

**The concerns of Pakeha men living on home haemodialysis:
a critical interpretive study**

by

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Abstract

This nursing study seeks to understand the experience of one group of people with chronic renal failure using renal replacement therapy, Pakeha men living on home haemodialysis. It is based on the assumptions that people living on dialysis have distinctive experiences that are characterized by common concerns reflecting their shared position as subjects of renal illness and therapy, but that these are not easy to discern because they are obscured by the professional viewpoint that is dominant in the renal setting.

In order to understand the experience of people living on dialysis this study develops a critical interpretive approach, seeking the participant's own interpretation of their individual experiences, but then reinterpreting them from a critical standpoint, recognizing that they can only be adequately understood by contextualizing them, in order to discern the common perspective underlying them in contrast to the dominant professional viewpoint in the renal setting. Using some ideas derived from the thought of Michel Foucault this study develops a critical nursing view of the renal setting, as a specialized healthcare context that is constituted by several interrelated discourses, primarily the dominant professional discourse, but also by several other discourses, in particular a client discourse that is a response to the dominant discourse. The different discourses reflect contrasting perspectives based on the different positions of various groups within the renal context.

The study presents accounts, derived from interviews, of the experience of six Pakeha men living on home haemodialysis. Reflecting on these accounts as a set, by contextualizing them in terms of the critical nursing view of the renal setting, I outline four concerns of Pakeha men living on home haemodialysis. Together these make up the renal client discourse that models the distinctive perspective from their

position within the renal context, underlying each of their individual accounts of their experience of illness and therapy. These concerns include symptoms from chronic renal failure and dialysis, limitations resulting from the negotiation of the therapeutic regime into their lifestyle, their sense of ongoingness and uncertainty of living on dialysis, and the altered interrelationship between autonomy and dependence inherent in living on dialysis.

The study suggests that the individual accounts can be understood as resulting from the interaction of the various dimensions of their own personal social locations, including their gender and ethnicity, with the concerns of client discourse, reflecting their common position as people living on dialysis. One important implication of this understanding is that the role of nursing in the renal setting can be articulated as a response to the experience of the person living on dialysis. The nurse can support the renal client in seeking to integrate the requirements of the therapeutic regime, reflecting the dominant discourse, into their personal situation, reflecting the interaction of their own personal location with their position as a person living on dialysis, outlined in the client discourse.

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I am grateful to various people who have contributed to this work in different ways.

From the people with chronic renal failure whom I have worked with, not only the men in this study but many others over the years, I have learned what I know about the experience of living with chronic illness. Many nursing colleagues, in the renal department where I work and elsewhere, have exemplified the expert practice that this study attempts to reflect on.

The Department of Nursing and Midwifery at Victoria University of Wellington provided a stimulating and supportive forum in which to think about on my work in nursing using models congruent with my own personal intellectual orientation. I have learned a great deal from all the staff and students at the schools I have attended over the last five years.

In particular I have felt fortunate in having Cheryle Moss as my supervisor, a person who exemplifies academic endeavor at its most playful and rigorous. During her absence Pamela Wood provided a valuable contrasting perspective. Both have helped to make this study a rewarding process for me.

Doing this study while the rest of my family was also studying has resulted in dialogue that has been mutually beneficial. My wife Linda's support, understanding and confidence has been crucial in enabling me to complete this work.

This study is dedicated to my father Ray.

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Section A. Addressing the consumer dimension of the renal setting

Chapter 1. Positioning this study

“How can the truth of the sick subject ever be told?” (Foucault, 1990, p. 30)

The renal setting is a classic instance of contemporary healthcare technology. Until the middle of the twentieth century the loss of function of the kidneys was an untreatable terminal condition. Since the development of renal replacement therapies the numbers of people on treatment for chronic renal failure (CRF) have steadily increased until today several million people, mainly in the affluent countries of the world, are maintained on the different modes of therapy now available, in-centre or home haemodialysis, various types of peritoneal dialysis and renal transplantation. While these treatment modalities are now considered routine they are all technically complex and the various forms of dialysis have a significant impact on the lives of those who are dependent on them.

In New Zealand the number of people on treatment has grown in line with international trends, recently at a rate of 9% per year, with new patients now at 96 per million population in comparison with the highest rates in other countries such as USA with over 250 per million. In New Zealand 1117 people now live on dialysis treatment while 934 have a functioning transplanted kidney (Disney, 1999). The rate is expected to accelerate in the next five years due the epidemic growth of Type 2 Diabetes in New Zealand, especially among indigenous Maori and immigrant Pacific nations people. The expansion renal replacement services from a

limited group of typically fit people to categories of people not formerly treated, especially the elderly and diabetic people with multiple co-morbid conditions, is altering the character of renal replacement services. Self-care modes of therapy have been normative in most of New Zealand (74%, Disney, 1999) but in recent years there has been a gradual increase in numbers of people on in-centre treatment of various sorts (26%, Disney, 1999).

Nurses are extensively involved in the renal setting. With the expansion of renal replacement services an increasing number of nurses are now spending their working lives in this speciality area. They provide therapies for people with CRF, teach them to participate in their own therapies and also monitor the efficacy of these therapies in managing their condition. I am an example of such a nurse, having spent twenty years working in the renal setting with people dependant on renal replacement therapy, primarily in in-centre dialysis but also more recently in the home dialysis services.

Over time my interest has focussed on the question of the well being of people living on dialysis. I was initially attracted to this nursing speciality because the chronicity of the condition means nurses develop long-term relationships with the people they work with. Studies in sociology in the eighties sensitised me to the influence of specific social contexts, such as specialized healthcare settings, on the lives of different groups of healthcare consumers, including those suffering from chronic illness. In my post-graduate nursing studies in the nineties, through formal reflection on my nursing experience informed by this sociological viewpoint, I have sought to articulate my interest in the experience of people living with this particular chronic illness and therapy.

The renal nursing literature, as a review will show, has focused on this issue of the well being of people living on renal replacement therapy, reflecting the nursing perspective in this particular specialized healthcare setting. However most studies use quantitative methodologies derived from other disciplines. While providing a useful overview of the attributes of certain groups using renal replacement therapy they are not oriented to seeking to understand the distinctive perspective of people

who are dependent on dialysis. There are very few qualitative studies exploring the experience of illness and therapy of people using renal replacement therapy. This thesis, *The concerns of Pakeha men living on home haemodialysis*, is a critical interpretive study that seeks to understand the experience of one group of people, Pakeha men, living on one form of renal replacement therapy, home haemodialysis.

1.1 Discerning the consumer perspective.

The healthcare setting of CRF has a number of dimensions. These include the fundamental scientific therapeutic dimension, the medical knowledge base defining CRF and establishing various renal replacement therapies. There is also an associated commercial technological dimension, the companies who develop and supply the technology for renal replacement therapies. There is a socio-political dimension, public attitudes and official policies influencing the provision of renal replacement services. Finally there is a personal consumer dimension, the experience of people with CRF who continue to live by using renal replacement therapies.

The role of nursing within the multi-dimensional renal setting is complex and even ambiguous. Nursing work, in this situation of a chronic condition requiring highly technical therapies, involves interactions with people living on dialysis that are intensive and ongoing. In my own experience as a renal nurse working in an in-centre dialysis unit for many years there are often tensions around these interactions, commonly focussed on the issue of compliance with the therapeutic regime, that are only occasionally discussed in some forms of renal literature (De Nour, 1994; Smirnow, 1995).

For nurses these difficulties associated with their clinical activities raise the question of the character of the personal consumer dimension and its relationship to the scientific therapeutic dimension. They also raise the issue of the relationship of nursing work to these two dimensions of the renal setting. This thesis is based on two assumptions. First people living on dialysis have distinctive experiences

characterized by common concerns reflecting their shared position as subjects of renal illness and therapy. These reflect the chronic character of this condition. This assumption interprets the nature of the consumer dimension in the renal setting. Second it is not easy for health professionals to understand the distinctive experiences of people living on dialysis. They are difficult for health professionals to understand because, given the character of this contemporary healthcare setting, they have a different view of CRF and renal replacement therapy. This assumption interprets the nature of the fundamental scientific therapeutic dimension of the renal setting.

Given this starting point it is apparent that renal healthcare institutions attempt to provide a comprehensive service that responds to the needs of people living on dialysis. However, the complexity of renal management necessitates intensive monitoring of a wide range of variables, not only tracking the effects of CRF on the different systems of the body but also assessing the efficacy of dialysis and its associated therapeutic regime. These management issues inevitably occupy much of the attention of renal health professionals. In a context where a mass of scientific data defines so fully the health status of the person living on dialysis, the necessity to focus on the required technical knowledge can limit awareness of other aspects of the reality of CRF for the person who is experiencing it.

When CRF is viewed in these terms, according to the dominant scientific therapeutic dimension of the renal setting, as a situation of functional failure of an organ and its sequelae, producing a complex problem of medical management, the person living on dialysis is viewed primarily in terms of their compliance with a therapeutic regime established by medical management. Given this approach, their own understanding of their situation, not integral to the scientific picture but only relevant in terms of its influence on their degree of compliance, can be neglected in the intensive process of technological management. The dominant professional viewpoint formally recognizes the well-being of the patient with CRF as the *raison d'être* of renal healthcare care services, but the necessary focus on the complex process of diagnosis and management tends to displace or marginalize the person and their views as the subject suffering from the illness, especially beyond the

question of their necessary compliance with the therapeutic regime. The perspective of people living on dialysis is obscured because of the dominance of the professional viewpoint.

When working in a professional role it is not easy to recognize renal healthcare consumers' personal understanding of their situation. What renal health professionals perhaps have most difficulty appreciating are the problems created by living with CRF and also by renal replacement therapy itself. A commitment to working in the renal setting, involving an assumption of the value and efficacy of the therapies offered, makes it difficult to hear clues from people about problematic aspects of their life on dialysis. The tensions in the relationships between people with CRF and health professionals could be understood as resulting from health professionals' lack of understanding of their distinctive experiences of living on dialysis. This professional viewpoint, prevalent in nephrology and throughout medicine in general, may also be one reason studies seeking to discover the viewpoint of those with CRF are unusual in healthcare research.

The motivation for this study seeking to discern the perspective of those living on dialysis is the recognition that health professionals cannot fully appreciate the impact on the lives of people living with CRF and the therapies that attempt to manage it. For renal health professionals CRF is primarily an objective set of symptoms caused by a pathological process that are ameliorated by dialysis treatment or transplantation. For the person suffering from CRF is a subjective experience that has a meaning for them. This experience includes not only the physical aspects of the disease process and the effects of therapy but also the way the person interprets these in terms of their impact on their whole life, their activities, relationships and sense of identity. Their perspective is inherently interpretive and relational. In terms of such an alternative perspective people with CRF can no longer be viewed according to the dominant viewpoint simply as objective examples of a disease entity ("a 43 year old Caucasian male presenting with mesangio-capillary glomerulonephritis..."), whose reactions are an aspect of their problem that are to be assessed, measured and treated. Rather people living on dialysis are recognised as subjects who have an experience of illness and therapy in

their own situation, which includes their response to the healthcare system and health professionals.

1.2 Renal disease and therapy

In order to appreciate any research study into the consumer dimension it is necessary to briefly set out the therapeutic scientific dimension that is the basis of the renal setting. This can be outlined through a definition of its core terminology (for example Challinor and Sedgewick, 1998). *Nephrology* is the branch of medicine that studies diseases of the kidney, their consequences and the therapies used to treat them. *Chronic renal failure (CRF)*, strictly *end stage renal disease*, is defined as the final phase of chronic disease processes in the kidneys caused by a variety of conditions, including glomerulonephritis and diabetes. *Uraemia* is the toxic state resulting from end stage renal disease, caused by the accumulation of waste products in the body because they are not being eliminated by the kidneys, that produces various symptoms for the patient. End stage renal disease is a terminal condition unless patients receive clinical intervention using *renal replacement therapies*, therapeutic technologies employed to replace the essential life-preserving functions of the kidneys, the removal of nitrogenous wastes, maintenance of serum electrolyte levels (especially avoiding high Potassium levels) and *fluid balance* between bodily fluid input and output. They include two forms of dialysis and also transplantation.

Dialysis is a generic term for two forms of renal replacement therapy, *haemodialysis* and *continuous ambulatory peritoneal dialysis (CAPD)*, that filter excess wastes, electrolytes and fluid from the bloodstream across a membrane into a specially constituted fluid, the dialysate solution. *Ultrafiltration* refers to the process of fluid removal during dialysis. The *target weight (dry weight)* is defined as the weight at which the patient on dialysis who passes little or no urine (is *oliguric* or *anuric*) is in correct fluid balance, having neither excess nor a deficit of fluid in their body. A patient is *fluid overloaded* when they have an excessive volume of fluid in their body, indicated by their actual weight being significantly above their target weight,

often resulting in symptoms, especially breathlessness, which are removed by ultrafiltration. Dialysis, to be effective, involves the patient controlling their fluid intake to avoid overload between treatments and also their diet to avoid dangerous elevation of their electrolyte levels between treatments. While dialysis replaces several life-sustaining functions of the kidneys it does not address other problems caused by their failure such as anaemia resulting from the loss of production of the hormone *Erythropoietin (EPO)*. Hence people on dialysis also often require associated therapies such as Erythropoietin replacement. This drug, a synthetic copy of a substance normally produced by the kidneys that is necessary for the manufacture of red cells in the bone marrow, is used to manage the anaemia associated with CRF for people on dialysis.

Haemodialysis is the form of renal replacement therapy employing an artificial membrane constituted as a *dialyser*. A *haemodialysis machine* pumps blood from the patient through one side of the membrane in the dialyser and another fluid, the *dialysate* that the machine itself mixes from purified water and electrolyte concentrates, through the other side of the membrane. The excess wastes, electrolytes and fluid diffuse from the blood through the membrane into the dialysate. This process, crudely mimicking the filtration action of the human kidneys, is normally performed in a regular schedule of three five-hour sessions each week. In *home haemodialysis* or *self-care haemodialysis* the patient is taught to perform their own treatment with a dialysis machine installed in their own home, often with some assistance from another family member. In *in-centre* or *clinic* haemodialysis the patient attends a facility where a health professional, commonly a nurse, performs the treatment.

Vascular access is a generic term for a variety of means used to enable blood to be drawn from and returned to the patient for haemodialysis. They include the surgically created *fistula* between an artery and a vein in the forearm and the surgically placed artificial *graft* into which special fistula needles can be inserted, or a catheter placed in a central vein such as the subclavian or internal jugular. Blockage from clotting or infection, common complications, may require surgical intervention to repair or replace vascular access. “*Going flat*” or “*being light*” are

common phrases used by both renal health professionals and people on dialysis to describe hypotension occurring as a consequence of ultrafiltration during haemodialysis. *Bicarbonate* and *acetate* are alternative components of the dialysate solution used in haemodialysis. Acetate, formerly normative, is being phased out because of frequent symptoms associated with bio-incompatibility.

Continuous ambulatory peritoneal dialysis (CAPD) is a form of renal replacement therapy employing the microvasculature of the peritoneum as a membrane. Bags of dialysate fluid are drained into the peritoneal space through a special catheter surgically placed in the abdomen, the *Tenkchoff catheter*, for a period of several hours at a time. Excess wastes, electrolytes and fluid diffuse from the blood through the microvascular walls into the dialysate. This process is repeated four times each day. The patient is taught to perform their own treatment in any suitable non-clinical setting, primarily their home but also, if appropriate their place of work or some other place as necessary. *Peritonitis* is a common complication of CAPD because the Tenkchoff catheter provides a route for microorganisms to enter the peritoneal space.

Transplantation is a form of renal replacement therapy involving implantation of a kidney, taken either from a cadaver or from a living donor, into the abdomen of the recipient. *Immunosuppressive drugs* are medications taken daily to prevent rejection of the organ *graft*. *Nephrectomy/ies*, the surgical removal of a person's own kidney/ies, is not normally necessary in CRF but may be done for some specific reason such as chronic infection. A transplanted kidney may be removed for some reason such as chronic rejection. Unlike dialysis transplantation replaces all the functions of the kidneys.

While it is necessary to grasp this technical language of the scientific therapeutic dimension in order to appreciate any renal study, nursing research seeking to understand the personal consumer dimension as the interpretation of the experience of illness and therapy requires an alternative methodology to those defined by the dominant scientific therapeutic dimension of the renal setting.

1.3 The interpretive paradigm

In order to address the consumer dimension in terms of the initial assumptions set out above, a methodology is needed that is congruent with the recognition of the client perspective as inherently interpretive and relational. In the dominant scientific therapeutic dimension of the renal setting, derived from the empirical analytic paradigm, the focus on objective knowledge of disease and therapy that is the basis of the renal setting also leads to neglect and negation of the subjective experience of illness as irrelevant. According to the prevalent objectivist view derived from this position any form of study of the consumer dimension is rejected unless scientifically verifiable methods are used.

By contrast, in the interpretive paradigm (Monti and Tingen, 1999) all human knowledge, including the empirical analytic paradigm itself, is viewed as a form of interpretative understanding. In the interpretive paradigm all patterns of human thinking are recognized as models, based on specific sets of assumptions and expressed in a particular language, giving different perspectives that can illuminate whatever reality is being focussed on in different ways. In these terms, while research in the empirical analytic paradigm is useful for the purpose of defining disease and developing therapeutic management strategies in a specific healthcare setting, the study of subjective human experience such as suffering from a particular illness, which is by its nature interpretive, cannot be adequately undertaken by objective scientific methods.

Rather the study of human subjectivity requires an approach based on the alternative interpretive paradigm. Within the renal setting such an approach can provide an alternative focus to explore the understanding of the experience of people with CRF. While the dominant professional viewpoint, based on the empirical analytic paradigm, speaks of the 'renal patient' (see Zola, 1991, p. 10), an interpretive approach, recognizing the distinctive perspective of the person living on dialysis, speaks of the 'renal client'. However given that the client perspective is obscured by the dominant professional viewpoint in the renal setting the interpretive approach will need a critical dimension in order to uncover it. In this study some ideas

derived from the thought of the French social philosopher Michel Foucault will be used as the basis to develop a critical nursing view of the renal setting in order to discern the client perspective. The value of using such an approach in this study, interpretive yet critical, currently unusual for most people working in the renal setting, is its potential to delineate the perspective of people living on dialysis, currently neglected in research in this clinical situation.

1.4 The concerns of the Pakeha men living on home haemodialysis

Given his questioning of the possibilities of establishing any definitive meaning, 'truth' is an unusual word for Foucault (1990, p. 30) to use in the opening quotation. While perhaps containing a touch of irony, this statement points towards the difficulty in discerning, maybe even by people themselves, the meaning of their experience as subjects with an illness such as CRF that is being managed by health experts in a contemporary specialized health setting. Recognizing such difficulties, the purpose of this study of the personal consumer dimension of CRF is to explore the understanding of one particular group within the renal setting, Pakeha men living on self-care haemodialysis at home.

For this study Pakeha men are considered as those who define themselves as men belonging to the dominant 'white' culture, descended from the European colonists, in contrast to those from the indigenous Maori culture or other ethnic minorities (King, 1999, pp. 234-239). This study focuses on Pakeha men because research from other countries (Boone, 2000; Brunier and McKeever, 1993; Owen, 1995; Reiss, D., Gonzales, S. and Kramer, N., 1986; Somer and Tucker, 1992; Soskolne and De Nour, 1989; Tell et al., 1995; Wolcott, Nissenson and Landsverk, 1988) suggests that the experience of living on dialysis could be somewhat different for women compared with men and also for people from different ethnic groups compared with people from a dominant white culture. This may result from the intersection of their experience on dialysis with broader societal issues relating to gender or ethnicity. In particular, rather than treating all men on dialysis as a homogeneous group, I focus on Pakeha men living on dialysis in recognition that

the experience of dialysis for Maori may be distinctive, both as a result of their specific cultural background and also their position in relation to the dominant culture. While Maori and Pakeha are culturally appropriate terms for designating local ethnicities being considered in this study I will use terms considered neutral in New Zealand when referring to ethnicities of other countries, for example Caucasian and Afro-American.

I am conscious, as a man researching a group of men, of the engendered nature of this study. From my work experience and study I understand nursing as an engendered profession made up primarily of women. I recognize the risk of replicating stereotypical cultural ordering of male and female in this research. A specific problem I faced in writing this thesis was that the English language does not have a word for the singular pronoun that is inclusive of both genders. Throughout this study, to avoid clumsiness, I will use the female pronoun when speaking of the nurse and the male pronoun when speaking of the nurse researcher. In both cases usage is simply a convenience, without hierarchical implications, reflecting the fact that most nurses are women and also my own position as a man researching men in this study.

Home haemodialysis is a form of renal replacement therapy in which the person with CRF is taught to manage their own therapy by independently operating a haemodialysis machine installed in their own home. They receive support by telephone and occasional visits from a group of nurses who provided the training. Now unusual in most developed countries, this form of renal replacement therapy remains common in New Zealand. This study is based on interviews with a small group of six Pakeha men on self-care haemodialysis at home in an urban area served by one department of renal medicine.

This study seeks to address the consumer dimension of the renal setting in terms of the 'concerns' of one particular group. This thesis is based on the assumption that the experience of people living on dialysis is characterized by common concerns, reflecting their shared position in the renal setting, that are not easy for renal health professionals to understand. The word concerns suggests an interpretive

understanding of their experience (Benner, 1994, p. 104; Lindqvist, Carlsson and Sjoden, 2000), as not simply straightforward but rather complex. It points towards the potential difficulties in living on dialysis.

The word concerns suggests their understanding of their experience as not easy to recognize or articulate because obscured by the professional viewpoint (Allen, 1955, p. 177; Thompson, 1990, p. 258), in the renal setting. It points towards the critical dimension necessary to discern their understanding within the specialized healthcare context of the renal setting. The word concerns suggests an understanding of their experience in terms of the shared perspective of people living on dialysis. It points towards common concerns underlying their individual experience of renal illness and therapy. The word concerns refers to the difficulties characteristic of living on replacement therapy that are difficult to discern in the renal setting. As an interpretive expression with a critical connotation this work reflects the research methodology that will be developed for this study.

1.5 The shape of this thesis

The first section of this thesis develops an approach to the research topic of the concerns of Pakeha men living on home Haemodialysis. In chapter two I will review the literature about the consumer dimension of the renal setting. I will consider the various types of studies about the well-being of people with CRF, not only common forms such as quality of life studies and reviews of stressors and coping or compliance, but also the few studies using alternative methodologies. Through this review I establish the value of an interpretive approach that incorporates a critical contextual dimension in order to understand the experience of illness and therapy for a group of people living on haemodialysis.

In chapter three I will develop a methodology for this research topic. After setting out an initial assumption about the nature of research underlying this study, I will briefly consider two traditions, hermeneutics and critical social science, which are relevant to nursing research in this sort of topic. Having reviewed the common combination of these two as critical hermeneutics, I will outline an alternative

critical methodology, an interpretive approach, which is appropriate to understand the experience of a specific group of renal healthcare consumers. In this approach the researcher seeks participants' interpretations of their experience according to a hermeneutic understanding but does so from a distinctive interpretive stance, a critical view of their social setting. I will use some ideas derived from the thought of Michel Foucault to enable a critical stance toward a specific contemporary healthcare setting for this interpretive approach.

In chapter four I will set out the study design. I will show how the methodology, developed to address this research topic, is actually employed to understand the experience of this group of Pakeha men living on home haemodialysis. I will review the study group, information collection and its analysis in this study. I will consider the ethical issues that arise from this specific study and discuss the criteria that can establish its value.

The second section of the thesis, chapter five, sketches a way of viewing the renal setting for this study. From reflections on my own nursing experience, developing the initial assumptions of the study, I will apply the Foucauldian ideas to this particular contemporary healthcare setting. From this critical nursing standpoint I will view the renal context as constituted by several interrelated discourses, reflecting the perspectives of different groups within it, including the dominant professional discourse and the renal client discourse made up of several different concerns.

The third section of the thesis presents accounts of six men's interpretations of their experience of living on dialysis. In chapter six I will introduce the accounts by positioning myself as researcher in relation to them through a reflection on issues arising from the process of interviewing them. In chapter seven I will set out each man's account of their experience of illness and therapy.

The fourth section of the thesis seeks to understand the experience of these men living on dialysis through an analysis of the accounts from the third section in terms of the sketch of the renal setting from the second section. In chapter eight I will

interpret material from the set of accounts of the men, using the sketch of the renal setting and information from the literature to critically contextualize them, in order to outline four concerns of the client discourse, modelling their shared perspective in the renal setting that underlies each man's account.

In chapter nine I will suggest the relationship between the concerns of the client discourse and the individual's accounts of their experience of illness and therapy. Each of the accounts can be interpreted as resulting from the interaction of the common concerns characterizing their position as people living on dialysis with their personal social location, including their male gender and Pakeha ethnicity.

In chapter ten I will explore one important implication of this nursing understanding of the experience of living on dialysis through a reflection on the character of nursing work in the renal setting. I will suggest, despite the difficulty discerning the consumer perspective in the renal setting, the potential of the nursing role, given their extensive involvement with people living on dialysis, as a response to the experience of living on dialysis. The expert renal nurse seeks to support people to integrate the demands of the therapeutic regime, reflecting the dominant professional viewpoint, with their own situation, reflecting the concerns of the client discourse. I will suggest that nursing work can mediate the dominant and client discourses in the renal setting. In chapter eleven I will summarize the key elements of this thesis.

In this research I am attempting to understand the experience of living on dialysis, that is not easy to recognize or articulate in the specialized healthcare setting of CRF. I am seeking to hear the quiet 'voice' of the people living on dialysis easily lost in the expert health talk dominating the renal setting. In order to approach the research topic of the concerns of Pakeha men living on home haemodialysis it is first necessary to consider the literature currently available about the consumer dimension of the renal setting. This is the purpose of the next chapter.

Chapter 2. Literature review: living on dialysis

Because this study is attempting to understand the experience of one group of people living on dialysis I will review several streams in the extensive academic literature about CRF and renal replacement therapy that focus on the consumer dimension of the renal setting. I will concentrate on a number of nursing studies and locate these within the general renal literature, including studies from other health disciplines.

I will briefly present the most prevalent forms of literature about the well-being of people with CRF, various types of quantitative studies, indicating their findings but suggesting their limitations for addressing this kind of research topic. I will then focus on the few nursing studies I have discovered that use a qualitative methodology to consider the well-being of people living on dialysis. These studies support the value of using an interpretive approach in this study seeking to understand their experience of renal illness and therapy. However analysis of them also points toward the necessity of a contextual dimension in order to discern the client perspective in the renal setting.

I will then consider a range of papers about the therapeutic behavior of people living on dialysis. I will suggest that the issues they raise can all be viewed as facets of the broader question of the adaptation of people to living on dialysis, that, in turn, reflects their interaction with the renal setting. Noting the rarity of studies that have a contextual dimension I will highlight certain studies that recognize that it would help to enhance the meaningfulness of their findings. I will then review one nursing study using an explicitly critical methodology that exemplifies the value of incorporating such a contextual dimension into a study like this, attempting to understand the concerns of Pakeha men living on home haemodialysis.

2.1 Quality of life studies

In the large medical literature on CRF texts are filled with the complexities of managing the sequelae of CRF in the different organ systems of the body. While a number of papers have also addressed the consumer dimension of the renal setting through studies of the well-being of various patient groups with CRF, consideration of the experience of people living with the demanding regimes of renal replacement therapy is almost absent. On the face of it the limited number of studies about the experience of people living on dialysis reflects an implicit assumption that it is relatively non-problematic.

The well-being of renal consumers has been addressed epidemiologically in several studies by measuring 'Quality of Life' in various populations of dialysis patients using standard tools developed in the social sciences (for example Bremer, McCauley, Wrona and Johnson, 1989; Evans et al., 1985; Ferrans and Powers, 1993; Gudex, 1995; Lok, 1996; Simmons and Abress, 1990; Wolcott et al., 1988). Typically these have examined several broad areas, categorized in particular ways, such as health and functioning, psychological, family, social, economic and spiritual well-being (see for example Ferrans and Powers, 1993). From answers given to questionnaires by a sample group from a population, researchers have used statistical methods in an attempt to quantify the psychosocial dimensions of the life of people living on renal replacement therapy. They have produced measures enabling comparison with the general population and between different modalities of renal replacement therapy, haemodialysis, continuous ambulatory peritoneal dialysis (CAPD) and transplantation. The scientifically measured statistical estimates of quality of life for groups with CRF commonly used in studies are referred to by the contraction QoL in this thesis, whereas the actual (unmeasurable) experience of the people with CRF is referred to by the phrase quality of life or well being.

Some of these studies have found people living on dialysis have a lower QoL than people who do not have to live on dialysis, while some find there is no significant difference between those living on dialysis and others. Typically it has been found

that those with transplants have the highest QoL, often that those with failed transplants have the lowest QoL. People on self-care dialysis at home have a higher QoL than those on in-centre dialysis (Bremer et al., 1989; Evans et al., 1985; Simmons and Abress, 1990).

In a similar approach several quantitative studies have used a psychological framework in attempting to delineate pathological responses to dialysis. They have looked at specific stressors for people living on dialysis, both physiological and psychosocial, and their range of coping mechanisms and adjustment to illness (Baldree, Murphy and Powers, 1982; Bihl, Ferrans and Powers, 1988; Blake and Courts, 1996; Cormier-Daigle and Stewart, 1997; Devins et al., 1993; Gurklis and Menke, 1988 and 1995; Keogh and Feehally, 1999; Lok, 1996; Parker and Bliwise, 1997; Welch and Austin, 1999). In all these studies questionnaires have been used to generate data that is converted to scales that are then analyzed to find statistically significant relationships. Common findings have included both physiological and psychosocial stressors as important. Both problem solving and affective methods are used to cope with these stressors.

While such studies of the well-being of people living on dialysis, when done by nurses, focus on topics that reflect a nursing perspective (Ferrans and Powers, 1993; Lok, 1996), the assumptions of the empirical analytic paradigm, derived from the scientific therapeutic dimension dominant in the renal setting, shape the methodologies that they have used, just as they do in other studies of this sort. While this approach is useful it also has its limitations. Respondents can only reply within the framework offered by the researcher (Mishler, 1986, p. 122); specifically they cannot, beyond the given framework, rate the relative significance of the items or comment on significant omissions. For example asking two questions about specific aspects of sexual activity, as was done in one of these studies (Bremer et al., 1989, p. 204), many would regard as an inadequate way of summarizing such a complex aspect of human life as a person's sexuality or intimate relationships.

Most importantly this approach does not seek the views of people living on dialysis about what factors they consider significantly affect their quality of life. It seeks to

measure QoL or coping in terms of a standard scale rather than discern the distinctive quality for the people themselves of their lives on dialysis (see Price, 1996, p. 275; Wellard, 1998, p. 51). It does not allow a researcher to discover what they feel and think, the meaning of their experience of living on dialysis for them. As a result survey research in the empirical analytic paradigm produces broad generalizations about the well-being of groups on dialysis but is unable to offer any depth of understanding about their situation.

Fundamentally these QoL and stressor studies, addressing the comparative well-being of people with CRF from the perspective of the scientific expert, tend to replicate the objective perspective of the medical health professional. Viewing CRF as a complex problem of organ failure that they will manage, clinicians necessarily abstract from the perspective of the person with the problem as irrelevant in order to obtain an objective analysis. QoL studies, while purporting to reflect patients' views, employ a similar methodology in which their responses to the expert's questions provide a basis for their subjective well-being as a group to be objectively formulated and quantified. This limits the expression of their views to the framework presented by the researcher, thus possibly actually constraining or even suppressing any distinctive perspective of the person with CRF. Even more significantly, the limited number of these studies about QoL or stressors and coping, peripheral to clinical practice in the renal setting, reflect the professional assumption that life on dialysis is non-problematic, having the effect of negating the client perspective.

2.2 The client perspective

Such studies are predicated on the assumption that consumers' distinctive perspective is not relevant, measuring rather their comparatively different levels of functioning and well-being. However several studies have suggested there are differences between the views of renal clients and those of renal health professionals about life on dialysis. Interestingly a disparity has often been found between other objective professional assessments of patients' health status and QoL

measures that do actually incorporate a significant degree of the renal clients' own assessment of their well-being (Cairns and Cooney, 1985; Evans et al., 1985, pp. 556-7; Ferrans and Powers, 1993, p. 579; Hoothay, DeStefano, Leary and Foley-Hartel, 1990, p. 363; Meers et al., 1995; Molzahn, Northcott and Dossetor, 1997). These suggest that while people on dialysis may not objectively be well they may still subjectively feel well.

A nursing study by Hoothay, DeStefano, Leary and Foley-Hartel (1990), with both quantitative and qualitative dimensions, examined "life satisfaction and coping" of people with diabetes on haemodialysis, the group with CRF with the worst prognosis. They found, surprisingly to their given their difficult medical situation, that diabetic people on dialysis rated their past lives highly, their expected future life satisfaction almost as highly and the present life satisfaction relatively highly (Hoothay et al., 1990, p. 362). This supports the suggestions from other studies that an expert medical view of the state of the organ system of the human body does not necessarily correlate with the sense of well-being of the human person. As Hoothay et al. (1990, p. 363) concluded, "our views do not reflect the patients' reality... (q)uality of life is a truly subjective entity and only be evaluated from the client's perspective."

However Hoothay et al. (1990, p. 363) themselves found, through a frequency analysis, recurring themes in the interviews that suggested patients managed "fears" associated with life on dialysis by "resignation," "living day -to-day" and "hope for the future." As the latter "lacked a realistic basis" the authors saw this as a coping mechanism, a deliberately adopted way of managing, to enable those on dialysis to continue to live in the difficult present (Hoothay et al., 1990, p. 363). This view, that such behavior represents "knowing avoidance," is only one possible interpretation of her material.

While Hoothay et al. (1990) considered that the disparity between their poor objective health status and their own views of their well-being reflects a coping strategy of avoidance, an obvious question that arises is how fully they have been informed by health professionals about their poor objective health status that

medical therapy is unable to correct. It could also be debated whether a frequency analysis of words suggesting coping mechanisms in the transcripts, especially from such a small group, gives information in a form which allows this sort of generalization, even for this group. While each of them was individually frequent across the group, the combination of themes may not have a single meaning, "knowing avoidance," for all of them, but rather may have different meanings for different respondents.

Further Hoothay et al.'s (1990) generalization rested on her view of their present life as "difficult," which they acknowledged did not correlate with their subjective view of present life satisfaction as "relatively high" (Hoothay et al., 1990, p. 362). Quotations in the paper from the interviews themselves about their life on dialysis do not support Hoothay et al.'s interpretation of their respondents' views. This study, perhaps inadvertently, highlights differences in perspectives between renal clients and health professionals who work with them about the experience of living on dialysis. It also demonstrates how difficult it is for researchers who are health professionals to avoid distorting the clients' views in terms of their own viewpoint when interpreting them.

This paper is valuable in indicating that the well-being of people living on dialysis is affected not only by their objective health status but also, perhaps equally, by how they view their own situation, which may include what they know about their objective health status. As Horne and Weinman (1994, p. 113) have summarized "patients perception of illness and treatment influence patients' coping patterns and quality of life." This suggests that while it is useful to objectively assess the well-being of groups of patients with CRF, it can also be of value to attempt to discover the subjective views of people living on dialysis about their well-being and what influences it.

O'Neill and Glasgow (1991) in their paper about *Patient perceptions of the haemodialysis regime* explicitly noted the differences in evaluations of the difficulty of life on dialysis between dialysis staff and people living on dialysis. Interestingly, while both groups agreed on control of fluid intake as a most important element of

the therapeutic regime, for renal clients thirst, a consequence of such control, was the most difficult aspect of treatment, whereas for staff, who never have to face it themselves, it was among the least difficult. People living on dialysis also reported many barriers to fluid intake control, from participation in social situations to hot weather.

While the renal health professional view made excessive drinking by renal patients appear simply irrational and self destructive, the renal clients' view showed the complex difficulty that they face, the need to control their drinking to maintain good health while living on dialysis against the symptoms of thirst and the realities of their way of life that they wish to maintain despite being dependent on renal replacement therapy. This dissonance points towards differences in understanding life on dialysis between people with CRF who actually experience it and the renal health professionals who work with them.

It has also been recognized in the standard quantitative studies referred to above that sub-groups in the dialysis population such as ethnic minorities or women may have different QoL on dialysis than other sub groups (Gray, Brogan and Kutner, 1985; Kutner, Feilding, Brogan and Hall, 1994; Somer and Tucker, 1992; Soskolne and De Nour, 1989; Tell et al., 1995; Williamson, 1992; Wolcott et al., 1988, p. 273). Owen (1995) analyzed data showing that Afro-Americans in the USA have a greater incidence of CRF, lower mortality and probably a better QoL, despite having a less adequate dose of dialysis than Caucasians. Mode of dialysis and employment status also influences QoL (Bremer et al., 1989; Evans et al., 1985; Peters, Hazel, Finkel and Colls, 1994). Several studies have suggested a relationship between QoL and socioeconomic status (O'Brien, 1990; Reiss et al., 1986; Reiss, 1990).

In these studies findings of the differences in QoL between Afro-Americans and Caucasians, women and men, employed and unemployed, people on self-care and in-centre dialysis, lower and middle class people on dialysis, point toward dimensions in the renal setting, involving clients' understanding of their experience of living on dialysis, or contextual influences on their lives on dialysis, that are inexplicable by the quantitative objectivist research method used. These findings

have then sometimes become the subject of speculation under the guise of analysis. Often in studies of QoL of people with CRF using statistical methods the discussion section has offered opinions about the significance of specific findings such as, for example, their 'surprisingly high' QoL given their objective state (Hoothay et al., 1990, above), or differences in QoL between different sub-groups living on dialysis (Evans et al., 1985; Ferrans and Powers, 1993; Hoothay et al., 1993). The disparity between professional objective assessments and QoL measures, and also the differences in QoL for different sub-groups on dialysis, raises questions about the meaning of their experience for people living on dialysis that cannot be adequately addressed using the analytic empirical paradigm but require different methodologies.

As a result of the approach typically used in addressing the consumer dimension of the renal setting, the experience of people living on dialysis is virtually absent from the renal literature. While the well-being of people living on dialysis has generally been studied by these statistical analyses of different parameters for groups of patients, a different approach is required in order to address their well-being by attempting to discern their own understanding of their experience. Given the difficulty, noted above, in delineating the subjective well-being of the person with CRF the researcher, rather than using a framework that constrains the participants' responses, needs a methodology that encourages open expression of their views by participants. Forms of research based in the interpretive tradition, an alternative to the standard empirical analytic paradigm, represent a different approach that is oriented to focus on questions such as the meaning of the experience from the perspective of the person living on dialysis.

2.3 Rittman et al.: An interpretive study of people living on dialysis

A paper by nurse researchers Rittman, Northsea, Hausauer, Green and Swanson (1993) reported a rare interpretive study, from the USA, about people *Living with Renal Failure*. In this paper the phenomenon of living on dialysis is related to a Heideggerian understanding of 'being'. Texts of one-hour interviews with six

subjects were given “analysis using Heideggerian hermeneutics” in seven stages. The researchers found three themes, “taking on a new understanding of being,” “maintaining hope” and “dwelling in dialysis.” They found a major constitutive pattern, “control: the meaning of technology” (Rittman et al., 1993, p. 327). The depth of insight in this study is of a different order than the quantitative studies of QoL of people with CRF. However the hermeneutic understanding presented in this paper itself raises some questions.

In this paper the experience of living on dialysis is described as starting a new way of life which Rittman et al. (1993, p. 329) name, in Heideggerian language, as “taking on a new understanding of being.” This new way of life gradually becomes a “normal way of being” (Rittman et al., 1993, p. 329). The theme of “dwelling in dialysis,” also using Heideggerian language, describes people on dialysis coming to feel “at home” in the dialysis unit (Rittman et al., 1993, p. 329).

The constitutive pattern “control: the meaning of technology” refers to their body being “controlled” by renal replacement therapy especially by the dialysis machine. They characterize the “dehumanizing effects of the high tech environment” as causing “alienation resulting from the use of technology, in controlling and objectifying the body,” (Rittman et al., 1993, p. 331). This distinctive understanding is echoed in a later paper by Bevan (1998), also employing a Heideggerian approach, who views the dialysis nurse as “enframed” by a dehumanizing technology that limits the art of caring. While Rittman et al.’s (1993) examples certainly exemplify the control entailed in renal replacement therapy, it is not obvious from their evidence that this is alienating for clients, especially given her characterization of living on dialysis for them as ‘normal’. The reader is left wondering whether Rittman et al.’s Heideggerian theorization has influenced their reading of the interviews, perhaps a reflection of the general difficulty in discovering the perspective of people living on dialysis.

Their discussion of the consumer response to therapy follows from the themes they have set out. According to Rittman et al. (1993, p. 331) failure to comply with the treatment regime should not be typed as non-compliance but rather be reconceived

as "a natural part of the change process," as part of "taking on a new understanding of being", requiring ongoing education as "information can only be understood as it fits the lived experience." Despite their view of renal replacement therapy as an alienating technology, they positively conceptualize the client response in terms of a process of adaptation, attempting to integrate renal therapy with their own life pattern, making it 'normal', rather than simply in terms of their degree of non-compliance with the therapeutic prescription.

While manifesting some potential difficulties with this sort of research, Rittman et al.'s (1993) work is a valuable exemplar of a study seeking to address the well-being of people living on dialysis by using a research methodology based on the interpretive paradigm in order to understand their experience, an alternative to the standard studies derived from the dominant empirical analytic approach. It is notable that in its approach to the person living on dialysis this study does not negatively assume that the therapeutic regime becomes problematic because of the way that the person living on dialysis manages it (as in frameworks around coping, stressors or compliance) but rather that the character of life on dialysis, derived from the renal setting, is itself potentially problematic for the person with CRF.

However although it is helpful to question the prevalent assumption of the beneficence of therapeutic technology, as Rittman et al. (1993) do, the alternative assumption that it is simply inherently alienating for the many people on living on dialysis is equally unconvincing. Rather a research approach based on the interpretive paradigm is necessary to address the issue of the meaning, probably complex and ambiguous, of renal replacement therapy for the person living on dialysis. In order to understand their experience the impact of the distinctive character of these therapeutic technologies for the renal consumer, rather than being assumed, needs to be explicitly considered. To achieve this an interpretive study needs a contextual aspect that addresses the influence of the renal setting itself on the person living on dialysis.

2.4 Cohen: a general qualitative study

Cohen (1995) used a general qualitative approach to examine the experience of living on maintenance haemodialysis in a thesis in health psychology. She intensively interviewed five subjects and their families from an unusual group, people who had been on dialysis for more than twenty years. These people had started dialysis in the early years of the therapy, most initially on self-care haemodialysis at home, a modality of care that has since almost disappeared in the USA. Interestingly half of those she approached to participate in the study refused, four explicitly indicating they did not wish to participate in any review about their haemodialysis.

From her interviews she discerned three distinct 'phases' in the lives of these people on dialysis, the initial or crisis phase of up to a year, the chronic living phase up to the fifteenth year and the downward health spiral from then on (Cohen, 1995, p. 2). Generally after the initial adjustment period their lives on dialysis went reasonably smoothly, despite periodic brief interruptions for complications of CRF or the therapy. After the fifteenth year the cumulative effect of these complications caused their health to deteriorate; at the same times stresses inherent in the personal relationships as a result of living on dialysis over a long time became manifest. These three phases seem to parallel the earlier work of Reiss (1990), who talked of "the initial or acute phase, the maturity or chronic phase and a terminal or bereavement phase" (Reiss, 1990, p. 195).

Her most significant finding was the profound impact on the families of those living on dialysis, not only spouses but also children. Often they coped in a supportive role over many years, despite limitations on their own social lives, but eventually the chronic demands of participation in the illness of their partner or parent, who became increasingly dependant as their health deteriorated over time, led to resentment and a distancing in the relationship (Cohen, 1995, pp. 67, 76, 111). Such resentment resulting from spousal involvement has also been highlighted recently in a study by Freisen (1997).

While successful treatment in fact depended upon family, especially spousal, support, health professionals simply assumed this would be forthcoming and non-problematic, rather than actively promoting it through supporting family members (Cohen, 1995, p. 108 and following pages). It was noted that the family members themselves also simply assumed they would provide support, but the study showed the ongoing cost to them, both in the initial phase and later, due to the effects of the chronicity of the condition and the therapy (Cohen, 1995, p. 71 and following pages). Cohen's (1995) study points towards the question, not explicitly raised by her, of the degree of awareness among renal health professionals of extent to which the efficacy of renal replacement therapy is dependent on other more general contextual influences such as the degree of social support available.

The people in this study themselves developed a new set of supportive relationships when they transferred to the dialysis unit (Cohen, 1995, pp. 61, 62, 114), with the staff working there, but their relatives had almost no contact with this group (Cohen, 1995, pp. 108, 114). While the author does not give a reason for this and suggests more support would be very desirable, often the family in this situation are happy to have some relief from the demands of support for their dialysis dependent relative. Reiss (1990, p. 199) has noted that in the third phase "the patient understands the burden, and seeking to relieve his family, bonds more firmly to the medical care system." Generally Cohen's (1995) study suggests that in focusing on the person with CRF the impact of the illness and therapy on the rest of the family is unnoticed. A study by Wagner (1996) demonstrated a difference in perception between dialysis nurses and families of patients on in-centre dialysis about their needs, with families emphasizing the need for information and for "comfort". Another recent study relating levels of "distress" and "involvement" in home haemodialysis "caregivers" has also highlighted this neglected group, the family of the person living on dialysis, in renal services (Bloggs, O'Shaunessy and Cairns, 1999).

Cohen's (1995) study, suggesting some of the complexities involved for the person living on dialysis and their families over the long term, demonstrates the value of research using an interpretive approach to address the well-being of renal consumers

by seeking to understand their experience in this type of setting. In Cohen's study a relatively successful therapy in maintaining the objective well-being of people with CRF is shown, from the perspective of the client and their family, to cause significant subjective difficulties that finally become apparent when the limitations of the therapy itself become manifest in the long term complications of CRF. The medical focus on the efficaciousness of the therapy itself neglects the psychosocial cost to the person living on dialysis and also, importantly, their family. The rich detail of the participants' own comments in Cohen's thesis reveals this, often in a moving way.

The findings of the study, about the importance of unrecognized family support for the success of self-care treatment, and also of the support gained from renal staff on entering the in-centre programme, both point toward the significance of influential interrelationships in the renal setting in contributing to the well-being of the person living on dialysis. This reading of Cohen's (1995) study, suggesting that the experience of the person living on dialysis can only be understood in relation to the general character of the renal setting, indicates, like the Rittman et al. (1993) study, that the consumer dimension in the renal setting can be most fully approached by a contextually oriented interpretive study.

2.5 Sloan: a hermeneutic study of treatment decisions and their consequences

A doctoral dissertation by Sloan (1996) used a Heideggerian hermeneutic approach to study treatment decisions by people with CRF and their families about whether to seek a kidney transplant or to remain on haemodialysis. Her work, applying an idea derived from Zola (1991) to the renal setting, "explores what is 'structurally silenced' from the current dialogue related to the patient's treatment decision" (Sloan, 1996, p. 18). From interviews with 30 people about their experiences she discerned four constitutive patterns, "surgery: more hospitals, more problems," "uncertainty: its not just a sure thing," "illness as lived in structured silence" and "altruism: passing on the gift of life" (Sloan, 1996, pp. 85-122).

While viewing her first two themes as well known to health professionals her text powerfully suggests the significance of these, not only in relation to treatment decisions but also as aspects of the experience of living on dialysis. Within "illness as lived in structured silence" she found two themes, health professionals "moving on" by ceasing to interact with them and "labeling" them in various ways as 'noncompliant,' 'unappreciative,' 'passive' or even just 'too old' if a person did not accept transplantation as an option (Sloan, 1996, pp. 97-103). The examples of 'non compliance' in her study led her to question this construct.

