people to change their practice (Harvey, Loftus-Hills, Rycroft-Malone, Titchen, Kitson, McCormack & Seers, 2002).

There is evidence to support the nurse consultant role as an ideal PD facilitator (Manley, 2000b, 2000a, 1997). Manley (1997) suggests that transformational leadership combined with clinical expertise is essential to practice change. The nurse consultant has an understanding of the real context in which patient care takes place. Being a skilled facilitator is a constant state of “becoming” in that there is always more learning to be done about being effective. Clinical leaders such as the CNC, need to develop skills in PD (Manley, 1997). The CNC may have the technical expertise but I would argue that the requirement to be an expert in facilitating the achievement of cultural change is more important. The major contribution the facilitator can make is the capacity to develop a sustainable process, enabling a culture to develop where the integration of evidence based practice is everyday (Dewing & Reid, 2003). Further information related to the method and process of PD is provided in chapter nine.

## **1.6 The CNC framework**

A framework proposed by Manley has been chosen to examine the evolution of my role as the NCNC. Manley (1997) conducted a comprehensive study to operationalise the role of nurse consultant (NC), and in so doing, facilitated the development of nurses and nursing for the purpose of providing better patient services. This study is discussed in detail in chapter three.

An outcome of Manley’s study was the development of a conceptual framework for a consultant nurse role (Manley, 1997). In summary, the components of this framework are:

- An expert practitioner in nursing either as a generalist or within a specialty;

- An educator, enabler and developer of others, thus enabling the development of practice;
- A researcher with specific expertise in practice based research methodologies;
- An expert and process consultant from the clinical to executive and strategic levels;
- A transformational leader, who enables a culture to develop where everyone can develop his or her leadership potential.

Within chapter ten the evolution of my role as NCNC from the inception of my doctoral studies to the completion of the thesis is presented. The framework proposed by Manley (1997) is used to discuss the changes that have occurred in my role during this time.

### **1.7 Chapter summary**

This chapter has provided an overview of the structure and components of the thesis. The thesis represents a journey of investigation and change associated with my concern regarding the provision of nursing care to patients requiring hospital haemodialysis. This concern lead me to review the pertinent literature, conduct a cultural study of the HHU and conduct PD with the nurses in an effort to change the way they provide care to patients within the HHU. The chronological development of the thesis reflects the development of my role as the NCNC and discussion on the evolution of my role is included in the thesis.

Chapter two provides a review of the literature examined in relation to the management of ESRF and the problems faced by patients requiring haemodialysis treatments.

## **PART A - LITERATURE REVIEW**

### **CHAPTER TWO - THE PATIENT REQUIRING HAEMODIALYSIS**

#### **2.1 Introduction**

Within this chapter I present a review of relevant literature examined in the substantive field of study. To place the study in context this chapter provides a review of ESRF and the renal replacement therapies used to manage patients. An overview of the way ESRF is managed in Australia is also presented. Literature related to the patient requiring haemodialysis and the physical and psychosocial problems they encounter are also reviewed.

#### **2.2 The treatment of end stage renal failure**

ESRF is the term used to describe a level of kidney function, where life cannot be supported without the assistance of renal replacement therapies (RRTs) (Mallick & Gokal, 1999). There are three RRTs used in the treatment of patients with ESRF: kidney transplantation, peritoneal dialysis and haemodialysis. When kidney function reaches a level where life cannot be supported, the patient is faced either with the decision to commence treatment with dialysis or transplantation and endure a life of chronic illness or the alternative, death. As the alternative option of death is unthinkable for many patients, the majority will opt to receive treatment.

##### **2.2.1 Kidney transplantation**

Kidney transplantation is the treatment of choice for suitable patients with ESRF (Mallick & Gokal, 1999). Transplantation frees the patient from dialysis and has the best long-term outcomes. However, it is only offered to patients who are relatively young and free of serious co-morbidities (Cameron, Whiteside, Katz, & Devins, 2000). Potential kidney transplant recipients undergo rigorous assessment before being deemed fit for the operation. The recipient must be able to tolerate major surgery and the side effects from the immunosuppressive drugs administered to prevent kidney rejection (Magee & Pascual, 2004). For many patients a suitable live donor may not be available and the wait for a cadaveric donor may take many years (Wallace, 2003).

These years of waiting must be spent supported by dialysis. The elderly, frail and those with significant co-morbidities, such as heart disease, are not suitable for transplantation. For these patients dialysis is the only life long option (Magee & Pascual, 2004).

### **2.2.2 Dialysis**

Unless there is a medical reason, patients are able to choose the type of dialysis option they feel will most suit their lifestyle. The two dialysis options are peritoneal dialysis and haemodialysis. In making the choice the patient will always be encouraged to attend the dialysis at home relieving the burden on hospital based programs (Mowatt, Vale, & MacLeod, 2004). Both peritoneal and haemodialysis depend upon the same principles; the transfer of solutes across a semi permeable membrane down a concentration gradient (Gokal & Hutchison, 2002). The following sections provide a more comprehensive explanation of these two forms of dialysis.

### **2.2.3 Peritoneal dialysis**

In peritoneal dialysis, the membrane lining the peritoneal cavity within the abdomen is used as the dialysis membrane. A silicon catheter is surgically placed into the peritoneal cavity and tunnelled out through the skin. The catheter becomes the conduit by which a sterile solution called dialysate is infused into the abdominal cavity. Removal of extra fluid is achieved by varying the amount of dextrose in the dialysate. The dextrose acts as the osmotic force allowing extra fluid to be drawn and then drained from the patient (Gokal & Hutchinson, 2002).

The patient is taught to perform peritoneal dialysis at home. The two forms of peritoneal dialysis commonly used are automated peritoneal dialysis (APD) and continuous ambulatory peritoneal dialysis (CAPD). CAPD involves fluid exchanges four times a day. The dialysate remains indwelling for four to six hours and is then drained and replaced (Gokal & Hutchinson, 2002). APD or nightly peritoneal dialysis involves the use of a machine, which regulates inflow and outflow of dialysate while the patient is sleeping (Gokal & Hutchinson,

2002). APD is increasing in popularity as the preferred peritoneal dialysis modality because it increases the quality of life of those patients who work, have a busy social life or rely on a carer to assist with exchanges (Gokal, 2002).

Peritonitis is the most common complication of both forms of peritoneal dialysis (Gokal, 2002; Woodrow, Turney, & Brownjohn, 1997). The dialysate exchanges must be attended with strict attention to sterile technique. Most peritonitis episodes are due to organisms commonly found as skin flora for example staphylococcus aureus and staphylococcus epidermidis (Gokal & Hutchinson, 2002). Peritoneal dialysis is not a therapy that usually remains viable for longer than five years (Gokal, 2002, 1999). The treatment is limited due to the risk of repeated episodes of peritonitis and eventual membrane failure results in the patient changing to haemodialysis (Woodrow et al., 1997).

#### **2.2.4 Haemodialysis**

The alternative dialysis option is haemodialysis and figure 1. shows a patient receiving a haemodialysis treatment. Haemodialysis utilises an artificial membrane, housed in a rigid walled cartridge called a dialyser. The haemodialysis process requires the removal of blood from the body. The blood is passed through the dialyser and then returned to the patient. Within the dialyser the solutes and electrolytes are filtered via the process of diffusion and pressure applied to the dialysate fluid enables the removal of extra fluid. A specially designed machine is used to support this process. The haemodialysis machine found in the HHU is described in detail in chapter five, section 5.4. Haemodialysis using a standard or low flux dialyser is required for at least four to five hours, three times a week (Gokal & Hutchinson, 2002). However, new therapies including long nocturnal and short daily haemodialysis are gaining in popularity because they offer better symptom control, relaxed dietary restrictions and are expected to have better long term patient outcomes (Locatelli, Buoncristiani, Canaud, Kohler, Petitsclere, & Zucchelli, 2005).

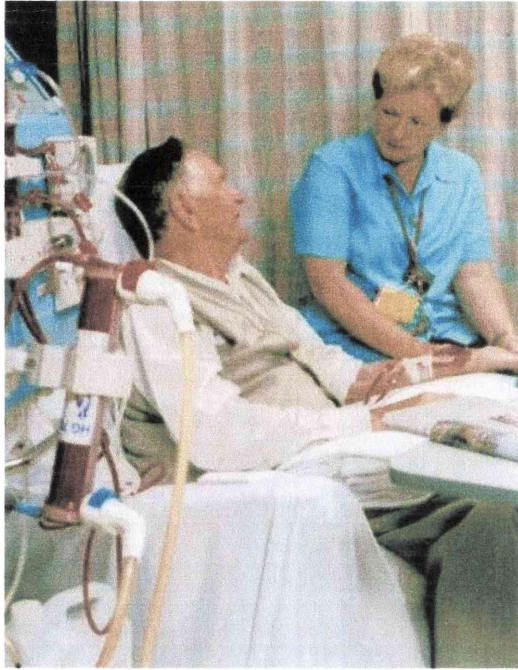


Figure 1. Patient receiving a haemodialysis treatment.  
(Permission obtained from patients to use photographs)

In order to connect the patient to the haemodialysis machine, access to the blood stream must be achieved. Access is by way of cannulae inserted into a surgically fashioned arterio-venous fistula or graft (see figure 2.) or by placement of a central venous catheter designed for haemodialysis purposes (see figure 3.) (Schwab, 1999). Vascular access is a crucial component of care as without access there is no link to the machine, which provides life-sustaining treatment.



Figure 2. A patient with cannulae inserted into an AV fistula for haemodialysis



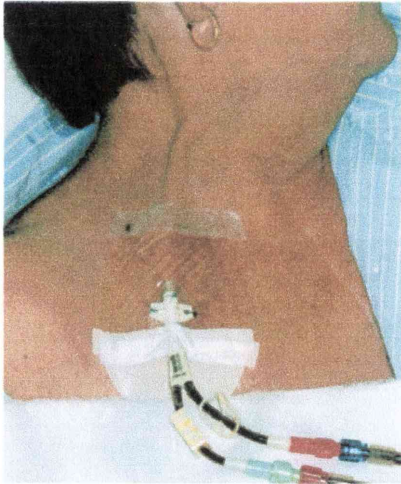


Figure 3. A specially designed central line or vascath used to gain access to the blood stream for haemodialysis.

Young medically stable patients who are capable of learning and managing the complex haemodialysis procedure are supported to perform treatments at home. Home therapies free up spaces on hospital programs and offer the opportunity to tailor the haemodialysis regimen more closely to individual requirements (Mowatt, Vale & MacLeod 2004). Haemodialysis treatments are also provided in hospital and satellite units. Satellite units are usually physically removed from the hospital setting and provide treatments for patients who are unable to perform home dialysis. Hospital haemodialysis units exist to provide treatments for in-patients but additionally are often the only option for out-patients who are elderly, frail and suffer from serious co-morbidities that require constant monitoring. The next section discusses the provision of dialysis therapies for ESRF in Australia.

### **2.3 The management of ESRF in Australia**

It is beyond the scope of this review to provide a comprehensive description of the Australian health care system. However, an overview of the Australian health care system is provided in Appendix A. Briefly, the State Government is responsible for health care delivery and provides funding for dialysis services. The cost of renal dialysis services including haemodialysis is covered under the national health scheme - Medicare and thus there is no cost to the patient (Commonwealth Department of Health and Aged Care, 2000).

Renal services are predominantly based within large public university teaching hospitals. These centres often operate satellite units in rural or remote areas as well as those in the city suburbs. In Australia, there are over 89 hospitals and 130 satellite facilities in which haemodialysis for ESRF is provided (ANZDATA Registry, 2004). There are a limited number of haemodialysis services within private hospitals and a small number of satellite centres operated by medical companies that distribute dialysis machines and related supplies.

The incidence of ESRF has almost tripled since 1981. While some of this increase may be attributed to a higher incidence of kidney failure, improved management of other illnesses and new technologies are likely to have contributed to the number of survivors on dialysis (Australian Institute of Health and Welfare, 2004a). In Australia, there has been a 6% increase in the number of patients on renal replacement therapies from 2002 to 2003 (ANZDATA Registry, 2004). The primary diagnoses of patients commencing RRTs during 2003 in Australia were glomerulonephritis (27%), diabetic nephropathy (26%) and hypertension (15%) (ANZDATA Registry, 2004).

At the end of 2003 there were 13,625 people in Australia receiving some form of RRT. The prevalence was higher in males (78 per 100,000) than in females (53 per 100,000). ESRF prevalence increases rapidly with age, being the highest (193 per 100,000) among persons aged 65-74 in 2002 (ANZDATA Registry, 2003). Of the patients requiring RRTs at the end of 2003, 5,951 had a functioning kidney transplant and 7,674 were on dialysis. The number of patients on peritoneal dialysis was 1,823 and the number on haemodialysis was 5,851 (ANZDATA Registry, 2004). There has been a steady increase in the number of patients on hospital haemodialysis programs. Table 2 shows the number of patients on the different dialysis modalities in Australia (ANZDATA Registry, 2004).

Table 2. The number of people on the different renal replacement therapies 1999 - 2003 (ANZDATA Registry, 2004).

Mode of treatment			1999	2000	2001	2002	2003
PD	APD		264	390	501	612	726
	CAPD		1414	1346	1306	1173	1097
		<b>Total</b>	<b>1678</b>	<b>1736</b>	<b>1807</b>	<b>1785</b>	<b>1823</b>
HD	Hospital		1636	1721	1807	2001	2091
	Home		706	742	773	777	772
	Satellite		2001	2211	2462	2702	2988
		<b>Total</b>	<b>4343</b>	<b>4674</b>	<b>5043</b>	<b>5480</b>	<b>5851</b>

“Care involving dialysis” was the leading cause of hospital separations in Australia in 2001-2002, with a total of 636,010 separations. This represents 10% of total hospital separations (Australian Institute of Health and Welfare, 2004b) and reflects the need for patients to attend the hospital to receive treatments at least three times per week.

Kidney Health Australia (KHA), formerly the Australian Kidney Foundation, is a major resource for the support of kidney disease management. KHA is a non-profit organisation which was officially formed 35 years ago. KHA has a mission to be the lead organisation promoting kidney and urinary tract health through research, advocacy, education and health service excellence (Kidney Health Australia, 2004). The Australian and New Zealand Data Registry (ANZDATA Registry) reports on all data related to patients on RRTs within Australia and New Zealand. The information from the registry is freely available for renal services to benchmark against other units and internationally.

In recent years there has been a move to develop guidelines for the provision of RRTs worldwide. The publication of the Dialysis Outcome Quality Initiative (DOQI) guidelines in the United States has led to the development of Australian draft guidelines called Caring for Australians with Renal Impairment (CARI) guidelines (CARI, 2001). The CARI guidelines are in constant

development and revision and are readily available for all nephrology health care workers in both hard copy and on the internet (Knight, 1999).

## **2.4 The patient requiring haemodialysis**

In this section, issues related to the patient requiring haemodialysis are presented. The physical and psychosocial problems faced by patients and the particular issues faced by the elderly on dialysis are discussed.

### **2.4.1 The problems**

Patients requiring haemodialysis experience a plethora of difficulties both physical and psychological in nature. The patient requiring haemodialysis will usually experience problems related to the underlying disease state. An example is the patient with ESRF as a consequence of diabetes who still must contend with the sequelae of diabetes, including eye and vascular problems (Ritz & Orth, 1999; Cooper, 1998). The physical manifestations of ESRF are numerous with cardiac disease (London, 2003), anaemia (Toto, 2003) and bone disease (Locatelli, Cannata-Andia, Druke, Horl, Forque, Heimbürger & Ritz, 2002; Adams, 2002) being the most significant.

Problems related to the provision of the dialysis involve the fashioning of the vascular access, which can be painful and present the patient with a distorted self image (Anel, Yevzlin, & Ivanovich, 2003; Allon & Robbin, 2002). Additional life stressors for the patient requiring haemodialysis include fluid and food restrictions (Lok, 1996). Restrictions are required, as the process of dialysis does not replace all functions of the kidney. Furthermore, haemodialysis is an intermittent therapy which results in a build up of fluid and toxins between dialysis sessions. The patient is also faced with limitations related to the length and frequency of the dialysis. In most cases the limitations prohibit the patient from achieving rehabilitation to a level where they can maintain employment or an acceptable social life (Blagg, 1994).

Welch and Austin (1999) report on a study describing the treatment related stressors on patients requiring hospital haemodialysis. They identified the relationships between stressors and selected demographic and illness

variables, and identified changes in stressors over time on dialysis. Patients from two units were interviewed. The subjects were categorised into two groups; younger (18-59) and older ( $\geq 60$ ). Fluid limitations, the length of dialysis and vacation limitations were the greatest stressors. These findings support previous studies (Gurkis & Menke, 1988; Baldree, Murphy & Powers, 1982). Findings suggested that stressors were higher in patients new to dialysis indicating they were particularly in need of interventions to help them cope with dialysis. Several significant age related differences were identified. The younger group reported more stress associated with role reversal, uncertainty about the future and changes in body appearance than the older subjects. An unexpected finding of the study was that many subjects stated they were not experiencing stress with fluid limitations because they did not follow the recommendations. Non-compliance with treatment regimens is a significant clinical problem for patients on haemodialysis (Morgan, 2000). The regimen is difficult but is necessary for patients to adhere to for their health and well-being.

Lok (1996) reports on an Australian study into the stressors, coping mechanisms and quality of life (QoL) among dialysis patients. Fifty-six patients requiring haemodialysis completed questionnaires. The most frequent stressors reported were limitation of physical activities, decreased social life, uncertainty concerning the future, fatigue and muscle cramps. Limitations concerning fluid were not ranked highly in this study.

ESRF also impacts on the spouses and family of patients requiring haemodialysis (White & Grenyer, 1999; Brunier & McKeever, 1993). White and Grenyer (1999) investigated the impact of dialysis on both the patient and partner. The sample of 22 patients and 22 partners were recruited from peritoneal dialysis and haemodialysis treatment groups and were considered representative of the Australian dialysis population. The findings of this phenomenological study suggest that life with dialysis is formidable and has a negative impact on the patient and his/her partner's QoL. The results show that both patients and partners have similar concerns yet having each other's

support helps to reduce or moderate the negative effects of dialysis. There are a limited number of studies in the literature investigating the effects of dialysis on partners. This study, although comprising a small sample, alerts the nurse to the need to be mindful of the influences of partners and families and the support they require when a loved one needs haemodialysis treatments. Although not stated in the study, the issue of patients without partners and the support they require has not yet been expressed in the literature. In the situation where there is no partner the patient may need extra support and resources from the treating physician and nurses.

The QoL of patients across a variety of RRTs has been studied at length (Ferrans & Powers, 1993; Bremer, McCauley, Wrona, & Johnson, 1989; Evans, Manninen, Garrison, Hart, Blagg, Gutman, Hull, & Lowrie, 1985). This literature establishes patients with a successful transplant as having a better QoL than patients on dialysis (Evans et al, 1985). A review of the measurement of QoL is difficult as there is no uniformity in the definitions and measurements used. Most contemporary studies of QoL utilise the short form 36 (SF 36) which is a generic instrument with demonstrated validity, reproducibility and responsiveness in ESRF patients (Ware & Sherbourne, 1981). The SF 36 can provide descriptive information regarding populations and can be used to compare populations. The SF 36 can also be used in individual patients to track patient's perceptions over time (Kimmel, 2000). Additionally, results in QoL studies have been found to vary depending on who evaluates the QoL - the investigator, health care workers or the patient themselves.

A more recent trend in the literature is to examine the experience of living on dialysis (Caress, Luker, & Owens, 2001; Lindqvist, Carlsson, & Sjoden, 2000). Polaschek (2003a) has reviewed eight qualitative studies from the literature seeking an understanding of the experience of people living on dialysis. Discussion in this review indicates "the renal client experience can be comprehensively interpreted as a response to renal illness and therapy within the specialised health care context of renal replacement therapy" (Polaschek, 2003 p.303). With a better understanding of the experience of people living on

dialysis, health care workers can more adequately support patients to live as full a life as possible.

The experience of suffering from ESRF has also been studied in patients requiring haemodialysis (Martin-McDonald, 2003; Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2001). The theoretical basis for the study undertaken by Hagren et al (2001) viewed suffering at three levels: sickness and treatment, care provided and the patient's unique life experience and existence. The small study of 15 Swedish patients aged 50-86 years revealed two main themes; "haemodialysis machine as a lifeline" and "alleviation of suffering". "Machine as a lifeline" depicted the way the machine was seen as an alternative to death. In opting for treatment, it meant that there was loss of freedom. "Alleviation of suffering" could be achieved by accepting dependence on the haemodialysis machine. Being seen as an individual by the caregivers was important for the patients in order to maintain autonomy.

Martin-McDonald (2003) utilised Morse and Penrod's (1999) model linking the concepts of enduring, uncertainty, suffering and hope in a study to reveal how patients requiring dialysis, who continue to suffer, perceive their identity. Morse and Penrod suggest that the patient with a chronic illness may move in a cyclical manor through these concepts until there is a reformation of self. Martin-McDonald (2003) found that some patients are able to reformulate their perception of themselves in a way that they found acceptable. For others the dialysis regimen is accompanied by so much suffering that they believe they are only a remnant of who they were prior to commencing dialysis. Martin-McDonald (2003) suggests a refinement of the Morse and Penrod model to include the remnant self. The nature of this study limits the sample size and only five patients requiring haemodialysis were included in the total study sample of ten. Nevertheless, the richness of the narratives of patients experiencing life on dialysis and the fact that the study was performed in Australia adds to credibility of this study.

#### **2.4.2 The older patient requiring haemodialysis**

The issue of older patients on haemodialysis is important due to the number of elderly patients receiving treatments in the HHU. Loos, Briancon, Frimat, Hanesse and Kessler (2003) studied the QoL of older patients. The study included 169 patients, 70 years and older, who were starting dialysis for the first time. The design of the study was important in that these subjects were compared to 169 age and sex matched non-ESRF controls with other chronic conditions. QoL was assessed using the SF 36 questionnaire an instrument with established validity and reliability. Information was also collected on co-morbid conditions, clinical symptoms and laboratory results. Findings revealed that older ESRF patients have a lower QoL than older patients with other chronic conditions. The most impaired dimensions were role physical and role emotional. The findings identified that older patients whose dialysis is unplanned have severely impaired QoL alerting health care professionals to the need for improving the pre dialysis management of older ESRF patients to optimise conditions at first dialysis.

A comprehensive systematic review of the international literature on the QoL of elderly patients on dialysis has been published by Kutner & Jassal (2002). Elderly dialysis patients' mental health, especially their reported satisfaction with their lives, has been shown for the most part to be as good as or better than that of younger dialysis patients and non-renal age matched peers. However, elderly dialysis patients have a significantly increased risk for impaired physical functioning and accompanying depression. This increased risk poses heavy care requirements on dialysis health care team members. The conclusions from the review indicate that preventative and rehabilitation programs, including comprehensive integrated care models, can promote healthy ageing and patient QoL on dialysis and help to contain the total burden of health care costs.

#### **2.5 Chapter summary**

Within this chapter a review of the most relevant literature on the provision of RRTs and the experiences of patients on dialysis has been discussed. The



treatment options for ESRF are transplantation, dialysis and no treatment if the patient wishes. There are two forms of dialysis – peritoneal and haemodialysis and this study focuses on patients receiving haemodialysis in hospital. The review of the literature into the issues faced by the patient requiring haemodialysis indicates that the illness experience is considerable, both in terms of the impact of the disease and associated treatment and the uncertainties around the treatment program.

Nurses within the HHU are the major care providers. I believed this care should be focusing on all of the patients' needs and not just the dialysis. I undertook a review of the literature into the area of haemodialysis nursing to investigate this concern. In the next chapter I provide a summary of this review.

## **CHAPTER THREE - HAEMODIALYSIS NURSING**

### **3.1 Introduction**

The previous chapter established the importance of the relationship between the patient and health care professionals, especially the nurse. The purpose of this chapter is to provide a review of the literature related to haemodialysis nursing. An overview of the evolution of haemodialysis nursing will be presented. Theoretical aspects of nursing and the influences of technology on nursing care delivery are also explored in order to provide a framework in which to examine the provision of nursing care within the HHU. The impact of the CNC role is central to this thesis and a review of the CNC role is the final component of the chapter.

### **3.2 The evolution of haemodialysis nursing**

Since the early days of dialysis, haemodialysis nursing has rapidly developed as a nursing specialty. There is little literature available on the evolution of dialysis in any country other than the United States. In the 1940s and 1950s, haemodialysis was only attempted in the treatment of patients experiencing acute kidney failure. The treatment was used to support the patient's uraemic symptoms until kidney function returned (Mapes, 1985). There was no specialty ward or unit, but a team of doctors, nurses and technicians who were specially trained to provide the tedious and cumbersome process. The doctor was the team leader, performing the cut down procedure for the insertion of the glass cannulae required to access the blood stream. The nurse's role was mainly to assist the doctor to prepare equipment and monitor the patient's vital signs (Hoffart, 1989).

The treatment of patients with ESRF has its genesis in the early 1960s (Hoffart, 1989). Although treatment was offered to ESRF patients, resources were scant and health professionals needed to operate the systems were few. Consequently, many hospitals in the United States had strict criteria as to who should receive chronic dialysis therapies (McCormick, 1993). Each individual case was heard by an acceptance committee of anonymous members from all

walks of life. The task of the committee was to view whether the patient was an acceptable candidate for the very limited amount of haemodialysis resources available (Corea, 1998). Criteria used to judge the social benefits to be gained from people who were candidates for renal dialysis included their age and gender, marital status and the number of dependents, income, emotional stability, educational background, occupation and future potential (Corea, 1998). The committee selected the person who would benefit the most, and provide the greatest social benefit for others through his or her contribution to the community (McCormick, 1993). The acceptance committees were disbanded with the introduction of legislation in the United States in 1976. Consequently, haemodialysis treatment became available to all citizens (Pfetscher, 1993).

Changes in the selection process made haemodialysis more freely available and the number of patients and dialysis units in the United States increased rapidly (McCormick, 1993). Haemodialysis also expanded into other western health care systems, including Australia. Consequently, haemodialysis became a viable option for maintaining the life of the ESRF patient. In Australia, dialysis for the treatment of acute renal failure was first performed in 1954. Transplantation and the dialysis of patients with ESRF have been performed since 1964 (George, 1991).

As haemodialysis services expanded, the demand for skilled, cost effective human resources resulted in the delegation of the dialysis procedure by medical to nursing staff (Hoffart, 1989). Nurses were trained and quickly became experts in the delivery of dialysis treatments. This was a remarkable landmark in nursing as previously nurses had not been able to commence intravenous infusions or administer blood transfusions in most hospitals (McCormick, 1993). Subsequently, due to the specialist knowledge and expertise required the provision of haemodialysis treatments quickly evolved into a nursing specialty.

Technological developments meant the dialysis equipment was less intrusive and awkward to operate. Patients no longer needed to remain in hospital and could be treated as out-patients or learn the procedure and attend to dialysis at home (McCormick, 1993). The first patient on home haemodialysis in Australia was reported in 1968 (Dawborn & Marshall, 1968). A 39 year old Australian businessman had fallen ill while in Washington, USA. Haemodialysis for ESRF was initiated in the United States and the patient transferred to Melbourne for home haemodialysis training. The training took eight weeks and the patient performed three ten hour overnight dialysis sessions per week. He was able to return to full time employment less than a year later. Before this time the use of long term haemodialysis and in particular home haemodialysis had received little support. The cost reported at the time for home haemodialysis was \$4,000 per year and the expense of the procedure was the major obstacle to wider application (Dawborn & Marshall, 1968).

In 1968, the National Ad-hoc Committee on Rationalisation of Facilities for Organ Transplantation and Renal Dialysis reported its recommendations. The major brief of the committee was to recommend a reasonable plan to make "wise use of resources, available and anticipated in a life-saving activity" (Anonymous, 1968 p.1190). The committee recommended that recurrent haemodialysis should be restricted to patients awaiting transplantation and that the selection criteria should not be rigid and focused on medical grounds only (Anonymous, 1968). The committee also recommended that there be no more than one and possibly two units providing transplantation and dialysis per state. As previously mentioned, today there are over 89 hospitals and 130 satellite facilities in which haemodialysis for ESRF is provided in Australia (ANZDATA Registry, 2003).

The expansion of dialysis services worldwide has come at a time when there are insufficient personnel to provide the treatments. There is a general shortage of registered nurses (RNs) in Australia and overseas (Australian Health Workforce Advisory Committee, 2003). To assist in the alleviation of the workload for RNs, Australian and overseas haemodialysis units have utilised

different categories of health care workers. Haemodialysis units in the United States employ dialysis technicians (Kammerer, 1988) who perform specific aspects of the dialysis procedure. These types of assistive personnel have been used successfully to ensure that the technical aspects of the dialysis procedure are accomplished. There are specialist training programs and delineated job descriptions for the dialysis technician (Dunetz & Paret, 1996). The use of dialysis technicians free up the RN to perform those aspects of care pertinent and specific to nursing. Burrows-Hudson (1990) lists these nursing activities as patient assessment, diagnosis, care planning, implementation of nursing interventions, coordination of the health care team and the evaluation of the patient's response to the treatment regimen and clinical course. This view is supported by Hamilton (1999) who stresses that support workers of any type can be trained in the more technical aspects of haemodialysis such as setting up equipment, care of lines, cannulation and connection and disconnection from the machine. This essential and skilled support can enable the RN to concentrate on care outcomes in collaboration with the patient and other members of the health care team. However, role strain has been seen where nurses and technicians perform haemodialysis (Gould, 1998).

In Europe there is also widespread use of dialysis technicians. Here the term is generally used for people entrusted with technically oriented tasks in a dialysis unit. There seems to be no set criteria or regulations on the work of the technician and the European situation is currently under examination (Lopot, 2001). In Australia, there are a small number of technicians employed in Victorian hospitals.

A number of Australian units are successfully employing enrolled nurses (ENs) to assist in dialysis procedures (Charman & Brown, 2004). Additionally, the Renal Therapy Attendant (RTA) is a new position of assistive personnel successfully employed in some South Australian units. RTAs are integral members of the dialysis team, performing cleaning and restocking duties and providing for patients' comfort needs (Frost, 2004).

### **3.3 Haemodialysis nurse education**

Postgraduate education programs have been developed to provide the specialist education required by the haemodialysis nurse. Traditionally, post graduate education incorporated all aspects of nephrology nursing including general ward practice, transplantation and dialysis techniques (Parker, 1998). Patient education was also emphasised. Such a comprehensive education enabled the nurse to support the patient through a complex treatment program consisting of one or more dialysis modalities (Stewart, Spencer, & Appel, 1995). Today there is a trend for nephrology nurses to specialise in one distinct area of practice. Haemodialysis nurses tend to remain in the unit, and do not rotate to generalist nephrology wards. This specialisation, coupled with the shortage of formal education programs in NSW, has resulted in unit-based education that uses a preceptorship model. The preceptorship model is positive in that the skills required for haemodialysis nursing are enhanced and practised. Nevertheless, the preceptorship model allows for poor practices to be reproduced without challenge and the generalist skills required to care for the whole patient are often lost or overlooked. The shortage of formal educational programs is an issue requiring debate in this state. Presently there are three options for renal nursing qualifications, none of which are university based. However, these renal nursing programs are recognised with tertiary providers and nurses can attain credit toward postgraduate studies on completion.

Specialty renal nursing organisations have developed as a forum for nephrology nurses to share and learn from nursing colleagues and to provide the means for nurses to have a voice in the renal care arena. The specialty group for nephrology nurses in the United States is the American Nephrology Nurses Association (ANNA). The American Association for Nephrology Nurses, the predecessor of ANNA, was formed in April 1969 (Hoffart, 1989). Major initiatives of ANNA include standards of clinical practice, certification of haemodialysis nurses and technicians and a core curriculum for nephrology nursing education (Mapes, 1985). The European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA) was

established in 1971 and has become the most important forum in Europe for the exchange of information and experience for all renal health care professionals (EDTNA/ERCA, 2004).

The Australian specialty organisation for nephrology nurses, technical support and allied health is the Renal Society of Australasia (RSA). The RSA was established in 1972 under the name of the Dialysis Society of Australasia. As the society grew the name changed and in 1998 the RSA was incorporated and a board of directors was formed. The RSA consists of a federal executive and branches in New Zealand and each Australian state. The RSA now has over 700 members in Australia and New Zealand and a national conference is held each year (RSA, 2004). The most pivotal project of the RSA to date has been the establishment of competencies for advanced renal nurses (Bonner & Stewart, 2001; RSA, 1999). These competencies do not appear to be widely used as there has been no evidence of evaluation of performance using the RSA competencies in the literature. Literature related to the role of the haemodialysis nurse will be discussed in the next section.

### **3.4 The role of the haemodialysis nurse**

Nursing within the haemodialysis clinical practice role includes caring for patients from childhood (Frank, 1997), to old age (Bevan, 2000b) in diverse settings including acute hospitals, out-patient and satellite units, home training centres and in the home (Stewart et al., 1995). The practice of haemodialysis nursing is performed by nurses at all levels of experience from the novice new graduate or beginning haemodialysis nurse to the expert who practises in advanced roles, such as clinical nurse specialist (CNS), clinical nurse consultant (CNC) and nurse practitioner (NP) (Headley & Wall, 2000; Hamilton, 1999).

The literature establishes the major role of the haemodialysis nurse as the provision of the dialysis treatment. This technical role is supported by Polischek (2003b) who suggests that the dominant action in the renal setting is the provision of the dialysis treatment. He suggests that the unique contribution

of the nurse in the haemodialysis unit is in responding to the experience of the person who is living on dialysis. Nurses in an Australian haemodialysis unit have described their role as that of supervising dialysis treatments and teaching patients to manage their own dialysis and symptoms related to complications of chronic renal failure and dialysis (Wellard, 1992). Ran and Hyde (1999) suggest nephrology nurses should take up the challenge of looking beyond the technical expertise to form an empathetic therapeutic relationship with patients. They believe the nephrology nurse should function within a patient support role with emphasis on the additional functions of caregiver, educator, advocate, facilitator, mentor and referral agent.

Patients receiving haemodialysis treatments in medical facilities such as a HHU have frequent interactions with caregivers. The caregivers contribute to shaping the social world of the dialysis unit in which the patient participates (Kutner, 1987). Due to the frequency of interactions with patients, the nurse is seen as the most prominent care provider; the patient's life is literally in the hands of the nurse (Kutner, 1987). A major role of the nurse in the renal multidisciplinary team is advocacy where the nurse assumes responsibility for ensuring that the patient's long-term needs are met. In performing the role the nurse may identify and refer patients to appropriate resources and services, change dialysis schedules to best meet the patient's needs, desires and requirements and act as a spokesperson for the patient with other staff and services within the health care system (Keogh, Pope, Anthony, Arnell-Cullen, & Hamilton, 2000). This situation provides the opportunity for the development of a unique therapeutic relationship between nurse and patient.

The nurse-patient relationship has warranted much attention in the literature. The close therapeutic relationship that develops between nurses and patients results in open communication and it is suggested that patients confide in the nurse particularly about sensitive matters and here the patient advocacy role comes to the fore (Stewart et al., 1995). Within the hospital haemodialysis unit the relationship between the nurse and patient has been described as approximating that of a patient-therapist relationship (Morehouse, Colvin, &



Maykut, 2001). The nurse takes on the roles of teacher, behavioural therapist and supportive counsellor to help the patient comply with dietary and medical regimens. Often the relationship between patients and renal nurses is long and well established enabling trust and respect on both sides. This relationship encourages nurses to form a partnership with patients in decision making (Aswanden, 2002; Hamilton, 1999).

An Australian study undertaken for a doctoral thesis examined the dilemmas faced by nurses in dialysis units and the context in which they occur (Wellard, 1992). The findings suggested that the dilemmas encountered in dialysis nursing arose out of conflicts in relationships with other people in the work environment including patients. On interview the nurses felt that there was difficulty in building an initial relationship with patients. Nurses have to win the trust of the patient and this develops over time. At times the nurses perceived patients as treating them poorly and patients frequently vented their anger on nurses. The anger the patients experienced was associated with being on dialysis and the complications and relationship failures which resulted. Many patients were described by nurses as demanding and some abusive and rude. All of these conflicts resulted in dilemmas for dialysis nurses (Wellard, 1992).

