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University of Southampton

**An Ethnographic Journey
to uncover the Culture of Dialysis Units**

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ABSTRACT

**FACULTY OF MEDICINE, HEALTH AND BIOLOGICAL SCIENCES
SCHOOL OF NURSING AND MIDWIFERY**

Doctor of Philosophy

An Ethnographic Journey to uncover the Culture of Dialysis Units

by Cordelia Ashwanden MSc (Dist), BSc (Hons), RGN.

A major challenge of the 21st century for the health-care professionals is to provide care for the ever-expanding population of people with renal-failure. Patient numbers are rising and specialist nurses, who are the pivotal factor in haemodialysis units, are becoming increasingly scarce. In this context it has become essential to understand the dynamics and functioning of haemodialysis units. The aim of this research project is to increase understanding of the lives of patients and carers by uncovering the culture of haemodialysis units.

Ethnography, from the naturalistic paradigm, is a holistic study of culture, developed out of classical philosophy. This study examines the entire social world of the dialysis unit. It describes the ethnographic journey made over twenty-four months' research in two different dialysis units. The participants were amongst patients and carers from these two units. The fieldwork, which facilitated data collection, was based on a participatory process of observation, interviews and participant feedback. These data were analysed into domains and themes using Spradley's Research development sequence (1980) and the reflexive process. Through the theme-based analysis used during the research and writing of this ethnographic study an emergent theory of partnership in care became apparent. Such a theory contributes to our understanding of the culture of the dialysis unit.

Uncovering the culture of dialysis units will not prevent the increase in numbers of people needing Renal Replacement Therapy. It does, however, shed light on the condition of living with renal failure and the nature of partnerships developed in the haemodialysis unit. It is these partnerships between people, machines and the environment that sets the dialysis unit apart in the hospital, giving it its own particular culture. Partnership means shared care where patients and carers work towards mutual goals. The realisation of these common goals leads towards the overall objective of better treatment outcomes.

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Preface

Ethnographic philosophy requires the researcher to look behind the obvious and reflect on the findings both during and after collecting data. I needed to have a clear vision to uncover the culture of haemodialysis units which is well formed and common to most dialysis units, but is unrecognised by many people who do not know dialysis units. I wanted to be able to explain to others why these units seem so different to other places within a hospital with different values and even a special vocabulary. With enough understanding I would like to be able to support and give the people who attend the units, the freedom not to go 'gentle into that good night' but to 'Rage, rage against the dying of the light.' (Dylan Thomas 1954). Although renal failure is an incurable illness, people should not feel condemned to a life without hope. For people with a chronic illness there is no fresh chapter to be started, no new page on which to start the new day. Every day brings the knowledge that life has to be lived with the disease, and for the patient receiving haemodialysis treatment, the day will also bring the insecurities of treatment.

People need to understand more about living with a chronic disease and this increased knowledge should assist both the sufferer and their significant others to achieve a better quality to their lives. If at the end of this research I could be a better advocate for the people with renal failure I feel I would have made a worthwhile contribution to the lives and deaths of those with renal failure. The struggles and ultimate deaths of so many friends would not have been in vain.

This thesis is dedicated to Sheila, Huberta, Charles and Roger and many like them in the renal world, who tried to live their lives despite renal failure, railing against the dark and not going gently into the good night. May their sufferings be for the benefit of others.

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My colleagues and friends amongst my own unit who have supported me and willingly discussed problems, and who were the inspiration for this research project. Special thanks to Swee for her unfailing pride in my achievements which were a serious deterrent to my failing to complete this study.

To all my children for their continued interest and restraint in allowing me to finish this work by keeping the grandchildren away despite my desires to the contrary; with especial thanks to Tom for his considerable literary skills.

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Abbreviations

ANNA	American Nephrology Nurses Association
BRI	Bristol Royal Infirmary
DRS	Development Research Sequence
EDTA	European Dialysis and Transplant Association
EDTNA	European Dialysis and Transplant Nurses Association
ERCA	European Renal Care Association
ESRD	End Stage Renal Disease
ESRF	End Stage Renal Failure
HCA	Health Care Assistant
HD	Haemodialysis
NHS	National Health Service
NSF	National Service Framework
NVQ	National Vocational Qualification
OED	Oxford English Dictionary
PD	Peritoneal dialysis
RRT	Renal Replacement Therapy
UK	United Kingdom

Chapter 1 Setting the Scene

1.1 The Research Project

'Understanding is the most perfect knowledge that is attainable for us humans.'

Johann Gustav Droysen

The overall aim of this research study is to uncover the culture of Haemodialysis (dialysis) Units in the United Kingdom. The purpose of this study is to increase knowledge and understanding, for those in the medical world and others affected by renal failure, to make known and understandable the previously unknown and non-understood. This thesis describes the ethnographic journey I took over a period of twenty four months spent in two separate haemodialysis units, whilst looking for the culture of the units. It is also the story of my metamorphosis from nurse practitioner to the role of ethnographer, disclosing the trials and tribulations of that metamorphosis, and acknowledging the influence of my experiences on that ethnographic journey.

Ethnography is research which looks at the integrated social scene. Reflexivity is a significant element of ethnography. It is the acknowledgement that researchers' interpretations are influenced by their background knowledge and socio-historic location, which includes values and interests (Hammersley & Atkinson 1995 p16). We are all part of the world we study and during this research project I have been a participant observer within the social world of the dialysis units. The reflexive process has made me reflect on the influence my experience, which has been gained from working in the renal field for over 30 years, will have on the interpretations of that world. Because research is an active process my actions and reflections changed during my journey from those of a nurse to those of a researcher. As my knowledge increased so my levels of participant observation and interpretations altered. Reflexivity is what gives this study its independent reality.

I have been examining the social scene of haemodialysis units and the relationships which occur therein. The patients as well as those who provide the treatment all have their own social worlds which are significant in the larger world of the unit. Using the reflexive process has demonstrated the importance of these other social worlds in the interpretations of my findings. The aim of this study is to promote understanding of the units while uncovering the culture within them to facilitate the overall objective of better treatment outcomes (Zrinyi 2001, Hedman 1998). Better treatment outcomes can be assessed by the clinical results. A good clinical profile should mean an improvement in the patient's overall

health (The Kidney Alliance 2001). Increased knowledge may encourage a more sympathetic understanding for those with kidney failure from the Health Care Team, and increased understanding of the disease for the sufferers from renal disease. Patients do not have enough knowledge about renal failure and all the effects of the disease. Increased knowledge could help the patient have more control over his life and illness thus enabling him to live a fuller life despite the chronic illness (Jenkins et al. 2002, Bevan 2000). For many there is a passive acceptance of Renal Replacement Therapy (RRT) without the knowledge about how life could be lived more fully (King et al. 2002, Bevan 2000). Haemodialysis units are special places where people who have kidney failure come for treatment on a regular basis, and life or death issues are faced daily (Curtin et al. 2002, Khan 2000). Therefore values and attitudes of both staff and patients are different from those held by people in traditional hospital wards (Bevan 2000), and a culture has developed which is unknown by the outside world as this study has demonstrated. I have used 'he' to describe my patients and 'she' for the nurses, for easier reading, except where I am writing about a specific person.

This thesis is studying the whole environment of the dialysis unit. The nurses, patients and ambulance drivers are the main routine population but this ethnography is also focusing on everyone who enters the units, the machines that deliver the programmed treatment and the total environment of the units. In this ethnography I am learning how all the relationships in the units affect the provision of treatment.

1.2 Rationale for this study

Kidney failure is a problem which both politicians and the medical profession are now discussing due to the explosion of the numbers of people with renal failure (Ahuja 2002, Charter 2002). The number of new patients starting RRT in the UK has risen from 3,876 in 1993 to 5,476 in 1998 (Ansell & Feest 2000), without the commensurate rise in the numbers of specialised staff to provide the care. Every patient receiving RRT receives at least 3 treatments weekly each lasting approximately 4 hours; therefore the rise in numbers of 1,600 patients means that an increase of 4,800 treatments has to be provided, or an increase of 19,200 hours of treatment per week which have to be supplied. The numbers of patients treated in 1999 worldwide is estimated to be over 1,000,000 (de Vos 2000). The social and economic implications of the treatment for kidney failure are very topical; the treatment of (RRT) is expensive and takes around 2% of the gross Health Care budget, yet there are at present only about 30,000 patients either on dialysis or living with a transplant and this

number will continue to rise, (Milburn 2001, Taylor 2000). In February 2001 the Health Secretary declared there had been long term under funding for those with kidney disease (Milburn 2001) but he had no panacea for solving the problem of the rising costs. The decrease in organs for transplantation due to various causes such as the Alder Hey scandal (Charter 2002), combined with increased survival rates for patients has led to a crisis in the provision of RRT (Hawkes & Norfolk 2002, Charter 2002, Winearls 1999).

People receiving RRT are a small but significant group of those receiving health care but there is little research to discover the life-world of these people. Renal failure is not a commonly discussed subject, there is no cure for this chronic disease and, as has been discussed, the number of transplants continues to decrease. As my experience showed, both as an experienced nurse and also when discussing this study, people outside the renal units, even within the medical professions, know little about renal failure and its treatment.

Haemodialysis patients are people with chronic renal failure. End stage renal failure means that their kidneys will never work again and death is certain without treatment (Khan 2000, Petersen 1995). These people are condemned to live a life apart, tied to a machine because of the treatment (Bevan 2000). People receiving dialysis treatment can often be in the unit for more than 6 hours on treatment days when waiting times are accounted for; therefore the dialysis unit becomes a place apart, neither home nor hospital. A place where special relationships may flourish and a culture is developed that produces its own special language and values. Because the only outcome without a transplant is death, values and attitudes are different to those of healthy people, altered because of the chronic life-threatening illness (Killingworth 1993). The people attending the unit leave behind the social world of home to enter into another environment, that of the dialysis unit, where there is another social world, peopled by those united through the common illness. The health care team do not recognise this separate social environment, it is for them the 'workplace'.

Haemodialysis units in the UK are, in the main, nurse led (The Kidney Alliance 2001, Bevan 1998). Although renal doctors diagnose and prescribe the treatment, it is the nurses who have the expertise and knowledge to provide the care and when necessary challenge and change the prescriptions (Bevan 1998). This study will discuss the roles of the nurses and other members of the health care team in the holistic scene of the dialysis units. It is the nurse who plans the day and ensures patients receive their appropriate treatment, but care of the patients involves all members of the health care team which includes social workers dietitians and doctors and many others. The nurse is responsible for the patients' wellbeing while they are in the unit and it is her knowledge and skills which make treatment as safe a

process as possible. Nurses spend much time and personal effort to remain fully knowledgeable and up to date with the latest technical and research developments in order to provide the treatments as is demonstrated in the journals which are devoted to this specialised field and supported in findings by Jung Ran, Hyde (1999).

The treatment of renal failure by RRT is complex and involves not only the world of the dialysis unit but also the wider social world (Auer 2002). The patient is trying to rationalise his life with treatment and facing the problems of two separate social worlds. Nurses have to deliver highly technical treatment, which changes with alarming frequency, in a holistic and humanitarian manner, and the doctors face the dilemma of the ever increasing renal population and changing techniques. The understanding of the illness lies in the awareness of and attention to the experiences, values, priorities and expectations of the patient. Illness changes perspectives and the ever-present shadow of death concentrates the mind on the immediate past and present. Within the dialysis unit, the need to survive each treatment is what affects people's values and attitudes (Dörner 2000). Unfortunately people do 'disappear' from the unit and those who are left behind are too aware that death is an ever-present threat. Harris & Brown (1998) claim that people receiving dialysis cannot help but be involved with other patients' complications, even death. They have to struggle daily under this burden of uncertainty, which does affect their attitude (Curtin et al. 2002, Bevan 2000, Dörner 2000).

1.3 Haemodialysis

Haemodialysis or dialysis (HD) is one of the three treatments offered to people with kidney failure. The other options are Peritoneal Dialysis (PD) or Transplantation. Kidney failure is fatal; if the person wishes to survive he has to accept either PD or HD. PD is a treatment which uses the body's peritoneal membranes as a filter for the waste materials that the kidneys can no longer process. It can be performed by the patients themselves after a period of instruction. It is not suitable for all patients for various reasons such as other disabilities, age or social conditions, but is a cheaper option than HD as it does not need a hospital unit. For those who want to work it can be a good option as the patient has more control over when and where the treatments have to be performed. The patient is taught and the 'exchanges' can be performed in any 'clean' area, but even with this treatment there are complications and the prescription of PD should not be made solely on the grounds of financial expediency.

Transplantation is unfortunately a rare option and the person has to be fit enough to accept a kidney as well as lucky enough to have one offered. Only 60% of those presenting with renal failure are considered fit enough to be placed on the transplant register (Ansell & Feest 2000), but there is no certainty of a kidney being available. Only 49% of these kidney patients on the list ever receive a transplant (Ansell & Feest 1999). Of the people on the waiting list for kidney transplants 4 % of them died during 2000 while still waiting (National Kidney Foundation 2002). The other option for those with kidney failure is no treatment, but this option is discussed infrequently and many people do not realise they do have this choice (Draper 2002). In kidney failure the kidneys stop functioning and the body becomes poisoned with waste matter which quickly kills the patient. Modern medicine and technological advances mean that people's lives are saved through treatment. Also the expectation of life while receiving treatment has increased from less than 2 years in the 1960s to more than 10 years in this new millennium (Ansell & Feest 1999), with the emphasis now on quality of life rather than just on survival (McGee & Bradley 1994).

There is an uncertain outcome to each RRT and there is always a possibility that the renal patient will collapse and die during or because of the treatment (Bevan 2000). This death then can become in the eyes of the law an 'unexpected death' leading to post mortem proceedings. This means that the unit personnel is vulnerable to criticism from the outside non-medical world. As Depner (1991 p ix) argues, if the treatment had been introduced today it probably would not have been accepted because of our modern stringent controls.

1.4 The treatment

In the chosen units the patients' ages ranged from 19 to the oldest patient who was in her 90s. In these units the age limits are not set rigidly; a teenager who needs treating in the adult unit can be accepted, body weight is more important than age once childhood is left behind. Survival means that the young age within the unit and the elderly patient gets even older.

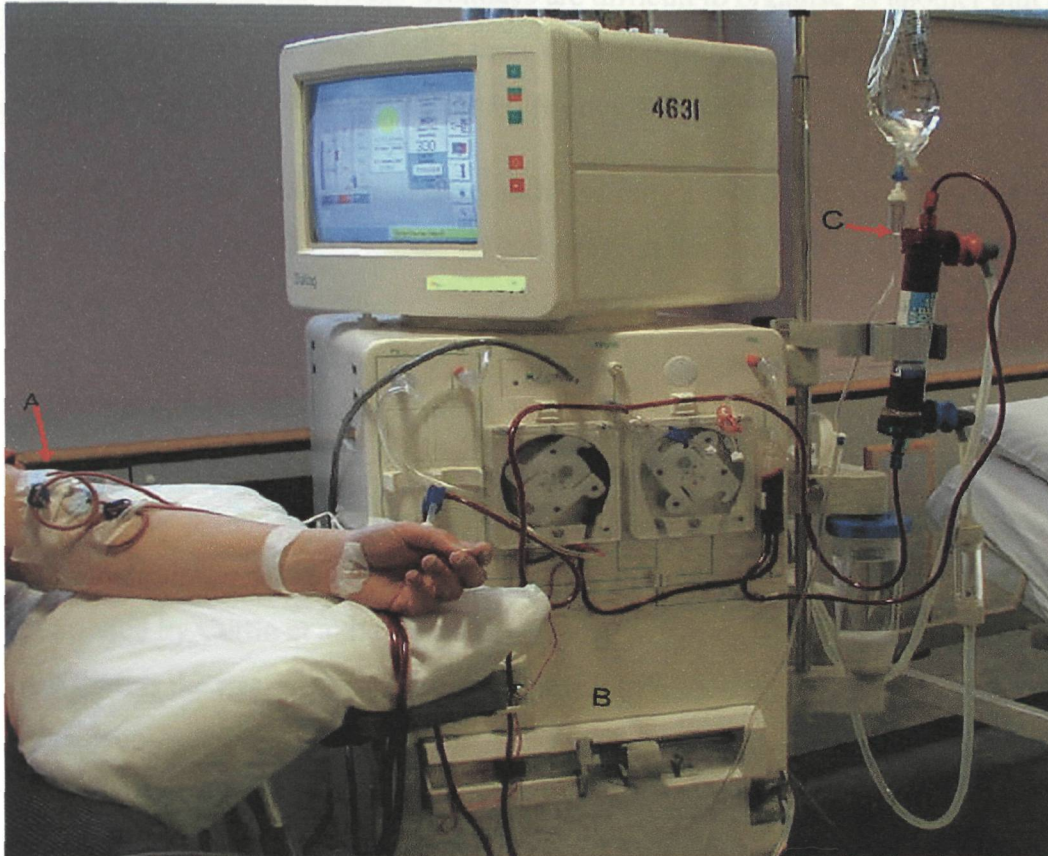
The treatment is generally performed in a haemodialysis (dialysis) unit. It is possible to do dialysis at home but this needs a personal machine, dedicated room or unit and significant technical and nursing support, and is not a preferred option in the UK (Lunts 1999).

Haemodialysis is the removal of waste molecules from the blood by means of a filter – the artificial kidney (dialyser). The circulation of the body has to be accessed either by means of a fistula or a catheter that is placed into the atrium of the heart. The fistula (Fig 1.1) is the preferred method of access but is not always possible due to other complications. A

fistula is formed by a surgical intervention joining an artery and vein together. Two needles are then placed in this joined vessel, one to remove the blood prior to washing it through the artificial kidney before returning it to the body via the other needle. This 'needling' happens at the start of every treatment. The blood flows through the arterial needle and within the tube it flows extra-corporeally round a machine, through the artificial kidney which is technically programmed to remove the unwanted molecules from the blood, and is returned to the body via the second or venous needle (Fig. 1.1). This treatment lasts from three to five hours in most centres, depending on the patient's blood results. The medical team can often see the patient as a specimen, the result of his blood results. This procedure is difficult for all the patients, but even more so for the elderly who have diverse other problems. A successful treatment is one which removes the correct amount of waste products from the blood, thus complying with the standards set by The Renal Association (1997). But the wellbeing of the whole patient is true therapeutic care, no treatment should be worse than the illness (de Vos 2002, Munshi et al. 2001, Fallowfield 1989). The holistic wellbeing of the patient is paramount and every treatment outcome should be measured by the total wellbeing. If for some this means a less aggressive treatment which results in a shorter but better life, then we should be prepared to work for quality of life not quantity of life years (Council of Royal College of Physicians 2001, Ashwanden 2000).

Figure 1.1 Picture of Treatment in Progress

A dialysis machine with the patient's arm showing the fistula



The Fistula (A) has two needles inserted. The blood flows around the machine (B) and through the artificial kidney – Dialyser (C) before returning to the patient.

The treatment is generally performed three times weekly, on the same days at the same time for individual patients. If the person attends on Mondays he will come Wednesday and Fridays, or on Tuesday, Thursday, Saturday. The patients are planned in groups so that all the machines are used for the maximum efficiency. If there are 10 stations then 10 patients will arrive for the first shift, four hours later another shift of patients have their appointments and finally a third shift of patients will have appointments in the late afternoon or evening. This is the most usual way of planning a unit but there are differences depending on the Health Care team, or patient population. There are many factors which have to be accounted for, 'going on' a machine (starting treatment) or 'coming off' (finishing treatment) requires a one-to-one intervention therefore the patients may have to wait for nurses to be available, also for treatment to begin the access has to function.

People have to be brought to the unit at the appointed time to permit treatment to happen, which means that transport to and from the unit is another factor in the time spent in the unit. All these issues conspire to make life in the unit a challenge. Because of the high occupancy of the units there are few opportunities to change treatment times and treatment has priority over most events. Holidays are difficult to organise as another unit has to accept the 'holiday patient' and in these days of infections such as Hepatitis B or C, many units are loath to do this, even if there are enough machines.

RRT carries many risks which are not always fully explained to the patient; the nurse becomes so used to them that she forgets them, as has been demonstrated in this thesis. But the unexpected can happen, patients are ill during treatments, or the access does not function, these uncertainties do add to the stress of the staff and patients. Living for the patient is restricted by this life saving treatment, dietary regimes and the regularity of treatments limit 'normal' social life. Haemodialysis treatment should be a shared modality between the patient, nurse, the rest of the multi-disciplinary team, and for some, the machine in order to produce the best treatment outcomes, as discussed in this study and supported by Curtin et al (2002). People accepting treatment have to agree to accept the constraints the treatment involves (Hedman 1998). Better outcomes are possible when the person co-operates and takes some control over his life (Ashwanden 2001). RRT is an expensive treatment; therefore it is very important that every treatment should facilitate the patient's wellbeing to enable him to be able to optimise his quality of life (Welsh 1994).

1.5 Myself as researcher and a nurse

I have been working in the renal field as a nurse for over thirty years, and have watched the changing renal world. Reflexive practice has enabled me to review the changes and understand their significance for the provision of RRT treatment which has a good clinical outcome in the context of this changing world. I completed a Masters degree studying the coping mechanisms of those living with renal failure and at the end was certain there was much still to be understood about life with renal failure (Ashwanden 1996). No longer, thanks to new drugs, is the renal patient condemned to live the life of an invalid (Jenkins et al. 2002). During my experience as a nurse I have helped patients achieve useful working lives again when they thought there was nothing left but the vista of perpetual and invasive treatment. In my role as manager of a unit I have been the confidante of mothers as they tried to combine the life on a machine with caring for the children and house, or the youngster whose sex life had disappeared almost before it had begun. It is my conviction

that these people with renal failure are the 'forgotten' sick. Society does not understand what it entails to be 'on dialysis' as the many quotes in this study demonstrate. Freeman et al. (2000), when looking at the provision and continuity of care, chose to study those with heart disease, diabetes, the elderly, not a mention of renal patients, and this is not the only report about chronic diseases that has no mention of renal patients. The dialysis unit has to deliver continuous care. Some of the benefits of belonging to the unit are because of its function as a day care centre where people coming for treatment receive companionship, warmth, food and drink and care on a regular basis as they enter the social world of the dialysis unit. But the continuity of care both in and outside the unit is one of the necessary components of successful holistic care of the renal patient.

This study has been influenced by my original need to know more about why dialysis units are special. I have visited many units and the literature reinforces my own experiences, that there is a common feeling of belonging in all of them (Jung Ran, Hyde 1999, Leibovitz 1998, Bevan 1998). In some, relationships are better developed than in others, but in every unit is the knowledge that the people there are 'special', both nurses and patients (Koutsopoulou et al. 2002). The patients are special, they are to be admired for their courage and commitment to staying alive (Curtin et al. 2002) even when the rebels make trouble for themselves and the staff. 'Better a short life and a merry one than just sitting here on dialysis' as one young man said. 30 years ago knowledge was limited and the prognosis was short. The side affects of dialysis on the rest of the body were not understood, and although knowledge has increased there is still much to learn and the long term effects of dialysis on the body are being continuously assessed (Lindley 2002, Trager 2002, Bevan 2000). At first people were only being given extra time, there was no thought of giving quality back to life. Now people's expectations are altered and treatment is expected to be only a small inconvenience (Auer 2002). But RRT is all pervading, it takes over one's life. Therefore compensations have to be found in the unit where a large part of life has to be lived. Knowledge has increased, my own included. I have a store of intuitive and experiential knowledge which this study has helped me to categorise and organise from a different perspective. During this study I have been examining the dialysis units in the context of the 'native' or actors using the reflexive process to put my new knowledge into the wider context of information about dialysis units. The knowledge I have gained has made me qualify and challenge my original knowledge, but I have found many times when reviewing research reports that results confirm and reinforce what I knew through intuition and experience as is suggested by (Benner 1994). All these have added greatly to my

understanding of why dialysis units are different to other hospital units caring for the chronically sick.

During the years since RRT began there have been many changes due to increasing knowledge and technology (Bevan 2000). In these days of financial constraints and accountability every intervention should be for the maximum good of the receiver. It is the right of every patient to expect the best treatment possible. But there are also the strains and stresses of caring for people with chronic illness in a highly technical setting, where stalking death has to be kept at bay on a daily basis (Kotzabassaki 2002). Because the philosophy behind ethnography encourages self-awareness through knowledge (see 3.5), I have been able to increase my own self-awareness helped by reflexivity and knowledge gained from this study.

1.6 The signposts for reading this thesis

Chapter 2 sets the scene and examines how this study is contextualised within the methodological and substantive literature. Understanding one's own culture is important for understanding this study because the use of the reflexive process means that interpretations are made from one's cultural background. Therefore the meanings of culture and the literature that helps explain it have been examined in this chapter. The literature which was used to challenge, compare and reinforce the data has been reviewed later in Chapter 4.

Chapter 3 looks at the research design, the philosophies and theoretical positions which support ethnography building on the literature in Chapter 2. The design and choice of ethnography for this study is justified through further discussion. The specific ethical problems which are particular to an ethnographer are examined. Ethnographic research has more ethical problems than many research methods because it is an intrusive study which is examining people's lives, their behaviours, attitudes and beliefs (Hammersley 1990). Research is guided by ethics and any researcher who is studying people has to be sure that no harm is done and everyone's human rights are protected. No preparation can foresee all the complex problems which ethnographic research may bring, but by being aware of the ethical boundaries I have tried forestall any problems.

Chapter 4 describes the methods that were used in this research study, and it falls into two distinct parts. The first describes how access was obtained and how the fieldwork was begun. This enables the reader to understand the actual steps taken in the method. The

second part of the chapter describes the method used to analyse the data with the help of diagrams and tables as examples. Fieldwork is part of the method and as it progresses so the analysis develops. The analysis cannot happen in isolation, it is evolutionary, it follows the fieldwork and is part of the fieldwork. The method used for the analysis can be understood as the analysis progresses.

Chapter 5 describes my ethnographic journey. To keep the descriptions true to life in the units, whilst maintaining the readability, I have included detailed description and verbatim quotes in the ethnographic description. I have tried to involve my reader in my experiences as I described the pains and pleasures of ethnographic research. I have shared my personal experiences with the reader. Hegel's philosophy supporting ethnography advocates the seeking of 'absolute freedom' through increased self-awareness (Norman 1976), so my personal exposure is justified in my search for increased self-awareness. The discovery of the culture of dialysis units slowly appeared as the ethnography was being written. Chapter 6 explains how the important phenomena or domains came out of the ethnography. I have discussed and shown in diagrams how these domains were interlinked and how the themes emerged from the domains. With the help of diagrams I have explained the discovery of the concept of partnership linking cultural themes and domains.

Chapter 7 is the conclusion to the research study. It looks at the aims and objective of this study and how far these have been fulfilled. This chapter gives a resume of the study, and discusses the significance of the findings. This final chapter contains the assessment of this study and the contribution this research makes to the provision of practice. There are recommendations for practice and further research, which evolve from the study. The final conclusion contains my personal reflections.

Chapter 2 Putting the study within the context of the literature

2.1 Introduction

The literature is reviewed to put the thesis within a literary context. This chapter discusses what culture is and explores the literature concerning culture from an anthropological stance. Malinowski (1922) refers to the set of issues which beset a research project as 'foreshadowed problems'. He considers that knowledge enables the researcher to appreciate the issues or problems. This chapter explores the literature which expands and illuminates the research problems and through which the researcher will be sensitised to areas which then can be explored (Brewer 2000, Hammersley & Atkinson 1995). Reflexive practice about my own experiences as well as the literature alerted me to issues such as the relationships within the unit which I would like to explore. The literature is also a source of data used for comparisons during the analysis some of which is reviewed later in the thesis.

The electronic databases of CINAHL, Web of Science, MEDLINE and the RCN data base all from 1997 to 2002 were some of the information services used to guide and reinforce this study. All articles with the words renal, ethnography, dialysis in the text were pursued. The original boundaries were extended for analysis of the data. The key renal journals such as Dialysis and Transplantation, Nephrology News and Issues, Nephrology Dialysis Transplantation and EDTNA/ERCA Journal are a source of modern relevant specialist information.

2.2 Culture

Van Maanen (1988) offers the idea that culture is human behaviour, but it is more than that. It is the woven tapestry of life, with the complex issues of faith, values, communications, historical settings, relationships and emotions as well as behaviour. This is a corroboration of Geertz (1973) who considered that it was essential to understand religious and social systems, symbols and ideologies before we can hope to understand the people we are studying. Hammersley (1992) with foreshadowed problems in mind warns ethnographers to be aware that their own individual interpretations of culture will be influenced by their cultural assumptions. Baum (1994 p210-216) considers that culture is what distinguishes human beings from other species, he claims that culture is shared customs, practices both

verbal and non verbal which a group of people share, which is significant in dialysis units as people share common treatment for renal failure. It is the learned behaviour of a group, the dialysis patient, and the practices are learnt as a result of that group membership. Spiro (1994) claims that the learned behaviour occurs when the contemplated action is expected to be beneficial to the actor, a relevant theory for dialysis units, where altruism is not the prime motivator. Culture is the means of understanding the imaginative worlds within which actors operate (Ortner 1999). It is a portrayal of life and life styles within a community with all the outside influences and environmental situations accounted for. The dialysis unit is a community with shared customs and beliefs. Morelli (1984) claims that a culture is a dynamic and organised phenomenon.

Spradley (1979) considers that within a culture people react to the meanings things have for them rather than the thing itself. Patients have to come to terms with machines and the control they have over the patients' lives, this is part of the culture in dialysis units. Silverman (1985 p8) considers there are two levels of cultural knowledge – tacit and explicit. He explains that both are necessary for understanding human behaviour. Culture is not visible in itself but is made visible through representation and interpretation of data (Atkinson & Hammersley 1998). Spradley (1980) offers his Research Development Process as a guide for analysing data to uncover a culture.

Morelli (1984) suggests a three dimensional approach to the study of culture, referral to these three themes in conjunction with the three aspects suggested by Spradley (1979) were helpful markers for this study.

1. The structure of the culture (Morelli 1984 p 81) To examine the relations between the parts of the culture and its whole will establish that each part is what it is by virtue of its functional relationship to the other parts. In this study there were many parts which were entities on their own but all affected the other parts.

2. The horizons of the individual These horizons should not only signify the range of people's knowledge, but also the anticipation of new knowledge. This relates not only to my knowledge but also to that of the participants within the study.

3. Experience and knowledge My interpretations of phenomena were influenced by my prior experience, and as the study progressed so my knowledge increased and again altered my interpretations. The knowledge and experience of those undergoing and delivering treatment was special to them and influenced their interpretations.

Smith (2001 p5) describes issues which he considers support the definitions of what is a culture.

1. Content Tools for understanding the make-up of the culture. Different traditions understand culture as values, ideologies, narratives and common sense as well as in other ways. Each of these different understandings has ways for interpreting the way culture works and what it means within each society. The function of the dialysis unit has the common theme of treating kidney failure, but it is how the various members of the units interpret that function which helped me to discover the culture of the units.

2. Social implications This issue looks at the way that social life develops within a culture, and how the conflict of power and equality is altered by dialectic theories. People who have renal failure have two social lives which impinge upon one another. This research is looking at the social life in the unit to discover the culture of that unit, but the outside social world influences the culture within the dialysis unit. The emerging picture of the culture reflects these influences.

3. How culture shapes human actions These theories demonstrate the connection between culture and the individual. Because of the uncertainties of illness, the people receiving treatment have an imposed behavioural pattern which encompasses their treatment but which has to be accounted for when looking for cultural patterns. One recent study (Wallace 2000) looked at the change in culture of two hospitals which had to amalgamate and demonstrated how the cultures had conflicted and merged. This research examines how changes made because of illness as well as the social world, develop and influence the cultural aspect of the unit.

2.3 Anthropology and culture

Historically anthropologists used to study unfamiliar people in their unfamiliar social scene. But Brewer (2000) postulates that anthropologists now study people within their own cultural settings as I am doing in this research study. The goal of the anthropologist is to describe and explain the regularities and variations in social behaviour (Silverman 1997 p13). Spradley (1979) considers that the study of culture involves three aspects of human behaviour:

- cultural behaviour
- cultural knowledge
- cultural artefacts

The anthropologist sees people within their own world without trying to affect or alter what he sees, but reporting phenomena with reflection and interpretation. Gardner & Lewis (1996) consider that anthropology promotes an attitude and outlook which encourage the researcher to listen and pay attention to alternative points of view, which I have done in this thesis. Also I had to go behind the obvious; to examine the complexities but also the inter-connectiveness of social and economic life and to be aware of my own cultural background and how this could influence my interpretations.

The anthropological tradition for looking at and understanding culture was established by Malinowski (1922) and Boas (1920) amongst others. Cairns (1944) considered that culture is the integral whole of the environmental, spiritual and human resources that man utilises to cope with the concrete specific problems which confront him, which for the dialysis patient are primarily concerned with survival. It is the development through history of the use of these resources which create the culture. This research reflects the importance that psychological influences have on it and the interpretations within it following the dictates of Malinowski (1922).

Malinowski considered that culture evolved to meet essential needs. Society has to survive and for that biological needs have to be satisfied (Maslow 1987). In order to survive there has to be law and order; therefore communities have to develop customs and laws which have to be accepted and maintained. Traditional values are developed and acknowledged and so a culture is born. History evolves, dialectic conflict causes world changes. Culture is a result of human beings interactions, their values and beliefs, and as through history these alter, so culture changes and develops. Because of the short length of time haemodialysis units have been in existence one has to ask what is history? Is it hundreds of years, a day, or even the last treatment? In the actual life span of the sick person every minute can be history. Illness changes perspectives, and impending death will concentrate the mind on the immediate past and present. People with renal failure are on the downward trajectory towards death from which there is no release, even the longed for transplant gives no certain promise of longevity (Bevan 2000). But life has changed from 30 years ago when the outcome of Renal Replacement Therapy was a swift end. Today the expectation of life on treatment can be towards 20 years (Ansell & Feest 2000) and, for some people, treatment is within dialysis units for most of that time. Improving technology alters treatment and outcomes. Therefore, although it could be argued that there is no long term history from which a culture has developed, there is a culture which is relevant only to dialysis units and about which little is known.

2.4 Background to the study

2.4.1 Dialysis Units

The Dialysis unit can be seen as a microcosm of society within the hospital world (see 1.2). The Health Care Team again have the same demographic mix as most hospital wards; whether the Renal Nurse is special and different to other nurses should be another research project - she is certainly the pivotal factor in the dialysis units (Jung Ran, Hyde 1999, Bevan 1998). The world of the dialysis unit has all sorts and conditions of people associated with it. It is special in that those within the unit all have one facet in common – that of either treating or being treated for Renal Failure. People have to learn to live with the disease and organise their lives around attendance at the unit (see 1.3). If culture is the interaction between people and the environment then dialysis units do have a lively and ever changing culture. This is made more changeable because of the instability of the dialysis population caused by the ravages of the disease, and the changing nursing staff due to the inability of renal units to maintain a stable workforce (Murphy 2002).

Vitri et al. (2001), looking at dialysis units, discuss the difference between what the patients expected from the nurses and what the nurses considered they should provide. This discussion showed that the patient considered the nurse should always there as the provider and comforter whereas the nurse considered her job was more as the provider of technical treatment as was shown in this study. The need for someone to listen to these patients and their problems is acknowledged by the social workers whose work is to listen (Auer 2002), but there are too many problems, too many patients and too often no solutions. To expect the nursing staff to be able to accept these extra problems is not plausible and is one of the causes of stress for staff (Aiken et al. 2002).

2.4.2 Chronic illness

End Stage Renal Disease (ESRD) is a chronic illness from which there is no cure. Living with a chronic illness involves coping with one's own emotional and material responses to the illness as well as the reactions and responses of others; it means having to accept a new life which entails relinquishing the old one (Wise 2002). Learning to live with ESRF means coping with the common problems of all chronic diseases but also patients have to agree to abide by the 'rules' or the regime of haemodialysis, by accepting these rules they are abdicating control over themselves and their right to choose (Wise 2002, Bevan 2000). The doctor takes control of the diseased body and the nurses control the treatment (Bevan 1998). Because of the all pervading course of the disease, the patient feels it is the medical team

who control his life which results in a loss of personhood (Heron 1992). The patient can either accept the 'patient role' with docility, obedient to the dictates of the health care team and the limitations of the disease, or rebel, refusing to hand over control, maintaining some vestige of self esteem and control by 'doing their own thing'. This can lead to non-conformity and rebellious attitudes, which are to be expected, but does not help the health providers give the best care. The hard pressed nurse who sees the patient arriving for treatment seemingly with a death wish, expressed through non-conformity, does have problems delivering treatment in a positive fashion as demonstrated in this study. The turnover of nurses in this highly specialised area is a matter for great concern (Winearls 1999).

It is difficult to accept the limitations of chronic renal failure (Auer 1990). Dörner (2000) has studied the psychological problems of those with chronic renal illness. He writes about the renal patient as a special case because of the difficulties caused through the regime of RRT. Patients have to accept a changed identity, no longer are they the same person as before the disease (Dörner 2000). Bevan (2000) looks at the machine as the controlling factor in their lives. Chronic illness means there is no cure. Chronically sick people have to adapt and find other values on which to base their lives (Fife & Wright 2000). They are, in essence, condemned to live a life apart with lives choreographed by others. The renal patients' hopes lie in increasing and improved technology. They are vulnerable to the uncertainties of treatment, the inability to plan ahead, and the reliance on technology and machines to stay alive (Bevan 2000).

All sufferers from chronic illness face the downward trajectory of the illness from which there is no cure, as well as their increasing disabilities (Miller 1992). Chronic illness causes isolation both because of the nature of the illness but also because of society's attitude towards sickness and ill health (Bevan 2000, Cassell 1991). Society as a whole is afraid of deviance and illness is a form of the abnormal, and therefore is deviant (Bevan 2000, Cassell 1991, Parsons 1951). Parsons (1951) explains the sick role as one which has rights and obligations, these are applicable to the dialysis patient who also has to 'agree' to abide by the rules which govern RRT. Sick people are given a low social standing by society (Garrett 1991); they have to face their own expectations and those of society while they are learning to cope with the role changes and adaptation to living with chronic illness (Kralik 2002). The renal patient is particularly vulnerable as not only does he have to comply with the regime of treatment but also this very treatment isolates him through its restraints as is shown in this study. The sick person is one who has fallen below the social 'norms' and

this can induce feelings of shame, loss of self esteem and loneliness (Kralik 2002, Cassell 1991). The outside social support system is then withdrawn from these 'deviant' people (Murphy & Kupshik 1992), leaving a gap which is filled by the staff in the dialysis unit who are fulfilling the caring role 'which is the essential requisite for all coping' as claimed by Benner & Wrubel (1989 p2). When renal failure is described by the health providers the problems are too often minimised and kidney failure is not portrayed as the limiting disease that, in truth, it is (Dörner 2000, Bevan 2000).

2.4.3 End Stage Renal Disease

The treatment for End Stage Renal Disease did not become widely acceptable until the 1970s, and the treatment has changed dramatically over the past 30 years (Cameron 2002). The older text books are no longer relevant to modern treatment methods but there is a large store of information about the modern technologies and treatments available for the renal patient which is constantly changing. The specialist journals all help to keep the renal health carer up to date with the latest developments.

Improving technology changes people's attitudes towards RRT. Today there is a much longer expectation of life, with good quality (Keogh et al. 2000, Welsh 1994). When RRT was first used to save people's lives, staying alive was all that mattered, quality of life was not assessed (McGee & Bradley 1994). Technological advances mean that the expected outcomes of years on dialysis are no longer the 'next to death' situation that they used to be. The outcome of each individual treatment is still uncertain but advancing technology has made the treatments more acceptable (Bevan 2000). People hope to work, although the economics affecting the work place make life and work difficult for those who have to attend treatment three times weekly (Auer 2002). But people are expected to live their lives and maximise on the expensive treatment offered (Bevan 2000).

Renal patients suffer two major identity crises (Auer 1997, Bevan 2000). First that of the illness: in order to survive the patients have to accept the only treatment available to them, that of RRT; therefore the perceptions must be that this is a life threatening disease; certainly without treatment they know they will die (Beder 1997), so the 'sickness role' is acceptable. Then second having accepted the treatment, expectations are reversed, they are encouraged not to consider themselves ill, even actively encouraged to continue working, but certainly to live as normal a life as possible as discussed in this study and corroborated by Howlett (2000) and Hyde (1998), which then negates the 'sickness role'.

As Benner (1994) states there is a proclivity to both excessive dependence and dangerous self-reliance inherent in any chronic illness, but certainly in renal failure; this dependence on the health providers and machines is also discussed by Bevan (2000, 1998). Those who rebel know they are at constant risk of death and certainly the medical team do not encourage them to pursue their own rebellious path. Research shows that although many ideas have been promoted to help patients 'conform' to the dialysis regime there is little evidence that it has altered people's life styles (King et al. 2002, Russell 2000, Saounatsou 1999). Bevan (2000) discusses the patient role in the dialysis unit and how the person becomes a collection of data processed by the machine and controlled by the Health Care team. The person who survives renal failure long enough to need RRT is generally determined to live despite the odds (Mallett 1990).

Faced with the constraints imposed by the treatment and the paternalistic attitudes of the health team, many renal patients become accepting, content to live within the 'safe' confines of the disease, but this does not always assist in compliance (Dörner 2000). The rebellious patient does not accept that life is contained in the dialysis unit as illustrated in this thesis and supported by Valentine (2000). He tries to live a normal life enjoying the larger social world and refusing to acknowledge the losses caused through illness. These are the people who find treatment difficult, it intrudes and often the rewards of being alive are not enough to compensate for the trials of renal failure (Taylor 2000, Bevan 2000). Relations between the hard pressed nurse and these 'difficult patients' are often strained and the nurse 'cannot be bothered' as was said by one nurse during this study.

Life with RRT is a life constrained often without quality (Keogh et al. 2000). The studies into Quality of Life (Ferrans & Powers 1985, 1992, 1993, McGee & Bradley 1994) have shown how different people view this concept and that reality does not always coincide with pre-conceived ideas. Ferrans & Powers (1985, 1992 and 1993) all used surveys to establish a quality of life criteria, they were looking at quality of life from the perspective of health investigating what the patients valued but missed now they had renal failure. Bradley & McGee (1994) and their contributors again were examining quality of life looking at the things patients felt they lacked due to ESRF. Quality of life studies have examined quality for the patient from the wellbeing or health aspect looking at the lost component as opposed to this study which is looking for quality which can be found within the units. There are also studies looking at the specific needs of the elderly renal population (Bernaert 2001, Munshi et al. 2001, Ashwanden 2000). But there are few studies which look at life lived in

the haemodialysis units within the social context of those units, examining what benefits can be gained from being a member of a unit.

At the heart of the treatment should be the patient (Nightingale 1859, Vitri et al. 2001, Auer 2002). This study shows how different attitudes of the carers and patients in the units towards the treatment can influence treatment outcomes which was confirmed by other research findings (Curtin et al. 2002, Zrinyi 2001, Morgan 2001). Through all the years of change the constant factor is the patient who is too often forgotten in the enthusiasm of high technology (Thomson 2000, Bevan 1998). 30 years ago there was little documented knowledge about how to treat renal failure, but the passage of years has led to an explosion of knowledge directed towards this speciality.

There is a wealth of recent research giving facts and figures about renal disease and the renal population, The Kidney Alliance Document (2001), Ansell & Feest (2000, 1999), and The Renal Association (1997). The National Service Framework (NSF) for renal work is in the embryonic stage but there are societies formed to promote learning and understanding in this specialised field. The psychological implications of being a dialysis patient are well explored in American journals such as the American Journal of Kidney Diseases, American Nephrology Nurses Association and Dialysis & Transplantation but the American model of care is directed to financial gain therefore the culture in the units is different and not applicable to units in the UK (Lee et al. 2002).

2.5 Methodological Literature on the background to Ethnography

2.5.1 Qualitative research literature

Ethnography comes within the qualitative research tradition; therefore literature about the methods, designs and use of qualitative research has been explored. The merits and problems of qualitative research are debated by Murphy et al. (1998). The problems of qualitative research are also discussed by Denzin & Lincoln 1998 a & b) as well as all their contributors. Methods of qualitative and quantitative research are explored by Silverman (1997, 1985) who debates their merits and problems giving many practical examples of the use of qualitative methods. Rigour and how it can be achieved in qualitative research is examined by Sandelowski (1993, 1986).

2.5.2 Philosophical and theoretical context of ethnographical literature

To learn about the philosophies and the theoretical ideas which guided this study, Passmore (1966) gives an overview of the lives and philosophical knowledge of the philosophers.

Norman (1976) in his translation of Hegel's work gives an understandable explanation of the philosopher's ideas. Goffman (1963 & 1961) expounds on the importance of self-knowledge and realisation of self in his works. Plager (1994) discusses the philosophical issues behind phenomenology, which influence the development of ethnographical philosophies. Rickman (2000) argues the place of philosophy in today's world.

2.5.3 An overview of the literature of the sources of ethnography

Malinowski (1944, 1922) and Boas (1920) base their work on traditional anthropological methods. They both were studying unknown tribes and their works were patronising in tone and viewpoint. However it has to be remembered that they considered they were both explorers from the Great British Empire and their traditional style is understandable in the climate and time of their research. Van Maanen (1995), Hammersley (1992), Kirk & Miller (1986) and Ellen (1984) stress that Malinowski did not follow his own teachings. He, together with Mead and other early ethnographers, could be said to be guilty of creative reporting about the cultures they studied. Malinowski (1922) in writing about his experiences wrote about the theory of culture which has provided a structure from which modern ethnographers have based their studies.