Both "moving on" and "labeling" inhibit dialogue between people with CRF and health professionals. Interestingly these themes shaping the client experience are created by health professionals and can only be passively endured by people with CRF. In contrast to the first two constitutive patterns, that describe the complexities and the uncertainties associated with transplantation from the point of view of the person living on dialysis, the themes of "moving on" and "labeling," indicate a professional viewpoint that tends to ignore the client perspective. This appears to be an implication of her application of the concept "the structured silence" (Zola, 1991, p. 2) in the experience of people with chronic illness, to the renal setting, in terms of "barriers that structurally silence dialogue between end stage renal disease patients and their care providers" (Sloan, 1996, p. 95). Her text implies that silence is structured by health professionals through "moving on" and "labeling" and perhaps in other ways. In a subsequent paper Sloan and Gittings (1999) have developed the application of the notion of 'silence' in the renal setting, considering patients, called to hospital for a transplant that was then given to someone else, whose experience is ignored or reframed in several ways.

In this thesis Sloan (1996) also revealed the altruistic dimension of such decisions declining to be accept an organ by people living on dialysis, both in relation to cadaver and live-related transplants. Representing active choices by people living on dialysis such altruistic attitudes are obscured by "moving on" and "labeling" initiated by health professionals. In general her constitutive patterns in relation to treatment decisions suggest the different viewpoints of renal health professionals and people with CRF that influence their relationship.

Sloan (1996), in the second half of her thesis, then illustrated the experiential consequences of such treatment choices through four narratives. These revealed three patterns, “great expectations”, “broken promises” and “true miracles” in their lived experience of dialysis in relation to the social institutions of marriage, parenthood, family and medicine (Sloan, 1996, p. 149). The narratives movingly show the different ways that living on dialysis influences individual lives. They show this influence as active specifically in various family relationships.

In her dissertation Sloan (1996) presents medicine as a vehicle of “great expectations” through its developing technology that can lead to the disappointment of “broken promises” or the fulfillment of “true miracles.” Using Heideggerian terms, derived from her interpretation of his (Heidegger, 1977) work *The Question concerning technology*, she says “the danger is in not recognizing the phenomenon of end stage renal disease as a lived experience surrounded by the essence of technology” (Sloan, 1996, p. 188). This allusive statement perhaps suggests that medical technology is not inherently problematic anymore than it is ‘miraculous’. It is only problematic within a professional viewpoint, promoting a miraculous potential, that neglects the experience of those living on dialysis.

From reading the thesis one is left wondering whether the two sets of patterns, about making decisions and the experiential consequences of those decisions, are linked and if so how. It may be that ‘structured silence’ itself provides the causal link between the themes related to the choice of renal replacement modality and the experiential patterns of expectations, broken promises and true miracles in relation to medicine. In general the notion of ‘structured silence’ points towards the importance of the contextual dimension of the renal setting in understanding the experience of people living on dialysis.

2.6 The question of non-compliance

Apart from QoL studies the consumer dimension of the renal setting has also been addressed in a number of papers examining the therapeutic behaviour of people with

CRF. Most commonly these have examined patient non-compliance, reflecting a significant issue for health professionals working in this area. Various studies have found problems with adherence to dietary restrictions, fluid intake control, medication regimes and the dialysis schedule itself, all of which are familiar to renal health professionals (Bame, Peterson and Wray, 1993; Curtin, Svarstad and Keller, 1999; Levy, 1995; Lundin, 1995; Mason, 1995; Morgan, 1999; O'Brien, 1990; Reiss, Gonzales and Kramer, 1986).

However several studies have produced provocative findings about compliance. A longitudinal study with a qualitative dimension by O'Brien (1990), *Compliance behavior and long-term maintenance dialysis*, found, "unexpectedly" (O'Brien, 1990, p. 213), that survival outcomes for those on dialysis who were less compliant were better than for those who were more compliant. In fact her study replicated an earlier finding by Reiss et al. (1986). Several other studies have questioned whether compliance actually improves outcomes (Reiss, 1990; Thorne, 1990; Ruggiero, Brantley, Bruce, McKnight and Cocke, 1992).

O'Brien (1990) attempted to explain this surprising finding by making a distinction between "reasoned" and "ritual" compliance (O'Brien 1990, p. 209), as did Reiss (Reiss, 1990, p. 199). However compliance in the study was defined as "adherence to the total therapeutic regime prescribed for an individual maintenance dialysis patient" (O'Brien 1990, p. 210). O'Brien's distinction between "ritual" compliance, following 'to the letter' (O'Brien 1990, p. 209), and "reasoned" or "active" compliance (O'Brien, 1990, p. 210), referring specifically to renal clients having "learned to manipulate the system," knowing that they can "tolerate a small portion of a usually forbidden food or drink" (O'Brien 1990, p. 213), is confused. What O'Brien calls reasoned or "active" compliance is plainly, by her own definition, calculated risk-taking non-compliance. Knowingly not to do what you have been told you need to do is her own definition of non-compliance (O'Brien 1990, p. 210).

Her speculation about why ritual compliance should lead to worse outcomes, namely an unthinking adherence to the prescribed regime, is unconvincing because ritualist renal clients tend also to be assiduous, even obsessive, in medical

consultations, seeking confirmation of the correctness of their exact adherence to the prescribed regime in an effort to guarantee the resulting dividends in terms of well-being. The distinction between ritual and reasoned compliance appears an inadequate way to explain the paradoxical nature of her disconcerting finding for health professionals, who seek to persuade people on dialysis to comply with difficult treatment regimes on the basis that it is 'therapeutic', that is, will enhance their chances of survival.

Levenson and Glocheski (1991) reported Cummings et al. (1982) as showing that compliance correlates with renal clients' beliefs about both the efficacy and difficulties with therapy. However a study by Reiss et al. (1986; see Reiss, 1990) showed compliant renal clients from intact, accomplished and intelligent families, motivated presumably by their understanding and belief in the efficacy of adherence to the treatment regime, had worse survival than renal clients from families that lacked these qualities. "The more accomplished the family were the more compliant they were" (Reiss, 1990, p. 198) but "the brightest families with the most patient education, the highest occupational status, and the largest household income had less patient survival than those who did not" (Reiss, 1990, p. 197).

This unusual outcome, that Levenson and Glocheski (1991, p. 386) for example had difficulty accepting, Reiss et al. (1986) attempted to explain in his study in terms of the greater adaptability of lower class, mainly black, families with extended kinship bonds, facilitated by different, less regular, employment patterns, in contrast to lesser adaptability of tightly knit, isolated, middle class, mainly white, families oriented to occupational achievement (Reiss et al., 1986, p. 802). The former adjusted to life on dialysis as yet another problem that could not be overcome but had to be accepted and managed in their lives. For the latter, used to utilizing their considerable resources to overcome any difficulties in their lives, the complex chronicity of life on dialysis, as a problem they could not solve that they were unable to manage (Reiss, 1990, p. 199).

What the findings of these studies raise, unintentionally, is the question of the adequacy of the concept of 'compliance' to consider the response of the person

living on dialysis. Despite their different views these papers, by O'Brien (1990), Levenson and Glocheski (1991) and Reiss et al. (1986), though based on the notion of compliance, point towards the significance of the attitudes of renal clients in shaping how they manage to live on dialysis. The concept of compliance is based on the perspective of the health professional (Manley and Sweeney, 1986; Wright, 1998) and research employing this concept replicates the perspective of the health professional. Uncritically accepting the concept of compliance, just as with the idea of QoL, prevents the researcher, as it does the health professional, from recognizing the client's perspective. Indeed, the use of compliance to characterize the behavior of people living on dialysis reflects the tensions in clinical interactions that derive from the dissonance between professional and client viewpoints.

The notion of compliance is not adequate to interpret the therapeutic behavior of people living on dialysis. It refers to a necessary dimension of clients' therapeutic behavior, as people living on dialysis must adhere to the therapeutic regimen to some extent to remain well. However compliance needs to be recognized as one aspect of the wider question of the response of the person in adapting to the requirements of therapy in their own life situation, a response that is based on their attitudes to renal illness and therapy.

2.7 Roles and control on dialysis

Another broader way in which therapeutic behavior in the consumer dimension has sometimes been studied is in papers examining the social roles of people living on dialysis. A study reported in articles by Hardiker, Pedley, Littlewood and Olley (1986) and Littlewood, Hardiker, Pedley and Olley (1990) from a social work perspective, *Coping with chronic renal failure*, attempted to develop an alternative to viewing the situation of people on dialysis "solely in terms of deviant adaptations to the stress of dialysis" (Hardiker et al., 1986, p. 216). From interviews with 20 subjects on self-care dialysis at home the authors described a typology of coping through "illness roles." In their view the health situation of CRF and its treatment by dialysis have a particular character which gives rise to several distinctive styles of

response to illness among people who enter that situation. These include denial (viewing renal illness as transitory), adaptation (attempting to maintain or reconstructing their lifestyle), resistance (rejecting alteration of their lifestyle) and resignation (giving up their lifestyle, see Hardiker et al., 1986, pp. 211-212).

Rather than viewing these people's response to life on dialysis in terms of coping mechanisms to stressors or degrees of compliance, in this study there was an attempt to discern the ways in which people with CRF address their situation, to discover their distinctive stances toward their illness and therapy, to describe the various approaches they use to manage to continue to live on dialysis. Even resistance was seen as a way of coping that was efficacious for some (Littlewood et al., 1990, p. 108). In a similar way a recent paper by Sloan (1999), using the concept of "guarded alliances," characterized several "styles of interaction" with health professionals including "hero worship," "resignation," "minimal involvement" and "team playing," each style recognized as able to "reflect and meet the patient's needs at a particular point in time" (Sloan, 1999, p. 504).

This study, reported by Hardiker et al. (1986) and Littlewood et al. (1990), contrasts with a number of other papers employing similar concepts. Artinian (1983, 1990) in several papers, and Morgan (1988) used the concept of "role identities," that are defined by general social expectations about illness and consequent expected behavior by sick people. These papers postulated a series of roles that are steps in the "career" of the person with CRF leading to the "true dialysis patient role" (Artinian, 1983, pp. 10-13). The sociologist Gerhardt (1990, 1996) explicitly developed the notion of the "patient career", in several papers, *Patient careers in End-stage Renal Failure* and *Narratives of Normality: end-stage-renal-failure patients experience of their transplant options*, based on the functionalist sociologist Parsons (Gerhardt, 1996:141). In Gerhardt's view people with chronic illnesses such as CRF seek and generally achieve "'survival optimal' patient careers," "optimal patterns of status achievement or status sequences" (Gerhardt, 1990, p. 143), in short 'normality' (Gerhardt, 1996). However her study group, the basis of this optimistic view, were men who had remained married, that is with a wife to support them while living on dialysis, the group in the dialysis population

with the best prospects of 'normality.' Interestingly in her later paper, specifically examining marital relationships, Gerhardt (1996) did not address the issue of possible gender differences in such role adjustment at all. In contrast to the work of Gerhardt (1990, 1996) another paper, also using the concept of "patient careers" (Price, 1996) to consider chronic illness generally, recognized people living with chronic illness as subjected to psychological stresses causing an increasing "pervasive helplessness" (Price, 1996, p. 276).

While Artinian (1983, 1990) found an end point of acceptance of the "true patient role" whereas Gerhardt (1990, 1996) found "normalcy," both of these studies, employing the concept of the 'sick role', exemplify research that examines the experience of people on dialysis using a construct predicated on the viewpoint of the healthcare professional (looking 'at' the patient) rather than seeking the perspective of the people living on dialysis themselves. By contrast in a recent qualitative study Lindqvist et al. (2000), explicitly seeking the client perspective, found an overall theme of "wishes for independence and normality" including sub-themes of "wishing to maintain normality," "wishing to manage one's own life," "deprivation of one's normal life" and "concerns" (Lindqvist et al., 2000, p. 293). Rather than presuming that normality is re-established this study found the idea of 'normality' to be complex in the experience of people living on dialysis, a site of contested meanings. Similarly in contrast to the papers by Gerhardt and Artinian the study reported in Hardiker et al. (1986) and Littlewood et al. (1990), despite their use of a similar language of 'illness roles', is notable for their attempt to describe how people manage to live with CRF from their own perspective, pointing beyond a typology of roles towards an understanding of their interpretation of their experience.

One specific aspect of the renal client's therapeutic behaviour, considered generally in terms of "roles," is the changing sense of control of people living on dialysis that was studied by Devins et al. (1984) in a paper *The emotional impact of End-Stage Renal Disease: importance of patients' perceptions of intrusiveness and control*. They defined intrusiveness as the "extent to which illness or treatment interferes with important facets of the patient's life," by causing losses as a result of "illness-

induced barriers,” and control as the “awareness of abilities to obtain positively valued outcomes and avoid negative ones” that is threatened by the “helplessness implicit in ESRD” (Devins et al., 1984, p. 328). They found that increased intrusiveness and limited control each contributed to renal client’s negative mood. The barriers suggested include the “threat of death, dependencies on medical machinery and personnel, economic burdens, the large amount of time required for treatment, travel limitations, and dietary and fluid limitations” (Devins et al., 1984, p. 338). The authors underline the importance of these sorts of “more general determinants of the emotional impact of illness” (Devins et al., 1984, p. 339) rather than the actual severity of the disease process itself.

This study, contrasting with some objective studies of the burden of treatment that did not use the clients’ own assessments (Eitel, Hatchett, Friend, Griffin and Wadhwa, 1995; Wicks, Milstead, Hathaway and Cetingok, 1997), supports the suggestion, noted several times above, that individual adaptation to illness and therapy in CRF may be more significantly related to client perceptions and attitudes than to their objective situation as perceived by health professionals (Horne and Weinman, 1994; Reiss, 1990).

One early nursing study (Stapleton, 1983) of a small group of people living on dialysis explicitly illuminated a range of sources of “powerlessness,” lack of control in their lives, for the renal client, including the effects of the disease and hospitalization, changing family and staff relationships, the treatment regime and their own work. With the orientation provided by the organizing concept of “powerlessness,” this study sought to express the perspective of the renal client, often in their own words, revealing the ambiguities and frustrations that are part of life on dialysis. The limitation in this concept by itself, perhaps reflecting the character of renal replacement therapy in earlier years, is that it neglects the active participation necessary by the person seeking to manage to continue their everyday lives while on dialysis, that complements the powerlessness involved in the dependence inherent in the therapy itself.

Horne and Weinman (1994) made this explicit, referring to the “‘double bind’ of the requirement be self-directed and independent in adjusting to ESRD while at the same time acknowledging complete dependence on dialysis” (Horne and Weinman, 1994, p. 125), pointing toward an ambiguity in the life of the person living on dialysis. In a recent somewhat unusual paper Bevan (2000) combines ideas from functionalism about the ‘sick role’ with concepts of surveillance and the clinical ‘gaze’ derived from the French social philosopher Michel Foucault (1975, 1977) to produce a critical view of dialysis therapy, suggesting that the medical “*deus ex machina*,” has the character of an uncertain experiment. Through his analysis he illuminates the same ambiguities inherent in the requirement on the person with CRF to be independent despite remaining controlled by medically directed therapy.

These studies of roles and control, like those on patient compliance, all represent different ways of addressing one aspect of the consumer dimension in the renal setting, the therapeutic behavior of people living on dialysis. They all raise the question of the client response to therapy, how people manage to live on dialysis by integrating the requirement or the therapeutic regime into their own lifestyle. All these papers in their own way, whatever the specific issue they deal with, suggest the complex question of the ambiguity of the meaning of independence for the person living on in dialysis. A research methodology based on the interpretive paradigm, uncovering the meaning of the experience of illness and therapy for people with CRF, would allow the question of their behaviour in relation to renal replacement therapy to be addressed in a broader framework than that of compliance, ‘roles’ or control. Such an approach could produce an alternative way of conceptualizing the relationship of people living on dialysis to their illness and therapy and also to health professionals who provide services to them.

More generally these papers on compliance, patient roles and control can be understood as reflecting the interaction of the renal client with the renal setting, the “more general determinants of the emotional impact of illness” Devins et al. (1984, p. 339) allude to. But such studies, in terms of compliance, roles or control, are attempting to consider the adaptation of renal consumers without explicit reference to the renal setting as the context of their response to renal illness and therapy. An

interpretive approach would need an explicit contextual dimension in order to adequately address the perspective of the people living on dialysis in terms of their interrelationship with the renal setting.

2.8 The context of renal replacement therapy

There are very few studies that have addressed the influence of the renal setting itself on the well-being of people living on dialysis, explicitly conceptualizing the consumer dimension in relation to other dimensions of the renal setting (De Nour, 1994). A number of early reviews, notably by Abram (1978), when dialysis was still a relatively novel therapy, recognized the unusual character of the renal replacement program in which people with CRF participate. In particular he noted the stress caused to renal clients by the unnatural process of having to connect their body to a machine, even to maintain their life, required by renal replacement therapy. Rittman et al.'s (1993) study discussed above, untypical in current studies of client well-being, reasserted the potential difficulty in having to continually undergo dialysis, in terms of alienation caused by the dehumanizing technology of renal replacement therapy.

The distinctive character of the renal setting may not have been recently considered in the literature because renal replacement therapies are now a routine form of healthcare service. This absence of study may result from the dominance of the professional viewpoint in this specialized healthcare context, reflecting health professionals' difficulty in recognizing any distinctive views among the renal clients they work with.

One study by Kutner (1987), *Social worlds and identity in End Stage Renal Disease*, presented the renal setting as a distinctive social world created by various relationships in the dialysis setting itself. In particular she delineated the complexities of relationships of renal clients with dialysis peers who constitute a quasi-family in the renal clinic, with their own family members themselves and also renal health professionals (Kutner, 1987, pp. 34, 57, 63). Often quoting their own

words, she showed the identity of people living on dialysis within the social world created by the relationships associated with renal replacement therapy as not simply therapeutic, but rather a "marginal status" (Kutner, 1987, p. 67) characterized by uncertainty and alteration, and also reflecting an ambiguity in their relationships with family and health professionals.

A rare study using a critical perspective, by nursing researchers Brunier and McKeever (1993), *The impact of home dialysis on the family: literature review*, pointed to the effect of wider social influences in the renal setting. They reviewed studies on home dialysis over three decades. Analyzing this literature revealed conclusions not made explicit or perhaps even considered by the original writers. They showed how people on both home haemodialysis and CAPD, especially in the USA, depended on women as unpaid dialysis assistants. In the 1960s married men were most likely to be accepted onto home haemodialysis programs, both as most worthy for the limited services available and as having wives who were suitable assistants (Brunier and McKeever, 1993, p. 654). In the 1970s as in-centre dialysis expanded men were more likely to stay on home dialysis because they could continue in employment and had wives who could assist them in the evenings (Brunier and McKeever, 1993, p. 656). In the 1980s the rise of CAPD enabled older and younger people to receive long-term dialysis, usually with the assistance of a female family member (Brunier and McKeever, 1993, p. 657).

The authors consider how the influence of ideologies of the family and stereotypical female roles combine with the actual multiple activities of women as homemaker, worker and caregiver to place those women in families with people living on dialysis in a difficult position, while at the same time rendering this situation invisible. A recent *Descriptive study of home haemodialysis spouses*, almost all of whom one discovers from the methods section are in fact women, epitomizes this (Freisen, 1997). Likewise an earlier study of the "family caregiver" was based on interviews with 19 women (Peterson, 1985).

Brunier and McKeever's (1993) study showed how the expansion of dialysis services through self-care at home, first haemodialysis and later CAPD, relied on

female assistants whose work was not recognized either by health professionals or in the renal literature, contributing to the invisibility of their role in dialysis services. Such "care-taking" (see Anderson and Elfert, 1989) was not noted because it was assumed to be naturally part of their role as "homemaker" (Brunier and McKeever, 1993, p. 654; see Soskolne and De Nour, 1991, p. 501). Interestingly although this burden on caregivers is recognized in some other chronic illness contexts (Davidhizar, 1994; Ell, 1996), the renal setting has been characterized by the uncritical assumption of family support for the person on dialysis by health professionals, even though, but also perhaps because this has been necessary for successful long-term treatment (see above Cohen, 1995).

Brunier and McKeever (1993) have uncovered the context of the renal client and their family according to one particular standpoint, a feminist framework, showing in this case the effect of patriarchal social assumptions and practices in the renal setting. This exemplifies the way in which the situation of the renal client can be influenced by the different dimensions of the renal setting. While not made explicit by the authors one issue their study specifically points toward, in its implication that patriarchal assumptions and practices are mediated via the professional viewpoint, is the way unconsidered assumptions implicit in the dominant professional viewpoint can influence the client's experience of illness and therapy.

This example, from a feminist critical perspective, throws into relief the narrow decontextualized focus in most studies of people with CRF. Often the marginal speculative opinions seeking to explain 'difficult' research findings, in otherwise narrow studies, suggest the context of these studies. Reiss et al. (1986), for example, attempted to explain their unusual findings of differences in outcomes for different social groups living on dialysis in their study by commenting on the different social situations of these various groups. As noted above poor Afro-Americans are considered as far more flexible and better socially supported than ordered isolated middle class whites. Likewise Kutner (1994) attempted to explain her findings that QoL was less negative for elderly Afro-Americans than elderly Caucasians by hypothesizing that life on dialysis involves "less 'relative deprivation' of life opportunities" for them than it does for older white persons (Kutner, 1994, p. 504).

Articles by Somer and Tucker (1992) and Curtin et al. (1999) also offered speculative explanations for variations in compliance according to ethnicity in their studies. Tell et al.'s (1995) study found that Afro-Americans consistently reported better QoL scores than Caucasians which could not be explained by any of the variables measured in the study, but also found that social support affected QoL suggesting that the "social environment meaningfully influences not only the experience and course of the disease but also level of functioning and HR [health related] QoL" (Tell et al., 1995, p. 306). This paper concluded by noting that further studies examining the influence of "social environment" were needed to explain the ethnic differences in dialysis outcomes.

Brunier and McKeever's (1993) review is valuable in explicitly analyzing one influence on the experience of people with CRF, beyond the nature of the illness and the mode of therapy, specifically the effects of societal assumptions and practices about gender. In general the article is exemplary of the influence, usually unexamined in renal studies, of the professional, social or even economic context, different dimensions of the setting of CRF. The implication to be drawn from this study is that the experience of people living on dialysis can be most fully understood as their response within the complex contextual setting in which it occurs. Brunier and McKeever's analysis of one influence on the lives of the families of people living with CRF points towards the consumer perspective as representing one particular dimension among several that constitute the renal setting.

Brunier and McKeever's (1993) article clearly demonstrates how the perspective of some groups within the renal setting can be difficult to discern, even invisible. Their review of earlier studies shows how the lack of recognition of the role of female dialysis caregivers in renal clinical practice itself is replicated in these research studies. A critical feminist framework was necessary to uncover the patriarchal influence within the renal setting. This example supports the assumption of this study that in general the absence of research into the experience of people living on dialysis reflects the dominance of the professional viewpoint, which is the reason that the client perspective is not easy to discern in the renal setting.

This points towards the necessity, suggested several times above, for research to explicitly contextualize the viewpoints of the participants, whether health professionals, renal clients themselves or others, in order to understand their perspective in the renal setting. Their article also suggests, in contrast to an alternative approach assuming the 'alienation' of the renal client (Rittman et al., 1993 above; Bevan, 1998), that such contextualization needs to incorporate a critical view of the renal setting itself in order to discern the character of the unnoticed, even obscured consumer perspective in such a specialized context.

2.9 The New Zealand context

Because the local situation is characterized by several distinctive features findings from studies from other countries cannot be simply translated into the New Zealand setting. Firstly in New Zealand there is a high percentage of patients on self-care treatment at home (74%, Disney, 1999) compared to in-centre or clinic treatment. Other countries have a higher percentage of in-centre patients, with very little home haemodialysis (1.9% in the USA, Bremer et al., 1989). In the United States 'home dialysis' is generally assumed to mean CAPD (Eitel et al., 1995; Horsburgh, Rice and Matuk, 1998). By contrast the only published review from New Zealand reports on thirty years of "universal home dialysis" in Christchurch (McGregor et al., 2000). Another feature of the New Zealand situation is that there are a high proportion of Maori and Pacific Island people on treatment in the dialysis population (48% of new renal clients, Disney, 1999). Other countries also have a high incidence of people with CRF from ethnic minorities but they do not constitute such a high proportion of the total dialysis population.

The participants in the studies by Rittman et al. (1993), Cohen (1995), Sloan (1996), O'Brien (1990), Hoothay et al. (1990) and Gurklis and Menke (1988, 1995) were all on in-centre haemodialysis, the normative mode of treatment in the USA. The long-term survivors in Cohen's study had begun on self-care before transferring to in-centre treatment over time, reflecting the trend in management in the USA. Given that some studies have suggested that the quality of life is lowest for people on in-

centre treatment and highest for those on self-care treatment at home (Bremer et al., 1989; Evans et al., 1985) any conclusions from their studies need to be carefully related to the New Zealand context, where the normative mode of treatment is self-care dialysis at home.

In terms of the few studies that do address the experience of people living on dialysis in some way, the greater independence of those on treatment at home may give rise to a different quality of experience than those receiving in-centre treatment who will be a more dependent group. Similarly the significance of concepts such as compliance may be somewhat different in a context where people are normally responsible for their own treatment rather than simply receiving dialysis as a health service at a clinic. Thus in New Zealand contexts the experience of people with CRF may have a somewhat different quality than that of people in different context in other countries.

To date the only study of the QoL of those on dialysis in New Zealand was a Kanovsky score on all patients in the ANZDATA survey (Disney, 1995) that has recently been abandoned. A study began in 1997 which is seeking to measure QoL of all new renal clients coming onto dialysis in New Zealand as part of a larger project to develop indicators as criteria to enable rationing decisions about selection to ESRD programs (Hadorn, 1997). There have been no published qualitative studies yet about the experience of renal clients living in New Zealand.

2.10 Conclusion: discerning the client perspective

In this review I have considered the range of studies about the well-being of people living on dialysis, not only common forms such as studies of QoL, stressors and coping or compliance, but also the few studies using alternative methodologies. I have critiqued these studies according to their potential to contribute to understanding the experience of people living on dialysis.

From this overview it is apparent that, although the consumer dimension is regularly considered in the professional renal literature, studies generally utilize methodologies derived from the scientific therapeutic dimension. The lack of studies outside these formats, that examine the 'target group' from the point of view of the health professionals who work with them, reflects the professional difficulty in discerning the client perspective in such a specialized health setting. By producing assessments of their well-being, coping and compliance in terms of objective parameters set by the researcher, they reinforce the obscurity of the perspective of people with CRF in the renal setting. Speculation about the significance of many of the findings in these studies of patient well-being and therapeutic behaviour, that cannot be addressed in terms of the quantitative methodology adopted, suggest the need for alternative methodologies in order to adequately delineate the consumer dimension of the renal setting.

This discussion of the literature on the consumer dimension in the renal setting has shown the limited work available at present that attempts to understand the experience of people living on dialysis. Although there is a growing literature on the experience of chronic illness (Buchanan, 1989; Kleinman, 1988; Toombs, 1992) and some studies on specific chronic illnesses (for example various diseases in Benner and Wrubel, 1989; asthma by Benner, Janson-Bjerklie, Ferkeitich and Becker, 1994; rheumatoid arthritis by Brown and Williams, 1995; diabetes by Hunt, Valenzula and Pugh, 1996; ulcerative colitis Kelly, 1992), there have been few qualitative studies on the experience of CRF. This may be because, despite its label, CRF is not primarily viewed as a chronic illness by renal health professionals but rather as a specific form of organ dysfunction that can be successfully technically replaced allowing a reasonably normal life.

Only a few nursing studies (Brunier and McKeever, 1993; Cohen, 1995; Rittman et al., 1993 and Sloan, 1996, above), have attempted to consider the kind of topic being addressed in this research study into the consumer dimension of the renal setting. Through this review, contrasting these papers suggesting alternatives with the typical forms of research reflecting the dominant approach, I have established the value of an interpretive approach that incorporates a contextual dimension in

order to understand the experience of illness and therapy for people living on dialysis. The studies about compliance and the 'roles' or control of people living on dialysis point to the wider question of the response of the person living on dialysis to therapy within the renal setting. Brunier and McKeever's (1993) article suggests that such a contextual dimension, reflecting the character of the renal setting, needs to be critical in order to discern their perspective that is obscured by the dominant professional viewpoint.

In terms of the research topic in this study the renal literature about the well-being and therapeutic behavior of people living on dialysis points toward a possibility yet to be fully explored. This study is an attempt to contribute to such an exploration. In order to understand the concerns of Pakeha men living on home haemodialysis an appropriate methodology, interpretive with a critical dimension, needs to be articulated. This is the purpose of the next chapter.

Chapter 3. Methodology: a critical interpretive approach

This chapter develops a methodology for this study. The literature review suggested that a research topic such as this is best addressed by an approach that is not simply interpretive but also has a contextual dimension. Given the initial assumptions of the study, that people living on dialysis have distinctive experiences that are difficult to discern in the renal setting, their interpretations of their experiences may be most adequately understood by being contextualized within a critical view of the renal setting.

After setting out an initial assumption about the nature of research underlying this study, I will briefly review two traditions, Heideggerian hermeneutics and critical social science, which have been common forms, respectively, of interpretive and critical approaches in nursing research into this kind of research topic. After considering these two traditions I will review and critique the combination of interpretive and critical approaches as critical hermeneutics that has been advocated by some nursing researchers. In setting out some ideas from the theories that inform these research approaches this review will utilize the work of a number of social and nursing theorists on the methodologies being considered, rather than the primary works that themselves constitute the theoretical bases of these various research approaches. My aim is not to fully articulate the theories that have been drawn on by the different methodologies, but simply to indicate the theoretical orientations that inform them, in order to review their potential contribution to this research topic.

This overview of these different approaches will provide a basis to develop and position the methodology to be used for this nursing study of the consumer dimension of the renal setting. I will present an alternative to critical hermeneutics, named simply a critical interpretive approach, as an appropriate methodology to

understand the experience of a specific group of healthcare consumers. In this approach a researcher seeks participants' interpretations according to a hermeneutic approach but does so from a distinctive interpretive stance, a critical view of the renal setting. I will then outline some ideas derived from the thought of Michel Foucault that will enable me to establish a critical standpoint toward a given contemporary healthcare setting within this interpretive approach. This chapter provides a theoretical framework for this study.

3.1 Introduction: the interpretive turn.

An initial assumption of this study that is supported by the literature review, the necessity to work within the interpretive paradigm because the empirical analytic approach is not adequate to address a research topic such as this, provides a starting point to develop a methodology for this nursing research project. The phrase the "interpretive turn," highlighted by Rabinow and Sullivan (1989) in their introduction to *Interpretive Social Science*, summarizes the position taken by certain contemporary thinkers, of treating all knowledge as actually interpretive, because it is rooted in human social life that is inherently interpretive in character. In this view all human understandings, including specialized forms such as research itself, must use the range of pre-existing interpretations which constitute human social life, a set of shared meanings, as well as specific subsets within this, such as, in the case of research, those which define academic work (Rabinow and Sullivan, 1989, p.7).

This position destabilizes the positivist view that is prevalent in contemporary thought (Rabinow and Sullivan, 1989, p.10, see also Guba and Lincoln, 1994, pp. 106-7; Lather, 1991, p.2), showing that even so called 'hard' scientific research is only 'true' within the empirical analytic framework of this particular theoretical perspective. Thus Allen (1985, 1995), a significant nursing writer on the theoretical bases of research used in nursing, in a survey article categorizing research into three streams, views the empirical as actually subsumed under the hermeneutic, noting (Allen, 1985, p. 62, quoting Thompson and Held, 1982) "that the only foundation for the natural sciences, social sciences, ethics or critical theory is the 'unsettled

ground of rationally motivated agreement among participants’.” Likewise Howard (1982), in his book *The three faces of hermeneutics*, adopts a similar approach.

In this “non-foundationalist” (Allen, 1985, p. 60; 1995, p. 176) or “radical relativist” (Schwandt, 1994, p. 126; Thompson, 1990, p. 252) stance, negating the claim to definitiveness by any one form of knowledge, every human understanding is always an interpretation within a social context and is only relatively true within that context. Recent postmodern thinking has further, perhaps decisively, undermined any foundationalist position on human knowledge (see Allen, 1995, p. 178; Bernstein, 1986, p. 370; Kincheloe and McLaren, 1994, p. 143). From the relativist position of the recognition of the interpretive turn the empirical analytic represents one paradigm of human understanding in contrast to others such as the explicitly interpretive.

A basic implication of the interpretive turn is the denial of the possibility of isolating any Archimedean point from which to objectively view human social life and, thus, discover any discernible core reality underlying it (Rabinow and Sullivan, 1989, p. 6; see Wachterhauser, 1986, pp. 7-9). No normative paradigm, based on such a privileged viewing point created by expert consensus, as has occurred in the physical sciences, is possible in the social sciences because of the inherently interpretive character of social life (Rabinow and Sullivan, 1989, p. 5). As Schwandt (1994), in his review *Constructivist, Interpretivist approaches to human inquiry* notes, the phrase the ‘interpretive turn’ implies “that the activity of interpretation is not simply a methodological option open to social science but rather the very condition of social inquiry itself” (Schwandt, 1994, p. 119). We always understand from a perspective (Wachterhauser, 1986, p. 24); we are always within the hermeneutic circle (Rabinow and Sullivan, 1989, p. 7).

While the recognition of the interpretive character of human experience negates the possibility of any definitive interpretation of human social life, the relative character of human knowledge does not necessarily imply that all understandings are equally meaningful. Crotty (1998), in a text called *The foundations of social science*, distinguishing positivism, subjectivism and constructionism, describes the latter as

the view that "all meaningful reality as such, is contingent on human practices, being constructed out of interaction between human beings and their world, and developed within an essentially social context" (Crotty, 1998, p. 42). Just as with physical realities so with social realities in such a view, some interpretive approaches produce 'models' that are more meaningful than others (Schwandt, 1994, p. 129). Wachterhauser (1986, p. 26), introducing a collection of articles in *Hermeneutics and modern philosophy* makes the same point in his distinction between a relativism that is "skeptical" and an understanding from "a certain perspective."

Inevitably then from the position of recognition of the interpretive turn there are a variety of approaches to understanding human social life. While it has been common to sharply distinguish different theories of social research according to their differences, the relativist position enables a different perspective. The claim to definitiveness of any theoretical stance becomes meaningless, but each of these different approaches can be viewed as one form of interpretation of social life, imaged by the nursing writer Thompson (1990) in an important review article of different approaches to research in nursing, *Hermeneutic Inquiry*, as falling within an "arc" of understandings (Thompson, 1990, p. 242) created by the recognition of the interpretive turn. As a range of theories and research approaches about social life is a natural consequence of the interpretive character of human understanding, different, even contradictory, traditions of understanding human social life, from the empirical analytic paradigm to the interpretive paradigm itself in its various forms such as Heideggerian hermeneutics, can be understood as falling within the arc of the interpretive turn (Crotty, 1998; Schwandt, 1994).

The relationship between the various theoretical traditions that have influenced social research such as Heideggerian hermeneutics, critical social science and more recent approaches like Foucauldian discourse analysis can be conceptualized in different ways. Within the perspective created by the arc of the interpretive turn, while they cannot simply be arbitrarily combined, given their obvious elements of incompatibility, strands from different approaches can potentially be carefully integrated to produce models that are helpful to understand different social

situations. This process of creative synthesis can be discerned throughout modern thought, from Marx, who incorporated “German philosophy, French politics and English economics” with insights derived from his Jewish background in his theories (Taylor, 1967, p. 12), to Foucault whose work responded to influences such as structuralism, Marx and Heidegger (Dreyfus and Rabinow, 1982). The recognition of the arc of the interpretive turn enables theorists and researchers within disciplines such as nursing to actively develop different approaches to understanding and research into aspects of human social life.

3.2 Heideggerian Hermeneutics

In their effort to address issues of human experience and understanding of the sort considered in this study an increasing number of nursing scholars have used an approach, within the interpretive paradigm, derived from a contemporary understanding of hermeneutics based on the work of philosophers Heidegger and Gadamer. Given that ‘hermeneutics’ and ‘the interpretive paradigm’ are commonly used interchangeably, for example by Thompson (1990, *Hermeneutic Inquiry*) and Habermas (1972), I will specifically refer to this particular strand of the interpretive tradition as Heideggerian hermeneutics. In this understanding all human living is interpretive. Every person makes sense of, gives meaning to their life, by self-interpretation implicit in their activities, based on accepted interpretations implicit in the common taken-for-granted everyday practices that constitute the activities of human be-ing. As Thompson (1990, p. 237) puts it “everything that exists in the world exists for people through acts of interpretation and understanding... we cannot have a world, cannot have life at the cultural level, except through acts of interpretation.”

Individual interpretations are meaningful in terms of the social setting in which they are made, the set of established pre-understandings that constitute their context. In Rabinow and Sullivan’s (1989, p. 14) words “the intelligibility of any action requires reference to its larger context, a cultural world.” Language is the key bearer of culture. Warnke (1987, p. 111) notes that in the hermeneutic view “language

gives us a world” and Hekman (1986, pp. 110-111) states more strikingly “it is more correct to say that language speaks us rather than that we speak it.” In general, as Palmer (1969, p. 131) notes, “for Heidegger understanding (“verstehen”) is the power to grasp one’s possibilities for being within the context of the life-world.” Such individual interpretations are not disinterested but rather engaged, with a quality of “mine-ness”, an attitude of care or concern (“sorge”, see Steiner, 1978, pp. 96-100) or, as Leonard (1994, p. 49) puts it, “things show up as mattering.” Feelings, emotions, attitudes and interests are as important in human be-ing as thoughts or ideologies. As reported by Wachterhauser (1986, p. 35) Gadamer (1975) speaks of the issues of concern (“sachen”) that human language focuses on.

Although he would personally have been suspicious of such an application (Cohen and Omery, 1994, p. 147), Heidegger’s hermeneutic philosophy of be-ing, and its subsequent development by Gadamer, establishes a basis for research within the interpretive paradigm. The focus on human be-ing rather than the human being, on time (historicity) and context (situatedness), on language and meaning (self-interpreting activity), which Wachterhasuer (1986, p. 16) summarizes as “a historically situated, linguistically mediated, contextualist and anti-foundationalist theory of understanding,” provides a framework within which to structure research in social science. Based on the viewpoint that all human understanding is interpretive, a hermeneutic approach to research attempts to understand human social life through a reflective or systematic form of interpretation (Thompson, 1990, p. 231). This is commonly presented in research in the social sciences and also in nursing as the study of “lived experience” (Benner and Wrubel, 1989; Van Manen, 1990), a phrase deriving from Dilthey, a seminal figure in the hermeneutic tradition. Its aim is “to study the life-world as we experience it, rather than as our conceptualizing, categorizing or theorizing about it” (Van Manen, 1990, p. 9), to seek “understanding” through “grasping the subjective meaning of a person’s action from the actor’s point of view” (MacLeod, 1996, p. 138).

In the hermeneutic understanding to describe is always to interpret (Thompson, 1990, p. 237). Human living is already an interpretation, a “text” (Ricouer, 1979, p. 73; Wachterhauser, 1986, pp. 51,52), a “reading of experience” (Hiraki, 1992, p. 2).

Research is a special form of interpretation, an interpretation of an interpretation (Rabinow and Sullivan, 1989, p. 7). The lives of those being studied have a meaning for participants, according to the horizon of their world. The researcher brings a perspective, according to his or her different horizon, to the social setting being studied. The resulting interpretation of the human situation that is being investigated represents neither of the original interpretations but another interpretation derived from them (Benner, 1985, p. 7; Hekman, 1986, p. 151). Understanding for Gadamer (1975, p. 340) is a "fusion of horizons" (see Thompson, 1990, p. 245; Wachterhauser, 1986, p. 37), a "dialectic of interpretation in which the horizon of the interpreter and the interpreted are fused" (Thompson, 1990, p. 255). Thus all human understanding, including research, is circular, occurring within the hermeneutic circle (Gadamer, 1975, p. 235), "a moving dialectically between a background of shared meanings and a more finite focussed experience within it" (Thompson, 1990, p. 243).

3.3 Heideggerian hermeneutics and nursing studies

When illness and healthcare services are viewed as phenomena of social life, and nursing work is understood as a practice discipline within the context of healthcare services, a position exemplified in the works of Benner and Wrubel (1989) and Bishop and Scudder (1990), Heideggerian hermeneutics is an appropriate for of interpretive methodology for research. Complementing the dominant empirical analytic approach in healthcare studies with a hermeneutic approach can enable an understanding of the experiences of the client, whose wellbeing is supposedly the *raison d'être* of healthcare services. In the past MacLeod (1993, p. 181) notes that even nursing studies have "consistently overlooked or paid scant attention to the meaning for patients of their experiences." Several nursing writers have suggested that the hegemony of the empirical analytic methodology in nursing research, a reflection of its colonization by the dominant medical perspective, needs to be critiqued by research based on alternative paradigms, using methodologies such as Heideggerian hermeneutics (Allen, 1985; Dzurec, 1989; Thompson, 1983).

Benner (1985, 1994), a seminal nursing theorist and scholar, has pioneered a Heideggerian hermeneutic approach in nursing research. When nursing is understood, in terms of the interpretivist tradition, as a practice involving the phenomenon of illness and caring (Benner, 1985, p. 5; 1994, p. 122), nursing research attempts to understand the various participants' interpretations of their lived experience within the context of the given meanings of their particular healthcare setting. "The interpreter seeks to hear the voice of the participants" as "an embodiment and lived understanding of a world and a set of local clearings" (Benner, 1994, pp. 100-1), through a recognition of various dimensions such as situation, embodiment, temporality, concerns and common meanings (Benner, 1994, pp. 104, 105). MacLeod has summarized the value of the hermeneutic approach for nursing study.

The act of interpretation reveals the relational and contextual nature of being-in-the-world. It is this focus of hermeneutic phenomenology, on disclosing the relational and contextual nature of being-in-the-world through interpretation, which makes it useful for revealing the nature of everyday experience in nursing practice.

(MacLeod, 1996, p. 139)

Seeking to address the research topic of the concerns of Pakeha men living on home haemodialysis, the studies by Rittman et al. (1993), Cohen (1995) and Sloan (1996), considered above, support the value of an interpretive approach as an appropriate methodology, given the initial assumption they have distinctive experiences that are characterized by common concerns reflecting their shared position in as subjects of renal illness and therapy. This research project embodies the assumptions of the Heideggerian hermeneutic approach, in this thesis that renal consumers, like all other groups in the renal setting, have an understanding based on their interpretation of their experience, that can only be delineated by a researcher through another interpretation expressing her understanding of their interpretation of their experience.

3.4 Critique

However, in addressing the research topic of the concerns of Pakeha men living on home haemodialysis we have recognized that renal consumers make their interpretations of their experience within a specialized healthcare setting. The initial assumption of the study, that consumers' interpretations are not easy to understand because they are obscured by a dominant professional viewpoint in the renal setting, makes it difficult for the researcher to discern the features of their understanding of their distinctive experience. Using a hermeneutic approach alone in this particular setting could readily produce an image of the client perspective that would simply reflect the dominant professional viewpoint.

While Heideggerian hermeneutics recognizes that actors' interpretations are made within a social world that creates a horizon of meaning (Benner, 1985, p. 6, 7), a researcher adopting a critical standpoint explicitly acknowledges that the social context is complex, containing a variety of interrelated meanings, some conflicting with one another, reflecting different positions within the setting (Allen, 1995, pp. 177, 180; Thompson, 1990, p. 258). When it is recognized that all interpretation occurs within the cultural horizon that is actually a socio-political context then it is no longer possible to simply seek common or typical interpretations of the social world on the assumption that they are normative. A critical perspective recognizes that not only can there be various interpretations from different positions within a context (Allen, 1995, p. 179), but all interpretations are not equally apparent within a context, "not all social actors are heard, many social meanings are hegemonic, represent the interests of the few" (Thompson, 1990, p. 258). Further an interpretation made by some participants may itself be limited or inadequate in terms of their position in their context (Thompson, 1990, pp. 258, 265), perhaps because of the influence of the dominant ideology on their thinking.

The critical standpoint in research has utilized critical social theory, a broad theoretical tradition originating in the theoretical works of Marx, (1963; 1967; see Crotty, 1998; Fay, 1987, pp. 5-6; Kincheloe and McLaren, 1994, p. 139). Marxian class analysis was the exemplar of the critical approach. Social power, for Marx the

control of the means of production, produced influential ideologies designed to legitimate and consolidate control by inculcating a 'false consciousness' of their position among large subjugated groups in a social situation, resulting in their 'alienation' from their human potential. Marx re-envisioned the different positions of groups in society, no longer simply accepting them as constituting a natural hierarchy as had generally formerly been assumed in conservative understandings, but critically re-viewing them as representing different material interests which are often in opposition to one another. Critical analysis of the oppressive ideologies in play in a social situation enables the possibility of emancipation for oppressed groups. Critical social theory, in various manifestations, has been applied to the working class in relation to the capitalist class, women in relation to men, or ethnic minorities in relation to the majority cultural group (see summary statements in Allen, 1995, p. 180; Crotty, 1998, p. 121; Fay, 1987, pp. 30-31; Giddens, 1971, pp. 61-64; Lather, 1991, pp. 1-4; Thompson, 1990, p. 258).

Critical social science recognizes the significance of the social structures that constitute the context of the interpretive views of those within it, the social context itself as influential in shaping the meanings that individuals create. Allen, Benner and Diekelmann (1986, p. 34) note that critical social science "differs from hermeneutics by its interest in the relationship between meanings - including embodied activity - and social structures or power." Rather than simply assuming as given the social horizon within which meanings arise, as in the hermeneutic approach, the critical approach analyses the social structures or "the conditions through which meaning is constructed" (Lutz, Dupree Jones and Kendall, 1997, p. 26; see Allen, 1995, p. 177). The critical perspective assumes that individual's interpretations are likely to be distorted by the dominant ideology and so need to be critically analyzed in terms of the social conditions that shape the context.

Not only does critical social science problematize the Heideggerian hermeneutic approach by suggesting that there are various conflicting interpretations reflecting different positions within a social situation, it also critiques the position of any researcher in relation to that setting, questioning how adequately he can discover the views of participants. The complexity of any social context being studied is further

complicated by the relationship of the researcher, who is within his own context, to it (Lather, 1991, p. 2). While the Heideggerian hermeneutic approach recognizes that an empathetic 'fusion' of the researcher with their understanding (Thomson, 1990, p. 246) resulting from research does not actually represent the participants' views, because the researcher is himself positioned in relation to the research, it assumes that the researcher's interpretation is valuable because it does to some extent reflect the participants' views. From a critical standpoint, by contrast, because the researcher is in a different position from the participants (Thompson, 1990, p. 228; 1991) the limitations of his capacity to grasp the participants' view is explicitly acknowledged.

In contrast to the Heideggerian hermeneutic approach the critical standpoint explicitly recognizes the "value ladenness of inquiry" (Lather, 1991, p. 2), that, as Thompson (1990, p. 228) puts it, "our interests always show up in the questions we ask, the concepts we use, the methods we choose," an insight that derives from Marx himself (Marx, 1967, pp. 102, 103). It can be said of all knowledge, including research, "what we call information always involves an act of human judgement" (Kincheloe and McLaren, 1994, p. 145) or, as Rabinow and Sullivan (1989, p. 26) note, "Theory is ... itself an interpretation." Lather (1991, p. 8) summarizes "we are both shaped by and shapers of the world... research paradigms inherently reflect our beliefs about the world we live in and want to live in." So not only are their different interpretations by various participants according to their position within a social context, there can be different interpretations by different researchers according to their position in relation to a context. A critical approach acknowledges that the researcher's position always involves a stance in his work.

Within nursing research some recent writing, from a critical perspective, has questioned the Heideggerian hermeneutic approach pioneered by Benner. Thompson (1990, p. 273) has observed that Benner's methodology is inconsistent with her Heideggerian theory because her approach in practice is objectivist as she "fails to situate herself in relation to the material" or "identify her interests in their practices as part of the larger cultural scene." Koch (1995, p. 834) notes that in Benner's work the "interpreter remains aloof" and thus her work is "hermeneutics practiced

outside the [hermeneutic] circle.” Allen (1995, p. 175) has also commented that Benner’s work “looks like” an objectivist analysis.