Other studies have reported negative findings regarding the nurse-patient relationship. A Portuguese study examined the nurse-patient relationship in a haemodialysis unit in view of assessing the total interaction between nurses and patients (Cristovao, Sausa, & Picado, 1996). Indicators used to assess the nurse-patient interaction were empathy, respect, availability and safety. Twelve nurses and 30 patients completed questionnaires. A major finding was that the doctor was considered by 50% of the nurses and 70% of the patients as the most appropriate person to talk to the patients about their problems. This finding is surprising in that nurses are the prime health care worker in the unit and would be the most available to speak with the patients about their problems. In order to improve the nurse-patient relationship 50% of the nurses suggested a reduction in the number of tasks, and 60% of the patients suggested a better nurse-patient ratio.

There has been little in the literature regarding the way that nursing work is conducted in a haemodialysis unit. Jovie, Calaway, Jorgensen and Swokowski (1988b; 1988a) describe the way primary nursing was introduced into a chronic haemodialysis service. The major responsibilities of the primary nurse are listed as the provision of clinical information to others who are involved in caring for patients in his/her absence, making information available to others in the problem-oriented medical record, instituting the steps in the nursing process when planning care for patients and finally discharge planning if appropriate. In the primary nursing model described by Jovie et al. (1988a) one nurse performs all the care tasks for assigned patients. In the absence of the primary nurse the patients are cared for by a core group of associate primary nurses. The authors argue that the implementation of this primary nursing model has led to the nurses having a better knowledge of the patient and therefore being able to provide more applicable and effective patient centred nursing care.

Primary nursing care in haemodialysis units has been described as having both positive and negative effects.

“Primary nurses in haemodialysis know their role is crucial to sustaining the lives of patients. They are involved not only in providing adequate dialysis treatments but in humanising the experience as much as possible” (Zander, 1980 p253).

The major problem identified when primary nursing is introduced into the haemodialysis unit is that in some instances the constant care by one nurse can lead to an over dependence on the nurse by the patient (Zander, 1980).

Primary nursing is an organisational concept originated in the United States in the 1960s and 1970s (Pontin, 1999). There has been a plethora of literature on the topic and the different ways of implementing primary nursing. It is beyond this literature review to address primary nursing in detail but it is important to note that there are ten elements said to underpin its use (Pontin, 1999). These elements are accountability, advocacy, assertiveness, authority, autonomy, collaboration, communication, commitment, continuity and coordination. All of

these elements would be essential criteria for the provision of patient centred care. The mode of care delivery in the HHU is termed primary nursing and data regarding the conduct of the nursing care collected during the study may be able to pinpoint whether this is the most effective means of caring for patients and whether the primary nursing practised in the HHU can be improved. Primary nursing is described as the usual method of organising care in haemodialysis units in the United States but Quirk (1998) suggests that functional care delivery, in which it is not unusual to have a different assignment each day is practiced in many units.

### **3.5 Technology and nursing in the haemodialysis unit**

The focus of the nursing care in the haemodialysis unit is the provision of the dialysis treatment. Consequently, other essential elements of whole person care may be overlooked to achieve this end. The HHU is an environment of ever increasing highly sophisticated health care technology. As a consequence, it is a major challenge to provide personalised care. Unfortunately, the HHU has undergone little study (Aswanden, 2002; Bevan, 2000a, 1998). Although there are many similarities between the ICU and the HHU, the uniqueness of the patient group and the chronic nature of renal disease sets the scene for an investigation into the way the nurse balances the provision of the technology with patient care. Nursing literature focusing on the intensive care unit (ICU) and the ICU nurses' provision of care to critically ill patients provides insight into the impact of the technological aspects of care (Walters, 1995a, 1995b; Cooper, 1993; Ray, 1987).

Bevan (1998) sees the work in the haemodialysis unit as akin to work on a factory production line. This situation has evolved due to the increased demand for haemodialysis surpassing the available resources. More elderly and sicker patients are entering hospital-based programs resulting in patients being more physically dependent on staff. Bevan (1998) believes that the emphasis on the technology leaves little time for the care, which has long been held as the core of nursing practice. The factory line analogy (Bevan, 1998) is frequently reinforced by the organisation of the HHU and the social pressure to

treat an increasing number of patients, despite no increase in nursing staff. Consequently, the focus of the care appears to be the technology rather than the whole patient.

Bevan (1998) suggests the nurse has become “enframed” by the technology of dialysis. The word enframed implies that the nurse is surrounded or enslaved by the technology. Without the technology, dialysis nursing would not exist. The enframing of the nurse by the technology results in the focus of the nursing work away from caring for the patient to the operation of the machine and associated technology. Bevan examines the context of dialysis from a critical and philosophical standpoint however his views are not research based. Hawthorne and Yurkovich (1995) noted this view of technology in nursing earlier and proposed that health care professions over emphasised the importance of technology to the detriment of the expression of caring. Consequently, caring for patients’ psycho-social needs often takes second place. The technology is not inherently bad; it has many benefits that help people to survive, however, the time used sustaining the technology means nurses may have insufficient opportunities to discuss psycho-social issues.

Other authors are not as damning in relation to the provision of nursing care in other wards and units where there is an emphasis on technology. Indeed, caring is not only possible but it can be positively enhanced by the nurse’s mastery of the technical environment (Walters, 1995b; Ray, 1987). The perceptions of nursing work in the ICU have revealed that nurses in ICU describe caring as a process involving feelings together with professional knowledge, competence, skill and nursing judgement. This caring involves the holistic care of the patient and relatives in order to meet their individual needs (Wilkin & Slevin, 2004). Machine technologies and caring in nursing can be harmonious aspects of clinical nursing practice (Locsin, 1995). Technology in the form of machinery enhances the nurse’s knowledge of the person for whom they are caring. However, an emphasis on technology can widen the gap between the nurse and the patient because of an unconscious disregard of the patient as a person (Cooper, 1993). The technical aspects of the work

are a major component that attracts nurses to work in haemodialysis units and this will be discussed in the following section.

### **3.6 What attracts nurses to haemodialysis nursing?**

There has been little study on what attracts nurses to the haemodialysis setting. Research by Lewis, Bonner, Campbell, Cooper and Willard (1994) focused on the relationships among personality types, personal and work-related stress, sense of coherence and coping resources of dialysis nurses. The study found that the distribution of personality types of dialysis nurses was different to that reported for nurses working in other contexts. Utilising the Myer-Briggs four dimensions of personality, the most common personality type in dialysis nurses was sensing-thinking. In other studies sensing-feeling types are more commonly reported for nurses. Sensing-thinking personalities focus their attention on facts and handle these with impersonal analysis. They tend to be practical and matter-of-fact. This study was conducted in the United States in the early 1990s and findings may not be applicable to nurses working in Australian haemodialysis units today.

The hours worked, an interest in the technological challenges and patient contact were the three reasons for choosing haemodialysis in a study of nurse-patient relationships in an out-patient dialysis setting (Morehouse, Colvin & Maycut, 2001). The study found that nurses gave a different answer when asked the question what keeps them in the dialysis setting. The emphasis was on the provision of continuity of care and working within a holistic framework.

The opportunity to establish long-term relationships with chronic renal patients is described as a favourite aspect of being a haemodialysis nurse (Elvin, 2003). This is in keeping with findings from a study carried out to ascertain nurses' perceptions of renal nursing as a career choice in the United Kingdom (Keogh et al., 2000). Telephone interviews were conducted with 51 nurses, 26 renal staff and 25 non-renal nurses. The interviewers asked the nurses about the positive and negative aspects of renal nursing. These results were compared with a focus group discussion with five experienced nurses. Non-

renal nurses had little idea of the specialty but perceived the work as technical and skilled. In contrast, renal nurses expressed a high level of job satisfaction, emphasised the good patient-nurse relationships and felt able to develop and achieve their own career goals. The small study demonstrated that renal nurses felt the specialty provided a stimulating and rewarding workplace. A major recommendation from the study was that students need to be aware of career opportunities in the specialty and mechanisms should be in place to ensure exposure of students to renal nursing. No literature could be found regarding what attracts nurses to work in haemodialysis settings in Australia.

Bevan (1998) suggests that the emphasis on the technology within the HHU setting is beneficial in that "the nurse is able to define the limits of his/her role and in doing so provide an area of security where generally his/her daily activities are predictable" (Bevan, 1998 p.735). This predictability of work is seen as comforting in the current health care climate and may be another factor that attracts people to work in a HHU. However, Jones and Cheek (2003) suggest that in most areas of nursing there is no longer such a thing as a typical day. Although their research did not include the haemodialysis environment which may still be more predictable than other areas of practice.

Bassett (2002) has identified that there are some interesting differences between what nurses and patients perceive as good care. Bassett reviewed the literature to determine nurses' perceptions of care and compared it with what patients want in terms of care. He found that the nurses value most highly the interpersonal aspects of the caring relationship. Patients also value these humanistic aspects of care, but perhaps not to the same levels as nurses. The most highly valued aspect of care for the nurse is creating a strong relationship with the patient whereas the patient values a high level of competency and skills in the nurse. This result would be associated with the context in which the investigation was conducted and a generalisation cannot be drawn across all contexts of nursing. However, these findings are consistent with those of Nagle (1998) who studied people with chronic renal failure and the meaning of the health care technology experience for them. This hermeneutic study involved

interviewing eleven patients receiving out-patient haemodialysis. The major themes identified were coming to terms with loss and limitation, abiding with technology and enduring the treatment environment. The most relevant findings around the care received were that participants talked about the clinical expertise and competence of the care providers. The technical competence of nurses and doctors were of utmost importance to the participants.

The NCNC is an evolving role with a responsibility to shape the HHU culture of caring. Therefore, the impact of the NCNC position is pivotal to the conduct of this thesis and an overview of the relevant literature on the CNC is provided in the next section.

### **3.7 The CNC Role**

The literature presents a number of conflicting titles for the position of CNC. The CNC is commonly described as an advanced practice role but the educational preparation and emphasis of the role varies between the North American and Australian literature. For this reason, I chose to focus this brief literature review on the publications emanating out of the United Kingdom and Australia where the roles seem to be more closely aligned.

The CNC position within New South Wales was introduced as far back as the late 1980s. The CNC role is not common to all Australian states and there has been little written on the CNC role in Australia. Dawson and Benson (1997) report on a review of the CNC role within a large Sydney Area Health Service. The review of 13 CNCs involved an analysis of how they spent their time, a comparison of this analysis with CNCs from another Area Health Service and a survey of the opinions of nurse managers regarding the CNC work. The four common domains of the CNC role identified were education, liaison/resource, research and clinical practice. The organisational needs and expectations, the nature of the specialty and the skills of the incumbent determine the amount of time each CNC spends working in each domain. The review highlighted the diversity of the CNC role.

Another study attempted to uncover the lived experience of CNCs by using phenomenological hermeneutics as the research approach (Walters, 1996). The participants in the study were ten CNCs who worked in a range of clinical specialty services in a large Sydney tertiary referral hospital. The two themes emerging from the study were the experience of diversity and the experience of working with people. The experience of diversity relates to the numerous and different clinical specialties in which CNCs are employed and the diverse role of each CNC. The experience of working with people as a nurse consultant requires a special form of relating to people that incorporates technical nursing expertise and a benevolent, humane and authentically caring attitude towards people. The author describes the theme of “a special form of relating to people” within a CNC-patient relationship and does not describe the other relationships considered fundamental to the CNC role which are those between the CNC and other nurses s/he must direct and support, and the relationships with other members of the multidisciplinary team. For this reason, the study presents a narrow focus of the CNC role being that of provider of expert care to a select group of patients and not the other domains in which the CNC practises.

There is little Australian literature regarding the role of the CNC since the late 1990s, although there have been a number of changes in health care affecting the CNC role. The most important of these changes is the introduction of the nurse practitioner (NP) role. In NSW, a NP is defined as a registered nurse practising at an advanced level authorised by the Nurses and Midwives Board, NSW to use the title “nurse practitioner”. Advanced practice incorporates the ability to provide care to a range of clients at a level that demands a repertoire of therapeutic responses, insightful and sophisticated clinical judgements and clinical decision-making that justifies the application of advanced knowledge (Nurses and Midwives Board of NSW, 2003). In some instances, CNCs have recognised that their role is that of a NP and they have obtained or are working toward NP status (NSW College of Nursing, 2001).



Within the United Kingdom, the equivalent of CNC is the nurse consultant (NC). The NC role is relatively new in the United Kingdom with the establishment of NC posts primarily being enacted in 2000 (Department of Health, 1999). The target outcomes of the establishment of the NC posts were to transform culture and to develop evidence based and patient centred care (Dewing & Reid, 2003). This is in contrast to the initiation of the CNC role in NSW, which was seen by nurses as providing a career pathway for nurses wishing to remain in clinical positions rather than having their expertise lost in management and education (Walters, 1996).

In a description of the role of the NC in tissue viability, Harker (2001) suggests the role must be flexible to meet the needs of the population and that it can be impeded by the expectations of the organisation. Harker (2001) suggests the major roles of the NC are:

- Expert practice, professional leadership and consultancy;
- Education training and development; and
- Practice and service development, research and evaluation.

Haines (2002) personally reflects on the effective establishment of a NC role in a paediatric intensive care. Here the expertise of a NC lies in being able to facilitate and enable others to change the practice culture.

The CNC role has been identified as an ideal role for facilitating PD (Manley, 2000a, 2000b, 1997) and two CNC colleagues have utilised PD as the methodology for their professional doctorate theses (Dempsey, 2004; Bothie, 2004). Indeed, at a Sydney teaching hospital the CNCs are being trained to be the practice developers for that institution (Dean, 2004). This initiative is being driven by a CNC in the role of PD consultant.

Manley (1997) conducted a comprehensive three-year study to operationalise the role of NC, and in so doing, facilitated the development of nurses and nursing for the purpose of providing better patient services. The NC position was based within a five-bedded intensive care unit and was a unique role in Britain at the time. The study method was action research and fell within three

broad but interconnected areas, each associated with several action research cycles. The first area was at the macro/strategic level, where the NC role was linked inextricably to the stated purpose of the unit and the facilitation of that purpose, namely developing a quality patient service. The second area involved action research cycles related to each of the unit's eight objectives that had been previously determined. The third area concerned the personal actions and reflections of the NC during the study period.

An outcome of the study was the development of a conceptual framework for a consultant nurse role (Manley, 1997). This framework arose out of the work done around the unit's eighth objective concerned with evaluating the NC position. A thematic analysis was performed on the diary and field notes kept by the NC. In addition to focus group discussions with nurses in the ICU exploring how staff felt about the position and whether any refinements were required. The resultant themes were used to construct a conceptual framework, which identifies the roles and skills necessary for operationalising a NC role, linked to essential contextual prerequisites and outcomes. The components of this framework are:

- An expert practitioner in nursing either as a generalist or within a specialty;
- An educator, enabler and developer of others, thus enabling the development of practice;
- A researcher with specific expertise in practice based research methodologies;
- An expert and process consultant from the clinical to executive and strategic levels;
- A transformational leader, who enables a culture to develop where everyone can develop his or her leadership potential.

Three core outcomes were seen when the nurse consultant role was effectively established within a conducive and supportive context: a transformational culture – one where change becomes a way of life with empowered staff and practice development (Manley, 1997). As highlighted in

the introduction, this framework will be used within the thesis conclusion to discuss the evolution of my role as CNC.

### **3.8 Research aims**

The literature reviewed in part A and my experiences with the patients in my journal story suggested that the care provided by nurses in the HHU was not centred on patients and their individual needs. Consequently, I decided to undertake further investigations to:

1. Acquire a comprehensive understanding of the patient care provided within the HHU;
2. Determine the structural and interpersonal enablers and barriers to patient centred care;
3. Engage nurses in a process of sustainable cultural change to enable the holistic management of the patients;
4. Examine and reflect on my role as CNC and my work as a developer of the culture in the HHU.

### **3.9 Chapter summary**

Over the past four decades haemodialysis nursing has evolved into a distinct specialty. There is a focus on technology within haemodialysis settings and this is understandable as the basis for the existence of the unit is the provision of haemodialysis treatments. The literature suggests the nurse's role extends beyond the provision of the dialysis to supporting each patient's holistic concerns, most importantly their adjustment to life as a dialysis patient. The relationships between nurses and patients are described as therapeutic and are unusual in that they are often long term, developing over a number of months or years.

This literature review has provided me with a clear understanding of the way that haemodialysis nursing is practiced both in Australia and internationally. Additionally, the review identified some of the forces that influence practice as a haemodialysis nurse. One of these key influences is the way the haemodialysis unit is set up to provide highly technical treatments encouraging

the nurse to be a skilled technician rather than a provider of patient centred care.

The review assisted me in determining the research aims and my first step was a further investigation of life on my particular HHU. Ethnography was the investigation method of choice and a discussion of the method is provided in the next chapter.

## **PART B – THE ETHNOGRAPHY**

### **CHAPTER FOUR – THE STUDY METHOD**

#### **4.1 Introduction**

The chapter provides discussion on two aspects of the study. The first section of the chapter is a discussion of ethnography as a research method. The section begins with an explanation of ethnography including the major forms of ethnography used in health care studies. Data collection methods and data analyses techniques particular to ethnography are also discussed. The section concludes with an explanation for the particular method for the study.

The second section of the chapter is the presentation of the conduct of the research. Discussion on the setting, participants, ethical considerations and data collection and analysis methods are provided in this section. An overview of the strategies I used to ensure rigour in the study are included at the end of the chapter.

#### **4.2 Ethnography**

There are various definitions of ethnography in the literature. Hammersley and Atkinson (1995) interpret the term ethnography in a liberal way. They see the term as referring primarily to a particular method or set of methods. In its most characteristic form ethnography:

Involves the ethnographer participating, overtly or covertly, in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions – in fact collecting whatever data are available to throw light on the issues that are the focus of the research (Hammersley & Atkinson, 1995, p1).

The notion of culture is central to ethnography. Culture can be defined as the: “total way of life of a group, the learnt behaviour which is socially constructed and transmitted“ (Holloway & Wheeler, 1996, p82). Individuals in a culture or subculture hold common ideas acquired through learning from other members of the group (Holloway & Wheeler, 1996). No matter what the setting the general questions guiding ethnographic studies are the same: “What is it like to

be a member of a particular culture? What are the rules guiding social behaviour?” (Roper & Shapiro, 2000, p3).

Ethnography is one of the major and most established approaches to qualitative research in the social sciences (Hammersley & Atkinson, 1995). Traditionally, anthropologists have used ethnography as the prime technique in the study of culture (Leininger, 1985, p34). Historically, the anthropologist would live within the culture they studied. The work of Malinowski (1922) and Mead (1935) are repeatedly identified in the ethnographic literature as classic examples of the ethnographic technique. These anthropologists lived in New Guinea and other Pacific Island villages and described the cultural norms, gender characteristics and roles of the indigenous peoples. Once the study of primitive cultures became exhausted, researchers began to study the cultures within their own society (Holloway & Wheeler, 1996). Consequently, the advantages of the ethnographic approach have now extended beyond the traditional discipline of anthropology into the disciplines of sociology, education, medicine and nursing (De Laine, 1997).

There are two broad types of ethnographic method; descriptive and critical (Holloway & Wheeler, 1996). Descriptive or conventional ethnography focuses on the description of culture or groups and through analysis, uncovers patterns, typologies and categories. The above anthropological studies are examples of descriptive ethnographies.

Critical ethnography shares some characteristics with conventional ethnography such as qualitative interpretation, ethnographic methods and reliance on symbolic interaction. However, critical ethnography goes beyond description and representation of the subject in order to empower the subject's voice and use that knowledge for change (Thomas, 1993). Critical ethnography involves the study of macro-social factors such as power and examines common sense assumptions and hidden agendas. It is described as being more political than the conventional type of ethnography.

#### **4.2.1 Methods of data collection**

Ethnography is a research process of learning about people by learning from them (Roper & Shapiro, 2000). The ethnographer's task is to collect information from the emic or insider's perspective and to make sense of the data from an etic or outsider's perspective. Fetterman (1989) aptly describes the ethnographer as a human instrument. The researcher collects data by the process of fieldwork. Fieldwork is a form of enquiry in which "one is immersed personally in the ongoing social activities of some individual or group for the purposes of research" (Wolcott, 1995, p66). Ethnographic data collection involves observations, interviews and the review of documents (Holloway & Wheeler, 1996).

Participant observation combines involvement in the lives of the people under study while maintaining some professional distance that allows for adequate observation and recording of data. It involves looking at the activities within the field, listening to what and how things are said and asking questions to clarify why a particular thing was done or said. In the role of participant observer, the researcher must become explicitly aware of all that is involved in the situation and not take anything for granted (Spradley, 1980). While in the observation role, the researcher becomes one of the group being studied (Spradley, 1980). The level of participation the researcher chooses is dependent on the context and the purpose of the research (Pretzlik, 1994). All that is seen and experienced is kept as a record by the participant observer. This record usually takes the form of a field note diary.

Interviews are also an important method of data collection in ethnography. Interviews can take various forms from informal conversations to formal prearranged meetings (Baillie, 1995). Informal interviews involve talking with people in the field when they say or do something that requires clarification for the researcher. The formal interviews may be structured or unstructured, the format depending on the issues for clarification arising from the field observations. Interviews should supplement observational data (Holloway & Wheeler, 1996). There are two processes within the ethnographic interview:

rapport and eliciting information (Spradley, 1979). Interviews are conducted with informants. Informants are chosen by the researcher because of their knowledge, insight and willingness to talk about the culture being studied. The key informants should be identified prior to commencing fieldwork (Leininger, 1985).

There is some ambiguity in the observation method literature related to the concept of “insider” versus “outsider” researcher and the associated merits of each role. The “insider” or “native” researcher are terms commonly used to define the role of the researcher in studying his or her own group (Kanuha, 2000). Ethnographic methods are more commonly being used by researchers to understand their own social groups (Allen, 2004). Bonner and Tolhurst (2002) describe the observation roles utilised for their research in detail. Tolhurst, as a researcher, adopted the role of “outsider” to explore clinical teachers’ attitudes within the acute care setting of major hospitals, country hospitals and health centres. The researcher was an “outsider” in all cultures studied. In contrast, Bonner adopted the “insider” role of a nephrology nurse studying nephrology nursing. Bonner and Tolhurst (2002) identified a number of advantages to being an “insider” researcher. These include having a greater understanding of the culture being studied, not altering the flow of social interaction unnaturally and having an established relationship between the researcher and participants, which promotes story telling and the judging of truth. It could be argued that if a nurse were to study nursing then the setting would not be totally unfamiliar and consequently the nurse would never be totally an outsider.

The awareness of the dynamic interactions between the investigator and the research environment is called reflexivity (Brewer, 2000). As a researcher using the data collection technique of observation, it is important to remain reflexive. Reflexivity involves interpersonal processes that require the researcher to maintain an astute awareness of self along with the ability to critically examine and question self. The observer brings to the setting his/her



own biases and the interactions which are occurring will have particular significance (Brewer, 2000).

#### **4.2.2 Ethnography in nursing**

The ethnographic method has been used widely by nurses over the last decade. Within nursing, a more focused study of a particular problem within a set context may be studied using the ethnographic method. Nursing ethnographies are generally much quicker to complete than traditional anthropological studies. These types of nursing ethnographic studies have been called micro ethnographies, focused ethnographies and mini ethnographies (Leininger, 1985).

There are a number of studies that illustrate the use of ethnography in nursing. The method was used to examine the day-to-day lives of peri operative nurses in an Australian operating room (OR) setting (Bull & Fitzgerald, 2004). Pressure to identify alternative health care workers to replace registered nurses in the OR necessitated the identification of the functions of existing OR nurses. Observations and interviews conducted over a nine-month period focused on OR nurses' knowledge and actions. The findings were then used to construct strong arguments about the contribution of nurses' work to the overall functioning of the OR.

Ethnography was used to investigate the culture of health care workers engaged in the routine care of people with HIV and AIDS (Hodgson, 2001). The study was conducted in the infectious diseases unit of a large teaching hospital by an academic. The researcher describes the process of conducting the ethnography in detail highlighting the process of negotiating entry into the field and the role of an outsider researcher.

Ethnography was the method used to examine the illness experience of patients with congestive heart failure and their family members (Mahoney, 2001). This study was described as a focused ethnography conducted in three clinics where heart failure patients were reviewed. Interviews were conducted

in informants' homes. The findings were that patients with heart failure and their family members experienced a process of disruption, incoherence and reconciling. Reconciling emerged as the salient experience described by informants and was manifest as struggling, participating in partnerships, finding purpose and meaning in the illness experience and surrendering to the disease. The researcher suggests these findings highlight the processes that individuals experience "as they navigate through the burdensome condition" (Mahoney, 2001, p8).

Aswanden completed a doctoral study in 2002 that used the ethnographic method to research the culture in two English haemodialysis units (Aswanden, 2002). Observations and formal and informal interviews were used. The study aimed to determine themes that would help to provide a theory to assist in the understanding of the culture of dialysis units. The themes were survival, belonging-teams, them and us, leadership, communications and environment. From the themes, a theory of partnership emerged. These partnerships are forged between the patient and his/her diseased body, the patient and the machine as well as with other people such as the caregivers. The researcher contends that a greater understanding of the culture of the haemodialysis unit could improve patients' well-being. Through this concept of partnership there can be increased understanding about culture that could contribute to delivering improved patient care. While the purpose of the Aswanden research was to study the culture of haemodialysis units however, the findings are different to those presented in this thesis.

#### **4.2.3 Data analysis**

Ethnographic data can be analysed in a number of ways using several methods (Leininger, 1985, p57). The major task of the analysis is to organise data so that sense can be made of what has been learnt during the research experience. Roper and Shapiro (2000) have consolidated information from a number of sources into a simplified series of steps, which can be used in ethnographic data analysis. These steps are:

- Step 1. Coding field notes and interviews

The numerous words, which have been gathered in the field, are first grouped into meaningful segments by way of coding. Codes are descriptive labels assigned to segments of words, sentences or paragraphs that are examined individually and then grouped to reveal broader and more abstract categories.

- Step 2. Sorting and identifying patterns

This step involves breaking data down into smaller groups or sets. Patterns or connections between the information become apparent and themes develop. Outliers are cases or situations, which do not fit with the patterns of the rest of the data. Roper and Shapiro (2000) stress that these should not be discarded as they can be used to test the remaining data. Outliers may strengthen the analysis and offer information that may lead to a better understanding and explanation of the findings.

- Step 3. Generalising constructs and theories

At this stage, data can be sorted using a data matrix. A matrix provides a simple systematic way to compare and contrast data and assist in the identification of emerging patterns in the data.

- Step 4. Memoing to note personal reflections and insights

Memoing occurs throughout the process of data collection and analysis. Memos are the ideas or insights that the researcher has about the data and provide the basis for deep and meaningful understandings of data.

The four steps in data analysis do not occur in a linear order but move backward and forward between the activities of coding, memoing, sorting for patterns and generalising. Roper and Shapiro (2000) suggest that an analytical paper trail be kept so that the process behind the formulation of the final concepts can be explained to others.

Spradley (1980) also proposes four major steps in ethnographic data analysis. In a general sense, the field notes are searched to discover cultural patterns. The first step is the search for cultural domains, which are the basic units in every culture. The second step is taxonomic analysis, which is the search for the way cultural domains are organised. Component analysis is the third step and involves a search for the attributes of terms in each domain. Component

analysis is looking for the meaning that is given to cultural categories. The final analysis is termed theme analysis. Theme analysis involves looking for relationships among domains and how they are linked to the overall cultural scene. A cultural theme is “any principle recurrent in a number of domains, tacit or explicit and serving as a relationship among subsystems of cultural meaning” (Spradley, 1980, p.141).

#### **4.2.4 Why ethnography?**

The decision to use ethnography as the study method was based on the understanding that an exploration of the culture would lead to a better understanding of nursing care provision within the HHU. The literature reveals a limited understanding of the nursing care within in a HHU and of the relationships between the various members within this social world. Prior to commencing this study there were no descriptive ethnographies of the culture of haemodialysis units. As stated in this chapter in section 4.2.2, a study of the culture of haemodialysis units in England was published after this research had commenced (Aswanden, 2002). Furthermore, Leininger suggests “When one attempts to discover what is happening, how it is happening, and the meaning or interpretation of what is happening ethnography and ethnonursing methodologies are most valuable” (Leininger, 1985, p39). The production of knowledge in the study area is only the first step, on the basis of this knowledge, nursing practice will be changed. Additionally, the experience of being a participant researcher in the HHU will provide great contextual meaning to the ways in which the people in the HHU interact and communicate.

Within this section discussion on ethnography as a research method has been presented. The next section will provide information in relation to the study in the HHU.

### **4.3 Conducting the research**

Within this section information regarding the study in the HHU will be provided.

#### **4.3.1 Study aims**

The aims of the ethnography were to study the culture of the HHU to acquire a comprehensive understanding of how nursing care was conducted and to identify the structural and interpersonal enablers and barriers to the provision of patient centred care within the HHU. The study involved fieldwork observations, informal and formal staff and patient interviews as well as the review of related documents.

#### **4.3.2 The setting**

The study was conducted within the HHU of a major Australian teaching hospital during 2002 and 2003. The setting is discussed in detail in chapter five.

#### **4.3.3 Participants**

As the study employed the ethnographic method, all people attending activities within the HHU were participants in the study. The participants included nurses, patients, doctors, other health care workers, domestic and catering staff and patient carers and visitors. The focus of the research was the interactions between the nurses and patients, who were the major informants within the HHU. Some participants were chosen to interview formally and these nurses and patients are described within the interview section 4.4.3.

#### **4.3.4 Ethical considerations**

Successful ethics applications were submitted to the University of Technology, Sydney and the South East Health Human Research Ethics Committee, Southern Section. The ethics committees identified that individual participant consent for the observational fieldwork would be extremely problematic and disruptive to the study. Institutional consent was accepted by the ethics committees as all observations were to be included in the study. A study information letter was distributed to all staff and patients (see appendix B.1 and B.2). The letter advised participants of the general nature of the study. Intricate explanation of the aims of the study was not given as it may have led to a change in the culture of the unit. The study was also discussed at department

meetings in an effort to inform other health care workers. Through both forums, potential participants were told that if they did not wish to participate or if they felt uncomfortable with my presence on the HHU as an observer, they should discuss these issues with me. Individual written consent was obtained for the formal nurse and patient interviews. Copies of these consent forms are found at appendices B.3 and B.4.

As the researcher in this study I adopted the role of “insider”. This decision was made after investigating the positive advantages of the role and more importantly the need to study my own HHU. Both ethics committees highlighted the issue of the relationship between the participants and myself as the researcher for additional consideration. This will be discussed in the section 4.5 - issues arising from the research.

The anonymity of the participants was maintained throughout the study. Pseudonyms were used in field notes and in the thesis. Participants were not able to access the field notes, as it may have been possible to identify individuals. The field and interview notes were kept in a locked filing cabinet only accessible by the researcher. The findings of the research will be made available through publication and on request from both the staff and patients.

#### **4.4 Data collection**

Within this section the methods of data collection utilised in the study are presented.

##### **4.4.1 Observation**

Spradley (1980) proposes a number of types of participant observers. The important contrast is the degree of the observer’s involvement in the field. The first type is the active participant. As an active participant, I would be expected to take a patient load and provide direct patient care. I decided that the active participant observer role would not be appropriate. Intricate or subtle encounters would have been missed while trying to concentrate on care provision.

The next type of observer is the moderate participant. "Moderate participation occurs when the ethnographer seeks to maintain a balance between being an insider and an outsider, between participation and observation" (Spradley, 1980, p60). The moderate participant observer would equate with what is alternatively called a partially involved observer. The partially involved observer gets involved selectively (Pretzlik, 1994). The final type of observation role is non-participant observation where the researcher is not involved in the day-to-day activities of the culture and is only in the field as an observer. I chose the role of moderate participant observer for the fieldwork. I identified that the moderate observer role was similar to my usual work role as a CNC for the unit. Within this role, my presence would not be as confronting for the participants as that of a non-participant observer. It was important to promote as little disruption by my presence, allowing for the participants to display their routine behaviour within the setting.

I remained employed in the NCNC position throughout the study period. The fieldwork observation was undertaken in 2002 with the assistance of a College of Nursing Scholarship. The scholarship allowed me to take leave without pay for selected periods. Job relief was arranged to cover the times when the fieldwork observation was conducted, allowing me to go into the field without disruptions related to work issues.

#### **4.4.2 Fieldwork Schedule**

Fieldwork observation was carried out one day a week over nine months. The times when the fieldwork observation was performed rotated from week to week to allow for the observation of patients and staff on evenings and weekends. Changes in observation times were scheduled in order to determine whether practices varied with the time of day and week. Observations for each session focused on one nurse and the patients for whom s/he cared. The observation of different nurses helped to identify differences in the way nurses interact with the same patients and visa versa. It is usual for one nurse to be responsible for the connection to dialysis of at least three patients during a shift.

The following situations were observed:

- The patient being received, assessed and connected to the haemodialysis machine;
- The interactions of the nurse with the patients and others in the unit during the course of a shift;
- The interactions of the patient with the nurse and others during the course of their treatment;
- The disconnection of the patient from the machine and discharge/transfer from the unit.

The above situations were conducted over an average of five hours and this was the minimum time for each observation period in the field.

Data from the fieldwork observations were entered in a diary. Initial observations were of an exploratory nature. As the time in the field progressed the focus of inquiry became narrower and concentrated more on the finer details. Initially, the routine activities within the unit were described. Later the focus was on the relationships between the participants in the HHU. Data recorded included my own reflections on time spent in the field as well as detailed descriptions of pertinent or intriguing events.

The decision to cease further observations and leave the field was made when saturation occurred (Germain, 1993). The situations being observed began to repeat and little new information was being acquired. Enough data have been gathered to describe the problem convincingly and significantly.

#### **4.4.3 Interviews**

Data were collected from interviews throughout the study. Informal interviews were conducted with participants in the field while formal interviews were conducted privately with selected nurses and patients.

The informal interviews were the conversations with participants in the field. I guided the conversations to elicit information regarding situations, which were



observed in the field. When I required clarification during the observation period I asked the patient or nurse what meaning the encounter had for them. Constant questioning added to the validity of the data.

Formal interviews were conducted with participants toward the end of the observation period. The literature gives no guidance on the number of patients or nurses to interview. I decided that ten nurses and ten patients would provide a range of opinions representative of the collective groups. When conducting the patient interviews I found discrepancies in the information I was collecting between the younger and more elderly patients. I chose to increase the number of younger patients interviewed to gather a greater understanding of age related issues. This resulted in 12 patient interviews being conducted. Rapport had been established with informants before the interviews were conducted. The initial plan was for the interviews to be audio taped and later transcribed. The first nurse to be interviewed expressed concerns about "being taped" during interviews. This concern resulted in notes being taken by me for both the nurse and patient interviews.

### **Nurse interviews**

Ten nurses were formally interviewed over a four-week period. Nurse interviews were conducted in an area away from the unit. An attempt was made to interview nurses with varying levels of experience within nursing and the HHU setting. Interviews were semi-structured and were 30-40 minutes in duration. One nurse did not consent to be interviewed.

A list of core questions was used to keep the conversation focused. The interview questions are found in appendix C.1. The initial questions put to the nurses were demographic in nature. Six nurses were born in Australia and two were from non-English speaking backgrounds (NESB). The nurses' ages ranged from 21.5 years to 46 years, which reflects the age range in the HHU. The mean age was 31.8 years. The range of years spent in nursing was 2-16 with the average being 8.5 years. The range in experience within

haemodialysis nursing was 0.2 to 11 years with the average experience in haemodialysis nursing being 3.9 years (see Table 3.).

Table 3. Age in years, years since graduation and years of haemodialysis nursing experience for ten nurses interviewed.

N=10	Range	Mean
Age in years	21.5 - 46	31.8
Years since graduation	2 - 16	8.5
Years experience in haemodialysis nursing	0.2 - 11	3.9

Four nurses had worked in other haemodialysis facilities. Seven of the nurses interviewed were working full time and three nurses worked part time. Four nurses had a post graduate qualification in nephrology nursing at certificate level. The certificate is conducted through a university and often involves clinical placement in a specialty setting. One nurse had studied midwifery.

During interview, the nurses were asked the question, “what attracted you to choose haemodialysis nursing?” This question was asked to gain an understanding of the reason why the nurse had become a haemodialysis nurse and to uncover any consistencies in the type of nurse that would be attracted to the HHU.

The second group of questions were focused on what the nurse thought it would be like to be a patient requiring haemodialysis in the HHU. These questions were asked to ascertain the nurses’ knowledge of holistic patient issues and to identify whether the nurse had an appreciation of what the issues for a patient requiring haemodialysis might be. There was discussion around nursing practice and nurses were asked whether they felt their work was valued. These questions were asked to identify satisfaction with the job and the type of nursing care provided to patients in the HHU.