Hammersley & Atkinson (1995, 1983), Atkinson & Hammersley (1998), Hammersley (1992, 1990), Van Maanen (1995, 1988), Silverman (1997), Agar (1995, 1985) and Brewer (2000) are some of the more modern writers whose work has influenced my research study. Hammersley with Atkinson (1995, 1983) discuss how to read and evaluate ethnography. In 'Reading Ethnography' (Hammersley 1990) is at pains to discuss the problems of understanding an ethnographical study. In 'What's wrong with Ethnography' Hammersley (1992) argues that ethnography does not represent a distinct paradigm but rather that it is part of the main stream of social research methodology. Hammersley and Atkinson (1995) in 'Ethnography' give instructions in every chapter for the novice ethnographer which is most helpful. Brewer (2000) reviews other books by authors such as Hammersley, Atkinson, Fetterman and Van Maanen, he offers few new ideas about ethnography, but critiques other ideas from ethnographers. All these writers discuss their ethnographic experiences from tribal disclosures to work with deviants and special sectors of society, looking at the cultures which motivate these groups. Van Maanen (1995, 1988) writes of his first hand experiences as a researcher in a foreign field, and describes vividly his daily life, his 'Tales from the Field' (1988) demonstrates how ethnography can be journalistic. Fetterman (1989) gives a clear explanation of the path to be followed by the ethnographer. Spradley (1980) gives his explanation of ethnography and discusses culture. Agar in 'The

Professional Stranger' (1996) discusses his approach to ethnographies, living with drunks and investigating the drug scene this book is full of practical issues. But none of these authors give help about how to write an ethnography.

2.6 Doing Ethnography

The literature gives little advice as to how to 'do' ethnography; there appears to be a minimal amount of literature about doing ethnography apart from studying and learning from the people under study. All the cited authors, Hammersley & Atkinson, Hammersley, Van Maanen, Agar amongst others, discuss this lack of instruction. Sanjek (1990) in his compilation of texts does much to explain the intricacies of fieldwork. Van Maanen (1988) paints living pictures in his 'Tales from the Field' which inspire the novice ethnographer to attempt this research method. Hammersley & Atkinson (1995 p23) consider there is a paucity of formal instructions because ethnography is 'replete with the unexpected'. Writing up this ethnography was guided by Spradley (1980) following his Research Development Sequence to analyse the findings. The literature appertaining to the findings of the ethnography are described later (see 7.4). I have to agree with Hammersley & Atkinson (1995) that only by 'doing' ethnography can one learn how to 'do' it.

2.7 The literary background to the substantive focus of this ethnography

A comprehensive search of the literature did not reveal ethnographies studying dialysis units. Luyas (1991) looks at the culture of Mexican-Americans and their understanding of diabetes. She calls it an ethnographic study but it is a study without great depth and does not offer an analysis of the data. The study shows that the researcher did not understand the culture she was studying. American studies on culture in dialysis units are not so relevant in the UK because of the commercial basis that motivates the running of their dialysis units (Lee et al. 2002). Savage (1995) researches nurses and their therapeutic involvement with patients in their care. She uses participant observation as well as interviews in her methods but omits to state that she is 'doing ethnography'. She works within her chosen research site and her interpretations and analysis of the data would suggest that the study is ethnographical. Ersser (1997) looked at nursing as a therapeutic activity. He learnt from nurses in a ward setting and he conducted a search into the literature looking for explanations of when nursing is therapeutic. He describes in detail his method of analysing the data using grounded theory rather than interpretative ethnography. His examination of the concept of therapeutic nursing has been used in this study because although clinical

outcomes of treatment can show whether the treatment is successful there is still a discussion about the therapeutic qualities of the nursing interventions.

Manias (2001) 'Rethinking ethnography' is looking at nursing relationships but is using critical ethnography for her study. This is an Australian study and she illustrates some of the problems she had especially with the ethical position of the ethnographic researcher, which correlate with this study. Greenall (2001) undertook an anthropological study on nurse-doctor communications in a neonatal intensive care unit. She conducted formal interviews as does this study. She offers interpretations of her findings but she does so without reference to her data. Costello (2002) uses ethnography to study older people and resuscitation orders. He uses a purposive sample for his semi-structured interviews with the staff, as in my study. The patients were not interviewed as ethical permission was not sought, which he regards as a limitation of his study. Certainly the patients in my study were of equal importance to the health care team. He remarks that he had problems interviewing the staff as they did not like to be away from the ward for too long but had a lot to contribute, which correlates with my problems in this study. Bailey & Tilley (2002) discuss the importance of story telling in qualitative research. They stress that it is the importance of the meaning of the phenomena rather than the truth as the researcher sees it. The descriptions of phenomena by the participants in this study were true for the participants, it was their individual interpretation which gave the phenomena their importance. Bevan (1998) used informal and formal interviews and participant observation when learning about nursing in a dialysis unit. He does not state he is 'doing ethnography' but his analysis would suggest that he is observing and interpreting the whole social scene following the principles of ethnography.

Savage (2000 p7329) observes that 'ethnography has been overlooked as a qualitative methodology for the in-depth study of health care issues in the context in which they occur'. This would support the lack of literature on ethnographic research. It is possible to compare and contrast the methods and findings of other ethnographies but the findings of this study remain unique. It is a study of the culture of dialysis units, and it stands alone at present. One of the purposes of this study is to provide more information about dialysis units and this need is demonstrated by the lack of previous studies.

2.7.1 Non ethnographic studies

De Vos (2002) used questionnaires to discover what the dialysis patients thought of their care. The results were analysed using SPSS and the results offered the workforce

opportunities to improve their practice. A survey of the microbiological content of the water used in renal units was used to find information about infections (Pansini et al. 2001). Lunts (2002) in his analysis of the workload in a dialysis unit found that having set appointment times would improve the quality of life for patients. Two separate cases were studied to provide information about dietetic inadequacy (Norman 1998) and another case study was used by Keogh & Macefield (2002) to examine how to give patients enough knowledge to make decisions. A survey with a large sample population was conducted in the USA to establish the different costs of the modalities of RRT, demonstrating the financial basis for treatment in the USA (Lee et al. 2002).

2.8 Aims and focus of this study

The aims of this research are to:

1. provide a descriptive–analytical account of the culture of dialysis units in the UK (staff and patients).
2. examine the relationships between people and the technology in dialysis units.
3. examine social relationships in the dialysis community
4. examine how the culture of dialysis units may influence the outcomes of treatment for patients.

The review of the literature has highlighted that this is the first ethnographic study about dialysis units. This study is looking at the benefits that can be gained from belonging to a unit, being part of a team with the support that emanates from the team. There are studies looking at the relationship between people and people and machines in dialysis units (Bevan 1998), but no studies which look at the impact of the relationships between people, machines and the environment. Increasing numbers of papers are being written about the psycho-social effects of treatment and asking the patients for their views (Auer 2002, 1997, de Vos 2002, Hippold 2001, Hedman 1998). This study brings together the whole unit looking at the influences of illness and the treatment on the people who receive and give the treatment accepting the physical, emotional and cultural effects of renal failure. There is information about how the patients react to chronic illness and treatment (Bruno 1999, Bernaert 2001, Bevan 2000) but there is still a lack of information about the valuation of self and how the environment influences this value.

Chapter 3 Ethnographic research – design and methodological considerations

3.1 Introduction

The chapter discusses what is ethnography and then qualifies the choice of ethnography as the research design. It looks at the philosophy which supports ethnography and how that philosophy is important for this study. The ethics and ethical considerations of ethnography are examined. The chapter ends with reflections on the fulfilment of the aims of this project.

3.2 Ethnography – The research design

Ethnography is the study of the culture of people in their own world, looking at their activities and social meanings through the participation of the researcher. It is a design which encompasses both scientific and humanistic research (Johnson & Johnson 1990). Agar (1996 p15) claims that as ethnography is a participatory research design all ethnographers are involved in participatory observation. The aim of ethnographic research is to understand the social meanings and activities of people within their social scene, the dialysis unit (Brewer 2000). Ethnography is a relevant research design for this study because the lives of those with renal failure are influenced not only by the unit but also by how their illness and treatment affects their social life both through the practicalities of the disease and the routine of treatment. Since culture is the intellectual, spiritual and aesthetic development of a group or society, the research design chosen must be capable of discovering things that make up that culture. Ethnography supports methods which discover the social meanings and involve the researcher in activities in the chosen social scene. I was in the unit as a participant as observer learning the actors' perspectives of the social life therein.

3.2.1 Reflexivity

Reflexivity is at the heart of ethnographic research (Hammersley and Atkinson 1995).

In order to maintain a reflexive stance I kept a reflexive journal in which I made analytic notes of my conduct and insights in the field. The reflexive process is built into the philosophical principles of ethnography and guides the analytical and interpretative

procedure in this research and is a critical part of the analysis as suggested by Hammersley & Atkinson (1983). The context of both the phenomena under study and the historical and cultural context of the researcher are all important. Brewer (2000 p132) cites issues that ethnographers need to reflect upon when practising reflexivity which are those necessary for establishing the authenticity of the study. Therefore they have implicitly been complied with in this study. Agar (1996 p27) states that 'no understanding is valid without representation of those members' voices'. In order for the reader to draw his own conclusions and inferences from the interpretations there must be enough extracts from the text and quotes to make the ethnography real and valid. This study is full of real quotes from the participants as well as my own reflexive thoughts. Through the reflexive process it can be seen how the ethnographic representation of the social world of the units does not always accord with the general view of that world of dialysis units.

3.2.2 The Philosophies relevant to ethnography

Phenomenology influences some ethnographic research and it is through its development that we can understand the philosophy of this ethnographic study (Hammersley & Atkinson 1995). Husserl, the founder of phenomenology, considered the human being as a being outside the world of objects, striving to gain knowledge about those objects (Gadamer 1975). Heidegger (1962) expanded the philosophies of Husserl to develop them into Hermeneutic Phenomenology (Norman 1976). Heidegger's philosophies considered that people are all part of the world not outsiders trying to understand the world of objects, but rather inside and part of that world as one of the beings (Gadamer 1975). This is fundamental to my research study; I was 'being there', a presence in the unit as part of that world. Heidegger considered one's actions are tied to who one is, and many actions are performed without conscious choice. In this philosophy lie the roots of the philosophy of this ethnography.

The essence of ethnography is in interpretation, our interaction and relationship with others in the social scene. This study demonstrates the importance of interaction and relationships. Hermeneutical phenomenology maintains that 'being in' the world means that there is a spatial relationship with others but also the perception of others is significant (Gadamer 1975), I was seeing a familiar scene through the perceptions of my participants. Gadamer (1975 p160) states that Hermeneutics is the 'philosophical art of interpretation'. The reflexive process is built into the philosophical principles of ethnography and is used in conjunction with interpretation to provide the independent reality to this study. I have been able to appreciate my own perspectives while learning the perspectives of the actors.

Ethnography goes beyond phenomenology; it gives a more complete picture of life in a dialysis unit, using not only the interview (as in hermeneutic phenomenology) but being a participating presence, seeing and entering into the daily life as I was able to do. The level of participation will depend on the continuum of the research process. I set out to record the total picture of the dialysis world by 'being there' and following the concepts of ethnography. I entered into the life in the unit and shared their emotions and then with the reflexive process attempted to understand and interpret the data. 'To rely on what people say they do or believe without observing what they do is to neglect the complex relationship between attitudes and behaviour, and risks misinterpreting their actions' (Hammersley 1995 p 12). To examine the links between the social world and that of person-hood is one of the aims of anthropological ethnography. When interpreting the data I was conscious of the influence person-hood and self had on the relationships in the unit as discussed by Goffman (1963). Hegel's philosophy claims that one cannot be aware of oneself, as a self, unless one is conscious of others as selves (Norman 1976). Knowledge of oneself as seen through others means that it is possible to recognise others as persons and be recognised in return by them as an individual person. Increased self-knowledge made me more aware and reflect on the problems which beset the dialysis patient.

The concept of freedom is a legacy from the philosophies of Hegel and Marx. We cannot be free unless we control our destinies. Freedom and the issue of control influence both the patients and carers in this study. The philosophies which guide ethnography are based on freedom and its realisation through knowledge. I am seeking for knowledge, both increased self-realisation and that which will come through the research process. I hope that increased knowledge will allow more freedom for the renal patient to be himself. Hegel's philosophy has as its ultimate goal Absolute Freedom, which is gained through ultimate knowledge. Ethnography is seeking for understanding and knowledge based on the dialectic processes, striving towards the goal of Absolute Freedom.

Hermeneutical phenomenology has a special emphasis on 'thick description' which is a characteristic of hermeneutics (Smith 2001, Brewer 2000, Hammersley 1995). Thick description requires the reflexive process from the researcher, which involves a critical attitude towards the data as in this study and the use of critical questioning for realistic interpretation. Geertz (1973) claims that one of the characteristics of thick description is that as the researcher is writing descriptions she will be testing theories even as they are described. In this ethnography I did not start with any theories; following Hegel's philosophy, I was in the unit to learn. But as the study progressed so I found questions

which needed further exploration which I pursued. Thin description, on the other hand, is an uninterpreted description of events – pure phenomenology, which also adds to the holistic picture.

3.3 Other approaches relevant to ethnography

3.3.1 Postmodernism

Although the philosophies supporting postmodernism are not those of ethnography, ethnographers such as Hammersley (1990), Van Maanen (1988) and Atkinson & Hammersley (1998) now question the ethnographers' ability to capture reality accurately, or to represent truthfully the social world. They consider that postmodernism offers a challenge to ethnographers to be realists and to integrate the perspectives of both the 'natives' and the researcher, which certainly happened in this study. Postmodernism came to be accepted in the search for truth and knowledge (Hammersley 1990, 1992). Postmodernist theories would argue that it is unattainable to produce objective truth in relation to knowledge, all knowledge is relative to the perspective of the knower (Brewer 2000 p 49). Using reflexivity in the light of the postmodernist traditions I did question not only my own interpretations of the events but also the individual interpretations that were made by participants. There are examples in this study showing how differently individuals can interpret the same phenomenon, and how these interpretations were influenced by the knowledge of the 'teller'.

3.3.2 Critical theory

Hammersley (1992 p 100) considers that critical theory is another approach for social research as it introduces realism. Critical theory is concerned with power – the emancipation, empowerment and enlightenment of the social participants of research. This research is concerned with the enlightenment of the occupants of the dialysis units, who could be considered as unempowered. I have used, in this study, constant systematic and rigorous reflection which is a method of critical theory, as advocated by Hammersley (1992 p 119), to help maintain the rigour in the collection of data. It is the reflexivity of the researcher that creates the originality of the social research and my reflexivity that will assist me to present a full picture of the culture of the hidden world of the dialysis unit.

3.3.3 Case studies

Case studies offer a possibility for generalisation of the data when used in ethnographic research. A case study could be said to be the detailed examination of phenomena

(Fetterman 1989). A case is only a phenomenon which is under study (Hammersley 1992). In this study cases are used as illustrations of a series of phenomena or instances which serve to give a fuller picture of the dialysis units. Even the case study which captures an instant in time with a specific person is a description of a phenomenon which could be generalised. Brewer (2000) states that the ethnographic case study is distinguished by the exploration of cases as they present themselves in the field of observation. Mitchell (1984) considers that case studies help establish valid connections between events and phenomena which would not otherwise be discovered, which can be seen in the cases described in this study.

3.3.4 Questionnaires

The objective of using questionnaires in ethnography is to collect generalised information such as demographic data which will add to the sum of the information in the ethnography (Fetterman 1989). When used in conjunction with phenomenological investigations the results of the questionnaire can be used as a basis in the quest for new knowledge, or to reinforce or challenge knowledge as happened in this study. Because their intention was to obtain information from a large sample they presented an opportunity for the researcher, myself, to introduce herself to a wide audience as suggested by Hammersley & Atkinson (1995).

3.4 Assessing the rigour of this research study

The identification of criteria on which to judge qualitative research is vital for the evaluation of the findings of the research (Lincoln and Guba 1985). These criteria are: 1) truth value, 2) applicability, 3) consistency 4) neutrality. These have been modified to assess this qualitative research as suggested by Murphy et al. (1998). Sandelowski (1986) agrees that rigor can be established if a reader is able to audit the events and influences of the researcher and if the findings of the study can be found outside the 'social scene' of the research. Sandelowski (1986) advocates the need for a clear audit trail for establishing consistency rather than repeatability which in qualitative research can be questionable. Validity is established through the researcher's descriptions of her experiences in relation to the behaviour of the subjects (Sandelowski 1986). Detailed descriptions of the process of gathering the data, as can be seen in this study, will also add to the validity of the text (Murphy et al. 1998).

3.5 Ethics and Ethical considerations within an ethnography

‘Ethics is a generic term for various ways of understanding and examining the moral life’ (Beauchamp & Childress 1994 p4). The prime concern of any research is that it shall respect human rights and not do any harm (Polit & Hungler 1995). These rights are set out in the European Convention of Human Rights and are concerned with freedom of the individual (Hegarty & Leonard 1999). Nursing research in the United Kingdom is guided by ‘Professional Rules’ which have been developed by the Council of Europe (1997). These Professional Rules are taken from the Guidelines for Professional Practice (UKCC 1996), the International Council for Nurses (1996), and the Code of Professional Conduct (UKCC 1992a). The Convention of Human Rights has implications for all practitioners and their clients (Hurst 2002).

3.5.1 Main issues for ethical consideration

The prima facie ethical principles for research are: autonomy, beneficence, non-maleficence and justice (Beauchamp & Childress 1994). These principles have to remain at the core of any research but it is their application in ethnographical research that is explored in this section. The British Sociological Association (2000) states that it does not provide a set of recipes for resolving ethical issues. It realises that many ethical dilemmas will have to be resolved on the basis of principles and values and what is best for the people involved. The basic ethical principles are all addressed in the context of the British Sociological Association (2000) and by Hammersley (1990), who is looking at issues particular to ethnographic research. Hammersley (1990) offers four issues around which he considers that ethical considerations revolve. On evaluating both his issues and the statement from the British Sociological Association, the comprehensive list of main issues which are relevant to this research appear to be:

- Access
- Professional and personal integrity
- Deception
- Relationships with all participants
- Privacy
- Consequences of the research

3.5.1.1 Access

Before the research study could begin, ethical clearance from the Ethics Committee had to be obtained. Since there had been a lack of understanding about the research design and

outcome, to protect my professional integrity and explain my objectives, I went before the committee to explain how ethnographic research would explore the culture of dialysis units. After the formal Ethics Approval, the important but informal process of gaining access to the chosen field was undertaken. This had to be done through 'gate keepers'. Depending on the site chosen the number of gate keepers differs. In the case of this research study, the main 'gate keeper' was the Medical Director who was happy to give his consent for access to the units which were in the study. Then consent from the people who were involved in the daily running of the units was sought and permission granted. Lastly the most important people were those who were directly involved in the study, those receiving treatment and participating in the giving of treatment. These people had to be informed and their consent given for the research study to proceed. It is demonstrated in this study that the pre-planning and information supplied to all significant people did facilitate my access to the units.

3.5.1.2 Professional and personal integrity

One ethical consideration which is important for this study is my femininity. My attitude, what I observe, hear, and my interpretations are influenced by my feminine viewpoint, also people's attitude towards me is influenced by my gender. Although I have been influenced by critical theories to question and reflect on everything I observe, there is no 'hidden agenda' and I am not looking for empowerment of myself nor the unempowered (the patients) through this study. To maintain my personal integrity this research reflects my philosophical beliefs and attitudes. Increased understanding of the relationships in the dialysis units is one of the aims of this study and ethnography is a method of social research which has been influenced by feminists who amongst others have special concerns with relationships (Hammersley 1990 p 13). I acknowledge that my own knowledge, history and feelings will affect everything I do and see and my interpretations. My beliefs and philosophies influence the very fact of undertaking the research. Agar (1996) claims that the problem is not the bias that the researcher brings to the research but what those biases are, and how they will affect the study. I have acknowledged my past experience and pre-knowledge and appreciate how my interpretations will be influenced by these factors.

Ethnographers have more acute ethical problems than many other researchers because of their involvement with their informants (Akeroyd 1984). I did find it very hard not to become too involved with many of my informants (see 6.4.9.1) and I realise that during the formal interviews I was very involved, giving a lot of myself. As Agar (1996 p 107) states 'The guidelines for the protection of human subjects were not designed with ethnography in

mind'. I, as most ethnographers, did not work in a vacuum; I was working with people, often trying to seek out innermost fears, secrets, failures or hates as suggested by Agar (1996). The dialysis unit is a 'closed' community. Therefore not only is it necessary to be careful about people's confidences in the larger social world but also within the world of the unit, although renal failure is a shared condition it is necessary to maintain people's privacy. The dialysis patient is out in the social world but often does not like to make known his illness to that world. This is borne out by many dialysis patients who do not admit to being 'disabled' despite the lack of benefits this may invoke; they prefer to continue to live their lives as if they had no illness. Dialysis patients have common problems, but it takes careful handling to encourage patients to discuss their problems amongst themselves as is shown in this study.

Care has to be taken not to intrude too far into the private lives of participants, the consequences of my visits to units could remain long after the research is finished. I was very aware of the sensitive nature of some of the data from my participants and used interpretations rather than quotes for more sensitive events. My letter of information stated that I would not intervene in any process unless life was at risk. This was to protect myself and the patients; it also reassured the staff that I would not interfere and use my expert knowledge in 'their' unit. I was careful not to offer opinions and always tried to give non-judgmental replies when advice was requested. Not offering advice was probably the hardest part of doing the ethnography.

My status and integrity could have been compromised by a request with which I agreed, that I should make reports with suggestions about some of the difficulties I saw in the units. These reports were requested, not as part of the research but as a result of my observations. The reports were completed and were given to the 'gate keeper' and the staff. These reports were not in the research brief and were only observations, but writing up the findings and interpreting the issues did help enlarge the picture of the dialysis units, which added to the overall picture of the culture as suggested by Fetterman (1989). The end result for the staff was generally considered to be positive. For myself, the work on the report helped to sort out some of my interpretations and gave more depth to the data. There has been feed back since the receipt of these reports all of which has been of a positive nature, indicating acceptance of the status of this project in the dialysis community.

3.5.1.3 Deception

This is the one of the commonest causes for disquiet (Hammersley 1990). Even when permission for access is granted and all the people in the field of study have been approached, the fieldworker is hoping to become so much part of the background that she will not be noticed. Therefore unless she continually waves a banner reminding everyone who she is and what she is doing, which I did not do, it could be considered that she is deceiving people. I was inclined not to mention the research project, hoping people would not be too conscious of it. I wore my badge stating who I was but despite this I did become part of the background. Although I informed the people in the unit that a study was taking place, I did not explain the minutiae of the study; therefore people did not know exactly for what I was looking.

It was logistically impossible to ensure I had everyone's written permission to do the research (see 4.5.1). To overcome this and to comply with the ethical guidelines, I asked everyone for verbal permission before speaking to him or her. Once I was better established in the units there was less chance of confusion, but unfortunately there is no proof that everyone included in the study was in full possession of the facts about the research. Beauchamp & Childress (1994) consider deception which is marginal and does not put the subject at risk is sometimes warranted in behavioural, social or psychological research.

The British Sociological Association (2000) and Hammersley (1990) suggest that it is necessary for the field worker to re-negotiate permission from participants as the time spent doing fieldwork can be very long. This was not practical in this instance. Moreover as time passed people in the field would inquire how I was getting on and what I had found. Most of the participants expected instant solutions to any problems and they saw me as the answer to all their dilemmas. I could only suggest ideas and was always mindful of my status. I was careful to maintain my status as 'the researcher' and if a problem about what I could or would do arose I would remove myself from the sensitive situation.

Ethnographers take on a role when exploring the culture and this role will influence the way she looks at problems (Brewer 2000, Agar 1996). I was a nurse but had to take on the role of researcher, it took time to accept this role but I realised it was necessary for the research study. I was known to many people in my chosen sites in my nurse role which could have influenced what I was told, but it could also have decreased the time it took for trust to be formed as suggested by Ersser (1996). My interpretations were influenced by my increased knowledge. There were instances of role change when I deliberately tried to encourage the

informant to forget my role as a researcher so that as much data as possible could be obtained without the 'interference' of the researcher role. It could be claimed there was a 'lack of openness' but no real planned deception, and the process did not become covert. Change of roles from the formal researcher to a less formal one of a friend, meant I could spend time enjoying a casual chat about gardening or playing Scrabble to help pass the time on a machine, and at these times information was given freely. But if this was deception it was only to facilitate the collection of information. Fetterman (1989 p140) considers that any deception is inappropriate in ethnographical research as it compromises the relationships which are built up during long term fieldwork. The relationships I was building were not very strong to begin with, and if I had been reinforcing my role as a researcher I might have had difficulties receiving information and the study could have suffered.

I made my notes out of sight of a participant which could be called an abuse of trust but if the phenomena warranted reporting then it could not be fair to the overall research project not to report incidents (Beauchamp & Childress 1994). I never turned on the tape recorder without permission because I knew I could not do it in the middle of a conversation without fear of stopping the flow of information.

3.5.1.4 Relationships with research participants

3.5.1.4.1 *The patients*

All researchers involved with social research must appreciate they enter into personal and moral relationships with those they study (British Sociological Association 2000). I agree with Brykczynska (1997) who considers that the relationship between the researcher and patient is one which has the possibility of being exploited therefore care has to be taken with the development of these relationships. The information gathered is often sensitive, it exposes people's private fears and worries and in some circumstances could harm them practically and emotionally. I have found, when writing the ethnography, that I have omitted some information because it was very personal but the interpretation of the material had value for the study while still preserving the confidentiality of the original data.

Once trust is established relationships develop and confidential and private issues can be discussed (Nelson-Jones 1990). Only when there is trust can the researcher hope to see the realities in the field, as I stated I was known to many of the participants which could have aided the formation of trust but I still had to work to develop this trust. However the data I collected were tangible evidence that I had built a good relationship with the participants.

This trust is expressed verbally and non-verbally, and I was ready to interpret the quick touch of the hand or tremor in the voice. I found listening to the daily tribulations of the patients and later the nurses was fascinating, again the information was often personal and I was honoured by the insight I was given into someone's private life and feelings. Fetterman (1989) warns that the researcher needs to be careful about self-presentation and manner. Body language expresses so many different attitudes, it is often undervalued, but when used knowingly can be an extra tool (Burnard 1997). During my years working in one dialysis unit I have learnt that by entering into people's worlds relationships have developed which have been supportive and dynamic. I agree with Tschudin (1997) who considers that we develop as people through our relationships with others. Nelson-Jones (1990 p195) claims that where caring represents love, the reward is in giving as well as the receiving of caring. Certainly I found these patients were prepared to share with me their private hopes and fears which have added depth to this research.

Patients in the dialysis unit, tied to a machine feel insecure and vulnerable (Bevan 2000). The sensitive researcher will make time to chat about good and bad issues as they occur, never leaving the person on the machine without someone to whom to turn. While working as a nurse in a dialysis unit I had learnt that the listening ear or sympathetic look for a patient enduring dialysis will bring forth many confidences. People receiving treatment are at their most unprotected, and there is always the great uncertainty of the outcome of each treatment (Curtin et al. 2002). A highlighted problem can become increasingly important and leave the patient with a feeling of rejection if left unresolved (Norman et al. 1992).

Because I had managed to become part of the patients' world I had a problem when I had to 'leave' that world to join the world of the health care providers. I felt that the patients might consider I had 'let them down'. There was nothing I could do to mitigate the situation. I had persuaded the patients to allow me to enter their world and now I was, in their eyes, going to the other side. The feeling of 'sides' was one of the problems within the units, especially Unit 1, and it did not help my unease. I did not know whether this change in our relationships would alter the future confidences I might receive from the patients.

3.5.1.5 Staff

The staff found me, in my researcher role, an unknown quantity since I was known to many of them as a nurse, but now I was a researcher therefore I was different. One unit was more 'closed' than the other, but the overall initial feeling in both units was one of fear of the unknown. I posed a threat in 'their' unit. I had to use my inter-personal skills to overcome

this hostility which came, in the main, from the health care assistants who work in the dialysis unit alongside the specialist nurses. It stems from the lack of confidence these untrained people have, the role of the HCA is always under review and a stranger can be a challenge to the ordered routine (Savage 1995). But better relations were established once I had found some HCAs who knew me. After explanations I was able to interest the staff in my project because it was appreciated that there is a significant amount of ignorance about RRT in the medical and 'real' world outside dialysis units.

A few of the participants expressed worries about the formal interviews before they began, but these were overcome by further explanations and promises of confidentiality. Without exception everyone admitted that despite their initial fears they had been pleased to 'tell all' and felt better having done so. I was aware that while interviewing the staff I had become their 'confidante', and was careful to allow enough time for any emotions expressed during the interviews to be discharged by discussion, without the tape. The information received has remained confidential but the insight into other people's perspectives gives depth to the data. My sample was a purposeful one and representative of highly trained renal staff with specialist knowledge.

3.5.2 Privacy

Privacy is considered to be an important issue in any research. Ethnographic research is intrusive by its nature, inquiring into the private lives of participants. But I did not force confidences out of any informants, rather once the flow of confidences started it was difficult to stop. I explained that anonymity and confidentiality would be respected as far as was possible within the design of the research. Ethnographic research does mean that information about private matters is disclosed because of the greater good (Beauchamp & Childress 1994), but as explained earlier, I have omitted sensitive issues. Every effort was made to give the feeling of privacy to the informant. But the dialysis unit is a place where other people can overhear what is being said because of the closeness of the dialysis stations. I sat on the patient's bed giving the feeling of intimacy, and this also helped engender the feeling of privacy. Body messages can support the messages of caring (De Hennezel 1997) and the results show that I did receive intimate details of people's lives.

The most pressing issue concerning privacy is, having collected the data, what data belong to whom? Having been given permission to study the units with all the occupants, to whom does the data belong? There are related instances when real harm was caused by the revelations in ethnographical research (Sheehan 1993, Van Maanen 1988). The researcher

needs a sensitive touch when writing up the data to try to minimise any harm that may come from exposure of facts. To people who asked me during my field work whether 'will I be in your research?' I explained about the use of pseudonyms, but did not promise them that they would be unrecognisable.

3.5.3 Social Concerns

It has been argued that ethnography uses the power relationship (Hammersley 1990). It is certainly true that modern ethnographic research is often focused on a relatively powerless group such as the studies on the drug scene (Agar 1996) or drunks (Fetterman 1989). This project was studying the whole Dialysis Unit. The patients I was looking at were a group with very little power but my intentions were not to manipulate these people, rather, by description I was hoping to increase understanding for them and the people who treated them. Because I have worked for many years in this environment I felt that I could understand their vulnerability and in writing up the ethnography, care was taken not to expose all their very private concerns to the outside world. Throughout writing this ethnography I had ask myself if the exposure of the problems I found during the project would be harmful for the people I was trying to help, but one of the purposes of this research is to open a window into how life is lived in the secret world of a dialysis unit.

3.5.4 Consequences of the research

The results of the research do not disappear when the ethnographer leaves. The intrusive nature of my observations might affect the well being of the people I was studying. The research was conducted with circumspection remembering that there will be others wishing to do further research. The technique of 'Critical Incident' (Flanagan 1954) demonstrates the dangers of asking questions which highlight problems, not previously acknowledged which then have to be addressed. It was important that the participants were not left with unanswered questions, but this is real life and unfortunately there are not always easy answers to problems. I was always as truthful as possible within my professional identity, but there are issues which my research has highlighted for which there are no solutions.

The main 'gate keeper' was a supporter of the project but it does not follow that everybody who features in the study will be as pleased with the outcome. All ethnographers have to be aware of the wider implications of the ethnography. The aim of research is to increase knowledge, but at what cost? If the findings of this research highlight shortcomings both in expertise and financial matters, will the right people be influenced to take action? Does an increase in knowledge help people to understand the culture of dialysis units, and will it

make the life of those in the study any easier? One decision the ethnographer has to make is what to publish and what to omit (Hammersley & Atkinson 1995). What format should the publication take? Most readers with any insight will be able to recognise the units in this study even though names and places have been changed. There are instances in the literature where participants were offended because they were not mentioned (Ellen 1984), or offended because they were (Brettell 1993). It is hoped that the outcome of increased knowledge about dialysis units will override the problems of who is or is not mentioned in the research project. A basic issue in ethnography is whether the study should have been undertaken. Should I have been in those chosen units and have I done harm which could affect the dialysis community? Because of the social and financial aspects (apart from the human suffering) of RRT, the most efficient use of dialysis units is a necessity, therefore research which will aid this use of the units is acceptable.

3.6 Conclusion

Ethnography is a suitable choice for the design of this research study with its ability to encompass both scientific and humanistic research. The overall aim of this research is to uncover the culture of dialysis units which can be achieved through ethnography. But ethnography has its particular ethical problems because it is a study of people in their social world, therefore I followed ethical guidelines to ensure that no harm was done to the participants. The dialysis unit is a place where science and human beings have to coexist, and this partnership is what helps to make the special secret world of the dialysis units. Personal interaction and relationships which are so important in ethnography, give this study its reality. The next chapter will discuss the methods used for sampling, collecting and analysing the data.

Chapter 4 The Methods used for sampling, collecting and analysing the data

The method of research is the means by which the research was conducted; the rules by which reliable and objective knowledge is obtained.

4.1 Introduction

The chapter discusses not only how things were done but also why. It gives the reader insight into the practicalities of doing ethnography. Having understood the methods used for this study the readers will be able to judge for themselves the validity and reliability of the research project. To augment the credibility I have shown an outline time plan for this research. This chapter is written in two distinct parts. The first part describes the methods I used to undertake the research, guided by criteria (see 3.4) which maintain the validity or authenticity of the project. I have discussed the choice of samples: sites, people, cases and even the time I chose to be in the units. In describing the method for collecting the data I have been explicit about practicalities of the research project and some of the ensuing problems. I used the same methods to collect the data in both units; therefore I have reviewed more briefly the methods used in Unit 2. The analysis reveals the different problems within each unit.

The second part of the chapter gives the method used for the analysis following the steps of Spradley (1980). The concurrent nature of the research design makes the description of the method of collecting data and its analysis simultaneous. The detailed method used for the analysis shows the reader the development of the cultural themes (Appendices 6, 7, 8), although they do not become visible until the writing of the ethnography, where they are discussed as findings of the analysis. Actual data are used for the examples of the different steps in the analysis to assist the reader to follow the ethnographic path. The responses to the questionnaire were analysed using SPSS and will be discussed later in this chapter. While writing the ethnography I was able to return to the field to find clarification, and to verify any problems that arose as I was writing up the daily events. At the end of the research process I returned to the units to discuss my findings with the participants of the study.

4.2 The criteria

The reason for discussing the method is to give validity and authenticity to the research project. The criteria (see 3.4) which give authenticity also help to establish the logical processes of the research, and when the steps for the processes are visible the whole research method becomes easier to understand. The data analysis is guided by Spradley (1980) and the criteria complied with his suggested steps (Appendix 5), thus giving the research an audit trail and establishing credibility.

4.3 Time Plan

Table 4.1 Time Plan showing the important events in each year of this project

Year 1.	University Approval of the research proposal. This involved reading and learning about research design.
Year 2	Reading and learning about the process of Ethnographic research. Identifying the research question, which changed as my knowledge increased. Ethical Approval granted. Letters written to all significant people in units.
Year 3	Start of Field work in Unit 1. Questionnaire piloted and finalised
Year 4	Resignation from Full Time post. Continuation of fieldwork in Unit 1. Start of fieldwork in Unit 2
Year 5	Fieldwork in Unit 2 Start of writing up process. Transfer viva
Year 6	Writing process continued and finished.

The fieldwork in Unit 1 was over a period of 15 months and in Unit 2 over 9 months. I spent longer in Unit 1 than Unit 2 because I was still working full time when I started my field work; therefore did not attend so regularly, but also I found my experiences in Unit 1 taught me how to obtain information more quickly.

4.4 Part one - the methods used to undertake the research

4.4.1 The Developmental Research Sequence

Spradley's (1980) developmental research plan (Appendix 5) is a series of steps which if followed, as in this study, guide the researcher through the process of data analysis (Appendix 6). The steps demonstrate how the focus of the research changes as more knowledge is gained. The researcher begins with finding the 'social scene' – the dialysis unit, and ends with writing the ethnography. Denzin & Lincoln (1998a p 24) use similar steps in their Research Process. I have used the steps to show how I undertook the data collection as well as the analysis (Appendices 6, 7, 8). The choice of Spradley is discussed later in this chapter. The research develops from wide focused descriptive observations looking at the whole unit or observing a group of phenomena, continuing into more focused observations when I reduced the focus of my attentions to smaller numbers or selective observations, choosing what or who to observe. Finally the focus returns to the wide screen and encompasses the whole unit. This follows the funnel analogy suggested by Agar (1996) and Spradley (1980). The three levels of focus happen simultaneously once the general situation has been observed. While writing the ethnography the levels of observation altered to help present the total picture of the dialysis unit in its cultural world.

4.4.1.1 First steps

4.4.1.1.1 The research question

The first step or rule is to identify the research question and establish its relevance. The question for this research was to discover whether there was a culture unique to dialysis units. The aims of this study are discussed in detail earlier (see 2.8). The overall aim is to discover the culture of dialysis units through increased knowledge.

After many years of working with people with renal failure I wanted to investigate in greater detail the renal patients, their lives and their feelings. I still did not understand why dialysis units were special and had a secret culture which was important to the 'owners' of the units. After due consideration I felt that more knowledge about this different and difficult life style of those receiving RRT could be obtained by using the ethnographic research method which would involve not only the patients, but everyone who came to the unit and the environment. I was looking for a culture of these units to be able to understand what made them different. This change of emphasis involved about nine months of intensive reading about ethnography which was, for me, a new and unknown research method. During this time I wrote a proposal which was accepted by the university. This

study is important because of the growing pressure on dialysis units due to the increase in numbers of people needing RRT and the lack of organs for transplantation.

4.4.1.1.2 *Choice of site*

I had to choose a site where I would be accepted and the research project helped by willing participants. Access to the field for an ethnographer can be a problem (Hammersley & Atkinson 1995 p60). It is not only the physical access that has to be considered but once in the social scene the researcher has to feel comfortable and know that the research activity can happen. I wished to learn about dialysis units and therefore chose 2 dialysis units within the same Health Authority. My rationale for choice is discussed (see 4.4.2.2). In this study I used the Medical Director of a Hospital Trust who was known to me and who, I hoped, would be a supporter of my project, using a personal network as suggested by Hammersley & Atkinson (1995).

4.4.1.1.3 *Establishing my authority as the researcher and my field role*

I was entering this specialised renal field with many years of experience and would become a participant as observer of the social life in the units, entering into the daily events and enjoying the company in the units. I would bring to the research project pre-knowledge and understanding of life in a dialysis unit (see 1.4). Spradley (1979 p47) considers that enculturation which is the natural process of learning about a culture is a good thing, but because of my past experiences I was concerned that I might be too encultured. I consider that this study has shown that the benefits of my pre-knowledge and understanding of renal disease far outweighed any disadvantages. But I was aware that one of the disadvantages of my past experience would be that I could easily miss important events and small but significant changes in the routine. I had none of the problems that Hammersley (1992 p143) discusses regarding the difficulties the outsider has in understanding some 'social scenes'. Rather there was the danger that I could miss significant linguistic exchanges because I was too familiar with the emic language and routine of a dialysis unit. I remained constantly aware of all these issues throughout the research process. The reflexive process helped me to see the scene from the perspective of the actors. I also realised that through my experiences I was in danger of 'going native' which can happen when the researcher is too familiar with the social scene as Agar (1996) claims. My pre-knowledge did influence my data collection and my interpretations. I also realise that despite or because of my reflexivity, the ethnography may have some substantive values of mine which could have prejudiced my interpretations.

4.4.2 Sampling Criteria

4.4.2.1 The site/The Haemodialysis unit

Selection of the site is important for validity. Hammersley and Atkinson (1995) argue that one of the criticisms of qualitative research is that it fails to meet the criterion of applicability to other areas. Burgess (1984) urges the researcher to discuss the principles by which some situations were selected while others were rejected.

4.4.2.2 The choice of the units

The decision to use two dialysis units within the same Hospital Trust was made because of the depth of study that could be accomplished using a small sample rather than attempting to visit numerous units, which might have given more transferable information but without the depth. The transferability of my information is discussed (see 4.8.2). I had considered studying the nine renal units within the London area but this became impractical due to diverse factors. Apart from the constraints of time and money, London has a large shifting multi-cultural population, many of whom are very temporary and I felt these factors could affect my findings of a 'typical' unit. The two chosen units were within a reasonable travelling distance of my home which was important not only from financial considerations but it meant I could visit the units frequently. I felt that by using two units from the same Trust they would have the same underlying philosophies and patients and therefore I would achieve a fair representation of renal patients from a large area of the country, and the gatekeeper, the Medical Director of this Trust had agreed to support the study. I have used the one very large unit which is the 'hub' of a region, and takes all sorts and conditions of renal patients then a smaller 'off site' unit, which has its own consultant and treats mainly stable chronic renal patients. Between these two units there would be a diverse range of patients and staff all with their own cultural behaviours which would give authority to this research project. Once the project started I realised that there were other sub-sites linked to the main site area which had also to be involved in the research.

4.4.3 The organisation of the treatment in the units studied

4.4.3.1 Unit 1

This unit has 20 stations – a station consists of a machine, a chair or bed for the patient and a bed table which is used both by the nurses for their equipment and also the patients for books magazines and general clutter - and generally treats between 54 and 58 patients in a day. Patient numbers are not important in themselves, one patient could be planned to need 3 sessions of dialysis in a week but if there were problems this could increase to 4 sessions

which increases the number of sessions performed without altering the patient numbers. The day starts at 06.00 for the nurses setting up the machines, the patients arrive from 07.00 onwards and they should be all on the machines receiving treatment by 09.30, depending on transport, traffic and the weather. This first session will continue until all the patients have been treated for their prescribed time (generally between 3½– 5 hours). As these patients' treatments are finished so the next patients arrive to receive treatment and will go on the machines as planned by the nurse in charge. This is an idealistic pattern as there are always emergencies, the transport does not arrive, someone is not where he should be, an extra treatment is needed, or access fails so the delay in going on the machine means that there is not a slot for one of the next session of patients. Staff shortages, for any reason, leave the unit short of 'pairs of hands' meaning that the going on and coming off processes will be lengthened. However the middle session of patients will hopefully be on the machines by 16.00. This scenario is repeated for the final group of patients all of whom should be on the machines by 19.00 ready to go home by 01.00. The final group of patients is not the full 20 as there has to be availability for extra patients and emergencies, but the unit is a busy place and planning is difficult. The average number of sessions performed per week in this unit is 360. Nurses work in shifts each shift lasting 7½ or 8 hours for the full time nurse. There are opportunities for part time work and flexible hours as the busy times in the unit are those when the patients are starting or finishing treatment.

4.4.3.2 Unit 2

There are 12 stations plus one for emergencies, but this extra station is generally in use. The day starts at 07.00 for the nurses with the patients arriving between 07.30 and 09.00, all 12 patients should be on the machines by 10.00. Again this first session of treatment lasts until the patients have received their prescribed treatment time. The next and final session starts around 14.00. The patients do not arrive until after 13.00 giving the staff time to get the first group of patients off their machines and get prepared for the second group. The second group of patients is all on the machines by 16.00 and the unit closes by 21.00. The number of patients treated in the day is generally 25. The average numbers of sessions performed per week is 140. There are still the emergencies and problems with access and transport which cause difficulties with the planning of the day. Because there is more time between the sessions, staff absence does not affect the 'change over' time as much as in Unit 1. Therefore pairs of hands are not so vital, and staff shortages do not impinge on the provision of treatment as in Unit 1. There are only two sessions and the patient numbers much smaller. As a result this unit is not so frenetic and planning the day is much easier

than in Unit 1. Again the nurses work 7½ hour shifts with plenty of opportunities in this unit for part time work.

4.4.3.3 Selection of participants within the units

The choice of people within the units is opportunistic or non-random sampling because for this research it was only possible to use the patients and the health care team in the dialysis units. I had the whole scene of the chosen dialysis unit, with all the actors and machines to observe. Machines are not always predictable and can produce incorrect results to treatments so they are significant factors in this field. By my presence in my field role, I was participator and observer. I observed the interactions between actors, their emotions and body language as well as open communications. I spoke to almost every patient and member of staff when introducing the project, then, with the exception of those who had declined permission, I talked with all the patients while they were in the dialysis units. Everyone was given the opportunity to talk, but the 'informants' chose themselves, and when I found a responsive talker I would return frequently. I tried to be available for all the patients and members of the health care team while in the unit so anyone would feel at liberty to chat to me. Stake (1998) considers that the criteria for selection should be who can offer the opportunity for the researcher to learn. I did not have the luxury of choice as treatment was the limiting factor. People came for, or to deliver, treatment. In the other sites connected to the main unit I observed and listened to staff, but patients were generally too sick to talk to me, so there was little conversational data collected from these sites, but these observations influenced the interpretations of the data.

4.4.3.4 Selection of cases

The cases chosen in this study illustrate behaviour, attitudes or phenomena, common or particular which I observed while I was in the unit, so could be listed as 'context samples' (Hammersley and Atkinson 1995). Some of the cases illustrate a specific configuration of events that are the result of some defined situation at a particular point in time as occurred in this study and show the emerging cultural scene. Other illustrations were a combination of many individual acts all contributing to the description of a whole case. Silverman (1987) argues that cases should be chosen not for their representativeness, but rather that they should expound some theoretical principle. The cases in this research project were not chosen to expound some theoretical principle, but Tomy's case (see 5.4.4.2) shows how it can illustrate a theoretical principle. Some cases were chosen to give depth to the descriptions of the units these could be considered intentional and systematic sampling (Hammersley and Atkinson 1995).

4.4.3.5 Selection of people to interview and receive the questionnaires

The subjects chosen for the formal interview were to provide a purposeful sample. I wanted information from a particular group of people within the units who could give me the special information. Therefore I chose the participants purposely from members of the trained health care staff who I considered could give me good detailed information as suggested by Agar (1996). The choice of person was also theoretical as I was looking for information which might clarify some of the hypotheses which had emerged during the fieldwork.