More generally Thompson (1990, pp 270, 272) identifies that Benner’s Heideggerian hermeneutic approach, which she summarizes as the search for “situated meaning,” lacks a “cultural frame of reference.” She is “not interested in the politics of situated meaning,” that “political contexts influence nursing practice,” how “the wisdom of nursing is gradually being eclipsed by the policies of political bureaucracies” (Thompson, 1990, p. 272). One consequence of this is that she tends to treat nursing itself as a unitary activity, failing to recognize the differences among nurses themselves in terms of class, ethnicity, gender or sexual preference (Thompson, 1990, p. 273). These reviews of Benner’s work, mixing critique of it both as inconsistent in terms of a Heideggerian approach and also as inadequate as hermeneutics from a critical standpoint, arise because she has not made explicit her own position as researcher.

In response to these criticisms in her recent publications Benner (1990, 1994) has attempted to position her work by characterizing her studies as “clinical ethnographies” that “uncover practical experiential knowledge gained by patients in recovery or in management of a chronic illness” whose purpose is to “understand the relationship between the lived experience of an illness (the bodily experience and know-how) and the illness as domesticated and understood theoretically and ‘scientifically’ by medicine” (Benner, 1994, p. 122). For example “instead of looking for ‘compliance’ or ‘non compliance’ the clinical ethnography seeks to understand the patient’s view of their situation” (Benner, 1994, p. 122). In Benner’s opinion, in her reply to Thompson (Benner, 1990), which distinguishes her own position from critical social science, she introduces an element of critique into her studies by discerning perspectives otherwise unnoticed through the use of a Heideggerian hermeneutic approach in contrast to the dominant empirical analytic paradigm. Certainly the distinction, between illness as lived and as domesticated by medicine, points towards the different perspectives of various groups of actors within a health setting. Her positioning in this paper articulates her stance in contrast to critical social science.

In this study seeking to address the concerns of Pakeha men living on home haemodialysis the studies by Brunier and McKeever (1993) and also Reiss et al. (1986; see Reiss, 1990), considered above, support the value of a critical approach that addresses the influential social context within which individuals' interpretations are made, given the initial assumptions of this study that their distinctive experience is not easy to understand because they are obscured by the dominant professional viewpoint in the renal setting. This study embodies the assumption of the critical approach that there are different interpretations within a social setting, some more powerful than others, reflecting the position of different groups within the setting. It recognizes that renal consumers' interpretations, although influenced by the scientific therapeutic ideology shaping this specialized health context, may differ from the dominant viewpoint in reflecting their own distinctive position within the renal setting.

3.5 Critical hermeneutics

Several nursing scholars have recently advocated a particular methodology, critical hermeneutics, which seeks to address the complex relationship between interpretation and context by combining the insights of the interpretive and critical traditions in social research. This approach is derived from the work of Habermas, a late theorist from the Frankfurt school. This group of theorists had reinterpreted Marxian alienation as being caused by a dehumanizing rationality reflecting the dominance of industrial technology and organizational bureaucracy in contemporary society. Habermas developed this critical approach, which already reflected the influence of Weber and Heidegger, by explicitly incorporating hermeneutics into his theory in which he attempted to reconstruct critical social science in a contemporary form, an exemplification of the creative synthesis of different traditions within the arc of the interpretive turn.

Habermas (1972) analyzed the dominance of scientific thinking in contemporary society through his well known characterization of three different forms of

'knowledge-constitutive human interests', the technical, the practical and the emancipatory, that motivate specific forms of human knowledge or rationality, the empirical analytic, the hermeneutic and the critical (see Habermas, 1972; Giddens, 1977, 1982; Ricoeur, 1986; Thompson and Held, 1982).

Habermas (1972) critiqued Marxism for its exclusive focus on the material basis of society, in his terms the technical interest, recognizing the hermeneutic as expressing a significant aspect of human social life, but then suggested that the interrelation of these two interests points toward the third decisive interest, the emancipatory (Giddens, 1995; Ricoeur, 1986). This emancipatory interest produces a critique of ideology, in capitalism a critique of the dominance of empirical analytic knowledge, the contemporary problem of "scientism" or "the universalization of technical reason" (McCarthy, 1978, quoted by Howard, 1982, p. 93; Roderick, 1986, p. 122). In modern society this ideological distortion, the colonization of the sphere of hermeneutic knowledge through the dominance of the technical interest as science and technology, requires a critique based on the emancipatory interest (see Giddens, 1995, p. 250).

Initially in *Knowledge and Human Interests* Habermas (1972) sought a basis for critique, a ground for distinguishing whether communication is distorted by ideology or not, in the example of Freudian psychoanalysis understood as a process in uncovering self-understanding hidden from the subject themselves. Later (1984) he moved to a broader base in linguistics in his theory of "communicative competence" as a foundation for critique. A "universal pragmatics" of language, in which "dialogue-constitutive universals", predicated on an "ideal speech situation", is proposed as a scientific theory providing a standard against which actual dialogue can be judged (see Bernstein, 1986, p. 355; Crotty, 1998, pp. 143-144; Giddens, 1977, pp. 143, 144; Howard, 1982, pp. 115, 117). This regulatory norm of the ideal speech situation constitutes a basis for the critical interest.

For Habermas (1972) the emancipatory interest results in critical thinking he characterizes as "depth hermeneutics", translated by Thompson (1981, p. 217) as

“critical hermeneutics.” While hermeneutics simply focuses on communication, the examination of systemic distortions in communication by ideology reinforcing human alienation in social settings requires “depth hermeneutics”, a form of self-reflection to enable what Ricoeur (1986, p. 320) has termed the “‘dissolving’ the constraints arising... from institutions.” Although recognizing the significance of hermeneutics in human social life, Habermas (1972) focuses on critical theory as revealing the social structures that influence individual interpretations to enable researchers to discern whether such interpretations are ideologically distorted or not. While the significance of hermeneutics is apparently recognized within his framework it is finally relativized by being subsumed within the critical, the interpretations of individual actors being viewed as determined by contextual conditions. Despite its name suggesting a specific form of hermeneutics, in fact this approach is a form of critical theory that incorporates the interpretive perspective.

Habermas’ (1972) theory, a key source of critical hermeneutics in nursing, has been influential because it reformulated the critical perspective derived from Marx in a challenging form in the contemporary setting, while also at the same time relating the perspectives of critical social science and hermeneutics in a single theory. However his work has been intensively critiqued in recent years in several ways.

It has been noted that Habermas (1972) has made rationality the basis of his theory, from the tripartite division of interests that shape rational thought to his notion of a rational consensus as the basis of unconstrained communication. This cerebral approach underrates the other aspects of human experience and communication, from esthetic to ethical, that other theorists from Marx to Heidegger have recognized in their thinking about the human condition. Thus Heller (1982) contrasts Marx with Habermas,

The sensuous, the needing, the feeling human being never ceased to be his [Marx] main concern. Habermasian man has, however, no body, no feelings; the structure of personality is identified with cognition, language, interaction.

(Heller, 1982, p. 22)

Further it has been pointed out that by focussing on distorted communication in accord with his rationalistic approach, Habermas has negated the complex relationship between rationality and power that has been questioned by theorists from Marx through Weber to Foucault (Smart, 1983, p. 123). According to the well-known social philosopher Giddens (1995), despite Habermas' (1972, 1984) overt orientation to the critique of domination, by focussing on the distortion of communication he fails to analyse the operation of power through control of resources, this being subsumed in what he narrowly characterizes as the technical interest. Giddens notes (1995, p. 256) "power is as integral a component of all social interaction as norms are.... The critique of domination [in Habermas' work] came to turn upon freedom of communication or dialogue rather than upon material transformation of power relations." As a result in his view, despite its intent, the critical edge of his analysis is vitiated.

A contrasting criticism has questioned the rationality of Habermas' (1972) theory. His thought reflects the critical tradition stemming from Marx, summarized in the labels of "scientific Marxism" or "historical materialism" (Roderick, 1986, p. 141), in claiming to be in some sense scientific (Bernstein 1986, p. 355; Rabinow and Sullivan, 1989, p. 19), to provide an objective structural analysis in order to discern the underlying social reality beyond appearances (Kincheloe and McLaren, 1994, pp. 139-142; Lather, 1991, p. 3, 4). Of Habermas' (1972) effort to ground the critical interest in the 'ideal speech situation' Bernstein (1986, p. 356) has asked whether any actual communicative situation, especially such an unusual one, can imply a "regulative ideal" that is "necessary" or "unavoidable" against which any communicative situation can be measured. If his theory of the 'ideal speech situation' cannot be formulated as a testable hypothesis in what sense is it scientific? Alternatively, if it is potentially disprovable is not the basis for the critical interest uncertain (Bernstein, 1986, p. 357)? Reflecting this criticism Hekman (1986, p. 139) has provocatively asked whether the 'ideal speech situation' is not in fact a surreptitious return to foundationalist thought?

3.6 The critical meta-narrative

Despite the various efforts to establish its basis as definitive, in general critical social science is problematic precisely because none of the specific versions in which it is presented, from Marx to Habermas, are convincing (Howard, 1982, p. 169). Recognition of the tradition as containing a sequence of attempts to demonstrate its basis as scientific clarifies a common intention to justify the critical standpoint that has already been accepted as valid. The definitiveness of the critical approach, through its self-characterization as scientific, is actually, as unproven, in its own terms an assumption.

From a postmodern perspective the different versions of critical social science, in assuming the critical perspective as normative, can be recognized as sharing in a common "grand narrative" or "meta-narrative" (Crotty, 1998, p. 211; Hoy, 1988, p. 37; Kincheloe and McLaren, 1994, p. 146) that has underpinned all critical theory since Marx. This narrative pattern, of oppression and liberation, embodying the idea that complex social structures negatively determining individuals' experiences must be replaced to enable them to realize their potential, is the key story that explains all other human stories. This critical meta-narrative is "a version of the modern meta-narrative of social and epistemological progress" (Hoy, 1988, p. 37) counter to the dominant conservative meta-narratives and also contemporary theories of social evolution based on empiricism. In this sense Habermas' theory, the source of critical hermeneutics, is indeed foundationalist as Hekman (1986) suggests.

Recognition of the interpretive turn implies the displacement of all meta-narratives that, in the postmodern milieu, have been decisively undermined. The critical meta-narrative that underlies critical social science from Marx to Habermas has as little authority as any other meta-narrative in a postmodern world (Kincheloe and McLaren, 1994, p. 146). Critical social science is obviously one among a number of

132). The character of the critical meta-narrative as precisely a narrative pattern expressing a view of the world rather than an objective analysis of it, becomes evident in the difficulty integrating various analyses based on it in different contexts, Marxist analyses of class with feminist analyses of gender and cultural analyses of colonization.

The underlying meta-narrative of oppression and emancipation that orients critical analysis represents a distinctive standpoint, a form of interpretive thinking in relation to a situation (Kincheloe and McLaren, 1994, p. 151; Lather, 1991, p. 4). The critical orientation is hermeneutic, one perspective that views the social context in a particular way as manifesting a variety of contrasting interpretations that are influenced by structural or contextual factors, where certain powerful views can suppress or distort other understandings. As Ricoeur (1986, p. 334, 335) has noted Habermas' (1972) emancipatory interest "presupposes" hermeneutics (see Thompson, 1981, p. 67). More generally Arnason (1987) has shown the hermeneutic subtext in critical theory. Thus although critical social science, in its various forms, claims to decisively delineate the complex conditions that determine individuals' interpretations in a social setting, such a view is not justifiable as definitive, but rather can be recognized as interpretation that is open to question. In these terms critical hermeneutics can be recognized as a specific interpretive approach that seeks to privilege critical social science over the interpretive itself.

The normative role given to the critical dimension in critical hermeneutics is untenable when it is recognized, in the light of postmodern perspective, to be an interpretive position reliant on the assumption of the meta-narrative of oppression and liberation. The critical strand in human traditions does not rest on any universal theoretically defined imperative, a quest of critical theorists from Marx to Habermas that actually reflected their own cultural location. The critical standpoint can rather be understood as an insightful perspective embedded within different human histories, Marxism and critical social science being the form in which this alternative perspective has been articulated in the modern Western tradition. The critical meta-narrative is one expression, shaping critical thought since Marx, of the critical perspective within the arc of the interpretive turn.

On the basis of their claim to a definitive social analysis critical social science theorists' have adopted a distinctive stance towards the social context they are analyzing, not simply accepting a social situation that they discover as in various forms of the hermeneutic approach, but actively seeking to alter the social situation on the basis of their analysis of "oppression" in terms of their goal of "emancipation" (Allen, 1985, p. 58; Kincheloe and McLaren, 1994, p. 154; Lather, 1991, p. 2). This is exemplified by the promotion of revolution by the masses by Marx, the founder of this tradition, who said the aim is not to understand history but to change it (Marx, 1963, p. 84). In a postmodern context this can be recognized as an attempt to realize the meta-narrative that inspired his analyses.

Lather (1991) has summarized a view, derived from feminist thought that is congruent with a postmodern awareness, suggesting that rather than confidently unmasking 'false consciousness', critical social scientists can only modestly offer to contribute analyses about the influential interrelationship of particular ideologies with the power relations in any social situation, in order to facilitate reflection on the possibility of alternatives to them, in short "empowerment" (Lather, 1991, p. 3; see Allen, 1985, p. 62; Thompson, 1991). In this approach the critical viewpoint is recognized as a stance that can be adopted if it is helpful in particular circumstances.

The writings of Ricoeur (1979, 1981, 1986) relating Habermas' (1972) thought to that of Gadamer (1975), another creative synthesis within the arc of the interpretive turn, points in this direction. Viewing hermeneutics and critical social science as illuminating different aspects of a dialectic inherent in social activity (Ricoeur, 1986, p. 328), he notes that "man can project his emancipation and anticipate an unlimited and unconstrained communication only on the basis of the creative reinterpretation of cultural heritage" (Ricoeur 1981, p. 97). In his own writings Ricoeur (1979) has focussed on the objective 'text' as a sign indicating a social reality beyond itself around which interpretations are organized. Through a process of "distanciation" and "appropriation" it is possible to discover "a sort of being-in-the-world unfolded in front of the text" (Ricoeur 1978, p. 40).

The notion of a dialectic of distancing and appropriation as a strategy to interpret a text that 'tells' of the social situation in which it was produced is a perspective that can be helpful for social research. However viewing the text as somehow objective, independent of its creator and interpreter (Ricoeur, 1986, pp. 328, 329, 331; see Hekman, 1986, pp. 141,143), as reflecting what Howard (1982, p. 170) has described as some inherent "generic communicative competence," ignores the fact that such a text is itself an embodied interpretation that can only be explicated through further interpretation. It has no meaning in itself at all. The text is only ever apprehended as interpreted by someone, it is never accessible in itself. The work cannot, as Ricoeur (1986, p. 329) suggests, "decontextualize[s] itself." It was produced within a specific context and is always read within a context, inevitably different with the passing of time from that in which it was produced.

Even the text itself does not necessarily simply persist but may be modified by scholarship. This is now specifically recognized in the postmodern awareness of "intertextuality" (Lather, 1991, p. 9), an expression of the "radical relativism" (Schwandt, 1994, p. 126) here characterized in terms of the arc of the interpretive turn. The dialectic of "belonging and distancing" (Ricoeur, 1986, p. 328) is not based on the apparent objectivity of the text but the location of the 'reader' in relation to the context within which the text was produced. In general Ricoeur's work, relating Habermas and Gadamer to produce a novel synthesis, can be read as provocatively reopening the question of interpretation and context through consideration of the relationship of hermeneutics and critical social science. His work points towards the critical as a perspective within the hermeneutic.

3.7 Critical hermeneutics in nursing research.

Within nursing research several writers, referencing Habermas (1972) and Ricoeur (1979, 1981, 1986), have advocated critical hermeneutics as a methodology addressing the limitations of a purely hermeneutic approach for research in nursing. In seeking, within the nursing literature, research methodologies incorporating

hermeneutics and a critical perspective, in order to address this research topic, I discovered various articles explicating critical hermeneutics.

For Allen (1985, 1995), in several articles reviewing different research approaches and their theoretical bases, critical hermeneutics is “the interpretive tradition that engages in debates about texts that have been coerced or systematically distorted by unequal power relations” (Allen, 1995, p. 176) with a “commitment to both understanding and exposing how power imbalances and systematic misunderstandings constrain and distort interpretation” (Allen, 1995, p. 180). This approach achieves this through the analysis of “the communicative conditions under which meaning is produced and the power/justice dimensions of intended and unintended social consequences of interpretations” (Allen, 1995, p. 180). In particular according to Allen nursing practice needs “to be interpreted in its social political locations” (Allen, 1995, p. 180). It cannot ignore its role in the American health industry (Allen, 1995, p. 174). If it does, according to Allen, nursing theory as discourse about nursing identity becomes part of “the misrepresentation of ideology” (Allen, 1985, p. 61) in the dominant medical discourse. In these terms “our current definition of nursing as a science that diagnoses and treats parodies objectifying medical language” (Allen, 1985, p. 63).

For Thompson (1990), in a major review article of different approaches to research and their theoretical bases developing her earlier doctoral work (1983), a critical hermeneutic approach is based on the recognition “that not all actors are heard, the tradition contains many socially accepted meanings that are hegemonic, that it is important to demystify socially oppressive meanings that may be unnoticed by the participants themselves” (Thompson, 1990, p. 258). This approach attempts “to deconstruct the role of tradition and the way tradition operates to establish meaning” (Thompson, 1990, p. 263). Critical research “uncovers hidden sources of coercion, power-over and domination that are embedded in every day experience of the fact world” (Thompson, 1987, p. 28) through “naming “sources of institutionalized power relations ... conditions and social practices that reproduce relations of domination” (Thompson, 1987, p. 28). It is “committed to critique of false consciousness and an active non-elitist engagement with participants to address

social injustices" (Thompson, 1990, p. 266). Thus nursing scholars need to recognize "our role in the social production of knowledge" (Thompson, 1990, p. 264), that "the interests of scholars are always involved in interpretation" (Thompson, 1990, p. 265). Lutz, Dupree Jones and Kendall (1997, p. 26), quoting from Allen and Thompson, note that critical hermeneutics involves the "combined application of the interpretive and critical traditions although it clearly lies more on the side of the critical than the interpretive tradition." Ruangjiratain and Kendall (1998), with similar referencing, repeat the same views.

These writers advocating the use of critical hermeneutics as an approach to research in nursing have followed Habermas by recognizing the interpretive perspective but bracketing it through a critique, contextualizing individual's interpretations in terms of the structures or conditions that influenced their interpretations (Allen and Hardin, 1998; Hiraki, 1992; Lutz et al., 1997; Thompson, 1983, 1990). But these articles also appear to reflect the ambiguities that have been critiqued in their source Habermas. While these writers formally recognize critical social science as one strand of the interpretive tradition (Allen, 1995, p. 178; Thompson, 1990, p. 258), their actual treatment of critical theory in their articles do not obviously reflect this perspective, but rather appear to follow a Habermasian approach, treating critical analysis as definitive, if not actually 'scientific'.

Allen (1985, 1995) explicitly affirms the non-foundational character of all human knowledge, that "all scientific activity is hermeneutic in that it is a socially structured, meaning generating and perspective dependant human pursuit" (Allen, 1995, p. 181). Yet when he moves beyond the hermeneutic question of "what people mean" (Allen, 1995, p. 179) to the critical question of "the conditions under which meaning is produced," talking of "power imbalances and systemic misunderstandings" and "social and political locations" (Allen, 1995, p. 180) these 'conditions' or social structures sound as if they are definitive, even objective entities, a language not obviously compatible with an underlying notion of all human understanding as hermeneutic. Indeed in his early article he follows Habermas in holding that "rationally motivated agreement" can be "settled" in terms

of an “ideal speech” situation manifesting the values of autonomy and responsibility (Allen, 1985, p. 62).

Thompson (1990, p. 258) likewise views critical hermeneutics as a “branch” of interpretive theory. She speaks of the “radical relativism” (Thompson, 1990, p. 252) of human knowledge reflecting what has been termed by White (quoted in Lather, 1991, p. 1) “the irreducible disparity between the world and the knowledge we might have of it.” However Thompson (1990, pp 260, 264, 265) describes critical hermeneutics as analyzing “oppressive conditions” or “structures,” “systemic features of contemporary society” or “distorted power relations” as if these were objective entities that are being definitively delineated rather than interpretations of social reality.

Generally these writings by Allen (1985, 1995) and Thompson (1983, 1987, 1990), insightful into the potential of the interpretive and critical approaches within nursing research and influential in shaping my thinking in this study, do appear, in their use of critical social science and Habermas, to uncritically embody the critical meta-narrative. Reflecting the context of the late eighties in which they were produced, they talk freely of oppression, injustice and liberation, constructs that are approached more cautiously in postmodern critical thinking where they are recognized as ambiguous and contestable (Crotty, 1998; Kincheloe and McLaren, 1994), as a more recent work by Thompson (1991) Allen and Hardin (1998) themselves suggests.

3.8 A critical interpretive approach

Recognition of critical hermeneutics as a form of interpretive approach, incorporating hermeneutics in a particular way into the critical social science tradition, allows the possibility, within the arc of the interpretive turn, of reconceptualizing the complex relationship between individual interpretation and social context in a different way. Given the critical is an interpretive stance, critical social science being its typical form in the 20th century, there are potentially

different ways in which it can be articulated. While critical hermeneutics is one methodology appropriate to address the character of social settings in which actors participate, an alternative formulation that is not reliant on Habermas and the critical meta-narrative, here called simply a critical interpretive approach, can be used in order to address research questions, such as the topic of this study, seeking to understand the experience of a specific group from their own perspective within a given social setting.

In contrast to the common approach of critical hermeneutics, seeking to analyse the social conditions, structures or discourses that influence individual interpretations within a setting, a critical interpretive approach is rather hermeneutic from a critical standpoint. Such an approach develops the hermeneutic awareness that the researcher can never be objective but is always positioned within the horizon of his or her 'world,' in terms of the insight of critical social science that there is no disinterested position in relation to a social context. Recognizing the critical approach in the contemporary postmodern setting as being itself an interpretive position, the researcher consciously adopts such a critical stance in contrast to more conservative views of other hermeneutic studies.

In a critical interpretive approach the researcher, in a study such as this, seeks the interpretation of the participants in a social setting according to the hermeneutic understanding, but does so from a distinctive interpretive stance, a critical view of the context itself. A critical interpretive approach involves engaging in interpretive work by adopting the critical standpoint that there can be a variety of interpretations reflecting different positions in a particular context, that certain interpretations may be distorted or obscured by the dominant ideology in a social setting. Recognizing the character of the context in terms of differences in knowledge and power of various groups within it, the researcher, using a hermeneutic approach with a critical orientation, does not simply accept the common interpretation at face value, but attempts to discern a range of interpretations in terms of the different positions of various groups within the social setting. By contextualizing the views he is given by participants he can discern interpretations that may be less visible, even opposed to the dominant viewpoint.

The researcher's interpretation of the participants' interpretations is in terms of his own interpretive stance, in this case a critical view of the situation. In order to understand the experience of a particular group, in contrast to other groups in the setting, the researcher using this critical interpretive approach may articulate his critical standpoint by producing a sketch of the "conditions" (Allen, 1995, p. 177) of the given context, the common interpretive perspectives from the different shared position within the setting, in order to contextualize the individual interpretations of their experience. Such a sketch could use different sources, such as, in this study, ideas from Foucault (1975, 1977, 1980), a controversial postmodern thinker who can be understood as pointing towards a new form of critical theorizing that no longer relies on the meta-narrative of oppression and liberation (Blackler, 1998; Hoy, 1988).

A critical interpretive approach entails a consciousness of the relationship of the researcher to the setting he is researching. In the critically focused hermeneutic view, the impossibility of objectivity is recognized according to the hermeneutic approach, that the researcher can never grasp the participants' understandings as such but will always only have his own researcher's understanding of the participants' interpretations. The researcher employing a critical interpretive approach also acknowledges the "distance" (Ricoeur, 1986, p. 328) between them, in accord with the insights of critical social science, the difficulties and limitations in reaching an empathetic understanding of their interpretations of their experience, because the researcher is in a different position than the participants. In particular the researcher's interpretation of the participants' interpretations can only be made in terms of his own view of their position within the setting.

But such a "critical distance" (Thompson, 1990, pp. 261, 263) actually enables a perspective, an explicit view of the situation that can be articulated in the researcher's sketch of the context. It is because his interpretation of the participants' interpretations are distanced that the researcher is able to contextualize the participants' views. This enables the researcher to reinterpret the participants' interpretations in terms of their context in a way that they cannot. The researcher

can recognize the interpretation of some participants as only one of several different interpretations within that context, according to his perspective on the positions of the various groups of participants in the context.

Aware of the common interpretation from his critical standpoint toward the context, the researcher, in a study such as this, is able to discern the interpretations of some of the participants in a particular position that may be obscured by the dominant ideology within the context. Interpretive understanding becomes explicit judgment, from the researcher's position, about various participants' interpretations as being more or less "constrained" by power imbalances and systemic misunderstandings (Allen, 1995, p. 180). Analysis of individual interpretations, through contextualizing them in terms of the critical sketch of the context, enables the researcher to represent their shared understanding as a group from their common position in the setting. A critical interpretive approach seeks participant's individual interpretations of their experience, but then critically reinterprets them as a group in order to understand their experiences.

The researcher's re-interpretation of their individual interpretations is a "construction" (Crotty, 1998, p. 42; Schwandt, 1994, p. 118), modelling the perspective of a group of participants in a given context, according to the critical stance articulated in his sketch of the setting. By explicitly recognizing the 'distance' between them, the critical interpretive approach gives the researcher a perspective that, paradoxically, can actually enable them to empathetically 'hear' of the quiet voice of participants from groups that are almost silenced by the dominant ideology. The dialectic of empathetic engagement and critical reflection in this approach reflects Ricoeur's (1986) dialectic of distancing and appropriation.

Such positioning, through recognizing the distance between them, also requires acknowledgment of the viewpoint, interest, of the researcher. It demands a recognition of the power of the researcher, as interpreter of the participants' interpretations, to distort or suppress their views (see Dickson, 1990, p. 24; Thompson, 1991, p. 33). Any researcher has some relationship to their study group, even if it is one of indifference other than to use them for academic advancement, a

position that in itself reflects the power of the researcher in relation to their study group. From the choice of research topic, through the manner of handling it, to the conclusions about it, the research reflects his own viewpoint. Positioning requires the researcher, rather than claiming either clear objectivity or an empathetic subjectivity, both of which mask his own stance, to acknowledge his own situation in relation to his research topic. Positioning finally means not simply locating himself but acknowledging that he adopts a stance in relation to what he is researching, in this form of research a critical interpretive standpoint.

Critical hermeneutics, the common synthesis of the hermeneutic and critical social science traditions, produces interpretations in terms of social conditions such as class, gender or ethnicity, that influence the understandings of groups in different settings. An alternative critical interpretive approach can produce interpretations of the understandings of specific groups within a given context in different terms. If one recognizes a combination of hermeneutics and critical social science as seeking to integrate the contrasting polarities of structure and agency in social theory (see Layder, 1994; Lupton, 1994, p. 161) then a critical interpretive approach focuses on agency, recognized as within a contextual structure, in contrast to critical hermeneutics, focusing on structure as the context for agency.

A critical interpretive approach is useful for a research topic such as the subject of this study, seeking to understand the experience of one group of people in a specific social setting. Given the initial assumptions of this thesis, that people living on dialysis have distinctive experiences characterized by common concerns reflecting their shared perspective that are not easy to discern because they are obscured by the dominant professional viewpoint in the renal setting, a critical interpretive approach offers a helpful methodology to address the research topic of the concerns of Pakeha men living on home haemodialysis. Such an approach, seeking to understand their interpretations of their individual experiences from a critical standpoint, recognizes they need to be contextualized in order to distinguish the common perspective that underlies them from the dominant professional viewpoint in the renal setting. A critical interpretive approach can delineate the renal consumer dimension that is

obscured by the other influential dimensions of such a specialized health setting as the renal setting.

3.9 Foucault: a postmodern critical thinker

Adopting a critical interpretive approach, in a study such as this, requires that a researcher explicitly position himself in order to establish a perspective on the situation being studied. He needs some framework to contextualize the study situation and also to orient himself in relation to it. On this basis he can articulate his critical standpoint (see Thompson, 1991, p. 31) through a sketch of the social setting that he is researching. The renal setting that is the subject of this study could, within a critical interpretive methodology, be viewed in various ways using the insights of one of a number of traditions. For example a Marxist framework could be used, if one wished to focus on the renal setting as reflective of class relations. The paper by Reiss et al. (1986), discussed above, pointed in this direction in its comparisons between poor Afro-Americans and middle class Caucasians. A feminist framework could be used, if one wished to focus on the domestic dimension of renal services. Such a framework is exemplified in the paper by Brunier and McKeever (1993) considered above, examining the hidden role of women in supporting family members on dialysis.

Some ideas derived from the work of the French social philosopher Michel Foucault offer a framework suitable for focussing on the consumer dimension of the renal setting in this study (Foucault, 1975, 1977, 1980; see Cheek and Rudge, 1994, 1997; Lupton, 1994, 1997; McHoul and Grace, 1993; Smart, 1983, 1985). Given its particular character as a contemporary specialized healthcare context with various interrelated dimensions including the scientific therapeutic and the consumer, Foucauldian thought, because it recognizes and addresses this form of contemporary social situation, provides a basis which will enable me, in the next section of this thesis, to position myself in relation to the research topic and to sketch the various interrelated interpretive positions within this complex setting.

Notably resistant to any definitive interpretation, Foucault's writings, though sometimes viewed as a neo-conservative (Fraser, 1989) are understood by other commentators as pointing towards a contemporary form of critical theorizing, beyond earlier critical theories such as that of Habermas' based on the meta-narrative of oppression and liberation (Blacker, 1998; Hoy, 1986, 1988). Explicitly anti-definitive, they exemplify the kind of provisional stance that is most intelligible in our postmodern setting.

Although his works often assert a reaction against earlier forms of theorizing such as hermeneutics or orthodox critical theories (see Dreyfus and Rabinow, 1982, p. xxii), the nursing theorist Dzurec (1989, p. 69), commenting on research in nursing, noted that Foucault's insights, exemplifying the current postmodern context of research thinking, actually point towards "the necessity for and evolution of multiple paradigms for nursing research." While Foucauldian thought has resulted in the specific research method of discourse analysis explicitly presented as an alternative to hermeneutics and critical social science, ideas derived from his work, understood within the arc of the interpretive turn, have the potential to be used in different methodologies such as the critical interpretive approach. A number of writers in the health context have used certain aspects of Foucault's stimulating analyses (Bevan, 2000; Cheek and Rudge, 1994, 1997; Dickson, 1990; Lupton, 1994, 1997). Especially valuable is his focus on power and its relation to knowledge, an aspect of social reality that is inadequately conceptualized in both hermeneutic and Habermas' thought.

The common critical stance, deriving from Marx, in which economic power is exerted through ideologies validating and reinforcing group divisions in society as a whole, such as class, gender and ethnicity, Foucault has localized, showing rather the association of power and knowledge as being "mutually generative" (Dreyfus and Rabinow, 1982, p. 114), as ubiquitous, always in play in various ways in the micro-networks that make up different social contexts (Foucault, 1977, pp. 27, 28; 1980). He is critical of the Marxist tradition, rejecting the view of power as centralized, external and negatively exerting control that needs to be overcome in order to achieve liberation; rather he views power as natural and normal, an energy

operational within social networks (Foucault, 1977, p. 194). "Power is exercised rather than possessed" (Foucault, 1977, p. 26). Associated with the action of power are discourses operative within a social setting (Foucault, 1977, p. 27, 1978, pp. 7-26), each being, as one commentator puts it, a "body of knowledge" that "constrains" thought about a subject in a particular way (McHoul and Grace, 1993, pp. 26, 31). As Hoy (1998, p. 25) summarizes, in contrast to the Marxist idea of a strategy of ideological control, "for the later Foucault the unthought that conditions knowledge is power."

Turner (1997, p. xiii), writing in the context of health research, notes that Foucault "spoke of knowledge in the plural (*savoirs*) in order to illustrate the notion that specific forms of power required highly specific and detailed formations of knowledge." Characteristic of the modern era are scientific discourses of the empirical analytic paradigm, in particular the social sciences, which give rise to "disciplinary technologies", procedures of surveillance and "normalization" (Foucault, 1975, 1977; see Dreyfus and Rabinow, 1982, pp. 153-156) manifested in social institutions such as prisons, factories, schools or hospitals which have produced the contemporary form of the human, the modern subject. These disciplinary technologies typically involve subtle control of the body through its environment (such as the layout of the factory), through standardization of activities (such as schedules and procedures of the production line) enforced by modern methods of surveillance and assessment of compliance with standards (such as systems of quality control or human resource management, Foucault, 1975, 1977; see Dzurec, 1989, p. 72; McHoul and Grace, 1993, pp. 68-71).

This process of normalization through surveillance produces a "docile body that may be subjected, used, transformed and improved" (Foucault, 1975, p. 198). In his works, that he styles archaeologies and genealogies, Foucault examined specific social contexts such as medicine (1975), criminology (1977) and sexuality (1980) to show the way our contemporary understanding of these dimensions of social life has developed. Dreyfus and Rabinow (1982, pp. 112, 113), in their distinctive interpretation of Foucault's (1975, 1977, 1980) work, summarize "one of Foucault's major achievements has been his ability to isolate and conceptualize the way in

which the body has become an essential component for the operation of power in modern society", to delineate the "political technology of the body." Some nursing researchers have taken up these suggestions about the social location of the body in their work (Dickson, 1990; Dzurec, 1989; Hickson and Holmes, 1994).

Individuals are socialized to understand themselves in terms of the discourses that constitute their social contexts. As Allen and Hardin (1998, unpaginated) say "every day experience is acquired by taking up discourses and practices" based on the fact that "we enact our roles and relationships in language". Such a view of discourses as shaping the social context, downplaying individual or group intentionality, characteristic of Foucault's early thought (1970; 1972), seems analogous to postmodern accounts "eclipsing the perspective of the subject" (Thompson, 1990, p. 268). However in his later works (1975, 1977, 1980), where the social world is viewed as a series of micro-contexts formed by networks of "knowledge/power", there are also other "subjugated knowledges" (Foucault, 1980a, p. 81,82), "counter discourses" (Foucault, 1977a, p. 209) produced in "resistance" (Foucault, 1977, p. 27; 1980, pp. 95, 96; 1984, p. 87), in reaction to the power of the dominant discourse in that particular context (see Fox, 1997, pp. 41, 43; Smart, 1985, pp. 132-136). Foucault's later (1975, 1977, 1980) works "pay attention to the 'marginal' discourses, especially those disqualified, taken less seriously or deemed inadequate by official histories" (McHoul and Grace, 1993, p. 15).

Foucault's (1975, 1977, 1980) effort to uncover marginal or subjugated discourses as resistance to oppressive forms of domination can be viewed as constituting a criticism enabling a "progressive politics" (McHoul and Grace, 1993, p. 87), the development of more fully human possibilities. Against this view some have seen Foucault's analysis as contradictory, as a critique of humanism which actually presupposes humanist values, as positing a resistance which his analysis demonstrates is impossible, as a neo-conservative, even finally as nihilistic as Nietzsche, his hidden mentor, is supposed to be (Blacker, 1998, p. 349; Fraser, 1989, pp. 35, 50; Hoy, 1988, p. 33). However in his defence it has been suggested this misreads his work in terms of a framework presuming definitive intentions, whereas Foucault (1975, 1977, 1980) is rather debating the possibilities in an open

way. He is actually demonstrating the contradictory character of humanism in practice in his studies and thus raising the possibility of resistance at the local level enabling social change (Hoy, 1986, p. 145; Smart, 1983, pp. 134, 137). While the operation of power is natural and normal it can adversely affect certain groups but, through resistance, creating a counter-power, they can improve their local situation.

As a result he deliberately does not offer a totalizing viewpoint, blueprints for radical reform, like Marxian universal intellectuals who sought to lead a societal revolution (Smart, 1986, p. 167). Rather, exemplary of the contemporary specialist thinker, the "specific intellectual", (Foucault, 1980a, p. 126) his works, showing how "truth" is "arbitrarily mass manufactured and disseminated" (Blackler, 1998, p. 357), aim at the disruption of particular "regimes of truth" (Smart, 1983, p. 135), "resistance at particular points to local exercises of power" (Hoy, 1986, p. 145). Foucault (1981, p. 13) himself states "Critique doesn't have to be the premise of a deduction that concludes: this then is what needs to be done. It should be an instrument for those who fight, those who resist and refuse what is." Hoy (1988, p. 37), more explicitly, suggests that "in the very act of giving a successful genealogy we become different, or postmodern, in that we understand ourselves differently."

In this view Foucault's (1975, 1977, 1980) works can be read as pointing towards is a new post-Marxian form of critique, what one might call a postmodern form of critique or "resistance postmodernism" (Kincheloe and McLaren, 1994, p. 144; Lather, 1991, p. 1), perhaps even simply a reflexive critique (Lawson, 1985), in that it no longer relies on the meta-narrative of oppression and liberation that is the basis of Marxism and many subsequent critical theories (Hoy, 1988, p. 37). His writings are exemplary of such an approach, offering hints and clues that have encouraged researchers to find new ways to critically examine specific social contexts.

3.10 Discourses in the health context

Foucault's (1975, 1977, 1980) thought, focussing on local networks of power based on specialized bodies of knowledge, indicates a possible framework to examine

social settings such as specific healthcare settings. While Foucault (1975, 1977, 1980) himself was interested in discerning how certain discourses arose in the modern situation, a derivation from his thought, based on his admittedly vague references to 'resistances' (see Sarup, 1993, p. 82) combined with his underlying concern for 'unheard' marginalized groups throughout his writings, provide the basis for a way of viewing contemporary healthcare contexts.

In general writers about healthcare settings who use ideas from Foucault (1975, 1977, 1980) do not articulate a view based on any one work but have drawn freely from his thought, often combining the ideas of discourse and the modern specialized expert in his earlier works with notions of knowledge/ power and resistance via the micro-network of social relations prevalent in his later writings. His ideas have been developed, beyond his own formulations, into a critical post-modern view of the character of contemporary healthcare contexts.

Lupton (1994, 1997) in several works summarizes an application of Foucault's approach to healthcare settings based on *The birth of the clinic* (1975) and *Discipline and punish* (1977).

The body and its various parts are understood as constructed through discourses and practices, by the 'clinical gaze' exerted by medical practitioners... the medical encounter is a disciplinary power that provides guidelines about how patients should understand, regulate and experience their bodies... a means of bringing into being the subjects 'doctor' and 'patient' and the phenomenon of the patient's 'illness.'

(Lupton, 1997, p. 99)

Cheek and Rudge (1994, 1997) explicate this approach in several articles in terms of several contrasting discourses within the healthcare context. The dominant medical discourse is a classic instance of a specialized body of knowledge based in the empirical analytic paradigm that is operative in defining a specific context in contemporary society. Diseases are dysfunctions of organs in the body that the medical expert defines through diagnosis and corrects or manages through therapy (Cheek and Rudge, 1994, p. 585). Medicine determines the "normalization" of the

body (Foucault, 1975, 1977) in terms of disease and health. The dominance of the medical discourse is maintained by “fabricating ‘health,’ ‘illness’ and patient subjectivity” (Mitchell, 1996, p. 203; see Bevan, 2000) via the clinical practices of the healthcare context (Fox, 1993, pp. 50, 51).

Through the powerful “gaze” of the healthcare expert in their examinations, the “picture of the patient constituted is from the perspective of the health professionals” (Cheek and Rudge, 1997, p. 709), epitomized by the observation chart (Henderson, 1994, p. 937) or the ward round (Fox, 1993, pp. 50-59). However there is also the possibility of an alternative “subjugated knowledge” (Foucault, 1980a, pp. 81, 82) based on the experience of the person who is ill.

The doctor-patient relationship is a central site at which subjugated knowledges and the practices of the self play a major role in the interrelation of institutional and localized power. When consulting a doctor, individuals may, on at least some occasions, and if they so choose, attempt to struggle against, challenge or subvert those disciplinary techniques they experience as restricting their autonomy.

(Lupton, 1997, p. 105)

The phenomenon of illness, often viewed as a world formed by general social discourse (Radley, 1993), is conceptualized in this approach as a specialized social context, or more accurately today a cluster of specialized clinical contexts derived from specialized variants of the medical discourse of the body (Cheek and Rudge, 1997, pp. 708-9), but also the alternative or contrasting discourses of the health client (Cheek and Rudge, 1994, pp. 585, 586; Lupton, 1994, p. 161).

Toombs (1992), in a phenomenological analysis of the meaning of illness, speaking in terms of Foucault’s language of the professional ‘gaze’ of the physician, says of the person with an illness:

one does not “see” one’s illness as primarily a disease process. Rather, one experiences it essentially in terms of its effects upon every day life. Thus, whereas the physician sees the patient’s illness as a typical example of a disease, the patient attends to the illness for its own sake.

This is supported by the literature on 'illness behavior', showing that "patients conceive of illness very differently than doctors" (Mechanic, 1995, p. 1208). Mishler (1984, p. 63), in his analysis of interviews between doctors and patients, spoke of the 'voices' representing two different normative orders, the "voice of medicine" and the "voice of the life-world" disrupting the "discourse of medicine" that shapes the interview. Benner (1994, p. 122), discussing her hermeneutic approach to nursing research using somewhat unusual language, makes the same distinction in contrasting "the lived experience of illness (the bodily experience and know-how) and the illness as domesticated and understood theoretically and "scientifically" by medicine." As Foucault (1975, p. 8) himself puts it "In order to know the truth of the pathological fact the doctor must abstract the patient... it is not the pathological that functions, in relation to life, as a *counternature*, but the patient in relation to the disease itself."

Most clearly Kleinman (1988, pp. xii, 3, 18, 171), in his study *The illness narratives*, notes "the difference between the patients experience of illness and the doctor's attention to disease" where "illness refers to how the sick person and the family or wider social network perceive, live with and respond to symptoms and disability" encompassing its "cultural significance", "social situations including the treatment setting." Thus illness, including the clinical therapy it entails, has a significance for the person suffering from it in terms of its alteration of their life experience in their social context. The contrast between disease and illness does not imply that one is more real than the other. Rather disease and its contextual framework, the patient, are artifacts of the objective biomedical paradigm (Armstrong, 1984, p. 743), medical diagnosis being not a discovery but a construction (Mishler, 1984, p. 11). Illness and its contextual framework, the health client, are artifacts of a subjective interpretive, perhaps "biocultural" paradigm (Morris, 1999).

Toombs (1992, p. 1), conscious of the "different perspectives of physician and patient", goes so far as to speak of them as inhabiting different "worlds." This

model emphasizes the different viewpoints of those suffering from illness and the professional group treating them (for Toombs, interestingly, the physician only), and also that the experience of illness may be only intermittently interrupted by involvement with health professionals. However the experience of people suffering from an illness is one of both illness and therapy, in which the experience of illness is to a considerable extent shaped by the professional understanding, 'naming' the problem, and also by the therapeutic intervention on the basis of this diagnosis. A more useful model than separate 'worlds' of physician and patient is perhaps, in Foucauldian terms, of a specialized healthcare context that a person enters, constituted by the intersection of the experience of illness and professional management of disease, in which the different participants have different perspectives. Characteristically in the contemporary situation the viewpoint of the specialized health expert has become dominant at the expense of the perspective of the subject suffering from the illness.

Underlying the dominant medical discourse of the body in its specialized variants in contemporary healthcare settings, rarely explicitly stated but shaping what is said and done within it, is the notion that medicine, as a specialized body of knowledge scientifically based in the empirical analytic paradigm, is efficacious in diagnosing and curing disease. This can be called the paradigm of biomedicine (Morris, 1999, pp. 4,5). For the person suffering from an illness, understanding their situation in terms of this paradigm, they have a problem that can only be defined and managed by a health expert whose advice and treatment they need to adhere to if they wish to become well again. The dominant healthcare discourse, in terms of the paradigm of biomedicine, is represented by health professionals both in their manner, language, ritualistic behaviour and even the 'clinical' character of the context in which they practise, having the dual effect of both justifying their authority and giving confidence to the person who seeks their professional advice.

An assumption implicit in this dominant professional viewpoint, derived from the biomedical paradigm, is expressed by Thorn (1977), quoted Toombs (1992, p. 112) in a leading medical textbook, *Harrison's Principles of Medicine*, "the discovery and cure of potentially serious disease represents a far greater service to our patients

than ministration in the course of an incurable disease.” Not only does this ideology of medicine as successful curative intervention in disease processes, what has recently been called “the rescue credo of high tech medicine” by the physician Nuland (quoted in Webb, 1996, p. 961), ignore the limitations and complications actually associated with any therapy, even curative, it also leads to distortion and neglect of the management of chronic illness because, decisive successful intervention not being possible, it is viewed as a “losing battle” (Toombs, 1992, p. 115). The ubiquitous language of the dominant healthcare discourse, based on the exemplar of a curative intervention, continues to be used, often inappropriately and confusingly for the subject of illness and therapy, in chronic healthcare contexts.

The dominant viewpoint is generally shared by the person who believes that they are consulting a health expert who can solve their healthcare problems. Zola (1991, pp. 3,4), a medical sociologist speaking from the perspective of a person with a chronic disability, uses the concept of the “structured silence of personal bodily experience” to refer to the individual’s difficulty of expressing, or even fully understanding, their experience of illness or disability, because of the dominant social construction of their disease that is reinforced by health professionals. However in naming this ‘silence’ he affirms the possibility of resistance to the hegemony of the dominant viewpoint. From a Foucauldian standpoint the dominant medical discourse shapes the healthcare context and the understandings of all within it, health professionals and sick persons, but it can also give rise to ‘resistances’ that can be characterized as alternative discourses. The mystifying ideology of the dominant professional discourse in a chronic setting may shape a resistant alternative discourse representing the perspective of view of the client.

Foucault’s (1990, p. 30) question, “how can the truth of the sick subject ever be known?” alludes to the difficulty of discerning the views of the person who is ill within the context of contemporary medical management. It perhaps suggests that the “sick subject”, socialized with the dominant discourse, may even have difficulty understanding their own situation. However his question also suggests the possibility of discovering a counter ‘truth’ to the dominant professional viewpoint that is generally deemed to be ‘the’ truth. The aspects of such ‘subjugated

knowledges' of people suffering from illness may not only be conceptual but also emotional and even spiritual. In terms of the distinction made by Van Manen (1997) in a different context, the counter-discourses of the subjects of illness and therapy are not only thematic but also expressive. In a setting of chronic illness the various aspects of the counter-discourse of the client can delineate the difficulties characteristically entailed in living on therapy for this condition. Named as "concerns" in this study they summarize the perspective underlying their experience of illness and therapy that is not easy to discern in a contemporary healthcare context.

While this analysis has focussed on the dominant discourse, reflecting the fundamental scientific therapeutic dimension, and the resistant client discourse, reflecting the consumer dimension, several other discourses can also be recognized as in play in a specialized healthcare setting such as the renal context. These reflect other dimensions of the renal setting such as the commercial technological or the socio political. Interacting with the other discourses to contribute to its distinctive character, the influence of these different discourses can be relevant in studies of a setting such as the renal context.

Most commonly in studies of the social situation of chronic illness people have been viewed as fitting into society through adopting illness 'role identities' or even 'careers', a framework that has been used in various forms in the renal setting (see above Hardiker et al., 1986; Gerhardt, 1990; Kutner, 1987; Littlewood et al., 1990). However in her generic study Thorne (1993, p. 104) noted that "chronic illness [itself] is a product of social construction." The alternative framework set out here, derived from Foucauldian thought, develops this insight by suggesting that specific illnesses are socially constructed through the interplay of contrasting discourses in particular specialized healthcare contexts, constituted primarily by particular objective diagnosed diseases and management strategies of health professionals on the one hand and subjective experiences of illness and therapy on the other.