As the interview proceeded, questions focused on nursing care provision. Questions were asked to identify whether nurses felt that they provided technical or patient centred care. The topic of primary nursing and the appropriateness of this nursing model for the unit was also discussed. The interview concluded by asking the nurses if they would like to change anything about their practice and what would it be.

### **Patient interviews**

Patients to be approached for formal interviews were randomly selected from the fieldwork schedule. Patients were interviewed either in a single room or a private area during a haemodialysis treatment in order to avoid prolonging the stay in the unit. Patient interviews were undertaken over three-weeks following the observation period. An attempt was made to interview patients of all ages and with varying lengths of experience as a patient requiring haemodialysis. The interviews were semi-structured and lasted from 40 minutes to one hour. A summary of the interview questions is found in appendix C.2. All patients approached consented to be interviewed.

Six male and six female patients were interviewed. The patients ranged in age from 40 - 82 years. The mean age was 62.8 years. The time that patients had required dialysis ranged from 9 months to 9 years. The average time on dialysis was 39 months (3 years and 3 months). Three patients had performed peritoneal dialysis before commencing haemodialysis. Table 4 shows the age of the patients and the time on dialysis for each patient interviewed.

Table 4. Age and time on dialysis in months of all patients interviewed

N=12	Range	Mean
Age in years	40 - 82	62.8
Years on dialysis	0.9 - 9	3.3

Five patients were from NESBs. Two were Mediterranean born, two were Pacific Islanders and one was Asian born. Although the patients were from NESBs their command of English was determined by myself and research

supervisor as satisfactory to participate in the interviews without the assistance of an interpreter. A strong religious belief was reported by all patients interviewed. All patients were well supported by friends and/or family. Table 5 shows the patient's primary support networks in place.

Table 5. Supportive relationships for patients.

Supported by	frequency
Wife	4
Husband	3
Children	2
Young grandson	1
Wife and nursing staff	1
Sister	1

The interview questions were selected to gain a deeper understanding of a patient's experiences within the HHU. Patients were asked questions about what is it like to be a patient on haemodialysis and about their physical, social and psychological symptoms and limitations. Patients were also asked what keeps them coming to the HHU for treatments and whether they understood the consequences of non attendance or withdrawal from dialysis. The nursing care and primary care model utilised within the unit were discussed. Patients were asked if they knew who their primary nurse was and what that role might be. The interview concluded by asking the patient what s/he would change about the nursing care received in the unit.

#### **4.4.4 Documents**

A number of documents were reviewed in the process of data collection. These documents included patient notes and charts, policy and procedure manuals and entries in the unit's communication book and diary. The nurses' work roster and patient schedule were reviewed each field day to ascertain the day to day work level of the unit. Historical data related to the unit's background were gleaned from annual departmental reports and minutes from meetings. Various patient education pamphlets were also reviewed.

#### **4.5 Issues arising from the research**

The very nature of the research question brought forth a number of ethical concerns. I had already identified that I may be perceived by the nurses as not regarding the nursing care of patients in the haemodialysis unit as optimal. In turn, this may have caused some animosity amongst the staff as to the true reason for the research. It was important to establish trust between the participants and myself. Fetterman (1989) suggests that trust can be achieved by being honest and professional in the way the fieldwork is approached. The concerns of the informants must be kept as the highest priority. Consequently, I endeavoured to be honest and open when discussing issues related to the research.

As part of the work role of NCNC, I constantly visit the HHU coordinating patient care and educating staff. This role changed significantly when the observer role was adopted. It was important for my presence to cause minimal disruption, allowing the participants to display their routine behaviours within the setting. The issue of role change from NCNC to researcher was addressed by the following strategies. Information sheets outlining the change in role and its significance were circulated and discussed with staff and patients. During the fieldwork periods, I dressed differently and wore an identification nametag, which said "researcher". The fact that the fieldwork observation was done during leave from the NCNC role also helped to gain support for the different role. Another nurse covered the NCNC role during this time and she was freely available to answer any questions regarding the day to day NCNC work.

The role of NCNC as researcher was accepted and facilitated by the nurses and was most evident during the period that patient interviews were being conducted. I took leave for a three-week period and attended the unit daily to conduct patient interviews. If a request was made to place a particular patient in a private area, the nurses ensured that this happened and the patient would be connected to the machine early to be ready for the interview. One day the demand on the HHU was so great that it was not possible for the nurses to place a patient in a private area. I was telephoned at home and advised that

interviews would not be possible. This avoided the inconvenience of attending the HHU unnecessarily. The nurses did not interrupt me while interviews were being conducted. Routine patient care and machine activities were left until the interviews were complete. These examples indicated that the nurses supported the research.

The issue of support for the research and role of the NCNC as researcher was also reinforced while conducting staff interviews. Two of the nurses who had not yet been approached for interview asked if they had missed out and was there any way they could be interviewed. The nurses were assured that they would be interviewed as part of the study.

I had assumed that the research role would be adopted and maintained constantly throughout the course of the fieldwork period. I had identified that at times when the unit was short staffed the observer role may be challenged. On one occasion during the final phase of the fieldwork, the observation period coincided with a time when there was excessive nurse sick leave in the HHU. This had not been established before I presented to the HHU at 0700. After discussion with senior management, it was decided that I should leave the field. My offer of assistance for the shift would jeopardise both the research and employment conditions, as I was on leave without pay from the NCNC position at the time. Adequate staffing was established during the course of the morning and the observation day was rescheduled. There were instances during observation periods when the workload of the HHU was very demanding due to high patient acuity or nursing shortages. During these times, I would assist only in situations where patient care would be compromised.

Before entering the field I had identified that if at any time an emergency arose I would need to relinquish the observer role and assist in necessary medical interventions. During the observation period, I assisted in the resuscitation of a patient who had experienced hypotension during a haemodialysis session. I stopped assisting when adequate staff were available to manage the situation. On another occasion, I administered pain relief to a patient with significant

headache symptoms who had been waiting for analgesia for an extended period. At the time there was an acutely sick patient demanding the attention of all the nurses in the HHU.

I had also identified before commencing the study that if a situation arose where I witnessed a nurse providing unsafe nursing care, intervention in front of the patient would only occur if the patient's safety was compromised. Whilst in the role of observer, I did not witness a nurse providing unsafe nursing care. However, I did observe nurses providing what I considered to be inappropriate nursing care based on my own beliefs that nursing care should be patient centred.

#### **4.6 Data analysis**

The method of analysis for this study has used components from both analytical processes proposed by Spradley (1980), and Roper and Shapiro (2000). Johnson (1995) suggests that attempts to be too logical in recording the development of a concept from its database brings the researcher back to the positivist way of thinking which is not in keeping with the analysis of ethnographic data. Analysis of the data began as data were being collected in the field. At the completion of each day in the field, the field notes were reviewed for significant events and memoing was attended. Memoing involved commenting on outstanding events and identifying prompts for questioning to clarify observation findings.

Further analysis of the data involved searching the data to identify the basic units and patterns using domain analysis (Spradley, 1980). Domain analysis of people found in the HHU reveals the categories of people who were present during the observations. Table 6 presents the people in the HHU and will be used as an example to guide the reader in the way data were analysed.

Table 6 Domain analysis of people in the HHU

Included term	Semantic relationship	Cover term
Patient	is a type of	person in the HHU
Nurse		
Doctor		
Carer		
Visitor		
Orderly		
Dietician		
Catering staff		
Social worker		
Biomedical engineer		

To perform domain analysis I constructed a worksheet. The worksheet was ruled and had three headings: cover term, included term and semantic relationship. Using the example of the people in the HHU the cover term is the name for the cultural domain – people in the HHU. The included terms are the names for all the smaller categories inside the domain such as nurses, patients and doctors. The third heading is the semantic relationship. The semantic relationship forms the link between the two categories. For example a patient is a type of person in the HHU.

This analysis became the basic method for analysing the domains and cultural themes. The result chapters for the study are presented as a narrative. The full domain analysis work sheets can be found in appendix D.

#### 4.7 Rigour

Qualitative research is often criticised for lacking the scientific rigour seen in the positivist methods traditionally used in biomedical research (Appleton, 1995). The reason for this criticism is that quantitative research is evaluated using the criteria of validity, reliability and generalisability and these criteria cannot be readily transferred to the evaluation of qualitative research studies (Tobin & Begley, 2004). More recently, goodness and trustworthiness have been used to evaluate the robustness or rigour of qualitative inquiry (Tobin & Begley, 2004).



Guba and Lincoln's (1981) factors of truth value, applicability, consistency and neutrality have been identified by Sandelowski (1986) as being appropriate for evaluating qualitative nursing studies. These criteria were chosen to substantiate the trustworthiness of this research because they have been cited as useful in determining rigour in a number of qualitative nursing studies (Bailey, 1997; Appleton, 1995; Beck, 1993). I will discuss each criterion and the strategies I used to establish them within the study.

### **Truth value**

Credibility is the proposed criterion in which the truth value of qualitative research is judged (Guba & Lincoln 1981). The credibility of the study is the extent to which data are a true reflection of the participant's understanding of the situation under study. Sandelowski (1986) suggests that the credibility of qualitative research can be enhanced through a range of strategies. These strategies include:

1. Triangulating across data sources and data collection procedures to determine the congruence of findings among them;
2. Checking for the representativeness of data as a whole and of coding categories and examples used to reduce and present data;
3. Checking that descriptions, explanations or theories about data contain the typical and atypical elements of data;
4. Trying to discount or disprove a conclusion drawn about these data;
5. Obtaining validation from the subjects themselves;
6. Prolonged contact with subjects and;
7. Independent analysis of data by another researcher.

These strategies also ensure the applicability or fittingness of a qualitative study and some will be addressed under that section. To ensure the credibility of the study I used a number of strategies.

The first strategy was the use of multiple methods of data collection. Patient and nurse interviews provided congruence for the findings from the observational data. Additionally comprehensive field notes were kept during the observations. Within the field note diary, I documented actions and events

as well as interactions. I also documented memos and personal reflections within the same field note diary. Transcripts of some of the observations and interviews were provided throughout the results sections of the thesis.

Secondly, the effects of my presence in the HHU as a researcher rather than the CNC needed to be considered. I identified that my presence may potentially alter the context and data collected. Initially, the nurses were uneasy with my research role especially the intentional observation of their nursing activities. Some of the nurses would joke and comment, “I hope you are not going to watch me” and s/he would then avoid being observed by leaving the room when I entered. This issue was raised on a personal level with each nurse where I provided reassurances about the purpose of the observations. The trust of each nurse was established because they returned to their usual practices and did not seem to react to my presence. The nurses openly engaged in discussion regarding their nursing practice and consistently answered questions regarding my observations of their practice.

As discussed in chapter one, I have over 20 years' experience in various nephrology settings. During this time, I have evolved my own ideas about the optimal practice of haemodialysis nursing, in particular the philosophy that care should be holistic and patient centred. To overcome the situation where I had known biases I utilised a number of strategies. I had to remain reflexive and constantly question the participants as to meanings they assign to the same encounters I was observing. At the start of the fieldwork, this process was difficult but became easier as more time was spent in the field. To assist in ensuring that I did not impose any of my own views onto the data analysis I met regularly with my supervisor during the data collection and analysis phases of the study. I needed confirmation that what I was interpreting was not my own views. The constant questioning and clarification with informants also assisted this process.

The data collection aspect of the study was conducted over a year. This allowed me to have prolonged contact with the participants another strategy for achieving truth value within qualitative research methods.

### **Applicability**

Applicability or fittingness considers the extent to which data are relevant to a number of contexts. Ethnography is a study of culture. In this instance a study of culture within a haemodialysis unit within the participating hospital. I considered that applicability was a difficult criterion to address. As discussed in section 1.4 there has been little study of the culture of hospital haemodialysis units and no published ethnographies within Australia to discuss the study findings. I regularly presented and discussed my findings with senior renal nursing colleagues from other haemodialysis units. Some of the major themes identified in the research were confirmed as major issues experienced by colleagues in other haemodialysis units both in Australia and internationally. In addition, Sandelowski (1986) suggests the strategies addressed under the heading of truth value are also useful strategies for achieving fittingness in qualitative research.

### **Consistency**

Consistency or auditability addresses the extent to which the researcher has made his/her actions clear within the research report. The inclusion of a clear audit trail or decision tree assists other investigators and readers follow the decisions made by the researcher at each stage of data analysis. To ensure that the decision trail was as clear as possible I have documented clearly throughout the thesis descriptions and explanations for the development and progress of the steps in the research study from the inception of the idea, the development of study aims and the collection and analysis of data.

To assist in making the decision trail as transparent as possible I firstly kept comprehensive observational notes within a field note diary. The raw data from the field note diary were identified by date and shift time. Each page was ruled into two columns. Within the first column, I would document any actions and

interactions, I observed and note the approximate time at which they occurred. In the second column I would identify questions from the initial notations that needed clarification. These memos alerted me to the need to discuss what I had documented with the informants and my supervisor. Each field note entry was documented in sequential order throughout the diary.

Interview transcripts were kept in two note books, one for patients and one for nurses. Each interview was dated and numbered. For example the first nurse interview was N1.

The third audit trail strategy was related to data reduction and analysis. Coloured pens were used for coding throughout the field note diary and interview note books. The colour coding became the way to identify categories for the domain analysis. Data reconstruction and synthesis involved transferring data to large poster size paper sheets. Here relationships between the categories were demonstrated in concept maps and the cultural themes identified.

### **Neutrality**

Neutrality or confirmability addresses the issue of whether the data as presented are recognisable by research participants as their own views. Sandelowski (1986) suggests that confirmability has been achieved when the strategies addressed in truth value, auditability and applicability are established.

Towards the end of the study I commenced practice development work with the nurses in the HHU. I conducted focus groups as part of this process. The major study themes were discussed and were identified as a true reflection of the nurses' experiences and perceptions about the provision of nursing care within the HHU.

#### **4.8 Chapter summary**

Within this chapter information related to the research method and the conduct of the ethnographic study have been provided. Ethnography was identified as the most appropriate approach to the study. Data collection methods and data analysis techniques common to ethnography have been described. Ethnography as a research method in nursing is becoming more common and some examples of the way nurses have used ethnography have been provided.

Participant observation is the mainstay to any cultural investigation and was used as the major form of data collection for this study. Additionally, formal interviews with nurses and patients and the examination of documents were conducted. An eclectic approach to data analysis that draws on aspects of a number of authors in the ethnographic method was utilised. Strategies to ensure the rigour of the research have been addressed.

The next three chapters report the results of data analysis of the observations, interviews and the review of relevant documents. Excerpts of data from all sources will be intermingled throughout. Chapter five is predominantly descriptive and provides the reader with a surface understanding of the layout of the HHU, people in the HHU and the activities they attend. Chapter six focuses on the behaviours and the relationships formed between the people within the HHU and Chapter seven presents the themes that emerged from these data.

## **CHAPTER FIVE – ETHNOGRAPHY RESULTS**

### **A BROAD OVERVIEW**

#### **5.1 Introduction**

Chapter five is the first of three chapters detailing the results of data analysis. The components of the analysis addressed in the chapter are predominantly descriptive. It provides a broad overview of the context in which the study was undertaken and becomes the foundation for the subsequent results chapters. Data have been obtained from HHU documentation, participant observations and interviews. A glossary of terms is provided in volume two and will assist the reader in understanding some of the terms used in this and subsequent chapters.

The discussion in this chapter starts with a brief historical account of the establishment of the HHU. The discussion traces the renal service from its inception and highlights the major events leading to the genesis of the HHU. The history of the HHU has been included in this chapter to highlight the way the HHU has evolved rapidly over time. A comprehensive description of the environment and physical layout is also presented. This is vital to any cultural investigation as environmental factors help shape the social world of the setting being examined.

The HHU has developed around the need for people to receive haemodialysis treatments. Consequently, the haemodialysis machine is an integral feature of the HHU. The machine components and general operating principles are briefly described and a diagram of the haemodialysis machine has been included. As the number of patients requiring haemodialysis treatments must be programmed to correspond with available machines, the dialysis schedule is used to organise the dialysis sessions. A discussion focusing on the schedule highlights the complexity of planning and maintaining the schedule especially in times of increased demand.

People who visit or work within the HHU are integral to the HHU social world. The people within the HHU include patients, nurses, doctors, other health care workers, catering and cleaning staff and patient visitors. An overview of the people and their roles and activities is provided. Domain analysis described in Chapter four, section 4.6 has been used for the analysis and the results are provided in the form of a narrative report. Full domain analysis is provided in Appendix D.

## **5.2 Historical development of the HHU**

A review of historical documents and personal correspondence with long term staff of the HHU has provided the following historical account of the genesis of the HHU. The HHU is located in a 500 bed teaching hospital in Sydney. Dialysis was introduced to the hospital in the late 1970s (Tranter & Gregory, 1993). Established dialysis services were available through other hospitals at that time but the new hospital service allowed for patients in the local community to receive treatments nearer to home. The renal service has constantly changed and evolved since its inception. Originally, the service consisted of the renal ward, incorporating six to seven in-patient beds and four haemodialysis machines. Peritoneal dialysis training for patients was introduced in the early 1980s. This gave patients an opportunity to attend to treatments at home, which until this time had only been a possibility for young, stable patients capable of performing home haemodialysis. A separate peritoneal dialysis unit was established adjacent to the hospital in 1994.

Initial development of the haemodialysis service was incremental. More and more haemodialysis machines were purchased and put into service, either with hospital or with charitable funding. In 1992, the renal ward was moved from its cramped facilities to the new hospital ward block. There were approximately eight dialysis machines operating at this time. The move allowed the renal service to open more in-patient beds and buy much needed new dialysis equipment. Later that year a satellite cottage was commissioned to accommodate the growing number of patients requiring haemodialysis. The satellite cottage is not in the hospital grounds although it is situated within 100

metres of the main campus. The satellite cottage accommodates 10 haemodialysis out-patients per shift and operates two shifts a day for six days a week. This allows for a total of 40 patients. All out-patients who had previously received haemodialysis treatments in the renal ward were moved to the satellite cottage when it opened.

Access to the satellite cottage is limited as there are steps to the front door and patients in wheelchairs must enter from the rear. Space within the unit does not allow patients to be transported on stretchers or receive haemodialysis while in a bed. There is also no connection with the hospital emergency response system. If a patient presents as unwell or becomes ill during treatment at the satellite cottage an ambulance is called to take them to the hospital's emergency department.

In-patient haemodialysis treatments were still attended on the renal ward following the opening of the satellite cottage. Within a short period, the service had to expand to accommodate the increase in demand as well as the sicker, less mobile patients who were not able to access the satellite cottage. A section of the renal ward was closed to form the HHU, which over time has grown resulting in the closure of more in-patient beds. The HHU rapidly developed to the stage where it now provides dialysis for almost fifty patients per week. The provision of more dialysis spaces occurred as a consequence of trying to meet increasing demand. Attempting to meet the demand for services meant that there was little time to plan or vision the development and nursing staff had no opportunity to develop a philosophy or objectives to direct their work.

### **5.3 The HHU**

While the ethnographic study was being conducted the service consisted of the HHU and the satellite cottage. The study was only performed in the HHU. The HHU is situated on the west wing of the fourth floor in the main hospital ward block. The unit has 12 haemodialysis stations located in two four-bedded areas and four single rooms. These areas were in-patient areas with specifically

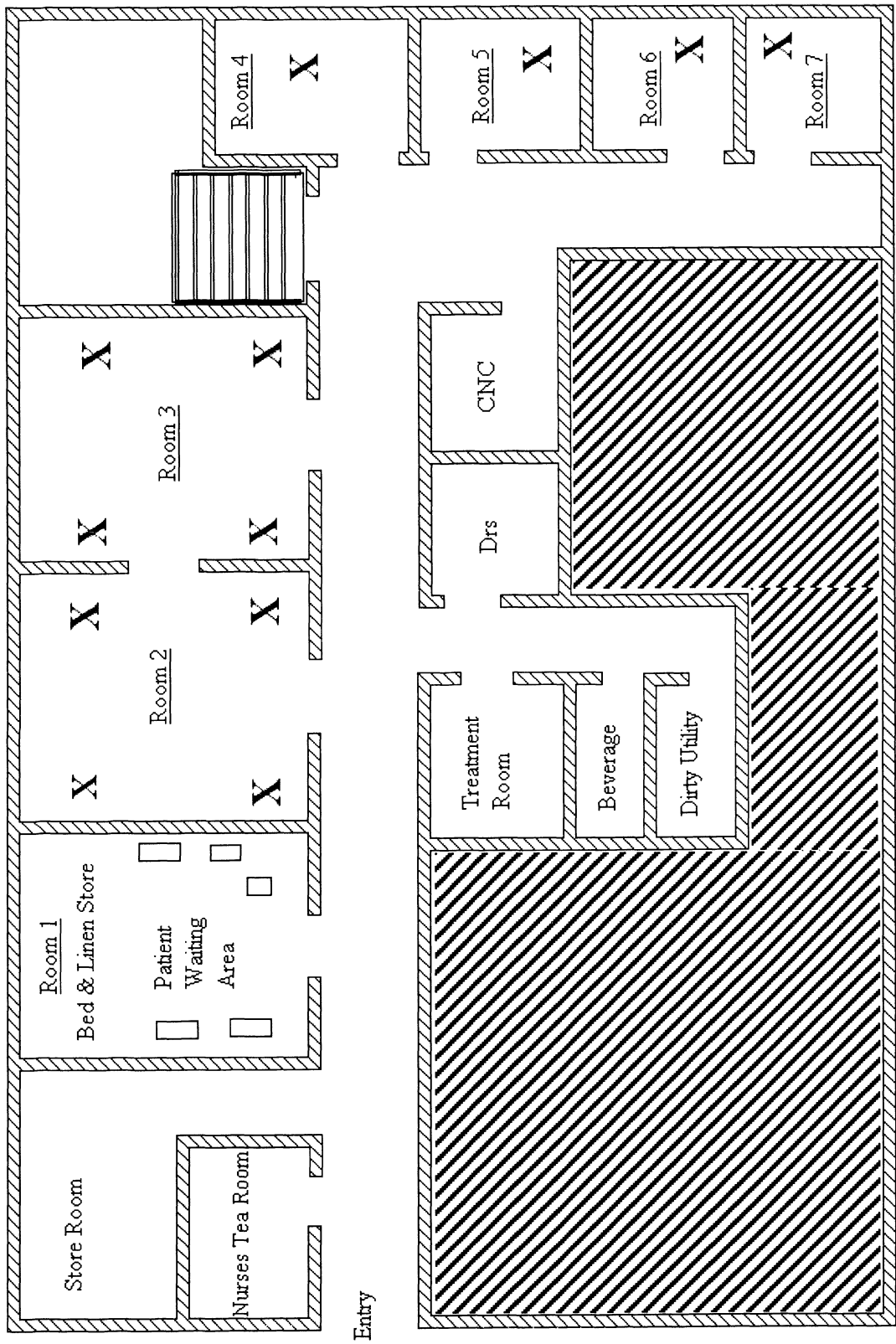


modified plumbing (water inlets and drains) to allow the haemodialysis machines to operate. Each area is identified by a room number.

Room one is the patients' waiting room, which is a multipurpose room housing the cleaning equipment, linen trolley, extra beds, machines and chairs. There are around six general-purpose chairs and a coffee table with a few magazines for the patients to read while they are waiting. Room two and three are four-bedded rooms and rooms four, five, six and seven are the four single rooms. Room three is the acute area where the unstable patients receive treatments and the main nurses' desk is situated. A doorway has been made in the wall between the two four-bedded rooms to allow easy access and patient supervision. Patients who require isolation due to infections with multiresistant staphylococcus aureus or who are more stable are treated in the single rooms where continuous surveillance is not possible. The space in the patient care areas of the HHU is adequate for the amount of machines. It would not be possible to add more machines within the existing space.

In addition to patient areas, there are offices for the nephrology clinical nurse consultant (NCNC) and the doctors, a dirty utility area and beverage and storage rooms. The nurses have "tea breaks" in a small room at the entrance to the HHU. The remaining areas on the west wing are concealed from view. Redevelopment work is being carried out that will result in an expanded unit, encompassing 34 haemodialysis stations. Figure 4 shows a floor plan setting out the location of the various rooms in the HHU.

Figure 4. Basic floor plan of the HHU.



#### **5.4 The haemodialysis machine**

There are 14 haemodialysis machines in the HHU. Two machines are left out of operation to cover for breakdowns and routine servicing. The purchase of machines for the HHU has been from the one manufacturer. Nurses become familiar with the one machine's operation and the biomedical technicians are able to keep one brand of parts to fix any machinery malfunctions.

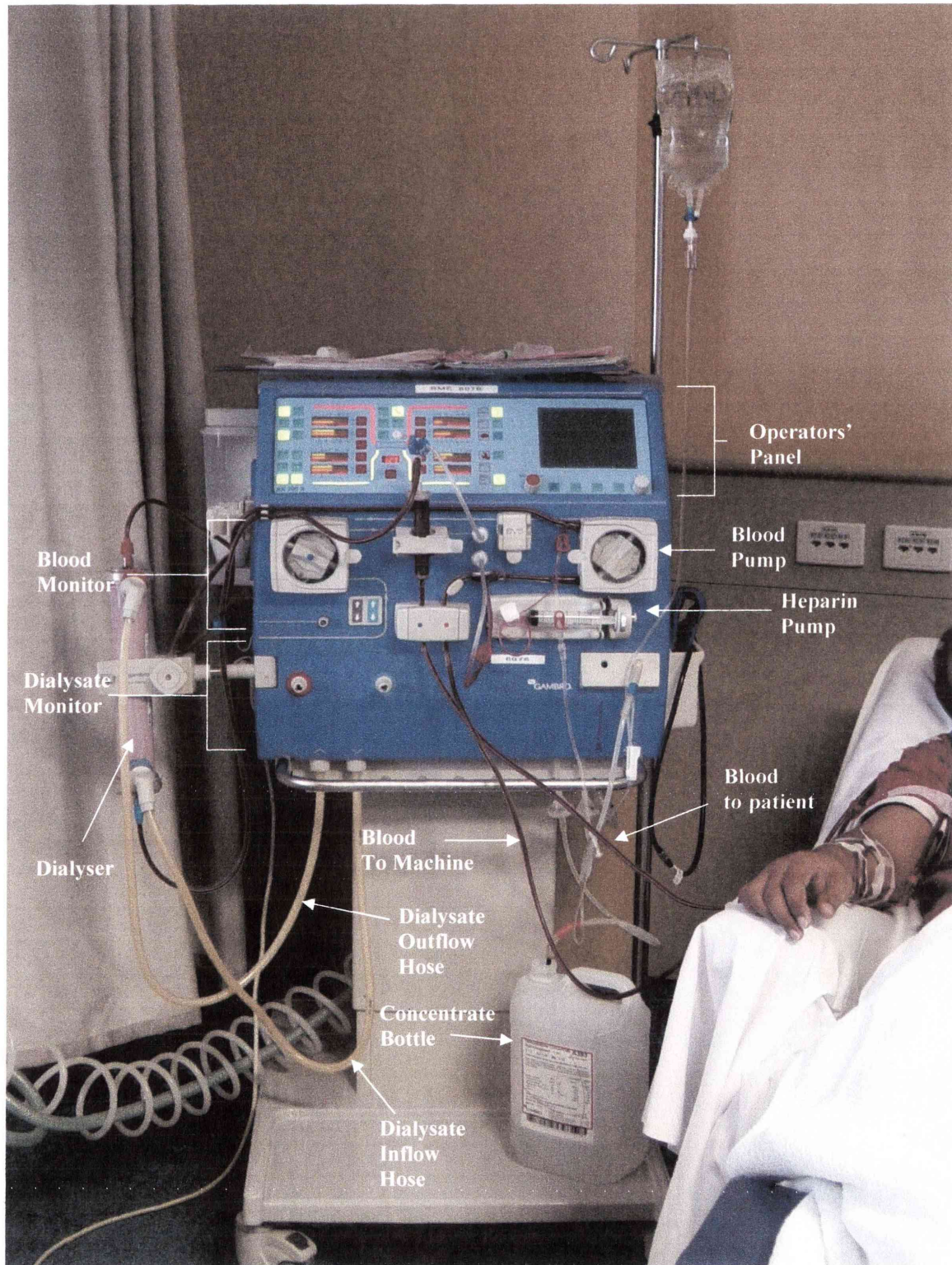
Haemodialysis utilises an artificial membrane, housed in a rigid walled cartridge called a dialyser. The haemodialysis process requires the removal of blood from the body. This blood is passed through the dialyser and then returned to the patient. Within the dialyser, the solute and electrolytes are filtered via the process of diffusion and pressure applied to the dialysis fluid (dialysate) enables the removal of extra fluid. A specially designed machine supports this process. Haemodialysis machines require electricity to function and the dialysis process relies on purified water. Water is processed firstly in a plant in the roof of the building and then the reverse osmosis filter housed with each machine processes it further. The machine discards the effluent down drains into the main hospital sewerage system.

Haemodialysis machines consist of two components: a blood monitor and a dialysate monitor. The design of the blood monitor allows the flow and monitoring of the patient's blood through the filter or dialyser and back into the patient. A blood pump housed on the blood monitor regulates the flow of blood from the patient. A heparin pump allows the infusion of heparin during the dialysis procedure thus averting the clotting of blood in the lines and dialyser.

The dialysate monitor delivers and monitors the dialysate. Dialysate is composed of purified water mixed with chemicals from a dialysate concentrate bottle. Dialysate delivered to the dialyser is monitored for temperature and chemical composition. The dialysate monitor checks the fluid from the dialyser for traces of blood and the volume of fluid (ultrafiltrate) removed from the patient. Figure 5 shows a haemodialysis machine with the major features labelled. Machine function is predominantly computerised. The machine

conducts a self-test when started to ensure that all components are in safe operating mode. Alarms are both visible and audible and alert the nurse if there is a problem within the blood or dialysate monitor.

Figure 5. A haemodialysis machine showing major features.



## **5.5 The haemodialysis schedule**

The activity of the HHU in general is influenced by a patient schedule. The schedule is a ruled A4 sheet of paper, providing the placement of 24 patients each day. The 24 positions on the schedule reflect the space and machine capacity of the HHU. The schedule is divided into six columns identifying the six days that the HHU operates. It is then divided horizontally into morning and afternoon sections. Each patient requires three, four to five hour haemodialysis treatments each week. The patient will attend the HHU on Monday, Wednesday and Friday mornings or afternoons or on Tuesday, Thursday and Saturday mornings or afternoons. Although there is an increase in demand, there is no more space within the unit to provide more dialysis treatments. The staffing is the only resource that can be manipulated to meet additional demands. If an extra dialysis session is required the staff will be required to work extra hours.

On Friday, the Clinical Co-ordinator transcribes the routine patients from the previous week onto the schedule for the following week. The patients may then be moved about on the schedule according to the level of patient acuity for the shift and special circumstances such as scheduling for surgery. Alterations to the schedule happen frequently and there are changes to the schedule on most days.

Any change in the schedule for any patient results in alterations at some other point. For example if a patient is unable to have dialysis because of surgery s/he will then take a position on another shift and someone from that shift will need to be organised into that patient's original position. If this cannot be organised it means that there will be two patients requiring the same machine at the same time. This is problematic and results in staff overtime or dialysis being "held off" for one of the patients until it can be rescheduled at the next convenient time.

Schedule changes are a significant problem for the nurses and patients in the HHU. If changes to the schedule are not accommodated easily it results in



overtime and disruptions to the nurses' personal lives. Patients are always inconvenienced by schedule changes. One patient will be asked to relinquish his or her usual position to accommodate another needy patient. Some of the patients oblige and seem to acknowledge that the change may have to be made on his/her behalf in the future. Other patients will resist the change and give reasons for not being able to accommodate the request. The most common reason for resisting a change to the patient's usual position on the schedule is lack of transport to the HHU. This situation is not easy to overcome and a patient who does not have transport problems is requested by the nurses to change positions more frequently.

## **5.6 The people in the HHU**

All people visiting or working in the HHU were participants in the study. The people entering the HHU during the study included patients, nurses, doctors, biomedical technicians, orderlies, catering and cleaning staff, the dietician, the social worker and patient visitors. The following is a descriptive analysis of the people in the HHU and their roles and activities. The full domain analysis for this section is found in Appendix D.1

### **5.6.1 The patients**

A review of the schedule revealed that there were forty-eight patients attending the unit on a regular basis, the majority in ESRF. The forty-eight patients attended three times per week and the average duration of a treatment is four to five hours.

I was able to identify different categories of patients when the data were analysed. The terms used to describe the patients are the titles the nurses used to describe the patients during observation or on interview. While these terms may seem a little confronting to those who are unfamiliar with the setting, the nurses did not use these titles when addressing the patients. The nurses address patients most commonly by their first name. If the patient was unfamiliar to the nurse they would be addressed by their surname eg Mrs

Brown. The nurses used the following titles in casual conversation and in handover to other nurses.

The first group of patients are the “acutes”. A small number of patients treated have acute renal failure. These patients are transient, in that the course of the disease is reversible; when renal function returns haemodialysis is no longer required. Nurses monitor the renal function of the acute patient closely to detect any return of renal function, indicating that dialysis can be ceased. “Acutes” may have dialysis treatments in the HHU or the nurses may need to attend the intensive care unit, coronary care unit or the high dependency unit to dialyse sicker patients. If a dialysis treatment is required in another unit, a nurse working a shift in the HHU or the “on call” nurse will attend to the dialysis treatment. This situation often leaves the HHU understaffed because the need is not predictable and extra staff are not rostered for this purpose.

The “chronics” are the long-term patients who have ESRF and attend the HHU three times a week. The “chronics” who are unstable during dialysis sessions or require additional nursing management are often called “acutes”. Consequently, the term “acute” is ambiguous and creates confusion at times.

“In-patients” are people who are hospitalised within one of the wards or units of the hospital. The Medical Specialties Ward is the designated renal ward for admission of “in-patients” requiring haemodialysis. The current medical or surgical needs of the patient will determine the most appropriate bed placement and results in a number of the patients being admitted to other specialty wards and units. “In-patients” often wait to be connected to the machine so that there is limited disruption for those patients who have come from home. The timing of the dialysis for “in-patients” is generally seen as flexible and “in-patients” can be moved from morning to afternoon positions on the schedule and vice-versa. The NCNC reviews the “in-patients” and liaises with the Clinical Co-ordinator regarding “in-patient” dialysis needs. “Out-patients” are patients who come for treatment from home or a residential care facility.

Patients who require shorter hours of treatment are the “four-hour” patients. Nurses refer to patients who require a longer treatment time as the “five-hour” patients. The “four-hour” patients wait while the nurses connect the “five-hour” patients, allowing for a more coordinated end to the dialysis session.

A number of factors determine the duration of dialysis. Patients who have been on dialysis for a long time often require more treatment time since they have little or no residual renal function. The body size of the patient may also determine the amount of dialysis required (Daugirdas, Blake, & Ing, 2001). The adequacy of the patient’s dialysis regimen is determined every six months by a test which estimates the amount of urea cleared from the plasma divided by the distribution volume (Kt/V) (Daugirdas et al., 2001). The determination of dialysis adequacy is complicated and it is beyond the scope of this work to explain in detail. In essence, Kt/V is an index for dialysis delivery and if the Kt/V result is not adequate, the treatment time may need to be increased.

The “easy” patients are those who the nurse has little difficulty cannulating the vascular access. The “hard” patients are the ones, whose vascular access is often difficult, requiring the expertise of a senior experienced nurse.

The “newies” are chronic patients who have been on dialysis no longer than two to three months. The “oldies” are the patients who have been on dialysis for at least two years, which is considered a long period. Nurses also refer to patients who are elderly as “oldies”. There is no set age but usually this term is used for patients who are 75 years or older. The mobility of the patient is also used by the nurses to identify someone as “an oldie”. The “youngans” are those patients who are less than 50 years old. I undertook a snapshot of the age of the patients six months into the observation period. The range in patient age at this time was 27 to 83 years. The mean age was 67.5 years. The mean age was skewed by one patient attending the unit for a short time who was 27 years old. Thirty patients (68%) were  $\geq 70$  years old. Four of these patients were  $\geq 80$  years. At this time there were 19 females sometimes referred to as “girls” and 25 males or “boys”. There is little discrimination from the nurses between the sexes and cultural background of the patients. The lack of



discrimination of different cultures may be due to the diverse cultures evident in the staff.

There are the “noncompliant” patients who will be discussed in more detail in chapter six. “Noncompliant” patients are those who do not adhere to the treatment regimen, especially the diet and fluid restrictions. There is no discussion around the “compliant” patient. The compliant patient is traditionally the patient who does adhere to the treatment regimen. The “compliant” patient is synonymous with the “good” patient. The “bad” patient has difficulty keeping to his/her haemodialysis schedule. “Bad” patients are often late or in some cases too early for dialysis and often ask for day or shift changes. These requests are considered by the nurses to threaten the timeliness of the schedule and are generally refused or ignored.