The people chosen to receive the questionnaire were a purposeful sample, I wanted information from as many nursing staff in the units as possible. It was given out to all the nursing staff who would accept it. The questionnaire was seeking demographic descriptive information from as large a purposeful sample as possible. The choice of using the staff within the dialysis unit rather than staff throughout the hospital makes it a chosen sample.

4.4.3.6 Time samples

The dialysis day runs from early morning to late at night six days a week. As explained (see 4.4.3.1 & 4.4.3.2) the patients' shifts change during these hours. I was present at some time during every shift and on every day of the dialysis week. The time and day decreed which patients were around, but also day and time made a difference to the collected data and, on reflection, my own interpretations.

4.4.3.7 Data choice

I did not consciously make a choice of what I observed and wrote down, I followed my intuitive hunches. The choice could be described as random but it was also purposeful as I needed to have as much thick data as possible.

4.4.4 Access

Before I prepared my application to the appropriate Ethics Committee, I contacted the Medical Director of the Regional Trust to discover whether he would be sympathetic towards his haemodialysis units being involved in a research study. He was my gate keeper and I needed his support. Having ascertained this support I began the preparations for the start of the study.

The Local Research Ethics committee granted permission for access to the two chosen units. There was a lack of knowledge about the uses and benefits of Ethnographic

Research; therefore I presented an information paper to the committee explaining the method and reasons for undertaking this research project. I found the committee ready to listen and interested in the proposed study. I complied with the local regulations concerning letters of information (Appendices 1 & 2) and consent forms for participants (Appendix 3) and ethical consent was duly given. My main gate keeper gave me a list of names with whom to communicate about the research project. These were the important local gate keepers who were involved in managing the two chosen haemodialysis units. I wrote to them explaining briefly the methodology of the project and my aims and expectations for the research (Appendix 4). The start of the collection of the data was delayed because of the constraints of my full time work. I finally committed myself to appearing by sending a letter to the manager of the unit announcing my imminent arrival.

4.5 Unit 1

4.5.1 Getting Established

I arrived reluctantly on Unit 1 to begin the fieldwork, but thanks to good preparations the first entry was not quite as difficult as I had imagined. Before entry I ensured that I was 'carefully labelled' as a researcher. Both physically by a label stating I was a researcher but I also had to be accepted as me, the researcher, by the staff. I discuss my identity management (see 4.6.2.2) but it was important that from the first time of entry I was 'A researcher'. On reflection I knew I still wanted to be a nurse as I considered the staff would be happier to welcome me as a nurse, but I had to establish myself as a researcher. I was expected and welcomed by the Nurse manager who introduced me to all the staff. I made certain that the staff accepted me as the researcher by explaining the research study.

To comply with the requirements of the Ethics Committee I had to request every patient in the unit to sign a consent form and ensure they understood about the research project. I used this opportunity to explain who I was and what my study was about, stressing how I was interested in everyone, not just patients, and the aim of my research was to increase understanding about dialysis and the units. People were interested and most patients were glad to be asked to participate. Only two people declined and I had to assure them they would not be in the study. I was careful to deal sensitively with those not wishing to participate. How someone is excluded from fieldwork presents problems; because the person is present, is it possible not to observe what is happening to him? Van Maanen (1988) agrees that to omit people entirely from a scenario is impossible, but I considered that I would be careful not to ask these people any questions. People often did not want to,

or physically could not, sign the consent form and many times I was requested to put a 'cross' by their name. If there are needles stuck into one arm it is not always physically possible to write and although I would request that the person signed after coming off the machine, too often it was forgotten. So I accepted that the intention was there even if the signing did not take place.

4.5.2 Fieldwork: the methods I used for collecting the data

4.5.2.1 The unit

I decided I would learn from every patient in one group, before changing my times and days to come to the unit. I had already made a decision to gather information from and about the patients, before I talked more exclusively to the Health Care Team. I identified the chosen social situation, the unit, with its actors and activities, and began collecting my field notes. As Clifford (1990) claims there is no definition of what constitutes a field note; mine were a personal and intimate record of my time in the units. As I spent time in the unit my observations levels shifted between wide and focused observations, whilst I was identifying features I wished to study, thus complying with the 'rules'.

4.5.2.2 Participant observation. Identity Management/field role

I was in the field as a participating observer but I was careful to keep a low profile during the first few weeks in the unit so people would learn to accept me as a researcher and not be threatened by my alien presence. I tried to remain unremarkable by watching what I wore as suggested by Hammersley (1990) and Nelson-Jones (1990) and trying to become part of the furniture. In my field role as the researcher I dressed smartly - I was a serious researcher - but not too smart as I did not wish to frighten my participants. I took care how I behaved - especially my reactions as I could not be seen to be judgmental. Too much eye contact can be threatening but too little can give the idea of lack of interest (Nelson-Jones 1990). So I was careful about my body language. I sat on the bed when the situation allowed to promote the feeling of intimacy (De Hennezel 1997). I would sometimes change roles to play games or very occasionally watch TV with a patient (see 5.4.4.1). I was often put into the role of 'comforter nurse' (Munshi et al. 2001, Smith & Gray 2000), expected to provide all the answers, but I did not have many solutions, in any chronic illness there are situations to which there are no answers (de Vos 2002).

If I took notes at a dialysis station by the patient, I would use a small notebook which fitted into a pocket, so that if any concerns were expressed I could 'lose' the notebook without problems. My presence was at first an obstruction to free communication, as Agar suggests

(1996 p108) I was a stranger expecting answers to intimate questions. Conversations stopped when I approached, I was an unknown person, maybe threatening and ‘what was I doing in the unit?’ I had to work to gain my actors’ friendship before we talked without constraints. The idea that I might also be taking notes was even more of a deterrent. The details of the conversations were difficult to capture as so much information and so many interactions happen simultaneously. I would have liked a tape recorder, but I made short notes which I enlarged as soon as I left the scene. I tried using the unit office to enlarge my notes but that labelled me as ‘one of them’ (staff) so I stopped doing this. The computer turned out to be a practical nightmare and I only brought it with me once. I did not like using the changing room to write as considered that if the nurses ‘caught’ me making notes they could become suspicious and my role as researcher would become even more difficult. I retreated to my car to fill in a more detailed version of the daily diary. The journey home (about an hour) provided an excellent space for reflection about the daily happenings. Once home, I wrote my notes about the daily events and also my feelings and interpretations on the day’s progress in the computer. I wrote up the notes every day after a visit realising the importance of memory in presenting the truth. I had a file for daily happenings with an adjacent column for my interpretations then another file for my own reflexive journal where I put down what I thought I had got out of the day. I found the reflexive journal a good place to put my moans (of which there seemed to be many).

4.5.2.3 The ethnographic record – field notes and reflexive journal

The Ethnographic researcher uses participant observation, informal and formal interviews, questionnaires and cases as methods in the research design. All these methods were used to collect my data. I also kept a reflexive journal where I noted my actions and feelings about the day. Fieldwork is the characteristic of ethnography, and participant observation is the main way to collect data. Participant observation occurs on different levels, from the complete active participator to passive observer (Spradley 1980); my observations used all levels (see Table 4.4 and Appendices 6 step 2 & 7 step 2). I was in the field, observing, asking seemingly stupid questions as (Fetterman 1989 p19) suggests, and noting down the answers. I wrote down as much as possible, describing events that happened in the units without making active choices about what to observe. At the beginning of every day I would take a few minutes to make notes about the environment, recording the same or different phenomena, I used my reflexive journal to record my feelings about my entry on that day, which differed with each entry. The daily routine is predictable, but as Fetterman (1989) claims it is the routine that forms culture and the exceptions help to identify this

routine so I noted any differences to the routine. Asking dyadic and triadic questions help define the culture (Spradley 1980 p126). I was conscious of 'being there' observing the whole social scene, as I talked, listened, observed and read notes.

My pre-knowledge was useful as it alerted me to the exceptions, but because of my familiarity with the social scene I constantly reflected that I could have missed some routine events. I knew the regular patients and health care team, and was greeted as a friend by most of the actors in the situation. Because of my pre-knowledge I did not have to learn the technical language of a dialysis unit. I accepted the 'native' terms as familiar, but because of that familiarity I could have overlooked some of the significance of special terms. It did mean that people could talk to me in the language of the renal unit and I could understand, I also understood many of the meanings of phenomena which were particular to a dialysis unit. Following the aspects that Spradley (1980 p5) suggests as necessary to understand culture, I was looking at behaviour, knowledge and artefacts within the cultural setting of the dialysis unit. I was attempting to discover the rules which govern the relationships and interactions between the chosen social setting and the behaviour of members of the dialysis units (Fielding 1993).

4.5.2.4 Informal interviews

The normal conversation with participants can become an informal interview which then is guided by the researcher when she is looking for information (Brewer 2000). Spradley (1980) considers that an informal interview occurs every time a question is asked during participant observation. Agar (1996 p155) stresses the importance of these directed talks which I used constantly. I would also begin informal interviews between the patients themselves when it was appropriate. These 'conversations' gave insight into the divergent interpretations people have of the same phenomenon such as treatment or illness. I quickly became adept at asking the right question at the correct time. I continued these informal interviews with anyone within the unit who had time to talk, appreciating the significance of the data I was collecting and using the reflexive process interpreting events in the units in the larger context of the social world. Once the data collection and analysis had started I discovered, as Spradley (1980) contends, that I was focusing on particular elements within the dialysis units, my fieldwork having narrowed to focusing on the particular, following a process of involuntary elimination. I concentrated on talking with people in my focused field.

4.5.2.5 The Staff

I knew that time was an element in my project so I had to consider when I was going to focus on collecting data from the staff rather than the patients. Although as an ethnographer one should not leave a field until every question is answered (Hammersley & Atkinson 1995), I consider that as my knowledge increased I always had more questions to ask even if they were only of a social nature. But once I felt that my data about the patients was as complete as I could make it at that time, it was time to move on; therefore I turned my focus to the staff. If I did need more information from a patient I could always return to that person to get an answer as I was there in the unit. Again there was hostility from the staff which I had to overcome. Once I proved myself 'reliable', not someone who would talk indiscreetly, trust followed and good relations and friendships were established over the months. I joined in the chat in the coffee room and around the nursing station trying hard not to be in the way but always looking for the opportunity to have an informal interview. Occasionally I fell upon a participant who really wanted to share his or her problems - beliefs and attitudes. I did have one occasion to regret the absence of the tape recorder as I had the most interesting participant, but on reflection a tape recorder might have inhibited the flow. We talked (unrecorded) for over an hour, I wrote down immediately as much of it as possible so as not to miss any nuances, but I still regret not having been able to record it.

Using the wide focus of observation, I met all the Health Care Team who visited the renal unit - doctors, social workers, dietitians, domestics and anyone else who appeared. It was often difficult to talk without feeling in the way, but with perseverance I managed many informal conversations. The domestic view of the dialysis unit came from a different perspective, which gave me pause for reflection. When a patient's relative came to the unit s/he were included in the project, as their perspectives were both from 'inside and outside' the unit culture. The porters were difficult to talk to as they were always needing to be somewhere else. I focused on the ambulance transport people as these drivers play a vital role in the lives of the dialysis patients attending for regular treatment (see 4.4.3.1 & 4.4.3.2) and their contribution had great significance. Without transport the person often could not come for treatment. These drivers had 'time to kill' while waiting for someone's treatment to finish so were able to chat to me. They were pleased to think that there would be more information available about renal failure and the treatment, as one of them said ' I never realised what these people had to put up with, I don't think I would do it'.

4.5.2.6 Formal Interviews

Spradley (1979) distinguishes formal interviews from informal ones because they are conversations which have been planned with a chosen participant. I agree with Brewer (2000), Agar (1996) and Spradley (1979) that they are a good way to collect information. The interviews were conducted in a room where I could be sure we would be undisturbed. I always asked permission to use the tape recorder explaining that I would make a transcript of our conversation which could be reviewed and corrected. I explained about the purpose of the interview. I had a list of core questions to help keep the conversation focused (Appendix 9), otherwise I let the conversation flow. Spradley (1979 p 78) considers there are two processes to the ethnographic interview. The first – rapport which was present before the interview was requested, I had only asked people to participate when I felt we had a good relationship (see 5.4.8). The second was eliciting information, in every case once the interviewee had started to talk there was too much information and both of us would have liked to continue for longer.

4.5.2.7 Questionnaires

I decided that a questionnaire would quickly give me a large amount of demographic information about the staff, which I could not obtain so easily from informal interviews or participant observations. I designed two questionnaires (Appendices 10 & 11) which I distributed to the nurses, one for the trained staff and another for Health Care Assistants (HCA), in the unit. The different content for trained and untrained staff would allow me to find information relevant to the status of each group. These questionnaires were seeking information from the staff, not the patients. They were designed and piloted in another unit before this study was started. If I had waited to plan the questionnaires until I had gathered some data the questions would have been very different, but at the time of planning I did not know what I needed to find out therefore the questions were unspecific. I wanted to know whether there was a determinate factor which decided people to work somewhere special and was expecting to uncover this through the answers but the converse was true (Appendix 12 Table 12.3). Demographic details of the work force as well as ascertaining details about people's perceived need for knowledge were other issues in the questionnaire. Fetterman (1989) suggests that researchers have a difficult role in some social situations. Certainly this questionnaire was helpful to demonstrate that I was doing something tangible as a researcher, not 'just looking' as was suggested by one member of staff. I gave out and collected the questionnaires myself and analysed the results using SSPS. I was looking for relationships, correlation and descriptive statistics. The results have been useful to reinforce

some of the facts emerging from the data, and have challenged some of my experiential theories, or could be the starting point for further research.

4.6 Unit 2

4.6.1 Getting Established

Access was granted through the same Ethics Committee as had been used for Unit 1, and I had made the same preparations prior to my arrival. The unit manager introduced me and once I had met the staff I explained the research aims and process to them. I found interest and willingness to give support, but there was still the underlying feeling of apprehension about this 'stranger' in their midst. After the preliminary talk with the staff I introduced myself to the patients. The unit is smaller than Unit 1 and one is immediately struck by the feeling of warmth and intimacy. I did not have to walk far to introduce myself within the treatment bays which were small enough for me to be able to tell all 6 patients who I was and what I was doing. By the time I went to the next bay the patients already knew who I was. Every patient was asked to sign the consent form and an information sheet explaining about the research study was given to all. I organised my time in the unit to coincide with the shifts of patients (see 4.4.3.2). Again there is doubt that everyone who became involved had signed a consent form. Agar (1996 p108) describes the problems of obtaining consent which are very relevant for me but even if the patients had not physically signed anything, they all had consented verbally to my study. The problem of the ever-changing population was common to both units, people died, new people joined the unit or others went back to the main unit for treatment. As happened in Unit 1, the only people not wishing to participate were those bothered by the phrase on the consent form about the tape recorder. It was only once the study had begun that the patients verbalised how they actually enjoyed talking to me, as I have reported in this study.

4.6.2 Fieldwork: the methods I used for collecting the data

4.6.2.1 The Unit

I had chosen this unit with the attendant actors and activities and became a participant observer. I entered into the life of the unit, observing, participating, again being a fieldworker in the field. After my experiences in Unit 1 I was more aware of the complexities of observing a social scene. I was finding information more easily and quickly than in the first unit. I was making selective observations and asking the right questions without realising. Even note taking was not such a problem, I could listen and would be able to remember and identify the significant themes without realising. I was able to join

with the general conversations without worrying whether my 'role' would be questioned thus raising my participation level.

4.6.2.2 Participant observation Identity management/field role

I came into the social scene in my research role as a participant as observer. I joined in with the everyday social life of the unit where it was appropriate and observed all the phenomena as I did so, still looking for the cultural behaviour and cultural attitudes. As in Unit 1 I was participating on different levels but was more confident after my experiences there. I had my label stating who I was and what I was doing, and I had informed myself about the personnel in the unit. Having written to all the significant actors I was accepted by the nurses and consultant. Once again I was careful about my dress code and kept neat and tidy, not in uniform but conforming to expected standards. I was receptive to what was going on and also aware that my pre-knowledge could make me insensitive to some of the experiences. The level of my participation altered according to the situation, and my level of observations altered becoming more or less focused as the situations demanded (Table 4.4 & Appendix 7). I changed roles to play games or watch TV with people on machines as in Unit 1, I did find this role change strange, sitting – almost daring to enjoy myself – while chatting or playing games. I talked to anybody who visited the unit. I joined in the nurses' report and was present observing when patients went on to the machines. Being a small unit I had to be more careful about to whom I talked, the staff were inclined to discuss the project and my actions amongst themselves so I had to be aware of any personal biases to the information I received once they had discussed a topic.

4.6.2.3 Selection of participants, time and data

See section 4.4.2 for a description of the criteria for sample selection. The choice of patients was an opportunist one as in Unit 1 (see 4.4.3.3). The number of patients is smaller than Unit 1 and therefore it was easier to talk to everyone who wanted to talk to me. I avoided those who were unwell or did not want to talk. The size and shape of the unit with the two bays, made easy the decision of who to talk to and when. Often when I started talking to someone on a machine the person next door or across the bay would join in and we had many joint informal interviews. I could observe both the bays at once from the nurses' station, but anything that happened anywhere in the unit was a source of interest to most of the patients as well as myself. I was used as the 'go-between' and if there was something happening in one bay the patients in the other bay were always interested so I was questioned about what was really happening. Since information is spread by one means or another, patient, nurse or even the drivers, I was happy to supply correct

information. The nurses I chose to interview were those with the same criteria as in Unit 1 (see 4.4.3.5). I spoke to everyone else who came into the unit – the domestic, consultant, the social worker, pharmacist, ambulance drivers, and the very occasional relative.

4.6.2.4 The Ethnographic record – field notes

The field notes were taken again using the little notebook which could be easily hidden in a pocket. But as in Unit 1, I wrote fuller notes in the car park before the journey home. The trip home (about 2 hours) was again an excellent place for reflection on the day's happenings. Once at home I put my notes onto the computer and wrote up my daily diary and my reflexive journal.

I followed the same principles as in Unit 1 observing, listening, and participating. Being a smaller unit away from a specialist hospital there were not many outside people who visited the unit. But I talked to everyone who did enter the unit, these included social workers and dietitians from Unit 1, and the Consultant who was present three days a week. Because of the geographical position of the unit, the transport – hospital cars or ambulances – were more integrated into the unit organisation, and the drivers seemed to have more inclination to talk about their passengers. Porters were a rare occurrence because the patients were self-sufficient and hospitalisation was less common. However the domestic was a vital source of information and she was very involved with the patients' wellbeing.

I had to establish trust between the patients, the Health Care team and myself. Some of the staff knew me, which proved a good introduction, but following the advice of Agar (1996) I stayed in the background until I felt the staff were accustomed to my presence. However once I was a familiar face the staff were very willing to talk to me when there was time. I expressed my gratitude to the people in the unit for their hospitality by helping with information when needed or ideas about some new project. Once again I was used as a confidante by some of the staff, this sometimes meant a role change back to nurse but as I grew in confidence I was able to remain a researcher.

4.6.2.5 Informal interviews

I talked to patients as they sat waiting for their treatment or while they were 'on' the machines. There was a lot of opportunity in this small unit to introduce a general subject and get diverse views from all the patients within the bays, everyone joining the general conversation. Fascinating bits of information or interpretations would be 'overheard' as the patients sat together in their bays and I would be at the nurses station or keeping myself

occupied within ear-shot but not an actual presence. The staff spent time chatting at the nurses' station but they also joined in with the patients' chatter so there were plenty of general discussions. The coffee room in this unit was used as a social meeting place and I was able to participate or observe in pleasant surroundings and chat in this small unit where time was not such a vital factor as in Unit 1. People did get their breaks without interruption. We chatted in the sitting room or gathered at the nurses' station to discuss the day's events.

4.6.2.6 Formal interviews

These followed the pattern set in Unit 1 (see 4.5.2.6). These were ethnographic interviews with a chosen sample of nurses. I did not attempt to interview anyone until I was certain that I had a good relationship with the person I wished to interview. Once again I had no trouble in eliciting information, rather it was hard to stop the flow when time ran out. I used core questions (Appendix 9) to keep the conversation relevant, but again the interviews encompassed a very wide range of subjects apart from unit business. The interviews were transcribed and returned to the interviewee for corrections and comments within three weeks of the interview.

4.6.2.7 The Questionnaire

The same questionnaires as had been used in Unit 1 (Appendices 10 & 11) were completed in Unit 2 by the staff. The staff numbers were much smaller on this unit so it was easier to ensure everybody had a questionnaire; therefore I had a better participation rate, although as usual not everyone did complete it. The results were analysed using SPSS, again looking for correlation, relativity and descriptive statistics.

4.7 Part two. The methods used to analyse the data

When looking at the data, the first objective is to uncover the domains before the analysis can begin. Therefore it is necessary to understand what is a domain.

4.7.1 A domain

To understand culture cultural behaviour, cultural attitudes and cultural values have to be studied. The cultural domain organises the elements of cultural meaning. 'A cultural domain is a category of cultural meaning that includes other smaller categories' (Spradley 1980 p89). They come out of the cultural meaning of a social situation - a dialysis machine is a social descriptive observation but the machine can be used for events which give it its

cultural meaning; therefore a machine could be a domain. A cultural domain has to possess three basic elements: cover term (machine) included elements (blue machine) and semantic relationship (is a kind of) (Table 4.3). The semantic relationship operates on the principle of *inclusion*, defining terms by placing them inside the cultural domain. There are many kinds of domains which all involve the use of language, phrases that give meaning to objects, such as: kind of, part of, the reason for. For instance the dialysis unit is a place until it is described as a place where people receive treatment, then it becomes a cultural domain. A health carer is a person which immediately makes that health carer a cultural domain. The machine becomes a cultural domain when described as the machine where the treatment occurs. The domains are in the data and there are hundreds of original domains all with a cultural function. These were very numerous but important as from them I focused onto my main domains. Because it would not be convenient to give a list of all the domains which I found during my first searches I have given an example of some of them to demonstrate what I was finding (Table 4.2).

4.7.2 The Method of Analysis

I have discussed the methods I used for collecting the data (see 4.5.2) in conjunction with the criteria for establishing the validity of this research project (see 3.4 & 4.8). These criteria are still adhered to in the next part of this chapter showing the method used for the analysis of the data. Because of the iterative nature of this research method the analysis of the data is simultaneous with the fieldwork and both are dependent on each other. Some of the analyses of the data from the questionnaire are shown in detail (Appendix 12).

Agar (1996 p 241) argues that in doing ethnography and reporting its results one has to have organisation and structure, Spradley (1980) has given me a structure within which I have organised my data. Because of my past knowledge and experience I was part of the world I was studying therefore I needed to work within a framework. Spradley's Developmental Research Sequence (DRS) (Appendices 5 & 6) offers a prescriptive plan which provided that framework.

Researchers such as Agar (1996 p199-200) use 'frames' to get data into lists which correspond with Spradley's domains. Agar also looks for relationships (1996 p212), in the questions he asks. Many of his concepts for analysis are in a similar form to Spradley, but as Agar claims, analysis is not easy nor does it follow any particular pattern. However Spradley has steps which help follow patterns. Agar (1996) discusses the use of linguistic links for analysis but these are still replying to the same questions as are asked by Spradley

– X is instead of Y, or X is a kind of Y, looking at relationships. Hammersley (1990) also suggests that the analysis starts with lists, finding what is important, again following the idea of domains. The concept of the funnel approach going from wide observations into more focused ones is used by Agar (1996), Hammersley & Atkinson (1995) and Spradley (1980). Agar (1996 p153) suggests that through constant studying of the data the same topic will reoccur. This is how the domains come into focus and get narrowed down until the ethnographer finds the most relevant domains (or topics). I followed Spradley's path, but when my data did not fit in with the prescribed steps it was still possible to see where the path was leading. Using the strict guidelines meant that I had to justify my interpretations; if or when they did not fit in I used ideas from critical theory (see 3.3.2) to reflect on answers and interpretations.

I used a computer to store my data; I wrote my notes on it every night and I was able to sort and retrieve data as I required. I made a separate file away from the diary where I wrote down my interpretations of the day's events. I wrote here my most private thoughts; it has been a most useful supply of interpretative data which has made me look at my interpretations using a different perspective. I did not use a computer in the analysis of the fieldwork, but I would not have liked to undertake a study this size without using its facilities. Agar (1996) discusses the use of ETHNOGRAPH and NUD*IST but concludes that computers can only do part of what is ethnography, they can chop and sort texts but they cannot do the actual ethnography - the being there. Richards & Richards (1998) consider that computers give no instant solutions to the vast amounts of qualitative data which need analysing, but they do offer the opportunity of sorting the data. I used the computers facilities for an informal 'sort and retrieval' of words to enable me to analyse the data in a free and more interpretative way than a formal computer programme would allow. I accept that I am more fallible than computers but I still prefer the personal interpretation that only I as the ethnographer could provide.

Hammersley & Atkinson (1995 p 199) warn of the dangers of something being 'frozen' or remaining uninvestigated once the initial code has been made, this could not happen because I was constantly revisiting my data. I reluctantly agree with Richards & Richards (1998 p237), that as a novice researcher I was hindered by anxiety about creating a perfect index system, thus I resorted to pen and paper, making copious lists while trying to make sense of the data.

4.7.3 SPSS

I chose SPSS as the programme to analyse the data collected from the questionnaires. The questionnaires contained open and closed questions. Therefore the programme had to be capable of analysing both types of data. The data was analysed looking at correlation, associations and descriptive statistics (Appendix 12). The relationship of staff grades to expectations was performed. The differing acknowledged need for information was correlated with grade of nurse. The descriptive statistics were used to discover reasons for choice of unit. The results were used to reinforce or challenge the findings in the ethnographic data by providing extra contextual information as shown in Chapter 5.

4.7.4 Spradley's Developmental Research Sequence

I have shown Spradley's steps in Appendix 5 which is followed by more detailed information about how each step was relevant to this data (Appendix 6). Following Spradley's sequence I derived some tables which show the methods I used to analyse my data; these appear in Chapter 6 and Appendices 7 & 8. I have not attempted to discuss my findings in this chapter as they are part of the ethnography.

4.7.4.1 The social situations

The dialysis unit was identified along with all its actors and activities as the 'social situation'. It was apparent, as claimed by Hammersley & Atkinson (1995), that there were other situations close to the main 'social situation' with similar activities, which had meaning and relevance to the activities in the main unit. These were the High Dependency Unit, the Renal Ward, the Transplant Ward and the Acute Unit. All these had to be included in the 'social situation' as they influenced the events in the main unit. The actors and the numerous activities were identified as I classified the important phenomena. All the tables shown are only examples of the extensive tables which I made for the purpose of the analysis. They show how I used my information and the path of my investigations.

I uncovered the domains during the course of the fieldwork. They did not appear in any significant order, rather as they came into my text (Table 4.2). They relate to the social scene, the actors and activities. This is not a complete list but it shows how varied are the domains. These domains were discovered while I was observing with a wide focus.

Table 4.2 The original domains

The original domains	
1. Care worker	10. Technical workers
2. Unit	11. Sayings of patients
3. Patients	12. High Dependency Unit
4. Treatment	13. Doctors
5. Machines	14. Transport
6. Feelings of patients	15. The weather
7. Illness	16. The machines
8. Access	17. Needling
9. Transport	18. Clothes

All these domains are made up of smaller domains (Table 4.3) and have a relationship with the original domain, for detailed information see (Appendix 6). Table 4.3 shows how a main domain includes smaller domains, showing the relationship with the main domain.

Table 4.3 The main domain of Care Worker with smaller domains which have a relationship

Main domain Care Worker	
	Is a kind of
	Nurse
	Doctor
	Ambulance driver
	Domestic cleaner
	Dietitian
	Social worker
	Friend

The relationship shown in Table 4.3 is 'kind of', all the smaller domains are kind of Care Workers and are included in the main domain because of this relationship.

4.7.4.2 Participant observations

While I was talking to a patient going on a machine I would be observing the interaction between the two participants. I would observe, noticing the differences between this going on and another with different actors, or on different days. Routine is actually never the same in a dialysis unit; I was 'explicitly aware' of the normal while seeing the differences.

My involvement levels would change depending on the situation and on my own feelings. Sometimes I felt I could not get involved (Table 4.4) (Appendix 7 step 2).

Table 4.4 The levels of participation in the ‘Going on’ process

Degree of involvement	Type of participation	Activity
High	Active	Helping to program the machine
	Moderate	Discussing treatment
Low	Passive	Watching and adding a few comments
No involvement	Nonparticipation	Observing without entering into the activity

During some observations the participants and I would be active and discuss why or how the treatment was going to be programmed. ‘I was so glad you were there as Sue couldn’t be too cross’; the patient considered my presence had made a difference to the actions of the nurse. Or watching the nursing report I was only a passive observer but the interpretations I made from these observations were important for the rest of the data.

4.7.4.3 Making an Ethnographic record

The brief notes I had in the unit were expanded before my journeys home and further expanded onto the computer as a nightly ritual as well as writing up my daily reflexive diary. When making brief notes I would underline quotes which then went into italics on the computer. I also stored them in a special file so they were easily retrievable. If I found different interpretations of the same phenomena these were again sorted for easy retrieval. Vocabulary which is emic to the unit such as ‘going on’, ‘needling’ and ‘blood flows’ was again sorted and I was interested to see how long it took for newcomers to the unit to understand these terms, for more emic terms see Appendix 7. I accept that I could easily have missed some special language due to my experience.

4.7.4.4 Descriptive Observations

The art of questioning in ethnographic research is to discover the question as well as the answer from the informant (Spradley 1979 p84). The question has to be meaningful to the person being questioned in order to provoke an answer. The descriptive question will be less likely to reflect the researcher’s culture and encourages people to talk about the object being described, such as ‘what do you feel about the renal diet?’ Asking for descriptions can lead to discovering other questions which then can be asked by the ethnographer. The

descriptions required can be those of wide focus such as ‘tell me about dialysis’ or can be narrowed down to talk about a specific incident, ‘what went wrong with the needles today?’ Different types of questions will receive different information about feelings, object, or time involved. Specific questions can be asked about experiences or native language which will give greater depth to the more detailed analysis.

4.7.4.5 Domain Analysis

A domain is a category which includes other smaller categories (see 4.7.1). The main domains all consisted of many smaller domains (Table 4.3 & 4.5). This next Table 4.5 shows the domain of Care Worker and how it includes many small domains. Some of these small domains answer the question of ‘included terms’ and some of ‘semantic relationships’ (Table 4.3), the cover term is ‘care worker’ but if I had shown a table of Access or Treatment as my main domain there would be different small categories. The goal of the domain analysis is to identify cultural categories in order to see an overview of the cultural scene.

Table 4.5 Domain of Care worker showing some of the many components

Main Domain – Care Worker	
Component of care worker	Component of care worker
Unit manager	Ward assistant
Nurse	Happy nurse in charge
Technician	Dietitian
Doctor	Social worker
HCW	Cleaner
Sister	Clinic nurse
Car driver	Chris
domestic	Transport people
F Grade	Receptionist
Dr. W	Porter
Tea Lady	Husband
June/secretary	Back to nursing student
Social worker	Course student
Tea Lady	G grade nurse
Named nurse	Wife
Nurse in charge	Red cross transport
Junior doctor	Doers HD nurses

The following table (Table 4.6) shows examples of the domains which I thought would give the focus for the final description. However after more analysis, the choice of the domains was further refined to those which had an even more relevant relationship with each other. The domains themselves were then analysed to show semantic relationships.

Table 4.6 Focused Domains

Focused domains	Focused domains
Care workers	Treatment
Patients	Machines
Saying concerning the Unit	Access for treatment
Feelings of the patients	Feelings of the nurses
Sayings of patients	Saying of nurses
Technical	Illness
The unit	Other relevant areas: HDU, Ward, Acute unit

Table 4.7 shows the defining of the domain Care worker, and the relationship within the domain. The ‘strict inclusion’ means that only those domains which related to the main domain could be included. Table 4.7 shows the relationship of ‘kind of’ for the components of the domain.

Table 4.7 Relationships – Strict inclusion

Domain	Relationship	Main domain	1. Strict inclusion
Nurse	Is a kind of	Care worker	Relationship to each other.
Doctor			
Porter			
Untrained nurse			

This analysis is done again with Cause-effect, asking the question: why were people in the Social situation with the main domain being renal failure (Table 4.8). The ‘cause effect’ is the motivation of the relationship and only those who answered the question ‘Why’ could be included.

Table 4.8 Relationships – cause effect

Domain	Relationship	Main Domain	2. Cause effect
Patient	As a result of illness	Renal failure	The reason for being in the unit
Trained Nurse	As a result of training		
Doctor	As a result of training		
Untrained nurse	As a result of wanting to work with people		

I analysed the domains into different relationships. Once the significant domains had been selected they were used for more intensive study.

4.7.4.6 Focused Observations

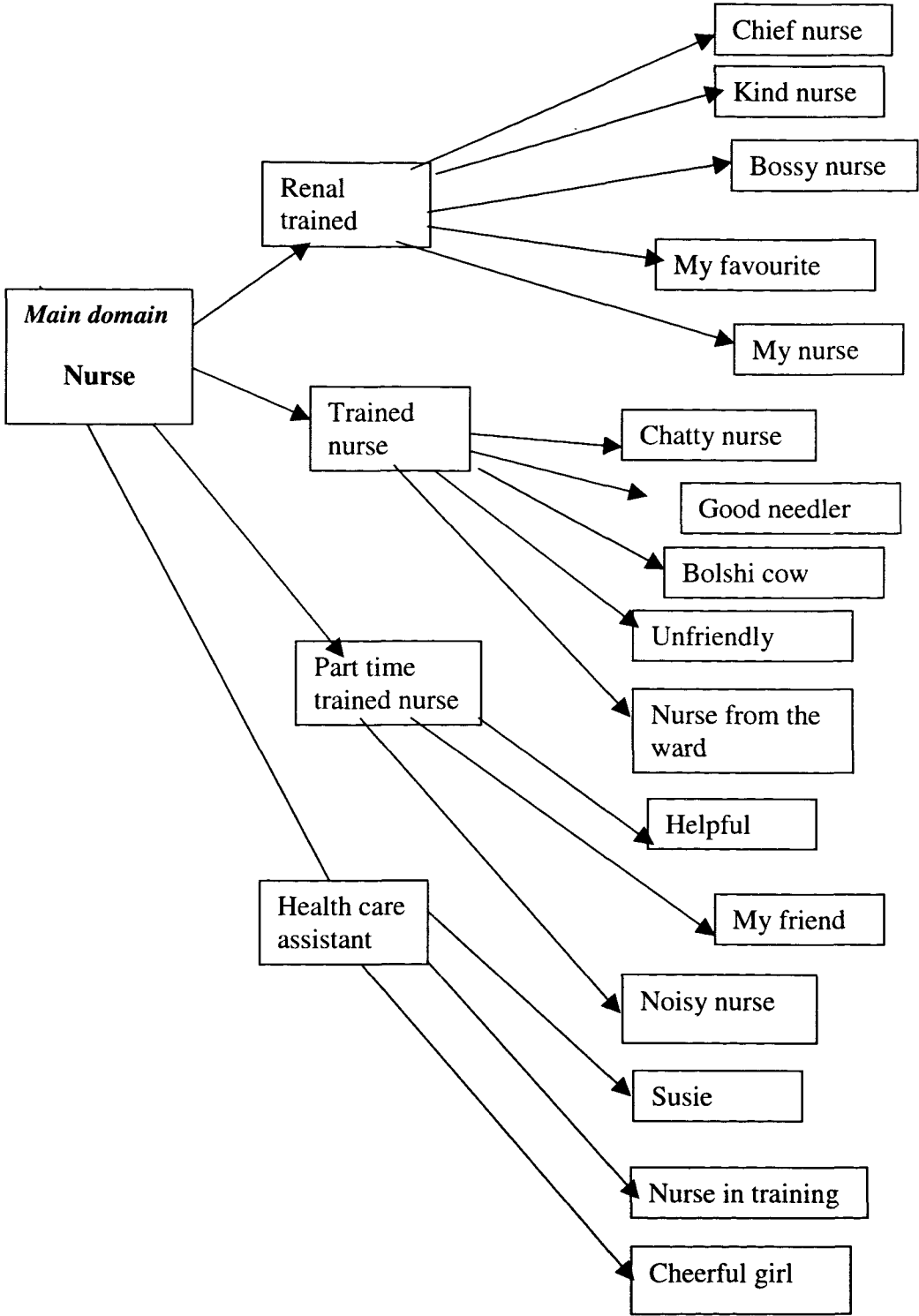
The domains are refined from the holistic view to the more particular while still keeping the observations of the wider scene (Appendix 6). The wide domain of care worker or renal disease consists of smaller domains which have a relationship under the cover term (Tables 4.7 & 4.8) (Appendix 6 steps 5 & 6). Nurses as domains can be subdivided into trained staff and untrained staff, these again divided further into even smaller groups or domains but they always had a relationship with the main domain of care worker and another relationship to renal disease. Another group within these domains are the porters and lab technicians who did not feature in my focused observations on the nurses unless their actions and presence altered a situation. The smaller domains can appear within several larger domains as seen here with nurses as long as they have the required relationship with the large domain. Treatment, another main domain, includes smaller domains such as the nurse and the patients which again can be focused into smaller domains so long as they relate to the main domain of Treatment.

The criteria for the choice of the focused observations reflect the aims of the research project which was to learn more about the relationships between staff and patients and influence of the illness and its treatment on this relationship, this was my focus of interest. The criteria for the choice of focused observations has to be a relationship to a main domain which again will answer the question of 'why' or 'what relationship' (Spradley 1980 p106) (Appendix 6 steps 5 & 6). Repeatable ethnographic questions such as 'why are you doing this?' or 'what do you feel about doing this?' helped to focus the observations. The answers they elicited resulted in analytic domains which were created by the cultural rules for behaviour used in the units which lead to the disclosure of cultural domains.

4.7.4.7 Making a Taxonomic Analysis

The taxonomy is a set of categories which are organised into single semantic relationships (Spradley 1980). They show the relationship amongst the things inside the domain. This taxonomy (Figure 4.1) shows the relationship between the nurse and subsets of nurse and then the relationship between the types of nurse. This taxonomic analysis can be organised to suit any ethnography so long as it is possible to see the relationship between the subsets. The taxonomy has different levels, this taxonomy (Figure 4.1) shows the cover term nurse, a domain, then terms included under nurse and the third level is the sort of nurse. The third level shows 'emic' or insider language used to describe nurse.

Figure 4.1 The Taxonomy of Nurse



The outline taxonomy (Figure 4.2) is another way of analysing data. It is a practical way to analyse activities and it stimulates reflection about why and what are the relationships between the actors and the activities. This taxonomy shows the detail of the process of

‘going on a machine’. This process can be continued in intense detail using a domain, such as weighing, within this first analysis until the actual treatment begins. The next activity - needling - can then be analysed using the same pattern.

Figure 4.2 The outline taxonomy: Activity ‘going on the machine’ for patient

Going on the Machine

I. Enter the unit

Nervously

Quietly

Pleased to get on

Very reluctantly

Needing assistance

i. Cannot see

ii Cannot walk alone

II. Check which machine to go to

Asking nurse

Checking machine is ready

III. Weighing

Go to scales

Ask for help to see weight

i. Poor vision

ii. Disabled in some way

iii. Poor memory

Write down weight or ask for help

4.7.4.8 Selected Observations

I moved from the wide focus of finding domains through the selected observations to in-depth ethnographic focus, choosing a few significant domains which I found were relevant for this ethnography. These domains related to the research aims, so I asked questions such as why do nurses/patients occur in most of the main domains? What is the relationship between nurses and treatment? Or what is the difference between this treatment or that one? Through the answers to my questions I was able to find the most significant domains.

My focused domains were:

Nurse

Patient

Treatment

Illness.

My focus changed as the information started to form a pattern. I looked at differences inside the cultural domains. I asked dyadic and triadic contrast questions, looking for two and three differences respectively. I would ask how a nurse and patient differed – they were all people but illness was a differential. Once contrasts or differences had been established I asked more questions about specific differences. This is the most focused part of the research analysis, and having found the domains I put them into different categories looking at differences. The discovery of differences helped show me where the cultural themes were emerging.

4.7.4.9 Making a Componential Analysis

This is the systematic search for the components of meaning of cultural categories (Spradley 1980 p 131). It is looking for the meaning that people give to cultural categories. I used a paradigm worksheet which, as Spradley (1980 p 132) suggests, shows all the categories and the dimensions of contrast (Table 4.9). The cultural domain or category has various attributes or meanings; these become dimensions of contrast showing where the contrasts are. This worksheet can be organised to fit the particular situations; it also shows clearly the missing attributes or meanings, so is an easy reference point to show where more knowledge is needed. If I could not have found in my field notes whether an HCA took charge I would have returned to my data or social scene to find the answer. Making the componential analysis meant going through my chosen four domains searching for contrasts. Table 4.9 shows the cultural domain of Unit with the cultural category of Nurse then it discovered the 3 dimensions of contrast by asking triadic questions. This table can be repeated keeping Unit as the cultural domain but using patient, illness or treatment as the cultural category.

Table 4.9 Paradigm worksheet showing the Unit as the Cultural Domain

Cultural Domain: UNIT		Dimensions of contrast		
		1	2	3
Cultural category: Nurse		Takes charge	Takes responsibility	Does not take responsibility
	Renal Trained	yes	yes	no
	Trained	yes	generally	sometimes
	Health Care Assistant	Yes, but should not	sometimes	yes

4.7.4.10 Discovering Cultural Themes

The 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 56). To find the cultural themes it is necessary to return to the wide focus seeing the unit as a whole. The themes are assertions about a belief which is held to be true. Cultural themes are elements in the pattern that make up a culture. One of the main cultural themes which runs throughout this data is that people on dialysis correctly believe that 'you have to have treatment or you will die'. There are sub themes which relate directly to this need to survive.

Universal Themes again are found looking at the whole unit. They are found in any culture and are generalised, such as rules of behaviour. These rules are common to the human race, politeness or conforming to a dress code such as the wearing of clothes rather than pyjamas as happens in the dialysis unit. These rules, as well as the cultural themes are relevant for an emerging theory. I wrote a short overview of the major domains and cultural themes to enable me to identify more cultural themes which began to show the culture of the dialysis unit. The list of cultural themes which emerged from the data related to the focused domains and were the same for both units. The definition of these cultural themes finally led me to be able to identify the idea that partnership might be a link between these cultural themes which would give understanding to the culture of dialysis units.

4.7.4.11 Making a Cultural Inventory

I reviewed all my raw field notes, the pages of lists along with the diary notes and the reflective diary I had made during the fieldwork. I reviewed the complete computer lists and tables. There were plenty of examples of phenomena with a large amount of thick data. The analysis of these notes stimulated much reflection and as I re-read the descriptions of events so the cultural themes became clearer. I began to organise my thoughts and notes, remembering special events or being reminded by the notes of particular people. I made lists of exceptional events; I knew the routine so was careful to remark on the exceptions.

4.7.4.12 Writing an Ethnography

This is the last step, and one of the rules for establishing validity is to explain the method of writing. For me, as I started to write this was the final hurdle. I could not see where the plan was leading and felt unsure that I would find my way through the maze of notes. Ottenberg (1990) gives some hints about how to focus and organise notes into categories, and Lederman (1990) discusses reflexivity and how this changes the interpretation of the

field notes. But there are no indicators of the method I used to write the ethnography. I constantly read and reread my notes using the computer to sort them and checking information in my diary and referring to my cultural inventory. My reflexive diary was important as it gave me more insight into my interpretations from other perspectives. The writing was never easy but writing refreshed my memory. I was writing on different levels going from the general to the particular but I could not subscribe to Spradley's suggested six levels as I found that the levels were not individually identified and boundaries were blurred. I began writing the ethnography when I was away from the units, without the distractions they offered, and able to concentrate on the development of my 'journey of discovery'. The concern with the particular or isolated domains will lead to an understanding of the general culture. These cultural themes led to an understanding of the culture of dialysis units. Through them a concept of partnership seemed to make the study more understandable. Having finished writing the ethnographic journey I returned to the units to discuss the authenticity and relevance of my findings.

4.8 Assessing the validity of this study

I modified four criteria from Lincoln and Guba (1985) as a basis for assessing this study. Sandelowski (1986) argues the relevance of these criteria to research on human beings, but she discusses quantitative as well as qualitative research. Murphy et al. (1998) argue that Lincoln and Guba's criteria are not applicable for quantitative research unless modified because of the differences between the qualitative and quantitative approaches. The modified criteria are 1) validity and reliability/truth value, 2) applicability, 3) consistency 4) neutrality.

4.8.1 Validity and reliability

Interpretations made by me or the participant are truthful from the view of the teller, as suggested by postmodernism. There are many thick descriptions which as Geertz (1973) suggests help establish truth within a study. Hammersley (1990 p60) suggests there are three steps in assessing the validity or truth of ethnographic claims.

- **Plausibility.** I have worked hard to establish the plausibility of the findings, so they can be accepted at their face value.
- **Credibility.** The claims are credible not only in my judgement but my interpretations of the phenomena are acceptable in the context of the research.
- **Evidence.** When I have not found supporting evidence I have tried to find other evidence before accepting the validity of the claim.

In assessing research for validity Brewer (2000) postulates that sociological researchers have to be aware of 'common sense' by which the ordinary people know and accept the world. He maintains that because knowledge is often parochial, the common sense theories do not necessarily hold true in the wider context. This is very relevant for this research the participants are human beings who know their world of the dialysis units through their own common sense. The interpretations of phenomena are true for the informant so they are accepted as truthful; Hammersley (1992) claims we can never know whether an account is true, for there is no independent reliable measurement of reality. The validity of the research has to be judged on its adequacy of the data. The findings in this research are credible enough to be accepted by common sense if not through empirical proof.