From this recognition of the character of a contemporary specialized healthcare context a complex relationship between the professional and the consumer

viewpoint has been delineated. The professional viewpoint is viewed not simply as oppressive, in accord with the critical meta-narrative, but as both therapeutic and also problematic for consumers, the client perspective being understood as a counter-discourse, both obscured by and developed in response and reaction to the influential dominant viewpoint. Such Foucauldian concepts provide a framework to critically view the renal setting. In this classic instance of a contemporary specialized medical technology the dominant renal discourse presents medical practice in terms of the acute curative paradigm of biomedicine. This is exemplified in its research methodology, as reflected in the dominant orientation of the renal literature reviewed in the last chapter. In order to develop an alternative understanding, based on personal interpretations of the experience of renal illness and therapy, a different methodology in the interpretive paradigm, such as set out in this chapter, is required. Foucauldian thought provides a suitable basis for a critical standpoint for such a study.

3.11 Conclusion: a methodology for this nursing research study

Given that, in terms of the interpretive paradigm, for any human being “to understand the world one must interpret it” (Schwandt, 1994, p. 118), the role of the researcher is to

elucidate the process of meaning construction and clarify what and how meanings are embodied in the language and actions of social actors. To prepare an interpretation is itself to construct a reading of these meanings; it is to offer the inquirer’s construction of the construction of the action one studies.

(Schwandt, 1994, p. 118)

In this chapter, on the basis of my initial assumption about the nature of research, I have reviewed and critiqued several traditions underlying different research methodologies relevant to this kind of topic. I have suggested that Heideggerian hermeneutic and the critical social science traditions, in particular critical hermeneutics, though offering necessary insights, have limitations in addressing a

research question such as the topic of this study. I have then, within the arc of the interpretive turn, outlined an alternative synthesis of the hermeneutic and critical traditions, a critical interpretive methodology, an interpretive approach with a critical contextual dimension, as an appropriate way to address this research topic attempting to understand the experience of people living on dialysis. Such an approach seeks their interpretations of their individual experiences, but then interprets them from a critical standpoint, recognizing that they can only be adequately understood by contextualizing them in order to discern the common perspective underlying them in contrast to the dominant viewpoint in the renal setting.

In using a critical interpretive approach in this study some ideas derived from Foucauldian thought offer the basis for a critical standpoint, to enable me to contextualize the study situation and orient myself in relation to it, in addressing this research topic of the concerns of Pakeha men living on home haemodialysis. Among several possibilities that could be adopted Foucauldian thought, despite its apparent incongruence with an interpretive approach appears apposite, when viewed within the arc of the interpretive turn, for this study of a contemporary healthcare setting shaped by a specialized body of knowledge.

Recognizing the understanding of renal clients will be difficult to discern, because of the hegemony of the professional viewpoint within the renal setting, the Foucauldian notion of a social context as shaped by the interplay of dominant and counter discourses has the potential to establish a critical standpoint to examine the character, significance and interrelationships of the various interpretations of different groups in a specific healthcare context such as that of renal replacement therapy.

In Foucault's early work (1970, 1972) 'discourse' meant a body of knowledge that influences individual interpretations within a context (Grace and McHoul, 1993, p. 31). Discourses were not interpretations at all but structures within the social setting that shape them. The common research methodology of discourse analysis derived from his work, based on this meaning, is valuable in uncovering social currents that

influence ideas and behaviours. However one criticism made of Foucault's work, is that, despite intending to uncover discourses affecting peoples lives in his writings he appears, as Layder (1994, p. 112) puts it, "strangely unconcerned with face-to-face encounters and behaviour that constitute by far the largest portion of 'everyday life'."

In contrast to discourse analysis research in the critical interpretive approach outlined in this chapter is specifically interested in everyday understandings. Some oblique references by Foucault himself point towards a possible alternative understanding of discourse in the context of a critical interpretive research methodology. While the notion of discourse initially suggested as external structural factors that influence individual interpretations, Foucault's own references in his later works (1977, p. 27; 1977a, p. 209; 1980a, pp. 81, 82, 96) to "resistances" by groups within a setting producing "subjugated knowledges" developing into the idea of "counter discourses," suggest that, in conceptualising a social context as constituted by several interrelated discourses, these relate to, even reflect the views of various groups within it.

Following these clues in the late Foucault, discourses, when used within a critical interpretive approach, are specifically understood as representing the shared interpretive perspective, from a common position within a setting, which orients individual interpretations expressed in practices and texts. Such a Foucauldian view of the renal setting is valuable for this study in suggesting that the experience of people living on dialysis can be understood as reflecting both the influence of the dominant professional viewpoint and also their shared perspective as renal clients that is a response to it.

In this thesis a critical sketch of the renal setting in Foucauldian terms will delineate the relationship between the professional viewpoint and the client perspective in terms of interrelated discourses in the renal context. It will help me to clarify my relationship as researcher with the participants in the study. It will enable me to critically interpret their accounts of their experiences by contextualizing them. Through using this Foucauldian sketch I can understand the experience of the men

in the study by delineating their concerns as aspects of the client discourse in the renal context.

In a study using a critical interpretive approach informed by Foucauldian ideas the researcher's own interpretive understanding will be presented in terms of the discourses that represent the common interpretive perspective underlying individual's accounts. The researcher with a critical focus produces these discourses, by reflectively discerning the commonalities expressed in the set of accounts or texts of various groups of individual participants, which reflect their common perspectives in a specific context.

The researcher is not able to simply articulate the viewpoint of any particular group within a specific context being studied because he does not share it. From his own position outside the context he can only analyze the interpretations of the participants as expressed in their practices and texts, according to his critical interpretive approach, in order to produce a "construction", in a different language and with a different perspective from the participants themselves, of one or more contrasting discourses that articulate the perspectives that orient their understandings. Through this process, from his position, he can clarify perspectives that may be obscure or hidden, potentially delineate the concerns of a particular group within a specific context in a way that might not be possible for the participants themselves.

The various discourses represent the perspectives of different groups of participants as understood from the researcher's standpoint. Any individual account may only partly reflect the viewpoint of the group in that position within the context. While particular accounts may express a shared understanding to a greater or lesser extent, the perspective that this represents may not be articulated fully by any of them, but only be discerned by the researcher reflecting on all of their accounts as a set. These are called 'discourses' because they do not simply represent the perspectives that underlie the interpretations of different groups of individuals but rather are constructions, interpretive models with a certain internal coherence created by the researcher, summarizing the perspectives that orient particular interpretations by

groups of participants. In particular, in a study such as this, the researcher can delineate the common concerns of a group of people receiving therapy for a chronic illness as the client discourse within a specific healthcare context.

The Foucauldian ideas outlined above provide a suitable basis for a critical stance to view the specialized healthcare context of renal replacement therapy that will orient the rest of the study. The sketch of the renal setting, in the second section of the thesis, will establish a standpoint from which I will set out, in the third section of the thesis, the accounts of their experience of illness and therapy from the six men in the study. It will also enable my interpretive "construction", in the fourth section of this thesis, produced through the analysis of their accounts as a set, seeking to "elucidate the process of meaning construction" (Schwandt, 1994, p. 118) by this group of renal consumers.

The critical interpretive approach I have articulated in this chapter establishes the theoretical framework for this study seeking to understand the experience of Pakeha men living on home haemodialysis. In the next chapter I will consider the application of this methodology to the research topic in order to produce an adequate design for the research process in this study.

Chapter 4. Research design for this study

This chapter describes how I use the methodology developed in the last chapter to address the research topic of the concerns of Pakeha men living on home haemodialysis. In it I will show the way that I apply the critical interpretive approach to produce a design for the study and how this design shapes this thesis. I will discuss the study group, the collection of information and its analysis. I will then consider the ethical issues raised by this research topic and the criteria by which the quality of this study may be judged.

To establish the shape of the research process I will first briefly indicate what the application of the methodology to this research question involves, in particular my position as researcher in relation to the participants' location. Then, using a couple of helpful sources, I will delineate the various phases of the design for this study in terms of the critical interpretive approach developed to address this research topic.

In order to understand the experience of Pakeha men living on home haemodialysis, using the critical interpretive approach, I am seeking the study participants' interpretation of their experience of illness and therapy, while recognizing that this is most meaningful when contextually located. I am also acknowledging that their interpretations are not directly accessible to me as researcher but only as mediated via my own contextually positioned interpretation. In this form of research even the interviews themselves are recognized as jointly created by the participants and researcher, both of whose perspectives are contextually determined (Mishler, 1986, p. iii). Finally in seeking to understand their experience using this research approach it is necessary to re-interpret their individual interpretations by contextually locating them, in terms of my own contextually positioning in relation to the renal setting, in order to delineate the characteristic concerns of this group of people living on dialysis.

Thus using the critical interpretive approach for this research project requires that I position myself in relation to the renal setting. It involves developing a critical standpoint from which to view the renal setting. Such a critical stance will be based on a reflection on my own renal nursing experience. It will entail the application of the Foucauldian view of contemporary healthcare settings, explicated in the next chapter, to the renal setting. On the basis of this standpoint I will then seek from each of the participants in the study their interpretation of their experience of renal illness and therapy. I will present the individual interpretations as accounts of their experience of living on dialysis.

Using the critical interpretive approach to understand the experience of Pakeha men living on home haemodialysis finally involves reinterpreting their accounts as a set, from my stance in terms of the Foucauldian view of the renal setting, in order to discern the common client perspective that underlies them. In this specialized healthcare context they tend to interpret their experience in terms of the dominant professional viewpoint that they have been socialized with. However through a critical reinterpretation of their accounts from my standpoint as researcher it is possible to produce an interpretive model of the client perspective, in Foucauldian terms the renal client discourse in contrast to the dominant discourse, that underlies their individual interpretations of their experiences of living on dialysis.

4.1 Design for this study

When thinking about how to actually use the critical interpretive approach for this project two works that I read in the early stages of this research, a short book by McCracken (1988), *The Long Interview*, and a renal research article by Hardiker et al. (1986) proved useful in formulating the design of this study. They helped me to apply the critical interpretive methodology to address this research topic.

The four-part method described by McCracken (1988, p. 9), intended to enable a “qualitative understanding of how culture mediates human action,” includes a review

of analytic categories (a literature review of the research area), a review of cultural categories (a reflection by the researcher in relation to the research area), the discovery of cultural categories (the interviewing process) and the discovery of analytic categories (the analysis of this material). The stages are logically interrelated with one following from the other. McCracken (1988, pp. 11, 12, 31, 33) is conscious of the importance of "the relationship between the researcher and his or her own culture" and views the literature review as a "way to manufacture distance" in order to use the "self as an instrument of inquiry" for the "delicate relationship ... constructed" between researcher and respondent. In particular the inclusion of reflection by the researcher, on their own relationship to the topic, as integral to the process appeared congruent with the methodological approach in this study. However McCracken (1988) does not extend this to the development of an explicit theoretical viewpoint in relation to the research topic, talking rather in terms of a creating "expectations" (McCracken, 1988, p. 31) that can be contradicted by the evidence of the interviews.

While not originally situated or developed within the interpretive paradigm, McCracken's (1988) framework offered a pattern for qualitative research using intensive interviews that enabled me to establish the research process, based on the critical interpretive approach developed in the last chapter, for this study. McCracken's (1988) work was useful because, pragmatic rather than theoretically oriented, it was amenable to adaptation in terms of the critical interpretive approach. I considered that this framework could enable me to translate the critical interpretive approach into a method that articulated clearly the process, interpretive engagement in the interviews and critical detachment in analysis, occurring between myself as an experienced renal nurse who was also a researcher and the participants in the study who were renal clients.

The research pattern set out by McCracken (1988) has some similarities to that used by Hardiker et al. (1986) in their article, from a social work perspective, on coping with CRF that I read during the literature review. Though not explicitly set out formally, the following elements in Hardiker et al.'s (1988) research method can be extracted from their study. First an initial theoretical framework is briefly stated, followed by the production of accounts from participants based on interviews with them, which are

then analysed in terms of the initial theoretical framework. In their study this results in the production of a typology of renal clients' responses to living on dialysis. Unlike McCracken (1988) Hardiker et al. (1986) are explicitly aware of the necessity to adopt a deliberate theoretical stance for their study and of the interrelationship between the three stages, the initial theoretical position of the researcher, information gathering and analysis. In their study analysis is the application of the theoretical framework to the information gathered. What their approach did not make explicit is the relationship of the researcher to the study group, the second step in McCracken's (1988) pattern, necessary in the study design for a research process using a critical interpretive approach.

While neither of these studies is explicitly hermeneutic or critical each, within somewhat similar qualitative research frameworks that could become congruent with a critical interpretive approach, offers contrasting insights, McCracken (1988) into the relationship between the researcher and the study group, and Hardiker et al. (1986) into the relationship between the theory and analysis. Using the insights from these works I will now describe the research process for this study in terms of three phases that are reflected in the four sections of this thesis.

The initial phase of this study is the development of an approach to the research topic. Reflection on my own renal nursing experience and a review of the relevant literature provide a basis for the study. With these I position the research topic (chapter one), consider how the renal literature informs it (chapter two), develop a methodology to address it (chapter three) and articulate this in a study design (this chapter). This is similar to McCracken's first two stages (1988, pp. 29-34), the review of analytic and cultural categories, but these are conceptualized more broadly. Rather than simply consisting of a literature review and a reflection on the researcher's own preconceptions, this initial phase encompasses the development of a theoretical framework for the study, the critical interpretive approach, as implied by Hardiker et al. (1986). It also involves positioning myself as researcher in relation to the renal setting, in terms of this methodology, through developing a standpoint from which to view the renal setting (chapter five). The first two sections of the thesis, establishing the critical interpretive approach, report the development of the basis for the study.

The next phase of the study is the process of information gathering leading to the production of participants' accounts of their experience of renal illness and therapy. In terms of the research methodology this is an interpretive response, from my critical position as researcher established in the initial phase, to the participants' interpretations of their experience in the renal setting as discerned in the interviews. Again this is similar to McCracken's third stage (1988, pp. 34-37), the discovery of cultural categories, but conceptualized more broadly, not simply as interviewing but as the whole process of information gathering, including the production of accounts (chapter seven), all of which is understood as a hermeneutic activity in terms of the critical interpretive approach. I attempt to clarify the written accounts as my hermeneutic effort to delineate their interpretation in their own location by explicitly framing them with my reflective responses to the discussions with the participants (chapters six). The third section of the thesis, the interpretive accounts of the participants' experience, reports the information gathering process in the study.

In the final phase of the study an analysis produces an outline of the concerns of Pakeha men living on home haemodialysis and suggests its significance. Through an explicit re-interpretation of the accounts reported in the third section of the thesis as a set, contextualizing them from my critical standpoint as researcher established in the sketch in the first and second sections of the thesis, I delineate the significant concerns for Pakeha men living on home haemodialysis (chapter eight). This outline of the common perspective that underlies their individual accounts, understood as the renal client discourse, is a construct that is the outcome of the whole critical interpretive research process. The value of this model is demonstrated by showing how it enables an understanding of their individual accounts (chapter nine) and also contributes to clarification of the character of nursing work in the renal setting (chapter ten). This is similar to McCracken's fourth stage (1988, pp. 37-41), the discovery of analytic categories. However this is more broadly conceptualised, not simply a generalization from the interview material but a critical analysis of the set of accounts in terms of the position in the first two sections, and also further reflection articulating the significance of the research outcome of the outline of client concerns in the renal setting. The fourth section of the thesis, through a critical reflection on interpretive

accounts of the men who participated, reports the conclusions and significance of the study.

4.2 The study Group, information collection and analysis

In order to discover the concerns of Pakeha men living on home haemodialysis in this study I interviewed a small group who appeared to be typical of Pakeha men living on dialysis. Participants in the study were Pakeha men who had been on self-care haemodialysis at home as part of the programme of the department of renal medicine for more than a year. They were considered physically and psychologically well adapted to life on self-care therapy from the point of view of staff supporting them. Pakeha men were defined as men born in or permanent residents of New Zealand who did not define themselves as being of Maori (the indigenous ethnicity in New Zealand), Pacific Island or Asian ethnicity (King, 1999, pp. 234-239). They belong to the dominant white culture. The selected group was made up of men, living on haemodialysis at home for more than one year, who were beyond the phase of initial adjustment to the therapy. They had not been at home on dialysis for longer than ten years, a timespan that meant that their memory of life without dialysis had become vague.

I decided to interview Pakeha men because the renal literature suggests that the experience of living on dialysis may be some what different for women compared with men and also for people from different ethnic groups compared with people from the dominant white culture (Brunier and McKeever, 1993; Owen, 1995; Reiss et al., 1986; Soskolne and De Nour, 1989; Somer and Tucker, 1992; Tell et al., 1995; Wolcott et al., 1988;). Working with a small number of participants who were from a relatively homogenous group I hoped would enable a fuller understanding of their experience than could be achieved with a more diverse group.

I sought a group of six Pakeha men living on home haemodialysis for participation. I considered that this would allow collection of information in some depth from a sufficient number of men with a range of different experiences, while producing a

volume of information that would remain manageable for analysis. Suitable potential participants from the dialysis population received a request to participate and the first six to accept were chosen. If any participant's interviews had been unusable, for example because they withdrew, another participant would have been chosen from the population. This was not necessary.

I recruited potential participants by sending them a letter to request they consider participating in the study. When they indicated willingness by telephoning me as requested I offered to meet them at their home or another place if more convenient to them. In fact all preferred to be visited in their homes. At this initial discussion all were given full information about the study and their questions answered to enable them to decide whether they wished to participate. Having indicated their willingness to participate I confirmed this at a phone call that set the time for the first interview. Before beginning the first interview they signed a formal consent form.

The method of information collection was through semi-structured interviews. In several discussions with each of the men I covered a range of topics, particular issues that had been suggested by the literature review and my own nursing experience and also other subjects that came up during the interviews. This format was used to facilitate participants freely stating their views about their life on dialysis rather than simply responding to questions according to a pattern determined by me as the researcher.

I interviewed the men in their homes on three occasions for about an hour. The discussions were taped. I suggested their homes as the locale for the interviews because, in contrast to a clinical setting like the renal department, I considered that they would feel in control of the interview situation in their own personal environment and more easily able to freely express their views. Also being interviewed in their own home was less intrusive on their time, avoiding the need to travel to an appointment in a schedule already constrained by the requirements of the dialysis regime. I suggested the alternative of another site for the interviews but all the men preferred to be interviewed in their own homes.

The first interview began with some introductory questions about their lives before reaching end stage renal failure in order to provide some context for their comments. I then asked some general questions seeking to discern significant areas of change in their lives since beginning dialysis from their perspective. From their responses followed some specific questions encouraging them to speak freely on particular areas recognized as potentially problematic for people on dialysis from the literature.

The second interview took place while the men were actually in the middle of their dialysis treatment at home. It covered issues about haemodialysis itself, their management of the process and how the regular regime of treatment impacted on their lives. I observed the men on the machine, and made notes after my visits of how they appeared to manage their dialysis treatment in their home context and how well it seemed to be integrated into their pattern of daily living.

At the third interview the men had the chance to comment on a written summary I had given them before the interview, to add, delete or modify their views as I had understood them from the first two discussions. This interview explored the way in which their experience of dialysis had changed their view of the future and also affected their sense of control over the lives.

I produced written accounts based on transcripts of the interviews and supplementary evidence from notes made of my own observations during the interviews. I sent them to the men inviting their comments. This resulted in slight modification to several of the texts. Chapter seven contains the men's accounts. I analysed the accounts by reviewing them as a set. I used clues derived from the renal nursing literature and my own renal nursing experience, suggesting possible issues of concern, to focus on the commonalities across the texts that I then elucidated in terms of the critical Foucauldian view of the renal setting. These common concerns do not necessarily reflect the views of any one particular man but rather are a construct that I produced, in terms of the critical positioning in relation to the renal setting, which models the perspective that underlies their individual views. The outcome of this analysis is the basis for chapter eight.

Having abstracted their common concerns from the set of accounts I then related them to their individual accounts. I showed that their individual accounts can be understood as the product of the interaction of the dimensions of their personal social location with the client discourse in the renal setting. By reviewing some relevant literature on gender and ethnicity in New Zealand I considered their influence on the experience of living on home haemodialysis as reflected in their accounts. The relationship between the renal client discourse and their accounts is discussed in chapter nine. In the final stage of analysis I drew out one implication of the understanding their experience of living on home haemodialysis, the potential role of nurses in the renal setting that it points towards. In this reflection I suggested that nursing work in the renal setting can be understood in relation to the concerns of the renal client discourse. In chapter ten I consider nursing in the renal setting.

4.3 Ethical issues

Ethically the study was justified in general terms, in the application for approval from the local Regional Health Authority Ethical Committee, because information was sought from participants on the basis that it had the potential to contribute to an improvement in their wellbeing as a group living on renal replacement therapy. However my own explicit positioning as researcher, in accord with the critical interpretive approach adopted for the study, itself raised several ethical issues because I was already known to the participants as a clinician working in the renal unit.

My role as a staff member meant that obtaining free consent from potential participants for the study was potentially ethically problematic. Although well informed about their rights as clients responsible for their own care, their dependence on the renal department for support on dialysis might have made it difficult for those who were asked to feel they could refuse to participate, especially to a researcher known to have a role with some authority in the renal department. This was addressed by making it clear in the letter of *Request for Participation* that only a very limited number of participants were needed for the study. I explicitly stated in the letter that if it was in any way inconvenient for them to participate then declining to do so would not cause

any problems for the research because I only needed a small number of participants and could easily recruit others. Potential participants were asked to ring me to signify their interest rather than being directly approached by me to elicit their interest. I made it clear to those men who agreed to participate that they could withdraw at any time during the research process if they found for any reason they did not wish to continue to participate. In fact everyone asked agreed to participate and no one withdrew during the research process.

Ensuring privacy of the information provided during in-depth interviews could have been a potential source of concern to participants. This could not be simply dealt with by guaranteeing anonymity in any presentation of findings because, as part of an identified sub-group of renal consumers in a relatively small renal client population, even though disguised with pseudonyms in the study they could have potentially been identifiable in presentations about the study to health professionals, or even possibly other renal clients, from particular details given in material used. Having informed them of potential problems about ensuring anonymity before the interviews began, they were later given the summaries of their interviews that were to be the basis of the study report, for their comment in terms of their privacy. They had the right to veto any aspects that were not acceptable in form or content to them. Two men did alter some aspects of their transcripts, not for reasons of privacy but to better reflect their views. For any use other than the final study report for the educational qualification being sought the *Consent Form* guaranteed they would be specifically asked for permission to use their material.

A related potential ethical issue, the possibility of inhibiting or misrepresenting their views because of my professional orientation, was recognized in my initial assumption of the difficulty of understanding their experience of living on dialysis. The methodology developed for this study and the study design produced to implement it attempt to explicitly address this issue as set out below in the section on Trustworthiness. Their own reviews of the summaries of the interviews by the participants also represents a form of member validation to protect against such distortion of their own views.

Renal clients would also naturally be concerned that any information that they might give to a researcher who is a renal health professional, in particular about their failure to adhere to aspects of their therapeutic regime, could affect their relationship with the renal service. This is especially the case in this situation where I, as researcher, actually worked for their renal service. Although there was no direct conflict, as I did not work personally as a clinician with the men involved in the study, a combination of roles that would have been ethically problematic, I did know the participants professionally. I had worked with most of them in the past in the dialysis unit and was recognized by them as a senior nurse. This issue was addressed through the explicit assurance of confidentiality of all information shared in the interviews and a guarantee of separation of this information from all other information given by the renal client to the renal team as part of their management. The research material was safely stored on different premises from where their clinical records were held.

Before the interviews I decided that if any information were to come out during the interviews which I considered should be known by the participants' clinicians, then the participant would be encouraged to share that information with one of his clinicians. In fact only one issue came up as a result of the interviews that it seemed desirable for the participant to discuss with a clinician. However several of the men made comments about specific events or relationships with staff members which, outside the context of the research, would certainly have warranted being followed up with the staff involved. Given the guarantee of confidentiality it was not possible to do this, although on several occasions the general issues behind the specific comments were discussed in an open staff forum.

All of these issues arose in part because I, as researcher, was interviewing a group of renal clients who are served by the department of renal medicine in which I work. While such issues could have been avoided by working with clients from another centre, in practice each department has a somewhat different approach to the clinical support of people living on chronic dialysis. I considered that familiarity with the way in which people with CRF are supported in one particular centre, not only the specific clinical practices but also the general ethos that orients the department's nursing work, would facilitate interpreting their understanding of their experience on dialysis.

Foucault characterizes the "specific intellectual" (Foucault, 1980, p. 126) as having the capacity to produce critical analyses within a particular specialized contemporary context. Given my initial assumption of the obscurity of the renal client perspective because of the influence of the dominant professional viewpoint, an understanding of the nuances of professional practice within the local renal setting facilitates a clarification of the understanding of renal clients.

More importantly, given the openness and trust that I knew generally characterize nursing relationships with clients within the local renal service, I considered that renal clients would be more willing to freely, honestly and fully participate with a researcher associated with the department. I believed that explicitly addressing the specific ethical issues that arose in working with participants known to the researcher, in the context of a positive local nursing ethos, would enable greater insight than would be possible in research with a more detached investigator that would have avoided such issues. I considered that the potential problems, which were manageable, were outweighed by the advantages of working with participants in a common context.

4.4 Trustworthiness in this study

What are the criteria to judge if this study achieves what it sets out to do? What is the extent of the applicability of the conclusions? How can the reasonableness of the research process and the value of the conclusions be demonstrated? The idea of 'trustworthiness' (Emden and Sandelowski, 1998; Koch, 1994 and 1996) of an interpretive study represents an alternative to the well-known standard of validity associated with the empirical analytic approach, suggesting the relational character of this research paradigm (Sandelowski, 1997, p. 131). Trustworthiness suggests that a study is not misleading or unhelpful in but rather faithful, insightful and helpful in understanding the topic being researched. It incorporates the ideas of meaningfulness and significance. Trustworthiness can be judged in terms of the coherence, transferability and relevance of a study, criteria that also judge its meaningfulness or significance.

The criterion of the coherence of a study refers to whether the actual research process accords with the underlying methodology adopted in it (Koch, 1996, p. 178). Such coherence is manifested in the transparency of the process in the research report, described by some in terms of an "audit trail" (Altheide and Johnson, 1994, p. 489; Koch, 1994, p. 976). As Koch (1994, p. 977) notes, "readers may not share the author's interpretation but they should be able to follow the way in which the author came to it." I attempt to demonstrate the coherence of the research process in this study, in terms of the critical interpretive approach adopted, through its transparency in the research report. This thesis itself, reflecting the design, is intended to support the trustworthiness of the study.

The critical interpretive approach developed for this study in the last chapter requires a dialectic of 'fusion' (Thompson, 1990, p. 255) or engagement, and 'distance' (Ricoeur, 1986, p. 328) or reflection, that is based on the different positions of the participants and myself as researcher in the research situation. Transparency, in accord with the critical interpretive approach, involves clearly positioning myself as researcher in relation to participants, "accounting" for myself (Altheide and Johnson, 1994, p. 493), especially given my role in this study as both renal health professional and researcher with a participant group known to myself.

The design manifests the play of this dialectic that is then reflected in the shape of the thesis itself. My own reflection as researcher on the research topic positioning myself to approach it, a recognition of my distance from the men's location in the renal setting, is set out in the first two sections of the thesis. My engagement with the participants, seeking an empathetic fusion with their views, but understood as shaped by my own positioned approach to the research question, is recorded in the accounts of the third section of the thesis. The analysis of the accounts of the third section as a set from my research position established in the first two sections, a reflection on our engagement based on our distance, is recorded in the last section of the thesis. The outcome of the dialectic of engagement and reflection is a "construction" (Koch, 1996, p. 175), understanding their experience of living on dialysis through a representation of the client perspective in terms of the critical interpretive approach adopted in the study.

The design, reflected in the thesis, clarifies the sequence of “transformative processes” (Reinharz, quoted Walters, 1995, p. 1000) occurring in the research study.

I began ‘accounting’ for myself in my role as both renal nurse and researcher in relation to the participants in the research process during the recruitment process as set out above. At the beginning of the interviews with the men I explicitly addressed with them the question of my complex relationship with them. I made it clear that this research was separate from my clinical role, that it represented an attempt to discover their perspective on their renal therapy in order to enable health professionals to better address their needs as a group. I hoped that being a renal health professional who is also a researcher and a Pakeha man would enhance appreciation of the intricacies of their experience as reported by participants, enabling an empathetic ‘fusion’ of some depth. However I recognized such a ‘fusion’ is itself complex, because in the interviewing process the participants actually re-interpreted their experiences in the light of the interpretive framework that was implicit in my questioning as interviewer, a manifestation of the ‘distance’ between us (a step not noted in Walter’s, 1995, schema above).

Recognizing the complex ambiguity of the interviewing process as reflecting the limitations of our relationship, in the light of the initial assumption of the study about the difficulty in discerning the renal consumer perspective, it is clear that it is not possible to be certain that I have avoided distorting their views or even whether they have shared fully their views with me. By acknowledging this from the outset I have endeavoured to minimize such distortion through the methodology, design and interviewing process itself for this study as set out in this thesis.

Given that interpretive research does not seek objectivity, how successfully the study achieves its aim cannot be directly tested. Within interpretive research trustworthiness is supported through its “faithful[ness]” (Koch, 1994, p. 976) to the subjective ‘lived experience’ of the participants, the congruence of the researcher’s interpretation with the evidence from the interviews with the participants. Emden and Sandelowski (1999, p.5) state findings in interpretive research are always “tentative”, according to the “criterion of uncertainty.” As noted above in initially considering the methodology to

be used in this study, while it is not possible in a relativist view to have certainty about study findings some models are more meaningful than others (Schwandt, 1994, p. 129). The transparency of the research process supports the trustworthiness of the findings.

Beyond the criterion of coherence, transferability and relevance are other tests of the trustworthiness and significance of a study such as this. Transferability (Emden and Sandelowski, 1998; Koch, 1996, p. 179) refers to the capacity for the conclusions of the study to be usefully applied beyond the participants in the study. Relevance refers to the potential for the study to contribute to the "transformation of understanding" (Sandelowski, 1997, p. 128). Sandelowski (1997, p. 131), following Lincoln (1995), summarizes the criteria characterizing good qualitative research as ultimately "'relational', or relative to the interests and values of various communities of knowledge producers and users," reflecting the relational character of the interpretive paradigm on which such research is based.

In the analysis of the fourth section of this thesis, through reviewing the participants' accounts as a set I will produce a construct, in chapter eight, that models the client perspective in the renal setting. The renal client discourse that I produce generalizes the meaning of the experience of the men in the study. I will make this explicit by relating this form of the renal client discourse to the other modes of renal replacement therapy.

Then, by relating this construct to the men's individual accounts, in chapter nine, I will suggest that their experience can be understood as the product of the interaction of the dimensions of their personal social location with the renal client discourse and the dominant professional viewpoint that they are inculcated with. I will specifically suggest that gender and ethnicity influence their accounts via the interaction with the renal client discourse. Through this analysis I will demonstrate the transferability of the conclusions of the study to other groups within the renal setting. I will suggest the relevance of the conclusions of the study, in chapter ten, by drawing out one implication, its capacity to clarify the meaning of nursing work in the renal setting. Through this analysis of the fourth section of the thesis I will seek to demonstrate the

transferability and relevance of this research, supporting the trustworthiness and significance of the study.

In this chapter I have shown how I apply the methodology developed in the last chapter to address the research topic of the concerns of Pakeha men living on home haemodialysis. The critical interpretive approach establishes the shape of the research process, underlying all phases of the design. In the first phase, through interpretive activity within the arc of the interpretive turn, I develop an approach to the research topic, including specifically positioning myself in relation to the renal setting. In the second phase an interpretive process, of reflection, interviewing and writing, will produce accounts setting out the participants' own interpretations of their experience. In the third phase the analysis will involve reinterpretation of these accounts in terms of my initial interpretive positioning. Within the hermeneutic approach a critical stance orients my initial interpretive positioning in the first phase that will be expressed in the sketch of the renal setting in terms of Foucauldian thought. The reinterpretation of the participants' accounts in the analysis of the third phase will be shaped by this critical sketch, in its formulation as various concerns of this group of renal consumers.

In setting out this research design for the study I have articulated the logic of the shape of the thesis itself. In reviewing the ethical issues raised by this research and outlining the criteria by which the trustworthiness of the study may be judged I have attempted to support the integrity of the thesis. To enable me to implement this critical interpretive design it is necessary to complete the development of my critical positioning in relation to the research topic. By applying the Foucauldian ideas outlined above I develop a sketch in the next chapter as a way of viewing the renal setting that can orient the rest of the study.

Section B. A critical view of the renal setting

Chapter 5. Sketch: The client discourse in the renal context

“It is more correct to say that language speaks us rather than that we speak it”

(Hekman, 1986, pp. 110-111).

In the second section of this thesis I will develop a way of viewing the renal setting establishing a critical standpoint, in order to use the critical interpretive approach according to the research design developed in the first section, to address the topic of the concerns of Pakeha men living on home haemodialysis. In terms of the “radically relativist” (Schwandt, 1994, p. 126) approach to reality that is an assumption of this study, a social setting such as that constituted by CRF and renal replacement therapy can be interpreted from different points of view. They include not only the viewpoint of health professionals in the renal setting, based on the dominant empirical analytic paradigm, but also alternative approaches based on the interpretive paradigm.

A critical interpretive approach, derived from the interpretive paradigm, involves a critical view that explicitly recognizes different ways of viewing the renal setting, including alternatives to the dominant professional viewpoint. The Foucauldian view set out in chapter three provides a framework to articulate a critical view of this specialized healthcare context. This chapter uses this framework as the basis for a sketch of the renal setting.

From an initial reflection based on my own renal nursing experience I will present the renal context as initially constituted by the dominant professional discourse. I will

highlight its ideological character in optimistically presenting renal replacement therapy as a successful suite of treatments for CRF by downplaying its limitations. Among several other discourses also contributing to the renal context I will point towards an obscure client discourse made up of several concerns.

Reflecting the client perspective underlying individual interpretations of their experience of illness and therapy, the renal client discourse can only be understood in relation to the dominant discourse that people living on dialysis have been socialized with. This Foucauldian sketch provides a way of delineating the various dimensions of the renal setting. Finally I will consider the distinctive characteristics of the local New Zealand renal context.

5.1 Dissonant perspectives

My own positioning in relation to this research study derives from my experience as a renal nurse and my academic studies. This includes my acceptance of the interpretive paradigm as an approach to reality underlying the methodology for this study. It also includes the initial assumptions, in accord with this approach, about the character of the renal setting, that people on dialysis have distinctive experiences characterized by common concerns that are not easy for renal health professionals to understand.

The idea for this research project arose from my own sense, growing during years in renal nursing practice, of a certain dissonance between the views of renal health professionals, nurses, doctors, social workers and dieticians, and the views of people with CRF receiving our services. Rather than simply being an understandable contrast of two complementary perspectives there seemed to be a dislocation between the professional and patient viewpoints (see Cameron and Gregor, 1987, p. 674).

I recognized this dissonance first in the difference between how renal health professionals talk among themselves about the clinical situations of patients, and the impression that renal clients sometimes indicate they have been left with about their clinical situation after their interaction with health professionals. Based on their

discussions with health professionals they often have a more optimistic view of their situation than the view that health professionals candidly share among themselves. This dislocation is also apparent in the gap between the expectations of health professionals, about their behaviour as recipients of renal health services, and the way many of them in practice actually live on dialysis. Often manifested in tensions within clinical interactions between nurses and people living on dialysis, this gap is currently described in the renal setting in the ubiquitous professional labeling of non-compliance (see Bame et al., 1993; Bevan, 2000; Curtin et al., 1999; O'Brien, 1990; Levy, 1995; Lundin, 1995; Manson, 1995; Wright, 1998). A paper such as O'Neill and Glasgow's (1991) study referred to above, showing contrasting views of daily fluid intake restriction, epitomizes this dissonance between the views of health professionals and people living on dialysis.

The difference between how renal health professionals talk about their patients' situations and how those renal clients understand what they are told can be explained by the inevitable disjunction between the understanding of the professional and the 'layperson', and further justified by the need to give some hope to patients in a difficult clinical situation. However I have come to wonder whether it is possible that the gap between the professional expectation and their actual practice in living on dialysis may result from their different perspective as people with CRF (see Cameron and Gregor, 1987, p. 674).

This different perspective may reflect their sense of dissonance between the professional view presented to them, giving them an optimistic view of their situation, and their own developing understanding, based on their experience as a person with CRF, that shapes their practice of dialysis and associated renal therapy. It may be that their view is influenced by the recognition, from their own history of renal replacement therapy, that the professional viewpoint does not adequately describe their situation as they experience it, which from their perspective is more complex and ambiguous than they were initially led to believe would be the case. Then they may come to contrast, on some issues and to some degree, their own understanding as renal subjects, with the professional viewpoint conveyed within the various interactions they have with members of the renal health team. The gap between professional expectations and their

behaviour as patients may be an outcome of the dislocation between the professional viewpoint and their own understanding based on their experience of living on dialysis. This could be a cause of the obscurity of the client perspective in the renal setting.

As a renal nurse my particular interest is in how the renal nursing practice fits into this complex situation. Initially in my own work I viewed the renal nurse as contributing to the efforts of the renal health team by assisting the person with CRF to manage their life on dialysis. Her work at its best had the function of attempting to bridge the gap between the professional viewpoint and the renal clients' own understanding of their experience (see Challinor and Sedgewick, 1998). However I came to acknowledge that renal nursing, as an integral element in the work of the renal health team, inevitably participates in the professional activities that cause the dissonance between the clients' developing understanding and the professional viewpoint in the first place. Given their actual functioning within the renal team any such mediating role by nurses could rather be interpreted as endeavoring, whatever its intention, to smooth or even disguise the dislocation between the professional and clients' perspectives.

Despite this inevitable participation in the dominant professional viewpoint, one could view nursing practice as helping the renal client to adjust to life on dialysis through adopting the role of humanizing a therapeutic regime that is in itself perhaps somewhat alien, highly technological and bureaucratic in its operation. But as the renal setting has increasingly been dominated by advanced therapeutic technology, renal nursing work itself has become increasingly technical, a practice context in which numbers are now routinely correlated with outcomes (epitomized by computer-based estimations of the adequacy of dialysis, or routine surveillance of patient compliance) as large volumes of patients are efficiently 'processed' by nurses and their assistants in clinical facilities (see Bevan, 1998).

Rather than acting in any real way as a mediating agent, humanizing such therapy as care, renal nursing practice could rather be interpreted as having come to reflect the technological approach dominant in renal management. It is not convincing for nurses to simply assert a distinction, often on the basis of the character of their profession as 'caring', from what is often described as the dominant medical approach, when in

practice it is often they who set the treatment prescription, then require and enforce patient compliance with it (see Allen, 1985, p. 63; Burns, 1995; Thompson, 1983, p. 271; Wellard, 1998, p. 54). The dissonance between the professional and client perspectives raises questions for renal nursing practice.

5.2 Living on dialysis

My view of the situation of people with CRF has also gradually altered during my years of working as a renal nurse. Initially I shared the optimistic view that, although they faced a life-threatening problem, renal replacement therapy offered people with CRF the opportunity for the positive outcome of a fairly normal life. Those people who were able to respond to the requirements of the therapeutic regime would, with the inevitable odd exception, maintain a reasonably normal lifestyle living on dialysis, while the minority who could not manage the therapeutic requirements would not. While some people, despite assiduous compliance, would have a negative outcome due to the vagaries of renal disease, in general those who could adjust to living on dialysis, especially if they had a positive relaxed attitude to their condition, would still be able to live fulfilling lives. The demands of the therapeutic regime were justified because they offered the prospect of a reasonably normal life.

Over time, like many experienced nurses working with renal clients, I have come to appreciate more clearly the complexity of the situation of the person with CRF. Most obviously, after working with people living on dialysis over a long period it is apparent that while renal replacement therapy initially enables a positive quality of life for most people with CRF, it is not possible to be confident of a reasonably normal life as their positive long-term outcome. Firstly there is always the potential for problems from the complications of CRF. Even optimal therapy does not inhibit the long-term effects of CRF so that debilitation, especially from bone disease and cardiac problems, though very variable, is ultimately common, generally correlating with the length of time on dialysis. Further, each form of renal replacement therapy has specific limitations and complications, especially with access, either vascular or peritoneal, through infection or occlusion, that cause problems for most people on dialysis at some stage.

While treatment has improved over the years for the person on haemodialysis, some symptoms of CRF, for example itching, cramping, 'restless legs' [uncontrollable nocturnal twitching] or sleeplessness are not alleviated in some people with CRF despite optimum treatment (Devins et al., 1993; Kimmel, 1989 Parker and Bliwise, 1997). Further some people still simply do not thrive on dialysis for reasons we cannot understand (De Nour, 1994). Finally, despite my sense of a dissonance between the professional and consumer perspective, like other experienced nurses I recognized that for the person with CRF, even when they are doing well on dialysis, the treatment regime can still have an impact on their lifestyle and life opportunities. Often in my own nursing practice general issues, beyond the therapy itself, were most important for my clients.

Over recent years, as more people who are older and have significant co-morbid conditions, especially from diabetes, have been treated with dialysis, the meaning of the benefits of a nearly normal life have also changed. These people's expectation of normality is different from that of an otherwise fit younger person who was formerly the typical person presenting for renal replacement therapy (Bevan, 1998, p. 731). For many people the demands of treatment, from fluid and dietary restrictions to the requirements of the dialysis regime, now being added to the physical limitations they are already subject to, only permit a lifestyle that is significantly less than normal. It is in this context that the question of QoL measurement, or more accurately deficits in it, have become prominent in the renal literature, as noted above (Evans et al., 1985; Ferrans and Powers, 1993; Lok, 1996). The issue of what constitutes a reasonably normal life for the person with CRF, and its relationship to QoL measurement, has been highlighted by the high rate of withdrawal from treatment reported among people living on renal replacement therapy in some countries that have high rates of entry to dialysis programs (Bajwa et al., 1996; Challinor and Sedgewick, 1998, p. 7,8).

The impact of this alteration in the demographics of the population living on renal replacement therapy has enhanced my own awareness of the difficulties in maintaining a nearly normal life for people living on dialysis. Combined with an increasing recognition of the dissonance between the client and the dominant professional perspective, it has become focused in the topic of this research study, how one group of

people with CRF, Pakeha men living on home haemodialysis, actually understand their own situation of living on dialysis.

5.3 The dominant discourse in the renal context

These reflections on my own experience of renal nursing develop the initial assumptions of the study about the consumer dimension of the renal setting, the obscurity of the distinctive experience of renal illness and therapy recognized as resulting from the dislocation between the professional viewpoint and the client perspective in the renal setting, and the difficulty in maintaining a nearly normal life on dialysis acknowledged as resulting from the limitations of this successful therapy. They suggest a critical interpretive approach can use Foucauldian ideas in order to address the research topic of this study. Recognized as a contemporary specialized healthcare context in terms of the methodology of chapter three, a Foucauldian framework provides the basis for a sketch of the renal setting that is a critical alternative to common approaches, especially based on the notion of “roles” or “patient careers” or even a “new understanding of being” (see Bevan, 2000; Gerhardt, 1990; Kutner, 1987; Rittman et al., 1993 discussed above).

Renal replacement therapy can be understood, in Foucauldian terms, as a ‘technology’ manifesting specialized renal power/knowledge. The experience of the person with CRF is normalized by the surveillance and discipline of renal health professionals (Foucault, 1977; see also Bevan, 2000, p. 441; McHoul and Grace, 1993, pp. 66-70; Rabinow, 1984, pp. 20-22). The dominant discourse in the renal context, expressing the fundamental scientific therapeutic dimension of the renal setting, is embodied in the set of diagnostic and therapeutic activities and procedures practiced in nephrology, with their associated assumptions and formulations derived from current nephrological theory (see Fox, 1993, p. 57 on the analogous surgical context). It is a variant of the wider medical discourse, based in the empirical analytic paradigm ubiquitous in contemporary society, but with its own distinctive orientation reflecting the particular character of renal disease and the therapeutic technologies that manage it.

In Foucauldian terms one can say that the renal discourse is one specific form of medical discourse of the body (Foucault, 1975; see also Cheek and Rudge, 1997, pp. 708-9). The 'clinical gaze' of the medical expert, the nephrologist, defining a person as a renal patient through the diagnosis of CRF, and then determining and supervising their renal replacement therapy of dialysis and transplantation, epitomizes the surveillance and normalization of modern 'disciplinary technology' producing the 'docile body' that Foucault sees as characterizing contemporary society (Foucault, 1977, p. 198; see also Bevan, 2000, p. 441; Lupton, 1997, p. 99; McHoul and Grace, 1993, p. 66). In this case the regime of treatment, including monitoring both its efficacy and also the compliance of the patient with CRF, produces the 'renally replaced' body. The patient's own body itself is modified to accept the technology (by the creation of a fistula or insertion of Tenchoff catheter for dialysis access), their bodily condition is defined by a range of parameters measured by medical technology (such as specific blood chemistries and radiological scanning), their bodily activities, their lifestyle, are altered to accommodate the technology (their therapeutic regime and dietary and fluid restrictions). In contrast to the negative view of modern technology as alienating the human subject (see Bevan, 1998, and Rittman et al., 1993, above following Heidegger, 1977), Foucauldian thought suggests a more sophisticated viewpoint, viewing modern medical technology as ambiguous, therapeutic yet also potentially problematic.

All involved in the renal setting participate in the dominant renal discourse, their understandings are created within it and reflect it. The person with a kidney problem becomes a renal patient as they learn to understand their experience in terms of the dominant discourse in the renal context, inculcated with the professional understanding of CRF that shapes renal replacement therapy (see Bevan, 2000, p. 440). However it is not just the renal patient who is constituted by the renal discourse. The renal physician and the dialysis nurse are equally constituted by the renal discourse that gives meaning and authority to their roles (see Fox, 1993, chapter 3 in the analogous surgical context). The renal context, the various positions and all the roles within it, are created by the dominant renal discourse establishing the basic scientific therapeutic dimension of the renal setting, because it is the therapies generated by this discourse that enable the treatment of CRF. Rather than the renal setting being created by the relationships

arising from within it (a view expressed by Kutner, 1987), in this view the renal context is constituted by the dominant discourse that creates the relationships within it. In terms of Hekman's (1986) quote that began this chapter the dominant discourse creates the language that constitutes all participants, through its use of them, in their roles in the renal setting.

The dominant discourse shapes all professional interactions with the renal patient, allowing a variable potential for interpersonal relationships within the renal setting that is dependent partly on the character of the professional discipline involved and partly on the character of the individual health professional working in the role. Such professional roles reflect a position in the renal context that is shaped by the interaction of the dominant renal discourse and the generic discourse constituting a particular healthcare profession. These influential roles can be mediated to some extent by individual character, reflecting a personal social location involving a matrix of dimensions, especially the significant experiences of their own history. Brief stylized interactions characterizing medical consultations (Mishler, 1984, p. 77) have a limited potential for interpersonal relationship, in contrast with the extensive interactions characterizing nursing work with people living on dialysis.

The dominant discourse itself is not only constituted by the scientific theories and policies that are the necessary basis of renal replacement therapies but also by the various assumptions and attitudes that inform professional interactions with renal clients. The dominant discourse is like a matrix of meanings that shapes the viewpoint that is shared in the renal context, including formal knowledge and informal views that contribute to its development. Such informal views within specific local renal contexts, expressed in health professionals' attitudes and activities, what has been called 'doctor talk' in relation to medical specialists (Loewe, Schwartzman, Freeman, Quinn and Zuckerman, 1998, p. 1267), can colour the dominant discourse in their setting, producing local 'dialects' of the formal renal language. Different attitudes towards the different modalities of renal replacement therapy, CAPD, home haemodialysis, in-centre haemodialysis or transplantation, within different renal departments epitomizes this.