### **The roles and activities of patients**

The role of the patient is to attend the HHU to receive dialysis treatments. There is no documentation to state that patients have to do anything else and patients offer minimal assistance in the treatment process. Patients’ activities can be described in terms of their journey through the dialysis process. There are six stages in the trajectory of the patient through the dialysis process and these are “coming in”, “setting up”, “going on”, “being on the machine”, “coming off the machine” and “going home”. These stages will now be described in detail.

#### **“Coming in”**

The first stage in the dialysis process is “coming in”. The most significant component of “coming in” for haemodialysis involves the transport used to travel to the HHU. A small number of patients are able to come in unaided and drive their own car or take public transport. Parking is a problem for patients who drive to the HHU. Disabled parking is limited and street parking has a two-hour limit. If the patients use the hospital parking areas they are able to pay at a staff rate but this is expensive if utilised three times a week. Parking issues are a major reason why patients choose not to drive their cars to the hospital.

Some patients travel to the HHU with the assistance of a relative. The relative will drop the patient at the door of the hospital or escort the patient to the HHU. The relative does not stay in the HHU as the time limit for “drop off” parking is ten minutes.

Patients who have difficulty with transport can take the dialysis bus. The dialysis bus is a new service for patients. The bus was purchased jointly with money from fundraising activities and the NSW Government. The 12-seater bus has a driver from the hospital patient transport pool. The bus picks patients up from their homes and returns them after the haemodialysis session. The service operates for both the morning and afternoon patient shifts. Patients who catch the bus are asked to donate money to the running costs of the service. Most patients are satisfied with the service, but there is a degree of waiting due to the number of patients who use the service. Patients who are picked up from home first, will need to travel on the bus until the other patients have been collected. Sometimes this might take an hour. Patients who are picked up first are dropped off first on the return trip.

Although the dialysis bus service adds extra travelling time, the service is more reliable than the ambulance service. Before the inception of the bus some of the patients would wait up to four hours to be picked up by ambulance from the HHU to be taken home. There are still patients who use the ambulance service because they are too frail to step up or to sit in the bus. Patients who travel to the HHU on an ambulance stretcher are transferred to beds.

Patients who travel to the HHU via other means are asked to wait in the waiting room. Patients are required to wait in the waiting room until called for dialysis which may be an hour or longer.

### **“Setting up”**

“Setting up” is the next step and involves preparing the machine, connection trolley and the patient area, either a bed or a recliner chair. The machine is lined and primed and sterile supplies are opened in preparation for connection

to the machine. New linen is required as well as a new protective sheet (bluey). The bluey protects the patient's clothes and the linen from the antiseptic solution used during the connection procedure. There are a small number of patients or carers who assist with the "setting up" procedure. If the patient or carer is able to "set up" they are called earlier from the waiting room to start preparation.

### **"Going on"**

"Going on" is the next stage. The patient is called from the waiting room when the "setting up" is complete. The patient will stop at the weigh machine and check his or her weight. The patient or nurse will write the weight on the haemodialysis record chart. The patient will then sit in the chair or lie on the bed, and be connected to the machine by the nurse. As the "going on" stage is attended by the nurse, this stage will be discussed in detail in the nursing activities section.

### **"Being on the machine"**

The next stage is "being on the machine". During the time patients are "on the machine" they engage in individualised activities to "make the time go faster". This may be sleeping, watching television or reading. There is minimal talking between the patients which is due to a number of factors. The patient area is configured with a machine between each patient and the patients are often not able to see the patient next to them. The most stable patients are placed in the four single rooms where communication is difficult. Some of the patients sleep during the procedure and some are unwell and do not like to be disturbed. A number of the patients are from non English speaking backgrounds with a limited command of English. However, there is one group of patients, attending on the one session, who have overcome these problems. They chat and joke with each other during the treatment. They also assist the nurses by helping prepare stock. This involves separating the pre-packaged syringes and needles or ampoules of normal saline into individual units. There is no organised group diversional activity in place. Patients are able to eat and some may drink while on the machine.

“Being on the machine” may have no sensation for some patients but others may experience symptoms or complications. The most common complication during the observation period was hypotension. The patient may feel dizzy or light-headed, nauseous, vomit, suddenly feel tired or may “go flat”. To “go flat” means to become unrousable or unconscious. Hypotension during dialysis often leaves the patient feeling fatigued and with a headache after the treatment. Headache is also associated with excess fluid or waste removal. If patients are experiencing any discomfort, they alert a nurse or a fellow patient who will call out or press the “nurse call” for the sick patient.

### **“Coming off the machine”**

When it is time to “come off the machine” the patient is required to “hold off” the cannulation sites or “spots” for 10 to 15 minutes applying firm pressure with two fingers. When the needle sites have ceased bleeding, gauze and tape are applied. Blood pressure, pulse and temperature are recorded and, if these readings are within normal parameters, the patient may stand. The patient will have his/her weight recorded before leaving the unit. Patients who are able are responsible for discarding the used linen in the linen skip and wiping the exterior of the machine with cleaning solution. If the patient is unable to attend to this task the carer may do it or it is left for the nurses.

### **“Going home”**

“Going home” involves patients leaving the HHU or the treatment area and waiting in the waiting room for the renal bus, ambulance or relative to collect them. Some patients will sit in the waiting room for hours to be collected by the ambulance to go home. During the observation period a trial commenced where patients who need to wait for an ambulance were transferred to the Patient Discharge Unit (PDU). This means that the patients are able to wait in a comfortable chair, sleep or watch the television under the supervision of the PDU staff.

This section has summarised the categories of patients found in the HHU. Although the patients are the reason why the unit exists, the description of the

trajectory of the patient through the dialysis process establishes that the patients have little role in the unit. They are responsible for turning up for dialysis sessions.

### **5.6.2 The nurses**

Nurses had a major presence in the HHU during the fieldwork period and the way in which the nurses carried out their work became the focus of observations. Nurses attend the HHU in two shifts. The morning shift starts at 0700 and ends at 1530. The afternoon shift commences at 1300 and ends at 2130. During the study period there were minimal alterations to the nursing staff employed on the HHU. The categories of nurses and their roles and activities within the HHU are outlined in this section.

There are a number of position classifications for nurses working in the HHU. The Nursing Unit Manager (NUM) oversees the dialysis service. The dialysis service includes the satellite cottage, the Peritoneal Dialysis Unit and the HHU. The NUM's office is found in the Peritoneal Dialysis Unit, which is located, adjacent to the hospital and next to the satellite cottage. A registered nurse (RN), often a clinical nurse specialist (CNS), is responsible for the day-to-day co-ordination of clinical activities within the HHU and s/he reports directly to the NUM. This nurse is called the "In charge" or Clinical Co-ordinator.

The NCNC is responsible for the nursing management of patients with renal conditions throughout the hospital. I usually visit the unit regularly to discuss patient issues.

The HHU is staffed by RNs with varying levels of experience. There are 15 nurses, 13 full-time employees and two-part time employees. The age range of nurses working the HHU was 21.5 years to 46 years. The mean age of nurses was 29 years. This is an interesting finding in that in 1999 the average age of all employed nurses in NSW was 41.6 years (NSW Health, 2002). The nurses in the HHU represent a younger group of nurses compared with the general

nursing workforce. There are no data to compare this finding with other HHUs within the state or country.

The nurses in the HHU have a separate roster to the nurses in the satellite cottage. Sometimes nurses are relocated from one area to fill either a temporary or a permanent gap in the roster in the other area. Nurses studying in postgraduate specialty courses and nurses training in haemodialysis also rotate between the areas.

Five CNSs within the unit are the senior clinical nurses. They are RNs who hold postgraduate qualifications in nephrology nursing or have at least three years' experience in the area. The CNS is remunerated at a higher level than the RN but is also expected to have a greater role in nurse education, participation in research and quality activities and is s/he is also able to act in-charge. The other 10 RNs have clinical experience ranging from six months to 10 years in haemodialysis nursing. Some RNs are more experienced than CNSs but choose not to pursue CNS status due to the increased responsibilities.

There are other labels for nurses that are not linked to professional status but were identified in the data. These labels are linked to the duration of time in the HHU and experience in haemodialysis nursing. For example the "junior" is a nurse who has had limited experience within the HHU. The amount of time required to be considered experienced is relative. It has not been quantified and depends on how many senior staff are on the shift. The senior staff are those nurses who hold CNS status or who have been working in the HHU for a long period of time. Again it is difficult to determine the exact difference in years of experience. A "new grad" is a junior member of staff who is undertaking a placement in the HHU during his/her transitional post graduation year. "New grads" are placed for three months in the HHU but often remain as permanent members of staff after they complete the placement. The "new nurse" is a "new grad" or a nurse recently employed in the HHU. These nurses

are seen as inexperienced and their work must be supervised by more senior staff who will precept them in learning the haemodialysis process.

### **The roles and activities of nurses**

This section describes the nurses' roles and activities within the HHU. There is no uniformity across the job descriptions for nurses working in the HHU. There are specific position descriptions for the NUM, Clinical Co-ordinator and NCNC. There is also a job description for the RN but this is generic to the hospital. These job descriptions have been included at appendix E.

Activities of nurses have been classified into four categories commonly used in studies designed to describe nursing care activities (Urden & Roode, 1997; Mayer, 1992). These categories are; direct care, indirect care, unit management and personal activities. It is recognised that this is not the only way of organising the work but as previously stated these subgroups are commonly used and provide a simple classification to structure the analysis of the nurses' activities and interactions with patients.

#### **Direct care**

Direct care activities are activities performed in the presence of the patient and/or family and include assessing patient needs, administration of medicines, all treatments and procedures related to, obtaining specimens, and all aspects of basic physical care associated with bathing, grooming, eating, toileting and ambulation. Direct care activities include explanations and communication with patients and families for planning care, teaching, interviewing and evaluating (Urden & Roode, 1997). The direct care activities of the nurses are described in terms of the activities attended in the course of the trajectory of the patient through the haemodialysis process.

There is no patient allocation system in the HHU. Each nurse is free to choose the patients s/he will "put on" and these decisions are seldom discussed with other nurses on the shift. The nurse calls a patient from the waiting room and asks the patient for his/her weight or the nurse will supervise the weight

recording if assistance is required. When the patient is positioned in the chair or bed, the nurse takes and records the blood pressure, temperature and pulse.

There are two methods for “going on the machine” with the one used depending on the type of vascular access. Some patients will have a “vascath”, which is a specially designed central venous catheter. Aseptic technique is used to cleanse the catheter, remove the heparin lock, flush the lumens and connect the catheter to the machine lines. The vascath dressing is attended at least weekly but some patients require a dressing at each dialysis session.

The majority of patients have an arteriovenous (AV) fistula or AV graft. Access to the blood stream is via the placement of two needles into the vascular access. These two needles or cannulae allow the outflow and return from the machine. Cannulation is a skilful process and is seen by the nurses as the activity with the highest importance. A tourniquet is used to assist in the determination of appropriate cannula sites. The nurse wears a full-face shield, washes hands and dons sterile gloves. Antiseptic solution is used to clean the patient’s arm and local anaesthetic is drawn up and injected into the two sites. Two patients have a needle aversion or phobia. These patients apply anaesthetic cream before attending the HHU and no injection is then required. Following the local anaesthetic the cannulae are inserted.

Cannulae are especially designed for the purposes of haemodialysis. The needles are large bore (15 or 16g) and are winged to allow for control of insertion. Cannulation of a mature AV fistula is quite simple. However, often there are problems in inserting cannulae into immature, failing AV fistulae or deep grafts. Sometimes it is necessary to replace cannulae if there is a “bomb”. A “bomb” is where the needle has entered and exited the vessel resulting in poor flow and a haematoma. When the needles are satisfactorily placed they are flushed and well secured with tape.



The “arterial” cannula is the cannula placed closest to the AV fistula anastomosis site. The “arterial” cannula is used to draw blood from the patient. The “arterial” cannula is connected to the arterial bloodline and the pump is started. This begins the patient “going on to the machine”. The patient is “bled out” until most of the normal saline prime has been rinsed from the lines. The “venous” cannula is the cannula placed furthest away from the AV fistula anastomosis and is used as a return for the patient’s blood. The “venous” cannula is then connected to the venous bloodline. The patient is now “on the machine” and the machine settings are checked. The nurse will then call another patient from the waiting room.

The machines are checked hourly and during this time some patients may require additional care such as recording the blood pressure. An “acute” patient may require further monitoring such as that required for heparin free dialysis. This involves flushing the lines and dialyser with normal saline at 30 minute intervals to assess the degree of clotting in the system.

Hypotension was the most common problem associated with “being on the machine” during the observation period. If the patient “is flat” it becomes an emergency and can sometimes be mistaken for cardiac arrest. The treatment for hypotension is to lay the patient with their head down or as flat as possible (Trendelenburg position), stop the removal of fluid and infuse a bolus of normal saline until the blood pressure returns to a stable level, usually a systolic reading greater than 100mmHg. True emergencies such as a cardiac arrest are infrequent. Machine breakdowns occurred regularly during dialysis and system problems such as clotted lines and dialysers were common during the observation period.

While the patient is “on the machine” the nurse will perform various procedures. There are a number of patients with diabetes mellitus and the blood sugar round (BSL) occurs some time before the patients eat. The BSL is taken from the bloodline and not from a direct skin puncture. The dialysate is changed according to the reading. Patients may also be given insulin if the

level is high or persuaded to eat or drink if the level is low. The nurses also distribute patients' meals that are delivered to the HHU by the catering staff.

At some time during the dialysis session erythropoietin (ERT) injections will also be administered to the patients. These injections are given intravenously once a week. In addition to ERT the patient may require an iron infusion to enhance the response to ERT. A course of iron injections is usually weekly over a ten week period with a blood test to review levels. Iron is administered during the last hour of dialysis through the heparin pump.

Blood transfusions are also given during the haemodialysis process. Infusions are necessary for patients who have had an acute drop in their haemoglobin more commonly due to bleeding from any source. These patients tend to be the "acutes" who may have been to surgery. One unit of packed cells is given over an hour via an infusion pump. There are usually no additional observations taken while the patient receives the infusion, as is the policy for patients on the general wards. Some nurses do follow the policy of taking extra observations if time permits but they are usually the nurses who have recently worked in the wards.

The machine measures the dialysis time and it is easy to check the time remaining by glancing at the machine. The machine "alarms" when the haemodialysis treatment is complete and it is time to "come off". In order to "come off," the blood in the machine system is returned to the patient. If the patient has a vascath the procedure will again involve a sterile technique where the connections are cleansed, disconnected from the bloodlines and the vascath lumens are then flushed and a heparin lock and cap applied. If the patient has cannulae in situ these will be removed one at a time and the patient will "hold off" the cannulation sites. Sometimes a patient may have a vascular access with high pressure resulting in a prolonged "holding off" time. The patient may tire and request assistance from a nurse. "Holding off" can be tedious for the nurse. While s/he is "holding off" there are other patients who need to "come off the machine".

Gauze dressings are taped over the cannulation sites when the bleeding has stopped. The patient's blood pressure, temperature and pulse are taken and recorded. Patients are told to weigh themselves and if all recordings are within satisfactory parameters they may leave the HHU.

The other categories of care commonly identified under direct patient care are seldom performed. These include explanations and communication with patients and families for planning care, teaching, interviewing and evaluating. The focus of the direct care is the technical competence around the dialysis treatment. There is minimal communication between the nurse and patient around the psychosocial needs of the patient. The nurse assesses the patient prior to the dialysis but this is essentially an assessment that focuses on data required for the safe and effective operation of the dialysis machine. Patient education is also a major component of providing direct patient care. There were no interactions of an information giving nature observed. Information brochures are available on some of the common issues related to dialysis but these were not given out or explained to any patients.

### **Indirect care activities**

Indirect care activities are defined as all nursing care activities conducted away from the patient but on a specific patient's behalf, including communication with other providers, giving reports, seeking consultations, preparing equipment, gathering supplies and preparing medications (Urden & Roode, 1997). All activities associated with reviewing or evaluating a patient's condition and care, including the review of patient data and the action of documenting, have been included in this category.

"Setting up" the machines is an activity most commonly undertaken by the nurses. "Setting up" involves turning the machine on, connecting the dialysis concentrate bottle and bicarbonate (BiCart) solution, lining and priming the machine. The process takes about 20 minutes. The machine performs a self-check before it is safe to proceed with patient connection. A metal trolley or

bedside table is cleaned and set with a dressing pack and equipment required to connect the patient to the machine. "Setting up" also involves preparing the patient area as described in the patient activities. The nurse may check the patient's blood levels on the computer before commencing the dialysis treatment. This is more commonly undertaken for the "acute" patient.

The time the patients are expected to finish the treatment is written on a white board so that it is obvious to the nurses when "coming off" will commence and what the workload will be like at the time. Following the disconnection procedure, the nurse will remove the lines and other equipment from the machine. The machine then commences an internal cleaning mode making it ready for use with the next patient. The internal cleaning process rinses the dialysate from the machine and heats the machine to a temperature where disinfection occurs.

Primary nursing is the term used to identify the way the patients are managed on the HHU. Within the HHU, a number of patients are allocated one nurse as the primary nurse. The primary nurse is not responsible for the provision of the dialysis. Nurses believe the major role of the primary nurse is to provide indirect care. The primary nurse might only talk with the patient fortnightly and put the patient "on the machine" infrequently. Nurses do not necessarily put their primary patients "on the machine" if they are present in the unit at the same time as the patient.

The major function of the primary nurse was observed to be compiling a letter to the patient's nephrologist before each visit, usually every four to six weeks. The letter is on a standard template but the nurse is able to convey any specific patient issues directly to the nephrologist via this letter. The letter is often the only contact the nurse has with the nephrologist. In order to write this letter the nurse must look up the most recent blood tests. Blood tests may flag an issue for the attention of the nephrologist or indicate a change to the nursing care plan/dialysis prescription. The liaison role of the primary nurse is

important to monitor the dialysis and to communicate the progress of the dialysis and any associated problems to the nephrologist.

The nurses undertake other important indirect care activities. Nurses spend a lot of time obtaining prescriptions for patients and ensuring the doctors have written current orders for iron, ERT and other medicines. Nurses also organise appointments for patients, which are usually made on non-dialysis days to avoid clashes with the dialysis schedule. Nurses also arrange transport bookings for patients going to and from the hospital. If a patient requires a dressing or follow up by community nurses the HHU nurses will also make these arrangements.

Reports are written on all patients at the end of the dialysis session. Handover is conducted between the morning and afternoon shift. The morning nurses inform the Clinical Co-ordinator of any patient issues during the course of the morning. The Clinical Co-ordinator then informs the afternoon shift of these issues and any particular orders for patients on the afternoon shift.

### **Unit management activities**

Unit management related activities are concerned with the general maintenance of the unit. They are not patient specific and include such duties as clerical work, cleaning, ordering supplies, checking equipment, attending meetings and running errands (Urden & Roode, 1997).

Much time is spent making changes to the schedule and this is usually the role of the Clinical Co-ordinator or the in-charge nurse. Much of the HHU nurses' time is involved in the restocking of trolleys. The trolleys are used in the connection procedure by both morning and afternoon staff. When all the patients are on dialysis the trolleys are taken into the storeroom and restocked. There are five trolleys and this activity commonly takes half an hour to perform depending on the availability of stock and the number of times the nurse is required to respond to machine alarms. Another activity is the selection and placement of dialysis supplies for the patients on the next shift. The patients'

notes, dialyser, lines and related equipment are placed on or behind the machines ready for the next dialysis session.

There is no ward clerk on the HHU and the nurses are responsible for answering all phone calls. Nurses answer the telephone, which rings constantly. Carers phone to find out the time their relative will be ready to take home. Nurses from other wards phone to find out when a patient is due for dialysis and doctors ring with orders or changes to orders. Staff from the Emergency Department phone to inform the unit that a patient has presented and is unwell. The hospital's admissions department requires the times the patients present to and leave the unit and the HHU nurses telephone this information to the Admissions Department at the end of each shift.

The nurse is also required to run errands. Nurses take urgent specimens to the Pathology Department, collect blood products from the Blood Bank and drop prescriptions to the Pharmacy Department. The errands have to coincide with the times the unit is fully staffed. If half the nurses are on break it means that only two nurses are on the unit. To ensure patient safety the HHU must be staffed by two nurses at all times. If the staffing is limited, a hospital volunteer or orderly can be called to run the errand. Nurses are responsible for the daily checking of the resuscitation equipment and the Schedule Eight drugs.

The cleaning of machines is also a unit-based activity. All machines and chairs are cleaned between patients. Machines also require a special internal chemical cleaning routine each week, which the weekend staff perform. The beds are cleaned by the hospital cleaning staff. The cleaner is not allocated to the HHU and has to complete work in another part of the hospital before s/he cleans beds in the HHU. Sometimes the cleaner is not timely in doing so and the nurses clean the beds so that the next patient is not held up. This is not considered by the nurses as appropriate. Although it has been requested, there has been no increase in cleaning services to the unit as this involves a change to the cleaning contract with the hospital. The nurse is also involved in

routine cleaning activities such as keeping the pan room and treatment room tidy.

The safe operation of the haemodialysis machines relies on the provision of quality water and nurses take turns in checking the chloramine level in the water daily. The HHU is secured overnight and on Sundays when the unit is not operating. Nurses are responsible for locking the doors and delivering the keys to the After-Hours Senior Nurse Manager.

Nurses are involved in a number of unit related management activities such as restocking, organising equipment and running errands. Some nurse expressed concern that there are a number of activities they perform which could easily be given to support personnel. For example a clerical assistant could attend many of the administrative activities but there is no clerical support in the HHU. This would free up time for the RNs to attend more direct patient care activities.

### **Personal care activities**

Personal care activities are related to morning and afternoon breaks, meal breaks, personal phone calls and socialising with co-workers (Urden & Roode, 1997).

Coffee is prepared and consumed at the desk each morning and afternoon. Nurses gather at the desk and discuss the plans for the shift or personal activities they attended over the previous day. In the morning this is the time that the NUM receives handover from the Clinical Co-ordinator. When the morning coffee is consumed the nurses arrange the morning tea break. There are four nurses on the morning and afternoon shift. The Clinical Co-ordinator is included in this number as the position is not supernumerary. It is usual for nurses to leave the unit for 30 minutes, two nurses are required on the floor at all times so this usually allows two nurses to go on break together. The nurses are expected to return from break on time to allow the remaining nurses to break.

Lunchtime follows the “taking off” of all morning patients and the handover to the afternoon staff. If all patients are not “off the machine” lunch will be delayed or one nurse will elect to work through lunch and go home early to compensate. This practice occurs frequently and is seen as a good option by most nurses. Lunch is usually taken late because the handover does not finish until around 1400 hours. When the nurses return from lunch they write the patients’ notes. The evening break is taken early so that all staff are back on the unit before the patients start to “come off the machines”.

Personal telephone calls are made at the desk, as there is no telephone in the tearoom. During the morning shift these calls are usually minimal and short. Personal telephone calls on the afternoon shift are more common.

Some nurses are often late for the shift (approximately 5-10 minutes). The other nurses overlook this behaviour. The NUM is not present in the HHU at the start of the shift and this may be one reason why punctuality is not enforced. Another reason nurses are late to shift is that they are held up in traffic or dropping children to childcare. If the nurse is going to be more than 10 minutes late it is courtesy to notify the HHU and let the staff know. It is usual practice to go home on time from a morning shift. If a meeting or in-service education session is running the nurses will start to leave at 1530 hours. Alternatively the nurses not involved in the meeting will enter the room, collect their belongings, and say they are going. This will result in an abrupt end to the meeting because there are not enough nurses left in the unit to observe the patients.

It is usual practice to go home early from an afternoon shift. This at times is one hour early. The nurses feel that early closure is warranted. Afternoon break is kept to a minimum and the early closure to the shift is seen as time in lieu by the nurses.

“We work hard and deserve to get off early, all the patients are off so that is when we are off” (Field note 21/05/02).



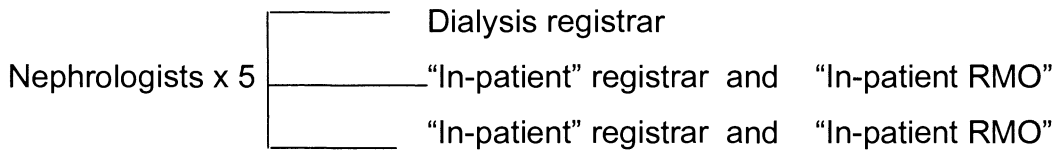
In essence, the roles and activities of the nurses revolve around monitoring the physical state of the patients related to their dialysis treatments. The nurses place emphasis on setting up, connecting and monitoring the patients on the machine. Nurses do not demonstrate a role in the monitoring of the other domains of the patient including their psychological, social and non-dialysis physical issues.

This section has summarised the categories of nurses and the roles and activities the nurses attend within the HHU. Another integral group within the HHU are the doctors. A description of the titles and the roles and activities of the doctors follows.

### **5.6.3 The doctors**

There are five senior doctors responsible for the management of patients with ESRF and other kidney disorders. These doctors have a number of titles but they all have the same meaning. The doctors are called nephrologists, physicians, consultants or kidney doctors. This group of doctors will here after be referred to as the nephrologists. The nephrologists only visit the in-patients while they are in the HHU if it is during ward rounds. Ward rounds vary depending on the usual schedule for the nephrologist. One nephrologist will visit the in-patients each afternoon and the remaining nephrologists will visit three times a week. The HHU out-patients are reviewed in clinics away from the HHU or in the nephrologists' private rooms. In addition to the nephrologists there are three registrars and two resident medical officers (RMO) (see figure 6). The doctors within the renal service are called the "renal team". Two registrars are allocated the in-patients admitted under the nephrologists, and one registrar (the dialysis registrar) is allocated to the out-patient clinics, peritoneal dialysis unit, satellite cottage and HHU.

Figure 6. Organisational chart for doctors (“renal team”) in the HHU



The “renal team” is based in the doctors’ office in the HHU. The doctors are rarely in the office because their duties are widely dispersed throughout the hospital. The in-patient registrars’ activities are most commonly carried out in other areas of the hospital and they are required to assist with some of the busier out-patient clinics. The in-patient registrars attend the HHU during the course of informal ward rounds with the RMO or formal ward rounds with the nephrologist. In-patient registrars may need to attend the HHU because of a telephone request by nursing staff. The in-patient registrars are required to assess the “sickies” and “acutes” before the commencement of dialysis and the most important component of the assessment is the patient’s volume status. Commonly it is necessary to commence the dialysis treatment before the patient has been assessed. The nurse will make a tentative judgment as to the amount of fluid loss required until the “renal team” has assessed the patient.

The dialysis registrar visits the HHU twice a day but the time varies from day to day. The dialysis registrar spends on average 30 minutes at a time on the unit. The dialysis registrar will assess out-patients if there has been a marked discrepancy in the patient’s established dry weight and a review is required. In addition, patients may need ongoing assessment related to vascular access function or symptoms during dialysis. The primary nurse calls the dialysis registrar to act on written orders from the nephrologist. The orders may include changes to medications, ordering of iron therapy or review by another medical team. Additionally, following the primary nurse’s surveillance of the recent blood tests, the dialysis registrar may be consulted regarding abnormal findings. Although the dialysis registrar is allocated the patients on the HHU s/he is also responsible for the patients on peritoneal dialysis, in the satellite

cottage and the out-patient clinics. This leaves minimal time to spend reviewing the patients in the HHU.

Other specialist doctors also visit the unit. The vascular surgeon is responsible for the creation of permanent vascular access. The “vascular team” is often called to review an access, which has failed or is repeatedly difficult to cannulate. Specialist doctors other than the “renal team” and “vascular team” rarely visit patients while on haemodialysis.

The general practitioner (GP) is the patient’s community doctor. The GP does not visit the HHU, but the patient will often bring a letter asking for assistance in a management issue. The haemodialysis nurses do not contact the GP but will refer on the problem to the dialysis registrar for review. Some patients have supportive GPs, while other patients do not have a designated GP. Some of the patients feel that the “renal team” should manage all of their health problems. A list of duties has been developed by the nephrologists in an effort to control the dialysis registrar’s workload. This allows the dialysis registrar to say, “No this is not my role” to the patients who seek assistance with non-dialysis related problems.

The lack of referral and correspondence between the nurses and GPs has been discussed in practice development meetings since the study and it is seen as an issue the nurses would like to change. The nurses are hesitant to contact the GP as often the GP indicates that the management of any issue regarding a patient on dialysis is beyond his/her expertise.

The doctors in the HHU place primary importance on the patient’s dialysis related problems. Arguably, this approach to patient management strengthens the reinforcement of similar behaviour in nurses.

#### **5.6.4 The other health care and hospital workers**

Other important participants observed during the study included the renal dietician and social worker, biomedical technicians and the orderlies. The

general hospital staff, including the catering and cleaning staff, were also observed. None of the staff mentioned above had a major presence in the HHU during the observation periods, consequently a brief overview of the role and activities of each follows.

**The renal dietician** has many years' experience in the specialty and she is only responsible for the patients who have renal and related disorders. The renal dietician has a job description and this is found in appendix E. The dietician provides dietary counselling, education and an individual nutrition plan. She also provides ongoing assessment and support to ensure that patients' nutritional needs are met. The dietician visits the unit on a daily basis to seek referrals and follow up patients with dietary issues. The dietician was observed to visit the unit most afternoons during the week. She sits at the computer and assesses the patients' latest blood chemistry and talks to the patients about their diet and any modifications that need to be made. The most common concerns the dietician addresses are fluid management and the ingestion of foods high in potassium or phosphate. The dietician also has a major role in the many clinics operated by the Department of Renal Medicine.

The Department of Renal Medicine has a dedicated **social worker** who provides care for patients admitted under the management of the nephrologists. Most new patients will be seen by the social worker to evaluate their social situation. The social worker will assess new patients' and carers' needs and provide support for adjustment to dialysis. The social worker visits the HHU when a referral has been made or when patient problems require follow up. These issues include changes to financial circumstances, accommodation or transportation concerns. The social worker also provides loss and grief counselling for staff, patients and carers. The social worker is also responsible for other duties related to the Social Work Department and a job description can be found at appendix E.

The dietician and social worker perform roles which in the past would have been considered part of nursing work. The two roles are supportive to the

nurses in the HHU but, due to the commitments of the allied staff in their other roles, patients sometimes wait extended periods for assistance. The nurses try to assist patients in urgent matters but sometimes allied health expertise is required. Since completion of the study another part time social worker and dietician have been employed.

The Biomedical Engineering Department employs a **biomedical technician** who is responsible for the maintenance of the haemodialysis machines. There have been a number of technicians in this role and the current technician is new to the service. A senior technician, experienced in the maintenance and repair of dialysis machines oversees the work of the less experienced technician. Both technicians were seen regularly during the observation period. Machine malfunctions occur frequently due to the sustained use and age of the machines. The increased usage has led to minimal down time for regular servicing.

If there is a machine malfunction the machine will “chuck a spanner”. This means there will be an audible alarm and a picture of a spanner will appear in the machine display. This alerts the nurse that the dialysis technician will need to be called to rectify the situation. The machine cannot be used and it will be withdrawn from service. Most machine faults occur before the patient is connected to the machine. If a fault occurs when the patient is “on the machine” the patient will be taken “off the machine” and the dialysis technician will be called urgently to rectify the situation. If this is done in a timely manner the dialysis can be resumed. If the problem cannot be easily rectified the nurses will need to prepare another machine so that the patient can complete the dialysis treatment.

If a machine requires extensive repairs it will be removed from the HHU. Sometimes there are delays to machine repairs if the technician needs to wait for parts to be delivered from the manufacturer. The dialysis technician is also responsible for the connection of the machine to the plumbing in outlying dialysis areas. After-hours the nurse will perform these connections.

**The orderlies** work within the Medical Division. They rotate between the wards and units of the division dependent upon the number of orderlies available and the acuity of the workload. Orderlies are called to the unit to assist with the transport of patients to and from the ward areas and the discharge unit. Rarely there is a need for the orderly to assist in the transfer or positioning of a sick patient. Orderlies are often delayed in responding to nursing requests. When asked by the nurses why they have not responded, the orderlies often state that they have been held up assisting with ward patients. This situation has been identified to Medical Division management. However, due to restricted funding and a shortage of orderlies, the situation persists. Nurses continue to work within the limitations of a lack of support staff. A job description for a medical orderly is found at appendix E.

The hospital employs private contractors for the catering service. **The catering staff** varies from day to day but three staff attended the unit on a regular basis. The three women who cater to the HHU have a minimal command of English. The catering staff bring a tea trolley to the HHU during the morning and again in the afternoon and rarely speak to the patients unless enquiring about what they would like to drink. The catering staff also provide light meals for patients. These meals are brought in the morning and early afternoon and left for the nursing staff to distribute to the patients during dialysis.

The hospital employs contract cleaners who are responsible for the cleaning of all areas. As the unit is occupied by patients from 0700 hours, **the cleaners** are responsible for the general cleaning of the unit between 0600 hours and the time the patients and staff arrive. A cleaner also attends the HHU to assist with cleaning and making the beds and emptying rubbish between patient shifts. The cleaner that attends in the afternoon is friendly and makes small talk with the staff and patients.

The **occupational therapists** and the **physiotherapists** rarely visit the HHU, as they are unable to provide treatments while patients are receiving

haemodialysis. During the observation period one physiotherapist attended the unit to find out information from an in-patient's notes.

**Pastoral care workers** rarely attend the unit and only if requested by the patient or family. There was no visit by pastoral care during the observational period.

In conclusion, other health care workers and hospital employees have a minimal presence on the HHU compared to the nurses. The biomedical engineer and medical orderlies are the most frequent visitors to the unit.

#### **5.6.5 The patients' visitors**

Patients' visitors to the unit include carers, spouses, siblings and children. There were few non-family visitors to the HHU during the observation period. When some of the patients were asked why this might be they suggested that the presence of complicated looking medical equipment and patient blood circulating on the machine would make the environment threatening to some "would-be" visitors, especially children. It was also suggested that nurses and patients do not openly welcome visitors to the HHU. This will be discussed later in more detail.

There is no particular role for visitors and carers. The visitors and carers do not adhere to hospital visiting times, as their major activity is to transport patients to and from the HHU. The relatives often telephone the HHU staff to find out the time that the patient will be "off the machine" and ready to go home.

Relatives of two patients accompany them for the entire time they are on dialysis. These relatives also assist the nurses by setting up the machines and connection trolleys. They will sit next to the patient or relax in the waiting room until the treatment is complete and then help clean the machine and patient area. These relatives say the reason they stay is that they have to travel a long distance to the hospital. They do not stay as company for the patient. Carers seem to prefer spending time doing personal activities or shopping or

housework while the patients are having treatment. This is understandable as the carer has the fulltime job of caring for the patient for 24 hours and the time the patient spends in the HHU is seen as free time for the carer.

## **5.7 Chapter summary**

The HHU has developed around the need for a steadily increasing number of people to receive haemodialysis treatments. In order to control and plan for this work, the patient schedule must be constantly reviewed and updated. Schedule changes are a significant problem and result in inconvenience for staff and patients. There are limited staff and spaces available in the HHU and the issue of finding enough positions to treat the patients becomes problematic. The HHU was undergoing structural redevelopment during the study period to increase space in order to provide more dialysis treatments.

The people who work or visit the HHU include patients, nurses, doctors, other health care workers, catering and cleaning staff and patients' visitors and carers. This chapter has described these people in detail and examined the roles and activities they perform. Essentially, the patients have a passive role presenting for dialysis only and contributing very little to the treatment process. The provision of the dialysis is in the hands of the nurse and a large amount of time is spent collecting equipment, preparing machines and connecting and disconnecting patients from the machine. Other indirect patient care activities include the surveillance of the patient's blood results and written correspondence with the nephrologist. There is little opportunity for talking and care planning with patients. Many of the indirect and unit management activities the nurses perform could be attended by assistive personnel but these are not available in the HHU.

A doctor is allocated to the HHU but due to a busy work load s/he is often unable to attend the unit in a timely manner. Additionally, the nephrologists are rarely present on the unit. The lack of timely medical support is seen by nurses as a tension between the nurses and doctors and this will be discussed further in the next chapter. Other health care workers and hospital staff have a minor



role and the major activities they undertake have been outlined. Carers visit the unit primarily to transport patients for dialysis.