4.8.2 Applicability: external validity

The social scene for this study was two dialysis units and their population. Every dialysis unit is unique, but many phenomena are replicable or transferable to other units, as most dialysis units contain equipment to perform the same treatment (see 1.3.1) and the patients and carers have many of the same interests and concerns. But the people and the interpretations cannot ever be the same. Murphy et al. (1998) argue that transferability as proposed by Lincoln and Guba (1985) will establish external validity. In this study the participants were not chosen but 'happened' as proposed by (Agar 1996); they were the patients and health care team in the dialysis units. They were an opportunist sample of people prepared to talk to me when I was in the units (see 4.4.3.3). Therefore the choice of the sample sizes in this study also help establish the external validity.

4.8.3 Consistency or Authenticity

Although this study could not be repeated because my presence has altered the social scene, Brewer (2000) offers other ideas for establishing the authenticity of the study.

- Applicability of the field to other sites. I have discussed how this study is applicable to other sites (see 4.4.2).
- Openness. I have signified what and why I had not done things.
- My past experience establishes my authority.
- Validity of data. I explained to the participants what I was doing and returned to them for further information when needed. At the end of my writing I returned to the units to share with them my findings.
- Evaluation of data. There are many quotes in the data extracts to allow the reader to evaluate the interpretations.

Analytical realism is based on the view that the social world is an interpreted one; therefore the reader has to accept that all analysis is made from the perspective of the researcher (Altheide & Johnson 1998). The realistic viewpoint of analytical realism together with the reflexive process has helped in this portrayal of a true picture of dialysis units.

4.8.4 Neutrality: objectivity versus confirmability

Neutrality cannot happen in this qualitative study as phenomena are changed through subjective interpretation and the influence of my pre-knowledge. Lincoln & Guba (1985) suggest that neutrality should be replaced by confirmability, which they consider occurs when the findings are established as truthful and an audit trail can follow the analysis process. My audit trail followed the steps of Spradley (1980) and is clearly visible which should give the study the confirmability required by Sandelowski (1986).

4.8.5 Rigour

The findings in two dialysis units were sensitively portrayed which enabled participators to follow the clear audit trail. But as Sandelowski (1993) claims, readers have their own experiences and may have difficulties in recognising other people's experiences. Each individual has a personal interpretation of phenomena and this interpretation is true for the individual. Realism or common sense, as advocated by Brewer (2000) has to play a part in the acceptance of explanations. If the event can be seen to have commonality with the reader's experiences as I would expect, then this gives authenticity to the description of the phenomenon. Audit has been achieved by portraying an exact and detailed account of the method by which the data was collected and how the research process developed. This ethnography is exploring the culture of the dialysis unit and culture is only visible through the ethnographic writing of that study, which should be as faithful a representation as is possible.

4.9 Conclusion

Ethnography is especially slanted towards learning from people in their own social settings or 'field' (the dialysis units) where the researcher should participate (Brewer 2000 p 27). To give validity to an ethnography is to produce data that accurately portrays the subject under study. Much of this data will be recognised by people who have knowledge of dialysis units, which fulfils Denzin & Lincoln's (1998a p 22) rules that any representation must legitimise itself when the author and the reader can make connections between the text

and the place under study. Through reflexive practice I interpreted my findings accepting the influence of my pre-knowledge and experience.

I have followed criteria to ensure the validity of this ethnography. Spradley's DRS has been the guide for the method for the analysis and the second part of this chapter has shown the method used to analyse the field notes. Because of the nature of ethnography, the analysis is dependent on the on-going fieldwork. There are no attempts to interpret the findings in this chapter because that is part of the ethnography. By following the steps discussed in this chapter the reader should be able to plot the course of the study and, despite the limitations on repeatability, it should be possible to evaluate the validity of the research project. On returning to both units to discuss my findings I found that the majority of the people in the units considered that they were relevant and did have validity for the special world of the dialysis unit.

The next chapter takes the reader on the ethnographic journey of discovery I made through the two dialysis units.

Chapter 5 The Ethnographic journey

5.1 Introduction

This ethnography is a description of the journey of discovery I made while uncovering the culture of dialysis units. I chose two units and although there are similarities in the aims of each unit, the differences help to establish the culture in each. This journey has taken me from my tentative arrival as a very new ethnographer through my adventures in the field, emerging as a confident researcher, and finally to the writing of the ethnography, probably the most difficult part of the whole study. I left each unit with sadness, as I had met some remarkable people and was still learning, but time and money were my constraining factors. The source of my data is from my field notes, the interviews, formal and informal and my reflective journal.

It is hoped that the reader will feel immersed in the atmosphere in the units through the pictures I have drawn. I have described and interpreted my impressions of the units, first Unit 1 and later Unit 2. I have used my field notes with interpretations and my reflective journal where my personal feelings were described. These helped me to question and reflect on my interpretations. In each unit I have first described the unit with its environment. Then I have written about my experiences with the patients before sharing my experiences with the health providers. I have given descriptive cases as examples of routine events and people in the units. Named people I have written about in detail and there are numerous direct quotes throughout the ethnography which will make this study more readable and realistic. There is no analysis of my findings in this chapter as this chapter is purely descriptive. The analysis follows in the next chapter because although the findings emerged as I wrote the ethnography, the analysis is iterative and it was not until the writing was finished that it was possible to see the whole picture of the units.

5.2 Background

There has been much research into the lives of those needing RRT (Cameron 2002, Gorkal 1993) and through medical science we now understand more about how treatment affects the bodies and minds of those undergoing treatment (Cameron 2002, Zrinyi 2001, Van Biesen 2000, Bruno 1999 amongst others). But there is still little information about how the patient comes to terms with life as a participator in a Unit, where everyone has a common

complaint and receives the same treatment. The absence of relevant literature shows that there is no research that discusses how the benefits of attending a unit and becoming part of that community can be maximised. The aims of this research are to increase knowledge about dialysis units, understanding the relationships within them and how the environment can affect these relationships and treatment. The common problem – renal failure - is often not openly discussed despite the acknowledged fact that open discussion will lessen the fear and feeling of isolation caused by the disease (Caress et al. 1997). There is information about how to select, train and maintain renal staff (Hurst 2002), but we do not know how they, the staff, cope with nursing people who are chronically ill but have to receive acute life-saving treatment on a regular basis. There is a need to understand more about the formation of relationships, why and how they do or do not develop. It is understanding these relationships which promotes the understanding of the unit culture.

5.3 First steps

The first step was to get established in the chosen 'social situation'. Having arrived, my ethnographic journey began. I frequently asked myself what right I had to be there and why was I doing this research. I also reflected almost daily on why I was putting myself through this soul-searching process. I had with difficulty overcome my reluctance to start the fieldwork. This was partly due to my own work constraints but mostly due to the psychological barriers, lack of knowledge about the research process being one. As Hammersley & Atkinson (1995) say, it is difficult to be told to go and do without knowing what it is that one has to 'do'. Moreover I was reluctant to put myself in a vulnerable position. Using my reflexive journal I concluded that my reluctance stemmed from the feeling that I could be compromising my professional status as a Unit manager by entering another unit where, although I was known, it would be hard to present myself in the position of learner. (This was one of the few times when I felt my renal expertise and knowledge was a disadvantage). I reflected on whether would the nurses welcome me as an outsider? Nurses, or anyone, working under pressure are often fearful of anybody or thing they see as a threat to their established practices (Mellot 1998). As manager of another unit, would the staff feel even more threatened by me and anxious about criticisms?

Silverman (1997 p12) considers that fieldwork is difficult because 'the observer has to accept a separation from his familiar universe, not only to be physically present in the new environment, but also to achieve personal proximity'. This was true, I was hesitant about being there and what the personal cost would be for me. But the overriding block to starting

the fieldwork was my feeling of inadequacy and ignorance. I kept asking myself why was I doing this, or, did the research have sufficient relevance (Brewer 2000) to justify the intrusion into people's social and working environment? I knew I had to enter this unfamiliar place in an unfamiliar role without support from colleagues, which is an important factor in the coping mechanism for nurses (Lewis et al. 1994). It was a difficult time as I felt I was playing a role in which I did not feel comfortable.

5.4 Unit 1

5.4.1 Getting established

There are different levels of getting established, the practical one which is getting there, then two more psychological ones, that of being accepted by others and finally personally feeling part of the establishment with the formation of bonds of trust and friendship. Entry to the first unit was finally achieved and I was welcomed by Jan, the unit manager, who had come in especially to greet me. Even this had its problems which, on reflection, could have added to the feeling of being isolated and an outsider. There was no proper recognised place for me to park the car. This seems a small thing in retrospect, but it mattered to me in my vulnerable state. Security could not recognise me as someone working in the dialysis unit until a special arrangement had been made by Jan. The feeling of being an outsider remained with me for a long time and I kept referring it in my journal, I found it difficult not to be one of the team. I needed to be accepted into the team, but after a few visits I realised that there was no real team, working together in a 'family' spirit in the unit, therefore it was not surprising that I could not join this non-existent team. Once I was more established and felt more confident in my researcher role, I was able to offer help in a concrete manner by giving information or assisting with educational matters which also helped establish my credibility with the Health Care providers. When I introduced myself to the patients I first told them about the research and explained about the study but I did add that I was a nurse; at the beginning of the research process I felt more comfortable in that role.

The walls of the 'social situation' having been breached, I realised there were various component parts which influenced the events in the main unit. Within the main room are fourteen treatment 'stations' which comprise of machines, chairs or beds, the patients and nurses, plus all the clutter: yellow bags for rubbish, patients books or magazines on machines, trolleys of various sorts and descriptions, and a general plethora of things patients bring to dialysis to help pass the time. Then there was the surrounding environment of the

unit. What hits anyone entering this unit for the first time is the floor space, - 'a vast space where one is vulnerable to hundreds of pairs of watching eyes'. The floor is washed lino, the windows are high and although the unit is light, one cannot see the countryside out of them. The lights are practical, harsh strip lighting illuminating the work area but not adding to a homely atmosphere. This is where it all happens, as one newcomer asked 'is that really blood in those tubes?' One's eyes stray to the 'nurses station' with the barrier between it and the room, furnished with computers, telephones and the 'wall' of the desk to sit behind.

To the side of the vast space is another smaller room with six stations where, despite the proximity to the large unit, it has a different feel. The décor is the same but the stations are closer and the feel is more intimate. Between the two rooms there is a corridor where people endlessly pass, adding to the feeling of perpetual movement. There are other areas which are instrumental in the dialysis procedure, the weighing machines in their own area, the washing facilities and the waiting areas. The hospital has grown around the renal unit and there are continual improvements and building works in progress.

To the uninitiated the first thing that strikes one on entering the unit is the noise, not human noise, but the machines perpetually bleeping alarms, and the continuous ringing of phones, waiting to be answered. In this large unit machinery makes more noise than the people being treated. The human noise levels alter with the time of day, first thing in the morning there is quiet purposeful bustle, people arriving and going on the machines. As the day passes so the noise levels rise and fall depending on who is being treated that day, or perhaps a football match on the TV. By the late evening all goes very quiet with people just wanting to get home. The smell of a unit is particular, not antiseptic as in many parts of a hospital, but the dialysis fluids have a particular smell which is mixed with a slight smell of dried blood and the smell of sweat. I realised that due to my familiarity with dialysis units it was not something I noticed, it had to be pointed out to me. Once I had been alerted to it I reflected that the smell of sweat was probably an outward sign of fear, which accompanies most treatments (see 5.4.3).

The dialysis day starts at 06.00 (see 4.4.3). The unit continues to deliver treatments, becoming increasingly frenetic as the day progresses. The worst times are generally mid morning when the emergencies all seem to appear from nowhere. Patients have to go to other parts of the hospital for treatments so there is the continuous stream of porters coming and going. Trolleys and chairs with waiting patients have to be avoided by the busy nurses who are getting on with the daily routine. There are various hospital personnel all with their own agendas, who either pass through or stop to perform their allotted tasks in the unit. The

number of treatments performed in a day is generally around 55 but this will alter depending on emergencies.

I realised that the adjoining units such as the Renal Ward, the High Dependency and Acute Unit all had direct influence on the Chronic dialysis unit; therefore they and their actors had to be included in the main social situation. The activities in the main unit consisted of the daily routine, treatments being started, continued and the 'coming off' process which includes cleaning the machines and resetting them for the next patients. There were patients waiting to go on and more patients waiting to be collected to go home, all routine activities. Reflexivity reminded me to be vigilant to reactions which I might miss because of my familiarity with the dialysis procedures.

The unit was always busy with extra personnel and the nurses coming and going from the other significant units. The High Dependency nurse looking for a spare machine where she could 'off load' one of her less ill patients. 'It could be done but can she wait until the afternoon?' was the answer to her rather desperate questioning. Or a phone call from the clinic demanding to know why Mrs K had not turned up for her appointment, 'because she was late for treatment' was the aside from the nurse. The focus was on the wide field without special focus, but this narrowed when any special phenomenon caught my attention.

It is the constantly repeated activities which help establish the cultural rules for behaviour (Spradley 1980). The repeated treatment cycle was easily seen as it was performed over 50 times a day. I reflected that every time a routine event such as daily treatment occurred it was unique because of the environment and participators.

Baum (1994 p213) considers that culture is the learned behaviour of a group or society and societies grow together through their acts of altruism or shared goals. He postulates that altruism is the hallmark of society. The goal in the unit was to be treated and survive but this was not a goal that could be shared through altruism, rather there was a feeling of 'me first' among the patients. Shapiro & Gabbard (1994) discuss how civilised society developed through altruistic and co-operative strategies, but treatment in the dialysis unit does not lend itself to altruism. The urge to survive overrides altruism, self preservation is the prevailing emotion (Arram et al. 1998). In the case of people needing RRT, this is to be on a machine which will keep them alive. The need to survive is the reason for undergoing treatment and the patients' commitment to staying alive. Even the friendships between the patients did little to mitigate the intense desire to 'be on the machine'. Baum (1994 p230) discusses 'The selfish gene' which is what makes us self interested at the expense of others.

It again reflects on the need to survive, which is the primitive motive for those with renal failure which is a fatal disease.

There has to be order for the unit to survive and rules help for the cultural scene (Smith 2001). Therefore there are rules and an order about who would have which machine, the machines are set up for a designated person. But the patient's impatience shows an apparent lack of understanding about the routine of treatment. This lack of comprehension also leads to a feeling of isolation for the patients as shown by these quotes from my field notes, 'No one understands how I feel' or 'no one understands why I need an early machine so I can get home early'. 'I hate waiting, it makes me feel ill, I really do need a machine as soon as I come in'. These feelings of isolation and self-interest do not induce a family atmosphere, but they do illustrate the 'selfish gene'. The lack of family atmosphere reflected the lack of time, time for one another, time to listen or even time to consider another's needs as I reflected in my journal. Mutual benefit depends on reciprocity and if there is little reciprocity there will be no feeling of society (Baum 1994), but this lack of feeling of society is part of the culture of this unit. At the beginning of my research I felt that the friendly outward appearances of the unit made up the 'family atmosphere'. But as time passed I reflected that there was an absence of real family feeling in the unit. Every patient was isolated in his/her own world of illness, and the carers in their individual worlds of treatments.

During my time in the unit I was participating in the social lives in the unit. The patients were pleased to have someone to talk to and therefore our talks would be lengthy. Interesting data was forthcoming from the informal interviews. I managed to write a shortened version of these conversations which was enlarged onto the computer. Once people grew accustomed to me many confidences were offered, as the 'professional stranger' (Agar 1996) who did not matter, but who was knowledgeable and understood about the problems of dialysis, thereby supporting the value of my pre-knowledge. 'I like talking to you because you understand' was a common comment as I read in my field notes. At this stage 'my role' was entirely with the patients who would talk to me without worrying that I might 'tell the nurses what they had said'. I was accepted as 'one of them'.

I still did not see the path of my journey clearly, despite the highlights from my 'fore-shadowed problems'. Only with hindsight, when writing the ethnography is it possible to discover the steps leading from one to another and to recognise that the highlighted issues had offered some direction. The cases emerged as illustrations of events and give in-depth examples of my fieldwork but they are also examples of thick description giving detailed

accounts of my talks with people as well as my reflections and interpretations of events and conversations.

5.4.2 Treatment routine

The daily routine of the unit was the same with patients going on the machines, but every day brought variations, every treatment outcome is unique (Curtin et al. 2002). Using my reflective journal I saw through the daily routine and found the different interpretations offered by participants about the same events. Looking for similarities there were the same patients, staff, machines and all the problems, but when I looked or listened more closely there were all the contrasts waiting to be found. Monday or Tuesday, as the first session of the week, always brought the problems of fluid overload, and with it the corresponding complaints of the patients who all blamed the extra day, and the nurses who all wished the patients would keep to their fluid allowance. Every treatment brings its problems as outcomes are uncertain (Curtin et al. 2002), but the Monday and Tuesday are the first in the week so problems are exacerbated because of the extra day between treatments (see 1.3.1). Treatments on the other days are without the stresses of the Mondays and Tuesdays, but otherwise follow the same routine.

My experience has shown me, and this has been reinforced by my field notes, how patients feared and longed for treatment because through the treatment is the chance of survival, but there is always the uncertainty of how the treatment will be: will one survive it, or feel ill while on the machine? Through experiential knowledge, reinforced by my notes and the literature (de Vos 2002), I know that patients waiting in the unit for treatment can become irritable and even physically unwell, blood pressure can rise, because of the stress of waiting and fear about the treatment. The nurse waits for the arrival of the patient with mixed feelings (see 5.4.2), anxiety is one of them, and she also suffers from the uncertainties caused because of treatment, will her patient survive it? My field notes reinforce my own knowledge that when the patient arrives with fluid overload nurses feel irritation because of the patient's inability to control his fluid intake (see 5.4.2 & 5.4.3). For some staff this becomes a personal issue, which adds to the stress. Then the nurse can feel it is 'her fault', her lack of control over 'her' patient, or her inability to understand the pressures for the patient, or even her impatience with someone who cannot or does not want to care. In any of these cases the social situation breaks down and the nurse becomes the controlling factor in the patient's situation of increasing helplessness. It is the nurse who prescribes the treatment and programmes the machine, sometimes not even informing the patient how the machine is programmed (Appendix 8). When challenged about this

oversight Sarah told me that it was better for the patient not to know as then she would not be so anxious. Often the patient's reaction is of rebellion as is demonstrated in these quotes from my field notes. 'I hate being told what to do', 'I want to know what is happening to me', 'why should I have to be careful when my mates are drinking'. 'I can never go to the pub without these women moaning at me', 'who does she think she is, telling me off'. 'I don't care anyway, I know I am going to die so who cares'.

There is much written about how much control the person should have over their treatment, and how much this helps with 'compliance', but few conclusions have emerged (Hippold 2001, Morgan 2001, Bower 1995 amongst others). The Health Belief Model (Becker 1974) is sometimes used to describe adherence to treatment (Khan 2000). But for the person with kidney failure there is no cure. Many of them, as shown in quotes from the field notes, which reinforce my experience, consider that they would have 'a short life and a merry one' rather than one that adheres rigidly to the regime when all joy is taken from living. 'I know I am going to die so I just get on with my life, I eat and drink what I like'. I found within these sentiments another cultural theme which was important for the patients but was one the health care team did not appreciate. 'There has to be life beyond dialysis' said Mark, a young patient, and he was certainly expressing the feelings of many of the younger set of patients. Survival but at what cost? I reflected. This was a question I had to ask myself as I reflected on the regime that the treatment imposed on people. I was seeing treatment from the perspective of the patient. Non survival, or death, is not a subject taken seriously by either the patients or Health Care Providers during the dialysis treatment, as shown in my field notes, each side shying away from significant discussions, content to make jokes to show that although everyone is aware, no one apparently takes the idea of dying very seriously (Antonoff & Mallinger 1991). Through experiential knowledge I knew that people do not want to discuss death but they still need reassurance that they will not die. I reflected on this as I listened and observed. The patients sit having treatment discussing their blood results. Every one of them knows they will be the exception to the expected prognosis, they will cheat death by living longer and being better or worse (either following or not heeding medical advice) than the others round them. When listening to the patients talking amongst themselves there was a kind of competition about whose results were the best as 'that means I shall live longer than 10 years' said one lady who was constantly overloaded and did not keep to the recommended diet. The factors that determine long term survival are not established as there are relatively few patients who have survived for over ten years (Curtin et al 2002), despite the expected life prognosis made by Ansell & Feest (1999).

5.4.3 Illustration of a routine event – ‘going on’

The interaction between a patient, Mary and nurse, Sarah when starting a treatment

This illustration came from the field notes and my reflective journal. Although I have written up my observations about one morning when I was with Mary and Sarah, this routine event was happening all round me in the unit, but with different actors and therefore different reactions to the event of ‘going on’ (Appendix 7).

Sarah was setting up the machine waiting for her patient and was muttering quietly about the problems she had had with her son over the weekend. She was concerned that Mary was late which would affect her ability to leave the unit on time, the machine was ready and she became increasingly impatient. ‘Why does this have to happen to me today? I need to be on time’. I could understand why she was not thinking about Mary and the forthcoming treatment, she was pre-occupied by her home problems. She also expected Mary would be overloaded involving her in extra time and care when she had ‘had it up to here over the weekend. I can’t stand the idea of problem patients, why don’t they look after themselves?’ ‘I honestly haven’t the time to be here today Nick needs me’. The weather was cold and wet and the atmosphere in the unit was purposeful without cheerful chatter. As Sarah told me later she had got ‘soaked’ as she was running from the car park and she was already starting a cold so she was not feeling very well, and this adding to her other worries, was making her irritable.

Mary, when she eventually arrived first complained about the lateness of transport and an unfamiliar driver. ‘He went all round the houses, I told him where to go but he said he knew best, it was pouring so we were even longer’. The unfamiliar driver does not appreciate that the patients do know the best routes through constant use, nor does he realise the importance of being punctual I reflected. Unfortunately Mary was overloaded; I observed that she had trouble breathing. Sarah took a deep breath trying to control her frustrations. Finally she managed to say in a pleasant voice ‘you realise that you will have to do an extra ½ hour to get some of that weight off and the rest will have to wait till Wednesday?’ Mary was obviously relieved that the reprimand had been no worse. She knew she was putting her life at risk; she had been told often enough (as she admitted to me later), and she had asthma which made her breathing problems even more acute. She got slowly and ponderously on the bed and waited for Sarah to needle her. ‘I do hate this bit, I always pray it will be OK. I don’t look because that might make things go wrong’, I reflected again about the effects of fear of treatment. Sarah, having completed her

procedures, made notes about the programmed machine. Mary's blood pressure was up but as Sarah said 'only to be expected with that amount to come off'. Once finished she turned to Mary with another warning 'I do wish you would be more careful, you know what happens, it'll kill you one day'. Sarah had no time to discuss Mary's problems with her, moreover I reflected that she was not interested, I considered how the interaction was altered by circumstances. Mary the 'worst bit' over sat back relieved she had 'got off lightly' and got out her magazine, ready to chat to Liz who was beside her that day. (For analysis of this illustrative case see Appendix 7 & 8).

Daily as I listened to the patients talking and complaining I would hear transport being discussed. On reading the field notes I had daily entries about transport problems. If the patients do not arrive they cannot be treated. If they do not arrive on time this leads to repercussions on the rest of the day; the next patient will have to wait which in turn leads to problems with homeward journeys (see 1.3.1). Reliable transport is vital for these patients I reflected. The dialysis patient is very vulnerable; life equates with treatment and transport is vital to get to treatment. The ambulance men/women have an active role in the lives of the person receiving RRT. If they become 'regulars' then they are the people the patients trust to bring them to and from treatment and quickly they become friends as shown in this chapter. I understood how the ambulance drivers are the 'transport' between the two worlds.

As demonstrated in the quotes from my field notes, the patients would chat for hours discussing who brought them, how long they had to wait to be fetched, who was going to take them home, and who was going in the transport with them. My field notes showed me that the nurses spend many hours worrying where the patients had got to and why the transport had not turned up. I wondered (in my reflexive journal) how many hours the nurses spent on the phone inquiring where the transport had got to. For those patients who were lucky enough to have a regular driver, these drivers became part of the dialysis world and would be prepared to give assistance to 'his patient' either in the unit or at home as discussed in this study. I enjoyed observing, as I read in the field notes, about the real friendship which was obvious between these people and their 'charges', the small gestures of help accepted gratefully from 'my friend'. The ambulance car drivers found satisfaction belonging to the team and being needed, 'I do enjoy this job', 'I find it great to have my car load all happy together' or 'you get so involved with the patients and I like hearing about their treatment'. The field notes told me that the drivers expressed pleasure at being able to help, to plan their regular trips and getting to know their patients. From my experience as a

nurse, I know that the provision of regular reliable transport makes a difference to this vulnerable section of the community and their well being, and this is reinforced by the data of this study.

While watching the interaction between various groups of people I reflected that it is impossible to define an order for watching people or the level for the observations. Observation of the patient entering the unit would tell me a lot about how they were feeling. Were they dreading or longing to start? Most people have the attitude that it is better to get on (the machine) with as little wait as possible. There is a lot of fear about treatment which, I realised from the reflexive journal, is not discussed. The patient worries about the weight he has put on 'I don't know what happens, I know I stick to my limits but I always seem to have put on too much', 'I hate and long to go on as I know I will feel better' and whether the nurse will be 'cross', then the fear of what might happen during treatment and the outcome. This fear was apparent to me as the observer (the observer with emic knowledge); it was intangible but I could almost feel it. Something in the way the person would hold himself together or be very quiet, or noisy, never the same reaction as different people expressed their fears as they affected them individually, I reflected. During informal conversations with the patients once they were 'on', I reflected on the many different uncertainties there are for them. First, will the access function? Without access dialysis is impossible and if the access does not work it entails a stay in hospital. 'Will the catheter run properly so treatment can happen?' 'how will the actual treatment be?' 'will I feel ill?', 'will my blood pressure drop?' and many more worries which are not expressed to the nurse. When talking to the nursing staff in the formal interviews I realised that they did not acknowledge these fears as problems because they did not realise they were present.

Going on the machine is never the same as I reflected when reading the field notes. The interaction between nurse and patient is affected by the environment and how both parties feel at that time. Dialysis units are out-patient units and people come in from home and it matters and affects them what sort of day it is. I noted in my field notes that spirits are lighter when the weather is good. 'I do like to see the sun', 'I find it hard to be in here when it is so lovely out there', 'it's nice and cool in here but I wish I didn't have to have treatment'. The different times of year do make a difference, but the dark mornings and evenings do not always bring depression. People enjoy the welcome of the unit with its bright lights, noise and warmth, after the damp, dark outside world as I found in my reflexive journal. 'I love coming to see all my friends' or just as important 'I know it will be warm here and I can't really afford the heating at home' 'its good, all these bright lights

and lots of noise, I get lonely at home with no one' and as one old lady said 'lovely, lovely my lovey'. I reflected that these expressions, which came from my informal conversations, are about belonging to the select world of the dialysis unit.

The environment did affect the patients and care workers as I observed. However as I knew, and was reinforced by my reflexive journal, care workers have other concerns as well as the delivery of care. They come to work with their own problems, personal, domestic or childcare as I was told in the formal interviews. When the unit is bright, tidy and all the machines are running smoothly, then the nurse feels in control and can do her job satisfactorily (Folkman 1984). My experience, reinforced in the reflexive journal, alerted me to how often other considerations intervene to prevent the nurse from giving that extra loving care to the person she is attending. Historically the ideology of nursing is based on vocation (Bradshaw 1997). Nightingale (1859) considered a good nurse would sublimate her own feelings and needs for the more important needs of the patient, but dialectic change has moved nursing from this 'vocational' provision of care to the acceptance of the needs of both parts of the equation (Smith & Gray 2000, Brykczynska 1997).

In the NHS relationships are encouraged which promote therapeutic care. (Calnan & Gabe 2001). Ersser (1997) evaluates the idea of nursing as a therapeutic activity. The literature is not clear about the definition of therapeutic care and who assesses it. In RRT the outcome can be clinically assessed through the blood results; therefore the treatment can be assessed as good or bad. The patients know that the nurse has to have the skills to set the machine correctly but that does not qualify a nursing action as therapeutic. The patient will feel better if the machine is correctly programmed and confidence in this nurse may induce a feeling of well being (Ersser 1997), but the nurse needs education and experience to deal with technology as my field notes and the results of the questionnaire told me.

Experience has shown me that the care worker is an important part of the equation and the human needs of the professional have to be acknowledged which is supported by Quinn & Smith (1987 p153). Health care providers do now see themselves as people with their own needs, rather than dedicated to the profession of being a care worker (Smith & Gray 2000). 'Caring is a professional moral imperative, but not *the* moral imperative' (Brykczynska 1997 p3). Field notes demonstrated that problems in the social world outside the hospital may make the care worker unwilling or unable to have the emotional strength to undertake the dynamic relationships which should be the hallmark of the dialysis units as discussed (see 5.4.3). People receiving treatment spend around a third of their week within the confines of the unit therefore there is time to enjoy one another's company and friendship.

The outside world has withdrawn its support because of the deviance of illness so this support network has to come from within the unit (Keogh & Macefield 2002, Murphy & Kupshik 1992). Reflection showed me that support is intrinsic for relationships but the friendship and support offered by the patient to the carer may go unheeded and unused. The nurse will turn to colleagues, but lacking that support she will be alone (see 5.4.9.2).

Observing and reflecting on the interaction between the patients themselves was another level of focus. The staff in the main unit have to accept people who have a need for treatment without being able to refuse to dialyse someone, unless there are very extenuating circumstances. This means that there is a large transient population and only a small core of 'regulars', many of these are elderly and frail or unwell. I reflected that the extra care and attention that the ever-increasing elderly population requires take their toll from the health care team (Bernaert 2001, Ashwanden 2000, Winearls 1999). One of the consequences of the increasing workload is that the team has less time to spend being social with the well patients. My field notes showed how this impacts on the 'regulars' who become irritated because they feel their needs are subjugated to the needs of others. The field notes demonstrate the feelings of the patients - 'All the nurses are so busy they won't talk to me', 'they are always so busy I don't like to bother them' or the marvellous statement from one octogenarian 'that lady is too old to come here for treatment' (the person was actually younger than the octogenarian). The unspoken criticism was that she would take up too much time. The regulars did feel neglected, unnecessarily as treatment was always provided, but that extra caring time was absent. 'I need someone to talk to' 'I like to come here to talk to the nurses, they make me feel safe', 'no one seems to have any time any longer'. These quotes taken from the field notes illustrate the feelings of the patients, as can be seen there is always praise as well as censure. I found that people enjoyed talking to me because I was not too busy to listen - 'you have time and its nice to be able to talk' 'I enjoy having a good chat', 'I like having you here to chat it makes the time go faster'. I reflected that it was satisfying to be able to learn and understand more about how people coped with their daily lives.

5.4.4 Illustrations of cases - Patients

5.4.4.1 John A younger patient

I sat and had 'informal interviews' with people once they were on the machines. Most people really loved to have someone to talk to 'it passes the time' and often poured out their private problems along with the moans about the unit. John was a young patient who was angry. He was in a permanent state of anger against fate, his illness, the treatment, the other

patients, the nurses and most of all, against life. He obviously realised the importance of treatment as he came regularly (some really difficult patients have to be persuaded to come for treatment, this has to be done over the phone generally by the nurse in charge). He railed against his illness 'why am I ill when my brother is well and can do what he likes?' 'I hate this treatment, it's so boring,' or 'the nurses are all against us'. Then in the next breath he complained that another of the patients was making the nurses do what she wanted. He hated the machines 'I hate these machines they make so much noise', the noise was only an excuse for his unformed dislike of the machine and his dependence on it, I reflected. He was very bitter under all these complaints, he was young, 22 years old at this time and he still was living with his parents because of the illness and he had no job. He was dependent on a machine for life and the restrictions of the disease prevented him from having a 'normal' life. His life was controlled by the illness and its treatment. His brother was well and self-dependent and this annoyed John intensely, there had to be someone to take the blame for his circumstances, I reflected.

Apart from listening there was nothing I could do to alleviate his illness. I sat and played games with him and listened to his tales of woe. He did not look after himself he came in overloaded every Monday; his blood results showed he was not keeping the diet, consequently the nurses would lose patience because he was regularly unwell on treatment. The health team did not have the time or the energy to deal, on a regular basis, with someone who should be better able to look after themselves. Therefore there was a resistance to attending to him every time he felt unwell, 'he's always like this I simply can't be bothered', 'why can't he grow up', or 'don't bother he'll be OK' were quotes taken from times when John called for assistance. He needed someone to spend time with him every treatment, I reflected that he was probably scared; I would have liked to have asked him about this but he did not realise his need. He felt life had cheated him and wanted the people 'in charge' to 'make things better'. Unfortunately dialysis patients do have a tendency to wish for 'someone to wave a magic wand' to make things better (Dörner 2000). Chronic illness augments the tendency for despair and hopelessness (Finkelstein & Finkelstein 2000, Thorne 1993), and renal failure is a disease with an uncertain prognosis. The length of survival is very variable, and as Chris (a patient who had had to give up his work because of his illness) said 'my life seems to have been given over to treatment' which is true, the treatment is inexorable but necessary for survival.

5.4.4.2 Tomy A younger patient

These data were gathered from observations and his patient notes. Tomy does not want to be alive any longer. His mother and aunt have both recently died of Huntingdon's chorea. He is kept in lodgings by the social services; he does not care for himself and appears at the unit unkempt and often semi-comatose. He does not attempt to remain within the set dietary requirements. He will not talk to anyone and becomes verbally abusive if kept waiting for a machine. He must realise the importance of the treatment because he could always refuse to come, but although he does not wish to live he has not the strength to die. He arrives for treatment well over the acceptable limit for fluid removal and is not well enough to withstand the harshness of treatment. He does not relate to the nurses, and they have a strangely ambivalent attitude towards him. They accept him for what he is and have stopped trying to make him be co-operative, only treating him for his symptoms, trying to remove what is possible without making him unwell, but they still care. I reflected that the nurses obviously felt sorry for him and understood his predicament but there seemed to be nothing they could do for him. The other patients are content to leave him alone, although I could sense a certain hesitation to be close to him. (He can be violent when annoyed). They accept him and his appearance and only when he becomes abusive do they talk among themselves. 'I don't know how they (the nurses) stand it' 'it isn't necessary you know these girls are only trying to help' and many other comments in the same vein. I reflected that these statements did show support which came from belonging.

The nurses have accepted that Tomy does not want to be receiving treatment but neither does he actively want to die, and he could always refuse to come for treatment. As long as he behaves in a socially acceptable manner in the unit in front of the other patients the nurses try not to bother him, but as soon as he becomes abusive there is a big surge of feeling against him. 'What does he think we're here for?', 'why does he come if he won't help himself?' 'I can't see why he has to come here', are some of the usual comments. When he did make a nurse cry by his rudeness, the atmosphere in the unit changed significantly. No one went near him once he was on, he even missed his precious cup of tea. I reflected that when Tomy's behaviour is culturally acceptable he is a member of the unit, but as soon as he rebels he is ostracised and the membership of this social world is withdrawn. The social worker spends much of her time trying to ensure he receives all the help he needs. The doctors spend time trying to make him conform, seemingly unable to understand that repeated warnings about the state of his health make no impression. I

reflected that Tomy will not change his way of life. My experience tells me that he will certainly die before he succumbs to Huntingdon's chorea, which is what he says he desires.

5.4.4.3 Sarah A younger patient

The data was collected from informal interviews and field notes. Sarah seemed to want to make her treatment time as difficult as she could for the nurses, whom she appeared to blame for her condition. She would demand attention on the slightest pretext; there was always something wrong. She had lost her book or the TV was not ready. She would take time when going on, complaining about her many ailments, all of which needed to be discussed before starting treatment. She would make every ailment, even a cold, a major event. I could understand how in these circumstances the busy health care worker did not enjoy caring for her. Sarah insisted on having one of the only TVs every time she was in. The nurses would provide the precious TV to 'keep her quiet' as I was told, but her demands for attention were not met in a truly caring fashion 'I just haven't time for all her moans', 'I can't be bothered with her, its always the same'. I talked about this in the formal interviews with the staff and the consensus of opinion was that she had do something to help herself. I noticed a lack of enthusiasm from the staff when she called for attention. I reflected the nurses had no time for a one sided relationship which would probably be unrewarding. Sarah was certain she was the only one who felt bad 'I hurt all over' 'I know I have worse colds than everyone', 'you should hear the doctors, they know I'm bad, the nurses here don't care', she considered that her symptoms were far worse than anyone else. I reflected in my journal that it is difficult to believe that people can be so self-centred, but this is one of the effects of chronic illness which is reinforced by (Kralik 2002).

Sarah was difficult to talk to; she would turn her face away from me as I approached. When finally we talked, I realised that she only wanted to use me to put forward some of her complaints, hoping that because I was a nurse people might listen to me, even if they did not listen to her. I hoped I could be the friend she had not got, and if she could confide in me it might make her life less of a struggle, but there appeared to be nobody in whom she confided I noted as I wrote my journal. She certainly had not come to terms with her chronic illness and it was difficult to see how to help her. She did not have friends in the unit as the other patients were scared of her abusive tongue and demanding ways. People did not want to dialyse beside her as she insisted on having the TV to suit her hearing powers (which were poor) and she would not join in any conversations. Also if *she* was receiving all the attention would the nurses have time to look after them? 'Who does she think she is?' 'is she any worse than me?'. The social work team tried to help, but she

wanted all the attention all the time she was in the unit and the nurses did not have the time, as I learnt in the formal interviews. Again there is no miracle cure (Dörner 2000), and people have to try to help themselves despite the chronic illness (Finkelstein & Finkelstein 2000).

Each person has to find how to cope with the despair created by chronic illness, despite and as well as the help the health care team supplies I reflected in my journal. Sarah's way of coping was denial and insistence on attention to make her feel safer. But she was scared, she was only in her 20s and her life had been difficult 'I hate my life'. My notes told me that she had had renal failure for 6 years and a transplant which had been short lived. She knew there was little likelihood of another transplant because of her antibodies, so she compensated and coped with her frustrations by being a nuisance and she could say with truth 'I haven't got any friends'. I reflected that she found life hard and felt everyone was against her.

People have problems adjusting to life with renal failure (Auer 2002, Cristóvão 1999), the young patient especially as the treatment takes over his life (Gabbai et al. 1999). There are no plus points to having kidney failure, and treatment is the only way of staying alive. Some people try, and do manage to become positive about their treatment as I saw from the field notes. These people are easier to treat and often do manage to achieve a good quality of life. But there are those for whom RRT is something to be denied. They find the restrictions of the treatment routine hard to accept, they lose control over their lives 'I can't stand this, I need not to be here'. Mavis could not ever arrive on time. This was her way of trying to maintain some control over her life; she drove herself to the unit and always had an excuse for being late, 'the shopping' or a dentist's appointment. Patients become isolated through the rigid regime and dietary restrictions, they cannot socialise with their friends as that means drinking or eating the wrong things, something I knew from my experience and was reinforced in informal interviews. Some people rebel so far as to refuse to come, but are generally persuaded by a phone call or the ambulance driver calling to collect the patient. I reflected how a person with chronic illness rebels against the 'rules' of the treatment as a way of trying to control the uncontrollable. They blame everybody, when they are not asking 'why me?' or 'what have I done to deserve this?'. The health care team finds this attitude hard to understand and it is difficult to give care to someone who cannot or will not take responsibility for themselves (Hippold 2001). Kidney failure is a fatal disease but not every patient can accept that (Copp 1999). Talking to the younger patients reminded me of the finality of the disease. Health care providers tell everyone how lucky

they are to have treatment and the carers are very positive about the survival rates, but the health care team also know that people with kidney failure have a poor prognosis (Ansell & Feest 2000). It is not the kidney failure that kills, it is the side effects and co-morbidities of the disease and treatment that cause death (Munshi et al 2001). It is accepted in the renal world that ESRF does affect the mental as well as the physical well being of the patient (Munshi et al 2002, Khan 2000, Finkelstein & Finkelstein 2000). There is a high rate of depression amongst people with renal failure which has been shown to affect the outcome of treatment (Finkelstein & Finkelstein 2000).

5.4.4.4 The older patient

Every one of the elderly could have been written up as an individual case study, but giving small vignettes with thick description means that I can include more examples of all the older patients. There were patients, mainly the elderly, who actually enjoyed coming for treatment. (Quotes from the field notes) 'Oh! It's so lovely here, everyone is so friendly and I enjoy it. You see, I spend my time alone so it's a nice change to see everyone'. 'I spend my time reading and I never have time at home'. 'I cannot get out so I do enjoy coming here'. 'The girls are so good to me, they really care'. 'I miss my husband (he died last year) and these are my friends', 'My driver is so kind he always helps me down the steps'. It appears from their conversations that the women really enjoy the social side of treatment. The men are more inclined to sleep or lie there without making an effort to chat to their neighbour. Generalisations are dangerous and I can remember one elderly man, Leslie, who would keep his companions laughing for the first half-hour of his treatment. Or, when the football came on the TV or radio, everyone would wake up and there would be great discussions as the game progressed, I became quite an expert on the prowess of the local team. The noise levels increased 100 fold on these afternoons as I noted in the field notes. Welch (1994) claims that the older patients do not expect so much and adjust better to the regime of treatment than do the younger patients. Some of them considered it was a 'club', as described in the field notes, and definitely looked forward to the companionship in the unit.

Alice was 80 on her treatment day, she brought in a cake for everyone to share, 'I like seeing everyone sharing my cake'. 'This is my third year on dialysis and I never thought I would survive, these girls are so marvellous'. She had sent her husband (aged 84) to the shops to buy this cake. She had some small gifts from other patients and the nurses had got her a card, it was a special occasion. The patients would bring in cakes and biscuits for the staff apart from birthdays, demonstrating the development of relationships despite the sterile

atmosphere in the unit. I found two of the older patients putting away their sandwiches (provided by the NHS). When I queried this I was told, 'Oh, it saves me having to get something to eat tonight', and 'well you see, my David never eats anything when I am here and I don't need them'.

For some of the elderly the visit to the unit is the only trip away from home (Ashwanden 2000). Due to the increasing infirmities caused by age and renal failure their horizons have shrunk and some of them are confined to one room, the social contact within the unit is the highlight of the week, demonstrating the importance of the 'day care' aspect of the unit. For these people the ambulance personnel, as well as the unit members, are important factors in their lives. I noted how the patients know and rely on the familiar ambulance person. It is the ambulance staff who goes into the home and can see how the patient is coping. I reflected on the fact that as the kidney patient relies on the Healthcare team in the unit to provide the medical care when needed their own GPs are often strangers. The nurses are expected to provide advice and expertise well outside the field of renal nursing as my notes demonstrated. Trust is built up between the frail elderly patient and his driver who can become a friend and confidant. It is sometimes the ambulance personnel who have to inform the unit that the patient has died alone at home, in-between treatments. During informal interviews with the drivers I found them very stoical but they do become affected by the deaths of 'their' patients. I found these personnel were pleased to have someone 'who understood' to listen to their stories. The staff does not have the time to listen, the next person has to be slotted into the now vacant station. There is no acknowledgement of the team and the team players, ambulance men are there for one job and the Unit staff for another.

My presence stimulated people to share their problems with me. I had time to listen, but my field notes reminded me of the many heart-rending stories. Eileen was on her own at home, her husband had died a year ago and she was finding it difficult to adjust without him, 'he was always there when I came home now I have to do it all myself'. 'I find it hard always to have to ask to find someone to take me shopping, people are so busy'. Many patients are very stoical and put up with their problems, especially the older people. ESRF is so overwhelming that they put up with smaller irritations (Welch 1994), 'I don't like to bother the busy nurses' was a common statement. In an informal interview I sat and listened to one lady, Rose, whose son had committed suicide. She was on her own as her husband had died many years ago and her son had lived with her. I had the story repeated every time I saw her, but she needed to talk. I reflected that at least I was able to be there for her even if

I could do nothing to ease her grief. She had all the remorse that follows a suicide as well as her grief (Finkelstein & Finkelstein 2000) and had to cope with the practical problems that her son's death had caused. She would now be on her own and would have no one to do the shopping. She had so many worries but I could do nothing for her except listen. I was a nurse therefore people expected me to be able to help. I reflected that I was being put into the 'comforter role' of the nurse (Smith & Gray 2000).

5.4.4.5 Mick an older man

These data were from my field notes. Mick was an angry old man and everyone could hear it. He was only in his 50s but looked like a very old man. He was sitting on the bed waiting for a nurse to come to put him on. 'Why am I having to wait? I've been here for hours', he had actually come in with the usual group of patients and he had already seen a nurse but she, according to him 'had disappeared, she obviously didn't want to do me'. I reflected that he obviously felt alone and afraid and there was no one to put him on the machine, there was no one 'there' supporting him. But there had been a problem. Mick was clearly unwell and the nurse wanted the doctor to see him before he went on the machine.

Checking the notes I saw that he had already been told why he was having to wait but he did not want to know. I was nearby and got a flood of information; he had to have someone to talk to. He told me about his chest and how he had only come out of hospital last week, 'but you see I can't do it all and there ain't anyone else'. 'I thought the social would be round but they didn't come', 'why doesn't someone do something for me?' By this time I observed he was getting very agitated and breathless. One of the nurses came to give him oxygen. She tried to reassure him but he knew all about his condition, 'I had all this last week but it didn't make me any better'- he still managed to talk to me despite the mask. When finally the doctor came he was told he would have to have an X-ray before treatment. This was almost too much and Mick had a prolonged coughing fit. At the end of a long wait a porter was found and Mick with his oxygen was wheeled away. I never saw him again as he died two days later.