While the dominant discourse shapes all the roles within the renal context, it is most closely aligned with the renal physician viewpoint, because not only have the medical profession been most influential in its development and controlled its application, the dominant discourse underpins their interest and power in the renal setting. By contrast the nursing role in the renal setting is ambiguous. In terms of the dominant discourse the nurse is a functionary implementing the requirements of the therapeutic prescription. However the distinctive character of the interpersonal relationships that nurses develop in their work with people living on renal replacement therapies, based on their extensive involvement with them, suggests another less obvious potential dimension in their role that is obscured by the dominant discourse within the renal context.

There can be other discourses expressing different dimensions within a specific setting such as the renal context. Public attitudes towards health in general, and specifically the role of medicine and healthcare institutions, can be influential. In New Zealand attitudes towards transplantation and organ donation, particularly among Maori people, significantly affect the renal context. Another increasingly influential discourse within the renal context is the economic view of policy makers that addresses renal healthcare services in terms of outcomes produced according to resource allocation required (see Hadorn, 1997). These discourses reflect the sociopolitical dimension of the renal context. A very discreet discourse, the commercial technological, reflects the powerful influence of the companies that supply renal technology and fund research.

The dominant discourse, the health professional viewpoint, especially of the physician group, is also itself influenced by a sociopolitical discourse expressing various social viewpoints, including public expectations and also health policies (for example in relation to broadening of acceptance criteria for renal replacement therapy). Likewise the dominant renal discourse itself also influences public expectations and policy positions, especially as health professionals publicize their views in an attempt to alter perceptions among the public (for example attempting to increase rates of organ donation) or policy makers (for example seeking funding to expand the use of expensive medications like synthetic Erythropoetin). The commercial technological discourse reflecting the interests of companies involved in the renal context also both

affects and is affected by the other discourses. For example designing dialysis machines for convenient use by a professional standing in front of it, rather than for use by a person who is sitting next to it dialysing themselves at home, promotes in-centre therapy that the companies themselves have an increasing involvement in, at the expense of home treatment that may be more beneficial for the person living on dialysis. Thus there is a constant interplay between the different discourses in the health sector as localized in specific contexts such as particular renal settings.

There is also a discourse, fragmentary and little heard, from the recipients of renal therapy themselves, expressing the consumer dimension of the renal setting. In Foucauldian terms the dominant discourse within the renal context, reflected in the professional viewpoint, may give rise to 'resistance,' a 'subjugated knowledge' which could be described as an alternative or counter-discourse reflecting the perspective of the renal client, from their position within the renal context (Foucault, 1980b, pp. 81-96; Smart, 1985, pp. 132-136).

5.4 The ideological character of the dominant discourse

As it is ubiquitous in the renal setting some aspects of the dominant discourse, especially unstated assumptions and attitudes are not easy to discern. What could be called the ideological character of the dominant discourse is manifested in the impression created for the person with CRF from what is directly said, from what is encoded within what is said and also from what is left unsaid in their interactions with renal health professionals.

Informing renal health professionals' interactions with people with CRF, the inculcation of this viewpoint is initiated by the medical staff who supervise patient management and generally reinforced by other health professionals such as nurses who provide therapy. In simple terms there is a tendency to represent the positive potential of renal replacement therapy as offering patients the prospect of a relatively normal life. To achieve this optimistic outlook the limitations and complications inherent in treatment are neglected or downplayed. By focussing on its short-term therapeutic

potential rather than the longer span of this chronic therapy the person with CRF is left with a positive view of the possibilities of renal replacement therapy rather than an awareness of the difficulties in maintaining a normal life while living dependant on the therapy.

My illustrations of the optimistic ideological character of the dominant discourse are, because it is not formally clearly articulated, of necessity derived from my own nursing experience. As a simple example, where there is a choice of CAPD as the treatment option, either as a result of patient preference or clinical desirability, the limitations of this modality are generally not fully discussed. Few patients are told that for most people, while CAPD is successful in the short-term it is usually a therapy with a limited duration of viability, and that a significant proportion of people on CAPD have to abandon the therapy within a few years, either because of simple inadequacy of therapeutic efficacy or because of deterioration in their peritoneum.

In general the difficulties inherent in maintaining a life on dialysis over time, from controlling daily fluid intake to coping with the chronicity of the therapy, do not appear to be explicitly addressed in discussions with people who are to commence dialysis. This is evident in their ignorance of the requirements of therapy when they begin treatment. Also, for people already living on haemodialysis, when vascular access problems become recurrent because of inherently poor vessels in the patient, the short-term plan of another surgical option available is generally presented, rather than acknowledging the grimmer overall situation that vascular access possibilities are gradually being exhausted. Likewise transplantation is often simply presented as the definitive therapeutic solution without serious consideration of the potential complications of this form of therapy, including the likelihood of graft failure itself.

There is a tendency to wait for complications to occur before talking with the patient on dialysis about them. Then, having already secured their acceptance of the necessity for treatment, complications of both CRF and therapy can be treated as exceptions or unavoidable results of treatment. As a consequence the concept of iatrogenic pathology, that is avoidable unchosen medical problems that result from a chosen medical treatment, is relatively meaningless in the renal context (see Bevan, 2000, p.

440). Instead of being treated as complications that are caused by therapy, that patients need to be informed about before deciding whether or not to undertake such therapy (as would happen in some other forms of medical therapy or surgery), such pathologies are viewed, in terms of the dominant discourse, as unavoidable complications that follow from a necessary beneficial treatment.

Any problems occurring on dialysis tend to be treated as discrete events rather than aspects of a process inherent in the chronicity of the condition and therapy. Although renal health professionals actually spend the majority of their time seeking to manage the complications of CRF and its treatment, patients are left with the impression from discussions with them that therapy for CRF is simply efficacious and any ongoing problems occurring can be dealt with. A crucial aspect of the prevalent optimistic viewpoint is renal clients' ignorance of the morbidity and mortality associated with the condition and its treatment. The positive assessment of their own situation by people living on dialysis, for example the diabetic group in Hoothay's study noted above, to the surprise of the researcher, epitomize this (Hoothay et al., 1990). In the dominant discourse the goal of relative normalcy for those living on dialysis is affirmed but the difficulties people with CRF may have in achieving or maintaining this goal are not acknowledged.

Renal health professionals, if faced with such a description, often have difficulty recognizing that they present renal replacement therapy in terms of the ideologically optimistic character of the dominant discourse, generally pointing out that people initially find the idea of dialysis difficult to accept and have to be convinced to begin it. However in fact they are almost always persuaded, by health professionals, who affirm the positive potential of a relatively normal life on treatment with the implication that the adjustment required will be worthwhile. Simply being offered the therapy by expert renal health professionals generally validates its efficacy against any of their own personal reservations, for the person with CRF. This is particularly important when self-care is presented as the optimal form of treatment, because it has to be manageable and offer the prospect of a reasonably normal life or there is no incentive for a person to make the effort to perform their own treatment at home. While a small minority of people with multiple comorbidities are given a negative view of possible renal therapy,

in an effort to discourage their participation, this throws into relief the positive view generally presented to patients.

The fundamental problem with renal replacement therapy, as I have recognized in my nursing experience, is that, while it is generally a successful treatment in the short-term to preserve life and enable a reasonable quality of life, management over time is more difficult. Treatment is less efficacious in the longer term, involving a range of limitations and complications, both from the therapy (for example with vascular or peritoneal access) and from CRF itself despite treatment (for example bone and cardiac problems). The term renal replacement therapy itself is a misnomer, embodying the dominant discourse in its implication that this therapeutic technology simply replaces the kidneys' functions, when evidence of the morbidity and mortality associated with CRF show that only some of their functions are partially replaced for a variable period. Health professionals are, of course, well aware of the limitations of therapy, informally often the subject of in-house black humour that contrasts with the optimistic ideological character of the renal discourse in their interactions with patients.

When presenting renal replacement therapy as the solution to the problem of CRF to patients, it is difficult for renal health professionals to make explicit the limitations of treatment that undercut the efficacy of the therapeutic solution being offered. Health professionals tend to be reluctant to clearly set out the long-term complications or prognostic realities because, highlighting the demands made by the therapy itself on the person with CRF by contrasting them with an uncertain outcome, they contradict the optimistic ideology of the dominant renal discourse.

Health professionals' advocacy of the efficacy of renal replacement therapy is highlighted in situations where they have difficulty either in recognizing or, if recognized, in discussing with the patient, when it may not be beneficial for them, either to begin or to continue dialysis treatment. The recurrent problem of the question of withdrawal from treatment, in situations where the continuation of this life-maintaining therapy is no longer appropriate given the patient's quality of life, has given rise to a literature around the question of "advance directives" (Challinor and Sedgewick, 1998, pp. 7-8). This reflects the difficulty patients and their families have

in raising problematic issues such as withdrawal from treatment in a context where therapy is viewed as normative and beneficial. Though probably not unusual (Bajwa et al., 1996) and perhaps often disguised as fatal non-compliance (Hertal, Fincher and Caruana, 1995), patient withdrawal from treatment, except when occasionally suggested by the physician, is viewed as an unusual aberration in the context of a successful therapy. While the right to decline treatment is formally recognized, in fact patients are often offered psychological assistance, usually for depression, on the basis that withdrawal from an efficacious therapy is irrational.

While this particular exploration of the optimistic character of the dominant discourse may reflect the local dialect of the dominant discourse in the centre where this study was completed, the general contours of the sketch reflect the renal context as a contemporary specialized healthcare setting. Underlying renal health professionals' discussions with patients is the assumption that, though CRF is a complex form of organ dysfunction, it can be treated using modern technological therapies of contemporary western medicine. The renal context epitomizes the general ideology of biomedicine dominant in the health sector that health experts can successfully manage problems provided patients are compliant (Bevan, 2000). The optimistic ideological character of the dominant discourse reflects the hegemony of biomedicine, the embodiment of the empirical analytic paradigm "where the metaphor of the machine permeates nearly every aspect of the social world" (Thompson, 1987, p. 32). Supported by the influential commercial technological discourse of the companies that supply medical technology in the current healthcare setting, this reinforces the general public confidence in the efficacy of modern medical practice.

This optimism reflects renal health professionals' commitment to the therapeutic value of the treatment modalities they offer in their work, their desire to avoid having to give 'bad news' but rather to give people with CRF hope. A potential alternative presentation of life on dialysis as an ongoing uncertain 'semi-life', contradicting the ideology of the efficacy of contemporary medical technologies, would undermine the confidence of people with CRF and also weaken health professionals' own role and identity in the renal setting.

The optimistic outlook of the dominant renal discourse is understandable, as renal replacement therapy is a classic example of a modern medical technology that was developed for a condition that was formerly untreatable. The redefinition of renal failure from a terminal to a chronic condition as a result of the creation of renal replacement therapies, now well known successful forms of contemporary medicine that have become routinized and institutionalized, has given rise to an positive orientation that has had the result of downplaying the limitations of treatment and the problems entailed in it.

The dominant renal discourse, in preserving life through various technological interventions, what Bevan characterizes as the “*deus ex machina*” of medicine (Bevan 2000, p. 440), epitomizes the acute curative paradigm of biomedicine (Morris, 1999). However the result of these successful interventions is to produce a chronic illness (Bevan, 2000, p. 440). But the biomedical paradigm, that continues to orient management of CRF following the initial successful interventions, is incongruent with the chronic character of the renal setting that it has created. The dominant discourse, based on the acute curative paradigm, neglects the significant demands of adherence to the therapeutic regime, the short and long term complications of therapy, the ongoing effects of CRF despite therapy and the consequent necessity for ongoing medical support and procedures that are integral to renal replacement therapy, given the chronicity of CRF. This incongruence results in paradoxical difficulties for health professionals themselves in addressing adequately client problems associated with renal therapy, and also the chronic character of the condition itself, within the renal context. It is the source of the dislocation between professional and client perspectives I have recognized in my nursing experience.

The dominance of the ubiquitous renal ideology of a group of successful medical technologies, in particular treating any issues reported by people with CRF as specific discrete problems to be managed rather than aspects of a complex and ambiguous process, makes it difficult to recognize a distinctive client perspective. A focus on biotechnological efficiency, reflected in the prevalence of biomedical over psychosocial studies in the renal literature noted above, neglects the human cost involved for the person who is receiving treatment (Bevan, 1998). The optimistic character of the

dominant discourse obscures the perspective of the person living on dialysis.

5.5 The renally replaced life

CRF could be described, developing Morris' (1999) notion of illness as biocultural, as a relatively recent invention of the medical profession. Renal failure was a naturally terminal process until the development of renal replacement therapies allowed it to be managed as a chronic condition. What many people experience now, since the medical development of renal replacement technologies, is living while being maintained on such therapies. CRF can be understood as the medically defined perspective on this experience, an objective scientific set of parameters, from parathyroid levels in the blood to renal isotope scans, measuring the complex dysfunctional effects in different body systems arising from the failure of one specific organ, which renal replacement therapies attempt to correct or manage. While the formal medical view of this reality of renally replaced life is necessary and important, indeed the basis without which it would not otherwise exist, it is, as a "radically relativist" (Thompson, 1990, p. 252) view of social reality makes clear, only one way of viewing this reality.

The renally replaced life, though initially defined by the medical profession whose technologies enable it, may be understood differently by the person who is the subject actually experiencing this somewhat abnormal form of life, perhaps for example as involving distortions and diminution of their expected human reality (see Kleinman, 1988; Toombs, 1992, on the experience of illness; Cohen, 1995; Rittman et al, 1993; Sloan, 1996, on living on dialysis). As one writer has put it CRF is "mainly the illness of hemodialysis [where] the treatment becomes the sickness" (Peitzman, 1992, p. 210). However this subjective understanding of the experience of CRF is difficult to discover or generalize, for several reasons. Such a subjective understanding could only be expressed in individual terms, that are always influenced by the professionally inculcated understanding of renal disease and, also, could only be based on the diminishing memory of a pre-dialysis 'normality'. Further such a subjective understanding would be difficult to articulate to health professionals, given that the possibility of such a distinctive perspective tends to be negated by the assumption of

the dominant discourse that renal replacement therapies allow nearly normal life.

In short, in terms of the interpretive paradigm, there is no experience of the renally replaced life as such. There is always an experience as interpreted, first in terms of the dominant professional viewpoint, and then, perhaps in somewhat different terms, from the perspective of the subject living on dialysis.

5.6 The renal client discourse

The common viewpoint of renal health professionals, conceptualized here in Foucauldian terms as the dominant renal discourse, can be contrasted with the perspective of people who are the recipients of renal replacement therapy. Although socialized with the dominant renal discourse, the views of people with CRF are not necessarily identical with those of health professionals involved in renal replacement therapies. People living on dialysis have a different perspective from nurses, doctors and other healthcare workers because of their different position in the renal context.

Over time the person with CRF, now the renal patient, may find that their experience does not seem to fully accord with the dominant viewpoint. Despite the optimism of the dominant discourse they may realize that, for them, living on renal replacement therapy has certain limitations and difficulties, leading them to question or even modify aspects of the understanding of their renal experience that they have been socialized with. Their individual interpretations of their experience of renal illness and therapy, though typically framed in the language of the dominant discourse, will also reflect the dislocation between the professional viewpoint and the client perspective. However their own understanding of their experience will be difficult to discern because it is obscured by the dominant professional ideology.

Their interpretations can be understood, in Foucauldian terms, as creating 'resistance' to the dominant discourse expressed through the professional 'gaze' of the health professional (Foucault, 1975; 1977, p. 27; 1980b, p. 82; Lupton 1997, p. 99; McHoul and Grace, 1993, pp. 15, 16, 26, 31; Smart, 1985, pp. 132-136). Reflecting differences

in power and knowledge between different groups in a social setting (Allen, 1995, pp. 179, 180; Thompson, 1990, p. 258) this 'subjugated knowledge' of people living on dialysis based on their 'resistance,' can be represented as a client discourse, counter to the dominant discourse, that expresses their common perspective based on their shared position in the renal context.

Different aspects of the counter-discourse delineate the difficulties characteristically entailed in living on therapy with this condition. Named as 'concerns' (Benner, 1994, pp. 104, 105; Leonard, 1994:49) in this study they summarize the common perspective underlying the individual experience of renal illness and therapy that is not easy to discern in this contemporary health context. In contrast to views based on patient 'roles' or 'careers' (Kutner, 1987; Gerhardt, 1990) that tend to model the behavior of people living on dialysis from the professional viewpoint, in this alternative view in a Foucauldian framework the concerns of the renal client discourse model the common perspective of people living on dialysis, recognized as a reaction to the dominant discourse in the renal setting.

Just as the dominant renal discourse can have a number of dialects, depending on differences in formal practice or informal attitudes towards therapy in different settings, so the client discourse can also potentially have a number of variants. These will depend on different modes of therapy being used, whether self-care haemodialysis, CAPD or in-centre haemodialysis. They may also reflect the character of the dominant discourse in a particular setting, resulting in different dialects in the client vernacular. The particular variants of those living on self-care modes of therapy will be more difficult to discern, because they have very limited opportunities to share their thoughts with other people living on dialysis and develop a common understanding, their experience, being rather characterized by its isolation from others on renal treatment.

People with CRF will have difficulty articulating problematic aspects of their experience of living on dialysis because they have been inculcated with the positive conceptualization of the dominant discourse from their induction into the renal setting. They have been taught to think of their situation only in terms of the language of the professional viewpoint. Especially early on, some people do express their own views,

for example a reticence about self-care treatment at home. Typically health professionals attempt to alter such views by encouraging them, for example in order to enable greater independence than they themselves may believe possible, to realize the positive potential of therapy in accord with the dominant discourse.

Generally the optimistic ideology of the dominant professional viewpoint tends to smooth any sense of dislocation, especially when manifested in tensions in clinical interactions, by downplaying or negating any expression of the limitations and difficulties in living on dialysis. It is not easy for clients to seriously question renal replacement therapy, a classic instance of modern therapeutic technology, because it is an aspect of the general medical discourse that is integral to contemporary understanding (Nuland, 1993, quoted Webb, 1996, p. 961). Further the optimism of the professional viewpoint instills necessary hope. As a result people living on dialysis themselves tend to downplay any problems that they may experience or consider them to be idiosyncratic, specific to themselves, rather than problems inherently associated with their condition or its treatment.

Other factors contribute to difficulty in the articulation of the views of people with CRF. Health professionals' focus on the disease entity and its management, conveyed in the specialized vocabulary used with patients, especially medical interrogation for purposes of diagnosis resulting in adjudication on therapy (see Mechanic, 1995, p. 1207; Mishler, 1984), can itself inhibit people from talking about their subjective feelings about their situation, which requires a different mode of expression. The objectifying language of the dominant discourse used by health professionals tends to negate personal self-expression. In the complex healthcare setting that is oriented towards 'managing' the patient's condition it is difficult for health professionals to respond to any expression of their individual experience. Often decisions about therapeutic options are made on the basis of objective evidence before consultation with the client about their personal point of view.

People receiving therapy may also have difficulty articulating their personal thoughts because of a sense of dependence on health experts who are rationing life-sustaining treatments, a feeling of intimidation in front of professionally trained people, or a

strategic stance that they must hide certain information that they believe will be unacceptable to health professionals. Dines (1994, p. 331) alludes to the difficulty in discerning what people really think about their illness, in the distinction between public and private accounts among patients, what they tell health professionals and what they think themselves. Sloan's (1996, p. 91) application of Zola's (1991) concept, characterizing the experience of chronic illness or disability in terms of 'structured silence,' to the renal setting as "barriers that structurally silence" the voice of the client because of nature of renal setting suggest this reflects the professional viewpoint (see also Sloan, 1999).

Some people living on dialysis for many years seem to imply by their attitude, manifested in occasional statements or even a refusal to discuss certain issues (see Cohen, 1995), that health professionals cannot really understand their situation and, oriented to the positive potential of renal replacement therapies, perhaps do not want to hear about ongoing, unsolvable, problems. The dislocation between the perspective of health professionals and people with CRF may reflect this complex situation, the difficulty that those living on dialysis have in expressing their own views in a context dominated by the different approach of health professionals.

As a result of the dissonance caused by the dominant discourse, their interpretations of their experience, if articulated, may have an oppositional dimension. This could relate to the negation of their perspective, perhaps to the role of staff in 'policing' compliance with the treatment regime, even simply to health professionals as advocates for a healthcare programme that they may come to view as relatively inhumane, giving rise to their difficulties. Problematic responses from renal clients causing tensions in clinical interactions, whether lack of compliance or aggression towards staff, that are often viewed as pathological by health professionals in terms of the dominant viewpoint (Artinian, 1983; Bevan, 1998, p. 735; Burns, 1995; Levy, 1995; Littlewood et al., 1990, p. 108; Lundin, 1995, pp. 174-176; Mason, 1995, pp. 187-181; Stapleton, 1983, pp. 141-143; Wellard, 1992, p. 955), could in fact reflect such a counter-viewpoint. The difficult areas of clinical practice, around issues such as compliance or withdrawal from therapy, manifesting the dislocation between the professional and client perspectives, are reflected in the contrast between the dominant and client

discourses.

As noted above the dominant discourse, in affirming the value of therapy and requiring compliance with it on the basis of its efficacy, reflects the acute curative paradigm of biomedicine (Morris, 1999). The incongruence between the dominant discourse and the chronicity of CRF and renal replacement therapy creates a sense of dissonance between the views of health professional and those of people living on dialysis. The common perspective underlying their understanding of the experience of chronic illness can be summarized in the contrasting client discourse that is a reaction to the dominant renal discourse. Although, in terms of Hekman's (1986) quote at the beginning of this chapter, the normative language of the renal context that constitutes them as renal patients tends to 'speak' them when they express their renal experience, they can to some extent articulate a different understanding, using alternate language available to them from their general experience to modify, subvert or reject the dominant discourse.

In the dominant discourse people with CRF are viewed and treated as objective examples of a disease entity ("a 43 year old Caucasian male presenting with mesingio capillary glomerulo nephritis..."), epitomized by the professional clinical review meeting at which the patient is absent, not only in person but often as person (a view Fox, 1993, extends to the ritual of the ward round). The person with CRF is the 'patient' (see Kutner, 1987, p. 65; Zola, 1991, p. 10), whose disease state is to be managed, either the passive recipient of expert therapy or delegated to perform 'self-care' under expert supervision by renal health professionals, whose only role is compliance with the treatment prescription that is itself monitored (Bevan, 2000, pp. 440-441). In terms of the counter discourse they can be recognized as the 'renal client' (see Kleinman, 1988, p. xii), expressing the perspective of people with CRF, who respond to their experience of renal illness and therapy.

While the dominant discourse reflects the ideology of biomedicine in the empirical analytic paradigm, discerning an alternate perspective that is based on personal interpretations of experience of illness requires a different methodology in the interpretive paradigm. In terms of the critical interpretive approach developed in this

study this sketch provides a way of viewing the renal setting to enable me to understand the experience of living on dialysis for one group of renal clients, through delineating their distinctive perspective in the renal setting, that is otherwise easily ignored by being subsumed within the dominant professional viewpoint.

5.7 The local version of the renal discourses

The dominant discourse, shaping renal replacement therapy in New Zealand, has distinctive features that reflect the local context in various ways. The local 'dialect' is influenced by the intersection of demographic factors with the character of available renal replacement therapies, and also by the distinctive approach to renal management developed by clinicians in New Zealand.

In the dominant discourse in New Zealand self-care dialysis has been viewed as the

in-centre dialysis in Australia in 1995 (Disney, 1995, p. 73) that has continued since then. This major difference in the practice of renal management between New Zealand and other countries reflects the different character of the dominant discourse in other countries, which does not promote self-care but rather presents in-centre care as normative.

The predominance of self-care dialysis in New Zealand, unique in the developed world, reflects the local version of the dominant discourse where self-care is presented as optimal for the wellbeing of the patient. However pragmatic considerations, the interrelated factors of geography and cost, have been at least equally influential in driving its development. As CRF is a relatively uncommon condition people with this problem are thinly spread across a country that is generally lightly populated. However as it is relatively complex and expensive to treat, renal replacement therapies are only based in a few major centers. Because the tiny minority of people with CRF are evenly spread across the country many renal clients live long distances from these few renal units.

In a more heavily populated country like the USA renal clients will usually have one or more clinics where they can receive dialysis treatment that are located reasonably near to their residence, contributing to this becoming the normative form of treatment in that country. In New Zealand, where the departments of renal medicine are many hours travel from renal clients living outside the few major cities, self-care treatment, though more demanding of the person with CRF, is often the only practicable option, avoiding extensive travel or even the necessity for a renal client to shift from their own social setting in order to be near a dialysis unit.

Several studies looking at relative costs in New Zealand have shown self-care dialysis options to be half the cost of in-centre dialysis care as presently provided (most recently Croxon and Ashton, 1990). Home haemodialysis programmes require lower staff/ client ratios than in-centre treatment. The higher cost of in-centre care compared to home treatment (Goeree, Manalich, Grootendorst, Beecroft and Churchill, 1995) is not such an issue in other countries, partly because home treatment has or is being abandoned for other reasons and partly because costs related to higher nurse/ client

ratios can be overcome to some extent by gaining economies of scale, by using less qualified staff for routine treatments, and also by general cost efficiencies driven by private profit seeking corporations. Small dialysis units with high staff/ client ratios can never be as cost efficient. In this situation self-care at home is a more cost-effective option for the health services than in-centre care. The local version of the dominant discourse, reflecting these demographic and economic realities, has promoted self-care as a practical way of developing renal replacement therapies in this country.

5.8 The philosophy of self-care

The third factor that is integral to the local dialect of the dominant discourse, often called the philosophy of self-care, also relates to the other two. While driven by geographic and economic practicalities to implement self-care treatment modalities, New Zealand renal clinicians have promoted self-care at home as being a better option than in-centre care for renal clients themselves. Though undocumented in the literature, discussion with physicians and nurses indicate that in their view in-centre care has certain inherent negative effects. The inflexible treatment schedules for people receiving in-centre care combined with travel, often long, to the dialysis unit, significantly disrupt the normal pattern of life of the person on dialysis, increasing the likelihood of negative effects such as loss of employment, stress on personal relationships and limitation of leisure activities.

Further, in the view of clinicians, it is not only the requirements of the dialysis unit treatment schedule that have negative effects for the renal client but also the inherent dependence created by in-centre care. This is epitomized by the ritual processing to which the patient is subjected in their treatment in the dialysis unit, tending to undermine the individual's sense of their capacity to manage their own lives (Bevan, 1998; Stapleton, 1983). The effects of the treatment schedule on the renal clients' lives are thus exacerbated by dependence on the dialysis unit for treatment, diminishing their personal autonomy and self-esteem.

In the philosophy of care promoted by most New Zealand renal clinicians, people with CRF can and should be taught to do their own treatment. Taking responsibility for their own care leads to a sense of control of their own situation, facilitating a nearly normal life while on dialysis. They control the treatment as they do the rest of their lives. Making a choice of the modality of self-care therapy that they consider personally suits them best, where clinically feasible, epitomizes this approach.

Instead of their life being dominated by the disease and its management by dialysis, they are taught to use a treatment that will enable them to live reasonably normal lives. They can schedule the treatment to best integrate it with their lifestyles, in particular being able to vary the timing of sessions according to their pattern of other activities that is not possible with inflexible in-centre schedules. Long periods of travel are not added to the lengthy periods already required for the treatment. Thus, in the local variant of the optimistic ideology of the dominant discourse, self-care dialysis at home permits and encourages greater independence. In the clinicians' view, as a result of their self-care, they are better rehabilitated. American studies (Evans et al., 1985; Oberely and Schatell, 1994) demonstrate this, showing, despite the prevalence of in-centre dialysis in that country, that home dialysis patients have a better quality of life. The ANZDATA statistics about New Zealand renal clients also support this (Disney, 1995, p. 43).

Historically in New Zealand, given the demographic influence set out above, the development of self-care dialysis enabled the expansion of dialysis services from the very limited initial group receiving in-centre treatment who were chosen for their independence in the rest of their lives. In the expansion of the renal service through home treatment programs to a wider group of people spread across the country independence remained the key selection criterion, being the indicator that self-care could be successfully undertaken (see De Nour, 1994, p. 34). As a marker of potential successful rehabilitation this independence was also a justification for the health resources expended in providing the therapy. Fully rehabilitated, they would be usefully contributing to society, as it were contributing to some of their own costs (Bevan, 2000, p. 439). However in recent years further expansion of dialysis services has extended to groups not generally treated in the past, such as the elderly or people

with diabetes, who often have a suite of co-morbid conditions accompanying their CRF that limit their capacity for independence.

The increasing treatment of these less independent groups of renal clients, in a context where self-care is normative, has produced a growing number of problematic cases. Most notable was that of Rau Williams, an elderly Maori man, who died after being turned down for treatment by a renal centre, having been deemed outside the accepted criteria for long-term renal replacement therapy (Barclay, 1997; Chisholm, 1997; Dekker, 1997; Revington, 1997). This highly publicized case, a focal point for the articulation and debate among various discourses reflecting the intersection of different dimensions of the renal setting, especially the sociopolitical and consumer, is an extreme example of a common situation that local units now regularly meet. Although self-care is still viewed as normative in most units in New Zealand, age or associated comorbidities often lead to difficulties for people with CRF initiating or maintaining self-care dialysis or even, in some cases, continuing to live independently at home on in-centre treatment.

Despite the continuing dominance of the ideology of self-care in New Zealand, in some renal departments in-centre care has steadily increased as a result of the broadening group of people accepted for treatment. As this treatment option is becoming more prevalent an increasing number of people who could manage self-care are resistant to doing so. Rather than accepting they can take control of the management of their CRF through self-care treatment at home, they consider treatment for such a complex medical problem to be a form of consumer service that should be provided by expert health professionals in a clinical setting. A health consumer discourse, viewing dialysis as another form of health entitlement, here opposes the dominant renal discourse, an aspect of the increasingly strident health consumer discourse within New Zealand society. This has led to some modification in the philosophy of the dominant discourse, acceptance for dialysis treatment now no longer being based on their capacity for independence, or requiring the justification of the renal client's possible contribution to society. In centres where the high population concentration has made clinic care a more economically viable option, the departments of renal medicines have been able to be more responsive to this consumer view, leading to the expansion of their in-centre

dialysis facilities.

However there are also signs of a subtle response to the expansion in expensive in-centre treatment in New Zealand. The prevalent notion of an individual right to complex therapy like dialysis, resulting in a growing demand for in-centre care overstressing limited resources, is beginning to be countered by discussions about appropriate use of scarce health resources. There is now an attempt to introduce explicit selection criteria for access to long-term dialysis programmes, through a research initiative called the *Dialysis Indicators Project* (Dekker, 1997; Hadorn, 1997; Randall, 1997), tending to restrict access once again to those who can undertake self-care or have an adequate QoL. This change in the social climate is signaled by the language of 'right' to treatment being supplanted in policy documents by language about "gaining entry to the region's renal replacement programme" including "identifying those who will not be offered the option of dialysis" (North Health, 1995). Here a policy discourse, reflecting the sociopolitical dimension of the renal health context, is attempting to modify the dominant discourse.

Despite a significant increase in the numbers of renal clients on in-centre treatment during the last couple of years, the department of renal medicine where this study was undertaken maintains a philosophy of care that presents self-care as a normative goal that is most beneficial for the renal clients. Further transplantation is promoted as the optimal treatment option for them. The local professional renal viewpoint might be characterized in summary by the integrated view that dialysis is a beneficial therapy, that self-care dialysis allows a more normal life than in-centre care, and that transplantation is optimal in freeing a person from the requirements of dialysis.

This local version of the dominant discourse, in particular the presentation of self-care as normative, stressing normalcy and autonomy for the person living on dialysis while tending to negate the recognition of the limitations and dependence inherent in life on dialysis (see in another context Thorne and Paterson, 1998), combined with the strong promotion of transplantation as the optimal form of renal replacement therapy, may influence the character of the client discourse in the local renal context. While the promotion of self-care treatment does to some extent offset the passivity of the renal

patient as the recipient of renal services in the dominant discourse, people dialyzing themselves at home remain dependent on the therapy and the healthcare professionals who provide it. Compliance with the therapeutic regime is still necessary and monitored. Treatment at home may actually heighten this sense of dependence into a paradox, the nearly normal life through self-care promoted in the dominant discourse contrasting with their own experience despite being independent on dialysis at home. As the concerns making up the renal client discourse are developed in response to the dominant discourse, the client discourse may have particular characteristics that reflect the distinctive features of the local version of the dominant discourse.

5.9 Conclusion: discerning the client perspective

In this chapter I have produced a critical view of the renal setting. Using the Foucauldian ideas about the character of specialized healthcare contexts I have developed the initial reflection on my nursing experience that recognized the dissonance between the optimism of the dominant professional viewpoint and the client experience of the ongoing difficulties of living on dialysis. I have sketched the renal setting as a specialized healthcare context constituted by several interrelated discourses, including a dominant discourse and a contrasting client discourse made up of several concerns. I have shown that the client perspective, underlying the individual's interpretation of their experience of illness and therapy, can only be understood in relation to the professional viewpoint, as a response to the dominant discourse they have been socialized with.

The Foucauldian framework of the expert professional 'gaze' producing resistant 'subjugated knowledges' (Foucault, 1975; 1980a, p. 82), when applied to this specific specialized healthcare context in terms of contrasting dominant and client discourses, produces a standpoint that acknowledges the complexity of the renal setting. In this approach the optimistic ideology dominant in the renal setting is resisted, but alternative approaches that simply characterize the renal setting negatively, for example in terms of a Heideggerian hermeneutic notion of technology (as in Bevan, 1998; Rittman et al., 1993), are also rejected as inadequate.

Rather, the renal setting is recognized as ambiguous, as a social context based on contemporary technological knowledge that is therapeutic yet also problematic for renal consumers. Such an approach provides a way to clearly conceptualize the character of the relationship of the client perspective to the dominant professional viewpoint. The concerns of the people living on dialysis are recognized as a perspective not only obscured by, but also both influenced by and a response to, the dominant professional viewpoint. This way of viewing the renal setting highlights, as a distinctive perspective that is otherwise easily overlooked in this highly specialized area of healthcare, the perspective of people who are the subjects experiencing renal illness and therapy.

The Foucauldian concept of discourse is understood in this research project, in terms of the critical interpretive approach developed for this study, as a summary of the interpretive perspective from a particular position within a given social context, in this case the renal setting. The renal client discourse represents the common perspective that underlies the individual interpretations of people living on dialysis. It is not a coherent view that individuals explicitly hold. It is a summary that is constructed by the researcher through a re-interpretation of participant's own interpretations of their experience of CRF and renal replacement therapy. The concerns making up the client perspective can be delineated by discerning certain commonalities present in obscured form in their accounts that are typically expressed in the language of the dominant discourse. The renal client discourse is a construction, from the standpoint of the researcher, which, by modeling the difficult aspects of living on renal replacement therapy, presents their common perspective as people living on dialysis.

This sketch enables a critical stance that can orient the rest of this study. It will facilitate me, as researcher, in positioning myself in relation to the men in the study and in producing accounts of their experience of illness and therapy in the next section of the thesis. Using it to analyze their accounts as a set in the fourth section of the thesis, will enable me to understand the experience of Pakeha men living on home haemodialysis. Finally, as one implication of this study, I will consider the role of renal nurses in terms of this sketch of the renal context as constituted by the dominant and client discourses.

This way of viewing the renal setting is an initial product of the study, showing how the client perspective, underlying individual interpretations of their experience of renal illness and therapy, is related to the dominant professional viewpoint in this contemporary healthcare context. Using this sketch of the renal context in a critical interpretive approach, according to the research design of the last chapter, I am seeking in this study to hear the 'voice' of people suffering from CRF, often lost in the professional health talk that dominates specialized healthcare contexts of the renal setting. In order to do that, in the next section of this thesis I will produce accounts of the experience of six Pakeha men living on home haemodialysis.

Section C. Living on home haemodialysis: six accounts

Chapter 6. Positioning myself in relation to the men in this study

“My life is probably quite abnormal but I’ve forgotten what normal is” Mark

The third section of this thesis presents accounts of the experience of renal illness and therapy based on interviews with six Pakeha men living on home haemodialysis. The initial assumptions of this study seeking to understand the experience of people living on dialysis were that people with CRF have distinctive experiences but that these are not easy to discern in the renal setting. From using the critical interpretive approach, developed on the basis of these assumptions to address the research topic, I present here interpretations of their experience by a number of individuals belonging to one particular group of renal clients.

Given the methodology used in this study, in seeking to present the experience of living on dialysis it is necessary that I clarify my relationship as researcher with the participants in the study, by critically contextualizing it within the renal setting. In accord with the critical interpretive approach I recognize that the men’s accounts are generated from my position in the renal setting. They are based on an interview process that I established as researcher. The interviews themselves were discussions that were jointly created by the participants and myself. The accounts of their experience presented here represent my reinterpretations of their own interpretations after transposing them from their own location, via the interviews, to my somewhat

different position in the renal setting. Through the clarification of our relationship in terms of our different perspectives as client and health professional that begins this section I am seeking to minimize the distortion of their views as I present them in the accounts.

Their individual interpretations of their experience presented here in the third section will then, in the fourth section, be analyzed as a set in order to understand their experience as Pakeha men living on home haemodialysis. Through this analysis I will delineate the common concerns that underlie their individual accounts as aspects of the renal client discourse. I will then suggest the way that the renal client discourse is related to their individual accounts of their experience. Finally I will consider one important implication of this understanding of their experience, the meaning of the nursing role in the renal setting. The set of accounts of the men's experience of renal illness and therapy in this third section of this thesis are the hermeneutic outcome of the use of the critical interpretive methodology developed in the first section for this study. They will be reinterpreted in the fourth section, in terms of the critical nursing view of the renal setting developed in the second section, to present an understanding of the concerns of Pakeha men living on home haemodialysis.

In this chapter I locate myself in relation to the men in the study. Having critically positioned myself as a renal nurse researcher in relation to the renal setting in the second section I will now consider various aspects of my interrelationship with the six men who are participants in the study. In accord with the critical interpretive approach this reflection will be based on a recognition of the limitations in these interrelationships. Despite us all participating in the renal setting, their views are not directly accessible to me because of the 'distance' (Thompson, 1990, pp. 261,263) between us, my different location from them within the renal setting. Clarifying our relationship enables me to position myself in relation to the process of interviewing and producing accounts of their experience of living on dialysis.

In this chapter I will recall going to the men's homes to interview them and the questions that this experience raised for me. I will indicate the ways in which I

attempted to address the issue of seeking, as a renal nurse researcher known to them, to interview these renal clients as subjects of the study. I will discuss the surprises I experienced in interviewing these men. Finally I will consider the unexpected dimensions of my professional involvement with these men since the interviews. Through this reflection 'accounting' (Altheide and Johnson, 1994, p. 493) for myself in my relationships with the participants I position myself in relation to the men whom I interviewed and thus, in accord with the research methodology for this study, contextualize the individual accounts presented in the third section of the thesis.

In order to recruit six men for the study I asked the nursing staff of the home haemodialysis training unit to list potential clients who were suitable, Pakeha men established on self-care haemodialysis for at least a year who lived locally. Those nominated were viewed by the staff as managing very successfully on this modality of renal replacement therapy. They rarely telephoned the nurses with problems, were never admitted to the ward for reasons related to lack of compliance with the therapeutic regime and appeared settled in their dialysis routine when visited at home by the nurses. Their regular blood tests gave excellent blood results reflecting effective dialysis. They maintained good blood pressure control according to their records of their treatment at home. From the point of view of the home haemodialysis staff they were model patients.

From their list given to me by the staff I sent out six letters. I chose men who provided a range of experience in terms of their ages, personal situations and length of time on therapy. After they had provisionally agreed to participate by phone, I visited each of the men in their home to discuss the study with them and obtain their formal consent. Having recruited the six men for the study I then returned to their homes on three further separate occasions to undertake interviews, each lasting about an hour. The process of interacting with them, interesting and at times challenging, raised a number of issues for me.

6.1 Meeting the men in their homes

I knew all the men who agreed to participate in the study. Having worked in the dialysis unit over a number of years I could remember personally performing the first dialysis treatment for several of the men. Another I remembered as having had a very difficult time initially because of problems creating adequate vascular access for treatment. Several of them I could not recall any specific involvement with, although they had been in the dialysis unit. As all of them had been successfully established on self-care dialysis at home for at least a year I had not spoken to any of them for more than a year, some for a number of years, prior to their response to the request to participate in the study.

Before I began interviewing the men in the study I had only once accompanied a home haemodialysis nurse making home visits to her clients. Visiting people on dialysis at home was a novel experience for me. Having worked for many years in the institutional context of the hospital dialysis unit I found my initial encounters with haemodialysis machines in a normal domestic context disturbing. I felt this on first seeing machines on my single day of home visiting before beginning the interviews and the feeling recurred during my discussions with the men. Often I did not see the machine during the first interview but I always felt the same when I did first observe it in each man's home. Being used to seeing dialysis machines in the clinical hospital setting over many years I found the sight of them in rooms in people's homes to be intrusive and alien. Yet it was also obvious that these men themselves were accustomed to the dialysis machine and accepted it as a normal part of the contents of their houses.

The issue for me, triggered by seeing the machines in the men's homes, was not a specific concern about the safety of performing dialysis in a non-clinical area but the way that it was integrated into their everyday lives. I was used to people coming to the hospital dialysis setting, a specific clinical context, as it were stepping out of their own world into the alternative world of the dialysis unit, not only a separate physical space but also a distinctive social environment where they had a set of specific relationships developed around the dialysis treatment. Despite formally

accepting the dominant professional view that self-care enabled a nearly normal life I had not really thought about the impact of the dialysis regime except in terms of requiring periods of time away from their normal daily life. It looked to me, as a hospital-oriented dialysis nurse, as if they were never able to escape the dialysis regime that had invaded their lives, the presence of the dialysis machine in their house being the concrete symbol of this intrusion.

This experience of feeling dislocated myself at finding the dialysis machine in an unusual context, in contrast to the attitude of my participants, problematised for me the question of what the experience of living on the machine meant for these men. Seeing the machines in their homes made me realize that the question for these men was not one of time spent away from of their everyday lives in the dialysis unit but of how they integrated the dialysis regime into the normal pattern of their everyday lives. For all of them their treatment was an integral part of their normal weekly routine, a subject that became a focus of our discussions.

When talking with the men at times when they were not connected to the dialysis machine our discussions always took place in the living room. When I talked with them while they were dialyzing on the machine it was in another room, in the case of all of these men except one, a special room within the house. In several cases it almost had the character of a den, with a computer, TV and bookshelves. Some people living on dialysis at home do have the machine in their bedroom or even the living room but usually it is in a separate room if possible. While it was useable for other purposes this 'dialysis' room was also in a sense separated from the rest of the house, occupied for the many hours required for dialysis, but able to be cut off when not in use. The distinctive character of this room, set up for the needs of the man who had to use it for so many hours a week yet 'disappearing' when the door was closed while not in use, suggested an ambiguity about the place of dialysis in their lives despite their ease with the machine and the procedure, an issue that came up in our discussions.

The initial assumption of this study, the obscurity of the client perspective in the renal setting, reflected my own sense of the dissonance between professional and

client perspectives in the renal setting. My experience in going to their homes to interview them, strongly reiterating that sense of dissonance for me in a novel way, confirmed this assumption. However I also recognized a risk of reading my own sense of the alien-ness of the process of dialyzing at home, reflecting my own professional background as a hospital dialysis nurse, into their accounts in my interpretation of them. The methodology developed for this study, as applied to this research topic in the design in chapter four, made explicit the necessity to address this issue of my relationship as renal nurse researcher to the participants.

6.2 Nurse researcher and client participant

Acknowledging my own location as renal nurse and researcher in accord with the critical interpretive approach, I was aware that the men and I were in different positions in the renal setting, in Foucauldian terms of a difference in power and knowledge between us in this highly specialized healthcare setting (Foucault, 1975, 1977). Recognizing that their distinctive understanding as renal healthcare consumers is obscure in the specialized renal context, a “subjugated knowledge” (Foucault, 1980, pp. 81, 82), I sought to move beyond talking in terms of the language of the dominant viewpoint that they are socialized with, in order to discern their own views. Positioning myself in relation to each man was crucial to enable me to do this.

I understood the potential difficulties for a client of the renal service in talking as a participant with a researcher who is also a representative of that service. We effectively control the therapy that keeps them alive which inevitably affects the way they relate to us. While having an understanding of their own therapy and being independent in performing their own treatment does to some extent offset this dependence they are still reliant on us if problems occur, for example with blockage of their vascular access or malfunctioning of the dialysis machines. This difference in power and knowledge cannot be simply overcome but can be acknowledged and addressed. The issue of their dependence on therapy, despite their independence on self-care treatment, became a topic of our discussions.

In talking with the men I attempted to bracket my usual clinical role, discussing with them how I wanted to hear their own views for the study, explicitly acknowledging that I recognized that as health professionals we might have difficulty appreciating their perspective. My hope was to tap into their experience of supportive nursing relationships within the department in order to encourage them to be open in discussion with me. I sought to position myself as within yet outside, within as able to understand because of my experience with people living on dialysis, but outside as not myself having experienced what it is like to actually have to live on dialysis.

I acknowledged difference in power and knowledge that existed between us, of provider and recipient of renal healthcare services, but also explicitly recognized that what each of them chose to do at home on dialysis, how they chose to manage their treatment and integrate it into their lives, was their decision that I respected. I said that the nursing service that they received from the home haemodialysis nurses, while giving guidelines to help them, was ultimately oriented to supporting them to manage their own treatment. I noted that the particular practice that each one had developed was successful because they were not having problems that led them to regularly contact the home training unit or caused them to be admitted acutely to the renal ward. Through this discussion of our relationship I attempted to make them comfortable about speaking freely of their dialysis practice, even if aspects of it did not fit the therapeutic prescription they had been given.

One of the reasons I had chosen to interview men was that I thought a natural empathy between us as men would make it easier for them to speak freely with me. In fact I found that I was more conscious of our differences in outlook and interests than our common masculinity and Pakeha culture. All these men lived in the outer suburbs of the city in houses built in the sixties or seventies. As one who had left the suburbs many years ago, and has since always been an inner city dweller living in an old wooden house, I found I was venturing into areas around the city I had only ever visited occasionally in the past. I was very conscious of the variations in socio-economic status of the different suburbs as I visited these men. Going into suburbs I never normally visited came to signify for me some of the differences

between us.

It is not possible to finally judge how successful my attempt to position myself in relation to them actually was. Getting beyond a pattern of me asking questions that they answered to a point where they simply talked freely about their situation was sometimes difficult. I found several talked very frankly at length but others were quite laconic and even terse in the discussions. I appreciated the insights that were shared in the discussions. At times, on review, I may have liked to have gone deeper into some issues. To some extent I allowed them to set the parameters of the discussion. For example I did not explicitly raise with them the question of the effect of dialysis on their sexuality but talked generally about their personal relationships. This partly reflected my own limited experience as an interviewer, a desire not to inhibit empathy established by being too probing or appearing voyeuristic. It also perhaps reflected an excessive sensitivity to the fragility of our relationship, because of my own sense of the differences in outlook and interests between us, and also my own natural reticence. In retrospect I wish I had more raised some more personal dimensions of their lives with several of the men.

Before the interviews I felt that I knew these men, some better than others, both from my own past clinical work with them and associated professional discussions with colleagues about aspects of their care. Going into their homes opened up a new dimension beyond what I knew about them from my past work with them in hospital. Even some whom I had thought I had come to know reasonably well at some point in the past I came to know, through the discussions, as somewhat different from my earlier impressions. Partly simply seeing them in their own setting opened their world to me. Also in their own environment they were able to talk about their renal therapy within the context of their own life situation rather than, as in the dialysis unit, talking about their treatment with their own life situation as a vague background.