This descriptive chapter has provided an overview of the HHU. It provides a context for further results focusing on the interactions and relationships of the people in the HHU. Chapter six will examine the relationships of the people in the HHU.

## CHAPTER SIX – ETHNOGRAPHY RESULTS

### RELATIONSHIPS IN THE HHU

#### 6.1 Introduction

In the previous chapter, the key characteristics of the HHU were identified. Nurses clearly had dominant roles in the work of the HHU. Nurses are the only health care workers who do not visit the unit. Nurses are the health care workers who are constantly present in the unit and the activities the nurses attend are integral to the functioning of the HHU. Nurses are the fulcrum to the process of dialysis and the activities of the HHU are finely balanced on their management of the patients.

Chapter six presents an analysis of the relationships between the nurses and the other people in the HHU. Relationships between the nurses and patients, nurses and their colleagues, nurses and doctors and nurses and carers/visitors will be discussed. Relationships between nurses and other health care workers are not included as other health care workers did not have a large presence within the HHU at the time of the observations and were not the focus of the study.

Additionally, the relationship between the patient and other peers is not discussed. Situations where patients were interacting with each other were minimal during the study. This may be attributed in part to the nature of the patients who are often elderly, are hospitalised and suffer from a number of co-morbid conditions. The patients also come from diverse cultural backgrounds, sometimes making it difficult for patients to communicate. Patients greet and converse with each other within the waiting room and this was geographically separated from the main dialysis area. There was only minimal observation within the waiting room as the focus of the study was the interactions between nurses and patients in the main HHU area. The major barrier to interactions between patients may be the physical environment of the HHU. Once the patients are “on the machine”, the machine obstructs the view of other patients

and becomes a barrier to communication. Patients placed in single rooms are unable to talk with others once “on the machine”.

In this chapter the relationships will firstly be discussed in terms of the rules and sanctions, which reflect the power of the individuals in the relationship. This area of analysis was chosen as it became evident early in the observation period that the rules and sanctions were major cultural aspects of the HHU. Essentially, rules are a set of regulations that tell you what you can and cannot do (Robinson, 1999). In sociology, a norm is a cultural rule or standard considered by most people to be actual practice. A sanction is a reward or punishment that a norm associates with a behaviour or appearance (Johnson, 2000).

Secondly, the patterns of communication which guide behaviour within the HHU will be examined. Communication is the transfer of messages using verbal or non verbal means from one party to another (Robinson, 1999). (See the glossary in volume two for comprehensive definitions of rules, sanctions, communication patterns and other common sociological terms used in this chapter). In order to examine the culture or social world within the HHU, I felt it was necessary to address these processes.

The chapter is based on the analysis of the observations, interviews and documents. The following is a narrative of the findings and a full domain analysis of the relationship results is found in appendix D.2.

## **6.2 The nurse-patient relationship**

As the previous chapter highlighted, the nurse-patient relationship is proposed as integral to the HHU. The nurses are employed in the unit to provide nursing care for patients attending haemodialysis treatments. I have observed that the relationship forged between nurses and patients can be long-term in nature, extending over months and years. For this reason the relationship is different to others in health care. Patients interact primarily with the person putting them

“on the machine” and caring for them during the treatment. The following section is an examination of the relationship between the nurses and patients.

### **6.2.1 Rules and sanctions**

There are a number of rules patients must adhere to concerning attending the HHU. These are rules the nurses put in place about controlling the patients and their behaviour. The rules are not written, however, some are explained by the nursing staff during the patients’ initial dialysis treatments. Another way the patients are informed of the rules is by speaking with other patients and by witnessing a “breach” by another patient that is corrected by the nurses. There are also a number of rules surrounding the way the patients must conduct their lives as patients requiring haemodialysis. All members of the health care team reinforce the rules. It is nurses who police breaches of rules, which are discussed in this section.

#### **Rules and sanctions within the HHU**

The most important but unwritten rule is that the patient must turn up for dialysis at the correct time and “spot” or position on the dialysis schedule. The “spot” on the dialysis schedule is allocated by the Clinical Co-ordinator. When a patient commences haemodialysis s/he will be given a “spot” which has been left open by a patient who has died, been transferred to another hospital or dialysis modality or who has received a transplant. The “spot” may not suit the new patient but there are no alternatives as the other positions on the schedule are all occupied. Some patients have been in the same “spot” since they started in the HHU. Others have changed “spots” because a more suitable one became vacant. Patients can wait for months and sometimes years before they are able to change their “spots” on the schedule. However, as discussed earlier nurses can request patients change their position on the schedule to assist the nurses.

If patients need to change their position, due to decreased health, this is seen as a priority by the nurses. The patient will be allocated the Monday, Wednesday and Friday morning shift, avoiding the weekend where there is

less medical support. The patient in the morning will be told that they need to change to an afternoon “spot” to allow for a sicker patient. Patients are encouraged not to ask for a temporary change to the ascribed “spot” to attend an important social occasion. The following is an example from the observation field notes.

One morning a patient asked the nurse putting her “on the machine” if it would be okay to change her position in two weeks due to a special family occasion. The nurse said she did not think it would be possible but she would get the Clinical Co-ordinator to come and speak with her when she was not busy.

The Clinical Co-ordinator came to talk with the patient later in the shift. The Clinical Co-ordinator was heard to say in a loud voice “If I change for you, everyone will think it is okay to change”.

When I questioned the Clinical Co-ordinator as to whether the patient’s “spot” could be changed she said “it would all depend on the unit’s work load in the couple of days before the request and I cannot make a decision until then. I try and make it hard so they do not make a habit of asking for changes”.

The outcome was that the patient’s “spot” was changed the day before and she attended the family gathering (field note 12/03/02).

Patients presenting for dialysis and at the correct times is seen as the most important rule because the nurses were obviously the most upset when there was a breach. If one patient does not turn up for dialysis it means that the position in the schedule is not filled and a time will need to be made as soon as possible for an alternative “spot” for the non-presenter to be dialysed. This upsets the schedule and means that the other patients and the staff are inconvenienced.

During the observation period a patient did not present for dialysis. The ambulance officers went to collect him from the nursing home. The patient refused to come with them and he told them to go away. The unit was contacted and the nurse rang the doctor seeking advice. The nurse was

instructed to ring the family to ask them to go to the patient and persuade him to come for dialysis. He presented the next day for dialysis but refused again the next week. He withdrew from dialysis within the month.

When asked what is the normal course of action when a patient does not come for dialysis one nurse replied;

“It depends on the particular patient. Some of the young ones “get tied up” and ring to tell the nurses they are not coming. If a patient who always comes on time did not present, the nurses would contact the patient. If there was no response they would call the police to check the patient’s home, in case the patient had a serious mishap” (Field note 15/09/02).

One patient repeatedly presented late due to work commitments. Often late presenters will have their time on the machine shortened. When questioned the nurse’s response was:

“We cut the time short so that we [the nurses] will not be late “off” the shift or do overtime and as a warning for the future treatment if the patient presents late again” (Field note 15/09/02).

Patients are expected to be punctual but not early. Patients who are either early because of their own doing or because they have had an appointment or test may sit for hours before they are called for dialysis. These patients are not given any privilege over those who are timely. This is an example of a negative sanction. The early patient is not welcome as s/he may enter the unit and hang around and expect to “go on the machine” early.

Another important rule is that the patient must wait in the waiting room until directed otherwise by the nurse. During the observation period the nurses repeatedly told patients who entered the HHU before the set time to return to the waiting room. An example of a negative sanction for not waiting until called is that of a “newie” who presented directly to the dialysis area:

The nurse, in a raised voice, said, “You should know better. Go back and wait [in the waiting room] until you are called”. The patient responded by quickly walking back to the waiting room. The remaining

three patients heard the nurse's scolding remarks and squirmed in their seats. It was as if they had learnt the same lesson when they were "newies". The patient was not aware of the rule because it was one of his first dialysis sessions and no one had informed him (field note 06/03/02).

The NUM was questioned regarding the rule of remaining in the waiting room until called.

"The rule applies to reduce the level of congestion in the unit enhancing staff and patient safety. This rule also exists to assist the nurses in controlling the work so that they can easily see that the shift's work is complete when the room is cleared of patients" (field note 06/03/02).

There did not seem to be any positive sanctions for remaining in the waiting room until called by the nurses, although these patients were greeted more warmly than those who did not.

Another important but unwritten rule is that patients who require longer dialysis are "put on the machine" first. This allows for a smooth finish to the shift and a timely exit from the unit for both staff and patients. The nurse will enter the waiting room and call the "five-hour" patients by name or ask who is on for five hours. The "four-hour" patients must wait while the "five-hour" patients go on:

A patient asks the nurse "why do I have to wait [to start dialysis] all the time?" The nurse replies: "We keep telling you to come later. If you come at 1.30 you have to wait because you are "four-hours". You have been told and there is nothing I can do about it. If you go on early they [the other patients] will all want to go on early". The patient pleads "but I have to get home early to care for my wife". The nurse says, "Everyone has a reason. I want to get home early too". There is silence as the patient is left to ponder the nurse's remarks. The patient was asked what he thought of the nurses' response. He said "She was flippant and I thought the nurses were here to care about the patients and not about what time they go home" (field note 11/06/02).

It is a common rule that “out-patients” are connected to the machine before the “in-patients”.

One morning an “in-patient” was transferred to the unit by an orderly. She arrived on the unit around 0745 hours. The woman was obviously in pain. She was confused and was waving her bandaged arm in the air. Two other patients were transferred around the same time. The three patients were placed in room 3. A nurse visited the room briefly to greet the patients and thank the orderly.

The nurses were busy putting on the “out-patients” (eight patients) in other areas of the unit. Half an hour later the nurses entered the room and started to prepare the machines for the three inpatients. The lady was connected to the machine at 0900 hours. She was then assisted with her breakfast. When asked why the lady was left until last the nurse connecting her replied.” We put the “out-patients” on first because they do not like to hang around. The “in-patients” aren’t usually going any where. She [the lady] is difficult and probably no one wanted to put her on so I ended up having to do it.”

When asked what difficult meant the nurse replied “needs lots of nursing care” (field note 06/03/02).

The patient in the example above waited one and half-hours to “go on the machine”. While she waited she was not offered pain relief or assistance with her breakfast which went cold. This example illustrates the issue that a patient’s need for fundamental nursing care activities are seen as difficult and thus avoided. The ramifications of this action and the treatment of this particular patient will be discussed further in chapter seven.

### **Rules and sanctions relating to life as an ESRF patient**

In addition to the rules regarding conduct as a patient requiring haemodialysis there are also a number of rules around the way patients must conduct their life while a patient requiring haemodialysis. The nurses are cognisant of the detrimental effects that non adherence to these rules has for the patient. Nurses spend a lot of time counselling patients and reiterating the



consequences of the patient's actions as they seem to have a genuine concern for the patient's well-being.

The patient must adhere to the prescribed fluid restriction. This is the most commonly breached rule. If the prescribed fluid restriction is not followed the patient will experience varying degrees of discomfort. If the fluid restriction is overrun the nurse will be aware due to an unusual increase in weight. Weight surveillance at the start of dialysis session is a way of keeping check on fluid consumption. If patients are markedly "over" they will firstly be counselled by the nurse who will warn them of the consequences of excess fluid consumption on their heart and the smooth progress of the dialysis treatment. If a patient continues to present for dialysis treatments "over" an acceptable weight the nurse will tell the patient that a consultation with the dietician will be organised. The nurse will also highlight this to the patient's physician in the next doctor's letter.

One patient requires assistance with the weigh machine as he feels it is reading incorrectly. He is 95.76kg and that is at least 4 kgs over his dry weight. The nurse goes to the machine to check the weight. The nurse is heard to say "Jesus X that is a hell of a lot to loose. What have you been doing wrong?" The patient dips his head and looks at the floor. He replies "I don't think I have been doing anything different". The nurse shakes her head and walks away (field note 12/03/04).

As highlighted above, the nurses use great rigour in reprimanding the patients for breaching the fluid restriction rule as it has major health consequences for patients as they will progress to heart failure as well as have difficulties with breathing due to pulmonary oedema and limited or reduced mobility due to peripheral oedema. The more fluid that is removed during the dialysis session the more the risk of a hypotensive episode. The patient must be monitored closely and if hypotension does occur this must be treated promptly.

Another important rule is that the patient must adhere to the prescribed dietary restrictions. Blood tests are taken monthly on all patients. Potassium excess is

common but a severe breach can result in the sudden death of the patient. For this reason the patient's serum potassium level is monitored closely. If the result is high the patient is counselled by the nurse and questioned as to his/her level of understanding of foods high in potassium. If the problem is severe or the patient's potassium is repeatedly high, the dietician is called to discuss the patient's particular diet knowledge.

The patient must adhere to the prescribed medicine regimen. A common example of a breach in medicine regimen is the patient who does not take phosphate binders. The kidneys in healthy people excrete phosphate but in ESRF the phosphate level will rise and cause symptoms such as itchiness but more importantly lead to a syndrome called renal bone disease or osteodystrophy. If the patient is not taking the prescribed phosphate binders it is evident by the high serum phosphate level and the physical signs of increased itching. The same process occurs as with diet breaches. The patient is firstly counselled by the nurse and a referral to the dietician is made if indicated.

Although adherence to treatment regimens is evident most patients have difficulty maintaining these restrictions while trying to maintain a normal lifestyle. Two examples taken from patient interviews illustrate this difficulty:

A 61-year-old gentleman had just given up work as a successful businessman because he found the restrictions around dialysis too difficult to adhere to. "I found the biggest problem was trying to restrict my fluids on business lunches. Drinking is a very social activity. I had to say no or just half a glass. There is no such thing as half a glass when you are out" (interview P1).

A 47-year-old female patient expressed her "emotional anger" at not being able to lead a normal life. "There is loss of freedom; there is loss of who you are. There are the up and down emotional feelings and the diet and fluid restrictions. You have to constantly think about food and explain to others why you cannot eat certain things".

“Dialysis days are “crap”. You feel “crap” afterwards. There is scarring on my body from head to toe. I wonder what my body would have looked like if I was not a dialysis patient. It [dialysis] affected the way I worked. There is not a part of you that is not affected” (interview P9).

There is an important rule that is explained to the patient by his/her nephrologist and enforced by the dialysis registrar and nursing staff. The patient should only seek the attention of the “renal team” for issues related to dialysis and kidney disease. All other health concerns and regular scripts are to be addressed with the GP. This becomes an issue when some of the patients are essentially house bound due to age or immobility and they have to attend the GP around the times of their dialysis program. Some patients struggle to find a GP who is not hesitant in caring for them and their complex concerns. The lack of GP support for some patients becomes problematic.

The lack of consultation from the “renal team” regarding patients’ non-dialysis related health issues results in the nurse being left without the support to trouble shoot complex issues unless it can be done within the bounds of the other multidisciplinary health team members. The nurses are reluctant to provide more holistic care as it is easier to conform to the renal team’s model of medical specialisation. Stronger ties have to be forged between the dialysis nurse and the GP but the nurses have expressed a hesitancy to do so because it is virtually unmarked territory. They are not accustomed to dealing with doctors outside of the hospital. The nurses have issues engaging the “renal team” and nephrologists and this will be discussed in the section related to the nurse-doctor relationship.

The rules and sanctions set out for patients within the HHU are in place for two reasons. Firstly, the majority of patients, no matter what age will spend the rest of their lives on dialysis. There is a need for patients to adhere to the total treatment regimen in order to promote their physical wellbeing and enhance their life expectancy. The total treatment regimen encompasses the dialysis treatments, dietary and fluid modifications and the prescribed medicines.

Typically patients with ESRF adhere to this regimen because they are constantly warned of the consequences of non-adherence and view the interventions as life sustaining.

Secondly the rules and sanctions serve the needs of the organisation and the nurses. The rules around keeping to time are in place to allow nurses to control the work. Demands on the service have led to the situation where the HHU needs to provide a large increase in haemodialysis treatments with no increase in resources. All patients require regular haemodialysis to survive; therefore the schedule must be maintained. To maintain control of this situation, the patients must attend the HHU on time and adhere to the schedule. Maintaining the schedule is a major rule for both staff and patients and the dilemma of trying to keep to the schedule has already been discussed.

### **6.2.2 Patterns of communication**

Communication is essential in building a relationship between the nurses and the patients within any health care setting. This section reviews the negative and positive issues related to communication in the nurse-patient relationship.

Both nurses and patients are referred to by their first names. Nurses greet the patients and ask "how are you?" Nurses ask the patients about their "days off" dialysis and what they did. The patients talk to the nurses about physical complaints they have, for example "my toe hurts", "I have not felt well since I left". At the commencement of dialysis the most common topic for discussion is around the increase in patient weight and the amount of fluid to be removed during the treatment.

Often the patient will sit quietly while the needles are placed so as not to disturb the nurse. Both the nurse and the patient respect this quiet time. Talking may take the nurse's concentration off the task of cannulation and s/he may make a mistake. The patient does not want the nurse to lose concentration and make a mistake because this will cause pain, discomfort and result in another needle being placed. Once the needles are placed the

patient may recommence the conversation. The nurse will continue to work while listening to the patient, nod the head while taping lines and pressing knobs on the machine. The nurse will complete the procedure by saying “okay then” or “there you go” and move off to the next patient. Patients are left to make themselves comfortable. The nurse call buzzer is not offered unless the patient requests the television control which is also located with the buzzer.

The nurse returns to the patient hourly to check the machine. If the patient has open eyes, the nurse may ask the patient how s/he is feeling. This is not always the case and nurses were observed doing their round of machine checks without checking on patients or entering into any conversation with them. The reason for this was not determined from the study. One explanation for this behaviour could be that if the nurse starts a conversation with the patient s/he will be delayed in completing the machine checks. There is minimal space between the patients in the four-bedded areas and it is unsuitable to discuss important or sensitive matters while patients are “on the machine”.

On completion of the dialysis session the nurse is often busy taking two patients “off the machine” at the same time. The patient is left to hold his/her cannulation sites while the nurse leaves to attend the other patients. This arrangement leaves little time for any meaningful communication as the patients are anxious to leave the unit at the end of the treatment. One patient was seen making her way down the corridor clutching the rail as she went. She was not asked if she was okay. The nurse yelled loudly down the corridor – “I hope you have written your weight down”, not seeming to notice the patient’s difficulty in mobilising.

The nurses often try to counsel the patients regarding health issues. The most common topic is the consequences of fluid overload. One patient was found to be well over her accepted weight every time she presented for dialysis.

“You must try and stop [drinking] for your own good. You will get bad side effects. Your heart will get floppy and just stop one day” (Field note 17/04/02).

The patient shakes her head and responds with “so hard, so hard”. The nurse ends the discussion there without determining why it is so hard for the patient to control her drinking. The nurse is busy as there are other patients to connect to the machine. Perhaps if the communication had continued there might have been an outcome for addressing the patient’s non adherence with the fluid restrictions.

Matters of an important nature affecting all patients are communicated via a letter or memo written by the NUM and given to each patient. For example information regarding Christmas closures and future redevelopment plans. Issues of major concern to the patient are usually told to the nurse connecting the patient and then relayed to the NUM who will have a private discussion with the patient. These issues are usually around schedule changes that have not been resolved in discussion with the Clinical Co-ordinator.

Communication between patients and nurses is generally of a superficial level. The nurses do not question the patient regarding personal or sensitive concerns and the patients are reluctant to offer such information. This situation may be explained by the fact that the nurses are seen to be busy and do not display behaviours that invites patients to talk. Nurses are involved in the technical aspects of care and do not appear to have as much time for the less technical care activities. Patients may not feel that the nurses have the expertise to assist in the resolution of more personal problems when they are busy tending the physical care activities. If the patients are not asked by the nurses then the patients may feel it is not the right venue to discuss such issues. The HHU may be seen as a place where the dialysis is performed and not a place to address other issues. The nurses have not identified that there should be a time in the day allocated to the support and counselling aspects of their role. The superficial communication observed may be a protective

behaviour to prevent the nurses getting involved in more sensitive non-dialysis related patient problems.

### **6.2.3 Section summary**

The relationship between the nurses and patients is controlled by the nurse who imposes rules and establishes sanctions for non-adherence. The nurse imposes these rules for two reasons, firstly for the well-being of the patient and secondly to maintain the schedule. Communication between nurses and patients is mainly superficial in nature concentrating on issues around the patient's treatment regimen. Sensitive issues are rarely addressed.

## **6.3 The nurse-nurse relationship**

Discussion in this section surrounds the relationship between the nurses employed in the HHU. A discussion of the rules and sanctions and patterns of communication between the nurses is provided.

### **6.3.1 Rules and sanctions**

The nurses working in the unit are expected to adhere to laws, policy and guidelines of the hospital and HHU. The underlying policy objective of the Nurses Act (1991) (Parliamentary Council's Office, 2004) and the Nurses and Midwives Regulation (2003) (Parliamentary Council's Office, 2003) is the regulation of nursing and midwifery to minimise the potential risk of harm posed to members of the public by unqualified, unscrupulous or substandard practitioners in the fields of nursing and midwifery. The nurse is expected to practise within the Code of Professional Conduct for Nurses in Australia (Australian Nursing and Midwifery Council, 2003), the Code of Ethics for Nurses in Australia (ANMC, 2002a) and the National Competency Standards for the Registered Nurse (ANMC, 2002b). The codes outline the minimum requirements of the profession to provide responsible, safe and accountable nursing care for the individual, group and the community. If nurses were to contravene these laws and codes, they would be brought before the Nurses' Tribunal and risk being dismissed or "struck off" the Register to practise. If the

situation is considered to breach the nurse's "duty of care" then legal action could be warranted.

One of the most important rules in the HHU is that the nurse must wear personal protective equipment (PPE) when dealing with patients' blood. This policy has been implemented to protect health care staff. The risk of contamination in activities where there is direct contact with blood and blood products is high. The haemodialysis nurse is in contact with patients' blood on cannulation, connection and disconnection from the machine and at various times when troubleshooting machine and vascular access problems. The major concern is the risk of contamination of health care workers with unknown pathogens including new strains of hepatitis. Junior nurses adhere to the use of PPE more often than experienced long-term nurses. This is because the more experienced nurses have not changed practice when PPE was introduced. There is no strong sanction for non-adherence to this rule. One nurse refuses to wear any type of face protection and she has been warned of the associated risks by the NCNC and NUM. Nurses support each other to adhere to this standard and often prompt each other to stop and get gloves before continuing with a procedure.

Nurses must use aseptic technique to connect and disconnect patients to the dialysis machine. Aseptic technique involves correct hand washing procedures, donning sterile gloves and non-touch dressing techniques. This standard is in place to protect the patient from cross infection. The patient requiring haemodialysis is immunosuppressed and at high risk of contracting most infections. The presence of vascular access devices poses the biggest risk. Sterility is also maintained when setting up and priming the blood circuit. If the dialysis lines drop on the floor or are contaminated in any way they are discarded and replaced. The rules surrounding the performance of activities using PPE and aseptic technique are documented in unit policy and procedure manuals.



There was no evidence of a breach of aseptic technique during the observation period. The adherence to aseptic technique can also be considered a positive aspect of the relationship between the nurse and patient in that the nurses do not wish the patients to experience any unnecessary infection. The nurses may have also adhered to this rule because they all agree that rules about asepsis are based on sound evidence and thus adhere to them. Additionally, this may be an effect of my presence as researcher in an observational role in the unit.

The nurse who spends extra time pouring over blood results and writing doctors' letters is "frowned on" by other nurses. There is a major informal rule for nurses. All nurses are required to "pull their weight" and do a fair share of the work. Everyone must be seen to be busy preferably doing machine related activities and restocking. Another informal rule is that the nurse connecting the patient to the machine is responsible for his or her care and usually the disconnection from the machine.

The nurse must be competent in technical procedures especially cannulation. The "good" nurse is a "good cannulator" who gets the needles in first time every time. A nurse is labelled a "poor cannulator" if s/he takes a long time and constantly seeks the help of others who don't "have time" to help. If a nurse is called to assist a colleague it will result in a delay for his or her patient.

A nurse is cannulating one of the patients. The nurse sees that the patient is anxious and tells her to close her eyes so she cannot see. The patient responds angrily with "Why don't you try it [having needles]? It is not that easy". The nurse tries to place a needle but she is obviously shaken by the patient's response and is not successful. The nurse is unable to cannulate the patient. The nurse tells the patient she will have to get someone else to cannulate her.

The nurse asks her closest colleague if she would be able to assist but she says "no" bluntly and continues connecting her patient to the machine without raising her head. The nurse then approaches another colleague to assist. The nurse is told that she will assist but she will

have to take over putting on the patient her colleague was going to put “on the machine”. “I will help you if you do my work so that I do not get late” her colleague insisted (field note 26/03/02).

The “good” haemodialysis nurse is also quick and can “put on” patients in the shortest possible time without making any mistakes. This is good for the flow of patients and the other nurses but can result in the nurse having to do more work by helping “put on” more patients.

### **6.3.2 Patterns of communication**

#### **Within the HHU**

The NUM visits the HHU each shift for an update. The “in charge” or Clinical Co-ordinator manages each shift and contacts the NUM if difficult decisions must be made. An example would be how to fit an extra patient into the full schedule or how to cover staff sick leave. Nurses report any adverse events to the “in charge” and if these occur in the morning a report is relayed to the NUM. Nurses are responsible for troubleshooting their own patient problems. Nurses report that this is an adequate way to communicate with the NUM but suggest it would be easier if the NUM was housed on the unit.

“We do not see the NUM very often. She has a number of areas to manage and we are a long way from her office. We are the busiest place and changes happen all the time. It leaves us out on our own a bit but we know she is only a phone call or a page away” (field note 10/09/02).

Nurses in the unit talk freely among themselves regarding issues of practice. Some social comments such as “how was your weekend?” are also discussed. Communication is kept to a minimum during the busy connection and disconnection period. The only discussion is related to adequately and safely completing the task. Communication with patients and general noise is also kept to a minimum when all patients are connected to the machines. This allows for patient rest and gives the nurse time to catch up on restocking and other unit related activities.

Nurses rarely involve the patients in discussion regarding their care and this will be examined further in the next chapter. Very sensitive issues are discussed at the nurses' desk but the desk is in the middle of the HHU so the voices must be kept low. Nurses talk openly but quietly about patients they feel should not be having dialysis due to old age or complex medical issues. This situation warrants further interpretation and will also be discussed at length in chapter seven.

### **Outside the HHU**

The nurses in the HHU also communicate with nurses in wards and units in other parts of the hospital. Staff trained in the care of dialysis patients are employed in the Medical Specialties Unit (MSU). Therefore, most of the hospital in-patients requiring haemodialysis have traditionally been admitted to the MSU. However, currently the patients are being cared for in wards and units where the nurses are unfamiliar with the care of patient requiring haemodialysis. There is a standard information leaflet called "Care of the patient requiring haemodialysis". This leaflet is available to assist nurses in the preparation of patients for haemodialysis however, when a patient transfers to the unit at the wrong time or is not adequately prepared, it provokes comments from the HHU nurses regarding the incompetent ward nurses. "No matter how many times they [the ward nurses] are asked to weigh the heavy patients it rarely happens" (field note 11/09/02). There is often a telephone call to the ward involved to speak with the NUM. A common resolution to the problem is that the HHU nurses place the "Care of the patient requiring haemodialysis" leaflet in the front of the notes as intended. This will occur for that particular patient but then it is forgotten again resulting in the cycle recurring.

The HHU evening "in-charge" nurse notifies the MSU by facsimile regarding which patients are required for dialysis. The facsimile is placed near the allocation board on the ward so that all nurses know which patients to prepare. The evening "in-charge" nurse also notifies other areas of the hospital about the in-patients' haemodialysis schedules by ringing the wards the night before. During the observation period messages often got lost. It seemed to depend

on whether the ward nurse communicates the information to the next nurse taking over care. Sometimes the nurses in the HHU will write in the notes the day and time for the next haemodialysis session. The patient is also aware of his/her usual time for dialysis and often prompts the ward nurse to check when s/he will be required in the HHU. This system has been revised a number of times. Faxing was trialled but not all areas have a facsimile machine or the facsimile was left in the machine until it was too late. There does not seem to be a fail-safe method for resolving this issue.

### **6.3.3 Section summary**

The unwritten rules for nurses are directed toward getting the work done in a timely manner. The pressures of high demand coupled with limited resources force the nurses to be time conscious and scrupulous in the management of the patient schedule. The nurses place emphasis on the technological aspects of care and a “good” nurse is one who is quick and skilled in technical functions such as cannulation. Communication between nurses is a way of debriefing about unit and patient concerns.

## **6.4 The nurse-doctor relationship**

The nurse-doctor relationship examined in the following section refers to the relationship of the nurses and the nephrologists and the doctors in the “renal team”. Other doctors who visit the HHU rarely interact with the nurses and for this reason have not been included.

### **6.4.1 Rules and sanctions**

The “renal team” frequently breaches the rule regarding not disrupting the schedule. The impact of these breaches mostly affects the nurses. The doctor telephones or walks into the HHU and says “there is an “acute” in the ED who needs dialysis as soon as possible” or “there is a new “chronic” you need to start this week”. The “renal team” supply the extra work for the nurses. The nurses then have to juggle the schedule and find a space for the patient or unwillingly organise overtime to cover the extra demand. The doctor has a major part in disrupting the predictable day. The doctors require the nurses to

do extra work in relation to the care of more elderly and sick patients. Some of these patients are identified by nurses as having a reduced quality of life (QoL). These inferences regarding the QoL of the patients are value judgements for which there is no supporting data.

In one example much counselling and support was given to a patient and family regarding the decision whether to proceed with dialysis. The patient was in his eighties and had a number of co morbidities. The nurses were not happy with the patient, family and doctor's decision to proceed with dialysis. Remarks such as "why are we doing this?" and "this is a waste of time" were aimed at the doctors. One nurse constantly visited the patient following the decision to try to persuade him to change his mind. The patient repeatedly said "yes" to dialysis. I asked the nurse why she was so persistent in her efforts and why yes was not a good enough answer for her. She responded angrily saying:

"I do not care about what the family or patient think. I just do not want to dialyse him. I don't care about him. He is falling apart. No heart and no legs. It is a waste of my time" (field note 17/5/02).

I noted that if the nurses were upset with any of the "renal team" members they would not accompany the doctor on his/her visit to the patient. This can create further problems as the doctor may write in the notes and not convey information directly to the nurse.

#### **6.4.2 Patterns of communication**

From the observations, it was clear that there were a number of communication problems between the doctors and nurses. The nurses in the HHU do not directly discuss patient issues or general concerns with the nephrologist. Most nurses are not known to the nephrologists or are only known as signatures on the doctors' letters. The Dialysis Registrar is the "go between" in patient management matters. There are no formal meetings between any of the members of the "renal team" and the nurses.

If the nurses require the Dialysis Registrar for a patient issue, the nurse will write in a special exercise book called the "job book". When the Dialysis Registrar has written up the medicines or reviewed the blood results, a nurse will cross out the job. The admitting "renal team" reviews the in-patients daily and orders are communicated to the nurses via telephone or the notes. Orders are more often written in patient notes and nurses find out there are special needs just before the dialysis session or after, if they have not read the notes.

If the nurses feel that an out-patient requires review at the time of the treatment, they will contact the Dialysis Registrar. The nurses have been asked by the Dialysis Registrar to record all patient concerns in the "job book". If the issue warrants prompt attention, the nurses must contact the Dialysis Registrar. All urgent requests for the doctor are to be made by the Clinical Co-ordinator or the "in charge" nurse. Contrary to this, the nurses constantly telephone the dialysis registrar with issues that do not require prompt attention. Different nurses also contact the dialysis registrar repeatedly regarding the same issue.

A nurse asked my advice regarding a patient's serum calcium level because she was "afraid" to call the Dialysis Registrar. It was suggested that the issue was important and that the doctor should be informed. The nurse asked if I could contact the Dialysis Registrar for her. The nurse explained "The nurses always get into trouble for contacting the dialysis registrar especially if it is not urgent".

The nurse was asked why she thought this was and she replied "I am not sure perhaps they are busy but we are too. There are certain ones who get angry more than the others. In the end you just don't ring and then they get angry because it is important and you didn't contact them". The Dialysis Registrar was found in the clinics and alerted to the patient's high serum calcium level. The patient's medication was changed accordingly without comment from the doctor regarding the nurse's behaviour (field note 06/07/02).

The nurses do not always get into trouble for contacting the doctor. If the Dialysis Registrar is busy s/he will be “short” with the nurses and tell them they will have to wait until s/he has time to deal with an issue.

The nurse converses with the nephrologist by way of a regular letter. The letter is faxed to the nephrologist’s rooms or sent with the patient to the clinic appointment. The letter uses a standard format and was designed by the nephrologists to enable the nurse to supply the critical information required to identify the patient’s response to the dialysis prescription. Suggestions for changes to the treatment regimen are made and two of the nephrologists respond with a prompt letter. The remaining nephrologists send a letter back to the nurse in the mail or convey a message via the patient.

The nurses feel the letter to the nephrologist is a useful way of keeping the doctors informed of the progress of the patient’s dialysis. One nurse has expressed concern over not being able to communicate problems, which are not related to the dialysis or kidney disease.

“I have put down things about other things such as a patient had a sore leg for a month and nothing was done. Perhaps he told the patient to go to the GP but he did not tell me. He did not respond in the letter to me about the leg. The patient can hardly walk and has trouble going to a GP so I just thought he could look at it. It is hard for us to try and deal with everything when the doctors don’t” (Field notes 13/09/02).

The rule regarding not contacting the nephrologist or renal team regarding non-dialysis issues has been discussed in the section on the nurse-patient relationship.

### **6.4.3 Section summary**

The relationship between the nurses and doctors is impersonal, lacking mutual respect. This is evidenced by the above discussion regarding the nurse-doctor rules and sanctions and communication patterns. Contributing to this relationship is the way the nurses blame the doctors for the increased

workload. The doctors are the group who make the most changes to the schedule. The inability of the “renal team” to attend the unit in a timely manner also creates tensions in the relationship. There is poor verbal communication between the nurses and nephrologists and to overcome this situation the prime method of communication is a letter.

## **6.5 Nurse-visitor/carer relationship**

Carers and visitors were also observed in the HHU. The carers only have a presence in the unit at the start and at the completion of the dialysis sessions. There are few patient visitors to the HHU. The following is an examination of the relationship between the nurses and the carers and visitors who attend the HHU.

### **6.5.1 Rules and sanctions**

Carers are acknowledged by the nurses when they enter the HHU with the patient. Some carers assist in the preparation of the patient or the machine. Although carers assist by making the patient and machine ready it does not mean that the patient is put on the machine earlier. If the patient is a “four hour” they will still have to wait until the “five hour” patients have been connected to the machine. The nurses appreciate the carer’s assistance in preparing machines. This assistance enables the nurses to quickly connect the patient to the machine relieving them from the tedious set up procedure which is routinely repeated throughout the day and every day.

Carers are usually told to wait in the waiting room if they are collecting the patient following dialysis. Crowding in the unit can occur if a number of patients are “off the machine” at the same time. Again carers who are willing to assist the nurse in “holding off” the patient’s cannulation sites or cleaning the machine and bed/chair area are always welcome.

There is a general rule that visitors and carers should not exceed two per patient, as space does not allow for their presence within the patient area. Visitors who come to HHU during the dialysis procedure are not openly



welcomed. Visitors are often not offered a chair and they stand beside the patient's bed or chair. If a visitor takes a chair from the waiting room the nurses expect it to be returned to the waiting room before leaving because it will crowd the area and the environment will become unsafe. The time the patient is "on the machine" may be taken as respite time for the carer. Additionally, the obvious technical machinery and blood may deter some visitors especially children. These may be reasons why there are few visitors in the unit.

### **6.5.2 Patterns of communication**

Familiar carers who transport patients to the HHU are acknowledged. There is often small talk between the carer and the nurses around superficial topics such as the weather. The carer will make comment around how the patient has been feeling since the last dialysis. This is usually dismissed by the nurse or the carer is told that dialysis will or will not fix it. A carer informed the nurse that his wife had been "pretty bad" since the last dialysis session. The nurse replied "never mind you get a break now while she is on the machine". There was no discussion around what "pretty bad" meant and how this issue might be addressed. The nurse was not the patient's primary nurse and was not the nurse who put the patient "on the machine".

As the major role of the carer is to transport patients to and from the hospital, carers are often on the unit during the busiest periods when the activity level is high. There is little time to communicate with carers during this time as the nurse is concentrating on preparing machines and "putting patients on" or "taking them off" the machines.

Unfamiliar visitors were not welcomed to the unit. Visitors of in-patients were acknowledged by a dip of the head but there was little verbal communication.