I had an informal interview with Dennis who was an elderly man in his 70s, whose wife has Alzheimer's disease, as soon as he returns from the unit he becomes the carer again, no rest after treatment for him. He spends his time on treatment worrying that his wife would be safe while he was away, but he was not going to tell anyone in case 'they took her away'. He told me that he had to hide the kettle as he was scared she would burn herself. He considered 'there were other people much worse off than me, I can manage'. I did not ask him whether he had made plans for the future, knowing the inexorableness of the disease,

the chances of him having to cope for too long were slim, I reflected. Once he died I reflected that the social services would look after his wife, but he might have appreciated help now, even if he did not think so. The elderly are often fiercely independent and hate the idea of strangers in their home (Ashwanden 2000). I did not offer any ideas apart from inquiring whether he had neighbours who might go and visit his wife while he was at treatment. This was not acceptable; he did not 'like other people in his house while he wasn't there'. He would continue to manage for as long as he could; I was left wishing I could be the daughter he did not have. I reflected on the immense effect these stories had on me as a person, as all the experienced ethnographers warn. I felt so ineffectual, not like myself at all, but I also learnt that I had been lucky during my working life to have relationships which did enable me to assist many of 'my' patients to have a happy family life.

I had time to listen. I learnt facts about patients' families that should have been known, certainly to the renal social workers. Ethically I could have had a problem, as in reality almost every case should have been discussed with them but I had promised confidentiality. I compromised by discussing generalities with the social work team if I thought there was a truly immediate problem. Because of the complexities of renal failure and the fact that these patients live a life divided between the unit and home they have many social problems (Auer 2002). Renal trained social workers are a luxury which this unit enjoyed, and the patients were lucky that there were people trained to understand their needs. The nurses also benefit as they can rely on the expertise of the social worker. But, as was the case with the ambulance drivers, there was little time to discuss specific cases as a team as I saw from my field notes.

5.4.5 Diet

Since the dietary restrictions are one of the hardest parts of the regime of RRT most patients, men and women, liked to talk about what they did or did not cook (Nevett 1997). During the informal interviews we discussed recipes, what they ate and who did the cooking. It was fascinating to listen to stories about one of the fundamental necessities of life. The patients' reaction to the dietitian is generally not one of pleasure. 'I cringe when I see her coming' 'she always tells me off' 'I can never think what I have eaten and don't know what to say', 'I pretend to be asleep so she won't talk to me'. Reflectively I could see that all these are negative statements, which makes the dietitians' role a difficult one. Dietary co-operation is necessary to maximise the benefit of treatment; this co-operation can be monitored by the blood results. Excess fluids make dialysis unpleasant because this

fluid has to be removed, and the limitations of the renal diet take a lot of the joy out of eating. The elderly have special problems in maintaining the renal diet (Munshi et al 2001). The lack of motivation added to the diminishing sense of smell and taste which comes with the ageing process (Denham 1997) means that it is often too much bother to cook the correct things. As quotes from the field notes demonstrate, they settle for a 'piece of toast, dear, it's so much easier and less trouble and it doesn't need washing up'. Talking about one of the essentials of life gave me insight into family structure in a way that surprised me. Reflexivity made me realise that food, who cooks it, how and where we eat it, is all part of the culture of the social world. It relates closely to who controls the household and is an essential part of 'role' within the social world. It is a part that the renal patient often has to forego, or adjust, if he is going to comply with the treatment regime. The mother loses her role as provider as cooking her regulated food at the same time as the family meal is almost impossible, and another 'loss' is added to the burden of the disease.

5.4.6 From friend to nurse

When I was around in the unit I could be seen by the patients to be 'on their side' as I had noted in the field notes. I reflected that I was becoming part of the world I was researching (I was losing some of the desire to remain a nurse in my preoccupation with my research study) in accordance with the advice of Van Maanen (1988), Hammersley & Atkinson (1995), Agar (1996) and Brewer (2000). They all cite the problems and dangers associated with this technique. But I considered my experience would protect me from psychological harm. Any problems which might have resulted from being part of the patients' world were discounted by the resulting data I collected. But as I explained (see 3.6.1.4), I did have worries when I had to leave the patients and join the Health Care Team. I was concerned about the affect this move to 'being a nurse' might have on the patients who had considered me their confidante. But time constraints meant that I had to move on and become a Health Care Professional again. Although my observations in the field notes showed I had become focused on the health care team I did not isolate myself from the patients. When I returned to see the unit people were still glad to see me, even if they only remembered me as someone to whom they could talk.

5.4.7 The Health Care Team

After being among the patients for such a long time I did find it a great relief to be able to be a nurse again. I felt able to be myself although there were still barriers. I reflected I was rebelling against being a researcher which is not my natural role. My presence became accepted and I posed no threat to their world. I made new friends and re-established old

ones, and soon my offers of help, which again placed me in the role of experienced nurse as well as researcher, were accepted. I reflected that I enjoyed being of use and was glad that my knowledge was being used. Once I was more certain of my welcome in the role of researcher I would occasionally sit at the Nurses' Station which was at the entrance to the unit and from where I could watch the whole unit observing and participating in the unit life as my notes explained. I came to all the sessions (see 1.3.1), sometimes coming to the unit before the patients arrived to be better able to understand the interaction of the staff amongst themselves and feel the culture of the 'social situation' without the patients. This was a good time for informal interviews with the staff. I observed that the interaction between all the Health care team was more relaxed without the patients, and there was a friendly atmosphere with everyone discussing home life or the expected problems in the unit.

5.4.8 The Staff Nurses

There were a large number of staff nurses of all grades and experiences. Generally they were co-operative and pleased to see me. I would try to listen to the report, in the role of researcher, as it seemed to be a good way of understanding what was going on in the unit, and having expert knowledge I thought I would be welcomed. One day as I sat to observe, the nurse who was in charge intimated that I was not wanted at the Nurses' Station. The team was gathered round and I was definitely excluded from the group. This re-occurred when the same nurse was in charge, but reflexivity showed me that he considered I was a threat to him and his authority. I was careful not to allow this to happen again, and was always busy somewhere else when he gave the report. I did interview him towards the end of my time in the unit by which time we had established a better relationship and the interview was most useful. Other nurses accepted my presence at report, and my opinion was requested, which gave me satisfaction as my knowledge and experience was being useful. Occasionally I would impart important information obtained through my being able to spend time talking to the patients. I had been shaken by my rebuff at the report, but it made me realise how vulnerable I still was despite my belief to the contrary.

I observed the nurses and their attitudes to one another. As I observed the interactions, I reflected on the hierarchical structure of nurse teams. In this unit there did not seem to be anyone to take responsibility and give the orders despite the supposed hierarchy. The unit manager had her office away from the unit so was cut off from the daily routine. She used to have time to work in the unit but her job has changed and she was busy with other responsibilities. The structure of the service, and staff shortages, meant there was not one

regular person in charge and it depended on the shift as to who was the senior nurse. I observed how some of the staff were better than others at communicating and had a natural authority but were unable to use it because of the culture of hierarchical command. The efficient nurse who was prepared for, and capable of, leadership was frustrated as she was barred from leadership by the nominal command structure as I noted in my field notes. The lack of a permanent leader was bad for communications and patient care (Scholes & Vaughan 2002). It led to added stress levels as it increased the competition to be the acknowledged leader, and gave an increased work-load for those who were in charge for a shift as is demonstrated in this study. The nurse in charge was left, without managerial support, to sort out the day's staffing. I reflected on the impossible task of trying to find pairs of hands to fill places of those off sick. The unit was suffering, as do many renal units, from acute staff shortages and the inability to recruit or retain its staff.

Dialysis units generally have 'named nurses' so that the patients can relate to one person and continuity of care is preserved. The report on Continuity of Care (Freeman et al 2000) demonstrates how important it is for the development of therapeutic relationships that care given by as few professionals as possible is beneficial for the patient. When I inquired I discovered that even if the nurses knew who were their patients, the patients did not seem to know who was 'their nurse'. The nurses acknowledged in the interviews, both formal and informal, that they had their own patients, but the general feeling was that they were too busy doing the work to have extra time to give to individual people. 'I know I have patients, their names are up there (on a board) but I can't manage to sort them out I'm far too busy', 'we will get round to named nurses when we have time' were some of the responses to my questions about named nurses in the interviews.

The main unit is the centre that takes patients from other units as well as the wards within this hospital. This means that the stress of being unable to plan treatments exacerbated the problems for the staff. ESRF patients have to have treatment or they will die (see 1.2); therefore it is generally impossible to say 'no' to a patient needing treatment. I reflected how the staff feel that moral pressure is exerted upon them. They know that a patient has to have treatment to survive, although this is denied by both doctors and management. The culture of never saying 'no' was obvious within this unit as could be seen when the extra patient from the High Dependency Unit had to be fitted in. Since each patient needs an allotted time on the machine the day was one of the continuous manipulating of machines for the nurse in charge. Support from those in authority or the medical team was lacking (see 5.4.9.1).

5.4.9 Illustrations of cases - Staff Nurses

5.4.9.1 Sally

These data are taken from field notes and informal interviews. Sally, the nurse in charge for the day had a crisis. A patient, Jack, who had been admitted to a ward needed dialysis immediately because of his blood results and the unit could not provide a station (they were all in use) for the next 3 hours. Unfortunately before his slot became available he died. Sally, having tried to organise his treatment was devastated and blamed herself for his death. The senior nurse who came to investigate the problem did not provide the needed support, rather asked Sally a lot of questions. After the explanations there was a curt reminder that Sally should write a report on the incident. She then was left to cope with herself and her emotions. Not only had she had to explain the unexpected death to her colleagues, but she also had known Jack and his relatives for some time. She was dealing with her grief, the grief of the staff, the expected grief of the relatives but also the recriminations of the people who were there to support her. Because of the long-term status of dialysis treatment, the staff know the patients well and relationships are established which would be impossible in other hospital wards. The dialysis staff have to cope with the death of their 'friends' (the patients) without assistance. Sally had the emotion of guilt on top of all her emotions of grief. She and I talked long and hard, discussing what she might have done which would have altered the outcome. I quickly returned to my role as expert nurse to give reassurance and a friendly hug. The patient's death was in no way her fault, but she did feel very let down by her managers. Even her colleagues were 'glad it had not happened to them', because it meant that someone else would take the blame if there were an inquiry. Sally found support and comfort from talking to me; a brief 'thanks' expressed a lot more than was said. She did trust my judgement because of my experience and I was grateful to have been there to have been of some real use and was happy to have been back in the nurse role once again.

5.4.9.2 Linda

The data are from informal interviews and my reflexive journal. Linda had been a staff nurse in the dialysis unit for many years. She had had many roles and various grades while fighting to keep her own role as mother and wife. Finally family problems had got the upper hand and she had had to settle for a less significant role in the unit once she returned, having spent time being a housewife. She felt unvalued and badly treated. She wanted to be given the responsibility she knew she could handle 'why don't they ask me I know I could do it'. She felt she could do things for the patients and was keen to help. She

questioned the management's reasons for not rewarding her loyalty and long service to the unit and giving her the grade she considered she deserved 'stupid lot, why should I work for this man when he doesn't know what he's doing?'. I listened and tried to give rational explanations, but reflectively I knew my personal sympathies were with her. I knew she felt unwanted and badly used. The staff were glad to have her expertise but there was no reward for her experience. I could not offer any solutions but was a friendly ear, again in the role of nurse, receptive to the not uncommon woes of staff.

When during interviews, nurses confided in me, or asked for advice I was always wary of compromising my position as researcher. Some of the nurses found in me the support that they were lacking from other sources 'its good to have you as you don't count', 'I can say what I like to you'. It was frustrating to have to consider my ethical position and researcher role before saying too much. I think in retrospect that my lack of meaningful role was the main cause of my unease in this unit. The nurses were all working to survive and I had no place in the hierarchy.

5.4.9.3 The Health Care Assistants

Amongst the health care team are the Health Care Assistants (HCA). These are staff who have no nursing or medical qualification but traditionally help in dialysis units. They have training in renal work and many become very skilled at their jobs. In this unit some of the HCAs did work for National Vocational Qualifications (NVQ) and they were very proud of their achievements. Some of them had been in the unit for a long time, longer than most of the staff. There is no career structure for these people; they come because they 'want to work with people', often they have left school without qualifications but 'would have liked to have been a nurse if only I had been clever enough'. Because of the long service of some of these people, and the continual changes in the trained staff, they considered that they knew the unit and how to run it better than the Staff Nurses. I was the recipient of many comments in informal interviews such as 'I wish they would get their act together', 'it's tedious working for someone who can't organise anything', 'I can't be bothered, I just get on with my work then go home', 'it's not like when Margaret (a previous unit manager) was here'.

5.4.9.4 Illustrations of cases - Health Care Assistants

5.4.9.4.1 Anne

This data are taken from field notes. One of the older well established HCAs, Anne, was certain she knew all about the running of the unit and would encourage the other HCAs to

do as she ordered rather than the, often scared, Staff Nurse who was nominally in charge. The culture was to do as dominant Anne said, even the staff nurses considered that it was easier to comply, 'anything for a quiet life' which was not good for the management of the unit. Anne was difficult to talk to and she would not discuss her job with me. She was an older woman who had come into the unit because she 'wanted to help people' but having been there for over 10 years she was frustrated with her role. She did not want to study for the NVQ qualifications 'what do I want those for?', but she considered she should have the right to organise the less experienced staff. I reflected that although she would have been horrified to realise it she was a bully, and did bully the less able staff who would not stand up to her. But she was also very kind and helpful towards new staff members. She thought the Staff Nurses needed her input for the smooth running of the unit, 'you have to be good at organising' was one comment, she felt she was 'doing her bit' for the unit.

I observed how Anne's attitude caused rival factions in the unit, those who supported her and those who did not. The staff nurses allowed the situation to develop because morale was low and they did not want to confront her, 'it was too much bother' and when staff shortages are acute a person who knows the work, even if she causes trouble, is someone worth having. There was not a team working together for the good of the patient. As Bella, an experienced HCA said, 'I am not prepared to rock the boat by complaining, anyway the staff nurses know, so what can I do?' People got on with their work and generally were glad Anne was around as she was a 'good worker'. Reflection told me that because there was a lack of leadership there was no one who would take the decisions and the unit suffered for this. Anne was a good competent worker and had talents which could have been used for the good of patients and staff.

The patients generally liked the HCAs, they were about, cleaning and tidying and were more approachable than some of the trained staff I observed. They were the recipients of confidences for which the nurses did not have time; I observed in my notes the interaction between the HCAs and the patients. Also these people did not have to perform some of the difficult treatments, therefore they were not there as a threat to the patients. Conversely, if there were problems, the patients preferred a trained nurse as they considered they were safer in their hands than in the care of an HCA (see 5.5.3.3.1). Having observed and noted the interaction between the health care team and patients, I reflected that there were many variables about who should care for a patient and how a team could function. Because of the organisation and staff shortages I noted that there was no choice about who 'put a patient on the machine', but even so I was told about preferences: 'I really like Jane (a S/N)

putting me on, she's good at needling', 'I don't care who does it as long as I get on', 'my line never works so one of the Staff nurses always has to do it'. There were those patients who always wanted the trained staff because 'they felt safer' but there were those who preferred the more informal chat of the HCA. Some of the experienced patients understood these problems but they only complained quietly to me 'I know I shouldn't say so but that girl does cause problems', 'I wish she (the unit manager) would come and see what's going on', but most people were only too pleased to have a machine on which to start treatment.

5.4.9.5 The Doctors

As I was present in the unit, I was observing and focusing on many levels simultaneously. I pounced on any of the health care team who came into the unit for an informal interview. The doctors did not take much notice of me except the medical director who was always pleased to see me. The junior doctors came into the unit at the request of the nursing staff to do certain procedures, but the unit nursing staff organised the daily routine. I talked to some of the doctors but they were very busy, only called in to solve a problem. I discovered, on reflection on my notes, that the junior doctors did not have any idea about the problems of 'being on dialysis' and what it meant to someone's life. Doctors are now being taught to accept the social consequences of medical decisions (Bates 2001) but there is a great difference in learning about it and understanding.

5.4.9.6 Illustrations of cases - Health Care Team

5.4.9.6.1 James - A Doctor

These data are taken from field notes and an informal interview. James is a more junior doctor. The doctors in this unit have chosen renal work as their speciality, and this hospital offers many opportunities for learning. They are not truly junior doctors as they have already gained much experience in general medicine, but within the renal field these doctors are inexperienced. I spoke to James as he was getting ready to create a temporary access for dialysis by inserting a catheter into a patient. James told me that he was only called to the unit when there were problems. He considered the nurses were a powerful force and 'some of them are quite scary'. He enjoyed coming to the unit but wished he had more input to the patients wellbeing 'I would like to have more time to understand all about dialysis', 'I only come when I am needed, I don't have time to get to know these people well', 'the nurses look after them, we doctors don't have much to do with them unless they are on the wards'. The only time he could influence care was when he saw patients in clinic. I talked to him about the patients and their social problems but reflected that he was remarkably ignorant of

the effects of dialysis on the lives of patients. He did not realise how many hours a patient could be in the unit and only knew that the staff complained when he was delayed and could not attend when requested. He expected that at the end of his time within this hospital he would be a competent renal doctor.

5.4.9.6.2 *Shena - The dietitian*

The data have been taken from informal interviews and field notes. Shena, the dietitian knew she had a difficult role but she enjoyed helping those of the patients who wanted to be helped, 'it's so good when you really make a difference'. She had a large population of people who needed her input and never the time to see everyone. Her information added to the general pattern of the data for me and because I knew through my pre-knowledge how difficult it is to keep to the renal diet, I had some long 'conversations' with Shena. She felt she was 'working on my own', and, 'I often have problems finding the patients I need to speak to. I can never find anyone to ask'. 'I cannot find those who need to see me while they are on the machines, and all the staff are so busy', highlighting the absence of team work. Then illustrating her difficult role 'sometimes when I do find the patients they won't speak to me'. It seemed a very thankless task and made worse by the lack of appreciation by the rest of the team of her important input. Dietary information was reported but there was much more information which was not passed on. My reflections about the role of the food provider had given me another perspective. Shena was not an accepted member of the team and she had no opportunities to pass on her important information, to the detriment of patients and staff.

5.4.9.6.3 *Thelma - The social worker*

The social workers were an occasional presence in the unit and the arrival of any of them would occasion a chorus of 'please come and see me today' from many patients. Both staff and patients always welcomed them. I did have many informal interviews with these vital and highly valued members of the team. I reflected that the staff do not realise how much these people do for the patients and how far their knowledge extends. The senior staff acknowledged the importance of unique knowledge of the social workers and how they could remove some of the emotional strain from the nurses. The results from the questionnaire reinforced this need for increased knowledge (Appendix 12 Table 12.2). After talking to the social workers I had to reassess my knowledge. Reflection showed me that I also did not realise how large was their workload. My notes told me that these people

provided practical, emotional and psychological support for patients and often their families. They were constantly on call for the dialysis unit, which produced immense strains. 'I hate walking in there to be confronted by all those people needing something from me, which I know I cannot supply', or 'I simply cannot see all the people who need me'. The ESRF patient has so many practical needs but also has a requirement for immense psychological support. Thelma did not enjoy coming in to the unit 'there are too many people who need me and I can't give them either the time or the financial help they deserve.' Social workers are involved with the holistic care of the patient, not only do they see the person on the machine, but visit the homes and see these patients in their other roles as mother, father, wife, etc. It is the social worker who knows better than most how the person coped with dialysis and how the home support functioned, 'I should spend more than half my time on home visits but that means I don't have time for the chaps here'. It is the social worker who has to organise help when home support falls apart. The nurses and the social workers are all too busy surviving in their own worlds, to have time to communicate.

5.4.9.6.4 *Ava - The Domestic*

The data are collected from field notes and informal interviews. According to my notes, the most welcomed person in the unit was the domestic, Ava. She arrived everyday to 'do the teas' for the patients. Her trolley was a welcomed sight for those people who had arrived at 06.30 and were desperate for a cup of tea by 08.00. She was a cheerful person full of chat for the patients. They shared their news with her, she had time to listen. Ava did regular tea rounds and sandwiches for the unit throughout the day. When not pushing the trolley, she would be around chatting or sorting out the shopping she had just done for someone. She knew the patients by name and most of their family histories. I was told by her that she worked in the unit because her mother had been looked after in this hospital. She enjoyed the patients, found some of the nurses very 'stuck up', but she was friendly to everybody. The nurses would 'chat her up to get a cup of tea from her trolley' but she did not like interference when she was 'doing her patients'. I noted that she was not receptive to the blandishments of the nurses, 'she can say what she likes but I haven't got the time to be dishing out cups of tea to everyone who wants'. She performed a necessary and welcomed service. The nurses were inclined to ignore her apart from the tea, not realising her undoubted knowledge about the patients which would have been a source of information as she certainly knew the family histories of the regulars. However she was seen as a domestic and that was her job.



5.4.10 The formal interview

I enjoyed the formal interviews. My participants were chosen as those who could give good information (Agar 1996). Every beginning was difficult, but once the interview started I found no need for the core questions apart from keeping the interview focused, as the interviewee would talk and talk. Very quickly the participant forgot the tape and started pouring out all her/his troubles. Unfortunately because of the length of some of the interviews I had to turn the tape during the conversation which did stop the flow and it generally took a short time to restart the flow again. Only on one occasion turning the tape over dammed the river of information, which was a pity. Information could not be forced so that interview stopped there. The general feeling at the end of our conversations was that we could have talked for 'ever'; 'I never thought I would feel so good', 'I could talk to you for ever but I must go and do some work', 'I wish we had someone who understood what its like, (*renal work*) like you do', 'I think we need more support', 'you understand so I can talk to you', 'it's so easy to talk to you'. The nurses were all desperate for someone to confide in who understood their jobs from the inside.

I chose to interview the staff nurses because they have to run the unit, and therefore were the most stressed, and without people in whom they could confide. I did these interviews towards the end of my journey in this unit. I also interviewed the chief social worker once I realised how complex was her role, and the chief medical director. The information I gained from all the interviews did reinforce many of my interpretations about the feelings and behaviour in the unit. The transcription of the interviews remains confidential and very personal.

5.4.11 The questionnaire

Giving out my questionnaires caused some rude comments. There was a general reluctance to filling in the form but once we had turned it into a joke about intelligence people were happier about answering it. The questionnaire (Appendices 10 & 11) was developed to find out demographic and descriptive information about the staff. 'where's the IQ test then?' 'can I be a staff nurse when I've done this?', 'do I get more pay?', were some of the comments, but 'I'm not doing that what's the point' was a comment from Anne.

5.4.12 The Reports

The reports which I wrote about the units were discussed by the staff at length. To begin with the staff were hostile but once the staff in both unit had got over their apprehension and fear of criticism they were very pleased to discuss items I had highlighted. Any items

which they considered I had 'got wrong' we discussed and I received increased knowledge from their input, but the consensus of opinion was that I had reported fairly.

5.4.13 Withdrawal from Unit 1

It was with sadness and apprehension that I left the unit. After a shaky start I had found friends amongst the participants in this unit. I had been ambivalent about my role, and to begin with had rejected the research role, but by the time I had finished talking to the patients I accepted that role more easily. However I had enjoyed joining the nurses and re-attaining my nurse role. That finally became subjugated as I learnt more and got more involved in the research. I had learnt a lot about the problems of working and being treated in such a large unit which had challenged my pre-knowledge as I was seeing the unit from the participants' perspectives. I felt my research would be able to give more understanding to those who worked in this unit and through this increased understanding they would be able to deliver better, more therapeutic care. The patients would have a better understanding of the problems of dialysis and why the unit functioned as it did.

5.5 Unit 2

My pattern of approach to my journey through Unit 2 was the same as in Unit 1 but modified by the responses from the participants and the knowledge gained from my experiences in Unit 1. Unit 2 follows the same treatment formula as Unit 1 (see 1.3.1). There are many ways in which this unit is a duplication of Unit 1 but it is much smaller and does not have the problems of being a 'main unit'. The patients are generally more chronic and the population is more stable, but treatment is the same and the patients have the same worries and concerns. In order not to duplicate the ethnography, in the description of this unit I have concentrated on events and happenings giving only a brief description of the routine of treatment. This study did find differences in the units and the population is different. But differences add to the cultural picture which is easier to understand through differences. The patients were not as ill in this unit and the nurses had more time. These different factors with many others have helped with the cultural picture of the units.

I made my preparations for starting in Unit 2. I wrote to the unit manager announcing my intended arrival. The day arrived and I checked into the unit with trepidation. I entered reluctantly wondering why I had decided to use two different units for my research. I reflected how I had just become accepted and finally was quite enjoying Unit 1, but had made myself give up the familiar and friendly to become, once again, the stranger in an unfamiliar world. I spent my first travel time deep in thought about what I would find, and

where the differences would lie. It was not as difficult to enter another new place as a 'stranger'. As Agar (1996) confirms, one becomes used to being a researcher, a strange role in a strange place. Moreover I had had experience of 'being a researcher' in Unit 1.

My field notes tell me how I was greeted on arrival by the unit manager, who made the necessary introductions to the staff. I was made to feel welcome and was immediately provided with a parking permit, very different to Unit 1, but this is a much smaller unit and parking is not such a problem for anyone. I had my badge giving me my status as a researcher. I did feel isolated but less so, the unit is much smaller with fewer staff, but I was still an outsider who might be a threat. I had to work to become the trusted friend who could be confided in. Having had the experience of the other unit I knew I could be useful in supplying information and general support. I did bring sweets to the staff but did not feel this was such a necessary part of being accepted. Because I had been confident at last in my role as a researcher I am certain about which role I had on entering this unit. Reflection makes me realise that I was both nurse and researcher to begin with but the researcher role took over quickly.

Walking into this unit one is not hit by the vast space and watching eyes. I recorded that it is a smaller more intimate place where the patients are all treated in two bays of six so that they can all talk together during treatment. There is a more subtle entrance to this unit. First one enters into a 'closed place', the waiting room guards the working part of the unit from prying eyes. Then there is a passage which finally opens out into the working part of the unit with its actors busy performing their roles. I reflected that the shock of arriving amongst machinery and people having treatment is mitigated by the feeling of being in a special, almost secret place. Again the noise of the machine alarms and ringing of the phones is present but thanks to the smallness of the unit the alarms do not reverberate round the walls, and because of the size of the unit the staff can answer alarms and phones more quickly. The overall impression is one of pleasant surroundings, the pink walls and light flowing from the windows, with general chatter of people calling out to one another and the nurses adding their ideas. It immediately struck me as being more homely, somewhere where it could be possible not to hate coming. The constant passage of people through the unit does not happen here; the unit is dedicated to its own dialysis community. Although it was a relief to come to somewhere where my own identity was not challenged by noise and bustle, once used to the atmosphere I reflected that I missed the excitement and technical achievement in the other unit.

The patients did not need me as they had in the other unit; they talked to each other and the nurses. The unit has 12 stations with an extra one for emergencies (see 1.3). Because the unit does not run at 100% occupancy it means that there is time to re-organise treatment times within the session so the frenetic feel of Unit 1 is missing, people do have more opportunity to change sessions. Due to the geographical position of this unit - it was miles from the main unit, and thus it depended even more on the nurses for its organisation and the delivery of treatment. As there was less support from the medical staff the nurses had to use their skills and knowledge.

I first became accustomed to the environment. I introduced myself to the patients who had the same pattern for treatment as in Unit 1, by going round explaining who I was and what I was trying to do, I was confident in my researcher role. I got to know everyone on one shift before moving to another shift. Because there were many fewer patients this did not pose so large a problem. I got the consent form signed by the patients and only had one refusal, again frightened by the idea that conversations might be taped. However I was careful to exclude this patient in the general chat, allowing her to join in when she wished. The patients were all very friendly and wanted to talk. Some of them had seen me while I was in the other unit so were able to tell the others about my research and me. This is so helpful as it breaks the barriers as suggested by Agar (1996). Again I used the small book to make notes while in the unit, which I enlarged in the car before the long journey home. Once at home I was rigorous about writing up my daily diary and report.

5.5.1 Fieldwork

I stood and observed or sat on someone's bed or by the chair to talk. Sitting on beds was more a cultural acceptance here, and I was able to chat informally and quietly to most of the patients, although it was difficult to be 'private'. I changed roles and played games and watched videos with people on the machines. I found it was difficult to change my working habit of being busy all the time to one of 'doing nothing'. I found having time to watch TV with a patient was foreign to my nature; I was definitely a stranger in an alien world. The patient population did not alter as much as in Unit 1 because these were established chronic renal patients. Therefore apart from the exceptions whose medical condition necessitated a visit to Unit 1 I could have informal interviews with everyone more easily.

Because I had quickly adopted the researcher role I felt more comfortable talking with the patients who soon got accustomed to my presence and were keen to communicate. The closeness of the dialysis stations meant there was even less chance than in Unit 1 of being

able to talk to someone on the machine without being overheard. But informal interviews became a common occurrence with me using the communal spirit to discuss daily happenings, irritations and pleasures between the people during their treatments. Everyone was eager to help and some of my problems were having too many willing 'informers'. We all enjoyed a general talk with everyone in the group joining in. I was able to reflect on the different reactions to treatment. Fred with his 'good' fistula was happy to be needled by any staff nurse, but Jill who had a new and difficult fistula preferred to wait for Jane or another experienced nurse. It was interesting and fun to instigate or join in conversations with the whole bay. I would occasionally ask controversial questions to promote good discussions. 'What would you like changed?' and the responses ranged from 'nothing' to 'not have renal failure' but there were good ideas such as 'balloting for the best time slots' or 'providing more meals'. Due to the smallness of the unit everybody knew about everyone else and their problems so I did not have to do a lot of questioning; conversations would flow with opinions from everybody, staff and patients. It also meant that problems could be shared and at least six different lots of advice would be given. When Jill's dog was unwell advice came from all sides. Luckily the dog did recover but we had anxious days. There was an enormous amount of interaction between the patients who all supported each other. There were the usual complaints about waiting for machines, but a few of the patients were capable of helping to set up their machines and this cut down the nurses' work, as well as giving the waiting patient something else to think about, apart from worrying about the impending treatment.

The size and shape of the unit meant that I could observe all the people on the machines and the working health care team at the same time. Routine was very organised and exceptions to the norm were noticeable. Informal interviews were easy; all the patients were pleased that there was someone interested in them. They all had opinions about how dialysis is not understood by people outside the units and hoped my research would make a difference. As before I became the recipient of many confidences.

5.5.2 The patients

Having done many months of fieldwork already and being adjusted to the research role, I was quicker at finding information. As I talked to the patients I found I was writing many quotes duplicated from the other unit. I watched the repeated process of arriving, going on the machines, coming off throughout the day. The shifts of patients were very regular so everyone knew each other really well. As the patients arrived they would go round the machines chatting to the others already having treatment, before getting ready for their own

treatment. Because it is a small unit, patients can see if another patient needed help and there would generally be someone to lend a hand to weigh or find the necessary chart. The patients knew all about the social life of the others. Problems were discussed amongst them while on the machines, and as I watched them chatting to each other I could see the caring that was present. There was genuine concern when people did not feel well. The anxiety of being 'sent' to the main unit was a uniting factor. Anyone who was told they would have to go had the immediate sympathy of the rest of the patients who would support the victim 'oh well it won't be for long' or 'at least it means your fistula will work'. But amongst themselves they were more concerned, not only for the victim but also because the reminder of the big unit was a reminder that people do not survive forever and 'things can go wrong in the other unit'. 'You remember Lou she was so ill, it was a shame' or 'I hate the thought of the other unit we all belong here'. It is unfortunate that when people are unwell they have to be sent to the other unit. The main unit has this reputation and the patients did fear going there.

The wait for the machines, which causes anxiety and irritation for the patients, was generally short. The day could be planned without the worry of extra unscheduled patients, and when the transport arrived the machines were ready for the arriving patients. There were the usual complaints about the transport when it did not turn up, or it was not the usual driver 'I had Brian today he always drives so slowly that's why I am late'. Because of the geographical situation of the unit there are long distances for the patients to travel, so the journeys can be long and the ambulance car drivers do become friends and part of the team. My field notes reminded me that there are always problems when the regular driver is not working and the patients do feel unsure and fearful. Judith a widow, was very upset one day because her usual driver did not arrive and he 'always got my shopping for me and now I have no milk for the cat'. Also the patients do not trust the unknown driver, who does not know the planned route with the regular drop off and pick up routines, these journeys could entail the patients being in the cars for over 2 hours, 'we went all round the country because he had to pick up someone for radio (*therapy*)'. When Elisabeth (a driver) was ill, the patients in her run collected money to send her flowers. She came into the unit before returning to work to see all her 'regulars'. I reflected how all the patients were so pleased to see her again, she was obviously a real friend.

The unit is small enough for pre-treatment problems, such as excess weight, to be a subject for discussion by all the other patients. But because the atmosphere is friendly and supportive they can laugh together about the excess fluid to be removed, this lightens the

situation and the patient concern is lessened. I reflected on the difference between this unit and Unit 1. Nurses schedule treatment and cope with difficult treatments routinely but can overlook the patient's human needs for sympathy and tolerance. The nurse feels that she is there to provide the treatment and the patient has a responsibility to himself (Vitri et al. 2001). There are conflicting interests. The nurse considers she can inform the patient about the dangers of over drinking, but it is the responsibility of the individual to keep within the limits (Hippold 2001). In the smaller unit there is time to listen to reasons behind the problems and discussion can prevent augmentation of problems.

5.5.2.1 Illustration of cases - patients

5.5.2.1.1 Margaret

The data are taken from field and patient notes, and informal interviews. Margaret had been attending the unit for many years, but she had always had problems adapting to the regime. Her diet and fluid control was poor. The dietitian, Ros, was a regular feature in her life but Ros found it hard because nothing she said made any difference. Margaret had been admitted to the main unit on several occasions to try to help with the non-compliance, but she was so miserable and requested to be returned quickly so she 'could be with her friends again'. When I saw her, she was not well. The fluid had affected her lungs and breathing was a problem. She talked to me for a little and I felt I helped her forget some of her problems. We talked about the weather and transport. She always had the same driver and she was very fond of him, 'he always comes in and helps me out of my chair'.

She was an unhappy person and needed more than I could give her. I did not know her well, although I had chatted to her during other times in the unit. One day she seemed to need more time to talk so I sat by her chair to listen putting myself into the role of comforter. 'I don't want to go on, I feel I am using a machine that should be used for a younger person, I'm useless. I have no one at home now, my husband died three years ago and my children don't come and see me except to tell me off.' Then many stops for breath and with much encouragement from me she started again. 'I love the nurses and my lot (the regular people with whom she had treatment) are all so friendly, but sometimes you have to do what you want, I can't do anything I want to do, the only days I get out are when I come here, I feel so useless'. The need for a miracle cure to make all things better struck me again. RRT is a treatment that needs support from all parts of the health care team I reflected. Margaret might have felt better if she could have been taken out by her family and made to feel special. I reflected on family situations and considered that her family found her a nuisance and only told her off. It was probably their way of coping with their

worries, but if they could have understood how she felt, they might have coped differently. Margaret needed social support, psychological support, nursing support but, underneath all this support she needed to feel special, to be given back her self-esteem and valued. When the next day for her treatment came the ambulance driver, her friend, who went to fetch her, phoned the unit to say he had found her dead at home, alone. The nurse in charge, John, had to tell her friends and support them through their distress. Unexpected death is not unusual and John followed the correct procedures. The family phoned the unit some days later to thank the staff for their care. The patients who knew Margaret organised a collection for her and something was bought for the unit in her memory. She was not forgotten but her place was quickly taken by another person needing dialysis. This is a regular occurrence. I reflected how there is no time for grieving, the machine has to be taken by someone else who then has to become part of the unit team.

5.5.2.1.2 *Phil*

The data are taken from an informal interview. Phil was a teacher. He came for treatment after a day at work. He was a cheerful man, always late, rushing in at the last moment complaining about the terrors of teaching. He was very popular with the others on his shift. He told racy tales about some of his daily problems. 'I have to come so I might as well make the best of it'. In his more serious moments he would talk about how lucky he was to have treatment. He had been diagnosed with renal failure 30 years ago, as a teenager, but had only needed treatment for the last 2 years. He was coping with it well and was hoping for a transplant. 'I know I am lucky to have treatment but I pray it won't be long before I get a kidney'. From my experiential knowledge I know that few patients appreciate that transplants are yet another form of treatment. The patient does not escape the medical input and has to co-operate with the regime permitted by the transplant. Phil had a young family who also was waiting for him to be transplanted. His wife wanted to give him a kidney as a live related donor, but he did not want her to take the risk.

The programme for live related donors is growing fast in the UK (Trevitt et al. 2001). It is one way to relieve the disastrous lack of cadaver kidneys which has grown worse since the Alder Hey disclosures (see 1.2). But it does have its risks not only for the recipient but even more so for the donor (Trevitt et al. 2001). I do not know whether Phil or his wife will win (or has won) this argument. When he spoke to me I advised him to go to the co-ordinator who could give him the facts and figures that should help him and his wife come to a decision. He used me as his listener, because as usual, he said that he felt that the staff did not have time to listen to his worries.

5.5.2.1.3 **David**

The data are taken from informal interviews and my field notes. David was a younger patient in his twenties who managed to keep a job despite having RRT. He was the manager of a shop. He would come in early in the morning. The nurses knew he was in a hurry so generally someone would get him on first. I questioned him about how he coped. 'well once I finish here I go home for a sleep then I am ready for work at 1 o'clock. I work till 6 on dialysis days, but it's hard'. 'I get very tired and never dare go out with my friends for a drink' 'they think I am a boring old sod' 'I haven't told them I have treatment I don't want them to know, I might lose my job'. He lives alone but near his mum who I gather worries and does a lot of cooking for him. As soon as he arrives in the unit he sets up the video for himself. 'I like to be alone I don't want to talk'. He would watch the video until he fell asleep. He was very pleasant but did not want to be part of the unit and the chatter. He was particular about where he sat and liked a special chair. I only heard him make a fuss on one morning and it turned out that he was feeling unwell. He had an infection and was sent to the other unit for treatment. He was most careful to phone his work himself to say he would not be in for a few days, demonstrating how so many of these patients live almost a double life (see 3.6.1.2) in their desire to be 'normal'.

Watching and listening on many different levels I found that I was observing much the same that I had seen and heard in the other unit. Reactions and interpretations although unique were often similar to those of the other unit. The units were different and each had a unique atmosphere, but in my role as researcher I could now observe differences and similarities between the communities in the units. I moved from being 'with' the patients to being part of the staff, but retaining my role as researcher. This was not such a big move because of the shared care in this unit where the patients are involved in their care and feel part of the team. As Mary said 'this is a second home', or Eva who considered that all 'her girls' (the people she came in with) were part of her family.

5.5.3 **The Health Care Team**

I changed my focus of observation from the patients to the health care team. The size of the unit and small staff numbers meant that I was already well known to all the team who came into the unit. I did not have as many worries about the transition of my role as in Unit 1. The patients had seen me with the nurses and joining in the general chat. There was Ros the dietitian, the same social worker as in the other unit, Thelma, and Chris and Caroline. The nursing staff were few in number, consisting of 10 trained and 4 untrained staff who all

worked different hours, some full and some part time. The unit had its own consultant Peter and occasionally a visiting junior doctor.

5.5.3.1 Illustrations of Cases

5.5.3.1.1 *The Consultant - Peter*

These data are taken from an informal interview and field notes. The consultant, Peter, came up three or four days in the week and saw the patients in a clinic in the unit. He knew all the patients and would spend time talking about family matters. Peter was easy to talk to and I could see that the nurses enjoyed his company and found him a useful resource. As discussed (see 1.2), these units are traditionally nurse led and the senior nurse, Jane was happy to take decisions when Peter was not around. He trusted the nurses and during reports he would join in giving his advice, which was generally heeded. The patients found him sympathetic and I never heard anyone complain about his treatment. He was interested in my project and expressed a desire to read the finished study. Occasionally a junior doctor would come up to do a special procedure, but apart from the health care team no one else interrupted this little community.

5.5.3.1.2 *The secretary – Caroline*

The data are taken from field notes and informal interviews. Caroline was a very necessary part of the patients' lives as the unit secretary. I reflected on the difference she made to their lives, she made all their appointments and knew about their family situations, she took her job very seriously and really tried to make a difference. She would go out of her way to ensure that Mabel's daughter, Liz, could come with her mum to the clinic. Mabel was 80 and very deaf, so certainly needed her daughter, but Caroline would phone the home to check the best day for Liz. She liaised between the consultant and the patients and was always willing to make special arrangements. Nothing seemed too much trouble. I had many an 'informal interview' with her; she was dedicated to her job and it was interesting to understand why she spent so much time helping the smooth running of the unit. She had worked in the NHS for some years but 'really enjoyed the atmosphere in the dialysis unit as it is different and liked knowing all the patients'. I reflected on Caroline's flair for organisation; her office reflected her personality, the files were neat, and information could be retrieved quickly and efficiently. She had a quiet manner, but the staff and patients knew she could be relied upon. She was content, she knew she was valued and an important part of the unit team.

5.5.3.1.3 *The Domestic - Chris*

The data are collected from the field notes and informal interviews. Chris, the domestic was chatty and enjoyed the bustle of the unit. She was so good to the patients. Nothing was too much trouble; she would do their shopping and often when a patient came in for treatment there was a Tesco bag waiting with the promised shopping. The patients all shared their news, joys and disasters with her. She pushed the trolley round the unit dispensing tea, sandwiches and good cheer every day. She was greatly missed during her holiday and her return was greeted with much joy. She was a valued member of the unit team and would chat to the staff as well as the patients. I reflected that neither she nor the staff realised the importance of her knowledge and casual chat.

5.5.3.2 *The Health Care Assistants*

The HCAs were there because they enjoyed working with people. There was one Jenny, who was in the middle of training to be a nurse and getting experience of working in the unit. She was enjoying the 'team spirit' and felt she was 'learning a lot and having an experience which she would never forget'. I asked her whether she would come back to the Renal field once she had qualified and after some consideration she thought that she might later on but she found it was a very stressful environment. She felt that 'one needed a lot of experience to cope with the stress of the treatment'. My field notes reported that she found the complexity of renal failure was daunting but she considered she was lucky to have been able to gain some specialist knowledge during her training.

I knew one of the HCAs from many years ago in the other unit which was useful as it gave me validity and status in the eyes of the others. I reflected that the HCAs do worry about interference and are threatened by the presence of an outsider. I tried to show them I was not threatening but again as in Unit 1, lack of knowledge about the outsider causes mistrust (Van Maanen 1995). These HCAs all enjoyed their work in the unit and felt they were 'part of the team'. There was more time for the patients so they were encouraged to chat as they did their work. The staff nurses trusted them to do their work which was well documented and the sense of order prevailed which made everyone's lives easier. I reflected on the presence of a good system of command and control so everyone knew what they were supposed to do and were valued for their work.

5.5.3.3 Illustrations of cases

5.5.3.3.1 An HCA - Guy

These data are taken from field notes. There were complaints about 'them and us' amongst the Health care team. One young man was very resentful about his lack of status. When a patient asked him for some advice he responded by 'you shouldn't ask me, I'm not qualified so I can't answer'. This is the first time I have ever heard an HCA telling the patient about his lack of status. The patient retorted very quickly 'well then why am I trusting you with my life?' This is interesting because traditionally these HCAs are much needed in the dialysis unit and are specially trained to perform techniques well beyond the normal competence of a health assistant. It was surprising to hear the retort from the patient as generally patients accept the treatment seemingly without question. I did not interfere and moved away. Much later I discussed the incident with a staff nurse, Liz, who was as surprised as I had been. She agreed to talk to the HCA to see if there was anything she could do to mitigate his feelings of inadequacy. We discussed finding some extra training or project that he could do to return some of his self esteem; I used my past knowledge but also knowledge from my researcher role. He was a good worker and it was sad that he was bitter about his lack of status. Liz said she would talk to all the trained staff to discuss the problem of the HCAs being undervalued.

5.5.3.4 Staff nurses

The staff nurses worked well together as a team. The unit manager was generally in the unit and seemed very much in control. The staff came in and out even on their days off to look at the Off Duty or to check on a special patient. They worked in two teams which functioned well. I felt that some of the newer nurses did not receive the supervision they needed or required. It is frightening to needle for the first few times and these newer staff needed more help. Carol, who was doing the Renal Course was very scared the first time she needled 'this is my first time and I feel really sick'. I wished I could help but my past experience told me my presence might make things worse, so I moved out of the bay. By the time I had finished my visits to this unit Carol had become an experienced needler and enjoyed the challenge. Mandy was hoping to get a new job with a better grade, which she got, but she was unconfident about her abilities 'I don't know what I can do that's special'. After some discussion with me (in both roles as expert nurse and researcher) she was more confident about her abilities, which as she reported later did help her get the job. We have become good friends and still keep in touch.

The nurses were able to spend time with the patients and get to know their social worlds outside the unit. I reflected how different this was to Unit 1 where the staff do not even know their colleagues' social worlds and certainly did not have time for the patients'. Problems were openly discussed and the patients were more co-operative. This unit did have less sick patients and it was in the patients' interests to observe the rules and stay well so they were not sent to the other unit. My field notes showed me that the staff here had time to listen and were more empathetic. The feeling of being part of the team did have a beneficial affect on treatment outcomes (Zrinyi 2001). On the whole the patients took responsibility for themselves and treatment outcomes were better. The policy of named nurses worked well in this unit and the patients knew and related to their own nurse, again different to Unit 1 (see 5.4.8). The nurses enjoyed having special patients to care for 'I really enjoy sorting out Judith's problems and I know it helps her' as Liz said. The nurses had time to ensure these patients knew their blood results and were being co-operative, knowledge bringing the sense of possession and control back to the patients. The nurses acknowledged the importance of being up to date with renal information which is reinforced by the data from the questionnaire. 'My nurse Clare always lets me know if there is anything wrong then I can be more careful' was a comment from Phil.

The staff had time to chat amongst themselves and although there was a barrier between the nurses' station and the action it did not have a psychological effect of stopping communications. The weighing scales were at the back of the nurses' station, so there were patients walking round the desk at all times, thus preventing the desk from becoming a physical barrier. Peter ran his clinic in the room behind the nurses' station which also helped the freedom of movement. I observed how the nurses could sit at the station and use the computers while still chatting to patients, reducing the psychological effects of a barrier. Because Caroline was so good at organisation many pressures of the paper work were removed from the staff. I reflected that there was a sense of security for the staff which came from the knowledge that a job would be done correctly.