We talked about their life on dialysis in their own setting where they were in charge. This helped redress the imbalance in power and knowledge between us, facilitating an openness in our communication. Also discussions about how their dialysis

related to the rest of their lives were dealt with in a different way than would have been possible in the renal department, more concretely as an aspect of their typical weekly routines of life in the house where we were actually talking. Overall I considered, from my own renal clinical experience, that they talked of how they felt about dialysis and their attitudes towards having to live on dialysis more openly than would be possible in a clinical context.

6.3 Surprises

Before beginning the study I envisaged that, having had some involvement with me clinically in the past, they would now be involved with me in a different way as a researcher for a limited period, and then perhaps at some point in the future might again be involved clinically with me in the dialysis unit. While I had assumed that, as established successful self-care clients, they would not have any requirement to dialyze in the dialysis unit throughout the short two-month period of information collecting, to my surprise, four of them did need to dialyze in the unit for various reasons during the time of our discussions. While being treated in the unit several of the men freely talked about participation in the study to staff who were caring for them. It was necessary for me in my clinical work to remember who had done so in order not to violate the privacy of those who had chosen to be discreet about this.

Having a number of otherwise well self-care clients needing in-centre treatment within a short space of time was unusual and unpredictable. However it graphically illustrated an aspect of their lives on dialysis, its uncertainty, becoming a focus for discussion for most of these men, as a point at which the limitations of the dominant renal ideology of dialysis as a successful therapy enabling a relatively normal life became apparent.

While I did not specifically seek their reactions to me as a renal nurse, several, late in the conversations, alluded to this. I was surprised how a couple of them, despite spending some time in the dialysis unit, felt they hardly knew me at all. Several said they found me a somewhat distant figure in the unit. This was somewhat

disconcerting to me because I considered I knew them reasonably well. On reflection I realized in fact how little I had had to do with some of them personally in my role as supervising nurse, because they had had uneventful visits to the unit, despite knowing about them from observing them in the dialysis unit and being involved in discussions with staff caring for them. In illustrating concretely how the relationship between nurse and client can appear different from the perspective of the client than it does from the nurse's viewpoint, this supported the initial assumption of this study that it is not easy for health professionals to understand the experience and perspective of people living on dialysis.

My hope had been that they would have positive memories of me from the time they had spent in the dialysis unit in the past. As a result they would be happy to discuss their life on dialysis at home with someone they believed had some understanding of their situation but remembered as fairly relaxed about the disciplinary aspect of therapy, encouraging people to fit the treatment in around the normal activities of their lives. Happily, despite not necessarily having the positive memories that I had been relying upon to encourage their initial participation, they all considered their actual participation worthwhile for various reasons, whether to help present the position of people on dialysis in order to increase understanding and improve service by renal health professionals, or as therapeutic for themselves personally, or even simply as helpful to me.

During the interviews one of the men described at length a negative experience of treatment in the dialysis unit, an outcome of the discussions that I had not anticipated, probably because of my own tendency to view positively the service provided in the unit. It did appear that the problem had arisen because on this occasion the nurse working with him had not listened to him, leading to negative consequences during the treatment. This event explicitly illustrated the dissonance between the client and professional viewpoints in the renal setting. Without discussing the specific situation we had some discussions in the unit about the need for dialogue with people living at home on dialysis who understand and normally manage their own treatment.

6.4 After the discussions

After I had completed the discussions with the participants in the study my role in the department changed and I took on the supervision of the home haemodialysis training units. While I still had no direct clinical involvement with the men whom I had interviewed, I began to work with the nurses who support these men at home on dialysis. As a result, since completing the interviews, I have had interactions with several of the men who participated in the study in my changed role coordinating the home dialysis services.

Having already been involved with them as researcher has complicated some of these interactions. In some cases knowing more about the situation I have been clearer about action necessary for their benefit. However in other cases it has been more difficult. The interviews have given me a greater insight into their lives, making me more sympathetic to their personal situations that constitute the backgrounds of requests they may be making or issues that need to be addressed in relation to their care. I have also known that, when speaking with me about these, they are aware that they have revealed themselves to me in a personal way and could feel betrayed if I am unresponsive. Any decision in relation to their therapy they will know was made with full knowledge of their situation. However in the nursing role it is necessary to make appropriate decisions according to departmental policies in relation to their therapy. While I have negotiated the situations that have come up to date it is possible I might need to seek some collegial assistance in the future for such situations.

Despite striving for methodological clarity about my role as nurse clinician and researcher, as set out above in chapter four on the design for the study, this chapter has suggested the complexity I found in practice with this dual role. My involvement with the men in the study did not follow the pattern that I had expected. My experience of participants' coming into the dialysis unit during the study, their reported perceptions of me as a nurse clinician and the one reported negative experience in the dialysis unit during the interviews, and their requests for assistance in the period following the interviews from me as supervisor for the

home training unit, all raised the question of the relationship between the nursing and researcher roles and finally the character of nursing work itself in the renal setting.

While my goal in my interactions with them as researcher was simply to be responsive to their experience, the clinical nursing role, whether as clinician or nursing manager, is more complex, inevitably balancing an empathetic responsiveness with a need for authoritative decisions. While interviewing participants whom I had worked with clinically as a nurse raised several issues I had not anticipated, it was my knowledge of their clinical situation from my experience as a renal nurse that allowed me to relate to these men living on dialysis in a way that would not have been possible for a person unfamiliar with the renal context. It was because I am a health professional, distinctively positioned in this specialist healthcare context as a nurse, what Foucault characterized as a "specific intellectual" (Foucault, 1980, p. 126), based within a particular specialized contemporary context that I can engage the men in this particular type of research project. My experience of this difference in the roles of clinician and researcher throughout the research process, in the events mentioned above, stimulated my reflection about one important implication of the study, the nature of the nursing role in the renal setting that is addressed in chapter ten in the fourth section of this thesis.

In raising the question of normality, questioning how 'normal' his life is because he can no longer remember clearly his pre-dialysis life, Mark's statement, quoted at the beginning of the chapter, potently suggests the ambiguity and difficulty in interpreting his life on dialysis, for himself, and, by implication, for a nurse or any other health professional working with him, let alone for a researcher. In this chapter I have attempted to carefully position myself in relation to the men in the study as required by the critical interpretive methodology developed to address the research topic. Critically contextualizing my relationship as researcher with the participants in the study, 'accounting' for myself in the research, facilitates the presentation of the accounts as their interpretation of their experience of illness and therapy.

The next chapter contains accounts of the experience of the six men in the study. These accounts framed by my reflections represent my attempt, using the methodology developed for this study, to discern their views that are obscure in the specialized renal context, by describing their interpretation of their lives on dialysis from my experience of interrelating with them in our discussions.

Chapter 7. Six accounts of living on haemodialysis at home

This chapter sets out accounts of the experience of illness and therapy from the six men who participated in the study. For each man, after briefly noting the key facts in his personal social location, his thoughts about his life on dialysis will be set out in an orderly fashion.

The accounts are based on tape recordings and my observations from the discussions I had with them. The semi-structured interviews covered a range of topics and encouraged the men to raise issues of importance to them. The transcripts of our discussions have been edited, associating ideas and statements from various parts of the interviews while removing peripheral material, using clues from my notes about our meetings, in order to focus on key elements that came up repeatedly or were given significance by each man in addressing what was important to him. The accounts summarize their thoughts in their own terms, generally using their own informal style of language rather than my own, often paraphrasing what they said or quoting their words directly. I have tried to create a coherent narrative moving from the most obvious features of their experience, through issues about the management of their treatment, to their profound response to having to continue to live on dialysis.

In terms of the dialectic of engagement and reflection that characterizes the critical interpretive approach these accounts represent my interpretive response to these men's experience of renal illness and therapy. In order to achieve coherence this methodology requires acknowledgment of the 'distance' between us, through positioning myself as researcher in relation to them. This facilitates a presentation of

their views from our engagement in the interviews that reflects their own interpretation of their experience. Such positioning includes not only orienting myself toward the men for the interviews themselves, as outlined in the last chapter, but also this recognizing the accounts as my own production. Giving them the opportunity to comment on the drafts, in terms of maintaining their own privacy but also to check that they accurately represent their own experience, helped ensure that each account, though my construction, conveys the meaning of their lives on dialysis for the man involved.

7.1 Mark

“Living on dialysis is very restrictive.”

The first account is from Mark. As a successful professional working in the high technology sector Mark is unlike the other men in the study. A younger man in his late twenties he lives alone in his own house in a middle class suburb. He has been living on home haemodialysis for seven years, is on the transplant waiting list for a transplant but has yet to receive one. Sensitive yet analytical, Mark offered detailed reflections about his experience of dialysis, expressively interpreting his own experience in terms of his considerable knowledge of CRF and renal replacement therapy. Having agreed to give his views as a person living on dialysis he carefully attempted to articulate his thoughts about his experience.

7.1.1 A restrictive life

Mark feels *“very tied to the machine,”* he has to live *“around”* the dialysis regime that cuts down what he can do throughout the week. The time taken to dialyze has the largest impact. When he is not working, dialyzing or sleeping he is doing housework or other home maintenance and so has very little free time. Even managing his stores, providing blood tests and maintaining his supplies of

medications, necessary aspects of living with CRF, take up time in a busy schedule. For example filling scripts at the hospital pharmacy for specific drugs, such as EPO, is difficult because it is only open in business hours, is distant from his work and the service is slow. *"Time is precious"*. Although the time required for dialysis makes his schedule tight, *"dialyzing becomes the break"* because he cannot do other things while he is on the machine.

While he feels lucky to have avoided some potential problems, Mark suffers from a range of symptoms at times. His feet are often uncomfortable, his joints sore, his skin is fragile and easily damaged, *"the same sorts of things as my grandmother, only she was 50 years older."* He has suffered from 'restless legs' [uncontrollable nocturnal spasms in the lower limbs] that he has treated by periodically extending his weekend treatment time. He has had *"symptoms like hypoglycaemia"* which he eventually combated by gaining weight. He also had a phase of troublesome nausea regularly in the mornings several years ago, which finally went away. On reflection *"my life is probably quite abnormal but I've forgotten what normal is."*

He is no longer able to do things he used to, especially physical activities like windsurfing and bike riding. He no longer has the energy or the time for them. He could still manage to do them now but not as well as he used to and he would be exhausted. *"It was very tough psychologically having to accept that."* Generally he has very little energy, and is easily tired. Everything is harder and takes longer, from work to routine chores. These days he rides a motorbike, something attractive to him since he was young, giving a sense of freedom, flowing movement, involvement, some of the things he liked about skiing and windsurfing that he can no longer do. He has been thinking of taking up some of his old activities in a new low-key way. He tried windsurfing again a while ago, had a good sail out but was too tired to come back, so had to rely on the tide. He might do some bike riding again in a more relaxed way.

In his late twenties, single, Mark is somewhat isolated, *"the number of new people I meets is minimal."* His opportunities are very limited by his lifestyle on dialysis. He was into the band scene and dancing before but he changed after he began haemodialysis. Partly being sick created a natural break, partly he didn't like to go back to a scene where he was reminded of the changes in his life and what he had lost, partly getting older he *"probably was moving to something different anyway."* Some normal socializing like going to the pub was very difficult because he couldn't drink, he doesn't tend to go to pubs much now. His workmates are a very important group to him socially. He also has a small group of other friends who socialize at cafes or watch home videos.

"It is pretty hard to have a relationship. Dialysis is so restrictive it makes it difficult to find a person. You've got to have time and be in the right place." He becomes very tired with the demands of establishing a relationship, both in time and energy. He feels like *"I'm restricting other person"* because of limitations on travel and activities. *"Often when people realise the full consequences of having a relationship with someone living on the machine they back away."* He ends up *"overwarning"* people at the beginning and putting them off. Also often they might want children and *"long term I'm not confident I could be a good parent, and anything they could say would not make any difference to that."* While *"I've never managed to make any work"* he does believe a long-term relationship is possible if he meets the right person.

His job takes so much time he has little time or energy left for much else. Work is such a focus in his life *"if it's not going well then life is not going well."* He has changed jobs a number of times and is very happy with his current position. While *"work is harder than it ought to be"* it stops him feeling isolated but rather *"feeling valuable and that I can achieve, fitting in with people there."* When he first began dialysis he was just beginning work and initially decided to focus on work to enable him to cope with having to live on the machine. Since then it has become the central positive feature in his life.

"Six hours dialysis and work I can just fit it in. The cost is there, the cost in time is quite high. It's a conscious decision to discard part of your life to manage dialysis. If you think of life as being job, sleep and leisure, then dialysis replaces recreation." If he was not working he could be a lot more flexible and would have some free time to do other things but he would lose the security and self esteem his work gives him.

He would like to holiday away *"on a Pacific island or to bike around the South Island"* but cannot because of the machine. While it wasn't a great goal to travel before he began dialysis it's still difficult that he can't travel like his friends do. His inability to travel has limited his work activities and cut off various attractive different job opportunities. He used to travel back to his hometown and dialyze in a centre nearby but now does not go anymore because it has never worked out well. He would only want to travel if he had confidence dialysis would be reliable and safe, but he has found that a *"holiday away from here on the machine never turns out to be a holiday"* because there are always problems with dialysis in other settings. It is easier to look after himself at home, he has all his things around and can do what he likes to do. Time in any hospital unit is wasted. At home he's confident and it's relaxing. So he is *"tied to here and tied to the machine."*

If he is sleeping well life is easier but there are times when he doesn't sleep well. He tries to sleep on the machine while dialyzing into the early morning during the week, then sleep until six after coming off, when he has to get up for work. Sometimes on the machine he feels restless or very itchy which prevents him from sleeping. If he is unable to sleep well he is very tired the next day, which makes it hard to perform well in his demanding job. If he does get tired during the week for any reason it is quite hard to recover.

"The concept of being in a feedback loop, people can get into a spiral. This downward spiral is quite common. Things not going well in one area tend to feed into the rest of your life. Adhering to the diet if you're not feeling good about

yourself, it's so much harder to do that, it takes a fair bit of strength. Sacrificing sleep for leisure can affect your job. Feeling bad physically can lead to feeling bad emotionally, to not looking after yourself well, a downward spiral, without you realising it. As long as you do recognise it's going on you can do something about it. Getting out of it is more like a ladder. The way to do it is small steps, make small changes."

7.1.2 A defined regime

Marks's dialysis regime is carefully defined, Tuesday and Thursday evenings after work till 3am, Sunday during the day. The pattern is shaped around his employment, designed to optimize his performance by ensuring his 'best' times are at work. His worst day, after his two-day break, is Sunday, which sets him up for the working week where he has only short breaks between treatments. Sometimes he varies it but tries not to. A year ago a planned day trip to Auckland for work became an "overnighter." He found it tough as his diet and fluid intake was planned on the basis of his intended treatment that evening that was then delayed by 24 hours. It was hard to focus the next day on work when relatively overloaded.

He normally doesn't vary his schedule for leisure time activities while he is working. *"You've got to weigh the costs of changing against the expected benefits. The costs of just changing that one day is quite a bit. No matter how I try I cannot guarantee that I'll be able to take a three-day break and feel good. There is quite an element there of sometimes it's better than others. If I'm not going to enjoy it because I'm not feeling well then what was the point of going away."* He can't have a weekend off because the price of a long break during the week is too high. *"I would rather work it so I don't have very difficult times. Largely it does run my life unfortunately."* He would ideally like dialysis to be "quicker, more regular and portable," because, in his view, it would interfere with his life less and he wouldn't have such ups and downs.

Going on the machine is *"a bit of a relief,"* because he knows he is getting the treatment he needs to stay well. He has a snack and drink that he would not normally have before going on, *"treat time."* However *"I find I'm on edge when beginning dialyzing, perhaps from the toxins, fluid, or my Blood Pressure being up."* If anything goes wrong *"I am always very concerned, it's very stressful. If the machine doesn't work it is very negative,"* and, in fact, the new machine has often malfunctioned. *"Not only is there quite an investment sticking needles in your arm so you don't want to do it without a result, you need the treatment and know the consequence of not getting it."* He finds it stressful before he goes on the machine because *"the machine sometimes just doesn't work. That's the worst time to find out it isn't going because there isn't any backup after hours."* He can't simply put off dialysis like others can. Delaying dialysis has a high cost. *"To work I need this to work."* When he's on the machine it's not so stressful, just *"background noise... dialysis has been pretty smooth, lots of little problems but pretty smooth really, better than I would have expected, I have not had significant problems."* While it was initially very difficult in the dialysis unit, at home there have been no major problems.

"Because you're so dependent on it, you're not detached from it like with other machines. It's just a computer" and, from his work experience, he knows they malfunction all the time. He feels *"entwined with it"* which is quite frightening. *"All the time while I'm connected to it I feel dependent on it. It's potentially a threat when I'm on and my focus is on operating it and the possibility of it going wrong. When I'm not actually on it I see it as more benign, as helpful."* He feels detached about his blood in the machine, doesn't feel he's wasting his blood if he loses some as he did when he stubbed his toe as a child. He does not feel so much master of the new model of machine as he did of the old one he used to use. The new machine is inflexible, hard to get going if it's had a problem, *"you can't trick it like the old machines."*

His only problem while on the machine is dehydration, which is less frequent than before but more unpleasant now when it happens. He considers that he is either less tolerant of fluid loss or alternatively more tolerant so it progresses further before he recognizes the symptoms and intervenes. If he does become "light" [hypovolemic] on the machine he feels mildly unwell the next day.

Mark does not have a lot to do with the home-training nurses. But he doesn't need to. *"They're basically pretty good. While they have a helpful attitude they often seem under pressure, more reactive than proactive, it can be frustrating at times."* Having to start dialysis quite suddenly *"your first impression of the dialysis room is pretty negative. At the start it is important to feel there are people around you, that you are not alone. In the unit there is a feeling of comradeship among the patients even if you don't talk too much. But it's better at home. I'm quite comfortable to be by myself. I'm quite happy for it to be part of my life which is in many ways quite cut off from the other parts of my life."* Home treatment is the only way to have the flexibility to continue work, but it suits him anyway.

Dialyzing alone without a helper doesn't bother him. He likes to run the process himself. While a second pair of hands could be useful with the clamps, to open a window or answer the door he likes to be in control of the process that is so important to his wellbeing.

"Fluid is the biggest battle, it's easy to get into the habit of drinking too much. I drink according to when my treatment is due, tailoring my intake to that. It's amazingly tough to avoid drinking socially, but one beer on Friday night can destroy my whole weekend. Fluid is the one I feel worst for, it can take a day to recover and get back to a balance from fluid changes, not taking it off but putting too much on or being dehydrated. Worst is that when you're overloaded for some reason you feel thirsty. When overloaded it is difficult to focus on anything requiring thought like work; if I'm overloaded by Sunday I might as well get on the machine as I'm unable to focus well on anything."

He has found with experience over the years that he can be a little more flexible in the diet than the rigid pattern he was given at first, "*Eat a banana and you will die*' was drummed into you." He will eat a small amount of avocado occasionally. Also tomato is difficult to find substitutes for in cooking. These however are controlled variations from a basic careful pattern.

He doesn't find much leeway in dialysis, feeling less well if he varies his schedule, but he has learned, from his practice over time, that by changing some things from what he was taught he can improve his treatment. At times he has had a very long treatment, about monthly on his weekend day, to reduce symptoms of 'restless legs' with some success. He also routinely takes his fluid off at a differential rate using a higher setting for the first couple of hours then cutting it back.

Finding and keeping a balance to ensure he feels well and functional is difficult. It's "*a fine line, a lot of fine lines,*" fluid intake and removal, dietary control with calorie intake, dialysis schedule with work and rest...

7.1.3 Waiting

Mark had expected to receive a transplant within a couple of years but had to alter his expectation when he didn't. Initially unable to do what he used to do, he decided to focus on his job in the short term until he received a transplant. After 3 or 4 years he decided to "*stop being in a holding pattern, there was not much point in waiting, you need to make the best of what you can... a hard transition.*"

"I felt, feel, I am waiting for life to begin again but as I know I may be stuck with this restriction forever, for the rest of my natural life I've given up waiting, I don't expect it to happen ever. On the other hand I do expect it to happen sometime. There's a cognitive dissonance there that I ignore. I can't reconcile those opposites but believe in both, try to live as if it won't happen, make the most of what I've got, but..."

Before he started dialysis he felt carefree, he didn't worry about what might happen, he felt "invulnerable" in the face of what life could deal him. Since then he has lost his sense of freedom and security, *"there are things that even a transplant wouldn't give back."* Not only does he have concerns about the machine, the process itself and also managing day-to-day dialysis to enable him to work, he is aware of his vulnerability. The prospects of coping after an earthquake, even with a transplant when dependent on regular medication, influenced his choice of location to buy a house. *"The transition to dependency, I've accepted it now, it's still a concern, not something I'm comfortable with, the loss of control, you're no longer the prime driver in your life. You still have to consider yourself that but you're always coming up against problems... usually nuisances but sometimes major issues."*

"It's been a quarter of my life, I've changed, it's changed me. Looking at life as experiences, it has been the perhaps the biggest single influence in my life. There are things I took for granted I don't any more. I was lucky when I was young, fit, able to achieve what I wanted, though I've had to fight for it. I feel I've lost a decade, in some ways like I've been in prison. I still have freedom to do some things but not as much as I would have expected. What I've tended to do, having less choice, is to focus on the things that I can do like buying a house, to achieve goals like that which I can achieve on dialysis. My main wish is to have more freedom of choice. The choices I do have are very important."

Since dialyzing he feels some gains, not just knowing more about physiology but an empathy for others with disabilities, more patience and appreciation of what he has in his life. *"Things I took for granted I don't anymore, I'm more grateful for my life, for each day."*

"Concerns with the future are many. Will the machine work next time I try? Will I get a transplant, what will happen when I do? Will it last, how long? A gradual deterioration would be difficult to accept." He knows that the long-term future for anyone living on dialysis is uncertain, with the prospect of bone disease, heart

damage, the effects of chronic low Haemoglobin. Without a transplant he has these fears but he knows a transplant also has potential problems.

When Mark is dialyzing he just gets on with it. He can view it like sleeping, a necessary part of life, but at times when off the machine he can be frustrated about spending so much time on the machine, is aware of how it limits his life and can feel depressed and wonder "why me?" He manages by being very much in a routine. He notices it when there's any type of change.

There are several ways he survives it all. *"I consider myself to be very stubborn. My concept of being stubborn is something I lean on, I'll push myself to get through the day... or in the bad times, I think, well, you have to get through it. Also the concept of a bad thing not being really a bad thing is strong. Any experience is a valid part of living whether it's good or bad. Some difficult things you've gone through can become a treasured memory even if you wouldn't want to go through it again. It's all part of the experience of living. And if there are really bad times when you think 'is it worth going on?' then I think as long as some time in the future there'll be a good time you owe it to yourself to wait for that time. Today might be really bad but sometime in the future someone will tell you a joke and you'll realise that life is good after all and you're glad to be here. Logically speaking that's either the case or it doesn't matter. Either you will have got through it or you'll be unconscious or dead."*

"After seven years it's starting to get a bit boring."

7.2 Chris

"Dialysis changes your life quite dramatically."

The second account is from Chris. He is unique among the men in having adopted the role of a househusband while on dialysis. Middle aged, Chris lives with his wife in the home they have owned for many years in a middle class area. Their children grown up, one daughter lives nearby. Chris came to New Zealand as a young adult and had a long career in industry that ended prematurely when he started dialysis. His wife works fulltime.

Chris has lived on renal replacement therapy for 7 years, initially on CAPD for several years, which he found very difficult. He changed to home haemodialysis, which, after some initial vascular access problems, has now gone uneventfully for some time. He is on the waiting list for a transplant but has yet to receive one. Between the second and third discussions he had another significant vascular access problem requiring several surgical interventions. Characteristically optimistic Chris tends to view his situation in a straightforward way. Open and friendly he was happy to help by participating in the study.

7.2.1 A rearranged life

"Living on dialysis everything in your life is rearranged. At first it was the end-all of everything, everything was geared around dialysis. Now it's part of my life, not all of it." For Chris one loss from living on dialysis is that he cannot maintain a full time job. He was coincidentally made redundant about the time he started dialysis. He has done several part-time jobs since beginning dialysis but couldn't maintain them properly because of the day-to-day uncertainty of living on dialysis. Limited energy, not feeling so good some days and having to go to hospital at short notice have prevented him from keeping a job. While he would much rather be able to work, even at a part time job, *"keeping healthy is more important than having a*

job." He has the "luxury" that he does not have to work and then rush home to perform his treatment. He has developed his interest in investments to keep his mind active. His wife is established in a good job, with a reasonable income, giving them financial peace of mind.

His CRF has brought the family closer together, especially him and his daughter. She might not be living so close if he was "well," not on dialysis. Then he would not see so much of his grandson. He currently looks after his grandson several days a week enabling his daughter to work part time. He enjoys this greatly and has a close relationship with the boy who rings him every morning. If he were still working he would not have had the time to develop such a close relationship with his grandson.

He also prepares dinner for his wife and does the grocery shopping. The advantage of home dialysis is that it allows him to do this sort of thing whereas going to the hospital for treatment is inflexible and takes all day. Doing self-care at home means he continues to feel in control of his life. *"It allows me to do other things, shopping, cooking dinner, washing, I don't feel as though I'm useless. In hospital everyone treats you as being sick. I don't class myself as being sick. I've got an illness but it's not 'sick' illness."*

The other loss living on dialysis is his inability to travel for holidays. Chris travelled widely when he was young. Then he and his wife used to holiday overseas every couple of years, which they have not been able to do since he started dialysis. They have travelled in New Zealand, staying at the holiday dialysis house, and, more recently, using the mobile dialysis van. He had some problems with the mobile machine itself and with water supplies for the van at some sites but managed to overcome them. They are booked to use it again this summer. Although his illness stops them travelling abroad now, he has travelled a great deal in the past and is happy. *"I've got my memories."*

His wife feels a sense of loss as his CRF occurred just when the children were off their hands and they could have looked forward to more freedom. While she enjoys her good job she is also aware that she needs to continue to work if they want to maintain their comfortable lifestyle. She regrets they cannot holiday overseas as they had expected at this time of their lives and she always has the "worry" of his illness. His family wonders if he has not received a kidney yet because of his age. But Chris considers *"I was fortunate to get kidney failure at the time of life when I did get it. I was quite able to adjust to it. If it had hit me when I was 26 or 27 I don't know how I would have reacted to it."*

His relationships with his wide circle of friends, long established, have *"changed not a bit."* They know his situation and adjust their dinners or outings to fit in with him. He has recently bought a boat since he has been feeling so well on haemodialysis, an old interest of his youth. He enjoys sailing with his grandson and son-in-law, loves generally *"mucking around in boats,"* and is doing a night course to get his day skipper's licence.

7.2.2 Dialyzing

He is feeling *"very good"* at this time on the machine. CAPD was very difficult. Recurrent peritonitis *"was terribly painful and caused stress to my family about why it kept happening when I knew I was doing it properly."* He always was careful and it turned out that it was not his *"fault"* but he *"had a bug that could not be got rid off."* Even when he didn't have peritonitis he felt *"very bloated all the time"* with the fluid in his abdomen.

Early on haemodialysis Chris had a series of problems with his vascular access that led to a number of admissions to hospital. A severe heart problem [cardiac arrhythmia] which led to an admission for a week in ICU was caused by his Magnesium levels, because of his dialysis, *"but tests since have shown my heart is fine so I'm not worried about that."* He has also had a parathyroidectomy, but has

always recovered very quickly from any surgery. Now he is very well. He used to sleep badly but now sleeps very soundly. He has an excellent appetite.

"Apart from having to sit here I don't have any problems, except sometimes my energy level. The only thing that bothers me now is occasionally when my Haemoglobin drops, I get very tired, can't walk easily, I get a tightness in the backs of my legs, get out of breath. Some days I feel as though I could jump over the moon, other days... I feel deflated, all my energy just sucked away. I can do most things if I do it at my pace. Some days I don't feel as good as others. I feel great today." If he got a transplant *"I've been told you can't believe the energy you've got, the feeling of wellbeing, you're able to be much more active."*

His dialysis pattern at present is Tuesday and Thursday evenings starting about 4pm and Sunday morning. This fits in with babysitting for his grandson during the week and enables a Sunday afternoon outing. He used to do Monday, Wednesday and Friday to keep the weekend free but has altered the pattern to suit his current activities. He will vary the treatment days according to social engagements, is quite flexible about it. His family do not help him dialyze or stay in the house while he is on the machine, but someone is always around in the local area when he is dialyzing.

His dialysis treatments are very uneventful. His weight is very stable. He was very consciously careful about his treatments when he first went home but now has confidence, *"it goes like clockwork."* He has had one major problem with blood loss on the machine when a fistula needle came out. He couldn't stop the bleeding, had to go to phone his daughter for help. He nearly passed out. He is confident the problem will not occur again. He is now carefully taping his arm in a new way. He also now has the phone by the machine. Occasional needle problems on the machine are easily dealt with. He has managed power failures without a problem. He hasn't been *"flat"* [hypotensive] for many months.

When he comes off the machine he often, after 3/4 of an hour, has a *"peculiar little feeling, it's hard to describe, I want to put my head down"*. I go to bed. Next morning I wake up *"fit as a fiddle."*

Initially Chris wondered how he would manage the machine at home but his work background meant he quickly adapted, *"it came naturally... It's a friend to me, keeping me alive."* Being in charge of his treatment doesn't worry him, *"I've taken it in my stride."* In contrast his wife sees it as a *"necessary evil."* Haemodialysis makes sense to him as the blood is obviously passing through the filter and being cleaned, he could never see how CAPD could work very well. When he needed to start treatment he didn't get a choice of treatment as others did and still wonders why. He only discovered that others have a choice when he was asked by medical staff to talk to some new people, about to start treatment, about the two forms of dialysis from his experience.

"I used to think 'I've got to go on tomorrow', I was more concerned with process then. Now I don't think about it, I have my week planned, include it and that's it... It's part of my life at the moment, sometimes boring, though I do reading and writing, business, I've got the phone and the Tele. But having to sit for five hours is not easy."

Chris follows his treatment as he was taught. *"There's not too many changes you can make but I've made a few wee adaptations here and there"* after discussion with the training staff. He tapes his arms differently, he has altered his heparin regime because of prolonged bleeding after taking his needles out. He always *"sticks to 5 hours,"* never varies it, and wouldn't *"do anything drastic"* without consulting them. However he happily disconnects himself from the machine temporarily during treatment to make himself a cup of tea.

He did experiment once, didn't take some of his medications for a week. His blood results didn't change so he knows he could miss them for a few days without a

problem. He could even miss his heart pills for a day or two, because he knows how his body feels. *"Now I can detect the slightest change in my body, in my weight or Blood Pressure."*

When told about the renal diet *"all the things I couldn't eat were all the things I liked... We eat healthier now. I miss them but it doesn't worry me."* He will eat a piece of tomato or chocolate but that's all. The only time he radically changed his diet, had a traditional Irish breakfast, his Potassium level came back very high. He will not do that again. Fluid restriction is not a problem, *"I can't really believe that I've got it under control so well."* Hot days are more difficult but he's trained himself to just have the odd mouthful of water or just one drink in the afternoon.

Chris has never had any problems with the renal nursing staff. *"It is not like a nurse/patient relationship, we're friends. I've known some of the nurses since the very first day I was sick."* He only occasionally rings the home haemodialysis nurses with a problem. They have told him that they know that if he rings he really has got a problem. He does wonder if they fully realise the impact of dialysis on people's lives, especially younger people.

After the second discussion about his life Chris's graft blocked. *"After going so well for over a year it's blocked up several times. The angio things [plasties] are not pleasant, I've had four of them. The surgeon told me we had to abandon that arm. I did hit bottom for a while when he talked about going back on CAPD. I told him I suffered too much on CAPD, I was only half the person I am now, I can't go back on that. So now he's looking at my right arm for one of these upper arm fistulas."*

"The line [central venous access catheter in the jugular vein], I've always had a bad time getting them in, so now each time I get them to knock me out. The line in my neck, I get so embarrassed when I go to the shops, people can't help staring at you. My friends are used to it but you tend not to go to public places. I disguise it

with a bandanna. Now I'm back on track again, in a positive frame of mind. You've got to look on the positive side."

7.2.3. A better future

"I don't think I could get it [dialysis] any better at the moment, I feel better in myself, confident in the machine... I know that if I look after my body the way I'm doing now, if a transplant comes along it will have a greater chance of taking... it would break my heart if a transplant came along and my bloods were up the shoot, my Potassium up, and they decided to give it to someone else."

In the past things were very difficult, *"I wondered when I was ever going to get on top of it. I just accepted, Murphy's law, if it could happen it would happen to me... and it did."* It *"drove me nearly daft"* when CAPD was not working despite him doing everything right. But he always recovered quickly. *"My wife never likes to hear me say I'm feeling good. 'When you say that something happens. Don't say anything, just accept it as it is'."*

His family is anxious about his wellbeing on dialysis, more worried than he is, *"they don't have the same faith in me that I have in me that I can control the machine."* They may be worried because of his severe problems in the past when his wife often had to go with him to the hospital as he was very sick with peritonitis or even septicaemia. Then there was the one time he had the significant problem with blood loss on the machine when the fistula needle came out. Also the fact that he dialyses alone. But he is confident he is trained to manage the machine. He does not want his wife to stay around when he dialyses, *"she has got to get out and have a life of her own."* He rings his wife or daughter after he has begun his treatment on the machine. Either of them or a neighbour can come to help him if necessary but they are not involved with his usual routine of treatment. But he has told them how to give him intravenous Normal Saline via the dialysis lines, if necessary, because

his blood pressure was low while he was on the machine and he was having difficulty doing it himself.

"A transplant would relieve my family of worry, they are more concerned than me." His daughter is compatible with him and his family can't understand why he will not accept her offer of a donor kidney but it is *"an awful decision."* He is prepared to *"let it ride for a while,"* they may want another child and he does not want to jeopardize anything for them, he can cope at present. *"It things came to the worst my daughter would give me a kidney, if I really got sick, she's fully compatible. If they couldn't get access [vascular access for haemodialysis], that's the time that my family would insist... if I knew there was no hope."*

He's always tried to adopt a positive attitude, *"always in the back of my mind, I've got to get my body in the best shape for a transplant so I won't miss out... that would be a death blow for me, nearly."* He keeps hoping for the day it will happen, it would give him the chance to live the last 20 years of his life normally. *"I'll take one tomorrow if you've got one."*

"Hopefully, I wouldn't want to sit here for the rest of my life doing it."

7.3 Keith

"With dialysis it's all on the day."

The third account is from Keith. While none of the other men are physically impaired Keith is crippled by complications of his CRF, using crutches to walk. An older man in his early sixties, he lives with wife, his children grown up with a daughter living nearby. They live in their own house in a middle class area. He is retired after a career in administrative work.

Keith has been on home haemodialysis for 6 years. After 4 years he received a transplant that never functioned and is on the waiting list for another. The last of the discussions was delayed because he had several admissions for a surgical procedure and subsequent complications. A naturally active practical person Keith is seeking to maintain his retired lifestyle through using professional medical expertise to address his various physical problems. He was happy to talk about his situation, perhaps as part of an ongoing attempt to come to terms with it.

7.3.1 A limited life

Keith suffers from significant physical symptoms. *"Every joint in my body has a problem, 80% from dialysis according to the doctors, especially an exceptionally sore ankle [requiring crutches at the moment], but also wrists, shoulders, hands. If I could get rid of the ankle pain I could bear any of the others."* His hip has been replaced. These ongoing problems are still being assessed medically to see what further can be done.

The dialysis treatment itself also affects how he feels. *"What you do after you finish treatment depends on how well you come off dialysis. If I dialyze on Friday night I could go out on Sunday evening and have good time like any other person... Some days you feel bright, some days you drag yourself out of bed, and only come right about midday. Often the day you come off you're not that brilliant, but the next day or the second day you would be like any other normal person... but then, you've got to go on [the dialysis machine] tonight, you can start to feel a nosedive coming."*

A major problem with living on dialysis for Keith is that it limits travel. In the past he did a lot of travelling for his leisure activities of bowls and fishing. He now feels *"I have had as good a life as anybody, I just can't travel much from home."* The first thing he thought of after his transplant was *"we're off to the Sydney Olympics."* He can still go away with friends for a couple of days after which he has to come back home again for treatment. *"Everybody else is having fun and you've got to go*

home. It isolates you a bit from the group you are in." The home dialysis training staff have told him he could stay the extra day but, *"as you go on you realise that you need dialysis, there's something changing there, I'd feel the extra day. Now my body tells me I need the dialysis machine."*

Any holidays away from home are difficult because there are a very limited number of dialysis units available for people on dialysis. Then you have to book in according to their inflexible schedule. *"It gets to the point where, what's the point in going for a week or ten days when you're going to spend so many days in hospital [at the dialysis unit]. I can't guarantee what I'm going to come off like anyway. You've got more security in your own home."* He realizes the increasing pressure on limited renal services throughout the country may make travel even more difficult in the future.

Apart from travelling away his leisure activities have changed to some degree, but not greatly. He used to play bowls but is unable to now because of his foot. He can *"work around things"* to enable him to go to rugby on Saturday afternoons, or social functions at other times. He continues to do a lot of fishing locally. He belongs to three social clubs, rugby, RSA and bowls and still has the same wide circle of friends related to his interests and past work.

While Keith had been very involved in his work he was thinking of scaling it down at the time when he started treatment. He was finally made redundant when he was only able to continue to work part time due to his dialysis schedule. However he is financially secure, so, for example, the costs involved in dialysis don't worry him. It is not in fact totally free as is claimed. When he was working he initially did 4 hour sessions, but he was then told by renal staff that he needed to increase them. *"That was crunch time, it would have been physically impossible to do what I had to do when working and do the hours [on the machine] I do now."* But about then he stopped work and has been able to manage 6 hour sessions since then.

Keith has a very supportive family, wife and children and grandchildren, who are very concerned about him when he is not so well. His daughter couldn't come into the room and watch the dialysis machine for three and a half years, but his grandchildren had no problem and that finally helped their mother. His son in law is very relaxed about it while his daughter *"worries like hell."* More distant family members ring or fax regularly. His relationship with his wife, *"superlative,"* has not altered since he began dialysis. She is very involved with his care. *"I don't know how I would have managed if I hadn't had so much support."*

7.3.2. Managing dialysis

Keith currently dialyses regularly during the weekdays in the afternoons. He has altered his schedule according to daylight saving in the past, starting his treatment early in the morning. He also varies the starting time to suit what he is doing on a particular day.

His wife helps him with particular tasks in the dialysis procedure, not only carrying the 5 litre containers of dialysate fluid that he could not manage at present, but also helping with setting up and the details of going on the machine, such as taping his fistula needle sites. At four hours she comes in and taps the Bicarbonate powder container to ensure that it lasts the full treatment. There's a *"terrific amount of teamwork, it's so much easier with someone helping, much more pleasurable, quicker if you work as a team... Sometimes you need half a dozen hands, especially if something goes wrong."* His wife keeps the running sheet for his treatments and does the stores ordering. He couldn't manage at home without her help.

His treatments on the machine are generally routine with only the occasional fistula needle problem. The scarring over his venous access points can make needling difficult so sometimes his wife holds his skin to help the needle go in through the scarring. At the beginning the fistula needles seem to be biggest fear for most people but *"once I realized there was an anaesthetic it was okay."* After he began

dialysis he had a sequence of vascular access problems, but these settled down eventually.

The only major problem he has on dialysis is with fluid removal. He had always been susceptible to cramps, even before he began dialysis, but now gets them even when at his dry weight, but especially if he miscalculates the fluid removal. If the "TMP" [the Trans-Membrane Pressure, the machine setting to remove fluid] is a fraction out he gets pain up his arm and his shoulders "*ache like hell*," he may get pains in his chest and abdomen 4 hours into the treatment. He uses a hot water bottle and Panadol for relief. The key thing is that "*even though you've got a target weight of 81 you need to look at a fraction above that, it's the bottom of the barrel. It's better to calculate it a bit higher.*" It has been difficult to estimate his weight at times because of his problems with mobility, "*a bit of a guessing game.*"

"After 4 hours I feel like a bloody dog, I'm tied up, I can't go anywhere, do anything. It's a long time... you need things to occupy yourself." He watches TV, reads or, these days, accesses the Internet on his computer. After dialysis the joint pains are more severe, he can get headaches. At night coming off the machine he doesn't feel like sleeping, can't sleep after the treatment, and now 'surfs' the Internet for hours at night. If he was working he couldn't do that. It used to be a problem when he was working, his wife sometimes had to drive him to work after dialysis, but during the day "*it came right.*"

About his fluid restriction he says "*I make it an issue; if I'm going to the club I will make sure that I can have a half pint with the boys. At first it was really tough but these days you don't have drinking schools as in the past. My friends, they understand my situation.*" While he has felt fluid overloaded on occasion he is okay if he doesn't gain more than three kilos. Diet is not a problem. "*The only thing I go against is the dietary advice,*" the instructions he was given originally, because they were too strict, as a later assessment showed he was doing well on his own diet.

Keith considers it is his business to run the dialysis machine properly. He also changes the filters and fuses, but for any other problems he calls the technicians who come out to repair it. *"I rely on its elements to protect me."* He has had some technical problems after a software upgrade, but thinks the very cold winter weather where he lives contributed to them. He generally follows carefully the procedure as he was taught. But *"whether it's right, wrong or otherwise it's my technique,"* to do certain things such as gradually increase the blood pump to full speed over the initial 1/2 hour, and to set the fluid removal so that he comes off the machine slightly over his target weight.

As the full set-up for treatment takes an hour they often do a basic set-up in the morning without actually priming the lines with Normal Saline. This gives them more freedom, if they are going out, to decide when they will come back home before going on dialysis in the afternoon. Though they know this may not be acceptable to the home haemodialysis training staff they are careful, can see no problems and it makes a big difference to their way life.

He has sometimes done 5 1/2 hours rather than his usual 6 because he is starting so late in the day but in general *"I don't deviate, it's not worth your while."* His excellent blood results make him feel he's doing well on the treatment. His Potassium was fine once after an unplanned longer break while he was away. He knows his bloods are good *"because I know what I eat and drink."* He wonders if he needs to do the full treatment hours, given his excellent blood results, but he has *"a near perfectionist wife"* who tells him *"that one day you'll get a kidney and you'll be glad you're in that sort of condition."*

He thinks that if a person doesn't know what they are doing they shouldn't be at home on dialysis. Also if a person who is managing well has a lot of problems on dialysis they shouldn't be at home. But while there are more options for therapy in the unit, medical backup is readily available, and *"it felt like a holiday when they put your needles in at the unit,"* if you are feeling well it's better to *"put up with*

what I've got" than travel to town regularly and be "regimented" into a rigid schedule. Treatment at home is much better because he can vary it to suit himself. But there is only limited support available at home and he feels that they are *"left to battle along on your own. At home you're left on your own with your medical problems, the only backup is the phone."* He considers that local dialysis centres with minimal staff to assist would be better for many people on dialysis.

The home haemodialysis nurses are a *"wonderful team,"* the technicians are very helpful. He sometimes wonders if they consider alternatives to the *"cottage industry"* approach of the home training houses. He has found the medical registrars vary in their skills, for example some are better at putting in central venous access catheters than others, *"a bloody frightening thing"*. He has known the senior doctors for a long time and has confidence in them. When he had the post-operative complications, which led to his kidney transplant being removed, the surgeon never came and talked to him at all, leaving him a state of great anxiety. Meeting the surgeon would have helped him come to terms with the loss of the kidney.

7.3.3. An uncertain future

Keith has difficult times *"when I go down the hole..."* usually because he is unwell. *"I can manage dialysis very well but there are times when you have real downer, not necessarily from dialysis, it can be flu, it can be just how you feel on the day, it can be anything at all, that's when it [dialysis] taxes you more."* His wife is very supportive at these times.

At the third discussion, after his admissions for a surgical procedure and subsequent complications, Keith admitted that over the past six months his life on dialysis had been getting more difficult and since his operation they *"have taken another step."* Whereas before he could manage most of his treatment with his wife helping him with a few aspects, now she is heavily involved in the treatment. While the home dialysis training unit would like her to be trained to perform most of the procedure,

in particular to insert the fistula needles, she doesn't want to do this and he thinks that is her right. If it got to the stage that he could not manage then *"maybe they should be looking at the whole thing again."*

"You're so-called independent but people keep asking whether you're all right... but patients know." Talking with others on his recent admissions he's realized that some patients are *"miles ahead of me, jump off the machine at the end of treatment"* but others have problems like him. *"You're fighting one thing, then you get another on top of it, then you're fighting on all sorts of fronts, you can't pull out of it, the degradation gradually comes through one's system doing this [dialysis]."*

His first four years were so good he hardly noticed as they went by. While the loss of his transplant kidney through a surgical complication was very difficult to accept he was told he would receive another. Since then he has wondered whether *"after you've had one go, do you go to the back of the queue?"* It is frustrating that he has not received another kidney transplant as he had hoped, because things could have been so different for him. He did not expect his life on renal treatment to go like this, *"I think you should be more honest from the beginning."* He has always sought medical advice expecting definite answers to deal with his problems but more often now he feels he has to wait for uncertain answers.

Keith is now very uncertain about future, feels *"defeatist... if I thought there was no hope... if it weren't for my wife I would make a decision, why go on like this, I'm limited in what I can do, where I can go... I might have thought of not going on if I had known that this would be the future, or come off at a certain point... It's the hell you've got to go through, I didn't know you'd go [die] this way."* He has wondered if it will still be possible to have a transplant after his recent operation but has been told that it will be considered again in a couple of months.

But he still has *"dreams,"* not only special activities like travel to the Olympics but simply working in his garden which he loves or being part of his family as it grows.

"I'd like to live for a few years so that I know that he [my grandson] will remember me." It is frustrating that he may not be able to realise his dreams because of increasing inactivity due to his physical problems resulting from living on dialysis.

"Sometimes we wonder if there's something better."

7.4. Paul

"Dialysis is not a problem if you can cope with the lifestyle you end up with."

The fourth account is from Paul. Obviously different from the other men he is relatively poor as a result of being unemployed. Since beginning dialysis he has been on a sickness benefit. A young man in his late twenties, he is a solo parent caring for his pre-adolescent son. He lives in a rented house in a lower middle class area where he has been for less than a year, having moved a number of times in the last few years.

Paul has lived on renal replacement therapy treatment for 7 years, the first 3 years on home haemodialysis, during which he received a transplant that never functioned. He then received a second transplant that functioned for 2 years. After that failed he has returned to home haemodialysis for the last 2 years and is again on the waiting list for another transplant. Straightforward and certain of his views, Paul understands his life with CRF purely in terms of his own experience of it and his own views about the meaning of his life, without reflective reference to objective information about dialysis. He talked freely and openly about his own experience on dialysis, stating at one point that he found it therapeutic to do so.

7.4.1 A hermit

Paul says he feels “*left out*” of social life. “*I can’t go out and socialize properly.*” He used to see a lot of his friends, socializing was an important part of his life. Now he doesn’t see them for months on end, “*I chose to stay away from them. They’re embarrassed because I can’t fit in.*” He can’t join in social activities, he has to refuse drinks, doesn’t want to get involved with women. Also dialyzing and sleeping take up most of his time, he feels lethargic and depressed. His friends are understanding.