A male visitor walked into the HHU. He asked the first nurse "how did my mother sleep last night?" The nurse replied "I do not know. I am only doing the dialysis" and hurried off. He went up to the next nurse he saw and asked the same question. The nurse replied "Sorry, I am not looking after her" and she turned and headed into one of the single

rooms. The visitor looked a little bewildered and turned and left the HHU. He returned about 10 minutes later and stood beside his mother's bed. When asked where he had gone he explained "None of the nurses here know anything about my mother so I went to find someone on the ward who did" (field note 25/06/04).

Discussion with visitors and carers on a deeper level can be time consuming and usually results in a request to speak to the doctor. This distracts from the nurse's work and the nurse would not get a very good response from the "renal team" if s/he were to contact one of them.

### **6.5.3 Section summary**

In summary, carers are usually only present on the unit when they are transporting patients to and from the hospital. The time that the carers are present is the busiest time and there is limited communication between nurses and carers for this reason. Nurses appreciate the assistance some carers provide by making patients ready and preparing and cleaning machines. Visitors during the dialysis session are not usually welcomed. Again, the nurse is busy and does not have time to talk with them. Visitors are also seen to be an obstruction and safety risk.

### **6.6 Chapter summary**

This chapter has identified the important issues in the relationships between the nurses and patients, nurses and their colleagues, nurses and doctors and nurses and visitors/carers within the HHU. These relationships are considered to be the most important within the HHU. Nurses are seen to control the nurse-patient relationship. This control is established by imposing rules to which the patients must adhere. Communication between nurses and patients centres on the topic of dialysis and other problems the patient may have are not addressed.

The pressures of high demand, with limited resources force the nurses to adhere to the patient schedule. Nurses are expected to "pull their weight" and

this is necessary to keep to the schedule. Technical functions of the nurses are valued above any other aspects of the role and a good nurse is one who is quick and skilled in cannulation. Communication between nurses is a way of debriefing about unit and patient concerns.

Nurses and doctors within the HHU seem to have a relationship which is not mutually respectful. Contributing to this relationship is the way the nurses blame the doctors for the increased workload that results in changes to the schedule. Nurses rely on the “renal team” to attend the unit as required and often this cannot occur in a timely manner creating tensions in the relationship. There is also poor communication between the nurses and doctors evidenced throughout the observation period.

Carers are usually only present on the unit when they are transporting patients to and from the hospital. The time that the carers are present is the busiest time and there is limited communication between nurses and carers for this reason. Visitors during the dialysis session are not usually welcomed.

Some of these issues will be addressed further in the following chapter which provides an in-depth analysis of the identified research themes.

## CHAPTER SEVEN – ETHNOGRAPHY RESULTS

### THE CULTURAL THEMES

#### 7.1 Introduction

The initial data analyses have been provided in chapters five and six. The themes emerging from the study data are presented and discussed in this chapter. Analysis of the themes has involved searching the domains for patterns or links between the major domains. I have identified over 28 categories and they are displayed in bold print. Five major themes emerged from the categories. These themes are: “doing more with less”, “who gets a machine?”, “technological creep”, “dialysis centred care” and “the bottom line”. Full domain analysis is provided at Appendix D.3. Each of these themes will be discussed in detail below.

#### 7.2 “Doing more with less”

In Australia over the last decade there has been an increasing demand for haemodialysis services. There is also a social expectation that people are able to access dialysis treatments. The increased demand has resulted in the HHU providing haemodialysis treatments for more patients. As discussed in chapter five, the number of patients on haemodialysis at the hospital has consistently increased from 1997 to 2003 (Department of Renal Medicine, 2004). On average there has been a yearly increase of 5 -7% and it is predicted that this yearly increase will continue over the next decade (ANZDATA Registry, 2003).

**Demand stretches the available physical and human resources.** The increase in demand for dialysis treatments in the HHU must be met with available resources. These resources include the physical space, the number of machines and the number of nursing staff.

The continuous and expanding pressure to dialyse more patients with available resources has led to the work being structured in order to achieve the schedule. The dialysis schedule has been developed to guide the nurses as they “process” an increasing number of patients. There are a limited number of

positions on the schedule and these must be juggled to ensure the maximum numbers of people are dialysed in the available time. **The focus of the nurses' work is to accomplish the schedule.**

Keeping to the schedule serves two purposes. First, owing to the increasing demand for haemodialysis and the organisational expectation to provide this service, nurses are required to dialyse more patients within existing resources. This level of service cannot be achieved unless the schedule is maintained. The schedule acts as an imaginary shield or a buffer to control the workload. The pressure to meet the schedule comes from the organisational expectation that the schedule will be consistently achieved. However, it can be argued that adherence to the schedule is artificial in that, if there are deviations from the schedule, the resulting outcomes are not devastating either for nurses or patients. At worst, there are inconveniences for both patients and staff. Nurses may have to do overtime and patients may need to present at a different time. The nurses have "manufactured" the significance of adhering rigidly to the schedule.

The second purpose for maintaining the schedule is that it supports the personal needs of the nurses. The workload in the unit has escalated leaving little "down time" for the nurses. The nurses need to go to meal breaks for the allotted time and to have adequate time to spend at the desk talking and catching up on paper work. Getting out of the unit early is something that is perpetuated by both patients and staff. The sooner the patients are "on" the sooner they are "off" and the sooner everyone goes home. **The three "Gs"** as it is known "get em on, get em off, and get home" is another category throughout the data, and these behaviours are supported by some of the rules in place. For example, the "five-hour" patients are placed "on the machine" before the "four-hour" patients to allow the timely completion of the work before the end of the shift. In the case of the afternoon shift "going home" is often an hour earlier than timetabled. Occasionally, if the shift is not going to end on time the nurse will shorten the patient's time on the machine. This time will

need to be added to the next dialysis treatment. Throughout the data the **management of time is of major importance to the HHU nurses.**

A shortage of nursing staff impinges on the nurses' ability to meet the needs of patients. Specific skills required for haemodialysis nursing are often not found in the general pool of nurses within an institution. In the absence of adequate staff to perform dialysis safely, the extra workload must be accommodated by the available haemodialysis RNs. This in turn adds to the stress level and lowers the morale of nurses in the unit. The dialysis nurse is forced to focus his/her attention away from the patient to the task at hand – setting up machines, cannulating, monitoring and disconnection. There is a problem recruiting extra nurses to work in the HHU but conversely retention of staff in the HHU has not been an issue.

The HHU is one area of the hospital where the nurses tend to stay for a prolonged period. Most nurses interviewed gave a similar response to the question - Why do you work in the HHU?

“The rosters are predictable in that there is no night duty and the unit is closed on Sunday. We always know that we have Sunday off unless we are “on call”. There is no chance of being rostered to work on Christmas or New Year’s Day because the unit is closed. The workload is not as heavy as ward work.”

When asked what is heavy about ward work the nurse replied:

“Heaviness is things like lifts, turns and bed baths. The work here [in the HHU] is not as “dirty” as ward work either.”

When asked what is meant by “dirty” the nurse replied:

“You know, getting pans all the time and doing those horrible long dressings. When you are in the ward you are not sure of what is going to happen next. Someone will be falling out of bed or you will be in a shower with someone and the buzzer rings. In “haemo” you tend to know what you are in for. Things do happen to throw you now and then. On a bad day you get problems like a fistula problem or a machine mucking up” (interview N2).

The HHU seems to attract nurses who prefer to work in a predictable environment. This becomes an issue when they are challenged by events that disrupt the pattern of the day or there is the need to introduce change. If the schedule is disrupted in any way it results in an uncontrolled and unpredictable day. **The nurses expect the work in the HHU to be predictable.** A “bad” **day** is one in which the work is unpredictable and where there is a sense of lack of control.

“It is important to keep to time. If everyone [patients] came on time and there is no sick leave this helps. Sometimes you think everything is okay and the patients will be “off” on time but there is a machine problem and someone is “off” late. If someone is “off” late it throws the whole shift out and we get to lunch late or someone works through [the lunch break]. On a bad day things happen one after another. When we have a good day everything happens when it should and there are no delays” (field note 12/03/02).

The issue of predicability of the work is supported by the literature as a reason why nurses might choose to work in a haemodialysis unit (Bevan, 1998). To maintain a predictable environment you need to control the work. To control the work the nurses have set the rules for the unit. The rules are mainly around keeping to the schedule and have been discussed in chapter six.

### **7.3 “Who gets a machine?”**

The next theme identified in the analysis is “who gets a machine?”. The haemodialysis service has experienced **the “changing face” of the patient requiring haemodialysis.** In the past, patients who were older or had significant co-morbidities were not candidates for dialysis treatments. Slowly, over the last decade there has been an increase in the number of older and sicker patients on the dialysis program. As the patient group is older and often has associated co-morbidities, this precludes them from home haemodialysis. Often the only management possible is the hospital haemodialysis program.

The study data are rich with examples of nurses expressing their reservations about dialysing aged people especially those with co-morbidities. Statements by nurses include “why are we doing this?”, “what good are we doing this patient?” and “the doctors must be daft continuing with this [dialysis in a particular patient]”. These reservations are only discussed between the nurses and not voiced to the nephrologists. Bevan (2000b) suggests a shift in philosophy from one of functionalism, which has dominated renal services in the past, to one of dependency. This shift has been noted in the study. Due to the increased dependency of the patients, the nurses don’t have the time to train patients to do self-care as they have done in the past in the satellite cottage.

It is difficult to pinpoint a distinct reason for the increase in the older and sicker patients being accepted onto dialysis. **There is a social expectation for longevity because the technology to support peoples’ expectations exists.** When faced with death as an alternative to dialysis the wish to survive is one obvious motivation for patients to endure years of dialysis treatments. This issue will be discussed at length in chapter eight. Individual nurses discuss their concerns regarding new patients in the HHU by debriefing with colleagues at the desk. **There is discussion around who “deserves” the machine and who does not.**

The nurses blame the organisation and the doctors for the increased number of patients receiving haemodialysis. Issues around who should be placed and maintained on the haemodialysis program are a cause of tension between the nurses and doctors and the nurses and some patients. This particular issue is beyond the control of the nurses. Nurses see the doctors as the people who dictate who should receive dialysis and the nurses are the mechanism to carry out the dialysis. There is little overt confrontation regarding this issue but the relationship between the doctors and nurses is strained. The relationship between the doctors and nurses has been described in chapter six and will be examined further later in this chapter.



#### 7.4 “Technological creep”: reorganisation of the work

Doctors would like the nurses to take on more functions in the HHU but the nurses are reluctant to take up any additional roles. The most common example of a function that should be taken up by the nurses is the assessment of patients' fluid status. The doctors determine a “dry weight” for each patient and this weight is reviewed at the next clinic visit. Sometimes there are marked changes in the patient's dry weight between clinic visits, warranting further adjustment to the fluid loss during dialysis. There are a number of examples during the observation period where the nurses waited for an extended period for a doctor to assess the amount of fluid to be removed during the dialysis treatment. On two occasions, the patient was “off the machine” before the doctor was able to attend the unit. When one nurse was asked why she did not assess the patient, she said:

“It is not my job to assess the patients. That is doing the doctor's work. I have enough to do without doing the doctors' work as well as my own.”

When asked whether she thought the lack of assessment had any detrimental effects for the patients she replied:

“Some times the patients come “off” on the wrong weight. We still take some fluid “off” but it is only our guess. If something goes wrong it would be the doctors' fault for not coming and doing their job” (field note 12/03/02).

Assessment of fluid status involves gathering data regarding the under or over hydration of the patient and estimating an amount of fluid to be removed during the dialysis treatment. Generally the nurses see this as a challenge as they do not want to make a mistake and take the blame if something goes wrong. Inadequate removal of fluid during dialysis places the patient at risk of over or under hydration. Nurses see this as a situation that should be avoided. However, because they identify assessment of fluid status as a doctor's job they accept no responsibility for the situation. Avoiding clinical responsibility acts to maintain doctors as the sole decision-makers perpetuating the anxiety of challenging the doctors or taking initiative. Comfortable in the current role, the nurses see the additional functions as “**doing the doctors' job**”.

“Technological creep” is a situation that is occurring throughout healthcare in general (Ryan, 1996). This involves health care workers dropping part of their role to take up new challenges. The nurses in the HHU would in all probability see current pressures from the nephrologists to enhance their role as **“technological dump”** rather than “technological creep”. Tensions exist between the doctors and the HHU nurses due to the nurses’ unwillingness to undertake functions previously performed by doctors. Resistance from nurses is enhanced as they are ill prepared to take on the new functions which realistically can only be achieved if the nurses in turn “dump” something from their role. The “inflated” value they placed on their competence in cannulating and other technical functions has led to a dilemma in trying to persuade the nurses that this is one aspect of their role which could be given safely to another level of nurse. This will be elaborated on within further sections of the thesis.

Another explanation for the nurses’ hesitancy in taking on the additional patient management functions is the lack of consultation regarding the work. The nurses have not been involved in patient management decisions and do not see themselves as accountable for the welfare of the patient. Traditionally patient issues could be highlighted with the nephrologist via the doctor’s letter, but changes to the therapy were only to be made by the nephrologist. In the past the nurses were not supported to take on extra functions. In contrast the doctors now feel the nurses should be more proactive in clinical decision making. This situation leaves the nurses confused about what their functions are and where the line is drawn between medical and nursing interventions. The nurses see the new functions **as extra work without extra pay**. There is no incentive for the nurses to take on more functions if there is no remuneration for their efforts. One way to resolve this is to leave things as they are. The reluctance of the nurses to take on the additional functions has major repercussions for patients in that they are receiving the dialysis but less than adequate long-term-care.

## 7.5 “Dialysis centred care”: a barrier to the development of interpersonal skills

The focus on the technology is seen as the major aspect of caring by doctors, nurses and patients within the HHU. On interview some of the nurses understood what patient centred care meant but felt they could not achieve it because of other issues impinging on their practice. These issues included the doctors’ ideas around their own specialist practice and their insistence on treating dialysis and dialysis related issues only. Dialysis related issues include access management, anaemia management, dialysis adequacy and complications from long-term treatment. Essentially, **the doctors’ care is focused around managing the technological aspects of care**. The nurses said they have “little room to move” as far as support for patient centred care is concerned. They believe that **the specialist medical model dominates** and this model does not provide for the management of non-dialysis issues, especially psychosocial considerations. The nurses do not see their practice as being distinct from the doctors and believe that they are conforming to the medical way of thinking. They do not believe that they have the power to change or dictate the practice although they are the providers and managers of patient care.

Another issue of concern is the level of communication between the senior nephrologists and the HHU nurses. **Nurses do not speak to the nephrologists and the nephrologists do not speak to the nurses**. The study has not been able to fully address why the nephrologists and nurses do not speak, however, the nurses suggest a number of reasons why this has occurred. Firstly, the nurses see the nephrologists as not having a presence in the unit.

**“The nephrologists rarely visit the unit.** If the nephrologists visit the unit they come with other members of the “renal team”. The visit to the unit is part of rounds to review the in-patients. During rounds they do not acknowledge or consult us about the patient’s condition” (field note 13/09/02).

When asked why the nurses are not often consulted the response was:

“The patient is an in-patient on the ward and not the unit. We do the dialysis. We would not have anything to contribute to discussion around the patient’s general condition. We would only know things about the dialysis” (field note 13/09/02).

The nurses’ behaviour perpetuates the situation of not knowing the full condition of the patient. Nurses are not concerned with general patient issues, as they are only required to perform the dialysis. The doctor realises he has no need to speak with the nurses unless there is a need to change the dialysis treatment. This situation has led to a **compartmentalisation of care and a loss of “whole patient” care by doctors and nurses.**

If the nurses are not involved in discussions regarding patients, the doctor does not approach the nurses to discuss any other issues, nor do they meet with the nurses to see how things are going generally. There is no relationship building and no formal meetings between the doctors and the nurses to discuss patient or unit issues. The NUM and NCNC meet with some of the doctors at the monthly department meeting and discussion is fed back to the nurses in the HHU. As discussed in chapter six, the nurses and doctors do not know what the other looks like. The doctors know some of the nurses’ names because they sign the doctors’ letter.

The lack of verbal communication between the nurses and nephrologists has established the written doctor’s letter as the vehicle for communication of patient issues between the two groups. The reliance on the doctor’s letter is a reflection of the artificial relationship between the doctors and nurses. The nurses send the nephrologist the letter regarding the patient’s dialysis. The nephrologist responds by making changes in the dialysis prescription. These are decisions the dialysis nurse has the knowledge and experience to make without medical input. Issues surrounding other aspects of the patient are often not commented on or are ignored by the nephrologist. One nurse was concerned regarding the way her constant efforts to discuss a particular patient’s non-dialysis condition was seemingly ignored by the nephrologist

(Field note 13/09/02). A similar finding in Wellard's (1992) study was that the nurses did not find the nephrologist accessible and communicated through the registrar. Wellard's study was conducted in the early 1990s however similar issues still exist in this HHU.

Within the HHU, **nurses are nursing the machine**. Seven of the nurses interviewed reported that the technology was a major reason for choosing to work in the HHU. The literature suggests that the technology attracts nurses to work in haemodialysis units (Morehouse et al., 2001; Bevan, 1998). A nurse on interview suggested that one reason she worked in the unit was that you get to know the patients well. On probing, it was found that this comment was related to remembering the names of the patients and the dialysis prescription from one encounter to the next because you are dealing with the same patients. By contrast:

“The ward patients are constantly changing and their treatment changes rapidly from moment to moment and it is difficult to keep track of what is happening” (interview N1).”

The issue of patient “sameness” also fits well under the category of appreciation of predictable work.

The non-technical work traditionally carried out by the HHU nurses has been abandoned. For example the nurses don't attend wound dressings unless they are related to the dialysis, for example, vascath dressings. The nurses go to great lengths to avoid other dressings. If the patient is an in-patient the dressing is left for the ward nurses to attend. If the out-patient requires a daily dressing, community nurses are organised to attend to the dressing before or after the patient presents to the HHU:

“**We are “haemo”** nurses and we should not be expected to do other things like dressings. We have enough to do without having to look after the other things that the patient has. It isn't an easy dressing and I really don't want to do it any way. There are other things I could be doing” (field note 06/03/02).

When asked what the other things might be the nurse above replied:

“I have the doctor’s letters to write for my patients and that takes time because I have to look up the results and check the charts for the last month” (field note 06/03/02).

The reluctance of the RNs to relinquish their engagement with the dialysis is central to this analysis. The nurses attend to dialysis treatments repeatedly, for some this is over the course of many years. This repetitive procedure of lining and priming the machines has led to repetitive strain injury (RSI) in some nurses due to the continual clamping and unclamping as well as twisting of dialysate bottle lids. Why is this seen as a worthwhile thing to do? Is it that the nurses find the procedure predictable compared to the unpredictable challenge of tackling the patients’ other concerns? Is it that they fear that if another worker takes the technology away they will be left to deal with other patient concerns, for which they feel ill equipped to manage? Is the technology seen as the essence of why they are there and then they will have a loss of identity? Arguably, it is all of these beliefs that enforce the nurses’ focus on the dialysis treatment. One nurse was able to provide personal insight into what makes the nurses hold onto the technology:

“I have been doing this [haemodialysis] for a long time. I enjoy my job a lot and that is why I have not left (not that there is anywhere else to go). I am a good cannulator and the new or junior nurses always ask me to teach them or to help them. If I did not do the dialysis I do not know what I would be able to do here. They would give the things I know how to do to the other nurses or ENs and I would have to take on other things. I do not think there would be a job here for me. I hope the ENs don’t take over “(interview N10).

It would seem that at least for this nurse there is no insight into what the roles of the RN could be if the technology were relinquished to another level of nurse. The nurse fears that she would lose her identity as a haemodialysis nurse. Being a haemodialysis nurse is something she takes pride in and it is difficult to imagine things any other way. The nurse went on to explain further her desire to provide the technical care in the HHU.

“Patients thank us [the nurses] when we put the needles in easily and without hurting. Other nurses praise nurses who are “good” cannulators. We are looked up to by nurses outside of dialysis for our expertise in cannulating. Cannulating was always a skill of the doctor and not a nurse. The nephrologists are most interested in talking with us about problems with cannulation and the dialysis process” (interview N10).

The technical aspects of the nurses’ work are the only facets of their work rewarded or given praise which maintains nurses’ desire to do that work function. Nurses in the HHU have traditionally received feedback on their psychomotor skills and this may have led to the situation of not seeing the worth of other nursing interventions. **The nurses in the HHU are proud of their technical skills.** As explained above, a good cannulator is synonymous with being a good nurse in the HHU.

Over time other interventions, including the management of non-dialysis related physical needs and psychosocial concerns, have been given less importance or the skills have been lost altogether. With increasing time pressures, the non-technical interventions have given way to a technological focus. The nurses value the technical aspects of their work to the detriment of the provision of patient centred nursing care. While this situation is sustained there will be no change in the work of the RN in the HHU.

The model of care stated by nurses to exist in the HHU is primary nursing. Both nurses and patients have offered opinions about the primary nurse role. Generally, nurses do not think there is an issue with the minimal amount of direct care the primary nurse provides for the patient. One nurse suggested, “If we were to put them on all the time they [the primary patients] would become too dependent on us” (field note 12/03/02).

Most patients are happy with the primary nursing role. “I don’t think there is anything more my primary nurse could do for me that she does not do already”

(interview P2). This patient went on to praise the assistance his primary nurse provides:

“She [primary nurse] looks after me a fair bit when I am here. She puts me on the machine every second time. That is pretty good because she only works a couple of days a week. She comes back for a chat when everyone is on. Writes the report to the doctor and makes it sound good so he knows what is going on. Works bloody hard. All the nurses do here. They are all so dedicated and caring” (interview P2).

Nevertheless, during the interviews some patients indicated that the lack of contact with their primary nurse was an issue. Some patients would like their primary nurses to spend more time putting them “on the machine” and just coming for a chat now and then.

One patient had a negative opinion of the primary nurse role.

“...I spend very little time with her [primary nurse]. She would “hook me up” twice a month if I am lucky. I understand she should take more care of me – more involvement. The one [primary nurse] I had before, I never saw. This one leaves you notes. Tells me my potassium is high. [She] must read my reports at night and then leaves me a note if something is wrong. I see very little care” (Interview P1).

When asked what he thought care was, the patient answered:

“Care would be spending time with you, getting to know you by having a chat. A primary nurse should be someone who spends time with you because wouldn’t someone have to spend time with you to know you and to truly care for you?”

In the HHU, primary nursing is simply a way to organise the work, lending more ambiguity to the term. It is a way of assigning patients to nurses to ensure that the strategic components of the management of the patient on dialysis are performed. These strategic components in the HHU are the surveillance of blood results and the writing of a doctor’s letter.



Nurses collectively said that the type of nursing they provided was effective and that they did not need to make any improvements. **The nurses were satisfied with the service they are providing.** One nurse was asked if she would make any changes to her nursing care:

“Primary nursing and the general way we do things is effective because things get done. We always get the patients on and if there are any problems we deal with them. If we had time to sit and chat with patients we would be seen as not being busy and they would decrease the amount of nurses on the unit. If I had more time I would not want to spend it with the patients, I would probably have more time out for me” (interview N1).

Analysis of data collected from interviews with patients regarding the care they receive in the HHU suggest that the dialysis treatment is the major reason for attending the HHU. The provision of care by the nurses is secondary. One patient expressed enjoyment at needing to attend the unit because the machine supports his life and **staying alive is of paramount importance** to him.

In general the patients prefer a more skilled nurse who does not make mistakes in cannulation and is expert at machine operation:

“I have no confidence in one of the nurses because she “blew” my arm. I know they have to learn somehow but I wish they would learn on someone else. I am frightened of her because she caused me the worst pain. I like the nurses that put the needles in and do not hurt you. There are some of those and I sit and hope they come to put me on. If one of the ones who have trouble comes I start to get upset on the inside. You cannot refuse the nurse you just have to put up with it and hope it does not hurt too much” (interview P8).

When this patient was asked if she ever talked about her phobia with any of the nurses she replied:

“They just say “there there” when I say I am scared. I have put up with it for a year now and it does not get any better. I just keep quiet now. I don’t suppose there is much they can do about it” (interview P8).

As discussed, this feedback may contribute to the way the nurses' attitudes have developed to become focused on technology. Patients feel that the expertise of the nurse in skilfully operating the equipment to achieve successful dialysis is an expression of their caring. This finding confirms the findings of the study undertaken by Hagren et al. (2001). The ESRF patients in their study felt it was important to be taken care of by someone with expertise. The dependence on the machines meant that the patients recognised and appreciated competence in machine operation. A competent nurse is one who knows what s/he is doing as well as knowing each patient's individual needs. It could be argued that the nurse in the HHU strives for competence in the provision and maintenance of the technology but does this to the detriment of knowing each patient's individual needs. Patients also expect to receive care focusing on dialysis. However, patients' expectations are limited because they do not expect more from nursing care than successful dialysis.

Within the HHU the doctors and nurses are focusing their attention on the machine and dialysis related issues. This focus on the machine rather than the holistic care of the patient has become a barrier to the development of interpersonal skills between the doctors and nurses and nurses and patients.

The next theme will concentrate on the effect the dialysis focused care is having on the interactions between nurses and patients. The relationship between doctors and patients was not the focus of this study.

#### **7.6 “The bottom line”: the dialysis is the focus of the nursing care**

**The bottom line** in any nursing care experience is the effect the nursing care is having on the patients. If adhering to the tenets of primary nursing theory the nurse would need to know the patient from a biological, psychological and social perspective to make the encounter productive and to allow the nurse to plan and implement human centred nursing care (Whittemore, 2000). **The nurses do not “know” the patients on a personal level.** The nurses know the patients' dialysis prescriptions and the best places to put the needles in

their vascular access, but they do not know how their patients lead their lives and function as individuals outside the HHU. The nurse has little knowledge or understanding of the effort the patient expends to hold down a job, maintain a relationship or just attain some normality in their life from day to day.

For any nurse to truly know the patient they must spend time with them (Radwin, 1996). This time is needed to develop a deeper level of interaction whereby the nurse and patient are engaged in a meaningful conversation. During this conversation the nurse must focus on what the patient is saying, rather than on the dialysis procedure. Time in the unit is spent taking observations, setting up and dismantling machines and cannulating the patients. **The focus of nursing work in the HHU is the provision of dialysis treatments.** Nurses expect that time will not be used for sitting and talking with patients as other nurses regard the nurse who spends time with the patient as “slack”. The nurse who is constantly sanctioned for spending time with patients reluctantly conforms to the expected behaviour or is forced to leave the unit and find an area of nursing where it is accepted behaviour.

Not knowing the patient personally appears to safeguard the nurse in a number of ways. Firstly, if the nurse truly knows the patient s/he is at risk of breaching the professional barrier. If the nurse sees a person three times a week for a number of years there is the opportunity for the development of a close friendship. Within the HHU the nurses seem to maintain a professional distance. **The nurse is at risk of becoming vulnerable when in a close relationship with a patient.** The nurse could feel deep loss and grief if the patient were to become gravely ill or die. S/he would also feel obliged to assist the patient in issues other than the dialysis, resulting in a great deal of time and effort on the part of the nurse. This time and effort is regarded as unproductive by colleagues as it does not assist the management of the schedule and in fact may be a hindrance. The nurse may feel s/he has to do favours for the patient. In the unit most patient requests are denied. An example is that used in chapter six when a patient asked if they could swap shifts to attend a special family occasion. “If I change the shift for one they will

think they can all do it” (field note 12/03/02). A strong supportive relationship between a primary nurse and patient may result in the patient becoming dependent on that particular nurse. This level of relationship is not supported in the HHU. Nurses who go beyond the general accepted level of intimacy with patients are sanctioned by colleagues to stop the behaviours.

On interview, patients were asked what they thought about the primary nursing role in the HHU. The patients were happy with the way they were assigned to a primary nurse, although a number expressed a wish for the nurse to spend more time with them. One patient wanted the nurses to spend more time “having a chat” so that he could get to know them better. He was concerned that he did not know his nurse. When asked what they would change about the primary nurse role, most patients felt that time should be allocated to talking about the treatment program and the reason for changes. These patients felt that the amount of information relayed to them about their treatment program and their level of health was minimal and that the nurse would be the best health care worker to discuss management issues. The patients felt that they were *told* things from both the nurses and doctors, but that this information was not *discussed* with them and that they had no input into the management plan. Consequently, there was no partnership in decision making between the patient and the health care workers and treatment was imposed on them without the patient having a clear understanding of the reason for the treatment.

**The lack of partnership in care** was a recurrent category throughout the data. The lack of partnership in care conflicts with the findings of Thorne and Peterson (1998). They conducted a meta-analysis of the qualitative studies into chronic illness over a two-decade period and found that in the 1990s there was an obvious shift from “client as patient” to “client as partner” within health care. The lack of partnership in care also conflicts with the findings of Aswanden (2002) who suggests that the concept of partnership linked the themes in her study. Partnership is the “entering into, supporting, being there, valuing and caring for others and this is all encompassed in the culture of

dialysis units (Aswanden, 2002, p151). In the HHU this situation has not evolved and the patients have minimal input into their care.

The lack of communication and involvement in care was identified as an issue for the younger patients. They felt that they had no say in any aspect of their treatment, especially the time and the days that they were scheduled for treatments. This resulted in dilemmas for the patients around such issues as child care and job loss resulting in financial concerns. One young female patient reported:

“They [health care workers] just don’t know. They just don’t know about the loss of freedom and the changes you have to make. They always say why aren’t you working? There is a misconception that dialysis gives you a normal life. It is a 24 hour problem and everything that happens to you outside the unit impinges on you as a dialysis patient in the unit” (interview P9).

In contrast, the more elderly, especially the retired patients, had little issue with the restrictions and the control that dialysis has. Their expectations of the care are less than the younger patients. On interview most patients expressed their gratitude to the nurses and the care they provide.

“The nurses are all lovely here and you cannot fault them. The nurses are all dedicated. I don’t know how they do it” (interview P2).

The patients are grateful because **the nurses operate the machinery that keeps them alive**. They are also content to allow the nurses to control the environment if it means that their “dialysis gets done”. The nurses also identified that they were crucial to patient management:

“The treatments we provide keep them [the patients] alive. I enjoy helping them [the patients] and keeping them alive but they [the patients] should be grateful for the care we provide” (interview N1).

One nurse described the patients as “lucky”:

“They [the patients] are lucky because they are receiving dialysis treatments. If they were in other countries just like the countries some of

the patients are from originally, they would be dead because there is no dialysis” (interview N2).

Nurses identified the most annoying patients as those who are ungrateful. The ungrateful patient whinges and is demanding all the time. The ungrateful patient tries to “lay down the rules”. These patients want to have control of their care but the nurses cannot condone this situation and clashes occur. The patient is sanctioned and requested to conform. The patients resist further confrontation because they must have the nurses “on side” because without the nurses there is no dialysis. The task orientated style the nurses work with offers a means by which relationships may be kept under control. The nurses have the control because they control the machinery in the HHU.

In the HHU the nurses do not want the patients to be involved in their care. One nurse commented “**If you give them an inch they will take a yard**”. The nurses control everything in the HHU. The ethos of home haemodialysis training is that the nurse hands everything over to the patient or the patient and his/her carer. In the HHU the behaviour is different. Patients are seen as not being able to take over any of their care. Patients are not receiving home dialysis for various reasons and this may preclude them from managing the entire dialysis process. The patients or carers who set up machines and assist with the dialysis have been trained to do so in the satellite cottage. They continue to assist in the HHU. Most nurses state they do not have the time or the knowledge to assess the patient’s self-care level. This is not regarded by nurses as a suitable way to spend time and thus is frowned on. If time were taken to bring every patient to their highest self-care level, the nurses would find that they have more time and the patients would become more empowered in their own management. However, the nurses might feel they would lose their sense of control if the patients were more self-caring.

On interview a number of patients identified the nurse as being busy:

“The nurses here are always busy so I do not interrupt them. They have their jobs to do and I do not want to disturb them with my problems” (interview P10).

The study reveals a small number of disturbing examples of nursing strategies to avoid contact with the patients. These include not noticing patients' efforts to attract the nurses' attention by being very busy, engaged in seemingly important tasks such that the patient feels inhibited about interrupting.

One patient was in obvious pain due to an ischaemic hand. She was very ill from sepsis and obviously found relief by raising her arm in the air. The problem was that the affected arm was the access arm in which her needles were placed. The only time that the arm raising gained any attention was when the arm raising triggered the machine alarms and then the nurse would yell from the desk to tell her to put her arm down. As described earlier the patient was not asked why she continually raised her arm and was not offered any pain relief (field note 26/03/02).

Another example is the way in which a particular patient would moan to try and attract the attention of the nurses. The nurses would avoid the patient by quickly passing the single room. The nurses were routinely seen to be efficiently and busily engaged in tasks with a manner that discouraged communication and relationships by imposing a barrier of activity. As the nurse is busy attending the dialysis procedures this is seen as a reason not to disturb the nurse with questions related to psychosocial problems. The nurses are not privy to the patient's individual concerns because the patients do not see the nurses as having time to listen or deal with them. This is a major barrier to the nurse's involvement in patient centred nursing care.

## **7.7 Chapter summary**

There are a number of recurring themes throughout the data and these themes impact on each other. The increased demand for dialysis services has resulted in the moral imperative to provide the treatments even though there are no extra resources. The nurses believe the quality of life of some patients starting dialysis is limited but this is not discussed with the nephrologists and the

nurses are not involved in the decision making processes regarding “who gets a machine”. Doctors require nurses to take on more functions and nurses see this situation as “technological dump”. They are hesitant to relinquish or “dump” part of their role to take on the challenge of the new functions.

The dialysis machine and associated treatment is the overarching construct in the HHU. Both doctors and nurses focus their attention on the dialysis treatment and this becomes a barrier to the development of interpersonal relationships between doctors, nurses and patients. The relationship between the doctors and nurses is impersonal and lacking mutual respect. Additionally the nurses are unable to form a therapeutic relationship with the patient where they can spend time getting to know the patient and his or her individual needs. The bottom line is that the management of the patient is less than adequate. Discussions on these themes and some possible ways of dealing with the issues are presented in the next chapter.



## **CHAPTER EIGHT - ETHNOGRAPHY DISCUSSION**

### **8.1 Introduction**

Five main themes from the study data have been identified and these themes are discussed further in this chapter. These themes have major implications for the provision of nursing care to patients in the HHU. The implications of the findings and proposed recommendations are addressed under each theme.

### **8.2 “Doing more with less”**

The major pressure on the HHU is the increased demand for services. The number of patients is steadily rising and is predicted to keep rising (Department of Renal Medicine, 2004). This increase in numbers must be met with the available resources including physical space, machines and nursing staff. Unacceptable pressures are often placed on nurses in haemodialysis units to do more. The HHU is understandably not alone in this problem. Haemodialysis units worldwide are facing a number of problems including increasing costs, the nursing shortage and a growth in patient numbers, the majority of whom are sicker and elderly (VanBuskirk, 2003).

#### **The shortage of money**

There are a number of reasons why the mismatch between demand and resources may never be resolved. The provision of haemodialysis involves the use of sophisticated machines and a variety of consumables for each treatment. Therefore haemodialysis is an expensive procedure with the price per treatment presently costed at \$62 (T. Blow, NUM personal communication, January 14, 2005). This cost is based on the purchase of consumables directly related to the dialysis treatment and does not include the costs of nursing staff and other hospital based services or pharmaceuticals. The cost for providing haemodialysis per patient per year is approximately \$50,000 Australian (Wilson, 2004; Biganti, McNeil, Atkins, & Knight, 1999). The budget for health is finite and to provide additional funding to one service would mean that it is taken from another. ESRF is just one of the chronic illness programs competing for a share of the health budget and there is no doubt that the number of patients with other chronic conditions is also increasing.

It is unlikely that there will be a major injection of funding to cope with the increasing demand in the HHU. A major enhancement would satisfy the problem in the short term and this is evidenced by the current situation in the HHU. Redevelopment of the service to allow for more space and machines was in progress throughout the study. At the time of thesis submission the new unit was fully operational. After only a short period, the expanded unit is now experiencing the same dilemma it faced prior to redevelopment, that is, a greater demand for dialysis than the unit can provide (T. Blow, NUM. personal communication, March 10, 2005).

### **The shortage of nurses**

In addition to the shortage of space, there is also a limit to the number of nurses available to the HHU to provide the service. There is currently a global nursing shortage affecting the recruitment and retention of nurses worldwide. This is predominantly due to the influences of an ageing workforce, a decline in enrolments in undergraduate programs, changing working conditions and a poor image of nursing as a profession (Janiszewski, 2003). In Australia the additional influences of an outdated career structure and a health care system increasingly unable to meet the growing demand compound the problem (Wickett, McCutcheon, & Long, 2003). Although the nurse shortage has been established for a number of years, recent initiatives in NSW have resulted in an improvement in the number of nurses in the workforce (NSW Health, 2005).