The family atmosphere was well developed, not only among the staff, but the patients also felt part of the family 'I enjoy the family feel, it's what I miss most on going to Unit 1'. The staff would discuss their reasons for choosing this unit which was reinforced by data from the questionnaire. The choice of unit was often made because of convenience for the important homes and families. One of the staff came in regularly with home cooked biscuits and cakes for staff and patients. She was well known for her cooking and everybody enjoyed it, 'I know its not good for my figure, but when I'm cooking for the kids

a few more make no difference'. She was a mother figure and everyone discussed their problems with her. She would take her cakes into the coffee room where people would congregate to eat the cakes and discuss their social lives. One of the girls was planning her wedding while I was in the unit and we all spent many hours discussing dresses and procedure. The patients also enjoyed offering their opinions and ideas, one of them offering the family car with her husband as chauffeur for the event. Everyone, patients and staff, discussed how to raise money for some needed alterations to the unit. It was decided to have a raffle amongst other things so everybody gave ideas about what they could donate.

5.5.3.5 Illustrations of cases

5.5.3.5.1 *Trained Nurse - Jane*

Data are from a formal interview, field notes and reflexive journal. Jane was the unit manager. She organised the unit quietly and efficiently. The staff respected her because of her fairness. She managed to keep a balance between being the manager and being one of the staff. This is a difficult task and managers of renal units have no peers due to the locations of renal units, so support is missing. I have known Jane for a long time and watched her grow in confidence. I reflected on the change I saw in her. She was now quietly confident in her role and enjoyed the challenge of the staff management and organisation of the patients. The patients all liked her, because of her quiet manner. She was always there for them when there were problems. I chose to have a formal interview with Jane because she was the unit manager and I had not interviewed the other unit manager, but also because of the loneliness of her position. Geographically the unit was a long way from not only the main unit but also other renal units, therefore Jane did not have the opportunity to see and talk to her peers. She was very dubious about the interview and wanted to refuse but felt she could not. During the first few minutes I could hear and feel her nervousness. However we started talking, and I used very general questions to put her at her ease. Once the information started flowing there were many other issues that Jane needed to talk about, as I had surmised. We talked about personal and managerial problems amongst other things. We talked about the unit and professional matters. The interview ran for a long time until finally Jane said reluctantly that she had to 'get back to the patients and other work'. At the end of our interview Jane turned to me and said, 'I never thought I would feel so good, thank you very much it was wonderful to talk to someone who understands'.

5.5.4 Formal interviews

These interviews all started slowly so the information did not come easily. Again I had a list of core questions to keep the interview focused on the unit. Once the flow started I was given exciting and significant data which helped to validate my interpretations. I did not receive so many important confidences and on reflection I consider that in this unit the staff are much more supportive and problems are discussed amongst themselves, and therefore there is not such a need for a confidante. However some of the information was very personal and again showed that these staff, who work under great pressure, do need a trusted colleague or friend to whom they can unburden themselves. Hospitals have supplied Support staff or Counsellors who are available to be consulted about any confidential matter, but from my experience as I nurse, I have heard that these people do not have many customers and the service is often of short duration.

Without exception all the participants of the formal interviews admitted how pleased they were to talk to me, they were glad to have talked to a familiar 'stranger who did not count'. The way the information flowed was data in itself. These interviews were conducted after I had been in the unit for some months. Trust had been built up and the realisation that I was impartial and genuinely interested in them and their work. Again as with the interviews from Unit 1 I used the data to validate my interpretations of situations and phenomena within the unit, and the increased knowledge altered my interpretations.

5.5.5 Questionnaires and report

The results of the questionnaire gave descriptive demographic information about the nurses. I learnt about the educational aspirations of the nurses which has been reinforced by the data in this study. The reasons given for the staff's choice of the unit was interesting as they did not correspond with my pre-conception. The results of the questions about working towards better grades again were contrary to my pre-conceived ideas. The report I wrote served to validate my findings and gave me feed back which I used to check my own interpretations as well as offering different perspectives which challenged my pre-knowledge.

Chapter 6 The cultural domains and themes

6.1 Introduction

This chapter follows on from Chapter 5 which gave the narrative account at the substantive level of the culture of dialysis units. This chapter gives the ethnography its theoretical framework highlighting the key concepts related to the study and their inter-relationships. In this chapter the cultural domains and cultural themes which emerged during the ethnographic journey are analysed. The domains are phenomena of interest, and themes are the conceptual elements which come from the domains. I described my journey through each unit separately but the domains and themes are common to both units. I have therefore discussed them together but shown the different emphases within each unit which reflect on the individual cultural development. It is the influence of data from all sources which led to the uncovering of the themes.

It became clear as I was conducting my analysis that the interrelationship between the themes and domains was reflected by a core organising concept of partnership which characterises the social relationships in dialysis units. Partnership is the organising concept which helps the understanding of the culture of dialysis units. All the cultural themes were interrelated but all depended on the organising concept. The concept of partnership depicts the culture and social relationships of the dialysis units in the UK as the data in this study have uncovered.

6.2 The domains

I followed the steps of Spradley's Development Research Sequence (1980) as discussed (see 4.4.1 & 4.7.2) to analyse the data from both the units. As I made my ethnographic record (Figure 6.1) the domains were revealed as symbolic categories that included other categories (Table 4.2 & 4.5). My focus narrowed from the wide spectrum of tens of domains onto four final domains which appeared to be the most relevant for this study. These were:

Nurse

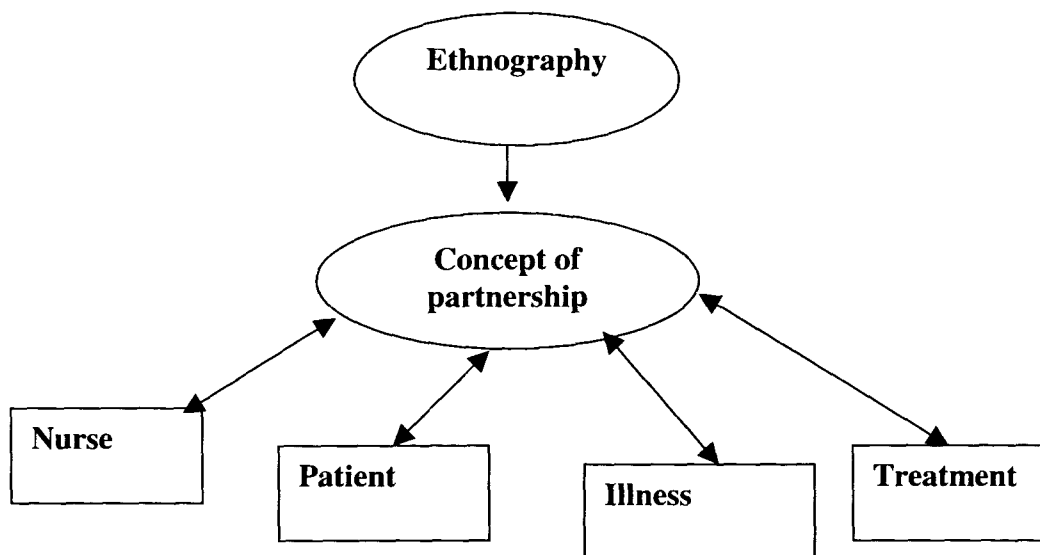
Patient

Treatment

Illness

The key cultural themes and aspects of social relations of the dialysis units centred around these four domains. The nurse is the pivotal factor providing care to the patients, without whom there would be no treatment, in the dialysis unit. The patient is the person around whom the care is focused. Treatment is delivered by the nurse to the patient. I studied all the levels of relationships, patient to patient, patient to nurse, nurse to patient and nurses to each other and other health care professionals, then all these people to the machines, to illness and the treatment. Finally I studied the social relationships that all the actors had to each other which was influenced by the environment of the unit. Illness did not appear immediately as a domain; 'illness' is not verbalised but having emerged from the data, I realised how its presence permeated every action, attitude and value in the units. Reflection led me to consider that I did not see illness immediately because I am accustomed to treating sick people.

Figure 6.1 *The inter-relationship between the ethnography and the cultural domains*



The concept of partnership is the central point, linking every cultural domain together.

6.3 The Cultural Themes

The themes are the conceptual elements derived from the domains. I studied the nurses and their cultural beliefs and behaviour towards each other and in the units looking after patients. I observed and discussed the staff's cultural attitude to illness and its treatment and reflected that renal failure brings with it all the complexities of chronic illness as well as unknown survival times. I observed the cultural behaviour and attitudes of the patients to the nurses, their treatment and their illness. As I wrote down my observations and interpreted them so seven cultural themes kept appearing (Figure 6.2). These themes

appeared as the most significant for nurses, patients, the illness and treatment; it was their influence, acknowledged or not, which was behind every interaction. The cultural themes that I found from the selected cultural domains are not necessarily the only themes which come out of the cultural domains but they were the ones which emerged from the data with the most significance. These themes were:

Survival

Them and us

Belonging – teams

Blame

Control-leadership-command

Communications

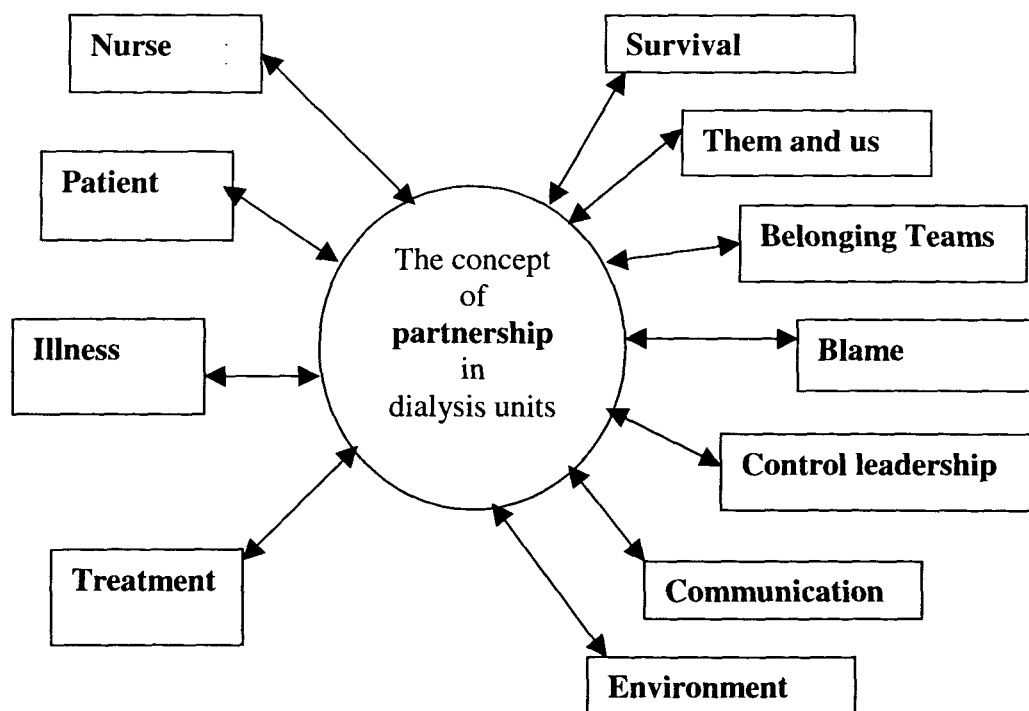
Environment

The concept of partnership is the central relationship that all the cultural domains has with each other and the cultural themes, which also related to each other and the domains.

Figure 6.2 The interrelationship between cultural domains and the themes in the dialysis units

Domains which all interact with each other.

The themes which appear from the domains



To show how all the cultural domains and cultural themes are interrelated it is possible to look at a single event such as the routine of 'going on' (Appendices 7 & 8). Even in the one example of 'going on' it is possible to understand how the cultural domains tie into each other and from them the cultural themes appear (Table 6.1). For example, the nurse's feelings had an influence on how the patient felt about coming to treatment (see 5.4.3). The patient's feelings can influence how the needles go in; which in turn may influence blood flows; thence the treatment and its outcome, thus effecting the course of the illness. Communications are different on days when things go well and the nurse and patient feel the treatment is going well. Both parties are relaxed so communications are good. Because the treatment goes well there is less stress and the patient can enjoy the companionship of others around her (see 5.4.3 & Appendix 8 for analysis).

6.3.1 The interaction and inter-dependency of the themes

Each individual event is part of the cultural scene of the unit and there are thousands of daily routine events all of which reflect the cultural scene. The cultural themes are woven into routine and unusual events and differences help expose the culture. Although I have attempted to describe each cultural theme individually on its own, they are difficult to discuss in isolation, the interaction of one theme resulting in another theme. They cannot be looked at as individual themes but as interdependent strands which together produce the woven texture of the culture of the dialysis unit.

6.4 Linking the evidence – cultural domains and themes

Agar (1996) suggests that through the constant study of the data, specific topics or themes will appear (Table 6.1). I have shown how the domains came from the data and were linked to the cultural themes through the central concept of partnership in dialysis units (Figure 6.2). For example, the patient is trying to survive by belonging to a team which will remove the division of 'them and us' between the nurses and the patients. The behaviours and attitudes of the nurses and patients will affect how the day passes and can affect the actual treatment outcome as is observed in this thesis. Life in the units has to be adjusted to accept the illness which affects the behaviour and attitudes of all the patients and their commitment to survival. The data showed how the nurses adjust to providing care to chronic patients when there is no cure and the patients' commitment to staying alive means they need to have an active part in their treatment - this is also supported by Curtin et al (2002) and Beder (1997).

Table 6.1 Linking the evidence - The cultural domains and evolution of the cultural themes

Domains	Relationship	Evolution of cultural themes
Nurse	Nurse cares for the patient by delivering treatment which is essential because of illness .	Patient has to have treatment to survive . She blames the extra day without treatment for her extra weight. Nurse surviving despite home problems. Treatment is vital for survival because of ESRF. Nurse communicates with patient about treatment, untruthfully because she does not want the patient to realise how harsh the treatment will be, no support from patient's friends. No team member helps so no support for patient or nurse. Leader not needed here except to give support to both domains (nurse and patient) and maybe advice about the machine programming. Environment does not help feeling of well being. Clinical outcome – not very good because of all the elements in the action, therefore survival of patient threatened.
Patient		
Treatment		
Illness		

6.4.1.1 The cultural theme of survival

Survival is the most primordial of all the cultural themes. It was apparent in the units without people comprehending or acknowledging its presence. The instinct to survive meant that individual needs were more important than the needs of others as was evident in Unit 1 (see 5.4.1). Although in Unit 2 survival was of major importance it was not so obvious. Explanations of the treatment and illness take time but explanations do help to mitigate worry as observed in Unit 2 and supported by Department of Health (1998a). People did not feel so threatened; there was more friendship between the patients and they were more prepared to help each other (see 5.5.2).

The need to survive obliged the patients to develop a relationship between themselves and the machines. Some patients found this relationship with a machine difficult, 'it's my blood going round there I don't want to look' as Mavis remarked, but there has to be a relationship with the machines for the patient to survive as Bevan discusses (2000). The patient has to trust the machine to deliver the treatment. The impatience shown when waiting for a machine was, I reflected, in reality expressing the need to survive. The worry about the outcome of treatment is again an acknowledged factor in the treatment, but was it again an unrecognised fear about survival? The field notes showed that because nurses treat patients routinely they forget, or do not appreciate, the fears that are present for the patient at every treatment. Mick had been seen by a nurse who had given him the necessary information but

had left him to attend to someone else (see **5.4.4.5**). He was scared and anxious which made him bad tempered. He was fearful about his future, he had been in hospital but it had not made any difference. Morgan said, 'I worry every time I come that I might not go home', or Stan who always 'was very careful to say good-bye to my wife when I leave home'. Altruism that is supposed to be essential for the evolution of culture as claimed by (Eshel & Shaked 2001), was not very evident in Unit 1 where a disregard for others was accepted as the normal behaviour, but the behaviour in Unit 2 was more caring and the patients supported each other.

Observing people going 'onto the machines' I reflected that as a nurse I also had been guilty of not appreciating what courage it must take to accept the machine to perform the programme which the nurse has correctly set up. There has to be a good relationship and trust to alleviate that anxiety which I saw in people waiting to begin treatment (see **5 4.3**). Unfortunately these people had little option but to accept treatment if they wished to stay alive. Unit humour reflected the cynical attitudes of some of the patients, 'it's my best friend' as Phil said one bad day. They joked about problems with weight and the resulting treatment. I reflected on how hard it is for the patients to accept their dependence on the machine, 'I hate these machines they make so much noise' as John said covering his fears by excuses. But as I have discussed, the underlying concern was to survive and if a machine keeps you alive then the machine has to become the partner to function where the body cannot.

I observed that the nurses did not acknowledge their own need for survival, and on reflection I considered they did not recognise their needs. In Unit 1 the nurses needed all their personal resources to keep up with the work (see **5.4.2**). Their problems were compounded by the emotional output involved in giving themselves to caring for people. When asked, the nurses admitted their need for more education to be able to cope with the increasing demands of the patients (Appendix **12**) but they did not freely admit to not coping with the emotional demands patients made. Many of them did not want to become involved, involvement with other people, especially people with problems means personal cost as seen in the exchanges between Mary and Sarah (see **5.4.3**). To sustain and give in a relationship means a personal commitment to the other person, 'emotional labour' as suggested by Smith & Gray (2000). Many carers in these units do not recognise that this takes time and emotional involvement, which is a reason for the absence of these relationships. They need the emotional support which is provided by friends - the team of

both nurses and the patients. Without this support they become unable to care emotionally or physically for other people and become increasingly frustrated (see **6.4**).

Field notes showed me that the staff would walk away from involvement, with their peers as well as the patients especially in Unit 1 where there was little team feeling; this would support Tschudin (1997 p 156) who claims that 'caring compassion can drain us emotionally, and the psychological cost of caring can result in professional burn-out or disillusionment'. Observations showed me that the feeling of being unsupported was prevalent though all the grades of staff. Survival did not only mean survival as a person but survival in one's job. The career prospects are difficult for renal nurses in any unit, everyone is highly specialised and there are few top jobs, financially, top grade nurses are not an economic option for the Health Trusts. As an experienced nurse I know that it takes years to become an expert renal nurse but the specialisation and expertise of these nurses is still not recognised, this is supported by the literature (Hurst 2002, The Kidney Alliance. 2001, Moores 1999). I reflected that there are few opportunities to attain the higher grades, and this causes frustration and unrest amongst the staff nurses which is discussed by Peach (1999). When a job at a higher grade was advertised while I was in the unit, I observed there was a great feeling of rivalry, followed by disappointment once the job had been awarded.

In Unit 2 there was more staff support from colleagues. Nurses were not so competitive about jobs as in Unit 1 as the work was where they needed to be and families and home life appeared to be more important than the unit life. They were choosing to work near home, as the data from the questionnaire demonstrated (Appendix **12** Table **12.3**). Moreover the demographic data showed there were more part time nurses working in Unit 2. But the competition for better jobs was fierce in both units. Renal work which is with the chronic sick is also routine and nurses do become bored (see **5.4.3**) as confirmed by Jung Ran, Hyde (1999). In Unit 2 there was less 'excitement' because the patients were healthier, so there was less incentive to extend one's practice. There were complaints about 'dead end jobs', but the family atmosphere and feeling of partnership within the unit did much to mitigate the boring routine and there was satisfaction gained from the friendship which formed in the unit (see **5.5.3.4**).

Observations showed that the need to survive carries fear in its wake. The patients feared for their lives, the staff feared for their positions. Although fear was not tangible it could be observed in individuals, more easily in Unit 1 than Unit 2, but it was in both units. I reflected that the patients in Unit 1 were on the whole sicker patients who were more

conscious of their illness so the threat of death was more imminent - this is supported by findings from Harris & Brown (1998). Moreover the patients in Unit 1 were often there to be treated for complications which occur because of dialysis (see 5.5.2), so there was fear about outcomes of interventions as well as fear of the treatment. Because of the transient nature of the patients in Unit 1 (see 4.4.2.2) there was less chance of the patients knowing each other so there were fewer opportunities for the development of supportive relationships.

Observations confirmed my experiential knowledge that the treatment itself causes fear. This can have a physiological effect and blood pressures are known to rise or fall because of the worry of going on the machine (see 5.4.3). For some such as Dennis whose wife has Alzheimer's Disease, he fears for her safety all the time he is away from home. He did not discuss his problems with other patients because he had not got a close relationship with anyone so he lacked support from friends in the unit. Behaviour can be governed by fear which is an emotion that is easily transmittable to others as was observed in the units and supported by Calman (2001). Mick was angry because of his fear (see 5.4.4.5). His fear and anger were obvious to the other patients who withdrew physically and emotionally; they needed to survive and his state reminded them of their own mortality. So Mick had no support from the other patients. The fear of death made co-operation from the patients better for a while after Margaret's death (see 5.5.2.1.1), which I know from my experiential knowledge can happen after a death in a unit. To counteract fear there needs to be support as agreed by Bailey & Tilley (2002). Fear needs the confidence of leadership to control it and the support of belonging to counteract it, this could be observed in the differences between the two units. In Unit 1 the leadership was inconsistent, there was no continuity and the environment did not facilitate the development of partnerships thus struggling to survive was a lonely task. The staff did not appreciate that they were struggling but this could be understood from the comments made in the formal interviews. 'I never seem to get on top of the job, there's always far too much to do' 'I have to take the forms home with me there isn't time in the unit'. The constant pressure of work as seen Unit 1 served to increase the stress for the staff, but stress was obvious in both units.

6.4.1.2 Cultural theme of them and us

The divide in the theme of 'them and us' is the divide between the 'classes' in the Units. It relates to the divide caused by the classes which occur between the nurses themselves, and other members of the health care team, exacerbated by the hierarchical structure of the health service, and the divide between the health care providers and the recipients as

confirmed by Major (2002). The small size of the unit with fewer carers in Unit 2 meant that everyone worked better together in partnership; there was less of a divide between the carers and receivers of care. The health care team was careful to include the patients in discussions about their care. The size of the unit meant that all the other patients would add their opinions and the feeling of mutual support was present. In both units, observations and informants from the staff and patients showed how they considered that their respective unit belonged to them; it was 'their unit', but it was more evident in Unit 2. In Unit 2 there was a real fear of being sent to the other unit; they all belonged together. 'It is like a second home for us and we all get on so well' and other comments were often made as I went round the unit. The patients had friends amongst their group, and hopefully sat next to them for treatment thereby giving support and comfort to each other (see 5.5.2). There was plenty of socialising outside the unit for the patients and staff. The staff went out for meals together and the patients met at gardening clubs or in town for tea. In neither unit did patients go to one another's home, despite the difference in the relationships in each unit. I spent a long time reflecting on this phenomenon but did not have an answer except that it suggests that the patients live two separate social lives which do not mix. The unit is a place apart but the partnerships which form in it support and maintain people through the daily routine of treatment.

In Unit 1 the special relationships which flourished in Unit 2 were lacking. Instead there was a divide between those who needed treatment and those who delivered it, not a homogeneous team with all parts supporting the others. The health care team remained within their cultural group; but in these groups there were divisions caused by the hierarchical structure, into trained and untrained staff, or doctors and nurses, or nurses and ancillary workers such as the domestic or the transport people and there was some animosity towards the other groups. The literature stresses the importance of partnerships in caring for people (Bates 2001, Auer 1997), but on many occasions does not address the problems when there is no partnership. The dialysis unit is a place where the significance of good partnership on treatment outcomes is not easily recognised by the carers. I observed how people were unaware of and so undervalued the contributions of others as discussed in Chapter 5 and confirmed in the Bristol Royal Infirmary report (BRI 2001).

The power ratio, which is the unequal relationship between the health carer and the receiver, is discussed by the Bristol Royal Infirmary report (2001) and Silverman (1987) and was obvious in both units. This power ratio exacerbates the 'them and us' feeling as was seen in both units. I reflected that the relationships which form in dialysis units because of the long

term care might be able to mitigate the acknowledged power ratio, this is also discussed by Major (2002) and the BRI (2001). The 'them and us' was obvious in Unit 1, the HCAs criticised the Staff Nurses for their inability to organise (see 5.4.9.3 & 5.4.9.4.1). As one of the HCAs said 'the place is a complete tip and no one bothers'. Or another day when the allocating of machines was disorganised, 'why doesn't she let me do it if she can't?'. It was not surprising that there was an absence of team feeling between the two groups. The HCAs thought the Staff Nurses 'sat around having report when there are things to do', and the staff nurses considered the HCAs did not 'have clue about what this job is all about'.

These common misunderstandings of other people's responsibilities can be minimised by good communications and more empathetic understanding of other people's needs as seen in Unit 2 and confirmed by the Bristol Royal Infirmary report (2001). There was not the time for friendships between the untrained and trained staff. The staff nurses did not recognise the vulnerability of the HCAs, who needed approbation of their work for their self-esteem. The Staff Nurses could only see what had been done, not how or whether the patient had benefited. Observations showed that there were few partnerships between the staff nurses and the HCAs which would have made 'shared care' easier. There are few rewards for the HCAs, no promotion or financial rewards for good work, therefore they needed to feel wanted and appreciated by their colleagues. But the trained staff had neither the time nor the energy to be concerned about the personal welfare of the HCAs, they were not friends but work colleagues, so there was no mutual support which should have emanated from partnerships. Moreover the competitive feelings between the trained staff themselves, meant there was no cultural attitude of caring as Linda and Sally found (see 5.4.9.1. & 5.4.9.2). I reflected that if there had been partnerships in the unit both these nurses would have found support to cope with their problems.

In Unit 1 the health care team was conscious of its role as care giver, which meant there was a divide between them and the patients, 'shared care' which is important for the patients (Caress et al. 1997) did not happen. This was less obvious in Unit 2; the patients were encouraged to participate in their care (see 5.5.3.4). The atmosphere was different to that in Unit 1 because there was a culture of good relationships between the two 'sides'. It was more intimate than Unit 1. This was due not only to the attitudes of the staff towards the patients but also the physical size of the unit and the number of patients. In the smaller unit there is more chance of relationships being formed due to many circumstances but partly because of the proximity of patients to one another during treatment and ability of the staff to get to know every one of the small number of patients. The patients in Unit 1 did not

announce their arrival or their departures going round everyone to say 'hello' or 'good-bye' as in Unit 2. Observation showed me that not everyone in Unit 1 even knew each other, this was due in part to the changing population of patients being treated as well as the ill health of many of the patients.

The behaviour of those nurses in Unit 1 where everyone was individually concentrating on getting their own jobs done left no opportunities to help anyone else. I observed that in order to preserve their own identity the staff remained in their own peer group. Even the language used to talk to the patients was not the easy vernacular of friendship, rather the more stilted exchanges which happen between social unequals. Once a person becomes labelled as a patient he loses his own identity, and the 'before self' is no longer an issue that counts (Goffman 1963), which I observed especially in Unit 1. But illness is no respecter of persons and anyone can have kidney failure. When the distinctions between the carers and the patients are removed better care results as could be seen in Unit 2 and is supported by MacIntosh & McCormack (2001) and DoH (2000). ESRF is a disease where the treatment has to become a way of life and no one can tell how he might react to having this illness. Differences were very apparent as I observed in the patients' reactions in the two units. Patients are people too, and have to be included in the health care team. It has been proved that to give control back to a patient will help with co-operation as demonstrated by this study and reinforced by The Kidney Alliance (2001) and Folkman (1984). The patients' own commitment to staying alive is vital in renal failure. Therefore the patients need to feel an important part of the team partnership. The accepted culture in Unit 1 appeared to exclude the patient from all but the most superficial discussions concerning his treatment and health, while still expecting the patient to take some responsibility for his well being. But as stated, when the culture of shared care is lacking, co-operation from all the patients is not going to happen. This is reinforced by the findings of the BRI report (2001). The doctors are taught to include patients in decision making (Bates 2001) as part of 'good practice' but first there has to be understanding, understanding of what it means to be a patient, to suffer all the changes in life style and role that illness causes. Renal failure is complicated with many facets and the impingement of this disease on the social world of the sufferer is not appreciated (Auer 2002), most medical people outside the renal field do not comprehend the effects of the disease (see 5.4.9.6.1). Every medical decision has social consequences and this is especially true of renal failure, where there is not enough understanding about the disease (Auer 2002).

6.4.1.3 The cultural themes of belonging and teams

On paper all the nurses belonged to a team, but in Unit 1 there was a lack of leadership and absence of support that should come from the team or partnership (BRI 2001). The Unit 1 patients felt they belonged to the unit but they had no control over their treatment which was delivered without the personal touches which make it more bearable (see 5.4.2). There are always exceptions and there were some nurses who worked at making people feel they belonged but too many staff were only in the unit 'to do a job' so the cohesion was lacking (see 5.4.3). The absence of team spirit led to the lack of the support that being in a team gives as illustrated by Sally's case (see 5.4.9.1.1). There was competition to be at the top as I observed when the F grade was awarded and no support for the unsuccessful candidates.

The absence of belonging to a team led to a certain lack of open communications, I observed, and there was not a free exchange of knowledge. The management team did not share their knowledge. Because of their work commitments they did not consider themselves to be in partnership with the staff in the units, and therefore observation showed that they were unable or unwilling to offer support in times of crisis (see 5.4.9.1). Hospital hierarchy is based on knowledge (Major 2002). Holden & Littlewood (1991) claim that the power of knowledge is the cornerstone of the structure of the hospital and maintains the hierarchical structure. Thus withholding of knowledge is a recipe for disaster for the nurses as well as the people for whom they care (Major 2002, BRI 2001); if the team feeling had been in evidence in Unit 1 knowledge would have been shared for the mutual benefit of everyone. The feeling of belonging to a team needed to be felt by everyone in the units to give support in this stressful environment. The lack of feeling of partnership which comes from belonging to a team meant that the struggle for survival had to be stronger as observed in Unit 1. If the sense of belonging and partnership had been better everyone would have had a common goal, all working together - which in turn promotes increased survival as confirmed by Lewis & Fink (2001). This study showed how the team in Unit 2 functioned better due to every member of the team being valued, confirming Trueman's (2001) contention that teamwork needs good leadership and a strong commitment to the communal good for optimum functioning.

In Unit 2 the feeling of belonging was more easily felt. The patients and nurses knew the unit belonged to them and they to the unit. Observations showed that the sense of community was strong and any proposed changes were discussed and opinions aired (see 5.5.3.4). Plans for improvements in the unit were discussed by everyone (see 5.5.3.4). Due

to the feeling of partnership in the unit there was a sense of commitment and ownership with everyone working towards the common goal of better health through better outcomes.

In Unit 1 since the teams were unacknowledged, the staff could not ask for help from members of the team to dissipate their workload. Outside the unit the staff did not mix in the wider social world and had less knowledge about each other's home backgrounds than in Unit 2. Unit 2's coffee room gossip was fun and supportive especially if anyone had problems, they were all together partners in trying to survive work with its difficulties. In Unit 1 the staff had little inclination or time to share home problems (see 5.4.8). The environment of their coffee room was not conducive to 'cosy chats', and the nurses station was not the place to talk socially; there were too many people appearing at the station asking for advice or directions. People survived through their own efforts and communal support was not usual. For those exceptional nurses who did support their colleagues and took time and effort to ensure the smooth running of the unit, the personal cost was high, higher than necessary because of the scarcity of mutual support as suggested by Smith & Gray (2000). The staff morale in Unit 1 was low, staff were undervalued, affecting the turnover rate as is confirmed by Findlayson (2002).

Both units had a divide between the HCAs and the trained staff but in Unit 1 there was a personality problem (see 5.4.9.4.1). In Unit 2 the senior HCA, Lisa, was very experienced and wanted the best for the unit. She had the experience to know that the patients are the ones who suffer when there is conflict amongst the staff. Her team (the HCAs) functioned as partners all working for the benefit of the unit. They knew this and I could see the whole team working together for the unit (see 5.5.3.2). The staff belonged as did the patients to The Unit. It was 'my unit' for all members of the team. In Unit 1 it was difficult to feel common goals when the teams were not working well. It takes a strong leader and a sympathetic environment to straighten out these problems and make teams work together, as corroborated by Major (2002). There were neither in Unit 1 but observations showed that what a difference was made by the strong leader in a sympathetic environment as in Unit 2.

The patients would have liked to be partners 'in the team' but often were not, as could be observed in Unit 1. Even though in Unit 2 they did have a lot of input into their treatment, it was not shared care on an equal plane. Patients need to be part of the health team and their opinions respected to optimise on treatment outcomes which is discussed by Bradshaw (2002) and the BRI report (2001). I reflected that renal patients have much to offer. They are taught about the disease but I observed that their knowledge is often overlooked despite

the fact that it is their bodies which are being treated. The caring process can be overtaken by technology as could be seen in both the units and is discussed by Erben (1999) and Bevan (1998). I reflected that patients are experts in their own spheres, and their bodies do belong to them. They need to be consulted about their care. When permitted, the reciprocal friendship of the patients support the health providers which then lessens the divide as demonstrated in Unit 2 and confirmed by Obrey (2002). When the patients are empowered to be part of the team there is more co-operation which motivates adherence to the dialysis regime as observed in Unit 2. As Watson (1985) advocates, reciprocal relationships will facilitate the development of partnerships. The growth of these personal relationships in a dialysis unit will help to counteract the technical and scientific treatment process which is dependent on machines. Greater attention to the emotional side of relationships offers a more human face to the increasingly technological nature of modern medicine especially that in the dialysis unit as demonstrated in Unit 2 and supported by Bevan (1998). Valuing the individual provides the mutual support which helps with self-esteem as could be seen in Unit 2 and confirmed by Obrey (2002). Although I did not observe a particular lack of self esteem in Unit 1 I reflected that it could be assumed from the passive acceptance of the treatment, which is supported by Folkman (1984).

6.4.1.4 The cultural theme of blame

The theme of blame is strongly present in the units as is demonstrated by the reactions of Sally and her colleagues (see 5.4.9.1) and after the death of Margaret (see 5.5.2.1.1). The unit is vulnerable to blame because of the culture which divides the unit and home and the treatment as discussed in Chapter 5 and by Bevan (1998). The patient divides his life between the unit and home and does not communicate events in the unit to his family; therefore unless the staff involve the family in the partnership of care, the relatives might not recognise the patient's declining health. Belief in the future is emphasised as part of the unit culture as I observed in the field notes, but this means that the adverse affects of treatment are not fully discussed and the death of the patient can be unexpected for the relatives.

The patients blame everyone including themselves for their condition (see 5.4.4.1 & 5.4.4.3). This is a natural reaction to the diagnosis of chronic illness (Miller 1992, Cassell 1991). But true co-operation or partnership means the dialysis patient has to accept responsibility for his wellbeing between treatments and this is difficult as shown in both units. Patients have little control over their treatment, the nurses sometimes omitting to tell the patient what the machine is programmed to do (see 5.4.2). The patients feel they are not

in partnership with the nurses. Therefore they will not realise the responsibility that is intrinsic with the partnership, blaming circumstances: 'it was the extra day', 'I had to go out to lunch with my wife', 'it was so hot' or even 'I have to have a binge or I would go mad' are some of the excuses for the extra fluid or bad blood results. Sometimes there are no excuses just a defiant 'well I don't care what you say'. They blame the staff for the harsh treatment that follows (see 5.4.4.1 & 5.4.4.3), or their families for not being supportive or for being too dictatorial. Nothing is ever quite right and their bodies are not the friendly refuge they were before this disease struck. This was an observation which held true for both units.

The nurses blame each other when things go wrong. They are accountable for their actions, but because their skills are too often undervalued and their decisions are questioned, they do not have confidence in their opinions as was observed in Unit 1. Since there is no partnership the nurses lack the support of their colleagues as could be observed especially in Unit 1. The isolation that comes because of lack of support or not belonging exacerbates the need to blame someone else as shown in both units. Sally's case study was a good illustration of how the staff all worried about the outcome of Jack's death (see 5.4.9.1). She was unsupported by the very people who should have cared for her. These observations are in accordance with the findings of Jowett et al. (2001) and BRI (2001). The BRI report (2001) states that we live in a litigious society. The renal staff are aware of problems that can occur in the medical world which are exacerbated in dialysis units (see 1.1); through experiential knowledge I know that team support mitigates the apprehension of blame (also confirmed by the BRI report (2001)).

In Unit 2 when Margaret died Ros blamed herself for not doing more, Jane blamed herself for not sending Margaret to Unit 1 so she could have been 'sorted out yet again'. Margaret's named nurse felt it was her fault for not recognising that Margaret needed extra help. It was no one's 'fault' but dialysis units are vulnerable as the public need to make someone responsible (see 1.1), so each member of the health care team feels she is culpable. This is a theme that is much in evidence throughout the NHS as the literature confirms. The Minister of State for Health (Milburn) as quoted in The Times (2001 p2) said 'we must get away from the blame culture, even the best doctors make mistakes'. Kennedy in the Bristol Royal Infirmary report (2001) discusses this blame culture and how demoralising it is for people working in the NHS. Bradshaw (2002) discusses the ambitious policies of the NHS that have led to the blame culture and the necessity to find someone to take the responsibility. When life and death issues are being discussed the outcomes may mean the

loss of someone's job. The BRI report (2001 p 259) stresses that too often there is a recourse to blame as a reflex action ignoring the environment or systemic failures which gave rise to the event as happened on the death of Jack in Unit 1 and Mary in Unit 2. There is scope for this culture to flourish in these dialysis units because the structure of the work force lacks cohesion. There are no partnerships, rather there is a hierarchical system, as seen in Unit 1 (see 5.4.7) and the illness of the people being treated (see 1.1). There is scant acknowledgement of the skills of the nurses on the part of the management as demonstrated in Chapter 5 and the support which should be there for the staff was not evident. RRT can continue for many years and although people do not die from renal failure, once they are receiving treatment, the co-morbidities can and do cause sudden, unexpected death. The 'unexpectedness' of death is exacerbated by the expectations of the patients and their relatives. My experiential knowledge as a nurse and observations bring me to the conclusion that when accepting a patient for treatment not enough emphasis is placed on the terminal nature of the disease. This is supported by Da Silva-Gane et al. (2002) and Dörner (2000).

Death is socially unacceptable, and for some doctors the death of one of their patients is still considered a failure of their art (Bates 2001, Buckman 1992). I observed that the dialysis nurses encouraged the patient to look forward, to hope in the future even in the areas that were caring for acutely sick patients. Hope is described by Herth (1990) as a positive outlook on life and a belief in the future no matter how short that future is to be. This has to be a philosophy for the renal patient with the very uncertain prognosis of this disease. Studies done on people with chronic illness (Rideout & Montemuro 1986) show that hope is essential for coping and it can alter the patient's capacity to respond positively to treatment irrespective of the severity of the disease. Therefore the renal patients are encouraged to look forward and the possibility of death is not discussed. But through my experiential knowledge I know that sudden death will generate anger as confirmed by Harvey (2000) and Copp (1999) and the grieving relative looks for someone to blame. Good leadership and the support of friends and partners in the health care team will counteract this culture of blame as was observed in Unit 2 and supported by the literature (Beech 2002, Bradshaw 2002, BRI 2001).

6.4.1.5 The cultural theme of control-leadership-command

These three ideas weave together to produce a single cultural theme. Society has to have order, rules have to be made and kept and there needs to be someone in command to lead and create order in a hospital environment (BRI 2001). It was possible to observe what

happened when there was no control or leadership in Unit 1. Data from the formal interviews showed that the staff in the units knew they needed some one in command to keep a sense of order and this was confirmed in observations on the units. The patients coming for treatment needed to feel someone was in control, 'I know when Liz is on everything will run smoothly' as said one of the staff nurses when we were discussing good leaders in Unit 2. The example of Anne (see 5.4.9.4.1) demonstrates the problems that occur when there is no leader to give command. The nurses in Unit 1 who realised the need for someone to command were often not acknowledged, but rather denounced by their peers and left unsupported (see 5.4.8). Unit 2 had a good leader in Jane and the unit functioned well in her absence. In Unit 2 the need for survival amongst the nurses was less competitive because they were happier in their roles, and life outside the unit was important but could be discussed at work. Observations showed that the person running Unit 2 did so with plenty of support from all the partners in the health care team and the shifts ran smoothly without adverse incidents. The HCAs in Unit 2 felt valued and part of the team (see 5.5.3.2). The patients enjoyed coming, and the unit functioned as a well-formed partnership of patients and staff. The staff enjoyed each other, communications were good, and what was lacking in chances for job advancement was made up for in general friendship (see 5.5.3.4). It takes skill to manage and create order. People management is a special skill requiring time and patience, as claimed by McBride & Clark (1996). A good manager needs self-knowledge and appreciation of the value of others in the partnership which was observed to be lacking in Unit 1.

I reflected how control is an issue in the dialysis units, it appears in many guises and circumstances. In Unit 1 there was no one in control therefore the unit lacked team spirit. In Unit 2, with a better team spirit and a good team leader, the nurses knew they were appreciated and there was someone in control. They functioned as more effective partners in a team which generally included the patients. Together they all considered they controlled the unit and did have some control over their lives and futures. In Unit 1 the nurses were uncertain and lacked confidence, because there was no leader organising and taking control. The reaction by some nurses to this lack of leadership was that they became paternalistic and exerted excessive control over the patients in their care (see 5.4.3), confirming the findings of Jackson et al. (2002).

I reflected how the disease had already taken control over the patient who had lost control over his life. As the patient goes on the machine he is handing over control to the nurse who sets the machine which is then in control. The partnership between a patient and his

machine is individual and illustrates the different culture of the unit (man to machine), but I observed that those who could accept the technological expertise of the machine were not so fearful about the outcome of treatments. Folkman (1984) discusses how returning control to a patient will augment his self-esteem. I reflected that unless the patient feels he is in partnership with the machine and his needs are acknowledged he feels undervalued and his self esteem is lessened which perpetuates the loss of control and helplessness. This is corroborated by Bevan (1998).

I reflected how fear enters this equation, the fear that the machine will not perform correctly or that the nurse has set it incorrectly, or the patient will not survive the treatment. The antidote to this fear is a strong 'controller', someone who can be trusted and show through his/her behaviour that s/he has the confidence and knowledge to order and deliver the correct treatment (Welford 2002). The medical team now has control over the patients' lives; there is no partnership between these 'teams' of carers and patients. The patients have to come to the unit when told, and there is no freedom to 'have a day off treatment' as many of them would wish (see 1.3.1). The disease has taken over and the invasiveness of the treatment means that the patient is never free from its effects. The patient is under the control of the health care team, instead of being part of this partnership which is striving for the same goals of survival and better health care. The patients in Unit 2 enjoyed better shared care. Their opinions were valued and the partnerships produced better co-operation with better treatment outcomes.

6.4.1.6 Cultural theme of communications

Communication is an important cultural theme joining all the other themes together. Good communications can lessen stress as well as reinforce the feeling of teamwork as claimed in the BRI report (2001), and the difference between these two dialysis units was very noticeable. The stress levels in Unit 1 were high, as can be seen from the high turnover of nurses, and care was compromised through lack of communications. The trained nurses with no support from their peers were not prepared to challenge a bad situation of relationships and command between themselves and the HCAs (see 5.4.9.4.1). Good communications promoted the 'Shared care' which I observed worked better in Unit 2. However in Unit 2 the patients were relatively stable; they were in better health than Unit 1 and there was time to enjoy each other and being in the unit, and therefore there was more opportunity for relationships to develop. In Unit 1 I observed that the poor communications led to poorer care provision this is confirmed by the BRI report (2001). Haemodialysis units have need for good communications and documentation to ensure continuity of care

because of the transient patient population and where every treatment is unique.

Communication is essential to the evolution of culture as claimed by MacIntosh & McCormack (2001) and Hammersley & Atkinson (1995). Communications are also vital to the development of relationships, as can be seen in both units, which then promote better treatment outcomes.

6.4.1.7 The cultural theme of environment

The culture of a unit is affected by the total environment which includes structural and human components. Unit 2 is arranged so people receiving treatment in two bays can all talk together thus promoting the development of social relationships. Daylight comes in through the windows and it is possible to see the outside world. This is a friendly 'cell' hidden from the outside but still part of the larger social world. The patients were able to be more self-caring and in better health. The staff who did come to the unit were 'friends', with designated jobs. The whole place felt friendly, it had a sunny feel even on wet days. There was a happy buzz of chatter, even the rain did not dampen people's spirits. The nurses' station was a pleasant place from where to sit and watch and chat to the patients and the staff. Life in Unit 2 was well organised and all the partners knew who was in control. The nurses mitigated their stress with chat and discussion of things outside the unit, their home circumstances featuring in many of the conversations. The environment was happy and friendly for people both giving and receiving care.

Unit 1 was big and the main room felt unfriendly with the machines all round the walls. There was an expanse of space, a 'vast black hole' with the dialysis stations round the edge of the room. The stations were too far apart to promote the feeling of companionship for the patients, who could not talk easily to one another once on the machines. This meant that they did not relate easily to each other and friendships were not formed. The environment in the waiting area was not conducive to a relaxed atmosphere. Although comfortable chairs are advocated by The Kidney Alliance (2001) they were not available and the environment of this room was like a dentist's waiting room. Also people sitting there were either waiting to go on a machine, or waiting for transport to go home both of which were stressful situations.

The smaller room of Unit 1 with its 6 stations had a friendlier atmosphere than the main area. The room although physically darker than the main room, was noisier due to conversations between patients and felt more relaxed and happier. The nurses often preferred to work in this area but this could not be ascribed only to the happier environment.

Certainly, despite the proximity of the two rooms the atmosphere was vastly different; it was a friendlier place and more chatting and laughing could be heard.

The nurses' station in the big room created a mental and physical barrier between the nurses' station and the room. It isolated the nurses from the patients. The nurses could resort to their station and appeared to be busy with the computers or having reports. The environment of the coffee room was not conducive for a private relaxing chat. The Unit lacked facilities for social intercourse because of its size and the staff did not meet outside the hospital so the culture was not one where relationships developed easily.