He copes with dialysis by having a defined pattern in his life. On weekdays he spends time with his mother. On the weekend he sees his sister-in-law. He talks on the phone with her every day. Otherwise he rarely leaves the house for any other reason except shopping or to see people at the Social Welfare or the hospital. He is “*a bit of a hermit.*”

Having been married before he really “*misses female companionship. Often I sit here alone, sometimes feel like I could burst into tears, I would like someone to talk with who could understand.*” He sees his mother every weekday. They are very close. His mother is concerned about him, keeps him positive and motivated. “*My mother keeps me on my toes, she’s a bit of a crutch for me. She says ‘you’re coping well, you don’t realise what you’ve gone through, you’ve gone through a hell of a lot’.*”

He is also very close to his sister-in-law, she is like a woman in his life, but he knows he will lose this when she starts another relationship. He and his son see her and her children on the weekend, “*it’s like having a wife and kids on the weekend.*” His relationships with his mother and his sister-in-law help him to cope with his lack of other relationships. Having easily made relationships in the past, he feels he now pushes women away. “*I won’t let it go any further.*”

"While you could see dialysis as negative, as preventing you having a relationship, you get past that. You want a relationship but you don't want to put them through it." His last partner was "so worried about me being isolated on dialysis she ended up like me, because she couldn't handle it... One time I heard her talking to her sister on the phone saying she couldn't cope any more. As far as I thought it was going well. She was hiding it. I walked out, I thought they'd have a happier life... When I saw what it did to her I don't want to put anyone else through that. They can say they'll put up with it, they don't realise the depression, mood swings, you're always tired, can't go anywhere. To somebody who is healthy and wants to get out and do things that's a bit drastic. It might be okay for a couple of months but it's going to get them down, they're going to end up like me, a hermit. It's not something that somebody else should have to bear." He is not prepared to get involved again until he has had another transplant.

"You don't realise the full impact that your partner or family feel. I didn't know until I heard her on the phone. It takes a hell of a lot out of other people around you, they have to be strong to put up with it."

Paul's life was much more sociable during the time when he had the transplant. He saw a lot of his friends, even got back together with his partner for a while, but she could not cope with his new, independent self, rather than her managing his life as before. While life on dialysis has made him a *"bit of a hermit, that's the way it has to be until I get a transplant."*

He hasn't seen his two daughters from an earlier relationship for two years because of dialysis, his ex-partner refusing to let him see them because of his early difficulties with treatment. He hopes to change this when he receives another transplant. His son chose to come and live with him as his transplant was failing, knowing he would have to go back on the machine. *"When I'm depressed I often fly off the handle, take it out on my son, but he accepts it, he knows I'm sick."* He is depressed that he can't be like any other father, do things with his son like other

fathers, and copes by avoiding him at times. He feels his son must be suffering as a result.

Paul worked after his transplant but needed help from the agency, Workbridge, to get a job. It went well, he enjoyed it, but stopped after going back on dialysis because he couldn't manage it. It is still open for him. Being on the benefit *"drags you down. The hassles that go with being on the benefit, they cut it, muck it around, it's depressing, they treat you as some sort of dole bludger, nagging at you, give you pressure."* They will not accept that he has a permanent problem until he gets a transplant. *"I didn't like to be classed like that. You're not on it because you want to be but because you have to be because of your renal failure."*

He can't afford things, especially for his son. Sometimes, such as for Christmas, he gets loans, sometimes his mother pays for them. He has no money to do anything himself but would be happy just to have the money for food and bills. However the benefit is always changing which is stressful, because he worries if he will even have enough to meet their basic needs. *"I can make my life better when I get work after I get a transplant."*

He can be depressed for long periods, weeks at a time, he doesn't know why. *"It sneaks up on you."* Living on dialysis, alone, without close company, even though he has accepted that, doesn't help. *"I can't explain why it comes, I think it's the dialyzing so often, it takes it out of your body."* Now he realizes when it's happening and tries to overcome it. *"I think I put up a front, I do cope, I try to stay positive."*

"I get depressed now but it's not the same as it was before. When I had dialysis the first time my life was a shambles really. All my relationships were going down hill, I was thinking it was best for her if I wasn't around. She talked me out of it. Last time all I had was my dialysis. I've got more to live for now. I want to see my son grow up and do well, I want to see my daughters again. I've got all that to look

forward to. Dialysis is a stepping stone, you have to dialyze until the transplant. Think of the transplant, that will get you through."

7.4.2. On the machine

Physically Paul's major problem living on dialysis is lack of energy. He does not do the things he used to do, even play with his son. *"I've got to force myself to do anything, not that I can't but I know how I will feel after, so I avoid it because the cost is too high."* This is made worse by being tired from lack of sleep due to his treatment pattern. When he had his transplant the main difference was his renewed energy, *"I felt like superman."* While generally feeling *"alright"* he feels unwell when at his target weight, *"on the border of being disoriented."* He feels *"crook"* if he eats certain foods, like a pork roast, *"it's down to what I eat"* how well he feels. After his long break from treatment he feels like he needs dialysis.

Paul dialyses for 8 hours three times a week from 11pm to 7am on Sunday, Tuesday and Thursday nights. He tries not to change this pattern. Very occasionally he varies his routine for a social event on the weekend. He might do two short sessions on the weekend to enable him to drink more freely. *"Dialysis doesn't make me feel any better. I don't feel any different for dialyzing. If I didn't know better I'd think I could go without dialysis because it doesn't seem to do anything. It doesn't make me feel better, it stops me feeling bad."* He very rarely reduces his hours, only for a good reason, and always feels worse for it, symptoms like 'restless legs' [periodic uncontrollable twitching of the lower limbs at night] returning.

While on the machine he dozes during the night at times. He sleeps in the morning after coming off. Then he wakes himself up, otherwise he'd sleep all day. He's tired all the time but able to do what he needs to do *"alright."* He dialyses at night, partly so he can be awake to look after his son during the day and partly because doing long hours in the day, taking up all of his waking time, is so boring that it is hard to stop himself from coming off treatment early. Being attached to the machine all day

"drives you barmy." Going to bed at night on the machine allows a more normal life, makes the routine easier.

It only takes him half an hour to get onto the machine, sometimes it is so automatic he wonders if he's done everything correctly after he's on. While he sometimes feels he can't be bothered going on, "*bugger it, why can't I do without for another day?*" he always does "*because I know how I'll feel if I don't dialyze.*" He has no problems operating the machine, "*it's second nature.*" He's never had problems with his fistula, not like some others he's seen at the dialysis unit or training house, with their machine alarming every five minutes, he feels he's been lucky.

He occasionally feels "*light*" [dizzy as a result of hypovolemia] on the machine, sometimes panics, calls his son to be ready provide help if necessary. He's worried about becoming too disoriented to give himself Normal Saline to raise his blood pressure. He has shown his son what to do. While this is difficult for him his son manages, and this is, Paul says, better than finding his dad "*out to it*" [dead] in the morning, a possibility he has not told his son about. The other night his son didn't sleep, saying "*I keep waking up thinking you're calling me, it's a hell of a thing for him.*"

He had one very bad experience recently on the machine when he thought he was having a heart attack, called his doctor who later told him he "*might not have woken up if he'd been asleep.*" He was "*paranoid*" for a while, kept himself awake all night, but has now settled back to normal. Another time "*one day a few months ago I was really crook, felt my speech was slurred, numbness down my arm... the signs of a stroke. The doctor found my blood pressure was sky high, put me onto Minoxidil and I got better. I get heart palpitations at times, sometimes wonder how long before I have a heart attack. I think I'm going to wake up one morning dead.*"

His machine, a new one, is "*brilliant*", works better than the old one, is very accurate in fluid removal. "*It's a security blanket, I trust it to do the job. I used to*

hate it last time. Now I use it and forget it... but I like to know it's near. When they took it out after my transplant it was like having your arm cut off, losing your pet, hard to watch. I rely on it because I know I couldn't go more than two days without dialyzing. After a weekend away I am glad to get back to it, the machine is there to fix things up. It's always in the back of your mind, 'I can't eat or drink, I've got to get home to dialyze', it's sending out Morse code, 'you've got to get home to dialyze, don't get carried away'."

"It's a lot easier at home than going to the unit. You don't have to travel, don't have to wait to start, don't have all the other people around, it's more private at home. I don't feel I'm sick, hospital is too clinical. Even if I don't feel like dialyzing at least I'm in my own home, can relax and do what I want." While he would love to have a holiday it would not be a real holiday with having to think about dialysis. He wouldn't be happy being away from the dialysis machine that is his "security blanket." He needs to get a transplant to have a real holiday.

"Proper fluid control is very hard. I drink more than I should but I've got it under control. I don't do 500 [drink only 500 mls a day] because I feel crook. At my target I feel on the border of being disoriented, I'm better if I'm carrying fluid, about a litre, Not a good thing to tell a doctor, going against their advice, but I can tell my own body after all these years. I drink a litre, I don't go beyond a certain point, I know my limits. Not everybody's the same, you find your own middle ground." From experience in the past he knows that "nothing is worse than being full of fluid."

"Fluid you can learn to go without, now I can't even drink too much at one time [if I tried], food is hard." He used to feel restricted by the diet. Soaking vegetables before cooking them "drove me nutty," was time consuming, depressing, so he stopped it. Now he doesn't watch what he eats but knows his limits. Rather than never eating them he will occasionally eat the forbidden foods. This helps him manage so "before it was always 'I can't have that', but now it's usually 'no

thanks'." With a transplant *"if I wanted to go and have a 2 litre bottle of coke and skull it, or if I wanted a big milkshake, straight down the gullet and don't think about it, I could. But all the things I crave when I'm dialyzing, when I had the transplant I didn't want them."*

He has learned to manage his fluid and diet by changing the rules somewhat bit to suit himself. *"Your life's more normal when you don't feel restricted. My life is a lot better coping the way I cope. If I'm not going to feel well then dialyzing is not worth it."* He has a *"happy medium between what I feel is good and what the docs say. Nurses can't tell you what it's like dialyzing, you need to alter it to suit yourself. I know I should do what he says but I'll go with what I know and how I feel. They treat everyone the same way but you know your own body, you need to find a middle ground with food and drink."*

The renal department staff, *"as far as being clinical people you wouldn't think so, more like one big family, more friendly than clinical, you're not going in there and they're just a nurse or a doctor, they're interested in how you are, they even recognise you in the street."* It's not like other places or even other dialysis units he's been in. He only ever had one problem, while he was in the ward, with a night nurse whom he only ever saw once, probably not a renal nurse but an agency nurse in the renal department who would not listen to him when he had a problem.

Paul doesn't see a great deal of the home dialysis training nurses. *"When I was down they came to see me, after my transplant failed they rang a lot, worried about how I would be."* He thinks they do not contact him often because they are confident he knows what he is doing. They often seem busy when he rings, with lots of background noise and interruptions. He does think *"there's not enough education, certain things they don't tell you, about rejection, the catheter, little things, there's more to it than you realise. It's better to know, you ought to be told."* He rarely ever talks to other patients but recently went to a meeting where he found it really good to hear about others with the same problems.

7.4.3. Waiting for the transplant

Life after the transplant was an amazing experience, like being “reborn.” He appreciated all the ordinary things he had taken for granted in life. What he noticed most was his great energy levels, especially simply being able to run. He found his whole attitude changed. He was able to manage dialysis again when he had to restart because of the hope of another transplant and being “reborn” again. Before his transplant he thought *“what the hell, if this is all I’ve got to look forward to, who cares. I’ve been lucky to have had the transplant and have it fail, it’s helped me this time to know what I have to do. I’m coping a hell of a lot better because I know what’s to come, either I’m going to have a transplant or one day or I’ll cark it. You might not wake up one morning, I don’t think about it, I know it’s something that could happen, I just live day to day.”*

“Life is not that special to me at the moment, apart from that I want to see my son grow up. I don’t want to go through life being like this. Now my life’s nothing, my whole world could fall down, my son could even go, but it still wouldn’t matter, so what, once I’ve had the transplant my life will take off like it did last time. I’m living for the transplant, that’s all I’m looking forward to. If some one said you can’t have a transplant that would be the end of it. Once I’ve had the transplant life is going to be so different. I know what’s coming, that’s what keeps me going. I ring psychics, have used charms, read the stars, to see what’s going to happen, maybe when the transplant is going to come, it gives you a little hope.”

“I’ve got to try to keep positive in order to stay well.” His philosophy from his experience is *“don’t let anything get you down. Things happen for a reason, they will fall into place like a jigsaw puzzle. It’s not ‘let it happen’ but ‘what is going to happen is going to happen’ so don’t stress over it.”*

“Why stress about something that stressful, it’s only a moment in time that will pass. I’m a lot better for it. Don’t worry about it. It’s something you have to go

through to get the end result. That's basically all my life is. Then life starts. Up until then don't worry about it, go with the flow. My life is already mapped out, it's going to happen no matter how much you try to change it, one way or another it's going to happen. I'm not religious but somebody's watching over me, I shouldn't be here, I'm being kept here for some reason, probably to bring up my son, he's missed out for so long, he's had such a shit house life."

Paul thinks he manages dialysis the second time around more successfully because he was in better physical shape when he restarted treatment after having some time with the transplant, whereas the first time he started after a period of increasing sickness. Also, having known what a difference a transplant made he is able to look forward with hope to another. Finally he knows his own body better, has adapted the dialysis routine better to his lifestyle. *"Health is no 1, everything else second, it's a case of having to have it that way. My life has got to be like it is, I've got to be at my fittest for when the transplant comes."*

"Wait for the transplant... that's all that's keeping me going."

7.5. John

"It's a case of having to be on it to live."

The fifth account is from John. John is the only one of the men who is self-employed in his own small business. He works long hours. A middle-aged man in his forties he lives with his second wife, their children having left home. They live in their own home in a lower middle class area. His wife manages their home.

John has been at home on haemodialysis for 15 months and is on the waiting list for a transplant. Between the second and third discussion there was a break because he had a surgical procedure related to his CRF with a complicated post-surgical course.

Laconic, even sardonic, John gives plain answers to my questions. He presents a detached view, often by commenting on his own situation in terms of what he has learned objectively about CRF. He was explicit that he was giving his own view of life on dialysis.

7.5.1 Business as usual

John's business is most important to him, being able to do a good job and ensuring his family's financial security. He has been able to continue his work as usual since beginning dialysis without any problems. Before he began treatment he felt very unwell, was unable to eat, sleep, felt sick all the time. It was hard to keep working. All these symptoms disappeared on treatment. He feels very well on the machine and now does his long workdays as before. The only thing he notices is that he can't do heavy work outside on his property as he used to.

He was early in his relationship with his wife when he discovered he was going to have to go on dialysis. They discussed it, whether to continue their relationship or not, then they decided to work through it together and have not needed to talk about it since. They have a good partnership, he works and does his treatment and his wife manages the household and provides him with support as necessary. He is not close to his own family, but has a few good friends who know about his treatment. He is *"not one to rely on other people,"* his life is based around his relationship with his wife.

While others may consider that life on dialysis is not normal *"what's normal, there's a normal life on dialysis which people don't know about. They get the wrong idea from media reports about a few people, don't realise that many people are getting on with it, doing well on it."* He feels that he has got his normal life back through dialysis removing his crippling symptoms. *"Nothing's changed except I don't get much sleep on the nights I dialyze, but I'm used to that, the lack of sleep*

doesn't really affect me... Other people often say how can you do it but, I say, if you had to you would."

The one drawback is *"the intrusion on your lifestyle... you can't go away for weekend at the drop of a hat"* but that doesn't bother him too much. The only thing he misses is Fiji. He'd been there twice with his wife before he started treatment, *"but you only want something when you can't have it."* He probably would go back if he could, but in fact he hasn't had a holiday for 3 years, he doesn't feel the need. *"Being self employed you have a different outlook."* Not being able to travel, *"that's the price you have to pay... if you're dead you can't go anywhere. I'd rather have a quality of life and be housebound as such."* The other problem with dialysis is the time it takes, *"it's a shame you can't plug in for 10 minutes and do the same thing."*

7.5.2. Dialyzing

John dialyses in the evenings on Wednesday and Friday and on Sunday morning. He doesn't start until late in the evening because of his 12-hour workday. He does accounts or watches TV while on the machine. Dialyzing at home enables him to continue with his work without problems. *"It's best in your own home for this sort of thing. In hospital you're at everyone's' beck and call. You do it when they want you to do it, because they have a business to run. At home I can do it at my own leisure."* He sometimes reduces or changes the dialysis regime to suit himself. He doesn't sleep on the machine during the week, as he can't get comfortable. He comes off at 3am.

He used to get headaches on the machine but doesn't anymore. One problem is that he sweats regularly after treatment, it pours off, he needs a towel around his neck. He also gets cramps and is unable to sleep. While he's on the machine he sometimes feels freezing, shivers and needs to have a heater on. But this sort of problem, *"it's*

a small price to pay to be alive." Compared with others he saw in the dialysis unit he feels that he is one of the lucky ones.

A self-reliant person, he does the whole dialysis procedure himself. In the methodical way that he deals with everything else in his life he follows a careful routine when going on the machine. His wife says *"he's got a certain way of doing everything."* She is there in the house while he's dialyzing, she was nervous about it at first, especially when things went wrong. She used to come quickly if she heard a machine alarm. Now she's confident that he knows what he's doing, but is there to assist if necessary. The only thing she regularly does is giving the IV Iron into the bloodlines each week. *"It's part of our life, we just get on with it. I don't think about what might happen, I don't worry until it does happen."*

In the early months he had a few bad events including going *"flat"* [becoming hypovolemic], having cramps and, once, lost some blood, *"spurting everywhere from a loose connection."* He has very few problems on dialysis now. *"The hardest thing is getting over problems. It always seems to work out when I've had a bad day, I'm not in the mood for it, something goes wrong. I get frustrated, kick the wall, but things have gone wrong through my own fault. I'm blaming work when it's something I've done, didn't do it right and it blew up. If you've had a stressful day it's easy to make a mistake. I'm not going to let my temper be the excuse for making a mistake."* He deals with this now by taking some time to relax after a hard day before he goes on the machine, to *"make sure I'm in the right frame of mind to do it."*

Managing his fluid intake is *"a commonsense thing"* he used to drink a lot, not alcohol, but had to *"slow down on fluid"* after beginning dialysis. He thinks, *"a lot of drinking is habitual."* He won't drink much or he will be a *"balloon of fluid."* His diet has changed but that is not a problem. It may be partly age, partly the advice of the dietitian. He no longer *"eats for the sake of it,"* has cut down on salt, and eats very little meat. Taking tablets, *"all renal patients are pill addicts for the*

rest of your life, I bloody rattle, it's essential to keep your balances right." As a child he played taking make-believe tablets with cut up dog biscuits, much to the disgust of his grandmother who was against such medications. He thinks now perhaps it was an omen.

When John began treatment the initial impact of having the fistula needles inserted in his arm was quite traumatic, especially when they couldn't find the vein. Nurses, *"they can only look at it from the clinical side, not from the patient's side, how they're feeling. Once I did it myself I broke through a barrier, I was okay, I've got an aptitude for that sort of thing."*

He looks after the machine, *"his"* machine, keeps it in good order. He does basic maintenance himself, changing bulbs or fuses. The machine is *"like my right arm really, there for my benefit. You look after it, it looks after you. It's there to do a job just like I am. I'm the boss, the machine has its job to do. It's like a working relationship. Driving a truck, the truck does its job for you, if it breaks down you get pissed off with it. It's another work tool, there for my health rather than my pocket. It doesn't chirp into life until I turn it on."* He was surprised at first that his blood was outside the machine, but he's not worried about blood loss on dialysis, *"if I lose it I lose it."*

"When I first started I enjoyed it, it was new. Now it does get tedious sometimes, it's a bit monotonous, it depends on your day. You've got to do it to be here. It's a routine, I suppose I don't want to do it sometimes, but you know you've got to do it. But it feels like a waste of time, 5 hours sitting on a machine plus an hour for set up and finishing up. On dialysis the machine runs your life, no matter how you look at it, the machine always wins." But for him *"The benefits outweigh the bad parts."* He wonders if it is worth it for some older people.

He views the renal staff as helping him to look after himself on the machine. *"They don't know how I feel, only I know how I feel. You've got to have guidelines, they*

give you guidelines, they've got to treat everyone equal, some need a regimented approach but I think there's room for flexibility. If I did it to the letter of the law I'd probably be a bit aggro with it. I do it how I want within the guidelines of the system. No one knows how a person feels except the person themselves. I know how I feel myself, I'll dictate what I can do. Certain things you keep to yourself. I don't want to offend people. They do their best for you. Now it's passed over to me I'm doing the best for me."

After doing three treatments a week when he first went home, as he had been told by the nurses, he felt worse. He had felt better in the dialysis unit on two treatments a week. He thought that three treatments a week was "excessive" because he still passed a lot of urine. As he felt better doing twice a week he changed back to that at home without telling the nurses. He has missed dialysis for a whole week once after a bad 'blow' [haematoma caused by problems with needling]. Now he usually does three times a week but sometimes shortens his hours or misses a session if it is necessary because he is very busy. After his kidneys are removed he knows he will need treatment three times a week consistently. *"Before I could miss dialysis here and there when I had kidneys, it's different now, I've got to be dedicated to it, can't be as flexible as I was."*

7.5.3. An unsettling event

He is having his own kidneys surgically removed because they are so large they are now preventing him from having a transplant. *"On the 29th into hospital, on the 30th the op, on the 31st Kidney pie... be able to feed a rugby team."* With a transplant he considers he should be healthier, he'd like to get rid of the cramps. Dialysis, *"to be quite honest I think I'll miss it, it's been a major part of my life, I'll miss the involvement with the machine... I don't think I love it yet, it's there to work, like me."*

At the third discussion, delayed for some time after the surgical procedure, John said the operation was difficult, the kidneys huge, 10 kilos. He had to return to hospital three times because of complications. The operation was *"a bloody disaster. A few times I felt like giving up, I'd just had enough. Emotionally I was a mess in hospital, it was very hard on my wife."* For her *"the way he was there was nothing I could do, felt useless, that it was a waste of time going to see him. He wasn't getting better, he was going down, giving it away."*

To John, *"the nurses are busy doing their job, they can't be tied up with emotional problems, it's hard enough to get a nurse to come and see you when you need something done, you don't see them all day. 'I'm not your nurse, I'll get your nurse.' At a certain stage you're eventually forgotten, left in the corner, it's a demoralizing thing."*

"Everyone was telling me I needed to eat, I knew where they were coming from, it wasn't that I didn't want to eat, I couldn't eat because I was so bloated." A nurse told him he was becoming addicted to pain relief so he stopped it. *"I'd rather suffer than listen to this shit. It pissed me off, the insinuation that I was getting addicted."* One time in the ward several doctors *"just walked in and attacked me"* to tap fluid from his lung. He couldn't believe he hadn't been consulted. His abdomen was very sore. *"Everyone thought I was a head case, neurotic, because I was so paranoid about my stomach... until the bandages came off and they saw it"...* tension sutures, distension and infection.

"Not being able to pass urine is an emotional thing. There was no follow up on that. You're left to dwell in your own misery. Social workers, they seem to think that all they're there for is to give you a discount. But they're supposed to be looking after your head, not your pocket. They don't really know, they haven't been through it. I ended up having a good talk with another patient who was going through what I was going through."

According to his wife, *"the nurses at home dialysis are the ones that really helped us. When I rang the surgical ward about the problem with the wound, they're were not interested, 'go to your GP'. Communication with the surgical ward was shocking. I rang Home Training, in 5 minutes flat everything was done, he was into the ward."*

For John, *"you've got to be strong about it. If I wasn't there's no way I'd be doing it now at home again after what I've gone through. The sooner I got back home and got into a normal routine the better up here [points to head] I'd be."* Since the operation he has had no cramps on dialysis. But he is going to be off work much longer than he had thought before the operation.

"With a transplant you can have a lifestyle for 10-15 years before complications like cancers set in. I'd rather have 15 years of quality life doing what we want to do, being free from the machine, than go on the way we are now forever, we're so restricted, it'd drive me up the wall. Doing it long-term is not part of the plan. It's been instilled into me by the doctors that a transplant is on the cards, that's why they took out the kidneys."

"If we get 10 happy years I don't give a shit after that. I'm not going to be unrealistic and say I will get 10 years of quality life. I don't know how long it's going to be. I could be like the guy in hospital and end up losing it after the operation. Rejection is something that happens... The anti rejection drugs give you cancer but if you don't take them you are likely to lose the kidney. You weigh up the odds. The sooner I'm freed up from this the sooner the machine is freed up for someone else."

"I don't stay on the machine because I don't want to die, I stay on it because I want to live."

7.6. Owen

"I have adjusted to life on dialysis quite well."

The sixth account is from Owen. Though not obviously different from several of the other men Owen is unique in the length of time he has lived on renal replacement therapy, well over two decades. An older man in his early sixties, he lives with his wife, his children having long grown up. They moved into their present home a few years ago in a middle class area. He is retired after an administrative career.

Owen has been on home haemodialysis for 2 years. He received a transplant when he was much younger that functioned successfully for many years. Before his transplant he had a few months on hospital haemodialysis. Physically well he is on the waiting list for another transplant. With his long and varied experience of renal replacement therapy, Owen, philosophical but weary from the influence of chronic illness on his life, tended to courteously answer my questions as given, occasionally judiciously offering his own insights. He clearly presents his view of limitations in the current renal service.

7.6.1 Adjusting his life

Owen considers that he has adapted to living on dialysis. Travel is limited, *"this is the biggest problem we face, we can't go anywhere really."* While he could dialyze in the unit in Auckland *"I've got into a routine at home, I would always be concerned about something being different... I know my own machine... after a bad dialysis there's no place like home."* He has been thinking of going away for a weekend that would not require dialysis away from the home but has not done it yet. *"Even the fact that your partner can't go on holiday is a concern, they've got to stay here with you."* He recently tried to encourage his wife to go away with her mother for a couple of weeks. While he could have managed his treatment by himself she was unwilling to leave him for that length of time.

Many friends have moved to Tauranga for the better weather and *"if I'd had my kidney I would have moved there myself."* He has stayed in Wellington because it is a good place for dialysis, regularly does renal transplants and he knows the staff well after many years. Living where he does near Wellington is *"a compromise"* between their desired lifestyle and managing the requirements of his treatment.

His first time on dialysis, many years ago, was much more difficult than this present period. Owen was in hospital for months, his experience of the treatment was *"shocking."* They had young children, he *"missed a hell of a lot."* His wife had to carry the burden, *"she probably lived through more than I did."* Dialysis is a lot easier this time, partly because the treatment itself is not so rigorous, partly because of his different life situation, his children having now grown up. He considers he is doing reasonably well without too many problems, but he still experiences some symptoms. On dialysis days he sometimes dehydrates himself, and so is *"useless on that day."* His blood pressure is often very low after treatment, he is dizzy on standing up, even at his Target Weight. Sometimes he feels all right when he finishes treatment but an hour later he feels unwell. He used to get cramps before becoming hypovolemic but now gets no warning of the problem. He has no other symptoms on the machine, no severe headaches as he used to have the first time he was on dialysis.

He has a significant problem with 'restless legs' [uncontrollable nocturnal spasms in the lower limbs]. He can no longer sleep in the double bed because his 'restless legs' disturb his wife. He doesn't notice it himself when he's asleep but his wife hears him *"thrashing around"* and he has *"kicked all the paint of the wall"* where his leg hits it. He considers it has a lot to do with diet causing high phosphate levels. The symptoms seem better if he does not have a meal in the evening. At times he has bad itching, *"it drives you barmy in the middle of night, it's worst in the heat."* He keeps a knife beside the bed, uses the blunt side to scratch his back. He thinks it is probably also related to high phosphate levels but is unwilling to routinely

lengthen his hours on the machine, as has been suggested by renal staff to try to get rid of it.

He doesn't sleep as well as he used to with the transplant, when he slept very soundly. Commonly he only sleeps for two or three hours, then is wide-awake and walks around at night with his 'restless legs'. Then he is tired in the day. *"Lack of sleep has a terrible effect on the body, both mentally and physically. My low periods always result from lack of sleep and negativity abounds until the next good sleep, when normality returns and with it a feeling of wellbeing."* He has tried sleeping tablets and naturopathic remedies but they did not help. Sometimes he has even tried to drop his blood pressure when dialyzing to promote sleep. Now he has given all that up, *"I've weaned myself off those things, now if I sleep I sleep."* Sleeping better at night would really improve his life. It is a major problem for people on dialysis that renal staff underestimate.

Owen considers he is *"80 % of what I was when the transplant was working well."* He doesn't jog now but still works outside, mixes concrete for building projects around the house, *"physically I can do most things I did before."* His leisure time activities have not changed on dialysis. He enjoys doing things around the house, especially gardening and carpentry. He is well on the way to having completely renovated their property. He goes for walks with his wife, or swims. He reads and enjoys listening to music. He's not keen on bowls, a common leisure activity in his area, *it "can control your life,"* but he might take it up at some time. Socially they do most of their visiting during the day. Interference with their social life by the dialysis schedule would have been a bigger problem in the past. Sometimes he can't go to social functions because of dialysis schedule. *"Most friends know when I go on, don't invite me to any function if I'm going to be on."* Casual social meetings often focus on dialysis, which is irritating to him. Other people bring it up, asking how he can manage. *"I don't like patronizing people, I feel that anyone would do it in the circumstances."* He dislikes such sympathy and prefers to forget about dialysis when he is not doing his treatment.

7.6.2. Coping with dialysis

Owen dialyses on a regular routine 6 hours on Mondays, 5 on Wednesdays and 6 on Fridays. Currently he usually starts at 3 or 4 am in the morning in order to maximize his free leisure time in the day. If the weather forecast is poor he will start later at 6 or 7 am. *"If it's a wet day you haven't missed anything."* He has tried dialyzing at night but this pattern suits him best. He will only vary it if circumstances dictate he has to, this pattern being best for his lifestyle.

His wife gets up to give him a hand going on the machine. She helps him with taping the fistula needles that are difficult to manage by yourself. She has helped him at other times, in particular when there were several power failures. *"Without a partner you couldn't do it, she had to get on a chair and squeeze the Normal Saline bag."* At the start of his treatment at home they had some problems, with blood spurting everywhere a few times, but worked together to deal with it; they've learned a lot through experience. While *"they [the training staff] inferred it was my operation, it takes me just under an hour to get on, would take much longer if she didn't help out with a few things."*

Going on the machine is no problem, it's *"second nature."* He is well set up. Hygiene is important, *"I'm very methodical about it."* An important decision going on is where to place the fistula needles. He tends to favour certain sites because of problems with others. Early on he had lots of problems and *"wondered 'why should I have to go through this?'"* Now his sessions go smoothly. *"The biggest decision while on the machine is the fluid levels, I usually have to take 2 off. If I get cramps during the treatment I will cut it back, I've only had to give myself Normal Saline twice."* The dialysis machine is *"a life line, more than a machine, an important part of my life. It keeps me alive, as simple as that."* He likes to be informed about it, does maintenance on it, receives valuable feedback from the technicians about its care.

While he dislikes the very restrictive fluid limits he manages his fluid intake well. During the day he will have two teas, one coffee and, in between, iceblocks made of fizzy drink to suck. He never feels overloaded. He does not have the appetite he used to have. He doesn't go out to restaurants for dinner because he *"can't do a meal justice, it's a waste of money."* Rather they go out for lunch. He can't face a large meal and his lack of appetite can be hard for his wife when she has cooked a meal for him. Restricting high potassium and phosphate foods can be a nuisance. He often feels most like eating sweet things between meals, which is not harmful because they are mainly sugar. He wonders if this may relate to dialysis treatment itself.

"Doing the dialysis yourself is not demanding, it's the boredom. I can't concentrate, often feel dozy at the start, I can't read. I listen to music, radio, watch the TV. I feel tethered to the machine, can't go outside to work. It's unproductive time on the machine." Generally his mind doesn't function as well when he is tired, he's not as alert in the evenings. For example he couldn't do the cryptic crossword in evening but it's easy in the morning.

After dialysis he often does not feel great. *"Because you might feel ill you can't plan your movements on treatment day. You set yourself up psychologically like that, you have the good days in between, you look forward to the two day break on the weekend. ... You don't enjoy it because of its limitations, [but] you have things to look forward to, which help you in coping with the routine, things you set up for yourself, a pattern of looking forward to things to enable you to manage."* He looks forward especially to the two day break at the weekend but also to the shorter five-hour session midweek. He had a similar approach to his transplant. *"When I first got the transplant I used to set myself an objective, first that I'd be happy if it would last six months, then a year. But finally it got to the point where I forgot about it, didn't set goals, and there was a long period where I didn't worry at all."*

He tries to minimise the sense of *"lack of freedom, the regimentation of dialysis. I'm always trying to maximize the hours available [to do other things], because you spend so much time on the machine."* While he does not have a tight weekly schedule since he has retired *"I guard jealously the in between days, I hate them being taken away from me, I feel I've lost a day. It's my lifeline, but I want to have a normal life during the day."* Going to town for health-related appointments is a nuisance. He considers it would be very hard to manage if he was employed, having to go on dialysis after working.

"There are certain things you have to do, dictated by the machine. I don't know if I'm doing everything as I was taught, I've modified things by observation of staff in the unit. Some things like putting in the local [anaesthetic] to both sites before needling are better. When I'm on the machine I may modify the fluid removal, alter the TMP [transmembrane pressure] according to my symptoms."

"I do my hours, I never shorten them, I've been told even longer hours might help the 'restless legs' but I can't regularly do longer. If I feel good on a particular day I'll do longer. I know after a two day break I'm ready for dialysis, I can feel it in my system." He has the same approach to a transplant. *"If someone's been good enough to give me a chance its part of my responsibility to look after myself."*

While going to the dialysis unit can be a relaxing change in some ways, *"sometimes when I go in to town and someone puts needles in it's a break,"* in other ways it is even worse, especially the boredom as *"every second seems like an hour in there."* While he has more control of the treatment at home, *"the regime is part of your life, I suppose it does run your life."*

When Owen was first at the training house his memory was not good, it was *"a pretty high learning curve."* The long involved manuals were difficult, he was expected to do everything from memory when learning, *"I used to sneak a piece of paper, my own little check list, I felt guilty about it. The process was inflexible and*

not tailored to the individual. If the pupil hasn't learned right the teacher hasn't taught right."

The relationship with the staff is much less close now than it used to be. *"Another aspect I've noticed since returning to dialysis is the lack of dialogue with specialist staff. When my transplant was working an appointment with a consultant was forthcoming at the first sign of trouble. Now the catch cry is 'go to your GP' whenever a problem occurs. I can't recall the last time I saw a consultant. I don't always get the results of my blood tests. We get very little feedback but we're the customers. At home you feel as though you're one of the forgotten people."* Now people on self-care dialysis have to pay for some of their medications such as Lignocaine but they're saving the health system money by treating themselves at home.

Recently when he was being treated in the unit *"I was efficiently connected to the dialysis machine but there was no communication. Six hours goes very slowly when you're tethered to a machine."* The nurse wouldn't listen to him and as a result he became dehydrated during the treatment.

He has little involvement with other patients except for some contact with one who lives nearby. He wonders if networking could be promoted so patients could share their experiences, perhaps even a newsletter.

7.6.3. Accepting the future

A recent blockage in his vascular access was a *"bit of a shock,"* it was a real nuisance to have to go to the hospital to have his fistula cleared. But he's been through it now, and is aware of the need to take aspirin each day to prevent a recurrence.

Owen is looking forward to a transplant now but a while ago *"if one had come up I don't know if I would have taken it."* He knows the "downsides" of transplantation, *"been there, done that."* He broke ribs a number of times when working outside, he had a number of skin cancers including a grade three melanoma, all consequences of long-term steroids taken to stop the transplant rejecting. *"The kidney lasting that long may have been a bad thing because of all the side effects that you have to put up with at the latter end of the period. Since I've been back on dialysis my skin is back to normal, my bones are better."* So he doesn't look forward to a transplant as perhaps others do. But dialysis also has its problems so he's back on the waiting list for a kidney. He has learned the limitations of all forms of renal treatment over time, he wasn't told them. *"You have a better lifestyle with a transplant but there are inherent problems with it over time. If they could fix up the problems with dialysis it would be more attractive."*

When he first started back on dialysis he was very overloaded, his heart was not working well, some valves leaking, he wondered if he was close to a heart attack. The transplant had its pluses and minuses, but *"I often wonder how long you can do this [dialysis] for, the likelihood of a transplant is not good, [but] if you couldn't have a transplant... it's not whether I can keep it up but whether my body will keep it up, it's no problem for me the way I am now but what if something goes wrong, I wonder whether over time I will physically deteriorate on dialysis so I am no longer able to do it. I don't have a high expectation of the system providing me with another transplant, because of the simple logistics of it, a limited number of organs with more people wanting them. There seems almost no hope of a transplant; in my age bracket perhaps the chances lessen, there's a certain amount of urgency as you get older."*

After years of involvement *"I feel pretty philosophical about things that occur, life is full of degrees [of experience] that you can't [grasp without having been through it] ... you don't know the meaning of the feeling of relief until you've suffered great pain, the most wonderful feeling on earth. I've learned through the illness... the*

highlighting of contrasts is fantastic. Without these negative experiences you can never appreciate how good life is."

"I wanted to give up once, I've no fear about passing on but I've got a fear about the people you're leaving behind." He wouldn't dream of accepting kidney from his daughter, he wouldn't want to leave her disadvantaged. From his experience of dialysis "you get a feeling for others who are disadvantaged from your condition as well. I get down to it occasionally, especially after a couple of nights without rest, then I think of people who are paraplegic or tetraplegic, there's always someone worse off than me."

"There's always the doubt how long you can stay on dialysis, it's just a stop-gap measure."

7.7 Conclusion

In each of these accounts I have presented the experience of renal illness and therapy of one of the men in the study. In terms of the critical interpretive approach developed for this research project these accounts attempt to express the participants' interpretation of their experience according to the hermeneutic understanding. They result from my reflection as researcher on my engagement with the participants in our discussions. I have expressed my understanding of their interpretations of their experience by editing the material in the transcripts of the interviews into orderly narratives.

As accounts they represent a product I have formulated as researcher, reflecting the 'distance' (Ricouer, 1986. p. 328) between us. However this 'distance' actually enables the reflection necessary to set out coherently their interpretations, derived from my interactions as a renal nurse with them in the interviews, using this narrative format. Given the initial assumption of this study, of the obscurity of the

distinctive experiences of people living on dialysis in the renal setting, these accounts of the experience of six Pakeha men represent an attempt to listen to the 'voice' of people living home haemodialysis. They articulate several individual experiences of the renally replaced life.

Within the critical interpretive approach these accounts can be reviewed in terms of the distinctive interpretive stance, articulated in the Foucauldian sketch of the renal setting, that orients the study. From this critical standpoint I recognize that although these men's understandings reflect the dominant renal discourse, they also reflect a client discourse expressing their own shared position in the renal setting as people living on dialysis.

When considering their accounts presented above it is apparent that, although each one of them reflects the distinctive contours of the individual man's experience, all of the accounts show certain similarities. In every account the man uses some of the specialized language of CRF and renal replacement therapy in talking of his experience. Their comments typically express an acceptance of the efficacy of renal replacement therapy. All view themselves as maintaining reasonably good health on dialysis. They consider that a transplant, which they are confident they will receive, offers the definitive solution to their CRF. Generally their language and views reflect the optimism of the dominant discourse in the renal context. An interesting interpretation of the requirement for compliance with the therapeutic regime by two of the men, David and Keith, their specific concern that they might not receive a kidney transplant if their bloods revealed they were inadequately dialysed when an organ became available for them, illustrates the pervasive influence of the dominant discourse in their thinking.

While these men's accounts reflect the language and ideology of the dominant discourse, through critical reflection I discerned, from hesitations, alterations and contradictions in their accounts, various points at which they found it difficult to simply use the language and ideas of the dominant discourse, because they did not

easily fit with their own experience. In terms of the critical interpretive methodology developed for this study, recognizing the "critical distance" (Thompson, 1990, p. 261,263) between us, as participants and researcher, enables an analysis of their accounts that focuses on discerning their distinctive understanding of their experience that is obscured by the dominant ideology in the renal setting (see Thompson, 1990, p. 258).

Having presented their individual interpretations of their experience in this third section of the thesis, the fourth section will, from my critical view of the renal setting articulated in the second section, reinterpret the accounts as a set. By contextualizing them, in terms of the sketch of the renal context, I will seek to discern some commonalities reflecting their shared position in the renal setting as people living on dialysis, in contrast to the dominant professional discourse, in order to produce an understanding of the experience of Pakeha men living on home haemodialysis as the concerns of the renal client discourse.

Section D. Analysis: understanding the experience of the renal client

Chapter 8. The concerns of the renal client discourse

“If anyone has ears to hear let them listen.” Mark 4:9 (New Revised Standard Version)

The fourth section of this thesis analyses the experience of renal illness and therapy of the six men in the study to present an understanding of the concerns of Pakeha men living on home haemodialysis. The initial assumptions of this study were that people living on dialysis have distinctive experiences characterized by common concerns that are difficult to discern because they are obscured by the dominant professional viewpoint. In this section, in accord with the critical interpretive approach developed in this study, I reinterpret the individual accounts from the third section as a set, in terms of the critical sketch of the renal setting in the second section, in order to discern the meaning of these men's experience.

This section is composed of four chapters, each one developing the analysis based on the accounts of their experience. In chapter eight I outline four concerns of the client discourse in the renal context derived from the set of accounts. Contrasting with the dominant discourse these concerns delineate the characteristic features the client perspective in the renal context that orient individual experiences of renal illness and therapy.

In chapter nine I will discuss the relationship between the concerns of the client discourse and the individual's accounts of their experience of illness and therapy.

Having abstracted the client discourse underlying the set of accounts in chapter eight I will show how it relates to the individual accounts. I will indicate that each of the accounts can be interpreted as resulting from the interaction of the aspects of the client discourse, characterizing their position as people living on dialysis, with the dimensions of their personal social location. After considering the influence of two elements of the dimension of their social status, their male gender and Pakeha ethnicity, I will briefly illustrate, for the men in the study, how the renal client discourse enables an understanding of the individual experience of living on dialysis.

The traditional quotation heading this chapter suggests that a message spoken can only be grasped by someone who has the capacity to do so. In terms of the language used in the first section of this thesis, given a range of possible interpretations within the arc of the interpretive turn, any situation can only be understood according to how it is interpreted. Different interpretations are always possible giving different possibilities for understanding. In this study I am attempting to 'listen' to the voice of some people with CRF by developing a capacity to 'hear' them through using the critical interpretive methodology, in order to understand the experience of one group of people living on dialysis from their own perspective. In chapter ten I will outline one important implication of this understanding of the experience of living on dialysis. I will suggest, through an explicit reflection on the character of renal nursing work, that it is the nurse with 'ears to hear' who is able to 'listen' to the client in the renal setting. chapter eleven, the conclusion, summarizes this study addressing the consumer dimension of the renal setting. It outlines the way this thesis has sought to understand the experience of Pakeha men living on home haemodialysis.

This section is opened by this chapter entitled *The concerns of the renal client discourse* where I present the outcome of my critical analysis of the interpretive accounts of the last section. The hermeneutic accounts of their individual experiences in the third section I critically reinterpret as a collective experience, in terms of its renal context as viewed critically in this study. Having already recognized some obvious commonalities reflecting the dominant discourse, I reinterpret the set of accounts by contextualizing them in terms of the critical sketch of the renal setting. Through reflection, from my own experience of working with people living on dialysis and clues from the renal

literature review above, I discern various less obvious commonalities in their interpretations of their personal experiences of renal illness and therapy. These reflect their shared perspective, as people living on dialysis, in contrast to the dominant discourse based on an objective scientific knowledge of renal disease and therapy. By showing the influence of their common position as people living on dialysis in the renal setting on their individual interpretations, I seek to develop an understanding of their shared experience of renal illness and therapy.

Reinterpreting the accounts as a set from my critical standpoint enables me to produce a "construction" (Crotty, 1998, p. 42; Schwandt, 1994, p. 118), four concerns of the renal client discourse, modelling the shared perspective from their common position in the renal context that underlies each of the individual accounts. The four concerns of the renal client discourse in which I summarize the common perspective underlying the accounts of the six men in the study include the following: suffering from the symptoms of CRF and dialysis, negotiating the requirements of dialysis to fit their lifestyle and the limitations involved, the ongoingness and uncertainty of life on dialysis and the hope of a transplant, the altered interrelationship of autonomy and dependence involved in living on dialysis. I will now set out these concerns of the client discourse. I will delineate each one of them in turn by collating and interpreting selected material from the set of accounts, using information from the literature and my own renal nursing experience, in order to outline the distinctive cluster of interrelated features that constitute it.

8.1. Suffering from the symptoms of CRF and dialysis

The first concern of the renal client discourse I name as suffering from the symptoms of CRF and dialysis. Dialysis is supposed to remove the symptoms of CRF by replacing their renal function according to the dominant discourse. While residual symptoms are recognized in the literature (Challinor and Sedgewick, 1998; Gutch, Stoner and Corea, 1999) they are viewed as a peripheral issue that generally reflects inadequate treatment. However, despite excellent treatment, all of these men reported some troubling symptoms while living on dialysis.

In delineating this concern I will first set out the routine symptoms that can be derived from the men's accounts. Then I will note the ways, reflecting the dominant discourse, in which they tended to downplay these common symptoms. Finally, despite this tendency to normalize their routine symptoms, I will describe some specific unusual symptoms, often associated with events related to the ongoing maintenance of their dialysis therapy neglected in the dominant discourse, of which they were very conscious.

8.1.1 Their common symptoms

The men suffered from a range of common symptoms that were normal for them on dialysis. General lack of energy was the most significant general symptom associated with their CRF that almost all of the men described. Most affected was Paul who said *"I've got to force myself to do anything, not that I can't but I know how I will feel after, so I avoid it because the cost is too high."* Another symptom from their life on dialysis that all but one of them mentioned, only occasionally considered in the literature (Devins et al., 1993; Kimmel, 1989; Locking-Cusolito, Huyge, and Strangio, 2001; Parker and Bliwise, 1997), was an altered sleep pattern limiting the length of time that they slept. For all but two, Chris and John, a general lack of energy, combined with tiredness due to a lack of sleep, produced general tiredness that affected their lives to a significant extent. Most clearly Owen said that his general wellbeing depended on how he had been able to sleep recently. *"Lack of sleep has a terrible effect on the body, both mentally and physically. My low periods always result from lack of sleep and negativity abounds until the next good sleep, when normality returns and with it a feeling of wellbeing."* Several of these men considered that lack of sleep arose in some way from the dialysis process itself, noting the difficulty in sleeping following treatment.

These men commonly reported certain symptoms, recognised as associated with CRF but poorly understood, particularly itching and 'restless legs.' Several, Paul and Peter, clearly associated this with their diet, in particular alluding to their rate of intake of phosphate-containing foods as the causative factor. These symptoms were not rated as very significant in themselves but were part of the suite of symptoms resulting in a lack of sleep and energy.

Hypotension was the commonest symptom associated with treatment itself. Three of the men often felt dizzy, sometimes "*disoriented*," at the end of their treatment or following it, even when the treatment had been uneventful and they had successfully achieved their target weight as set by medical staff. General non-specific malaise following treatment, apart from hypotension related to fluid removal, was another common symptom, specifically reported by most of the men. These symptoms were influential because they meant they could not confidently plan to do anything for the rest of the day following their treatment.

All these men except John, who had begun treatment most recently, reported some variability about how well they felt on different days. For some of the men this variability of wellbeing was explicitly cyclical. They felt better at some times than others in relation to their dialysis cycle, probably due to fluctuating levels of toxins and fluid in their bodies. Keith noted that "*often the day that you come off you're not that brilliant, but the next day or the second day you would be like any other normal person.*" Mark had arranged his dialysis schedule to optimize his wellbeing when he was at work, with his worst day, after his two-day break, being Sunday. For Owen "*because you might feel ill you can't plan your movements on treatment day. You set yourself up psychologically like that, you have the good days in between, you look forward to the two day break at the weekend.*" Even Chris, who did not otherwise note variations in his wellbeing as cyclical, did commonly need to sleep immediately following his dialysis treatment.

The men regularly referred to a heightened awareness of their own bodies and to their sense, after several days, of 'needing' the machine. Owen said "*I know after a two day break I'm ready for dialysis, I can feel it in my system.*" Mark stated "*I find I'm on edge when beginning dialyzing, perhaps from the toxins, fluid, or my blood pressure being up The cost of changing that one day is quite a bit. No matter how I try I cannot guarantee that I'll be able to take a three day break and feel good.*" Keith said "*I'd feel the extra day. Now my body tells me I need the dialysis machine.*" Despite greater potential flexibility as a self-care client at home, in comparison to those on in-centre dialysis, in fact these men managed their cyclical sense of wellbeing, reflecting their

residual symptoms, by adopting a defined dialysis schedule that reduced their actual flexibility in their weekly schedule.