The nursing shortage affects the ability of the HHU to attract extra staff and as haemodialysis nursing requires specialist skills and knowledge, the problem is more critical. Renal/dialysis is one of the key areas of shortage Australia wide (Department of Education Science and Training, 2002). There is limited response to advertisements for nursing staff and there is often more interest from nurses without haemodialysis experience for positions in the HHU (T. Blow, personal communication, March 10, 2005). Recruitment of inexperienced staff means the experienced staff have to carry the extra load until the new nurses are able to perform the treatments unsupervised. Additionally, the issue of specialist skills means it is impossible to get staff from the casual pool with

skills to assist in times of increased pressure due to staff sick leave or high patient acuity levels. Again the HHU nurses have to carry an extra load. The issue of limited nurses available to meet the increased demand is a critical one. If the nurses are pressed to continually provide more and more treatments, the time will come when the nurses will be so stressed that they will become “burnt out” and leave the unit and perhaps nursing altogether.

There are limited recommendations to ease the effects of the nursing shortage on the HHU. With no foreseeable end to the RN shortage, nurses will have to find innovative ways to care for patients and this cannot be done without the assistance of a lower level nurse. The EN would be the most appropriate category of assistive nursing personnel in the HHU. The precedent of employing ENs in haemodialysis units in this country has established this category of nurse as an effective and conscientious member of the renal health care team (Charman & Brown, 2004). The introduction of the EN role would free up the RN to provide more patient centred care. The introduction of the EN role into the HHU will be discussed further under the theme “dialysis centred care”.

### **The shortage of space**

The increased demand for dialysis results in a shortage of spaces to dialyse the patients. As discussed this has economic implications as more spaces can only be provided with more funds. Further redevelopment plans for haemodialysis services at the hospital highlights the way economic decisions are made in health care. The HHU is housed in an acute care hospital. It is situated there because of the medical and related services required to back up elderly and sickly patients who require treatments. Increased demand for services necessitated a plan to increase the total number of machine spaces. The best action to address this problem would be to relocate the new positions away from the hospital in a satellite area similar but larger than the current satellite cottage. The most cost effective redevelopment plan resulted in the satellite cottage and some additional spaces being relocated onto the ward area of the hospital leading to a further closure of acute care beds. There

seems to be no real insight into the best processes of care, just the most economical short-term way of approaching the issue. The redeveloped HHU is now over stretched and there are no more acute beds that can be closed to accommodate further expansion. Plans to find an appropriate place for a satellite unit is a priority and planning for a satellite unit began at the time of thesis submission.

An obvious solution to the problem of increased demand and the lack of space would be to decrease the number of people who require haemodialysis in hospital. There are a number of initiatives that would be useful in addressing this issue. If people with risk factors for renal failure were identified early and managed closely this would decrease the number of people presenting to renal units for end stage treatments (Johnson, 2004). Early detection and effective management are known to reduce the progression of chronic renal failure by 20-50% (Kidney Health Australia, 2004a). At least 1.7 million Australians are estimated to have early renal insufficiency. Additionally, around six million Australians have at least one of the following risk factors for the development of chronic renal failure - hypertension, aged more than fifty years, smoking, diabetes mellitus, proteinuria and Aboriginal or Torres Strait Islander (Chadban, Briganti, Kerr, Dunstan, Welborn, Zimmet & Atkins, 2003).

Currently, there is no national policy or strategy in place to reverse or manage the rapidly spiralling epidemic of chronic kidney disease (Kidney Health Australia 2004a). Kidney Health Australia is lobbying the government for a Ministerial Taskforce with the defined role to recommend national kidney health awareness, prevention and management programs. This taskforce is said to target a saving of \$780 million over ten years (Kidney Health Australia 2004a). As highlighted, there is a finite supply of money to fund every health initiative. Nevertheless, more funding at a health preventative level may result in reduced costs at the acute and more costly treatment end of health care.

People with early renal failure should be referred to a nephrologist promptly as late referral has consistently been associated with poor outcomes in patients

with chronic kidney disease (Huisman, 2004). Additionally, there is much in the literature about “renoprotection” and the way rigorous attention to aspects of management with blood pressure control a priority can stave off dialysis in most patient groups (Johnson, 2004). There is also evidence that people managed on pre-dialysis programs are more informed, more likely to take up home therapies and can result in a decreased risk of adverse patient outcomes at the time of dialysis initiation than those who are not managed this way (Holland & Lam, 2000). The meticulous attention to the above initiatives by general practitioners and nephrologists or the initiation of nurse practitioner clinics would also assist in reducing the number of people reaching ESRF requiring dialysis.

The introduction of a conservative pathway is an initiative being considered by the nephrologists. The conservative pathway will be the alternative to the pre dialysis pathway for ESRF management in elderly patients and those with serious co-morbidities who decline dialysis therapies. Patients may choose the conservative pathway, recognising that they will be supported to their death, overcoming the fear of abandonment that occurs when dialysis is not the chosen option (Oreopoulos, 1995). New patients approaching ESRF will also meet with the palliative care team so that they identify the service. This will enable less stress when the time comes that a patient requests withdraw from dialysis or treatment becomes futile (Weisbord, Carmody, Bruns, Rotondi, Cohen, Zeidel & Arnold, 2003).

It is evident that little can be done to stem the flow of patients into dialysis programs without a total reform of health care provision in this country. There is an emphasis on the sickness and curative model, which does not allow funding for health promotional activities. This is the major reason why national screening programs as suggested above are not in place. Additionally, there needs to be a shift in the management of patients with chronic diseases. There have been small changes with the NSW Health Chronic and Complex Disease Initiatives but ESRF was not an area chosen for this program (NSW

Health, 2004). Consequently, there are no recent initiatives in management of these patients.

Dialysis treatments in Australia are predominantly offered in government-run public hospitals. Only one private haemodialysis unit operates within NSW. Support for further units may ease the demand on the public system by allowing the privately insured patient to have treatments in the private system. This is something that is encouraged in other states but does not currently have the support of many nephrologists in New South Wales.

A further recommendation to reduce the demand on the haemodialysis service is to increase the number of patients eligible for transplantation. At the time of final writing, the issue of increased transplantation has been addressed. There are a number of patients who have been on the transplant waiting list for a protracted length of time for some longer than ten years (ANZDATA Registry, 2004). The likelihood of being offered a transplant with the current system of organ allocation was minimal. The system of organ allocation has changed at the start of 2004 and this has allowed an increased weighting for the length of time on dialysis (TSANZ, 2004). There has been an increase in transplants performed at the hospital from an average of nine per year to a total of 16 for 2004. This increase in transplant operations has not resulted in an easing of demand on the HHU. To be on the transplant waiting list the patient must be well and usually below 65 years in age. The major pool of patients on the transplant waiting list is the home haemodialysis group. Nevertheless, since the new initiative three patients from the HHU have received a transplant.

A move to provide for more patients to go home on haemodialysis may help alleviate the burden on hospital services. However, additional services are required to support patients in the home. The current service provides training and follow up for patients or carers able to attend haemodialysis at home unaided. Patients deemed unsuitable to perform the dialysis are not candidates for home haemodialysis and they continue to hold spaces in the HHU. A home visiting nursing service could assist patients "going onto the

machine”, most commonly seen as the most skilful component of the treatment. The new role of home nurse would be attractive for haemodialysis trained nurses and may prevent them becoming “burnt out” and leaving the profession. Home assistance is another overlooked health reform and nurses also need to lobby health care decision-makers for this initiative to become a reality.

Most factors leading to the increased demand for more dialysis are predominantly outside of the HHU and impinging on it. As discussed, there are a number of recommendations which can be considered to address this escalating problem. Renal nurses nationwide must be proactive in lobbying for early prevention programs and chronic renal failure management strategies that will aid in reducing the number of patients on hospital haemodialysis programs. Although there are shortages, nurses are the largest health care group providing renal care. Nurses in the HHU require a “voice”. If the nurses had a voice in their professional association they would be able to lobby the government for strategies to help stem the rise in dialysis patients.

### **8.3 “Who gets a machine?”**

“Who gets a machine?” is the second theme identified from the data. This theme flows from the first in that it can be argued that, if the nurses were not pressured to provide more dialysis treatments, there would be little discussion around who should and should not be having the dialysis. The majority of patients commencing hospital haemodialysis programs are older and sicker than in previous years. In Australia, all age groups showed an increase in the number of people requiring dialysis but the largest increase was in the age group 75-84 years (351 to 364 per million) and 65-74 years (351 to 375 per million) (ANZDATA Registry, 2003). This shift is evidenced in the HHU where 68% of patients are over 70 years of age with the oldest attendee being 83 years. To compound this problem, the demographics of the population in the hospital catchment area are more elderly than in other local areas. Hospital data indicates that the numbers of patients with significant co-morbidities

(cardiovascular, cerebrovascular, chronic lung disease or peripheral vascular disease) are also high (Department of Renal Medicine, 2004).

Nurses between themselves questioned the decisions to start or continue dialysis in some elderly patients as evidenced by a nurse's comments regarding the dialysis of elderly patients with co-morbidities. This finding is consistent with literature on this topic. A study was conducted to determine the percentage of elderly patients (65 years and over) nephrology nurses (NNs) believed should not have dialysis and to identify nephrology nurses' concerns about the appropriate use of dialysis for these patients (Badzek, Cline, Moss, & Hines, 2000). NNs across the United States were randomly sampled and surveyed. The significant finding was that NNs believed 15% of elderly dialysis patients should not be dialysed and most (80%) were troubled about the decision to start dialysis for some elderly patients. Quality of life issues were the primary concerns for NNs and the nurses were not concerned with the cost or considered age a factor in the appropriate use of dialysis for elderly patients.

Nurses, especially those who have been nursing dialysis patients for a considerable length of time, are keenly aware of the effect that dialysis has on the patient's quality of life. Indeed this issue highlights the fact that in some cases nurses do identify that patients are suffering. Nurses, as patient advocates, can do little about this issue when it arises. However, when nurses identify that patients are suffering or are in considerable discomfort this matter needs to be discussed with both the patient and nephrologist to ensure a resolution.

There are possibly a number of reasons why the more elderly and sicker patients are opting for dialysis treatments. An attempt to prolong life to its maximum has accompanied the successes of medicine and society's expectation for a long and healthy life. The previously held attitude of supporting people suffering with a chronic illness towards their death has been replaced with the philosophy that death should be forestalled by employing the advancing technology at our disposal (Trnobranski, 2001). Additionally, there is



a broad consensus in this country that people in our society, regardless of age, race, sex, religion and underlying disease, have equal rights of access to public medical facilities without consideration of the cost the treatment may ultimately entail (CARI, 2001). This situation is based on the principle of justice – the equitable distribution of goods and services among all persons (Botes, 2000).

The issue of the more informed patient may also provide support for patients expecting dialysis treatments to be available for them. Today health information regarding diseases and treatments are readily accessible via the Internet. Families of older patients have access to information that had previously been available to the medical profession only. In the past if dialysis were not seen as an appropriate treatment option, it would not have been discussed with the patient and s/he would have died “none the wiser”. Today the patient is aware of the possible treatment options and is proactive in discussing them with the doctor. Additionally there is strong pressure on the medical profession by the community and there is an accompanying expectation that the medical service provided is mistake free (Department of Education Science and Training, 2002).

The major implication of the more elderly and sicker patients having dialysis treatments is the financial strain this places on the health system. As discussed under the previous theme, the health system is stretched trying to provide services with limited resources. The life expectancy of the Australian population has increased steadily. The average life expectancy at birth in 1997 was 75.9 years for males and 81.5 years for females (Australian Institute of Health and Welfare, 2004a).

Dialysis of the elderly and those with co-morbidities presents more ethical considerations for health care workers. Paramount is the dilemma that arises when dialysis shifts from being a measure to prolong life to one which merely prolongs the dying process (Oreopoulos, 1995). Prolonging the process of dying is not in the patient's best interest, as it goes against the ethical

principles of beneficence - the moral obligation to act for the benefit of the patient and non-maleficence – the moral obligation not to inflict harm intentionally (Beauchamp & Childress, 1994). The moral objectives in health care subscribe to both the principles of beneficence and non-maleficence. When faced with decisions regarding the giving and withholding of therapeutic interventions, health professionals are required to estimate risk of harm versus potential benefit to the patient (Trnabranski, 1996).

The notion of a beneficial action relies on one's philosophical stance regarding the extent to which life should be preserved. A deontological ethical perspective is that the sanctity of life is of paramount importance and that life is considered to be absolutely sacred and invaluable. A utilitarian ethical perspective engenders an alternate view: the belief that the quality of life is of fundamental importance (Beauchamp & Childress, 1994). In the situation where decisions are made by physicians alone, the doctor's own personal stance would dictate the course of action s/he was to suggest. This could be in conflict with the patient's own beliefs. The decisions lie within the bounds of the physician-patient discussion, with family input for patients who are not competent to make such decisions. Decisions should be based on the medical capacity of the patient to sustain the treatment. The futility of care should be explained to the patient so that patients can make an informed decision regarding dialysis treatments.

### **Recommendations**

The first recommendation related to “who gets a machine?” is a contentious one. Previous attempts to control the allocation of dialysis treatments resulted in the formation of selection panels in the United States (Corea, 1998). These panels and the selection criteria used have been discussed in detail in the literature review section 3.2. Using resources only for those who are most likely to benefit from them when treatment cannot be provided for all is a utilitarian approach to solving this health care dilemma. This is not in keeping with principles of equity for all and the value of human life. These acceptance committees were disbanded with the introduction of legislation in the United

States in 1973, which made haemodialysis treatments available for all citizens (Pfetscher, 1993). As discussed, decisions in Australia regarding health care are based upon the ethic of health for all and equal accessibility to care. Acceptance committees, like those imposed in the United States in the 1960s, had very exclusive criteria and so do not comply with this belief.

Attempts at trying to formalise such issues as acceptance into a dialysis program have met with mixed responses in the literature. Moss, Rettig and Cassel (1993) support the development of guidelines for acceptance onto a dialysis program. Others have disagreed with formalising this issue, especially where guidelines would exclude patients with specific diagnoses (Miller, 1992; Kammerer, 1992). Price (1992) believes that acceptance criteria should be developed because of the costs to society of ESRF programs, especially when the patient is not benefiting. For over twenty years a scoring system known as the APACHE 11 has been used widely for the evaluation of disease severity and mortality prediction especially for Intensive care (IC) patients (Knaus, Draper, Wagner, & Zimmerman, 1985). A scoring system similar to the APACHE II could be developed for use in accepting patients onto dialysis programs.

Price (1992) suggested that decisions should be made and supported at a macro level and all practitioners should use the same medical criteria for determining who should or should not receive dialysis. Pfetscher (1993) argues that such a system might be more equitable than individuals being screened by an acceptance panel, as patients would be accepted or denied treatment based on a universally used set of guidelines. Additionally, a decision not to dialyse a patient can result in a legal challenge and this is one issue that is considered by the nephrologist when making decisions with the patient and family. Guidelines developed in the United States (Moss, 2001) in the last five years advocate a team approach involving all health team members as well as the patient and family.

“Macro” guidelines for acceptance onto dialysis have been developed in this country (CARI, 2001). CARI guidelines include a number of statements based on principles including ethical considerations. Guidelines can be used by health care workers to inform the decision to offer patients dialysis (CARI, 2001). There has been no formal evaluation of these guidelines and I am unsure whether they are utilised in practice. The problem with national guidelines is that all nephrologists and health care workers need to support them. If the decision was made not to dialyse a patient by the nephrologists at this hospital, the patient may be able to look around for a second opinion at another hospital and perhaps be accepted.

A second option available to the hospital dialysis service is to lobby for a committee responsible for reviewing difficult cases. Acute clinical ethics committees are not widely utilised in Australia. Gill, Saul, McPhee and Kerridge (2004) report on an acute clinical ethics committee that has been operational in a large Australian teaching hospital since 1999. The hospital-wide service has reviewed around 12 cases each year and each consultation varied widely in origin, content, purpose and motivation. Where possible the committee comprised someone with a legal perspective, someone from the health care professions, a member of the non-health community and a representative from the chaplaincy. The experience of the committee suggests that the acute clinical ethics consultation service may have a role to play in Australian hospitals. This type of committee should be explored as a hospital wide initiative and the renal service would make use of the service in making decisions regarding difficult cases.

Thirdly, nurses need to have a greater involvement in decision making around acceptance onto the dialysis program. This could be achieved by nurses becoming involved in the pre-dialysis program. This may only be feasible if the work of the nurses was reshaped to allow time to support such activities. The NCNC provides the pre dialysis education and assessment of patients but the HHU nurses may be able to have input by conducting the unit tours and organising discussions with patients already on the program. The nurses in

the HHU blame the doctors for the extra dialysis demand. Perhaps greater involvement in the acceptance process would give nurses insight into the process and difficulties of who should and who should not have dialysis. This is one initiative that the CNC could facilitate as part of practice development within the HHU.

Currently there is no case management meeting conducted within the dialysis service. This type of meeting is common in other dialysis units and is seen to be beneficial by all involved (Bannister & Torpey, 2004). The delineation of the ownership of the patient makes it difficult to conduct such a meeting without the presence of all nephrologists and for this reason there has been resistance from the nephrologists in the past. The issue of having a forum to openly address nurses' concerns regarding the dialysis of particular patients should be considered.

A fourth recommendation is for greater involvement of the hospital's palliative care team in the management of patients on haemodialysis. There is much in the literature around end of life care for ESRF patients, especially those who withdraw from dialysis. There has been little work on the effect of a palliative care intervention while patients are on dialysis. A pilot study to determine the acceptance of palliative care involvement in patients on haemodialysis has been reported (Weisbord et al., 2003). The study used a number of tools to assess seriously ill dialysis patients. Patients with a high rating on an instrument designed to quantify co-morbid illness (The modified Charlson Co-morbidity Index) were selected for inclusion in the study. The intervention involved assessment by a palliative care physician and the presentation of the patient at a multidisciplinary palliative care meeting where recommendations were generated. The recommendations were discussed with both patient and nephrologist and it was the responsibility of the nephrologist to implement the recommendations. The patient was again reviewed four weeks later to evaluate the patient's response to the recommendations and to offer further suggestions for improved care.

The major findings from the above study were that the patients' marked symptom burden, considerably impaired health related quality of life (HRQoL) and frequent lack of advanced directives made these patients appropriate candidates for palliative care. There was no difference observed in symptoms, HRQoL or number of patients establishing advanced directives as a result of the intervention. The patients and nephrologists perceived palliative care favourably despite its lack of effect in the study. This study was a pilot and further investigations of a similar nature are required. A palliative care intervention may be a useful initiative to support the hospital haemodialysis population.

As discussed, the issue of "who gets a machine?" is ethically and morally a contentious one. Debate regarding the best way to approach this situation is required. There have been papers on the specific needs of our elderly dialysis patients, but how to shape our practice to meet these needs has not been addressed. Perhaps the HHU is experiencing this situation well before other dialysis units, making it more important that the issue be discussed with colleagues from other renal services. Moves have been made to plan for our ageing population (Commonwealth Department of Health and Aging, 1999) but if this process does not gain momentum this will have disastrous results on the already stressed health care system. Nurses need to consider future health care requirements and start planning now.

#### **8.4 "Technological creep": reorganisation of the work**

Historically, the haemodialysis process was a task performed by the nephrologist with the assistance of a number of nurses and support technicians (Hoffart, 1989). With the expansion of the therapy it became obvious that, in order to sustain the viability of the haemodialysis procedure, there was a need to assign more human resources to the process. The doctors relinquished the haemodialysis process to the nurses. Nurses took up the challenge and have been major providers ever since.

The nephrologists have identified that keeping patients alive on dialysis is no longer an issue. The main challenge is to support patients over a prolonged period of time to enhance physical outcomes and support a reasonable quality of life (Fukuhara, Lopez, Bragg-Gresham, Kurokawa, Mapes, Akizawa, Bommer, Canaud, Oport, & Held, 2003; Dhingra & Laski, 2003). This broadened view encompasses close surveillance and proactive management of vascular access, anaemia, bone disease, cardiovascular and peripheral vascular disease. The realisation that issues of lifestyle are valuable for a good long-term outcome is also slowly gaining more attention. The resultant workload for the nephrologist is beyond the scope of reasonable practice as s/he in turn takes on higher level challenges inherent in the “technological creep”. Other functions that have now become important for the nephrologist are involvement in research, academia and private practice. The nephrologist also has an increase in the number of dialysis and non-dialysis patients s/he is required to manage.

Some of the nephrologists have recognised that they are unable to manage demands placed on their time and wish to relinquish more functions to the RNs in the HHU. The difficulty is that the nurses in the HHU do not wish to take on these functions. The nurses are resentful toward the doctors because they have not been included in the decision making and see the new functions as the doctors “dumping” more work on them. In turn, the nurses are also hesitant about relinquishing the technical aspects of their work to another level nurse.

The attitude of the nurses is not consistent with the literature regarding the increased scope of practice of the RN. In the current health care climate medical and technical advances compel nurses to continually examine their practice. The impact of the advances mean that nurses are often placed in the position where they need to broaden their scope of nursing practice in order to keep up with the changing environment. This results in the nurses taking up the challenge by doing more of the traditional work undertaken by doctors (Chaboyer, Forrester, & Harris, 1999).

“Technological creep” is not only pertinent to dialysis but is seen in health in general. “Technological creep” is an obvious progression throughout health care over time (Ryan, 1996). It has resulted in practitioners at all levels requiring an increase in skill and by doing so dropping an aspect of their role which is presumably picked up by the next level practitioner. Nephrology nurses today fundamentally function as doctors have in the past (Iley, 2004; Rinard, 1996).

### **Recommendations**

It is recommended that the nurses be encouraged to become involved in the decision making processes related to their practice. The nurses also need to identify that they are accountable for their practice. These issues are also discussed further under the next theme. It is hoped that working with the nurses in a practice development framework will allow them to critically examine their practice and identify the need to move with changes in health care and to have a voice in the decisions around the way they would like to progress their scope of practice.

### **8.5 “Dialysis centred care”: a barrier to the development of interpersonal skills**

There is an overarching construct within the HHU where the machine and the provision of the dialysis treatment dominate and little else is seen. The doctors focus their attention on the dialysis and the related physical symptoms and management of ESRF. It can be argued that the doctors see the nurse as an extension of the dialysis process and therefore this obscures the nurses as co-professionals and dialysis treatments becomes a barrier to the development of interpersonal skills between the doctors and nurses. The nurses also focus on the dialysis, rather than the patient. This results in the nurses not wanting to or being unable to recognise the suffering and pain and discomfort patients may be experiencing. Depersonalisation is occurring across the HHU because the emphasis of the care is on the dialysis treatment and not on the patient.



The emphasis on the dialysis also acts as a barrier to the development of interpersonal skills between the doctors and nurses and nurses and patients. Tension exists between doctors and nurses over a number of issues in the HHU. Firstly, there is conflict regarding the selection of new patients to be included in the dialysis program. Nurses have no control over who receives the dialysis. They blame the increasing number of patients and the number of elderly sick patients receiving dialysis on the doctors. This situation adds to the tension on the relationship and has been addressed under the second theme, "who gets a machine?". Secondly, there are tensions regarding the work organisation within the HHU. Some of the doctors would like the nurses to take on more functions but the nurses are reluctant to do so. Thirdly, there is little communication between doctors and nurses. The two groups rarely speak to each other and only communicate through a letter. Although the letter is an adequate way of conveying information regarding the effect of the dialysis treatment on the patient, it does not enable the development of relationships based on mutual respect.

Within the HHU, the status and power reflected in medical dominance has been sustained over the years and tolerated either intentionally or unintentionally by nurses. The aetiology of medical dominance is multifactorial and includes the historical legacy of the development of dialysis services at the hospital since the late 1970s. The HHU service has been based on medical protocols and the nursing care has evolved and been guided by the medical staff. The nurses have traditionally been the providers of the dialysis and not the decision-makers. Until recently senior nurses have had little input into protocol review and strategic planning for the renal service. Unfortunately, the nurses within the HHU still have minimal involvement in the way the service is operated. Consequently, the nurses feel they have no voice and are hesitant to be involved in decision making because they lack the confidence and skills to participate. This situation is encultured in the HHU and the nurses maintain the status quo by not challenging the power of the doctors.

Friction in the relationship between nurses and doctors is not unique to the HHU. There is a considerable amount of literature addressing the relationships and interactions between doctors and nurses, for example Ryan (1996), Sweet & Norman (1995), Stein, Watts & Timothy (1990), Stein (1967) and Hughes (1988). Suggested reasons for the tensions in the relationship between doctors and nurses have been attributed to gender and associated sex role stereotyping, historical origins of the professions and disparities between the socioeconomic status, education and socialisation of the two professions (Larson, 1999). Additionally, changing domains of practice and changing role relationships have been identified as contributing factors (Ryan, 1996).

Stein (1967) argues that the traditional dominance/subservient relationship that has developed between doctors and nurses is a result of the initial socialisation of students in medical and nursing programs and continues throughout their respective careers. Stein's landmark article, "The doctor nurse game" describes how nurses were required to be bold, have initiative, and be responsible for making important recommendations, while at the same time appearing to defer passively to the doctor's authority (Stein, 1967). Nurses were required to communicate their recommendations without appearing to make them. Stein, Watts and Howell revisited the doctor-nurse game in 1990. They noted that significant changes to health care had resulted in changes to the "game". Firstly, there were more females in the medical profession, which meant that elements of the game related to male dominance and female submissiveness were missing. Secondly, they noted that a shortage of nurses in some areas had highlighted the value of nursing in health care and that nurses were better qualified with improved responsibility, roles and independent duties. Stein and his colleagues believed that the majority of nurses had stopped playing the "game" and that it was the assertiveness of the nurses that had absolved them from the "game" (Stein et al., 1990).

Hughes (1988) conducted a participant observation study in an emergency department to examine doctor-nurse relationships. He found that the dominance of the doctor was considerably lessened. The situation was due to

the contribution made by nurses in the diagnosis and treatment of patients in the specific setting. This situation can be seen in the HHU between nurses and inexperienced doctors, especially a new dialysis registrar. Although, some of Stein's original insights into the doctor-nurse relationship are present in the relationship between nephrologists and nurses in the HHU today. An example is the way the nurses compile a letter to the nephrologist before each patient visit. Issues of concern are highlighted by nurses on the letter but they are unable to effect changes to the patient's treatment regimen without formal medical approval which comes as a response to the letter. Nurses may have initiated discussion on these areas of concern but they rely on communication from the nephrologists to confirm them. Wellard (1992) studied the dilemmas that exist for haemodialysis nurses in dialysis units. The study revealed that the relationships formed, including those between doctors and nurses, were a dilemma for nurses. One finding was that nephrologists were generally not readily accessible to the nurses and the majority of communication was through the registrars.

The relationship between the doctors and nurses appears to be self-fulfilling in that it is not challenged and the two groups appear to continue without openly confronting each other. The reason this situation is perpetuated is the focus by the two groups on the dialysis treatment and not on building relationships in which there is mutual respect.

### **Recommendations**

I believe cultural change is an imperative within the HHU. If there are to be changes in the working relationship between the doctors and nurses in the HHU a change in attitude and perspective of both groups toward one another would be essential. This might be achieved with improved communication. Nurses and doctors need to be more aware of the conditions under which the other practises. There needs to be an exploration of shared values and a change in behaviour to ensure they are upheld. Nephrologists need to have a presence on the unit in order to build a relationship with the nurses. Meetings in which the doctors and nurses discuss cases or departmental issues would

assist in breaking down the divide. Decisions about patient care should be collaborative and this is also seen as a remedy to assist factors contributing to all themes.

I believe an emancipatory approach to practice would enable the nurses to reconstruct their nursing practice enabling challenges to the status quo. Nurses need to critically examine the manner in which they participate in and perpetuate the insidious nature of their oppression. The nurses need to be involved in the decision making processes. Nurses have to be empowered to change their care and to be more autonomous and accountable (Chiarella, 2002). The dialysis nurses underestimate the power and expertise they possess as a group. Nurses are the biggest health care providers and they need to join and be active in professional groups.

The study has established that nurses within the HHU are focused on providing dialysis treatments. Nurses in the HHU spend much of their time preparing machinery, connecting and disconnecting patients from the machine and attending non-direct patient care activities. In essence, the nurse is nursing the machine and not the patient. Factors that support the technologically focused care are the time constraints of an increased workload, an unwillingness to take on new roles and an evolving shared attitude that the nurses are in the unit to provide the dialysis. The culture has evolved where nurses are both unable and in some cases unwilling to provide patient centred care which addresses the total needs of the patient. Nurses are providing more dialysis treatments to more dependant patients. The patients are sometimes suffering without recognition because the nurses are focused on managing the dialysis process.

Technology focused care is not consistent with the core values of nursing. The review of the literature on the provision of nursing care to patients requiring haemodialysis (chapter two) endorses the caring component of nursing and emphasises that a nurse is responsible for caring for the “entire” person. Additionally, machine focused care is not consistent with the literature related

to the role of dialysis nurses. Ran and Hyde (1999) argue that the role of the dialysis nurse goes beyond technical expertise to include the roles of care giver, advocate, educator, facilitator, mentor and referral agent. The relationship between the dialysis nurse and patient is described as being a close therapeutic one which results in open communication in which the patient may confide in the nurse about sensitive issues (Stewart et al., 1995).

Findings regarding the roles of the nurse have major implications for future nursing in the HHU. The hospital is employing registered nurses, some with CNS status to provide technology-focused care. There are a number of aspects of the RN role that could be safely and effectively relinquished to other workers. Nurses were witnessed performing a large amount of unit related administrative duties which could be allocated to a ward clerk. This situation has been resolved since the study was undertaken with the introduction of a unit ward clerk. The non-nursing tasks such as restocking and cleaning could be given to a non-nursing assistant such as renal therapy attendants (RTA). RTAs are currently employed in some South Australian haemodialysis units and are seen as integral members of the team (Frost, 2004).

Traditionally, throughout the hospital, in situations where only technical expertise is required, the RN position has been relinquished to a technician. This includes, for example, electrocardiograph recording and phlebotomy. The literature reveals that there is a precedent for employing technicians within the haemodialysis setting (Dunetz & Paret, 1996; Burrows-Hudson, 1990; Kammerer, 1988). ENs are also a category of personnel who could become the major providers of treatments in the unit. Recent legislative changes have enabled ENs an increased scope of practice with the inclusion of medication administration (Nurses and Midwives Board of NSW, 2004a). The EN now has the capacity to administer the medications essential to the process of dialysis. More units are successfully employing ENs in the role of dialysis providers.

Replacement of RNs by trained technicians or ENs would reduce staff costs substantially. For example the annual wage of an EN is around \$38,000 and

the wage of a RN is from \$48,000 to \$58,000 depending on year of service (Nurses and Midwives Board of NSW, 2004b). Both wage rates are exclusive of penalties. There is no legitimacy in saying that tasks should be performed by RNs because they always have been.

At the time of submission of this thesis, ENs had been introduced into the HHU. This change was not seen as a way to free up the RNs but as a means of increasing nurse numbers in an acute RN shortage. The ENs were introduced in an assistive role taking over the non-nursing duties and some of the dialysis procedures. The numbers are minimal (four only) but there are tensions between the two groups. It is common for tensions to occur when RNs are working with ENs (Anonymous, 2004; Murphy, 2004). The RNs feel threatened and fear that the EN role may develop to take over all of the technology including the cannulation. If this occurs they believe that they will lose their place in the unit and there will not be a role for the RN.

There is a counter argument that once other supportive personnel are introduced into the HHU, RNs would need to re-establish their role. RNs would be free to manage a caseload of patients concentrating not on the technical care but on patients' total needs. These needs include the review and evaluation of the individual dialysis prescription, the education of patients and families willing to have more input into management and the proactive management of dialysis related side effects such as anaemia, vascular access monitoring and bone disease. The RN would also have time to spend with patients assessing care needs from a patient centred focus and supporting and referring as required. This new role of the RN can only become a reality if the RNs in the unit want it and identify that it can happen and approach it as a team. The new role would require greater expertise and accountability for care. The study results identified that a number of nurses were not willing to be seen as accountable in this way. Increasing accountability would require a total shift in philosophy and attitude. The other drawback is the RNs' lack of knowledge of the strategies necessary to deal with patient centred issues. Intensive

education of nurses based on individual needs can be provided by the current education and support staff.

There still remains the issue of RNs being willing to balance the technology with case management roles. Interviews with RNs have revealed a preference to maintain the management of the technology in their work. The technology seems to be a major enticement to working in the unit and most nurses expressed their pleasure in operating the technology. However the risk of maintaining the status quo is that if a reshape of the RN work were not forthcoming the RNs could be totally replaced. Technicians or ENs could provide the dialysis and a nurse practitioner and social worker could concentrate on the patient management issues.

In summary, the dialysis and not the patient is the focus of care in the HHU. The outcome of this technology focused care is the lack of development of effective interpersonal skills between doctors and nurses and nurses and patients. The affect of an ineffective relationship between doctors and nurses must surely result in a diminished quality of patient care. Clearly the actions performed by doctors and nurses in the clinical setting have a significant impact on each other and on the patients receiving care. The failure of nurses and doctors to work together, to share decision-making and to communicate is not only undesirable but also actually unethical because such behaviour fails to focus on patient needs and can produce harm (Larson, 1999). Doctors and nurses can both benefit if their relationship becomes more mutually interdependent as subservient and dominant roles are both psychologically restrictive.

Where the patient group is most needy, the nurse is not acting as s/he could to help the patient to overcome the difficulties. The nurse is providing the treatment only, that is, nursing in the HHU is about nursing the dialysis and not the patient. This is not in keeping with the traditional values of nursing and the provision of patient centred care. Therefore, nurses need to decide whether they wish to change their practice or risk being replaced in the future. Nurses

may feel vulnerable about changing their practice so change must be approached with sensitivity and recognition of the need and commitment to change from the nurses. This situation may be achieved by exploring the nurses' value systems to identify what it is to be a "good" nurse. Nursing in the HHU revolves around doing the tasks of dialysis and technical competence alone is valued. The NCNC needs to work with the nurses to identify what the focus of the role of the RN in the future could be and what difference a more patient centred approach would make to the long-term patient outcomes.

The haemodialysis nurse is "technologically enframed" and it is a dilemma for nurses (Bevan, 1998). An inability to provide the nursing care may lead to a loss of identity. There is a need for nurses to consider their future in the unit and skilfully plan for change. The nurses will need to decide whether the care they provide will remain aligned with the technology of the dialysis treatment or if they must relinquish this aspect of management to concentrate on more patient focused care. With a continued focus on the technology and not the person, the nurse is not in an appropriate place to be able to recognise or respond to the holistic concerns of the patient.

### **8.6 "The bottom line": the dialysis is the focus of the nursing care**

"The bottom line" is that the patient is powerless within the relationships in the HHU. Dialysis is a life supporting treatment and patients expect and want to have dialysis provided for them. Patients present to the HHU and receive the dialysis but little support is provided in relation to life style issues. As may be expected, the literature review has identified a plethora of problems for the patient living with dialysis (see chapter two). These issues are not seen as the responsibility of the health care team and patients need to seek out help with non-dialysis issues on their own. This is problematic for patients who are elderly and infirm or working under time restrictions due to dialysis commitments. In a number of instances non-dialysis needs remain unmet resulting in unnecessary suffering and discomfort for patients.



Patients interface most frequently with nurses because they are the major care providers in terms of time. The reductionist nature of the nursing is highlighted by nurses focusing on the technology, resulting in other patient care needs being left unmet. If the nurse was to identify and address problems with the patient it would improve the patient's quality of life.

### **Recommendations**

It is recommended that the nurses in the HHU urgently review their practice and develop an appropriate way of redesigning the work so that the patient, rather than the provision of the dialysis, is central to practice. I suggest a two step approach to the problem. Firstly, it is necessary to examine the skill mix within the unit. The employment of other assistive personnel may free up time for RNs to provide more patient centred care. Secondly, nurses need to investigate models of care that address the needs of the chronic patient requiring haemodialysis and identify the way that these models might be effective in the HHU.

My vision is that whatever model is chosen or developed should have a case management focus. RNs could be called primary nurses but have an increased input into aspects of care that have been traditionally the domains of the doctor. These aspects of care would include referral regarding non-dialysis physical issues, management of social, psychological and spiritual problems and the proactive surveillance and management of long-term effects of the treatment. RNs would be able to balance a comprehensive primary nursing role with the technology if assisted by ENs. This is only one solution and the nurses may be able to identify others during practice development work.