6.5 The Concept of partnership

From the analysis described above emerged the realisation that it was an organising concept of partnership which links the cultural domains to cultural themes (Figure 6.2). Partnership emerges as the organising core concept which ties the cultural themes and domains together and also leads to the understanding of the culture of dialysis units. The degree to which the partnership is formed will influence the culture of the units. It is this degree of partnership which differentiates the culture in dialysis units from other units in a hospital. Every cultural theme found in this thesis is dependent on a concept of partnership. Therefore the culture of the unit is better understood through this concept. Partnership is the phenomenon promoted by the NHS to give better care, but in the dialysis units it is more than a phenomenon. This thesis has demonstrated how every cultural theme leads towards a concept of partnership which in the dialysis units is on a very special level involving human beings and technology and the survival of the patients is dependent on this technology.

Partnership has many meanings but the commonly accepted meaning is about people and objects working together for the greater good (Clarke 2000). This entails common knowledge, shared ideas and attitudes all striving for a common goal, as is discussed throughout the thesis. The common goal in the NHS is the better treatment of the patient, but in the absence of partnerships this goal can be overlooked. In the dialysis unit again the common goal is better treatment but this better treatment can lead to longer survival, the struggle for which is part of the culture of the units.

Partnership is mutual respect which values other people and things but value has individual meanings for individual people which is why all the partnerships are different. The values in the dialysis unit are again different because of the culture of these units. Partnerships are on different levels between different people and things as the exposure of the cultural

domains and cultural themes show. The culture in the dialysis units means that these partnerships depend on the cultural attitudes, behaviour and values which are special to dialysis units.

Partnerships are based on respect and trust (Clarke 2000). Without trust there would be no treatment, no patients. Trust is implicit in the acceptance of any treatment. The level of partnership determines the extent to which that trust is justified. The issues presented in this thesis by the themes are all fundamentally shaped by trust. Therefore within all the themes there is the accepted element of trust. I did not look for trust in the data I collected. Reflection led me to understand that this was because of my past experiences, and I accepted trust as implicit in the giving and receiving of treatment.

As every cultural theme is examined it is possible to understand how a concept of a partnership is central to the culture of dialysis units. Partnership as a method of preventing the blame culture is discussed at length by the BRI report (2001). A solution which is appropriate to dialysis units is to understand how the system works, which entails studying the interrelationships between people, the machines and the environment and why these relationships break down. As has been discussed, RRT is a treatment vulnerable to criticism which makes the units stressful environments but is part of the culture of those units. The BRI report (2001) stresses the importance of good communications to help mitigate the vulnerability of areas of high technology where treatment outcomes are uncertain.

This study has demonstrated that good partnerships will enhance better care but promoting partnerships means involving people in their own care which may mean a change in cultural behaviour and attitudes, as discussed in this thesis. There is proof that people wish for more involvement in their care as observed in this thesis and confirmed by the BRI report (2001), but with involvement comes a responsibility towards oneself which patients are not always prepared to accept (see 5.4.4.1 & 5.4.4.3). No longer can the knowledgeable renal patient blame circumstances or lack of knowledge for his non-adherence to the regime (see 5.4.2).

Patients learn about their bodies and this disease in order to survive. They have to understand the limitations of renal disease as discussed in this thesis. RRT is only one part of surviving (Khan 2000). The dialysis patient is required to be in partnership with his body, to adhere to a permanent dietary regime and to understand signs and symptoms of ill health which have special significance for those with ESRF. Their commitment to survive is what helps to keep them alive. Margaret could not seem to help herself and the end result for her

was death (see 5.5.2.1.1). Nurses become the active partners with the patient in the provision of health care, not only are they the patients' advocates but they often prescribe and facilitate the care (see 1.1). They are the people who programme the life saving machines. Partnership gives both partners knowledge of, and respect for, the views of the others, armed with this knowledge the individual requirements of each patient can be fulfilled where possible thus promoting better treatment outcomes.

Renal units have a common treatment, which should lead to partnerships but as this study shows partnerships do not happen without effort and a sympathetic environment. Christensen (1993) talks about the shared venture, which establishes partnerships. This shared venture could be the dialysis treatment where a partnership builds between the people, who form a team with a shared goal. The bond between patients stimulates co-operation with the regime therefore better results from the treatment are obtained and problems also can be openly discussed, but as this study showed this does not always happen, a conclusion also arrived at by Dörner (2000). For those who receive treatment over many years in the same unit, relationships do develop so that the unit becomes a 'second home' and the members, staff and patients all become a family as in Unit 2. This close relationship stimulates partnership through participation, and therefore the shared goal of better treatment outcomes is more achievable.

As this thesis indicates, better partnerships between the patient and their families and the families and the units need to be considered. People in the dialysis unit do form strong bonds with work colleagues and with other people receiving treatment to the exclusion of those outside the unit as seen in the evidence from both units. This is reinforced by Eshel and Shaked (2001) who consider that these bonds of friendship can be stronger than those of kinship. Even in Unit 2, where good partnerships have developed, unit and home are not mixed. This gives the unit some of its 'secret' status which is part of its culture. The bonds of family and relations are at home but do not intrude into the unit. However the regular occurrence of one patient's partner who drove her husband to treatment did mean that she did become part of the unit partnership and part of the unit culture, bringing into the unit some of the outside world culture. But generally the culture of the unit is influenced only by the values that are relevant to the unit, and partnerships are formed within the units which do not relate to the larger social world.

6.5.1 The negative aspects of partnership

It is important for the ethnographer to assess and examine the negative aspects of partnership since not all relationships end in partnerships. It is seldom that partnerships in health care would not improve the caring (MacIntosh & McCormack 2001). I talked to many nurses who could only cope with the delivery of treatment and did not wish to get involved to the detriment of the provision of care (see 5.4.2). Linda was one of those who now only wished to deliver treatment. She had been let down too often by lack of support from colleagues when she had given herself and her own emotions to help a patient (see 5.4.9.2). She wanted to help people and was prepared to offer herself. But seemingly again and again she had not received support from friends or management. 'I have got fed up with trying to sort out these problems on my own, no one else seems to care', she admitted to me, when once again she had tried to organise something for a patient. Sally and Ros as shown (see 5.4.9.1 & 5.5.2.1.1) became emotionally involved with the circumstances surrounding the death of patients; no one was there for them. As this thesis has demonstrated, partnerships break down when there are no relationships between the groups, nurse to patient (see 5.4.3) and nurse to nurse (see 5.4.8).

The patient has a partnership with the dialysis machine, which outside a dialysis unit would be unusual. Without the machine the patient would die, so it is in his interest to maintain this partnership which is part of his commitment to staying alive and part of the culture of the units. The patient is continually reminded of his vulnerability and his dependence on the machine through this partnership. The patient trusts the machine to deliver treatment appropriately for his illness and the nurse is trusted to programme the machine which she in turn trusts to deliver the programmed treatment. This cultural behaviour and attitudes are components of the culture of the dialysis units and serve to make them unique in a hospital.

I observed in the renal units the nurses perform technical wizardry well beyond the comprehension of the patients or other medical professionals. The established 'expert' nurse can, by instinct, know when a patient is about to 'go off' (collapse) even before the patient knows; this is partnership on a highly sensitive level. Nurses learn skills which could appear to put them beyond the caring roles; there is the danger that operating technical machines obscures the need to care as seen in this thesis and as suggested by de Vos (2002), Jung Ran, Hyde (1999), Bevan (1998). The partnership role becomes lost with the preoccupation of 'performance'. This is an attitude which is part of the culture of the unit as has been discussed.

6.6 The concept of partnership in the literature

Our modern NHS has taken the concept of partnership and advocates for the delivery of better therapeutic care using partnership (Trueman 2001, Calnan & Gabe 2001, DoH 1998b). In the renal world as elsewhere, optimal treatment outcomes depend on patient adherence to the regimes. It is accepted that people will co-operate better when there is good partnership (Lewis & Fink 2001, Ashwanden 2000, Hedman 1998), but in the dialysis units it is the level of partnership which makes the units different with a special culture. People's cultural behaviour and beliefs demonstrate how the concept of partnership does affect survival as shown in this thesis. MacIntosh & McCormack (2001) postulate that when nurses partner the people they care for, the care is likely to be more acceptable. The dialysis unit is no exception to this; it is a place where, because of the special relationships, the care should be empathetic with the emphasis on the whole patient rather than only the technical outcomes of the treatment as discussed by de Vos (2002).

The patient has to be encouraged to accept responsibility for his body within the confines of the disease as discussed by Hippold (2001), Erben (1999) and Hedman (1998). But illness makes people vulnerable (Cassell 1991), and as has been explained in this thesis, the patients and health care team in dialysis units are vulnerable. Too often the medical team in the dialysis units make the decisions and continue to do so. This loss of control is another role change in the illness process (Folkman 1984). It will take a change of the cultural attitudes and beliefs to alter this paternalistic behaviour. Role changes increase the patients' vulnerability and sick people welcome the decisions of the 'wonderful doctors'. They are happy to resign responsibility for their own health especially the older patient, immediately the mutual respect and equality becomes weighted in favour of the medical team as was observed in the dialysis units and is discussed in the BRI report (2001). This passivity may also be attributed to the loss of self-esteem which has been caused by the loss of control as was observed in Unit 1 and discussed in this chapter.

The NHS advocates for more empowerment for patients through partnership (Calnan & Gabe 2001), but patient empowerment is not accepted as a general rule. In the dialysis unit the power lies with the doctors or the nurses delivering the treatment. To create the right balance between the professional and the client entails a change of cultural attitude from the traditional acceptance of medical wisdom to a more challenging one where the medical authority is not accepted without question. The dialysis unit is different because here the traditional acceptance of medical dictates is challenged by nurses who are in charge of the provision of care. It is the nurses who are the specialists, they become the patients'

advocates when challenging decisions, but to maintain this level of specialisation they realise they need more education (Appendix 12 Table 12.3).

Smith & Gray (2000) and Fabricius (1999) discuss how making relationships takes effort and emotional output for which the busy nurse does not necessarily have time or inclination, as was demonstrated in this study. The way out for the busy nurse is not to communicate, to withdraw into her own world. This helps her to preserve her own integrity as a person, but does little for the patient who needs to be participating. One way to survive is not to become involved, to concentrate on one's own personal needs to the exclusion of others as was seen (see 5.4.3). But nurses have to survive. Their problems are compounded by the emotional output involved in the giving and caring for people as suggested by Smith & Gray (2000), which in the dialysis units can be for as long as the patient is alive which makes the emotional commitment that much harder to bear.

Tschudin (1997) claims that the emotional cost of nursing can be measured in terms of medical conditions. It can also be counted by the 'non-functioning' nurse, the nurse who does her tasks but no more as was observed in the units. Nurses need support and care to be able to care for others. Because of the crises in renal patient numbers the renal unit can become like a factory, processing people through treatment with not enough time to care. The busy nurse becomes ever more frustrated and in order to survive will give increasingly less of herself as this thesis has demonstrated. Tschudin (1997) promulgates that the nurse has to balance her own needs with caring for others and is constantly disappointed by the system thus becomes increasingly frustrated with her role as happened to Linda (see 5.4.9.2). Although work in the dialysis unit is frustrating because there are 'no cures', good partnership decreases the frustration and promotes the achievement of the goals of better treatment as was demonstrated in Unit 2. But when partnership is lacking relationships do not flourish, and the circle diminishes until caring ceases which is what happened to Sarah (see 5.4.2) and is a finding supported by Keogh et al. (2000).

Emotional labour is being involved with other people's feelings which may be more than the nurse is willing, or able to do. This is reinforced by James (1993) in her work on the importance of emotions in holistic caring. The culture in the dialysis units should facilitate the giving of this emotional labour but there appears to be little support for the nurse who is prepared to give herself. The nurse who can care creates a bond of partnership which enhances care and makes nursing a special gift as in Unit 2 described in this thesis.

Christensen (1993) writes about the 'Nursing Partnership' and explores her developing theory. She considers that therapeutic nursing is enhanced by this special partnership which forms during the limited stay in hospital between the nurse and patient. Ersser (1997 p 302) considers that the nurses' actions are not appreciated and therefore they may not be understood as therapeutic. Christensen (1993) examines the relationships between nurses and their patients in the normal hospital setting where patients are admitted for a limited time. She discloses that the nurses do not remember the names of individual patients after they have left the hospital, but the situation is different in the dialysis units. In the dialysis unit there is no passage of treatment, patients come for treatment as long as they survive. It is not a pause or crisis-time in life's journey which resolves after a short stay in hospital. Every day is the same treatment, and dialysis-dependent people receive treatment to survive while continuing to try to live their normal lives. Relationships have to be long term and it is no good excusing a poor relationship in the expectation that the patient will be gone tomorrow back to his normal life outside the hospital, a finding supported by Auer (2002).

I observed that nurses expressed the need to understand the working of the machines but too often seemed to forget the need to understand their patients. It has to be possible to overcome the 'factory style' of processing the patients through treatment and have time to care and develop reciprocal partnerships as suggested by Lunts (2002). Once the need to care supersedes the technical expertise, which happens with increasing knowledge, and, as was seen in the units, the nurses can reassume their caring roles. But for many 'novice' nurses faced with high technology, the immediacy of having to 'get it right' is what counts and relationships with the person receiving the treatment are postponed. The culture in the dialysis units is a blend of these attitudes with the traditional caring behaviour.

Chapter 7 Conclusion

'Somehow we have lost the human and passionate element of research. Becoming immersed in a study requires passion: passion for people, passion for communications, and passion for understanding people'.

(Janesick 1997 p 51).

The experience of working for many years in dialysis units suggested to me that the regular treatments involving patients and staff brought together in long term relationships created a very special environment. In searching for further information, I found that there was little in the literature which identified anything which was special to dialysis units and the long term relationships which form therein. This was the impetus for my study.

This thesis has provided a descriptive-analytical account of the culture of dialysis units in the UK, which has included the life-world of staff and patients in these units. In the early chapters of the study I have explained the treatment for kidney failure in dialysis units and discussed the organisation of the units. The literature which provided the background for the study has been critically reviewed to set the scene and the aims of the study discussed in the light of the paucity of relevant literature. The methodological stance of ethnography and its philosophical basis has been developed and the justification for using ethnography to address the research aims has been presented. The methods I have used to collect the data have been explained in detail to give validity and an audit trail to this research.

Reflexivity is the core of ethnography; it is what gives it its reality and validity. The reflexive process also helps to maintain the rigour of the research. I used reflexivity to monitor my aims in the light of my cultural beliefs. Throughout the exposition of the data I have been careful to be explicit about the sources of my data. These came from my field notes, observations, interviews both formal and informal, my own reflections and where appropriate, the contributions and interpretations of the participants.

I have tried to deal sensitively with issues which are of concern to patients and nurses but about which they have no control, such as the inevitability of treatment which leads ultimately to the death of the patient and low staffing levels with the ensuing stress. I have

observed the relationships between people and technology in dialysis units. I have studied the social relationships in the dialysis community examining cultural behaviour, attitudes and values.

7.1 Summary of findings

I have in this thesis discovered a culture of dialysis units and derived an ethnography. To uncover this culture I sought to understand the cultural behaviour, values, beliefs and attitudes which make up the secret world of dialysis units in the UK. The overriding conclusion is that the culture of dialysis units can be better understood through the explanation of a core concept of partnership which links the cultural themes and cultural domains embodied in the social life of dialysis units. The degree to which the partnership is formed and performs influences the culture of the units.

In writing the ethnography I uncovered four significant cultural domains which are: nurses, patients, illness (renal failure) and treatment of that illness. The study of these cultural domains led to the emergence of the cultural themes which are: survival, 'them and us', blame, belonging - teams, control and leadership, communications and the environment. Nurses are the crucial factor in dialysis units; it is they who deliver treatment and support the patients through the daily trials of chronic illness. A study of the cultural themes showed that a concept of partnership linked the cultural domains and cultural themes. Partnerships are formed between the nurses, the patients themselves, the nurses and the patients, the nurses and the machines, the patients and the machines and finally the patients and their own sick bodies. The experienced nurse can form a partnership between the patient's sick body and herself but that offers a special intuitive partnership which is occasioned by the very expert practitioner. It is the partnership which offers support making survival easier for both patients in their ill health and for the nurses as they perform the daily routine of the life-saving treatments within the environment of the dialysis units. It is the partnership which removes the feelings of insecurity, and helps form the teams which assist the patient and nurse to survive the daily problems. Partnership is the entering into, supporting, being there, valuing and caring for others which is all encompassed in the culture on the units. This study has shown how this concept of partnership is the core concept which helps to understand the culture of dialysis units.

These observed partnerships are affected by closeness in varying degrees, with those in Unit 2 bearing more resemblance to the ideal family partnerships. Nurses were caring with more than duty, as the field notes disclosed they were providing care to people as if they were

family members and this affected the treatment outcomes. From observations and informants' statements it becomes clear that the skill in the relationships which form in the dialysis units lies in the nurses' ability to create the feeling of 'specialness' and closeness for the patients. The feeling of belonging is of great importance to the patients who make the units the centre of their fight for survival. The culture of the dialysis units is such that the cultural behaviour, attitudes and beliefs in these units are acceptable because of the closed and prolonged social contact of staff and patients. It is this degree of partnership which differentiates the culture in dialysis units from other units in a hospital.

7.2 Appraisal of this study with reflections

7.2.1 The research design

On completion of this study its limitations need to be reviewed. The goal of ethnography is to understand the culture of the social scene under study. This ethnography has explored the dialysis units and from the data it is possible to understand about the culture which is in these units. The design of ethnography with reflexivity as a pivotal factor has allowed me the freedom to look, listen, participate and finally interpret. The reflexive process has facilitated my looking behind the mundane and questioning my own knowledge and experiences. I did have a problem when first entering the units as I was not comfortable in my role as researcher. Using the reflexive process I was able to examine the data in the light of my own knowledge and experience in renal nursing. I found that the data reinforced my knowledge but also my preconceptions were challenged and sometimes altered by the reflexive process. Care has been taken, when analysing the data, to attribute them to the correct sources. The design of ethnography was complicated, far more so than I had expected; but it has produced an in depth study of dialysis units. In common with many ethnographers I started out with very little idea what ethnography would entail, the fieldwork was difficult and finding myself an alien being in a strange land was very uncomfortable. I was a participant as observer in an apparently familiar culture and this was a key challenge for this study. However the discipline and technique of the ethnographic approach enabled me to start examining my own culture through the interpretations of others and which led me to the enjoyment of my researcher role. One of the limitations for any inexperienced ethnographer is lack of knowledge of 'how to do it' (Agar 1996, Hammersley & Atkinson 1996, Van Maanen 1995), which I suffered. I could now repeat this study with greater finesse.

7.2.2 Validity and external validity

My findings have been truthfully reported from the two dialysis units to maintain the credibility and plausibility of the study. The dialysis units are typical of each other in that they all have the same goal, but with a different population which makes the people and their relationship to illness and treatment unique. In using two units I have given my readers enough scope for finding commonalties and variations, which conforms with Sandelowski (1986) who requires the findings to be recognised outside the direct area of study. I have defended my choice of two units (see 4.4.2.2) which meant I had over a hundred participants to whom to talk. From these people I received an overall picture of the cultural attitudes, values, beliefs and behaviour in dialysis units.

7.2.3 Validity of data

I have included as many verbatim quotes and detailed descriptions as possible to equate with good writing in order to fulfil Brewer's (2000) requirements for authenticity of the data. I have supported my quotes with discussion as suggested by Hammersley (1992). To maintain the authenticity of the data I was able to verify unanswered questions by returning to the units. Through the reflexive process I could understand how my experience and knowledge had influenced my interpretations of the fieldwork and I have sought meticulously to attribute the sources of my cultural descriptions.

7.2.4 The relevance of the ethnography

The ever increasing number of people needing RRT coupled with the crises in staffing means that it is important to understand more about life with renal failure. Money and resources have to be found to establish enough units to treat these people (Milburn 2001). But patients also have to be helped to maximise the benefits of treatment, which happens with active partnership. The BRI report (2001) illustrates how the provision of care collapses without active partnerships which is also evident in this thesis in its application to renal dialysis units.

7.3 The significance of this study

The significance of my study for the future of nursing in dialysis units is that for the first time, this thesis has defined the essential elements of the cultural life in a dialysis unit for the patients and every member of the health care team. These are the social relationships, cultural behaviour, values, beliefs and attitudes towards each other and technology. This

study has discussed the daily problems that face people with renal failure, and how better understanding of life in the dialysis unit could improve the patients' wellbeing.

Unlike episodes of acute illness on the wards in hospitals, in the dialysis unit there is no passage of treatment, patients come for treatment forever, however long that is. Every day the routine is the same, and dialysis-dependent people receive treatment to survive while continuing to try to live their normal lives. From observations and informants it can be seen that partnerships have to be built for the long term and it is no good avoiding a partnership in the expectation that the patient will be gone tomorrow back to his normal life outside the hospital. The patients' commitment to staying alive also affects the cultural values of the dialysis units. The resulting culture in dialysis units means that the partnerships depend on the cultural attitudes, behaviour and values which are special to dialysis units.

The culture of the units is generally influenced only by values that are relevant to the unit, as shown in this thesis, and partnerships are formed within the units which do not relate to the larger social world. This could be the reason for the patients and nurses not having relationships with other patients or nurses outside the units, as discussed (see 6.4.1.2). One of the key elements of the culture is the constant awareness of the vulnerability of the unit and the attendant blame for any perceived failure. This in turn affects the cultural behaviour of both staff and patients. Belief in the future is emphasised as part of the unit culture as this thesis has demonstrated. Survival is one of the cultural themes, but this means that the adverse affects of treatment are not fully discussed and the death of the patient can be unexpected for the relatives. The study revealed how because of the culture of the unit, the patient divides his life between the unit and home and does not communicate events in the unit to his family. Unless the staff can involve the family in the partnership of care, the relatives may not recognise the patient's declining health, which leads to increased stress for patients, relatives and staff.

Behaviour which would not accord with the norms in other parts of a hospital is accepted as part of the unit culture. Altruism that is supposed to be essential for the evolution of culture was not evident amongst the patients in Unit 1 where a disregard for others was accepted as normal behaviour. The cultural behaviour in Unit 2 was far more caring where the patients and staff supported each other and the outcome of treatment tended to be the better for it. The nurses in both units still were careful for each other but those in Unit 2 had more time to care which made the retention of staff in this unit easier as this thesis has shown.

This thesis has studied human nature which is unpredictable and where every social encounter is unique. Therefore the conclusions I have come to in this research study would not be wholly applicable if another study was completed. I have maintained the rigour of this study through its credibility and audit trail which is discussed in Chapter 4. I have used as my social scene dialysis units, all of which have the same goal, that of the treatment of renal failure by RRT, which would suggest that other researchers could undertake another research project using other dialysis units. The generalisability of this study is debatable because of the passage of time and social events, but the cultural attitudes, beliefs and behaviours will be in essence similar. The findings of this study can therefore be considered to be valid.

The more the cultural themes are investigated the greater the number of new cultural themes which will appear in these complex units. The concept of partnership came out of the cultural themes and cultural domains linking them together, but other studies could produce other outcomes. This thesis is one more step along the journey to a real understanding of the culture in dialysis units.

This ethnography has described life within a dialysis unit. It gives an insight into patients' real expectations, satisfactions and complaints at a crucial time when government policy is giving emphasis to understanding the patient/user views. In writing my ethnographic journey I have sought to expose the culture of these units in order to deepen my own and others' understanding of how this culture impacts on care. In doing this I have tried to paint a picture of what it means to be alive, alive with renal failure, trying to make the best of life, and the problems the specialised staff have in caring for these very special, chronically sick people. The increased knowledge from this thesis may inspire the patients to 'rage against the dying of their light' (Dylan Thomas 1954) instead of accepting the inevitable end as the present cultural beliefs encourage, and to enjoy their curtailed lives both in and outside the dialysis units.

This research is a unique contribution to a hitherto unexplored clinical field within nursing which is becoming increasingly in demand as the number of renal patients rises and specialist nurses become ever more scarce. The scarcity of the literature illustrated how the study of the culture of dialysis units in the UK has not yet been explored. As the first in-depth study of the culture of dialysis units this thesis has identified some elements which can be addressed to ensure increased understanding of that culture. Although many of these elements are beyond the scope of this study, some are recommended here for further research.

7.4 Recommendations

The concept of partnership in the culture of dialysis units has highlighted some recommendations for policy and practice which have evolved from the knowledge gained from this study. The ethnographic data may be used to challenge and examine the health care policy which will be relevant when the National Service Framework for Renal practice is printed. It could be used to challenge or support the data in the Renal Association publications and National Kidney Foundation papers. Practice will be altered by the changes, if made, from the policy recommendations. I have also made some recommendations for future research to help supply answers to some of the questions which my study uncovered.

7.4.1 Recommendations for policy and practice

7.4.1.1 Education

7.4.1.1.1 The renal nurse and doctor need to know about the culture of dialysis units where close social relationships exist. The nurse needs knowledge and confidence to challenge preconceived ideas and to be able to control the treatment (as shown by the results from the questionnaire). This is made more difficult because of the pace of the change of modern technology and the diversity of needs of the renal patient. Nurses require the necessary knowledge to support the patients through their life long commitment to treatment.

7.4.1.1.2 Family education would mean that the family would not be so isolated, the patient could receive more support and understanding, and the nurses would know that the family had a better understanding of the meaning of kidney failure and its treatment.

7.4.1.2 Long term planning The problems in the provision of the Renal Services mirror those of the NHS. There is no stability within the financing of the service. Therefore health authorities cannot plan long term, and renal patients are a long term problem. The units continue to have to take patients for whom there is little provision as seen in Unit 1. There is no contingency planning for emergencies and therefore unexpected patients have to be treated in already overcrowded units (see 5.4). The continued increase in the dialysis population augments staff stress (see 5.4.8).

7.4.1.3 Environment It should be possible to provide smaller areas for treatment, offering an environment where the spirit of friendship and partnership can flourish

for staff and patients as demonstrated in Unit 2. Large impersonal units do not promote the development of relationships as is demonstrated in this study.

For practice, communications promote more effective partnerships. Better communications between the world of home and the dialysis unit would help promote partnerships to the benefit of the patient, his family and the nurses. Partnership is based on mutual respect, opinions need to be respected, and staff and patients should be valued members of the same team. There is a need for an insight into the dialysis patients' expectations, satisfactions or problems at a time when their views are crucial to current health policy.

7.4.2 Recommendations for research

7.4.2.1 Concept of partnership

The concept of partnership as a framework could be refined to explain the culture of dialysis units in greater depth. Further investigations could discover why effective partnerships do not develop and suggest how to encourage their growth. The influence of different social cultures outside the dialysis units on the culture of the units needs to be examined. Investigations into whether chronic illness is a factor in the development of effective partnerships could lead to increased understanding about partnerships in the units.

7.4.2.2 Cultural themes

Research into cultural themes such as fear and anxiety which were found in the data but not examined in this thesis could lead to increased understanding of the culture of dialysis units.

7.4.2.3 Educational needs

The questionnaire showed that a majority of staff realised they needed more education to meet the new developments in renal health care and the ever-changing technology e.g. the design and function of new machinery. The more specialised the nurse becomes, the greater her need for specialised knowledge. More research is required into how best to meet these needs and to sustain a lively and satisfied health care team.

7.4.2.4 Transport

The problems with the provision of transport in UK dialysis units should be investigated and these problems should be publicised. This research would involve an outside body and co-operation from another part of the NHS.

7.5 Conclusion

At the end of my ethnographic journey I am a different person to the one who nervously started out into the unknown. I thought I had not enjoyed the journey, the fear of the unexpected worried me. However as this study is finished I realise that I have a great satisfaction from the knowledge I have gained and from its completion. I have made the transition from nurse to ethnographer with the attendant demands of intellectual discipline. I have attributed my findings to the data sources and now comprehend the use of reflexivity in interpretation of the data in the wider social context.

I have studied two dialysis units searching for their culture, experiencing the life-world in this social setting. One of the challenges that face the health providers in this 21st Century is how they are to cope with the ever-growing population of people with renal disease. There is no single answer to this problem, but the concept of partnership offers the opportunity for increased understanding about dialysis units. Although it does not solve the problems of caring for the ever expanding renal population, the greater awareness and understanding of the needs and issues in these key settings for chronic illness management gained from this study should mean that the people receiving treatment have an increased chance of benefiting from renal replacement therapy.

Appendices

Appendix 1. Patient Information Sheet.

An Ethnographical inquiry into Haemodialysis units.

How can you help other people understand what life is like when attending a dialysis unit.

To the person undergoing haemodialysis treatment.

I am doing research into life in the dialysis unit. I shall be present in the unit watching the daily routine of the unit and taking notes about what happens. I shall have many questions about the way life happens here in the unit and I hope you will be able to answer my questions.. I hope to talk to you as you are here on the dialysis unit in an informal manner.

I shall make notes as I watch the unit at work. If we have a long conversation I shall request that you allow me to use my tape recorder. All the notes and the tapes of conversations I make will be kept in a locked filing cabinet at my home and are only for my use.

My research will mean that I study all the notes of things I have seen and discussed with the people in the unit. I shall then write up my findings. When you read the report you may recognise things you have said.

All the names of people and places will be changed when the report is being written up so they are unrecognisable. However you may be able to recognise yourself if you read the report but you will only be discoverable by yourself.

This research project is hoping to discover how dialysis units function. To promote understanding about the people who receive treatment and those who give this treatment. This should assist in providing treatment which is in the best interests of the dialysis population.

I hope that you feel you can agree to helping me in this way, but if you do feel you do not want to do so I shall quite understand and this will in no way affect your treatment in the unit. If at any time during this research you do not wish to continue to participate do not be afraid to say so.

Please feel completely free to ask any questions now or at any time when I am on the unit. Thank you very much for your help.

Cordelia Ashwanden

Appendix 2. Health carer Information Sheet.

An Ethnographical inquiry into Haemodialysis units.

How can you help other people understand what life within the dialysis unit is like with its different values and attitudes.

For those delivering Health Care within the dialysis unit.

I am doing research into life in the dialysis unit trying to discover what makes the unit a special place to give and receive treatment. I shall be present in the unit watching the daily routine of the unit and taking notes about what happens. I shall have many questions about the way life happens here in the unit and I hope you will be able to answer my questions. I would like to ask you some questions about what you feel makes life with dialysis different to other treatments. I hope to talk to you as you work in an informal manner but I shall not be an obstacle to your work.

I shall make notes as I watch the unit at work. If we have a long conversation I shall request that you allow me to use my tape recorder. All the notes and the tapes of conversations I make will be kept in a locked filing cabinet at my home and are only for my use.

My research will mean that I study all the notes of things I have seen and discussed with the people in the unit. I shall then write up my findings.

I shall never intervene unless it is a matter of saving life through an intervention. I am here as a researcher and hopefully you will regard me as a friend who is learning from you in all you do, I am not here to make comparisons only to observe.

All the names of people and places will be changed when the report is being written up so they are unrecognisable. However you may be able to recognise yourself if you read the report but you will only be discoverable by yourself.

This research project is hoping to discover how dialysis units function. To promote understanding about the people who receive treatment and those who give this treatment. This should assist in providing treatment which is in the best interests of the dialysis population. It is also hoped that it may make it easier to describe to nurse recruits what this branch of Renal nursing is all about.

I hope that you feel you will agree to helping me in this way, but if you do feel you do not want to do so I shall quite understand and I will endeavour never to report happenings in which you are instrumental. If at any time during this research you do not wish to continue to participate do not be afraid to say so.

Please feel completely free to ask any questions now or at any time when I am on the unit.

Thank you very much for your help.

Cordelia Ashwanden PhD Research Student.

Appendix 3. Consent form

A study into how dialysis units and their population work.

- Have you read the Patient Information Sheet? YES/NO
- Have you had an opportunity to ask questions and discuss this study? YES/NO
- Have you received satisfactory answers to all your questions? YES/NO
- Do you think you understand about this study? YES/NO
- Do you understand that you are free to withdraw from the study:
- a) At anytime
 - b) Without having to give a reason for withdrawing
 - c) And without affecting your future medical care? YES/NO
- Do you agree to take part in this study YES/NO?

Signed..... Date

Printed Name.....

Appendix 4. Letter of information for 'Gate keepers'

**The Haemodialysis Unit,
The Hosptial.
UK.**

Tel:

April 6th 1998.

Dear Dr. M.....,

I am planning to use the Chronic dialysis units based in theHospital and at to try to explore the culture of dialysis units. I have been to see Dr..... and he was very supportive about my proposal, but he did suggest that I wrote to everybody who might wish to know what I was doing. I would hate to upset anyone when doing this study. Therefore I enclose a brief proposal about the study and hope that this will give you all the information you need. If you require any more information I shall be happy to answer any questions. I do hope you will support me in this exciting study as I certainly will need assistance.

Having completed a Bsc (Hons) and and Msc (Distinction), I am studying at The University of Southampton. I am hoping to complete my formal education with a PhD concerning the renal population. I want to study the world of the Haemodialysis unit in order to learn more about how and why the Unit functions as it does and to discover what makes the special culture within the unit for those who receive treatment and those who work therein. I feel there is much information to be gained from the study of the people who attend the units and the Renal health care team.

Because these units do have their own culture, which so far is not researched, it is a world that is unacknowledged and the benefits that may be obtained from utilising this special world are being neglected. I had to decide which research method would accurately investigate and capture the special atmosphere of life within the Renal unit. After much reading and research, I considered that an Ethnographical study would be most appropriate method to investigate the culture of the renal unit. I am therefore planning an Ethnographical study looking at the culture of renal units. This research will hope to uncover new knowledge which will contribute to a better understanding of the dialysis patient and the renal care worker which will benefit both the patient and care giver and will also be the basis for further research.

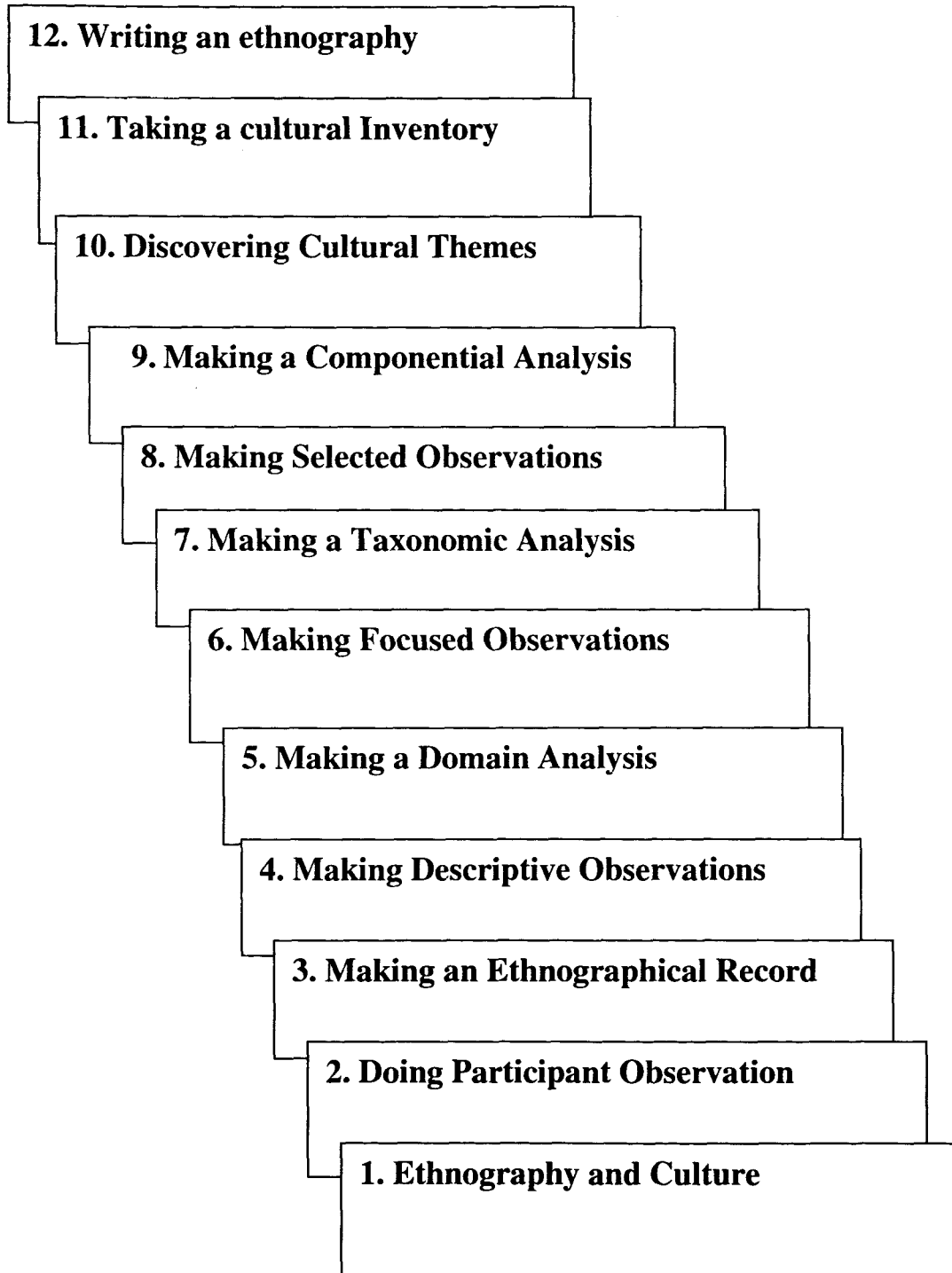
Yours sincerely

Cordelia Ashwanden.
Unit Manager Haemodialysis Unit.

Appendix 5. Spradley's Steps

The Development Research Sequence

Showing the Development Steps (Spradley 1980)



Appendix 6. A break down of the steps used in ethnography (Spradley 1980)

Step 1 Ethnography and culture.

- Define the research question
- Finding a social scene with participants.
- Selection of scene, actors, time
- Asking ethnographic questions

Step 2 *Participant observation*

- Ordinary participant
- Participant observer
- Levels of participant observer
 - Explicit awareness
 - Insider/outsider experience
 - Reflexive process and introspection

Step 3 *Making an ethnographic record*

- Language There are many kinds of language used and these have to be identified
 - Verbatim quotes
 - Amalgated language - Emic and Etic
 - Descriptive language
 - Interpreted language
- Fieldnotes
 - Condensed accounts
 - Expanded accounts
 - Reflexive diary
 - Interpreted notes

Step 4 *Descriptive Observations*

- Overview of events looking at:
 - Activity
 - Actor
 - Time
 - Space
 - Objective
 - Feelings
- Details of the overview findings
 - What activity involved what actor
 - What time did the activity take
 - Where was the activity
 - What was the purpose or outcome of the activity
 - What were the feelings of the participants/researcher
- This can be repeated with every factor in the overview

Step 5 *Making a domain analysis*

- This is moving the focus to find the cultural information in the patterns in a social scene.
- A domain as a cultural category is made up of three basic elements: cover terms, included terms and semantic relationship.
- Cultural domain is a category of cultural meaning which includes smaller categories.
 - It has a category of meaning.
 - Cultural domain - Kind of person in analysis unit
 - Domains:-

Nurse
Patient
Doctor
Driver

These domains all relate to each other and are cover terms.

Table to show the semantic relationship of 'activities'

Included terms	Semantic relationship	Cover term/domain
Nurse	Cares for	PATIENT
Sick Patient		
Doctor		
Driver		

Table to show the semantic relationship of 'Means to an end'

Included terms	Semantic relationship Means to end	Cover term
Patient ready	Is a way to	TREATMENT
Neck line not working		
Needles in place		
Nurse ready		

The relationship in this table could also be 'part of' or 'kind of'

This can be repeated to give an overview of cultural domains in the dialysis units.

Step 6 Focused Observations

Selecting an ethnographic focus

Tentative selection looking at either a single domain or relationships

The unit with the nurse, patient, treatment and illness were all related

Using the issues in Step 4 Descriptive observations to focus on general cultural domains

Use structural questions to select focus for observations

Use a general domain to focus on the selection.

Kidney Failure is the 'organising domain' and organises the cultural meaning of the dialysis unit.

Using that general organising domain it is possible to focus on to the chosen domains.

Step 7 Taxonomic analysis

This differs from a domain in one respect: it shows the relationships between all the included terms in a domain.

It reveals the subsets and the way they relate back to the domain.

Kind of person

1.The compliant patient

Obeys the rules

Uses information correctly

Has good blood results

2.The non compliant patient

Overloaded with fluid

Forgets to take medication

Difficult to needle

Takes more time for dialysis

Step 8 Selected observations

Using the interviews – formal and informal

Using contrast questions

Dyadic contrast questions – looking for 2 differences.

Triadic contrast questions – looking for 3 differences.

By asking about and observing the differences leads to focused observations.

Step 9 Componential Analysis

Using a domain with a small number of 'included terms' (step 7) Search for contrasts

Group them into dimensions of contrasts

Then observe using descriptive, focused and selective observation.

Step 10 Discovering a cultural theme

This is observing with the wide focus looking at the whole scene.

Using the cultural domains looking of contrasts and similarities.

E.g. a) clothing worn in dialysis unit –

Different to wards in hospital

Home clothes not bed wear.

b) Humour –

Jokes about survival
treatment
machines
weight
other activities

Step 11 Taking a cultural inventory.

This is a review of all the field notes: everything that has been written while doing field work.

Make a list of the cultural domains.

Check to the analysed domains and from those completely analysed the ethnographic focus will emerge.

List all the themes which have emerged.

Make a contents list to show all the categories and topics.

Step 12 Writing an ethnography

See Chapter 5.

Appendix 7. How the Routine event ‘going on’ fits into the analysis

Because the analysis is concurrent with writing the ethnography I have analysed my interpretations at the same time as writing the actions.

Step 1 Choice of scene

Dialysis unit Action - going on machine. Time - every other day for every patient

Step 2 Participant observation.

The machines, nurses, patients, treatments equipment, drivers, environment

Action 1 getting ready.

Levels of researcher participation

Low	Watching Sarah set up the dialysis machine
	Seeing the rest of the unit in the same state
Medium	Talking to other people in the unit
	Listening and hearing other people
High	Talking to Sarah
	Carrying some equipment for Sarah
	Helping fix some equipment

Action 2 entrance of Mary

Levels of researcher participation

Low	
Medium	Watching Sarah cross the floor
	Hearing and answering Sarah and Mary
High	Joining the conversation and adding my opinions

Action 3 Getting ready for treatment.

Levels of researcher participation

Low	watching without interpretation
Medium	Listening and reacting to the conversations
High	Helping Mary to get onto the bed
	Writing in the weight
	Helping set up the machine
	Getting magazine for Mary

Step 3 Making an ethnographic record

Language identification

Making a list of emic words for ‘going on’

All these are expressions which are in general use at the beginning of treatments

e.g. Going on. Getting the machine. Sticking. Being stuck. Needling. Being on. Run up the machine. UF-ing. Into UF. Too much to lose (weight). Overloaded. More time. BP level. Joining up. Running round. Flows.

I would make a condensed account of the process which I enlarged in the car and further enlarged at home on the computer. I made my own reflections into my journal.

Step 4 Making descriptive observations

These were made from my field notes which were made as I observed.

What actors participated? Sarah, Mary. (myself at medium level).

What is the goal – treatment.

What are the feelings – relief for Mary. Just a job for Sarah

Step 5 Domain analysis

The domain analysis - going on the machine.

Again this happened and was written in the data with interpretations and reflections. The relationships of kind of nurse, kind of patient, kind of treatment can be found in the notes. It is possible to see the semantic relationship between the actors and activities.

The cultural behaviour - Mary coming in and getting ready in the accepted way.

Sarah accepting Mary for treatment with problems which she sorted out. Again there is a use of terms accepted in the culture of the unit.

Step 6 Focused observations

Again from the analysis of 'Going on' as seen in my field notes. I was focusing on the important actors, the nurses and patients. They were providing or receiving treatment because of the illness of renal failure.

Step 7 Taxonomic analysis. This is not used in my example of going on the machine but it can be applied as the analysis was done in my own notes to check the domain.

Treatment is the main domain category.

Split into different kinds of machine which can be further split into machines in different places, doing different treatments, being used or not.

Step 8 Selected observations

Interviews. I sat and chatted with Mary and her friend once they were both on their machines. I had already talked to Sarah while she was getting the machine ready.

Questions. I asked the contrast questions and checked the different dimensions of contrasts.

Mary was a patient who was very happy to be on the machine but terrified on going on. Why? Because she knew the machine saved her life but also the treatment could make her ill. Then I could look at the illness or how the attitude of the nurse could relate to Mary's feelings. I could see how the treatment affected the illness and ask what might help the fear Mary had.

Step 9 Componential analysis

Attributes of meaning associated with treatment in the activity of going on the machine, such as a good or bad treatment. Successful or not needling. High or low BP because of the illness or treatment. Then the relationships between these factors becomes visible.

The treatment can be good because the nurse needled well and the patient felt well at the end of treatment. Or the BP was high because of the illness of the patient who was scared because of the treatment which could have meant that the needles did not go in so well leading to a poor treatment which made the patient increasingly ill. The nurse did not have time to reassure the patient which reflected on the treatment outcome.

This shows how the domains of nurse, patient, treatment and illness became significant.

Step 10 Discovering cultural themes

Revisit the wide focus.

Talking to Sarah while waiting for the patient she was certain that the first patient being late would affect the day routine. Talking to the patients they knew and discussed the need for treatment and knew about their bodies even if they did not obey the rules.