A comprehensive primary nursing model provides the nurse with the time to get to know his/her patient on a holistic level and not just know information about the dialysis. Nurses would have the time to spend with patients assessing their self-care level and coaching them to achieve an optimum quality of life. Nurses could discuss issues around management with patients

resulting in the patients having greater input into their own management. It is assumed that not all patients want a partnership in care. Some, especially the more elderly and sicker, are maybe happy for the nurses to provide the care. If the nurse truly knows the patient, s/he would be able to identify the level of involvement in care the patient wishes.

Redesigning nursing care to ensure the nurses are nursing the patient rather than the dialysis treatment is one area the nurse could play a major role in changing. Nurses in the HHU feel that they have no input into decision making and do not need to change their practice. For this reason it is important to work with the nurses in a practice development framework in order to empower them to review and examine their own practice. The above are some suggestions about the changes that need to be made. If the nurses were given the opportunity and support to examine their own practice they may identify other ideas which have meaning for them. The problem of the patient getting less than adequate care would hopefully lessen from the efforts to address the other themes arising out of this study.

## **8.7 Ethnography summary and conclusion**

This section has reported the findings of a study primarily investigating the interactions between patients and nurses in the HHU. The study has described the culture of the HHU to address the research aims to:

- 1 Acquire a comprehensive understanding of how nursing care is conducted;  
and
- 2 Identify the structural and interpersonal enablers and barriers to the provision of patient centred care.

The ethnographic method utilised observations and interviews to address the research aims. Five major themes were identified: “doing more with less”, “who gets a machine?”, “technological creep”, “dialysis centred care” and “the bottom line”. All of these themes were seen to impinge on the nurses’ ability to provide patient centred care to patients in the HHU.

Traditional systems of care delivery are being scrutinised for their clinical and cost effectiveness. Nurses in the HHU need to feel confident about their role by beginning to understand how delivery of these activities can be improved to take account of wider social, economic and technological changes. Haemodialysis nurses need to stand back and view their current practice and the effect these pressures have on their ability to provide nursing care for the patient. The bottom line is that it is affecting nurses' ability to identify and address patient issues negatively.

The findings from the study provide evidence that nurses in the HHU do not provide patient centred care. These findings were conveyed to the nurses during the next phase of my research. The practice development work conducted with the nurses in the HHU is the next component of the thesis.

## **PART C – PRACTICE DEVELOPMENT (PD)**

### **CHAPTER NINE – THE KEY TO SUSTAINABLE CULTURAL CHANGE**

#### **9.1 Introduction**

The final component of the thesis is a discussion on the practice development (PD) conducted with the nurses in the HHU. The PD project was commenced using findings of the ethnographic study. This process was undertaken to enable the RNs working on the unit to have ownership of the changes and evolution of the clinical work.

A definition of PD and an overview of the literature are provided. Some examples of the way that nurses have effectively used PD as a process to effect change in practice are incorporated. As the facilitator role is integral to the PD process, the role and required attributes of the facilitator will be examined. The additional knowledge, skills and support mechanisms I needed to ensure effective facilitation are also discussed. The final section of the chapter is a discussion of the activities and outcomes of the PD work.

#### **9.2 Practice development**

The PD movement has arisen out of efforts to modernise the National Health Care Service in Britain. As a result, much of the work published regarding PD has emanated from the United Kingdom. Within the literature there seems to be a lack of clarity regarding what PD involves. The need to clarify the concept of PD was the impetus for a major study by McCormack, Manley and Garbett (2004). The three-stage study aimed to describe the foci of PD work and the approaches used as well as to develop a framework to help clarify and focus the work for those who engage in PD. The first stage involved a literature analysis of 117 items of published material. The second stage, attribute verification, involved looking for the use of concepts identified in stage one. A selective search of the literature in addition to focus group interviews were conducted with nurses involved in PD. Stage three, identifying manifestations of the concept, involved refining the components of the concept and describing

how they are manifest in different groups and settings. Focus groups and telephone interviews were the methods used for exploring the meaning and dimensions of key ideas emerging from the study. The following comprehensive definition clarifies the concept of PD:

“Practice development is a continuous process of improvement towards increased effectiveness in patient centred care. This is brought about by helping health care teams to develop their knowledge and skills and to transform the culture and context of care. It is enabled and supported by facilitators committed to systematic, rigorous continuous processes of emancipatory change that reflect the perspectives of service users (Garbett & McCormack, 2002 p88).

The key purpose of PD is to transform the culture of care so that it becomes and remains patient centred and evidence based. The literature reports a number of instances where PD has been used successfully to achieve this goal. For example Wilson and Keachie (2003) report on practice development within a special care nursery. The staff of this unit began an action learning set, one of the key methods used in PD. An action learning set allows a group, with guidance of a facilitator, to discuss matters of concern and potential methods for resolving these and the process has the power to develop more effective leaders (McGill & Beaty, 1992). Wilson and Keachie (2003) describe the way nurses established the action learning set and the personal growth they experienced from participation. The initiation of action learning sets would be limited within the HHU. To allow an effective process there would need to be a number of action learning sets. Each action learning set meets for two hours to half a day at least monthly. The workload within the HHU does not allow all nurses to have release time to meet. This is one strategy worth considering with a select group of nurses for example the clinical nurse specialists. This group may benefit most from the development of their clinical leadership skills.

PD has been used as an approach to working with older people in an effort to improve patient care provision and to develop a new key facilitator role (Wright

& McCormack, 2001). The project demonstrated a systematic approach to PD utilising a ward leader in the part time role of PD facilitator. The aim of the project was to identify how nurses could contribute to the rehabilitation of older people, to devise a program of change that would improve the overall quality of care, and enable nurses to assume the role of case manager. A number of measures were used in a baseline evaluation of the ward including patient interviews, a documentation audit, an RN questionnaire and a QUALPAC score for the ward. The QUALPAC is a well validated instrument with known reliability used to measure the quality of care. Adoption of a four-phase framework ensured a systematic approach to the change process and enabled the ward leader to develop her role as a facilitator of change. The four phases were orientation, preparation for change, process of change and its evaluation and comparative analysis. The nurses, under the facilitation of the ward leader, worked through the four phases.

The major practice initiatives focused on changes to the routines and rituals of the ward. Additionally, an action learning set facilitated by the ward leader aimed to encourage and support the nurses in learning and developing professionally and personally through reflection on their shared leadership experience. The same evaluation methods were utilised following the project. The outcome of the project was that registered nurses developed their skills and knowledge in clinical leadership and nursing care moved away from only meeting the physical needs of the patients, to a more individualised approach to patient care (Wright & McCormack, 2001). These are only two examples of the many ways that PD is used in nursing.

### **9.3 Facilitating practice development**

Though the facilitator role is crucial to the PD process, there is little in the literature related to the facilitation of PD. A study has been conducted to describe the meaning of facilitation, exploring its key features and characteristics and reviewing research into the effectiveness of facilitation in relation to clinical practice (Harvey, Loftus-Hills, Rycroft-Malone, Titchen, Kitson, McCormack, & Seers, 2002). The study involved a review of the health

care literature focusing on the use of facilitation where an explicit facilitator role was adopted to promote change in clinical practice. The review indicated that for facilitation to exist as a discrete concept, certain key elements need to be in place. These elements are a clear understanding of the facilitation process, an appropriate role (the facilitator) to enable the process, with the right set of skills to achieve effective facilitation (Harvey et al., 2002).

There are two approaches to facilitation - the technical (task) and the emancipatory (holistic) approach (Manley & McCormack, 2003). The aim of the technical approach is to achieve a goal or task. When working in the technical mode of facilitation the facilitator is seen as the expert and it is usually the ideas of the facilitator that are being worked on by the group. To achieve emancipatory PD (EPD) the facilitator works differently. EPD focuses on the social system as well as the individual practice of the group members (Manley & McCormack, 2004). The facilitator of EPD:

“fosters a climate of critical intent through reflective discussion involving various “ideas” of the group members and assists the group’s enlightenment through nurturing a culture which enables individuals and the group to act” (Manley & McCormack, 2004, p42).

Simply, the overall aim of the emancipatory approach is to enable individuals and teams to become empowered to develop a transformational culture in their individual and collective service that can nurture and sustain the development of a particular goal or task.

Rather than viewing technical and emancipatory facilitation styles as being two different styles, I chose to integrate the technical with the EPD approach in the work conducted within the HHU. An integrated approach was chosen as I supplied the group with the problem. Initially, the problem was my concern rather than the nurses’. I had a clear idea of the direction in which I wanted the work to proceed – toward the nurses providing more patient centred care. I also believed that the PD would do more than just enhance the amount of patient centred care within the unit. By facilitating PD I was aware that it could also change or “shift” the culture within the HHU. For this to be a realistic and

sustainable change I had to introduce aspects of EPD. Although I initiated the PD and supplied the problem it was necessary for the nurses to work within the group to critically examine their practice, reflect on the processes and implement change in their practice behaviours.

#### **9.4 Preparation of the NCNC for the PD facilitation role**

As the NCNC, I was in the position to facilitate PD with the nurses in the HHU. Initially, apart from technical skills, I had limited formal skills or knowledge in the facilitation of PD. To overcome this I attended the International Conference in Practice Development and a five-day summer school to enhance my skills in PD facilitation (See Portfolio A and B).

Although I had attended forums on PD, I was still a novice PD facilitator. I initiated two strategies to support me further in the facilitator role. The first strategy was to seek out a critical companion. Critical companionship is:

“a helping relationship in which an experienced facilitator accompanies another on an experimental learning journey, using methods of high challenge and high support in a trusting relationship” (Titchen, 2003 p33).

I identified that PD work with the nurses would be a challenge requiring constant support to “keep it going”. The critical companion I chose offered me the type of support I required, I met with her regularly and continue to meet during ongoing PD work.

The second strategy I initiated to assist in the PD was an action learning set. I circulated an expression of interest to all CNCs and educators within the Medical Division. I was overwhelmed with the number of responses I received. A group was formed that had no prior experience with an action-learning mode of development. Subsequently all have found the process an effective way to reflect on their practice within a high support and high challenge environment. The group meets monthly for two hours. The action learning set was convened to assist me to develop as a facilitator so that I could more effectively facilitate the PD work in the HHU.



## **9.5 The setting and participants**

I commenced PD with the nurses in the HHU at the end of 2003. At this time, the HHU building redevelopment was complete. The satellite cottage closed resulting in the relocation of staff and patients to the main HHU area. The total capacity of the HHU is now 34 patients each shift (136 in total). The unit is divided into two distinct areas. "Acute Care" is the section originally established as the HHU, and "Minimal Care" is the section, which was originally the satellite cottage. Staff and patients remain separated in either the acute or minimal care area with some movement between areas depending on staffing levels and the acuity of the patient. Patients from the minimal care area who require extra supervision or who are hospitalised are dialysed in the acute area in exchange for a more stable patient from the acute area. Reversal of the situation occurs when the patient recovers or leaves hospital. This was essentially the same process as had been conducted previously when the two areas were geographically separated. Staff are moved between the areas depending on sick leave and in some instances patient acuity. The staffing level in acute care is higher than minimal care due to the higher level of patient acuity.

Although I had conducted the ethnography in the previous HHU, the practices witnessed in the new combined unit were similar. I considered it necessary to conduct the PD work with all staff now employed in the HHU. There were around 30 staff employed in the unit at the commencement of PD work in 2003 and this number has grown to 43 RNs in 2005.

## **9.6 Preparation for practice development**

Prior to commencing PD in the HHU, a meeting with the NUM was arranged in order to discuss my intentions. The NUM provided her support for the project and offered whatever assistance was required. My biggest request was for assistance in the provision of time for the exercise and for the NUM to be present at as many meetings as possible. I felt that implicit in the presence of the NUM would be the acknowledgement that management supported the activity. Following consultation with nursing staff, PD meetings were scheduled

for the second Thursday of each month. The meetings were held at times normally allocated for meetings or education. Additional meetings and focus groups were convened as required.

I performed a literature search and prepared a Microsoft PowerPoint presentation on PD and how it has been used by others in examining practice. I believed that this would be an effective way to introduce the PD process to the nurses.

### **9.7 Practice development study aims**

I had conducted the ethnography to identify nursing care practices within the HHU. The preliminary data analysis showed that nurses focused on managing the dialysis process and not on the patient and their individual needs. I made the nurses aware of these findings firstly through a presentation at the hospital's nephrology nurses' education day and then through focus groups discussions which formed part of the initial PD work.

The overall aim of the PD work was to move the practice in the unit from one of machine and dialysis focused care to one where holistic management of the patient was undertaken. I also believed that the process of conducting PD with nurses would develop their capacity to become more involved in decision making processes about patient care which were previously lacking within the HHU and expressed in the ethnography findings. I felt that these two aims could be achieved through:

- Providing the nurses with the forum and support to discuss practice;
- Examining the barriers to patient centred care that had been identified in the ethnography and identifying areas that could be changed;
- Providing a mechanism by which the shared values and beliefs of the group could be made explicit;
- Developing clinical nurse specialists as leaders.

## **9.8 The process**

PD was a new concept for the nurses in the HHU and the first task was to provide nurses with information related to PD. A PowerPoint presentation on PD was given followed by discussion and an open invitation for interested nurses to participate in the project. There were over 30 nurses employed in the unit at the time and I identified that participant numbers may be an obstacle in programming meetings where all interested nurses could attend. I decided to start the process with as many nurses as possible and see what transpired.

Some of the themes identified in the ethnography encompass factors which are outside the unit but impinge on it. Working with the nurses using PD will not overcome barriers to patient centred care that are beyond the influences of the HHU nurses. The increased demand for dialysis services and the desire of more elderly patients to have dialysis are primarily dependant on societal influences and can't be affected by nurses at a local level. However, it is hoped that the process of conducting PD with nurses will develop their capacity to become involved in the decision making processes previously lacking within the HHU and expressed in the major research themes.

## **9.9 Practice development activities**

Within this section the activities achieved during PD work are presented.

### **Philosophy and Objectives**

To promote a cultural change the shared values and beliefs of the group should be explored and made explicit (Manley, 2004). Two focus groups were conducted in order to try to identify the shared values and beliefs of the nurses in relation to the nursing care they wished to provide. These focus groups were well attended with 20 nurses present at each session. The three major areas of the environment, the patient and the nurse were used as a framework for these brainstorming exercises. Information from this process helped to guide future directions and a draft unit nursing philosophy and objectives. Due to heavy workloads and reduced staffing levels, it became almost impossible to meet with the nurses during the following four months. To overcome the restriction of not being able to meet with the nurses formally, the philosophy and objectives

were circulated widely and repeatedly for comment. There were numerous drafts before the final document was established. The espoused philosophy clearly articulates the values and beliefs of the HHU nurses. The philosophy is posted in the nurses' tearoom and has become the common vision for them. A copy of the philosophy and objectives for the HHU is provided in portfolio C.

The major problem identified by the nurses was that they were unsure of how they could meet the statements contained within the philosophy. My research findings clearly established that the current practice of nurses did not reflect the philosophy. The philosophy statements were not representations of the way nursing was but the way the nurses wanted it to be. For the two to be congruent, the nurses have a major task ahead of them. Discussion with the nurses emphasised the importance of slow but effective processes aimed at cultural change. The outcome from these processes would not be immediate and could take a number of years to achieve.

#### **Patient information brochure**

The initial focus group discussions provided an enormous number of issues for the nurses to address. I suggested the group start with a small project that they could complete in the short term. This would enable the nurses to have a sense of achievement and provide the momentum to continue. The issue chosen was one that I had identified during the observation period.

The amalgamation of the two dialysis areas had resulted in a large flow of patients onto the HHU especially in the afternoons. Congestion of the dialysis area occurred regularly due to patients presenting early and not wanting to wait in the waiting area. It was obvious to the nurses that patients had a limited knowledge and understanding of the routine of the new HHU. There was a mismatch between patients' expectations and what the nurses were able to provide. The group suggested that the development of an information brochure would assist in communicating some of the rules and routines of the unit to the patients especially the "newies". A core group of six nurses worked on this project.

The next PD activity completed was the patient information brochure. The brochure outlines the HHU operating hours and the rules and routines that are particular to the HHU and the rationale for their existence. Discussion between the nurse and the patient and family around the brochure content has become the first component in the orientation of new patients to the HHU. Provision of a brochure to all patients within the HHU has ensured that they are cognisant with the HHU rules and routine. Patients were given the opportunity to read and comment on the brochure before it was finalised. The process of devising the brochure made it necessary for the nurses to critique the unwritten HHU rules and consider why they are in place. The rules essentially remained the same with the addition of an explanation of why the nurses would not tolerate violent behaviour toward nurses. This is in light of a number of incidents involving a difficult patient that have occurred within the unit. A copy of the patient information brochure is provided in portfolio D.

#### **What should the RN role be?**

During 2004, there were two major practice changes in the HHU. The first was the employment of ENs within the HHU. The sustained increase in demand resulted in the need to employ more nurses but unfortunately, there was limited interest from RNs. A job description was quickly developed to cater for the role of the EN. This job description is essentially the same as the generic job description for the EN employed in the hospital with the addition of tasks associated with the provision of dialysis. Although the introduction of ENs was a hurried process, the RNs welcomed the assistance of the ENs, as they were able to leave some of the more mundane tasks of restocking and organising to the ENs. ENs also "set up" and disconnect patients from the machines. Six-month evaluation of the pilot of ENs had identified that the ENs are effective in the provision of technical dialysis tasks.

The next step is for cannulation to be introduced into the EN role depending on whether the EN has completed the medication program. Currently only one EN has achieved the medication competency but this will not be an issue in the future as more ENs graduate with or pursue the medication program. The RNs

are hesitant about letting the ENs cannulate. This hesitancy was identified in the ethnography and continues to be the current situation. The RNs are happy for the ENs to assist them in the mundane aspects of their work but not in taking on the cannulation. There is ongoing discussion about the scope of the EN role in the HHU.

The developing role of ENs in the HHU has led RNs to examine what their future role might be. The RNs have expressed concerns regarding relinquishing all of the technical tasks to the ENs. They are currently exploring how they can balance the technical with the patient focused aspects of the role and how they can achieve the unit philosophy and objectives. I have conducted four focus groups with the RNs to help shape their job description. Six nurses attended each session. Discussions during these sessions focused on what nurses perceive their current practice to be and what it could be like in the future. The nurses also identified the barriers and supports for the development of their role. The focus groups were recorded on flip chart paper. I formulated the major discussion points from the focus groups into a discussion paper for wide circulation. The discussion points and additional comments were used to develop a draft RN job description. There has not been a job description for an RN in haemodialysis for many years. A job description for RNs in the satellite cottage was developed at the inception of the cottage but this has not been revised. The draft RN job description meets many more of the objectives stated on the unit philosophy. Copies of the discussion paper and draft job description are found in portfolio E and F.

### **Expanding the scope of practice**

The issue of nurses being involved in decision making is the key to the success of practice change in the HHU. Issues addressed so far in PD reflect aspects over which the nurses have control. The second practice change imposed on the nurses during the previous year, is that of the nurse initiated iron protocol. I identified in the research that the doctors wished to delegate more of their tasks to the RNs. Doctors and some senior staff with little input from the nurses in the unit developed the nurse led iron protocol. The protocol

was supported by the provision of intensive education and has been positively evaluated in that the iron and anaemia management on the unit has improved. The nurses identify that there is a need for such a protocol but feel that it adds to the increased demands on their time. Although they are doing the work and doing it well they begrudgingly do it as they were not consulted before the change. It is also an addition to their already heavy workload. Perhaps the nurse initiated iron protocol would have been better accepted if it had been introduced through PD processes to look at the RN role and in consultation with the group rather than on their behalf. The exercise has highlighted for me, the importance of PD in relation to all aspects of practice.

Another area of PD work has been in relation to the fluid assessment of patients. The ethnographic study identified that the nurses waited sometimes for prolonged periods for doctors to fluid assess patients. This issue has also been raised as a problem in focus groups. The nurses recognise that there is a problem related to the timely fluid assessment of patients and are currently investigating ways in which they can implement a better process. The nephrologists have been approached and give their support for the RNs to take responsibility for the fluid assessment of chronic patients.

### **9.10 The outcomes**

The positive outcomes of the PD work are reflected in the amount of activities and changes that have occurred since commencement. Although I planned to use both technical and emancipatory PD approaches, most of the work to date has been technical. Initially the process was slow but it has now gained momentum. A unit philosophy and objectives and a patient information brochure have been developed. Discussion by RNs about their patient care has led them to undertake values' clarification exercises. The outcome of these exercises was the formulation and enactment of a new draft job description. The aim was to provide care focused more on individual patient needs. The nurses are currently implementing these changes by undertaking fluid assessment of chronic patients which is essentially a medical function that has

been taken on by the nurses to improve patient care. The PD work is ongoing but the work for the thesis ended after development of the draft job description. The main aim of the PD work is to shift the culture from a more nurse focused model of care to one which is patient centred. All PD activities performed to date directly or indirectly arise from this issue. The majority of the PD work has been within the technical approach and this alone has led to shifts in the way the nurses approach their practice. The next step is to provide the nurses with a mechanism for sustainable personal and professional growth. I hope to enable this process by commencing action learning sets. There are now over 40 nurses employed within the HHU and the one drawback is the logistics of formulating the groups and allowing the time for the sets to meet. In a time when the HHU is busy and there are not enough skilled nurses this becomes problematic. The plan now is to introduce two action learning sets with the CNS staff. This will become the pilot and further implementation of action learning will depend on the outcomes of this process.

### **9.11 PD summary and conclusion**

The role of the RN in haemodialysis is evolving and taking on a new direction. RNs have been given the opportunity to explore their practice as a collective and there have been changes as a result. The process of PD has gathered momentum and is ongoing. Actions to define the role of the RN have resulted in the unit becoming more patient focused. Issues to address the need to meet the holistic nature of the philosophy are providing new and effective ways for the nurses to redesign their work to get back to the values underpinning nursing. From this work is evolving a new model of care which is in partnership with ENs and is focused toward the provision of the best possible care for patients. Cultural change is a slow process and it is hoped that practice development continues to be the means of supporting nurses to constantly examine practice that will effect cultural shifts in the organisation of the work.

In this chapter information on the process of PD has been discussed. The NCNC is in an ideal role to facilitate PD and I discussed the strategies utilised in my efforts to enhance my facilitation skills and prepare for PD with the



nurses. The aims of the PD work have been made explicit. The conduct of the PD work and the activities and outcomes to date have been provided. The next chapter is the thesis conclusion.

## CHAPTER TEN – CONCLUSION

### 10.1 Thesis summary

Patients in ESRF attending the hospital for haemodialysis are faced with a myriad of physical and psychosocial challenges. The physical manifestations of ESRF are numerous with cardiac disease, anaemia and bone disease being the most significant. Problems related to the provision of the dialysis involve the fashioning of the vascular access, which can be painful and present the patient with a distorted self image.

Dialysis is required three times a week and for most patients this will be for the rest of their lives. Patients must attend on the days and at the times allocated to allow for an increasing number of people receiving dialysis treatments within the HHU. In most cases, the limitations prohibit the patient from achieving rehabilitation to a level where they can maintain employment or an acceptable social life. Additional to the monotony of the dialysis regimen are the many restrictions placed on the patients and the way they lead their lives while not on dialysis. Rigid medication, diet and fluid regimens are required, as the process of dialysis does not replace all of the normal kidney functions. Furthermore, haemodialysis is an intermittent therapy, which results in a build up of fluid and toxins between dialysis sessions. ESRF also impacts on the spouses and family of patients requiring haemodialysis.

The ethnography showed that there is not one part of the patients' lives left untouched by renal disease and the associated treatment. In many instances physical and psychological suffering and discomfort is evident in patients who attend the HHU. The haemodialysis nurse, as the primary carer, is the best-placed health care professional to offer support to patients whom are suffering or feeling discomfort due to their treatment. The ethnographic study confirmed that the nursing culture in the HHU did not enable nurses the opportunity to recognise patients' suffering and discomfort and failed to provide any interventions to ameliorate it. The focus for nurses within the HHU needed to shift from care associated with the dialysis procedure to a more holistic patient centred model.

It became clear to me that as the NCNC, I was responsible for promoting the existing culture and therefore must be the person who would lead the change and promote a different model of care. I was motivated to improve the nursing practice within the HHU and embarked on a Professional Doctorate program to assist with the change process.

To investigate my concern about the model of nursing care being enacted I embarked on an ethnographic study of the HHU. Five themes were identified. These themes supported my original belief that nursing care in the HHU was not as patient centred as it could be. I considered that there could be no meaningful and sustained change to the way nursing care was conducted in the HHU unless I engaged the nurses in discussing and critically evaluating their own work practices.

During the course of doctoral study I was introduced to PD as a useful methodology for engaging the nurses in the examination of their nursing practice. I acquired skills in the facilitation of PD and commenced working with the HHU nurses. The nurses had support to shape their own practice and collectively the issue of the lack of patient centred care was addressed. Some change was initiated and there is growing evidence of a shift in the culture within the HHU. This shift is from a focus on the machine and the technical aspects of care to the patient and their individual needs. The PD work for this thesis is complete but within my role as NCNC, I have continued to facilitate the ongoing PD within the HHU. It is my vision that other natural leaders will emerge from the PD work that will enable the process to sustain without the NCNC.

## **10.2 The evolving NCNC role**

As highlighted in the introduction to this thesis, I have chosen a framework proposed by Manley to examine the evolution of my role as a NCNC. The development of my consultant role has occurred in conjunction with my experiences within the Professional Doctorate program. Figure 6 is a diagrammatical representation of how my role has changed within the five

areas proposed by the Manley framework. I will take each component of the framework individually and discuss the changes that have occurred.

The first component is that of **expert practitioner in nursing either as a generalist or within a specialty.**

When I commenced in the NCNC role six years ago the major emphasis of my work was the provision of expert clinical care to renal patients. I was regularly called upon by the nurses to troubleshoot difficult patient issues. In my journey as a doctoral student, there has been a slow but obvious shift in the emphasis of my work and I am no longer a technical expert as far as active involvement in direct clinical nursing practice. This role change has been most evident within the HHU. Within the HHU, there are now a number of clinical nurse specialists (CNSs) who have the technical skills required to manage the most difficult haemodialysis treatment. Notwithstanding these experiences, throughout the thesis I have highlighted my concerns regarding the nurses' lack of holistic care delivery.

The second component is the role of **educator, enabler and developer of others, thus enabling the development of practice.**

In my early days as NCNC, I spent much time instructing nurses on the basic concepts of renal nursing care. This was usually undertaken in the time allocated for weekday inservice. I have now relinquished all basic education to the senior nurses in the HHU. I now spend more time educating in specialty courses and university programs. Additionally, more of my time is now spent instructing nurses how to present an educational offering rather than presenting one myself. I used to enjoy troubleshooting difficult clinical situations because I was praised by doctors, nurses and patients for doing so. I have realised that it is okay to "dive in and fix things" but this provides others with few opportunities to learn. I have learnt to value the importance of sharing knowledge and enabling others to learn.

The third component is that of **researcher with specific expertise in practice based research methodologies.**

Before embarking on the Professional Doctorate program, I had little experience in research. The program provided me with the support to perform a qualitative research study, something I had not performed before. My knowledge and skills in research methodologies are in no way complete. However, I now have an appreciation of the different methodologies and I am aware of the resources available to assist me in further research attempts.

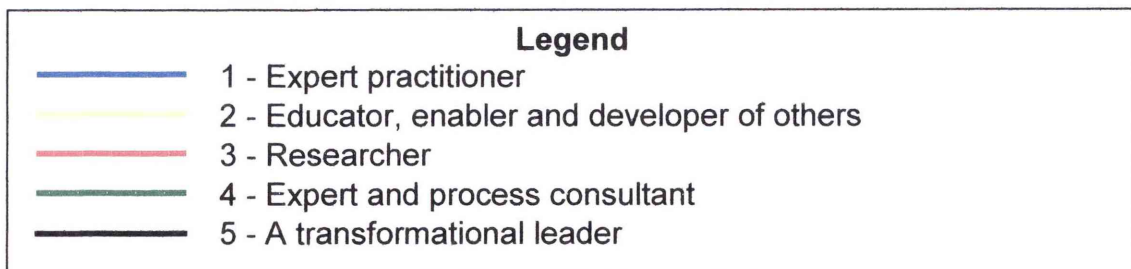
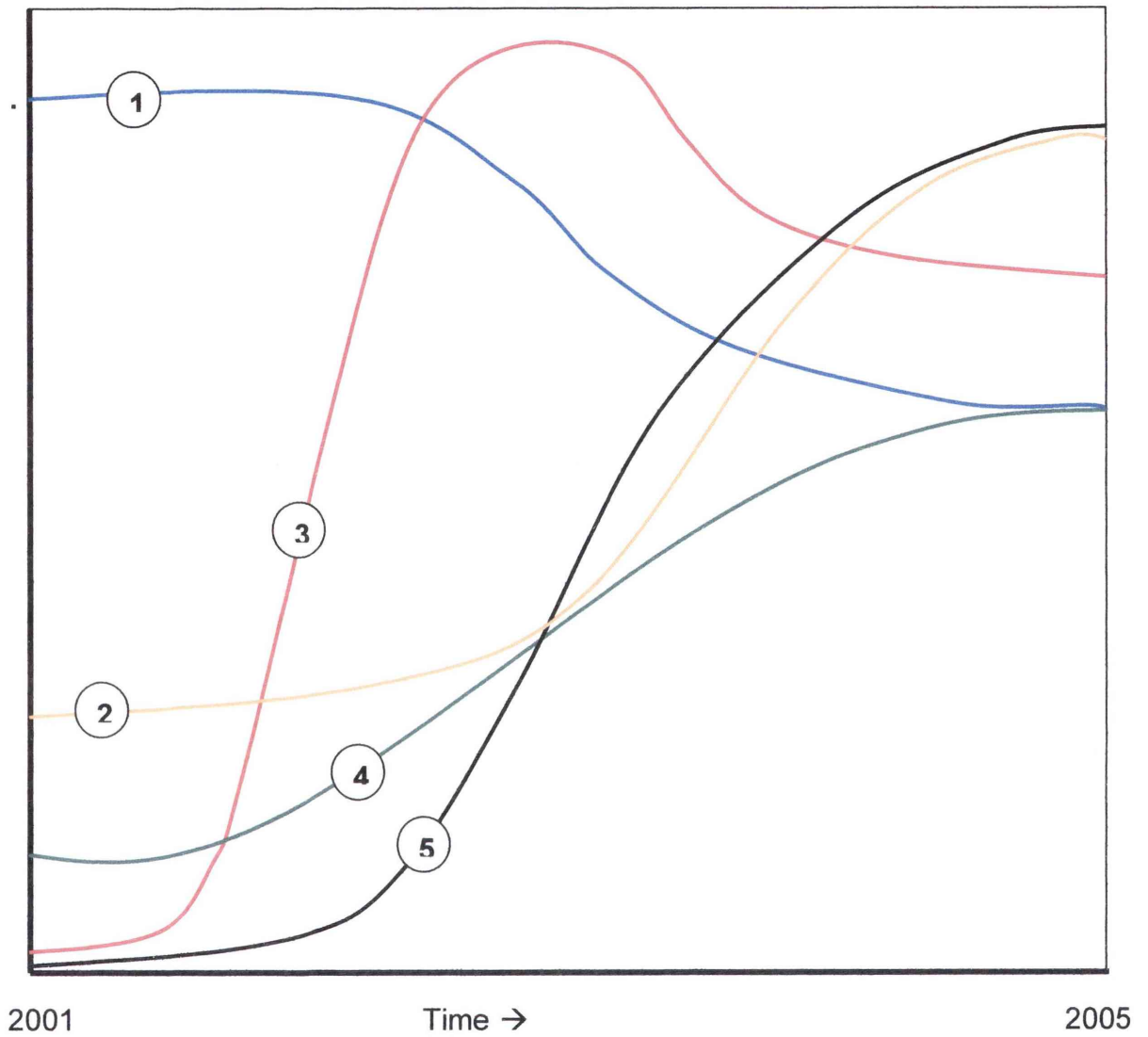
**An expert and process consultant from the clinical to executive and strategic levels** is the fourth component.

One area which has shown the biggest shift is my facilitation skills. This is most evident in the way I conduct and have input into meetings at all levels. It was necessary to advance my facilitation skills during the Professional Doctorate to conduct interviews for the ethnographic study and focus groups with nurses. Opting to facilitate action learning sets has also provided me with invaluable experiences and opportunities to facilitate difficult situations and discussions.

**A transformational leader, who enables a culture to develop where everyone can develop his or her leadership potential** is the final component.

The CNC usually relies on expert rather than managerial power therefore; clinical expertise gave me the power I required to make a difference within the NCNC role. I have now moved on to see myself not only as a clinical expert but a clinical leader. An effective clinical leader needs a vision and supports others through the change process. I am now helping others to develop and work towards an agreed vision. In this way, I am demonstrating transformational and transformative leadership.

Figure 6 - My Evolving Role as CNC



### **10.3 Limitations of the research**

This research was undertaken in a major Sydney teaching hospital. One limitation to the study is the continually evolving context of care. The health system is in constant change. I went to study the culture in the HHU and the physical unit was being redeveloped to form a newer and larger unit. A major redevelopment of the HHU was underway as the study was taking place and consequently the building redesign and development impacted upon the day to day running of the HHU. Although at the end of the ethnography a new unit opened, the practices identified in the research sustained in the new unit. Although the physical environment changed the culture of the HHU remained the same.

The ethnographic study identified that there were increased demands on the nurses and the workload of the unit was a problem during the PD component of the study. The nurses were not always available to meet at scheduled times and did not have time to allocate to the PD meetings. The issues addressed in the PD work included relinquishing some functions usually undertaken by RNs to other level nurses to free up time to spend with patients. As the PD work progresses beyond that documented for the thesis it is envisaged that the nurses will progressively recognise the importance and need for the PD work and will allocate precious time accordingly.

Nurses need to appreciate the social value of their work and to be able to defend and speak up for what they do. Nurses need the opportunity to talk about their work, to discuss ways of understanding nursing work so that the emphasis remains or becomes the centre of care. The nursing role and clinical behaviour requires close scrutiny as a basis for critique, analysis and reflection. Reflection, a demanding process, is an examination of the reality as each nurse finds it and all the dilemmas presented. I have presented a series of dilemmas for the HHU nurse, with more than one acceptable option for resolution. The options are consistent with different value stances and ways of understanding the world. The work done for this thesis is meaningful for the

nurses within the HHU but may be assessed and approached differently in another haemodialysis unit.

#### **10.4 Recommendations for further research**

This research has laid the groundwork for future work in the HHU. The study was undertaken to determine the provision of nursing care within the HHU but these issues should also be addressed in a wider perspective. There needs to be greater insight into what it means to be a nurse in the health care system and the demands placed on nurses. Nurses cannot be complacent. Nurses need to accept their own worth and to be vocal or the number of “burnt-out” nurses who leave nursing completely will increase. Nurses are valuable within a society that prizes excellence in health care provision and therefore nurses need to be supported if they are to stay in the profession.

Although the focus of the ethnography was the interactions between nurses and patients, issues around the relationship between the nurse and the doctor were identified. These warrant a more in-depth investigation. In this HHU the nurse-doctor relationship acts as a barrier to the provision of patient centred care. As previously stated, the findings related to the relationship between nurses and doctors are considered in keeping with the findings from a previous study (Wellard, 1992). The relationship between the nurse and the patient’s carer is also worthy of further investigation. The literature review identified that carers are under considerable stress and their lives are shaken by the patient’s condition (see chapter two).

Conduct of further work underpinning any of the issues identified within the HHU could investigate appropriate strategies to address these issues. Meaningful changes cannot occur if these are imposed on the nurses, as has been the tradition in the past. Nurses may change their practice if they identify that it needs changing and processes such as action learning (Rayner, Chisholm, & Appleby, 2002) and critical companionship (Titchen, 2003) may be the way to proceed because these strategies have been found to be effective by other researchers (Wright & McCormack, 2001).



In summary, the journey with the nurses in the HHU and personally within a doctoral program has enabled me to develop within the role of CNC. This highlights the importance of the academic development within the CNC role and the essential contribution the CNC can make in clinical leadership.

This journey has also enabled me to develop professionally in ways that have impacted on my colleagues but more importantly benefited patients. The research has enabled nurses to identify the model of care they enact on a daily basis and the impact of this care on patients. Engagement of PD as an ongoing process means that patients will become the focus of care and decisions made about how the care is provided.