Step 11

Reviewing the whole episode

Step 12

Writing the ethnography

Appendix 8. The analysis in my notes of the Routine event of 'Going on'

Actor	Action	Observation	Reflection
Sarah	Setting up machine	Cross Tired Fed up Efficient	Did not want to be here. Wanted to chat with her friends about the weekend. There is never enough time for the nurses to chat about home problems. helped by listening.
<u>Interpretation</u>	Sarah was doing her job OK but she was not interested. She needed a friend in which to confide. She set up the machine quickly showing efficiency but how the tasks become mindless, there was nothing to interest her until Mary arrived since she could not chat to her friends. She complained to me but I didn't know her well enough for her to confide in me in detail. She did not want to talk to Mary as she was always in trouble. She was getting impatient which increased her short temper.		
Mary	Getting ready to go on	Nervous. Scared. Worried. Over weight. Unwell. Breathless. AS she kicked off her shoes I could smell them. Thankful to be here, with friends.	She was frightened by her extra weight but thankful to be here. She was scared waiting for Sarah's reaction but also the outcome of the treatment. Her feet smelt but was that because of fear? Treatment would make her feel better but she wished she wasn't so heavy. She was pleased to see her friends and looking forward to the chat. I still wished I could ask her why, some people do not actually know.
<u>Interpretation</u>	Mary had not kept to the rules she knew this and was worried about the reaction of Sarah and the treatment. She was thankful to be having treatment as that would make her feel better but again at what cost. She had felt ill during the week end and so was frightened about what was happening to her. Fear can produce anxiety which induces sweating so was that why her feet smelt?		

Actors	Action	Observation	Reflexive
Sarah	Putting on machine	Pleased to see M arrive Efficient. Good needler. Less cross, but not concentrating on patients. BP check	She was thankful that M arrived finally as it would not make too many difficulties during the rest of the day. I considered she was good at needling but was not concentrating on M and her needs. She was very competent, programmed the machine to deal with M's extra weight. Expert as knew that the BP was raised due to extra weight as she should being renal trained. I was dying to ask about the weekend to get answers from Mary. I saw that she dialled up more than the expected weight loss probably because she knew Mary would not be able to reduce her intake.

<u>Interpretation</u>	She was good at needling, was an expert nurse so helped sort out M's weight problems without having to ask. , But she was not interested in finding out why there was the extra weight, she just wanted to get the job done and get home at the end. She did not realise how scared M was of being needled.		
Actors	Action	Observation	Reflexive
Mary	Going on	Struggled onto the bed. Sat very still without talking while needles were going in. Once in she relaxed and started to chat to S, about the weekend.	Very scared of the needles. Didn't like looking in case anything went wrong. Pleased S was putting her on. Upset but resigned about the extra time she would have on the machine.
<u>Interpretation</u>	She was scared and showed it in her manner and sweating. She wanted S to offer some solutions to the extra weight which she could use as excuses. Once the needles were in she was much happier. She never said to S how scared she was of the needles.		

Actor	Action	Observation	Reflexive
Sarah	Setting up machine and leaving M	Dialled in the amount that M could loose in her expert opinion. Told M what she had done. Checked M see if she was comfortable and left. for the next patient	She was an expert as did not need to be told how to programme the machine. She informed M of what she had done. M looked worried, again because the weight loss might make her feel ill. S was impatient to get on with her allotted people as wanted to go home.
<u>Interpretation</u>	Although she knew her work and her patient she had no time for investigating M's troubles. There was very little chat apart from technical talk about going on and the machine. When she left to go to someone else it was with the same resigned air of someone who wishes they were somewhere else.		
Mary	During treatment	Once the treatment had started she spoke to the person in the next chair. She got out her magazine and was given a cup of tea.	The relief of being on was visible. She could start her day with talking to the lady next to her. Her whole body told me how thankful she was. She did not ask S to get her mag out of her bag as reckoned S was too busy. The cup of tea came at the right time. We were able to have an informal interview after this.
<u>Interpretation</u>	If only S had realised how scarred M was she would have be able to relieve some of it by talking or reassurance, which is not really very good as every patient knows things can go wrong. The cup of tea came along at just the right time but it doesn't always depends on the domestic. I had to find the magazine for M as S was in too much of a hurry.		

Appendix 9. Questions for formal interviews

Core Questions

Used to keep the Formal interview focused.

These can be used in any order depending on the responses. I die not use all the questions, but these were useful as a prompt.

1. Do you enjoy your work here?
2. Do you consider you have a lot of influence on : the nurses, patients, doctors?
3. Can you do your work here or do you have to take some home?
4. Who plans the work schedule?
5. Do you do the Off Duty?
6. What happens if there is a crisis?
7. Do you find the Doctors. Nurses Managers supportive?
8. How are you off for staff?
9. Do you have problems getting/ recruiting staff?
10. Do you have enough patient contact?
11. Are there enough learning opportunities for your Grade?
12. Do you set up courses for the staff? Help with learning opportunitites?
13. Who writes your unit policies?
14. Is there anyone to whom you can talk who understands?
15. Who chooses the type of machines?
16. Do the techs come when you call them?
17. What is your most pressing worry when you arrive at work?

Appendix 10. Questionnaire Staff nurses

Questionnaire for Staff Nurses in Dialysis Unit

1. How long have you worked in this Unit?
 Less than 6 mnths Between 6mnths and 2 years 2-5years More than 5 yrs.
☐ ☐ ☐ ☐
2. How long have you worked at this Hospital?
 Less than 6 mnths Between 6mnths and 2 years 2-5years More than 5 yrs.
☐ ☐ ☐ ☐
3. How many hours per week do you work?
 Full Time 28-36hrs 18-27hrs. Less than 18hrs.
☐ ☐ ☐ ☐
4. Do you work for the Bank?
 Yes No
☐ ☐
5. If Yes how many extra hours (approx) do you work in a month?
6. Do you have a choice about the hours you can work during the 24 hrs.
 Yes No
☐ ☐
7. Do you have the ENB Renal course? Doing it at present
 Yes No. Yes
☐ ☐ ☐
8. Do you have other qualifications as well as RGN?
 P2000 Diploma 1st degree Masters. Teaching Other
☐ ☐ ☐ ☐ ☐ ☐
9. Do you want to undertake further education?
 Yes No
☐ ☐
10. Which RRT you do like most?
 Chronic Haemo Acute Haemo PD Ward work
☐ ☐ ☐ ☐
11. Do you have a choice in which discipline you work?
 Yes No
☐ ☐

12. Why did you choose to come to this Hospital?

.....
.....

13. Will you be looking for a better Grade after your work in this unit?

Yes
☐

No
☐

14. If **yes** will it be

within this unit

☐

within this hospital

☐

another hospital?

☐

15. If **no** can you give any reasons?

.....
.....

16. What Grade are you at present?

G
☐

F
☐

E
☐

D
☐

17. Do you have a good working relationship with
Your nursing colleagues.

Yes
☐

No
☐

Doctors

Yes
☐

No
☐

Dieticians

Yes
☐

No
☐

Social workers.

Yes
☐

No
☐

18. Do you think you know enough **medical background** about the patients you treat?

Yes
☐

No
☐

19. Do you think you know enough **social background** about the patients you treat?

Yes
☐

No
☐

20. Do you have a formal system for gaining information about patients?

Yes
☐

No
☐

21. Can you give any suggestions as to how you could gain more information about patients?

.....
.....

22. Do you have your 'own' patients

Yes
☐

No
☐

23. If No would you like your 'own' patients?

Yes

☐

No

☐

24. Do you think it is easier to get to know patients if you have a designated number of patients?

Yes

☐

No

☐

25. Do you consider it is easier to treat people if you know about their social situations?

Yes

☐

No

☐

26. RRT has psychological implications. Do you get involved with this side of treatment?

Yes

☐

No

☐

27. Would you like to be more involved in the psychological side of treatment?

Yes

☐

No

☐

28. Can you alter the patients' immediate dialysis prescription without reference to a Doctor?

Yes

☐

No

☐

29. Is there anything you would like to see changed regarding the patients' treatment?

.....
.....

30. Can you give reasons for these changes?

.....
.....

31. Have you any suggestions to encourage staff to come to this Unit?

.....
.....

32. Have you any suggestions to encourage staff to remain working in this Unit?

.....
.....

Thank you very much for completing this form. All the information will remain anonymous and will be analysed using the program SPSS.

Appendix 11. Questionnaire Health Care Assistants

Questionnaire for Health Care Assistants in Dialysis Units

1. How long have you worked in this Unit?

Less than 6 mnths

☐

Between 6mnths and 2 years

☐

2-5years

☐

More than 5 yrs.

☐

2. How long have you worked at this Hospital?

Less than 6 mnths

☐

Between 6mnths and 2 years

☐

2-5years

☐

More than 5 yrs.

☐

3. How many hours per week do you work?

Full Time

☐

28-36hrs

☐

18-27hrs.

☐

Less than 18hrs.

☐

4. Do you work for the Bank?

Yes

☐

No

☐

5. If Yes how many extra hours (approx) do you work in a month?

6. Do you have a choice about the shifts you can work during the 24 hrs.

Yes

☐

No

☐

7. Which RRT you do like most?

Chronic Haemo

☐

Acute Haemo

☐

PD

☐

Ward work

☐

8. Do you have a choice in which discipline you work?

Yes

☐

No

☐

9. Why did you choose to come to this Hospital?

.....

10. Will you be looking for a better Grade?

Yes

☐

No

☐

11. If yes will it be

within this unit

☐

within this hospital

☐

another hospital?

☐

12. What Grade are you at present?

A
☐

B
☐

C
☐

13. Have you done your NVQ?

Yes
☐

No
☐

14. Do you want to do your NVQ?

Yes
☐

No
☐

15. Would you like more training in Renal nursing?

Yes
☐

No
☐

16. Do you have other qualifications. (eg typing skills degrees)

Yes
☐

No
☐

state what.
☐☐☐☐

17. Do you have a good working relationship with
Your HCA colleagues.

Yes
☐

No
☐

The Staff Nurses

Yes
☐

No
☐

Doctors

Yes
☐

No
☐

Other Members of Health Care Team

Yes
☐

No
☐

18. Do you think you know enough **medical background** about the patients you treat?

Yes
☐

No
☐

19. Do you think you know enough **social background** about the patients you treat?

Yes
☐

No
☐

20. Do you have your 'own' patients

Yes
☐

No
☐

21. If No would you like your 'own' patients?

Yes
☐

No
☐

22. Do you think it is easier to get to know patients if you have a designated number of patients?

Yes
☐

No
☐

23. Do you consider it is easier to treat people if you know about their social situations?

Yes
☐

No
☐

24. RRT has psychological implications. Do you get involved with this side of treatment?

Yes

☐

No

☐

25. If **Yes** can you give any examples?

.....

.....

26. If **No** would you like to be more involved in this side of the treatment?

Yes

☐

No

☐

27. Is there anything you would like to see changed regarding the patients' treatment?

.....

.....

.....

28. Can you give reasons for these changes?

.....

.....

.....

29. Have you any suggestions to encourage other HCAs to come to this Unit?

.....

.....

30. Have you any suggestions to encourage HCAs to remain working in this Unit?

.....

.....

Thank you very much for completing this form. All the information will remain anonymous and will be analysed using the program SPSS.

Table 12.4: Availability and adequacy of information to treat patients (%)

Appendix 12. Some Statistics

Table 12.1: Career Expectations (%)

Unit	Unit 1				Unit 2			
Grade	G	F	E	D	G	F	E	D
Looking for better grade	9	9	36	23	50	5	14	0
Not looking for better grade	0	5	14	0	0	9	27	0

Showing the % looking for better grades relative to their present grades.

Table 12.2: Educational aspirations (%)

Unit	Unit 1				Unit 2			
Grade	G	F	E	D	G	F	E	D
Want further education	5	14	32	23	9	0	64	0
Do not want further education	5	0	0	0	0	18	9	0

Showing the % of trained nurses who want further education

Table 12.3: Reasons for choosing Hospital (%)

Unit	Unit 1	Unit 2
Near home	63.6	36.4
Suitable working hours	4.5	9.1
Good Prospects	0	9.1
Like renal work	27.3	36.4
Other	4.5	0

Showing how nurses chose the unit. The greater % chose because the unit was it suited them geographically, not many of them were here to further their careers

Table 12.4: Availability and adequacy of information to treat patients (%)

Unit	Unit 1	Unit 2
We have a formal information system about patients	77.3	36.4
We need a formal information system	22.7	63.6
We have enough Medical background for patients	68.2	54.5
We do not have enough Medical background for patients	31.8	45.5

Showing how the % of trained staff felt about information to enable them to treat the patients adequately.

Table 12.5: Information to treat patients by grade of respondent (overall %)

Unit	Unit 1				Unit 2			
Grade	G	F	E	D	G	F	E	D
We have a formal information system about patients	5	14	36	22	0	9	27	0
We need a formal information system	9	0	14	0	9	9	46	0
We have enough Medical background for patients	9	14	32	13	0	18	36	0
We do not have enough Medical background for patients	5	0	18	9	9	0	36	0

Showing by % of grades whether the trained staff felt they had enough information about the patients.

References

- Agar, M. 1985. *Speaking of Ethnography*. Sage Publ. Beverly Hills USA
- Agar M. 1995. Literary Journalism as Ethnography. in *Representation in Ethnography*. Van Maanen J. (Ed). Sage Publications Inc. California USA
- Agar M. 1996 2nd.Ed. *The Professional Stranger* Academic Press, Inc. California USA.
- Ahuja A. 2002. System Failure in *The Times* February 6 2002 pp22
- Aiken L. Clarke S. Sloane D. Sochalski J. Silber J. 2000. Hospital Nurse Staffing and Patient Mortality, Nurse Burnout, and Job Dissatisfaction *J.of American Medical Association* Vol 288 no.16 pp1987-1993
- Akeroyd A. 1984. Ethics in relation to informants, the profession and governments. in *Ethnographic Research A Guide to General conduct*. Ellen R (Ed). Academic Press. London UK.
- Altheide D & Johnson M. 1998. Criteria for assessing interpretative validity in qualitative research. In *Collecting and Interpreting Qualitative Material*. Denzin N & Lincoln Y (Eds). Sage London UK
- Ansell D & Feest T (Eds). 2000. *UK Renal Registry Report*. Published by UK Renal Registry, Bristol UK
- Ansell D & Feest T (Eds). 1999. *UK Renal Registry Survey*. Published by UK Renal Registry, Bristol UK
- Antonoff A. Mallinger A. 1991. Vocational rehabilitation: Limitations and resistance to renal patients. *Dialysis & Transplantation* 20 (10) 1991 pp604-609
- Arram M. Streedhara R. Muttman N. 1998. Long term survival in end-stage-renal disease. *Dialysis & Transplantation* 1998 27 (1) 11-21,24
- Ashwanden C. 2001. Quality versus Quantity: Ethics and provision of renal replacement therapy. *EDTNA/ERCA Journal XXVII no.1* 2001.pp 31-33
- Ashwanden C. 2000. The needs of the Elderly Renal Patient. *EDTNA/ERCA Journal XXVI no.3*, 2000 pp 24-28
- Ashwanden C. 1996 What strategies are used by haemodialysis patients to cope in their daily lives. *EDTNA/ERCA Journal XXII Supplement 1* p 28
- Atkinson P & Hammersley M. 1998. Ethnography and participant observation. in. *Strategies of Qualitative Inquiry*. Denzin N.& Lincoln Y (Eds). Sage London UK
- Auer J. 2002. Dialysis – A family matter. A personal tribute to the relatives of kidney patients. *EDTNA/ERCA Journal XXVIII no.3* 2002.pp 141-144
- Auer J. 1997. The psychological Impact of Treatment. in *Renal Nursing* Smith T (Ed). Baillière Tindall London UK.
- Auer J. 1990. Psychological problems in chronic illness. In *Social Work Practice in Health Care* Radawi M & Biamonti B (Eds). Woodhead Faulkner, Cambridge UK
- Bailey P & Tilley S. 2002. Storytelling and the interpretation of meaning in qualitative research. *J of Advanced Nursing* 38 (6) 2002 pp574-583
- Bates C. 2001. The good doctor. *Clinical medicine Vol 1 no 2*. 2001.pp 128-131
- Baum W. 1994. *Understanding Behaviorism. Science, Behavior and Culture*. Harper Collins
- Beauchamp T & Childress C. 1994 4th.Ed. *Principles of Biomedical Ethics* Oxford University Press Oxford. UK
- Becker M (Ed). 1974. The health belief model and personal health behaviour. *Health Education Monographs* 2. 1974 p 326
- Beder J. 1997. Withdrawal from dialysis: Mobilization of the Healthcare team. *Dialysis & Transplantation* Vol 26 (8) 1997 pp 535-540

- Beech M. 2002. Leaders or managers: the drive for effective leadership *Nursing Standard* Vol 16(30) 2002 pp 35-36
- Benner P. Ed.1994. *Interpretative Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*. Sage Publ.Inc.California. USA.
- Benner P. & Wrubel J. 1989. *The Primacy of caring: Stress and coping in health and illness*. Addison-Wesley. Mass. USA
- Bernaert P. 2001. Care of the Geriatric patient in chronic renal failure. *EDTNA/ERCA Journal*. XXVII no 3 2001.pp 147-150
- Bevan M. 2000. Dialysis as 'deus ex machina': a critical analysis of haemodialysis *J of Advanced Nursing* 31 (2) 2000 pp 437-443
- Bevan M. 1998. Nursing in the dialysis unit: technical enframing and declining art, or an imperative for caring. *J of Advanced Nursing* 1998 27 pp730-736
- Boas F. 1920. The Method of Ethnology. *American Anthropologist* 22. 1920 pp 311-321
- Bower J. 1995. The Issue: the role of the professional in the management of non-compliant or problem dialysis patients. in *Dialysis & Transplantation*. 24 (4) 173.1995. pp 196-197
- Bradshaw A. 1997. The historical tradition of care. in *The Compassion and Wisdom of Nursing*. Brykczynska G (Ed). Hodder Headline Group. London UK
- Bradshaw P. 2002. Managers, blame culture and highly ambitious policies in the British NHS *J of Nursing Management* 10 pp1-4
- Brettell C. 1993. *When they Read what we Write: The Politics of Ethnography*. Bergin & Gravey Connecticut. USA
- Brewer J.D. 2000. *Ethnography*. Open University Press. Buckingham UK
- Bristol Royal Infirmary Inquiry. 2001. Command Paper CM 5207. *Learning from Bristol: The report of the Public Inquiry into Children's Heart Surgery at the BRI*. 1984-1995. HSMO. London UK
- British Sociological Association. 2000. *Statement of Ethical Practice*. @ Web site: www.britisoc.org.uk
- Bruno E. 1999. The dark side of the moon: how clients face dialysis. *EDTNA/ERCA Journal* XXV 3 1999 pp 15-18
- Brykczynska G. 1997. A brief overview of the epistemology of caring. in *The Compassion and Wisdom of Nursing*. Hodder Headline Group. London UK
- Buckman R. 1992. *How to break bad news*. Papermac Macmillan Publishing. London.
- Burgess R. 1984. *In the Field*. Routledge London UK.
- Burnard P. 1997. Why care? Ethical and Spiritual issues in caring in nursing. in *The compassion and wisdom of nursing*. Brykczynska G (Ed). Hodder Headline Group. London UK.
- Cairns H. 1944. Preface in *A Scientific Theory of Culture*. Malinowski. University of North Carolina USA
- Calman K. 2001. A study in storytelling, humour and learning in medicine. in *Clinical Medicine vol 1 no.3*. 2001.pp 227-229
- Calnan M & Gabe J. 2001. From Consumerism to Partnership? Britain's National Health Service at the Turn of the Century. *International Journal of Health Services*. Vol 32. No1 2001. pp119-131
- Cameron J. 2002. *A History of the Treatment of Renal Failure by Dialysis*. Oxford University Press Oxford UK
- Caress A. Luker K. Ackrill P. 1997. Patient-sensitive treatment decision-making? Preferences and perceptions in a sample of renal patients. *NT Research Vol 3 no5* 1997.pp 354-372

- Cassell E. 1991. *The Nature of Suffering and the Goals of Medicine* Oxford University Press. New York USA.
- Charter D 2002. Organ shortage puts transplant service at risk. *The Times* August 2002 pp17
- Christensen B. 1993. *Nursing Partnerships*. Churchill Livingstone. Edinburgh. UK
- Clark G. 2000. Partnership – the options. www.srds.co.uk/partnerships/options.htm
- Clifford C. 1990. Notes on (Field)notes. in *Fieldnotes. The Makings of Anthropology*. Sanjek R (Ed). Cornell University Process Ithaca & London. UK.
- Copp G. 1999. *Facing Impending Death. Experiences of patients and their nurses*. Nursing Times Books. London UK.
- Costello J. 2002. Do Not Resuscitate orders and older patients: findings from an ethnographic study of hospital wards for older people. *J. of Advanced Nursing* 2002 39(5) pp493-499
- Council of Europe. 1997. Explanatory report: convention on human rights and biomedicine. Strasbourg: *DIR/JUR* (97) 1
- Council of Royal College of Physicians. 2001. Medical treatment at the end of life: A position statement. *Clinical Medicine* vol.1 no2 2001 pp115-117
- Cristóvão F. 1999. Stress, coping and quality of life among chronic haemodialysis patients. *EDTNA/ERCA Journal* XXV 4 1999 pp 35-38
- Curtin R. Mapes D. Petrillo M. Oberley E. 2002. Long term Dialysis Survivors: A transformational experience. *Quality Health Research* Vol 12 (5) 2002 pp 609-624
- Da Silva-Gane M. Goovaerts T. Lindley L. Elseviers M. 2002. Information and counselling for patients approaching end-stage renal failure in selected centres across Europe *EDTNA/ERCA Journal* XXVIII no 1 pp 49-55
- Denham M. 1997. *Continuing Care for elderly people*. Cambridge University Press. Cambridge UK.
- Denzin N. & Lincoln Y (Eds). 1998a. *Collecting and Interpreting Qualitative materials* Sage London UK
- Denzin N. & Lincoln Y (Eds). 1998b. *Strategies of Qualitative Inquiry*. Sage Publications California USA
- De Hennezel M. 1997. *Intimate Death*. Transl. Janeway C. Little, Brown & Co. London UK.
- Depner T. 1991. *Prescribing Haemodialysis. A Guide to Urea Kinetic Modelling*. Kluwer Academic Boston USA
- de Vos J. 2002. KT/V: The final truth. *EDTNA/ERCA Journal* XXVIII 4 2002 174-175
- de Vos J. 2000. Year 2000. Technology of the future and rediscovering home haemodialysis. *EDTNA/ERCA Journal* XXVI 1 2000. pp 4-5
- Dörner K. 2000. How can we help chronic patients not to abandon hope? *EDTNA/ERCA Journal* XXVI 2. 2000. pp 14, 15 & 18.
- DoH. 1998a. The New NHS: Working together: Securing a Quality Workforce for the NHS. HMSO London UK
- DoH. 1998b. Partnership in Action: New Opportunities for Joint Working between Health and Social Services. HMSO London UK
- DoH. 2000. The NHS Plan. A plan for investment. A plan for reform. The Stationery Office London UK
- Draper H. 2002. Ethical aspects of withdrawing/withholding renal replacement therapies on patients in acute renal failure in an intensive care unit. *EDTNA/ERCA Journal Supplement 2* 2002. pp 39-42.

- Dylan Thomas. 1954. Do not go gentle into that good night. in *The New Oxford Book of English Verse*. Gardner L (Ed). Oxford University Press 1985
- Ellen R. (Ed). 1984. *Ethnographic Research. A Guide to General Conduct*. Academic Press. London UK
- Erben K. 1999. Future developments in renal care, the patient's perspective. *EDTNA/ERCA Journal* XXV no 1 1999 pp 9-11
- Ersser S. 1996. Ethnography in Clinical Situations: an Ethical Appraisal. *Nursing Research: an Ethical and Legal Appraisal* de Raeve L (Ed). Baillière Tindall, London 1996
- Ersser S. 1997. Nursing as a Therapeutic Activity. An Ethnography. Avebury Aldershot UK
- Eshel I & Shaked A. 2001. Partnership. *Journal Theor. Biol* 208 2001 pp 457-474
- Fabricius J. 1999. The crisis in nursing. *Psychoanalytic Psychotherapy*. Vol 13 3 1999 pp 203-206
- Fallowfield L. 1989. Quality of Life. Human Horizon Series. Blackwells Publ.UK.
- Ferrans C & Powers M. 1985. Quality of Life Index: Development and psychometric properties. *Advances in Nursing Science*. 8 15-24.
- Ferrans C & Powers M. 1992. Psychometric assessment of the Quality of Life Index. *Research in Nursing and Health*. 15 1992. pp 29-38
- Ferrans C & Powers M. 1993. Quality of Life of Hemodialysis Patients. *ANNA Journal*. Vol 20[5] 1993. pp 575-581
- Fetterman D. 1989. *Ethnography. Step by Step*. Sage Publ. California USA.
- Fielding N. 1993. Ethnography. in *Researching Social Life* Gilbert N (Ed). Sage Publ. Ltd. UK.
- Findlayson B. 2002. Counting the smiles: morale and motivation in the NHS. *King's Fund research*. www.kingsfund.org.uk
- Finkelstein F & Finkelstein S. 2000. Depression in chronic dialysis patients: assessment and treatment. *Nephrology Dialysis Transplantation* 15 2000 pp 1911-1913
- Fife B & Wright E. 2000. The dimensionality of stigma – A comparison of its impact on the self of persons with HIV/AIDS and cancer. *J of Health & Social Behaviour* 41 (1) 2000 pp50-67
- Flanagan J. 1954. The Critical Incident Technique. *Psychological Bulletin* Vol 51 No 4. 1954. pp 327-358
- Folkman S. 1984. Personal Control and Stress and Coping Processes: A Theoretical Analysis. *J. of Personality and Social Psychology*. Vol.46[4] 1984 pp 839-852
- Freeman G. Shepperd S. Robinson I. Ehrich K. Richards S. et al. 2000. SDO Scoping Exercise. *Continuity of care*. NCCSDO.London UK.
- Gabbai N. Rauch-Elnekave H. Spitz M. Weissman I. 1999. Treatment decisions in paediatric dialysis: children's versus parental rights. *EDTNA/ERCA Journal* XXV no 4 1999 pp 39-41
- Gadamer H. 1975 2nd.Ed. *Truth and Method* Transl. Glen Doepel. Sheed & Ward, London UK
- Gardner K. & Lewis D. 1996. *Anthropology, Development and the Post-modern Challenge*. Pluto Press UK.
- Garrett G. 1991. Team work: an equal partnership in *How many nurses do I need?* Dunne L (Ed). Wolfe Publishing London UK
- Geertz C. 1973. *The Interpretation of cultures. Selected Essays*. Basic Books. Inc. New York.USA.

- Goffman E. 1963. *Stigma. Notes on the Management of Spoiled Identity*. Penguin Books London UK.
- Goffman E. 1961. *Asylums*. Doubleday, New York. USA
- Gorkal R. 1993. Quality of life in patients undergoing renal replacement therapy. *Kidney International* 1993 Supplement (40) pp S23-S27
- Greenall F. 2001 Doctor-nurse communication in the neonatal intensive care unit: An anthropological analysis. *J of Neonatal Nursing* Vol. 7 no 4 2001 pp 110-114
- Hammersley M. 1992. *What's wrong with Ethnography? Methodological explorations*. Routledge London UK.
- Hammersley M. 1990. *Reading Ethnographic Research. A Critical Guide*. Longman Group UK
- Hammersley M & Atkinson P. 1995 2nd.Ed. *Ethnography. Principles in Practice*. Routledge London UK
- Hammersley M & Atkinson P. 1983. *Ethnography: Principles in Practice*. Tavistock London UK
- Harris S & Brown E. 1998. Patients surviving more than 10 years of Haemodialysis: The natural history of complications of treatment. *Nephrology, Dialysis & Transplantation*. 13 (5) 1998 pp1226-1233
- Harvey B. 2000. Complications of complicated grief in renal failure. *EDTNA/ERCA XXVI no 1* 2000 pp 36-37
- Hawkes N & Norfolk A. 2002. Transplant service fails to learn from Spain. *The Times* August 2002 p 2
- Hedman H. 1998. Patient compliance in renal replacement therapy *EDTNA/ERCA J. XXIV No.4* 1998 pp 15-16.
- Hegarty A. Leonard S (Eds). 1999. *Human Rights: An agenda for the 21st Century*. Cavendish London UK.
- Heidegger M. 1962. *Being and Time* Transl. by Macquarrie J. & Robinson E. Harper & Row, New York USA
- Heron J. 1992. *Feeling and Personhood. Psychology in Another Key*. Sage Publ. London UK.
- Herth K. 1990. Fostering Hope in terminally ill people. *Journal of Advanced Nursing*. 15 (11) 1990 pp1250-9
- Hippold I. 2001. The grown-up patient – The new customer in dialysis or – how to handle the demanding and emancipated dialysis patient. *EDTNA/ERCA J. XXVII no 4* 2001 pp190-191
- Holden P & Littlewood J. (Eds). 1991. *Anthropology and Nursing*. Routledge London UK.
- Houlgate S. 2001. G.W.F.Hegel. in *The Blackwell Guide to Modern Philosophers*. Emmanuel S (Ed). Blackwell Publ. Ltd. Massachusetts USA
- Howlett C. 2000. The biographical approach in Renal Care. *EDTNA/ERCA J. XXVI no.2* 2000 pp31-32
- Hurst J. 2002. The role of the renal specialist nurse in prevention of renal failure. *EDTNA/ERCA J. XXVIII no 3* 2002 pp138-140
- Hyde C. 1998. Quality of life and coping in home haemodialysis patients *EDTNA/ERCA J. XXIV no.3* 1998 pp 10-12
- International Council of Nurses. 1996. *Ethical Guidelines for Nursing Research*. ICN. Geneva Switzerland.
- Jackson D. Clarke J. Mannix J. 2002. Who would be a nurse? Violence in the workplace – a factor in recruitment and retention *J of Nursing Management* 10 2002 pp13-20

- James N. 1993. Divisions of Emotional Labour: Disclosure and Cancer. in *Emotion in Organisations*. Stephen F (Ed). Sage London UK
- Janesick V. 1997. The Dance of qualitative research design: metaphor, methodology and meaning in *Collecting and Interpreting Qualitative materials* Denzin N & Lincoln Y (Eds). Sage London UK
- Jenkins K. Bennett L. Lancaster L. O'Donoghue D. Carillo F. 2002. Improving the nurse-patient relationship: a multi-faceted approach. *EDTNA/ERCA Journal XXVIII* 3 2002 pp 145-149
- Johnson A & Johnson O. 1990. Quality into Quantity: On the Measurement Potential of Ethnographic Fieldnotes in *Fieldnotes. The Makings of Anthropology*, Sanjek R (Ed). Cornell University Process Ithaca & London.UK.
- Jowett S. Petres M. Reynolds H. Wilson-Barnett J. 2001. The UKCC's Scope of Professional Practice – some implications for health care delivery *J of Nursing Management* Vol 9(2) 2001 PP93-100
- Jung Ran K. Hyde C. 1999. Nephrology nursing practice: more than technical expertise. *EDTNA/ERCA Journal XXV* 4 1999 pp 4-7
- Keogh A. Carfray A. Andrews S. Jenkins F. Longmate R. Nichols N. Farine C. Wilde D. 2000. Assessing quality of life in routine clinical practice: A pilot study *EDTNA/ERCA Journal XXVI* 2 2000 pp27-31
- Keogh A. Macefield J. 2002. The use of clinical reasoning to promote patient choice. *EDTNA/ERCA Journal XXVIII* no 3 2002 pp151-152
- Khan I H. 2000. Factors leading to Increased Mortality in ESRF. *EDTNA/ERCA Journal XXVI* 2 2000 pp 11-13
- Killingworth A. 1993. Psychosocial impact of end-stage renal disease. in *British Journal of Nursing* 18 (2) pp 905-908
- King N. Carroll C. Newton P. Dorman T. 2002. 'You Can't Cure It so You Have to Endure It.' The Experience of Adaptation to Diabetic Renal Disease. *Quality Health Research* Vol 12 No 3 2002 pp 329-346
- Kirk J.& Miller M. 1986. *Reliability and Validity in Qualitative Research*. Sage Publications London UK.
- Koch T. 1993. Establishing rigor in qualitative research: the decision trail. in *Journal of Advanced Nursing. No.19*. 1993 pp 976-986
- Kotzabassaki S. 2002. The Problems of burnout in renal care professionals. *EDTNA/ERCA Journal XXVIII* 2002 supplement 1 pp17
- Koutsopoulou V. Theodosopoulou E. Vantsi E. Kotrotsiou E. Dounousi E. 2002. Personality dimensions of haemodialysis patients related to initial renal disease. *EDTNA/ERCA Journal XXVIII* no 1 pp21-24
- Kralik D. 2002. The quest for ordinariness: transition experienced by midlife women living with chronic illness. *J of Advanced Nursing* Vol 39(2) 2002 pp 146-154
- Lederman R. 1990. Pretexts for Ethnography: On reading Fieldnotes. in *Fieldnotes. The Makings of Anthropology*. Sanjek R (Ed). Cornell University Process Ithaca & London.UK.
- Lee H. Manns B. Taub K. Ghali W. Dean S. Johnson D. 2002. Cost analysis of ongoing care of patients with end-stage renal disease: the impact of dialysis modality and dialysis access *American J of Kidney Disease* 2002 Vol 40 (3) pp 1053-1061
- Leibovitz Z. 1998. Humour and dialysis. *EDTNA/ERCA Journal XXIV* 4 1998 pp17-18
- Lewis S. Bonner P. Campbell M. Cooper C. Willard A. 1994. Personality, Stress, Coping, and Sense of Coherence among Nephrology Nurses in Dialysis Settings. *ANNA Journal Vol.21 No 6* 1994 pp 325-335

- Lewis R & Fink J. 2001. Promoting adherence to inhaled therapy: building partners in education *Respiratory Care Clinical Nurse of America*. June 7(2) 2001 pp 277-301
- Lincoln Y & Guba E. 1985. *Naturalistic Inquiry*. Sage California USA
- Lindley L 2002. EDTNA/ERCA Guidelines: Technical Section XXVIII no 3 2002 pp107-115
- Lunts P. 2002. Improving care and efficiency: Appointment times in a haemodialysis unit *EDTNA/ERCA Journal XXVIII* no 1 2002 pp7-10
- Lunts P. 1999. Rediscovering home haemodialysis: returning choice to the patients. *EDTNA/ERCA Journal XXV* 1 1999 pp40-42
- Luyas G. 1991. An explanatory Model of Diabetes. *Western J. of Nursing Research* 1991 13 (6) pp 681-697
- Malinowski B. 1922. *Argonauts of the Western Pacific: an Account of Native Enterprise and Adventure in the Archipelagos of Melanesian New Guinea*. Routledge & Kegan Paul. London
- Malinowski B. 1944. *A Scientific Theory of Culture*. University of North Carolina Press USA
- Mallett C. 1990. What those 'difficult' renal patients need from you. *J of Renal Nursing* April.1990 pp25-27
- Manias E. 2001. Rethinking ethnography: reconstructing nursing relationships. *J of Advanced Nursing* 33 (2) 2001 pp 234-242
- Maslow A. 1987. 3rd Ed. *Motivation and Personality*. Harper & Row. New York. USA
- Major S. 2002. Dysfunctional teams: A HEALTH AND RESOURCE WARNING *Nursing Management* Vol 9(2) 2002 pp25-28
- McBride J & Clark N. 1996. *Steps to better management* BBC books London UK
- McGee H. & Bradley C. 1994. *Quality of Life following Renal Failure*. Harwood Academic Publishers Switzerland
- MacIntosh J. & McCormack D. 2001. Partnerships identified within primary health care literature. *International J. of Nursing Studies*. 38. 2001 pp 547-555
- Mellot R. 1998. Stress Skills for Turbulent times. *Audio Tape* USA.
- Milburn A. 2001. Health Status in our Hospitals. *The Times* June 27th 2001 p2.
- Miller J. 1992. *Coping with Chronic Illness: Overcoming powerlessness*. F A Davies Philadelphia USA.
- Mitchell Clyde M. 1984. Producing data. in *Ethnographic Research. A Guide to General Conduct*. Ellen R (Ed). Academic Press London UK.
- Moore Y.1999 The future of nursing. *EDTNA/ERCA Journal XXV* no 1 1999 pp5-8
- Morelli M. 1984. *Philosophy's Place in culture. A Model*. University Press of America. USA.
- Morgan L. 2001. A decade review: Methods to improve adherence to the treatment regimen among haemodialysis patients. *EDTNA/ERCA Journal XXVII*. No.1 2001 pp 7-11
- Munshi S. Vijayakumaar N. Taub N. et al. 2001. Outcome of renal replacement therapy in the very elderly. *Nephrology Dialysis and Transplantation*. No.16 2000 pp128-133
- Murphy F. 2002. An investigation into stress levels amongst renal nurses. *EDTNA/ERCA Journal XXVIII* 2002 Supplement 1 pp24
- Murphy E. Dingwall R. Greatbatch D et al. 1998. *Health Technology Assessment*. Vol 2 No.16 1998
- Murphy P. Kupshik G. 1992. *Loneliness, Stress and Well-being*. Tavistock. Routledge London UK

- National Kidney Foundation www.kidney.org.uk February 2002
- Nelson-Jones R. 1990. *Human Relationship Skills*. Cassell Educational Ltd. London UK.
- Nevett G. 1997. Malnutrition of the hospitalised patient – assessment of provision of diet and dietary intake. *EDTNA/ERCA J.* XXIII no 4 1997 pp 22-24
- Nightingale F. 1859. *Notes on Nursing*. Republished 1980 Churchill Livingstone Edinburgh. UK
- Norman L. 1998. Chronic renal failure in infancy. Two dietetic case reports. *EDTNA/ERCA J.* 1998 XXIV (3) pp6-9
- Norman I. Redfern S. Tomalin D. Oliver S. 1992. Developing Flanagan's critical incident technique to elicit indicators of high and low quality nursing care from patients and their nurses. *Journal of Advanced Nursing No 17*. 1992. pp590-600
- Norman R. 1976. *Hegel's Phenomenology. A Philosophical Introduction*. Sussex University Press. UK.
- Obrey A. 2002. Securing the future of the NHS: Developing and supporting staff nurses *Nursing Management Vol 9(2)* 2002 pp15-17
- Ortner S. 1999. *The Fate of 'Culture'*. University of California Press. California. USA
- Ottenberg S. 1990. Thirty Years of Fieldnotes: Changing Relationships to the Text. In. *Fieldnotes. The Makings of Anthropology*. Sanjek R (Ed). Cornell University Process. Ithaca & London. UK.
- Pansini S. Degaetano R. Boccassini D. Turi E. 2001. Microbiological survey of dialysate: Advantage of use of sterile bag concentrate *EDTNA/ERCA Journal XXVII* 3 2001pp 132-134
- Parsons T. 1951. *The Social System* Routledge & Kegan London UK
- Passmore J. 1966. *A Hundred Years of Philosophy*. Pelican Books. London. UK
- Patton M. 1999. *Utilization-Focused Evaluation*. Sage Publications. Beverly Hills USA.
- Peach L. 1999. Introduction *Fitness to Practice: The UKCC Commission for Nursing and Midwifery Education*. UKCC London UK
- Petersen C. 1995. *Chronic renal failure in nephrology*. Waverley Co. London UK
- Plager K. 1994. Assumptions and Basic Philosophical Issues of Hermeneutic Phenomenology. in *Interpretative Phenomenology*. Benner P. (Ed) Sage Publications California USA
- Polit D. & Hungler B. 1995. 5th Ed. *Nursing Research: Principles and Methods*. J. Phillincott Co. Philadelphia USA.
- Quinn C. & Smith M. 1987. *The Professional Commitment: Issues and Ethics in Nursing*. Publ. Saunders. Philadelphia USA
- Richards T. & Richards L. 1998. Using computers in Qualitative Research. In *Collecting and Interpreting Qualitative materials*. Denzin N. & Lincoln Y. (Eds). Sage Publications. London UK
- Rickman H. 2000. *The challenge of Philosophy*. Open Gate Press. London UK
- Rideout E. & Montemuro M. 1986. Hope, morale and adaptation in patients with chronic heart failure. *Journal of Advanced Nursing* 11 (2) 1986. Pp 346-352
- Russell L. 2000 Improving Nutritional Intake in Dialysis Patients. *EDTNA/ERCA Journal XXVI* 2 2000 pp 39-40
- Sandelowski M. 1993. Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science*. vol.16 (2) 1993 pp 1-8
- Sandelowski M. 1986. The problem of rigor in qualitative research. *Advances in Nursing Science*. vol 8 (3) 1986 pp 27-37

- Sanjek R. 1990. *Fieldnotes. The Makings of Anthropology*. Cornell University Process. Ithaca & London.UK.
- Saounatsou M. 1999. Relations between response to illness and compliance in haemodialysis patients. *EDTNA/ERCA Journal XXV 4* 1999 pp 32-34
- Savage J. 2000. Ethnography and health care. (Education and Debate). *British Medical Journal* Dec. 2 2000 pp 7327-7331
- Savage J. 1995. *Nursing Intimacy. An Ethnographic Approach to Nurse-Patient Interaction*. Scutari Press.London UK
- Scholes J & Vaughan B. 2002. Cross-boundary working: implications for the multi-professional team *J. of Clinical Nursing Vol.11 (3)* 2002 pp 399-408
- Shapiro Y & Gabbard G. 1994. A Reconsideration of Altruism from an Evolutionary and Psychodynamic Perspective. *Ethics & Behaviour 4 (1)* 1990 pp3-42
- Sheehan E. 1993. The Student of Culture and the Ethnography of Irish Intellectuals. in *When They Read What We Write*. Brettell C (Ed). Bergin & Gravey Connecticut. USA.
- Silverman D. 1997. *Qualitative Research. Theory, Method and Practice*. Sage Publications London UK.
- Silverman D. 1987. *Communication and Medical Practice. Social relations and the clinic*. Sage Publications London UK
- Silverman D. 1985. *Qualitative Methodology and Sociology. Describing the Social World*. Gower Publishing Co. Ltd. Aldershot Hants.UK.
- Smith P. 2001. *Cultural Theory. An Introduction*. Blackwell Publishers. Inc. Massachusetts USA
- Smith P & Gray B. 2000. The Emotional Labour of Nursing: How Student and Qualified Nurses Learn to Care. www.health-fc.sbu.ac.uk/emlab/
- Spiro.M. 1994. *Culture and Human Nature*. Transaction Publication. New Brunswick USA.
- Spradley J. 1980. *Participant Observation*. Holt, Rinehart & Wilson. New York USA.
- Spradley J. 1979. *The Ethnographic Interview*. Holt, Rinehart & Winston. New York USA.
- Stake R. 1998. Case Studies. In *Strategies of Qualitative Inquiry*. Denzin N & Lincoln Y (Eds). Sage Publications. London UK.
- Taylor K. 2000. Renal dialysis – does the burden of treatment outweigh the benefit. *Nephrology News Summer 2000* pp 4,5.
- The Kidney Alliance Document. 2001. *End Stage Renal Failure – A Framework for Planning and Service Delivery*. HSMO. London UK
- The Renal Association. 1997 2nd Ed. *Treatments of adult patients with renal failure. Recommended standards and audit measures*. The Laverham Press Ltd. Suffolk UK.
- Thomson T. 2000. An adequacy nurse improves adequacy of dialysis *EDTNA/ERCA Journal XXVI 4* 2000 pp19-21
- Thorne S. 1993. *Negotiating Health Care. The Social Context of Chronic Illness*. Sage Publications. California USA
- Trager H. 2002. The influence of bacteria in dialysis water on its endotoxin level. *EDTNA/ERCA Journal XXVIII no 3* 2002 pp121-124
- Trevitt R. Whittaker. C. Ball E. Fitzgerald L. 2001. Drop-out rate during living donor selection. *EDTNA/ERCA Journal XXVII 2*. 2001 pp 88-91
- Trueman I. 2001. Specialist palliative care in the UK: its future and the effects of NHS reforms. *International J. of Palliative Nursing Vol7. No4* 2001 pp 198-203
- Tschudin V. 1997. The emotional cost of caring. In *Caring. The Compassion and Wisdom of Nursing*. Brykczynska G. (Ed). Hodder Headline Group London UK.

- UKCC. 1996. *Guidelines for Professional Practice*. Published by UKCC London UK
- UKCC. 1992a *Code of Professional Conduct*, Published by UKCC London UK.
- Valentine A. 2000. Is it surprising they omit their tablets? *EDTNA/ERCA Journal XXVI vol 2 2000 pp 36-38*
- Van Biesen P. 2000. An evaluation of an interrogative care approach for End Stage Renal Disease patients. *Journal of American Society of Nephrology. No.11. 2000 pp 116-125*
- Van Maanen J. 1995. An end to Innocence. in *Representation in Ethnography*. Van Maanen J. (Ed). Sage Publications California USA
- Van Maanen J. (1988). *Tales of the Field. On Writing Ethnography*. University of Chicago Press. USA
- Vitri N. Attias M. Banayahu. M. Elharrat K. Hener T. 2001. The social climate in chronic haemodialysis units as perceived by patients and nurses. *EDTNA/ERCA Journal XXVII 4. 2001 pp 178-180*
- Wallace L & colleagues. 2000. Question of attitude.
www.hsi.co.uk/collections/attitude.htm.
- Watson J. 1985. *Nursing: The philosophy and Science of Caring* Colorado Associated University Press. Boulder USA
- Welford C. 2002 Matching Theory to Practice. *Nursing Management Vol 9 (4) 2002 pp7-11*
- Welsh G. 1994. Assessment of quality of life following renal failure. in. *Quality of Life Following Renal Failure*. McGee H. & Bradley C. (Eds) Harwood Academic Publ. Switzerland.
- Winearls C. 1999. Crisis in renal replacement service provision. *British Journal of Renal Medicine. Vol 4 no.1 1999 pp 4*
- Wise B. 2002. In Their Own Words: The Lived Experience of Paediatric Live Transplant Patients. *Quality Health Research. Vol 12 no 1 2002 pp74-90*
- Zrinyi M. 2001. The influence of staff-patient interactions on adherence behaviours. *EDTNA/ERCA Journal XXVII. 1. 2001 pp 13-16*