8.1.2 Downplaying their symptoms

Although these men suffered from a range of symptoms they generally tended to downplay them. The common tendency, manifested by most of these men in different ways, was to initially describe their life on dialysis as resulting in minimal symptoms and then, throughout the course of the discussion, to recall a range of symptoms they in fact suffered from. During the conversation, as he called to mind the range of symptoms he suffered from, Owen specifically expressed surprise about how much he had forgotten about when he first stated he suffered from few symptoms. He initially forgot to mention itching of such severity at night that he routinely used the back of a knife to deal with it. Likewise Chris, John and Paul all tended to initially minimize symptoms they suffered from.

The tendency to initially underestimate their symptoms probably reflects the fact that, as they live with the symptoms on an ongoing basis, they have become an aspect of their lives that are coped with in part by being 'normalized'. There is always a tendency to forget what is normal, to treat as normal what has to be accepted. Further the men naturally tended to conceptualize their situation positively, in accord with the optimistic professional viewpoint, viewing their symptoms as a residual or an idiosyncratic problem. Even Mark and Chris considered, despite their symptoms that they recognised, that they were doing well on dialysis.

While tending to minimize their symptoms, the men, when they did acknowledge them, often considered that alterations to their therapeutic regime could remove them. While Owen had been told that longer treatment hours might get rid of the specific symptom of 'restless legs,' he was not willing to increase his dialysis hours because of the impact on his lifestyle. He also considered that not eating in the evening improved his symptoms but continued to eat, although with less enthusiasm. Hence his symptoms, he recognised, could potentially be lessened, if not removed, if he acted differently, and so could be conceptualised as being to a degree as self-imposed. Most of the men

expressed the view that their wellbeing was dependent on their careful adherence to treatment, reflecting the dominant professional viewpoint that their degree of compliance with the treatment regime prescribed for them determined their wellbeing on treatment. Thus the men downplayed their experience that, against their expectations derived from health professionals, they had symptoms while on dialysis.

They made it clear, when they reviewed the symptoms they did actually suffer from, that they had now accepted these as part of their life on dialysis. For example John, who considered, very positively, that he was living normally on dialysis, but was no longer able to do heavy work around the garden, often felt chilled or had sweats while on treatment and was unable to sleep after treatment, stated this was a "*small price to pay*." Finally this acceptance of their symptoms may have led these men to minimize them, as being a necessary consequence of the therapy that keeps them alive.

8.1.3 Symptoms from specific events

While they tended to take for granted certain ubiquitous symptoms in their life on dialysis most of the men were conscious of particular symptoms associated with specific events as part of their renal histories. Sometimes these reflected their condition or dialysis at certain times. When fluid overloaded, in the days before recommencing dialysis again after his transplant had failed, Owen thought he was going to have a heart attack. One time, when off the machine, Paul experienced symptoms, slurred speech and numbness down his arm that he thought meant he was about to have a stroke, that subsided when medically treated. Chris, on one occasion while on the machine, lost so much blood from bleeding he was unable to control when a fistula needle accidentally came out of his arm, that he nearly "*passed out*." Although such symptoms created acute anxiety at the time this gradually lessened as the men's treatment continued without problems, though sometimes leaving a chronic underlying sense of anxiety about the possibility of future recurrences.

The experience of pain, not normally a symptom of treatment itself but a periodic consequence of the complications of the treatment of their CRF, had been a significant symptom in the experience of all these men at some time during their renal history. All

the men specifically noted that they had suffered from pain associated with various vascular access procedures, from radiological (to clear clots from their fistulae or grafts in their arm) to insertion of central venous lines (to maintain short term dialysis access until long term access was surgically re-established), as part of their experience of their ongoing treatment for CRF.

For example Chris, generally very positive about his care and the professionals who provided it, found recurrent temporary vascular access procedures, both angioplasties and central venous line insertions, so painful he now asked to be "*knocked out*" with drugs before they occurred. John, stoic and laconic about his situation as a person with CRF, found the pain associated with his surgery excruciating, complicated by failure of his epidural pain relief to work successfully, and subsequently some nurses' reluctance to give regular pain relief.

Though generally treated as occasional, and thus peripheral to the renal patient's experience, by health professionals according to the men in the study, they indicated that for them such periodically recurring painful events come to be viewed as an integral aspect of their renal management by many renal clients. Reflecting the experience reported by these men, Sloan (1996) has highlighted the experience of repeated surgical interventions as influential in the decision not to pursue a transplant.

According to the dominant discourse dialysis generally works effectively to remove symptoms for people with CRF. However the experience of these men suggests that some symptoms persist despite their renal replacement therapy for CRF and others occur as a consequence of using the therapy itself. Symptoms from the effects of CRF or renal replacement therapy are recognized in the literature (Challinor and Sedgewick, 1998; Gutch et al., 1999) but they are viewed as a residual problem in a successful therapy. By contrast for these men, when actually acknowledged, they were significant as a concern that to some extent undercut the efficacy of the therapy. This is the basic aspect of the renal client discourse.

8.2 Negotiating the requirements of dialysis to fit their lifestyle and the limitations involved.

The second concern of the renal client discourse I name as negotiating the requirements of dialysis to fit their lifestyle and the limitations involved. According to the dominant discourse dialysis is supposed to be able to be fitted into a person's regular routine to enable them to continue their way of life without a great deal of disruption. While some studies acknowledge the need for initial adjustment the treatment regime is generally presumed to become part of the patient's normal pattern of life (Artinian, 1990; Gerhardt, 1990, 1996; Lindqvist et al., 2000). However all of these men reported that it actually had a significant impact on their lifestyle.

In delineating this concern I will first illustrate the negotiation required to integrate dialysis into their regular pattern of life and the limitations that this causes in their lifestyle from these men's' accounts. I will note the way their adoption of a defined dialysis schedule, in order to manage the therapy itself, compounds the impact of the therapeutic regime on their lifestyle. Finally I will describe their alteration of aspects of the therapeutic regime itself, as part of this process of negotiation, in their effort to fit it into the normal pattern of their lives.

8.2.1 The impact of the treatment regime on their normal life pattern

Despite the professional recommendation was to treat themselves at night to minimize the effect of the time required for dialysis on their normal activities, seven to nine hours three times a week, none of these men was able to sleep normally on dialysis. Only one of them, Paul, simply dialyzed at night, though he did not sleep normally while on treatment. Several either started in the evening and dialyzed until the early hours of the morning, 2 or 3 am (John and Mark), or started in the early hours of the morning, 2 or 3 am (Owen), and dialyzed until the late morning. These unusual patterns showed how difficult they found it to integrate the therapeutic regime into their ordinary lives in a satisfactory way. Through the various regimes that they adopted the men sought to minimize the time taken out of their day by their treatment, given that they were unable

to sleep while on the machine at night. They increased their free time in the day as much as possible but at the cost of chronic tiredness.

In order to integrate his dialysis regime into his life to enable him to achieve his primary aim of continuing in his job, Mark had established a rigidly defined pattern for his entire weekly schedule. During the week he went on the machine straight after work, dialyzed until 3am, then slept until 6am when he got up for work. He dialyzed all day Sunday to get a good start to his working week. Any alteration to his schedule, from an unexpected overnight stay out of town for work to a machine malfunction, disturbed his regime with negative consequences to his wellbeing for the rest of the week. Dialysis-related tasks additional to his normal pattern, like ordering his dialysis stores or having to go to the hospital pharmacy to get his EPO in working hours, took up still more of his precious free time.

Negotiating dialysis into his lifestyle to ensure he maintained his job resulted in the limitation, consciously accepted, of almost no social life. As a consequence he had not been able to establish a permanent intimate relationship. For John likewise, the negotiation required to integrate dialysis into his lifestyle in order to enable him to continue his job, resulted in a very tight weekly schedule. Dialyzing late into the night enabled him to maintain his long hours at work. Because he was married, with his wife looking after the house and his social life well established, the rigidly defined pattern required to integrate the dialysis regime into his weekly schedule had not impacted as negatively on his lifestyle as they had for Mark.

Chris had positively adapted his weekly schedule to the requirements of the dialysis regime to enable him to be a househusband and care for his grandson. However living on dialysis had meant he has not been able to return to employment as he wished. He had taken jobs several times but the requirements of his dialysis therapy meant he had been unable to continue them. Because his wife works their living standard had not been adversely affected. While he had negotiated dialysis to fit into his lifestyle the extent of the limitation involved for Chris became clear when he indicated he would again seek work if it were possible, for example after a transplant. In stark contrast, while Paul was able to manage his dialysis regime to allow him to continue look after his son, he was

unable to work and had almost no social life because of the effects of CRF and dialysis on his wellbeing. He had abandoned hope of an intimate relationship because of the impact of the treatment regime on his last partner. Having to negotiate dialysis into his regular weekly schedule had destroyed his lifestyle and he survived in the hope that the crippling limitations would be reversed by a transplant.

Keith, now retired, had moved to part time work to enable him to manage his dialysis regime but was made redundant. As he had no financial problems and was approaching retirement anyway the adjustment required had little impact for him compared with Paul. Likewise Owen, also retired, noted how difficult it would have been to fit dialysis in with working fulltime with children at home. Even so they both found that the impact of the treatment regime, though not creating as tight a weekly schedule as it did for the men who were working, equally onerous. While acknowledging it was much easier to deal with dialysis now than it would have been when they were younger, they keenly felt the limitations on their time that resulted from having to negotiate the dialysis regime into their lifestyle, perhaps because of their expectation that at this stage of their lives they should be free of defined schedules in the week. As Owen said *"I jealously guard the in-between days, I hate them being taken away from me, I feel I've lost a day. It's my lifeline, but I want to have a normal life during the day."*

8.2.2 A defined dialysis schedule

Their negotiation to integrate the dialysis regime into their lifestyle was influenced by their symptoms from CRF and dialysis. The variability in their sense of wellbeing following treatment, limiting their capacity to plan activities on the days when they dialyzed, combined with their generally cyclical sense of wellbeing while living on dialysis, meant that, despite greater potential flexibility as self-care clients at home, these men in their negotiation adopted a defined dialysis schedule as part of their regular weekly schedule. They managed their residual symptoms by regularizing their dialysis pattern. They also clearly stated that having a defined pattern helped them to cope with having to manage dialysis themselves at home. This rigid treatment pattern exacerbated the limitation in their lifestyle caused by the negotiation required to integrate dialysis into their lifestyles.

All contrasted positively self-care at home with in-centre therapy, specifically in terms of greater flexibility and a more normal life, but in fact, having adopted a rigid dialysis schedule they tended to fit their social lives around it. While some emphasized that their social life was unaffected by dialysis, others recognized the limitation in their social life caused by dialysis. Mark stated "*the number of new people I meet is minimal.*" Keith said that dialysis "*isolates you a bit.*" Paul described himself as "*a bit of a hermit.*"

Further, for all of these men, to their relatively rigid dialysis schedules was added the need to visit health professionals regularly, either for routine appointments to monitor their wellbeing or periodically, at short notice, to manage specific problems such as with vascular access. Their experience of the effects of these additional time-consuming visits, which were generally beyond their control and could not be negotiated into their lifestyles, increased the limitation cause by the dialysis regime.

All mentioned inability to travel on holidays as the most obvious limitation caused by living on haemodialysis. As Mark said he was *tied to here and tied to the machine.*" While it is possible to holiday away from home, only one, Chris, was doing this regularly. Mark used to do it but no longer did so because of problems that meant it simply *"wasn't a holiday."* While these men had successfully negotiated the dialysis regime into their normal lives, the additional demands made by holidays away, especially the additional organization required and the uncertainties about managing the therapy in an unusual context away from home, highlighted the limitations, despite their best efforts, inherent in negotiating dialysis into their normal lifestyle.

Several of the men, Owen and Paul, said they could not have a 'real' holiday while living on dialysis. Aspects of a holiday, such as relaxation and freedom from a regular schedule, were contradicted by the requirements of the dialysis regime, which are more difficult to manage in an unfamiliar setting. The stresses involved meant that they preferred to maintain their regularly patterned lifestyle with a defined dialysis schedule that they successfully managed. While accepting this they noted the inability to go away on holidays, perhaps for them an aspect on the normal life they had expected on dialysis according to the dominant professional viewpoint, as a specific limitation caused by the necessity to negotiate dialysis into their lifestyles.

8.2.3 Altering their own treatment regime

For most of the men the negotiation required to integrate the requirements of renal replacement therapy into their weekly schedule not only influenced their regular pattern of living but also resulted in some alteration of their dialysis or other aspects of the treatment regime in order to manage it in their lives. Paul and Keith both found they could not tolerate their prescribed target weight and so aimed to come off somewhat higher. Mark normally removed his fluid at a differential rate, rather than a steady rate as he was taught, because he considered this worked better, even at times using an ad hoc method of ultrafiltration, when he considered it necessary, through manipulation of the dialysis machine. These men considered the alterations in their ultrafiltration necessary to feel well after treatment.

The men had altered other aspects of their therapeutic prescription. Keith, generally meticulous in completing his treatments, regularly partially 'set up' his machine in the mornings to enable more free time out with his wife before he began treatment in the afternoon. Chris, diligent in other matters such as his fluid intake, had experimented with his medication regime and diet in the past. While dialyzing alone in the house, upon occasion he regularly disconnected himself during treatment leaving his blood 'recirculating' in the blood lines, in order to make himself a cup of tea.

Several of the men, Owen and Keith and recently John, taught to manage their treatment by themselves, now had their wives taking a significant part in their treatment. Owen said that while "*they inferred it was my operation*" he found it quicker and easier to have his wife help. Most strikingly John, who had only received two treatments week while in the hospital unit and still had a normal urine output volume, found he felt worse on his prescribed schedule of three treatments a week at home and so regularly reduced to two, even at one point going a week without treatment after a bad 'blow' [haematoma occurring during needling] on his fistula.

Most men stressed their adherence to the instructions of health professionals but also, apparently unaware of the contradiction, mentioned practices in their dialysis that differed from the pattern they were taught by the home-training nurses. However

sometimes they indicated the rationale for changes, emphasizing that these did not reduce the efficacy of the treatment while improving their own lives on dialysis. Several men made it clear that changes they made to their dialysis practice were not discussed with the home training nurses. Keith stated *"whether it's right or wrong or otherwise it's my technique."* Paul made it explicit that, while he did not want to appear to reject professional advice, whatever the health professionals said only he knew how he felt. *"I know I should do what he says but I'll go with what I know and how I feel."*

John most clearly articulated the view that being in control of his treatment at home meant he could manipulate the treatment in order to integrate it into the requirements of his own weekly schedule. He also clearly expressed his recognition that he could not freely express this to the health professionals who support him because his choices were unacceptable to them, 'non compliant' with the treatment prescription they have given him. He noted *"they don't know how I feel, only I know how I feel. If I did it to the letter of the law I'd probably be a bit agggro with it. They do their best for you, now it's passed over to me, I'm doing the best for me."*

Several of the men who were generally assiduous in adhering to their dialysis schedule, Keith and Owen, had declined to increase their treatment hours, as suggested by the renal health team, to see if certain symptoms they suffered from would disappear with more extensive dialysis. These experienced men living on dialysis had refused to modify their dialysis regime because they were not willing to further compromise their lifestyle by reducing their free time. The significance of the negotiation required and limitation involved for them is evident from their resistance to further intrusion on their lifestyle from their treatment, especially alterations to their dialysis schedule.

Though generally relatively minor for these men, viewed as 'compliant patients' by health professionals, they all had still made some modifications to the recommended regime in order to negotiate the requirements of dialysis into their lives. Others make far more significant alterations to their regime, for example reducing their treatment hours, bending it to fit in with their lifestyles in ways that clearly compromise its efficacy.

Because the men in this study had already relatively successfully made the adjustment necessary to integrate the requirements of dialysis into their lives, having accepted the limitations involved for them in a positive adaptation in Hardiker et al.'s (1986) terms, they had no difficulty in talking, in terms of the dominant discourse, about dialysis enabling them to successfully continue a relatively normal life. Such a positive self-image is probably necessary to cope with the demands of self-care treatment at home. They all, even Paul, considered themselves well adjusted to life on dialysis. The impact of the recurring obligatory interruptions to their lifestyle caused by living on dialysis, characterized in a recent study as "deprivation from normal life" (Linqvist et al., 2000, p. 295), would be more graphically illustrated in the lives of some others living on dialysis.

According to the dominant discourse dialysis, in particular self-care treatment at home, can be readily fitted into a patient's regular pattern of activities to enable a nearly normal lifestyle. After an initial period they will adjust to their new roles (see above Hardiker et al., 1986; Gerhardt, 1990; Kutner, 1987; Littlewood et al., 1990). However all of these men, although tending to initially emphasize continuity of their lives in accord with the dominant viewpoint, on reflection revealed that integrating the requirements of the dialysis regime into their weekly schedules had required negotiation that resulted in some limitations in their lifestyle that had to be accepted. For most of them it also involved some alterations of the dialysis therapy itself to fit it into their lifestyle. While contradicting the common generic stereotype of chronic illness as characterized by passivity, the dominant renal discourse, in optimistically presenting the positive possibility of life on dialysis, underrates the effort required (see Thorne, 1993, p. 54). This represents another aspect of the renal client discourse.

8.3 The ongoingness and uncertainty of life on dialysis and the hope of a transplant.

The third concern of the renal client discourse I name as the ongoingness and uncertainty of life on dialysis and the hope of a transplant. Dialysis is supposed to be gradually seamlessly interwoven into their lives these people according to the dominant

discourse. Although the long terms complications of CRF are a major topic of the renal literature the impact of the morbidity and mortality associated with these on the lives of people living on dialysis is rarely considered. However the men in this study manifested a continuing sense of dislocation between their lives on dialysis and their normal lifestyle.

In delineating this concern I will first outline their sense of the 'ongoingness' of living on dialysis. I will then note, despite this sense of the chronicity of their situation, how at the same time they are conscious of the inherent uncertainty associated with life on dialysis. Finally I will describe how they cope with this tension between ongoingness and uncertainty in their lives on dialysis through their expectation, according to the dominant discourse, of a transplant.

8.3.1 Experiencing life on dialysis as ongoing

These men found that as time passed they gradually recognised what could be called the 'ongoingness' of life on dialysis, a personal sense of the chronicity of both CRF and renal replacement therapy. This discovery, that could only be learned through experience, had several aspects. The continuing symptoms that some of the men suffered from were a reminder of the chronic character of CRF. Also, despite having integrated the dialysis regime into their lives, their sense of the limitations it caused in their lifestyle did not necessarily diminish but were often even exacerbated over time as they came to realize how these must be endured indefinitely. This sense of the ongoingness of their lives was not generally expressed directly. Rather several issues they raised had this as the underlying theme.

The many hours of their lives taken up by the treatment were the obvious focus of their sense of the ongoingness of life on dialysis. While several made the most of their time on treatment, notably the two employed men, Mark, for whom it was a real break, and John, who did some of his work on the machine, most felt it was time wasted which they could better use for other activities. As the time that they had lived on dialysis had lengthened they had become frustrated that a significant proportion of their life was taken up by dialysis treatment, and sought to minimize the loss of time by adjusting of

their dialysis schedules, resulting in the unusual patterns referred to above. Having a defined schedule and also a special room for dialysis, enabling them to symbolically 'close the door' on dialysis, separating their therapy from their everyday lives, also helped them to cope with the inherent chronicity of their condition and therapy.

While they did not immediately speak of it most of the men eventually alluded to their sense of constriction at being attached to the machine for the many hours required for the treatment. It was perhaps an inescapable aspect of life on dialysis they preferred not to articulate. Paul did not dialyze in the day because being attached to the machine for so long "*drives you barmy*" resulting in him shortening his treatments. Mark felt dialysis was "*very restrictive ...largely it does run my life unfortunately... [I'm] tied to here and tied to the machine very tied to the machine*". Owen said "*your life's normal when you don't feel restricted.*" John noted, "*it feels like a waste of time, on dialysis the machine runs your life.*" Most graphically Keith described it, "*after four hours I feel like a bloody dog. I'm tied up, I can't go anywhere, do anything.*" Owen also spoke several times of being "*tethered*" to the dialysis machine. While they understood the necessity for dialysis these allusions seemed freighted with significance, suggesting a cumulative sense of constriction resulting from the treatment, an expression of the experience of the ongoingness of their life on dialysis.

The sense of the ongoingness of life on dialysis was also obliquely expressed in their comments around the word 'normality' in relation to their lives. Keith asserted that on many days his life was "*like any other normal person,*" implicitly acknowledging that on others it was not. Likewise John questioned what people generally mean by 'normal', stating his life was not as abnormal as the public might think, but implicitly acknowledging that regularly dialyzing raised an issue about the normality of his life. Owen was explicit that his aim is to achieve a "*normal life during the day*" through his efforts to minimize the limitations caused by the dialysis regime. Although he considered his life on dialysis as very good Chris wanted a transplant in order to have a "*normal*" life for his last years.

Paul, explaining his rationale for altering elements of the treatment regime, suggested the abnormality created by it, saying "*your life is more normal when you don't feel*

restricted.” Mark stated very clearly yet poignantly that his life was “*probably abnormal but I’ve forgotten what normal is.*” The complexity of their use of ‘normality’ in speaking of their experience of living on dialysis contrasts with Gerhardt’s (1990) notion of “narratives of normality,” rather reflecting Linqvist et al’s (2000) recognition of the idea of ‘normality’ as a site of contested meaning. Their use of the word ‘normal’ implies a global assessment of the state of their own lives in comparison to their idea of the lives of other people not living on dialysis. Through its use the men in this study expressed a realization over time of the distortions in their lives caused by the effects of the chronicity of CRF and the dialysis regime, the ongoingness of life on dialysis for them.

8.3.2 Uncertainty about the future

These men also had a growing awareness, in their own experience or in those of others they knew on dialysis, of the long-term complications of life on dialysis, whether from the progressive symptoms of CRF, such as chronic bone pathology caused by abnormalities in their calcium/phosphate balance, or the complications of the therapy itself, such as vascular access problems. While dialysis is supposed to be a successful therapy, given compliance by the patient, these men had realized over time that development of the long term complications of CRF are not necessarily inhibited by optimal therapy. They knew that even careful treatment, which these men often emphasized was reflected in their excellent blood results, will not necessarily prevent these problems progressing.

A developing understanding, contrary to the optimism of the professional viewpoint, of the limitations of the efficaciousness of dialysis as a therapy for CRF, gave rise to a sense of uncertainty about the future. Even though these men considered that their treatment was going well at that point they all, from their experience of past, often unexpected, difficulties, expressed some anxiety about potential problems that could arise in the future or the prospect of premature death. A recurring uncertainty about their own wellbeing after each treatment was perhaps a reminder of the underlying uncertainty associated with renal replacement therapy.

For John, with a very positive view of his current life on dialysis in comparison to his pre-dialysis condition that he could still remember well, his experience of surgery and its subsequent complications had altered his perspective. Not only was this event a difficult and painful outcome of his CRF that he had not expected, causing significant disruption of his life, it suggested to him the potential for ongoing problems in the future following from his CRF, even though his dialysis itself might be going well. Recognizing his the uncertainty of the future on dialysis, he now hoped a transplant will give him a limited period, hopefully *"ten good years of quality life"* with his wife.

Chris, though characteristically optimistic, tending to suppress any uncertainty about the future, recognised that his family had significant worries about his life on dialysis. While he considered his present dialysis therapy was optimal, his recent vascular access complications, after a long period with no problems at all, leading to several disruptive and painful surgical procedures, had reawakened his sense of the uncertainty of life on dialysis, which only a transplant could overcome for him.

Owen, stoically accepting the limitations and symptoms associated with long term dialysis, was nevertheless frustrated by having to put up with the arbitrary intrusions on his life from both the effects of the dialysis regime itself and the unscheduled admissions such as his recent trip to hospital have his vascular access cleared. He looked forward to another transplant to free him from the inherent uncertainties of living on dialysis, while knowing that the prospect was itself very uncertain. He wondered how long he would be able to manage on dialysis if his physical wellbeing were to diminish, expressing the inherent uncertainty associated with living on dialysis over a long period. *"I often wonder how long you can do this for... there seems almost no hope of a transplant; in my age bracket perhaps the chances lessen, there's a certain amount of urgency as you get older."*

Mark sensitive yet analytic, was aware of the fragility of his physical wellbeing, even with optimal therapy, the arbitrary and unpredictable effects caused by CRF and the dialysis regime in his life. He was concerned about the prospect of long-term complications of CRF as years went by on dialysis. The only possibility of change lay in a transplant, a possibility he somberly recognised, given how long he has been on

dialysis without receiving one, was very uncertain. Mark spoke eloquently of a sense of vulnerability, loss of confidence in the future, of wondering if anything would change, of a tendency towards a "*downward spiral, [that is] quite common,*" of a concern in the future that "*a gradual deterioration would be difficult to accept.*" This vivid spiral image combined his sense of the limitations of life on dialysis with its inherent ongoingness and uncertainty.

Paul, from his own past experiences of complications of CRF and dialysis, whether the one stroke-like event or occasional arrhythmia's he had suffered on treatment, has been at times been "*paranoid*" that he will "*cark it.*" While acknowledging the inherent uncertainty of living on dialysis, "*I think I'm going to wake up one morning dead,*" he coped through his quasi-religious confidence that he will receive another successful transplant.

Keith, suffering from the increasing long term complications of CRF as the years on dialysis went by, which his optimal dialysis therapy could not halt, was gradually coming to recognise he faced the prospect of further deterioration. The frustration of the continual limitations on his activities while living on dialysis could only be overcome, he knew, by receiving another transplant. But now he wondered if he would be well enough to receive one when he gets the opportunity. Obliquely referring to his uncertain future Keith said, "*you can't pull out of it, the degradation [that] gradually comes through your system doing this [dialysis]... I might not have thought of going on if I had known that this would be the future, or come off at a certain point.*"

These men's experience was of a sense of ongoingness in their lives that was periodically arbitrarily interrupted by problems associated with their condition or treatment reminding them of its inherent uncertainty. While the ongoingness of life on dialysis was frustrating, the routinization of their lives caused by their therapeutic regime actually enabled them to cope with the uncertainty inherent in life on dialysis. Despite the potential freedom available in self-care treatment at home, adopting a fixed treatment pattern made it easier to cope with the uncertainty of life on dialysis. Mark articulated this clearly by saying that he coped by being in a routine, any change from this routine reminding him of his fragile situation on dialysis. A number of the other

men also said that routinizing their treatment, having a defined dialysis schedule as part of their regular weekly schedule, helped them to manage having to continue to live on dialysis.

8.3.3 The expectation of a transplant

Concerned by the ongoingness of their life on dialysis, and also the uncertainty created by periodic problematic episodes that interrupted it, these men looked forward to a different event that would both break the routine and address their uncertainty. They coped with the ongoingness and uncertainty of living on dialysis through their hope of a kidney transplant. All of these men viewed their life on dialysis as a provisional state. Paul clearly expressed this, saying *"dialysis is a stepping stone until you get the transplant."* Their common theme was that, although they had not yet received a transplant, they expected that they soon would because, as John stated, it had been *"instilled"* by renal health professionals that they could expect a new organ within a few years. Most simply remained confident that they would be transplanted shortly despite having waited for some years.

Only a couple of the more reflective, Mark and Owen, aware of the limited availability of organs, realized that they might not receive a transplant and, if they did, it might not solve their problems or might even cause others. Mark had expected a transplant within a few years of starting on dialysis, viewing his life on dialysis as provisional as a result, but, never having received one after a number of years, had been forced to alter his expectations as time passed and recognise that his dialysis could continue for the indefinite future. In contrast to others' confidence in a coming transplant, for Mark the final aspect of uncertainty about life on dialysis was over whether or not he would ever get a transplant.

In the most sophisticated analysis, based on his extensive experience of the *"downsides"* of both, Owen viewed the two modes of renal replacement therapy as complementary, dialysis having certain problematic aspects which a transplant addresses, but transplantation also having certain problematic aspects, in his case the effects of long term steroid use, which returning to dialysis had addressed. He acknowledged that,

unfortunately, generally one could not choose when to switch from one renal replacement modality to the other. As with Mark this was the final uncertainty about life on renal replacement therapy. Even though their experience had muted the confidence of these two men in a transplant, for all of them it remained their central hope.

The significance of a transplant as their main hope was underlined when the possibility of not receiving one was raised. Several made it explicit that to be permanently taken off the list of people awaiting transplant for any reason would be very difficult to bear. Paul, able to manage dialysis only because he believes he will get a transplant shortly, is hardly able to contemplate such a possibility. For him it is not a question of if but when. For Keith while recognizing that a transplant was now becoming less likely, this had been the hope that had enabled him to manage dialysis and the prospect that it might not ever be possible led him to wonder, given his current difficulties, about the value in continuing treatment. Even for Chris, managing well on dialysis and optimistic about his future, to discover that a transplant would not be possible would be *"a death blow for me, nearly."*

Other than Mark and Owen the men showed almost no recognition of the degree of uncertainty about receiving a transplant, let alone any awareness of the potential problems with transplantation itself, not only the possibility of the transplanted kidney failing to function for some reason but also the long term complications associated with transplantation such as increased risk of life threatening infections or cancers. Their 'hope', while it appears objectively "unrealistic" (Hoothay et al., 1990; Rittman et al., 1993), perhaps a necessary psychological mechanism to cope with the uncertainties of living on renal replacement therapy, also reflects the optimism of the professional viewpoint. These men's hope expressed in their expectation of a transplant, reflecting the local 'dialect' of the professional viewpoint, can be contrasted with a different renal setting, where clients' concerns about the uncertainties associated with transplantation itself, reflecting a different version of the professional viewpoint, were influential in their decisions about whether to seek a transplant (Sloan, 1996, p. 91).

According to the dominant discourse, dialysis becomes a normal part of the lives of renal patients over time as they become habituated to it. However the experience of these men suggested rather, despite successfully negotiating the requirements of the dialysis regime into their lifestyle, a gradual realization of both the ongoingness of life on dialysis and also its inherent uncertainty. They coped through their hope that life on dialysis did not have to be accepted as permanent but was rather provisional, because they would in the future receive a transplant to enable them to escape from dialysis. Their concern about the influence of the chronicity of the condition and therapy in their lives is another aspect of the client discourse.

8.4. The altered interrelationship of autonomy and dependence involved in living on dialysis.

The fourth concern of the renal client discourse I name as the altered interrelationship of autonomy and dependence involved in living on dialysis. According to the dominant discourse living on dialysis at home is supposed to enhance personal independence. Very few studies address the impact of the dialysis regime on the autonomy of the individual living on dialysis (Devins et al., 1984; Horne and Weinman, 1994; Reiss, 1990; Stapleton, 1983). However the men in the study all manifested an altered interrelationship between autonomy and dependence in their lives in various ways.

In delineating this concern I will first set out, despite their competence in self-dialysis, an increased dependence in their personal relationships resulting from their treatment. Then I will note the ambiguity, in terms of autonomy and dependence, in their new relationships with health professionals that arose from their CRF. Finally I will describe, despite their independence in managing their own treatment, their dependence on dialysis technology for their continuing life.

8.4.1 Changing personal relationships

The men did not lack confidence in their own competence to manage their treatment at home, which was "*second nature*" to them now. Most of them had had some problems

with their treatment when they first started at home but these never happened now. While performing their own dialysis involved a considerable responsibility, with limited professional support to manage any complications that occurred, they did not generally have any anxiety about their treatment. Even those who dialyzed alone at home did not find this problematic. Mark, who did report intermittent malfunctioning of his machine, noted that this caused him anxiety but this was not because of lack of confidence but primarily because of the disruption to his tight daily schedule that such events beyond his control caused. *"To work I need this to work."*

Their mastery of dialysis affirmed their sense of autonomy. While reflecting the professional viewpoint that self-care fosters independence, they made it clear that this was also their own view. As one said explicitly he had *"an aptitude for that sort of thing,"* namely running a mechanized process involving a degree of manual dexterity, suggesting that performing haemodialysis fitted their male self-image as practical and technical minded.

All of the men in the study were clear that living on self-care dialysis at home did help them to maintain a more 'normal' life in comparison to receiving haemodialysis at the hospital dialysis unit. They all stated that treating themselves, even if this required some effort, was far better than being treated by others in an in-centre unit because it gave them more control of their lives by avoiding the particular restrictions to their lifestyle caused by dependence on the unit. They did not have to travel to dialysis or wait for treatment to begin, were not tied to precise times for beginning treatment and had greater privacy and more leisure on the machine at home. Those who worked, Mark and John, could not have continued with their jobs if they were on in-centre dialysis. The others were better able to continue their usual pattern of everyday activities by treating themselves at home.

However the obvious capacity of these men to manage the therapy itself, affirming their autonomy in accord with the professional viewpoint, tended to obscure other aspects of their lives on dialysis, less obvious, manifesting a complex interrelationship between autonomy and dependence.

The men's accounts suggested that living on dialysis had affected their relationships with their families and friends. Generally they tended to emphasize the ordinary character of their relationships, such as the understanding of friends who accommodated their dialysis in planning social activities or the easy acceptance of their treatment by grandchildren playing around the machine while they were dialysing. Other reactions, whether sympathy from neighbours to inability of some friends to accept the sight of them on treatment, or even sensing people noticing an 'eye-catching' visible internal jugular catheter in public, perhaps enhancing their sense of being different from others, they tended to treat as exceptional.

It was in their personal relationships that the influence of living on dialysis was apparent. While the younger men dialyzing at home alone, Mark and Paul, were apparently most autonomous, their inability to develop or maintain a range of personal relationships, especially an intimate partnership, they recognised as a consequence of their dialysis regime. Mark stated that the number of new people he met was "*minimal*." He noted several problems, from having time to meet someone, to his concern about restricting the other person leading him to "*overwarn*" them about dialysis. His fiercely independent stance was his way of coping with living on dialysis, including the difficulty in establishing personal relationships. Paul had stopped seeing his friends, feeling "*left out ... a bit of a hermit*." Although he had no partner by choice as a result of his experiences, he acknowledged his dependence on his only significant relationships, with two women. While Mark and Paul were both managing their personal situations in different ways being alone was not simply a sign of independence for them. Rather their sense of being "*isolated*" they recognized as a consequence of their dependence in living on dialysis.

For the other men their relationship with their partners, all well established, remained strong, but had altered somewhat in character. In particular most of the men had their wives helping them with part of the dialysis procedure. While all but one could manage dialysis alone, they stated that the help of their wives made the procedure much easier for them. Their wives had adapted their own lifestyles to be present in the house when the men were doing their treatment, providing for their needs while they were attached to the machine. The only one who did not have his wife present or helping him with the

procedure, Chris, had altered their relationship in another way, becoming a househusband.

From the professional viewpoint performing one's own treatment promotes the autonomy of the person on dialysis. As Owen said "*they inferred it was my business.*" While most men stressed they were in charge of their treatment, they acknowledged the help of their partners in performing their treatment. Keith summarized this saying there was a "*terrific amount of teamwork, it's so much easier with some helping, much more pleasurable, quicker if you work as team.*" In fact these men and their wives saw dialysis as a joint problem in that it affected the wife as well as the man (see Soskolne and De Nour, 1989, p. 501). Hence each couple had worked out the best way to deal with it together.

Their appreciation of their partner's help reflected an increased reliance on them in comparison to their former independence in most activities, not only for their dialysis but in other ways associated with their therapy, for example in altering their cooking to provide the special dietary requirements or in accompanying them to the hospital for periodic consultations when necessary. All of the men recognized some costs to their partners from them being on dialysis, whether in terms of limiting their own activities or the stress of having to cope with their husband's illness and its treatment. Their comments accord with Brunier and McKeever (1993), who noted the burden placed on women as supporters of their husbands on dialysis that is often unnoticed in assessments of the effects caused by life on dialysis, and also Cohen's (1995) study that showed the hidden psychological cost to the families of people living on dialysis. In general the dialysis regime and associated care required the help of their partners in ways that had not been necessary before in the men's lives, altering the balance between autonomy and dependence in the relationship.

Paul, who had had several relationships during his CRF, reflected most graphically on the stresses caused by dialysis on a relationship with a partner. He recalled his own increasing dependence in the relationship while on dialysis, the distortion created in his partner's life by living with someone on the machine, eventually causing her to become somewhat like himself, leading him, when he realized this, to end the relationship for

her sake. His subsequent partner, used to his dependence in the relationship while on dialysis, was unable to cope with his recovered independence when he received the transplant, resulting in the end of that relationship. Because of his experience of the complexity of having a relationship while on dialysis Paul was reluctant to enter another relationship until he was transplanted again.

The other men, while responding to the demands of renal replacement therapy by asserting their autonomy in managing their own dialysis treatment, indicated their dependence in new ways on their partners in activities related to their treatment. As these men had managed to successfully cope with the changes that had occurred in their relationships to accommodate life on dialysis, they tended to stress that their relationships had essentially continued as before. However for all of the men the character of their relationships, the balance between autonomy and dependence, had altered somewhat as a result of living on dialysis.

8.4.2 Their new healthcare relationships

These men had also developed new relationships with health professionals since needing to begin dialysis. Most of the men tended to spontaneously express a positive view of their relationship with renal health professionals, especially the home training nurses who provided them with support at home. This was summarized by Chris in his comment *"it's not like a nurse/patient relationship, we're friends,"* reflecting the equality they felt, their sense of autonomy fostered by their relationship with renal staff. Generally they felt trusted to manage their own care.

However they were also aware of the limitations in support service available for those at home when they did have a problem. For Mark the fact that a machine malfunction could not be fixed immediately by support staff was disruptive to his tightly scheduled lifestyle. Keith felt somewhat isolated, *"left to battle along on your own... the only backup is the phone."* Owen expressed this by saying that as a person on dialysis *"at home you feel as though you're one of the forgotten people."* While affirmed in their autonomy in managing their own dialysis at home, their awareness of the limited support actually available to them indicated their dependence on renal staff. This

became explicit for people living on dialysis at times when they needed admission to the renal ward for some problem such as vascular access blockage, disrupting the usual pattern of their lifestyle. Keith, having some problems managing at home recently, was acutely aware of the ambiguity. *"You're so-called independent, but people keep asking if you're all right... but patients know."*

Further, despite their friendly relationship with renal staff supporting them, most of the men finally indicated that there were some aspects of their life on dialysis that they felt they could not discuss with them. In particular they were generally unable to talk about the variations they made to the therapeutic regime in order to enable them to negotiate the requirements of treatment into their lifestyles, because these did not follow, or even contradicted, the pattern that they had been taught and were expected to adhere to. The men did not think health professionals would understand. Paul said *"nurses can't tell you what its like dialyzing, you need to alter it to suit yourself. I know I should do what he says but I'll go with what I know and how I feel. They treat every one the same but you know your own body, you need to find a middle ground with food and drink."* John stated *"they give you guidelines, they've got to treat every one equal, some need a regimented approach but I think there's some room for flexibility. Certain things you keep to yourself. I don't want to offend people. They do their best for you. Now it's passed over to me I'm doing my best for me."*

This inability to talk to health professionals about alterations to their prescribed treatment regime reveals a paradox. While dialysis, according to the professional viewpoint, enables a nearly normal lifestyle and self-care promotes autonomy, to be efficacious dialysis requires compliance with the therapeutic prescription. But in interfering with their usual lifestyle, while creating a dependence on both the health professionals who provide it and the therapeutic regime, dialysis actually impairs the autonomy of the person with CRF. Altering the therapeutic regime to enable a more 'normal' lifestyle, a reaffirmation of their autonomy, cannot be made explicit to health professionals who, despite their promotion of the normality of life on dialysis, require compliance to ensure the efficaciousness of the therapeutic regime. Such behaviour, from the professional viewpoint negatively typed as non-compliance, can, alternatively, be positively characterized as "reasoned compliance" (O'Brien, 1990) or, more

accurately, "constructive non-compliance" (Thorne, 1990), reflecting the complex interrelationship between autonomy and dependence in their lives on dialysis.

Although they felt positive about their relationship with health care professionals these men were sensitive to any perceived lack of being fully informed about their condition, therapy or its effects. Sometimes they expressed a sense of having been misled by renal health professionals. As Paul said "*certain things they don't tell you about... its better to know, you ought to be told.*" Chris, who wondered why he was never initially offered the option of home haemodialysis, was then, ironically even to this optimistic man, asked by medical staff to talk to others, who had the choice, about the differences between CAPD and haemodialysis. Keith noted "*I might have thought of not going on if I had know that this would be the future.*" Such sensitivity to lack of information reflected an awareness, by people who had been encouraged to be independent, of their ultimate dependence on professional expertise for management of their treatment. Such moments showed them, despite its overt equality, the underlying asymmetry of their relationships with renal health professionals.

Despite having a positive view of their support staff and generally of all renal staff who cared for them, most had had at least one interaction with some health professional that had been negative for them. Usually these had not been with staff that they know well, during admissions, with staff unfamiliar with CRF and dialysis who had not listened to them when they made requests based on their long renal experience. For these men these interactions involved a degree of weariness at having to yet again endure inevitable confusions and delays during admissions to hospital, a reflection of their sense of the ongoingness and uncertainty associated with living on dialysis. Contrasting with their usual interactions with renal staff, these events had made a strong impression on them, as people with a chronic condition who, though encouraged to be independent, were at these points forcibly reminded of their dependence on the healthcare system and a range of health professionals.

Generally, while these men felt positive about their relationships with renal health professionals they were also aware of the ambiguity in these relationships that had

resulted from their CRF, a reflection of the complex interrelationship between autonomy and dependence in their lives on dialysis.

8.4.3 Dependence on the dialysis machine

Finally, while dialysis, especially self-care at home, generally enabled the men to continue with many of their usual activities, ultimately they remain dependent on treatment for their wellbeing. The ideology of independent self-care in the professional viewpoint disguises their dependence on therapy (Thorne and Patterson, 1998) but the "intrusiveness" of their treatment reminds them that their situation is beyond their control (Devins et al., 1984), shaping the pattern of their lives in ways that are inescapable.

Establishing a defined treatment schedule was the strategy by which the men sought to manage their lives on dialysis and minimize their sense of dependence on the dialysis machine. This reduced their residual symptoms and even their sensitized bodily awareness, that reminded them of their condition and dependence on treatment. As Owen noted *"I know after a two day break I'm ready for dialysis, I can feel it in my system"*. Mark said *"the cost of changing just one day is quite a bit... I'd rather work it so I don't have very difficult times."* Keith stated clearly *"I'd feel the extra day, my body tells me I need the dialysis machine. I don't deviate, it's not worth your while."*

The rigid therapeutic regime, separating dialysis from the rest of their lives, also facilitated a reasonably ordinary life for most of the time. For the two who were working, Mark and John, maintaining their demanding treatment schedules enabled them to continue normally in their work lives where their status as persons on dialysis was not significant, generally unknown. Of the men not working Owen expressed the importance of this separation between treatment and his usual activities most clearly when he said *"I jealously guard the in-between days, I hate them being taken away from me, I feel I've lost a day."*

The defined treatment schedule produces a reassuring routinization of their regular weekly activities reducing their sense of uncertainty about living on dialysis. Their

general rejection of holidays away from home followed from this need for routine as a way of coping with dependence involved in living on dialysis. While a holiday might seem an opportunity to express their autonomy, in fact, because of potential unpredictable and perhaps uncontrollable problems in an unusual situation, the prospect of a change from the normal pattern they could control highlighted their underlying dependence so they avoided it, helping them to maintain their sense of autonomy.

However, despite this common strategy of seeking to manage their lives on dialysis by maintaining a strict therapeutic regime, they are still regularly reminded, by residual symptoms, limitations in their ordinary lives caused by the therapeutic regime and occasional unexpected events underlining the uncertainty of life on dialysis, of their dependence on the therapeutic regime for their continued wellbeing.

Further their sense of dialysis therapy as "*restrictive*," expressing their sense of the ongoingness of life on dialysis, continually reminds them of their dependence on dialysis. As Mark said "*all the time I'm connected to it I feel dependent on it... you're no longer the prime driver of your life. You still have to consider yourself that but you're always coming up against problems... Largely it does run my life unfortunately... tied to here and tied to the machine.*" Paul expressed this sense of dependence on the machine to stay well most graphically "*its a security blanket... when they took it out after having my transplant it was like having my arm cut off, losing your pet.*" This sort of characterization of the dialysis machine, as "*pet*" or "*friend*" by several of these men, while apparently contradicting the notion, presented by some writers, of dialysis as alienating (Cooper, 1998; Rittman et al., 1993; Stapleton, 1983), suggests a complexity underlying their overt confidence in their use of the machine as "*second nature*." These unusual emotive expressions of their acceptance of dialysis as a therapeutic technology, in accord with the dominant professional viewpoint, imply a subtext pointing toward the dialysis machine itself as the focus for their sense of dependence.

While all people living on haemodialysis have to cope with the paradox of being dependent on the dialysis machine while remaining autonomous in the rest of their lives, for the person on self-care treatment this is most acute. They experience the "double bind" of being autonomous by taking responsibility for their own care while being

dependent on dialysis (Horne and Weinman, 1994, p. 125), a contradiction that cannot be resolved but has to be lived with. They control the machine but the machine controls them. Comments by John, relatively new to life on dialysis, epitomized this ambiguity. *"It's there for my benefit... I'm the boss, the machine has it's job to do... the machine runs your life, no matter how you look at it, the machine always wins... to be quite honest I think I'll miss it [when I get a transplant], it's been a major part of my life, I'll miss the involvement with the machine. I don't think I love it yet, it's there to work, like me."* This paradox has recently been simply summarized in the cryptic phrase, a **"wish** [my emphasis] to manage one's own life" (Lindvist et al., 2000, p. 294,5).

According to the dominant discourse living on dialysis enables a nearly normal life and managing their own treatment promotes their own independence. The experience of these men, although acknowledging that performing self-care treatment did affirm their sense of autonomy, manifested a complex interrelationship between autonomy and dependence in various areas of their lives on dialysis, in the alteration in their personal relationships, in the ambiguity of their new relationships with healthcare professionals and, finally, in their reliance on renal replacement therapy, symbolized by the dialysis machine, for continuing life. Ultimately they can only achieve autonomy through compliance with the "disciplinary technology" (Lupton, 1997, p. 99) of the dominant discourse itself, involving a contradictory dependence on the prescribed therapeutic regime. The altered interrelationship between autonomy and dependence inherent in living on dialysis is the final aspect of the client discourse.

8.5 Conclusion: a variant of the client discourse

In this chapter, through an interpretation of the six individual accounts of their experience of renal illness and therapy from the third section as a set, in terms of the critical view of the renal setting from the second section, I have delineated four concerns of Pakeha men living on haemodialysis. These aspects of the renal client discourse, contrasting with the dominant discourse in the renal setting, include suffering from the symptoms of CRF and dialysis, negotiating dialysis to fit into their lifestyle and the limitations involved, the ongoingness and uncertainty of life on dialysis and the hope of

a transplant and the altered interrelationship between autonomy and dependence in living on dialysis.

Within the critical interpretive methodology developed for this study this reinterpretation of the hermeneutic understanding of their individual accounts as a collective experience, by critically contextualizing them, produces an understanding of the experience of renal illness and therapy for this group of people living on dialysis. Having discerned their individual experiences through my hermeneutic engagement with them I have now presented, through reflection based on our 'critical distance,' an understanding of their collective experience. The concerns of the renal client discourse, derived from the individual accounts, model the shared perspective from their common position in the renal context that underlies each of their individual accounts.

Dialysis is a successful therapy in managing CRF that enables a reasonably normal life according to the dominant discourse. Difficulties with living on dialysis are peripheral to the efficacy of the therapy. However the analysis of the set of accounts in this chapter has shown that, from the point of view of people living on dialysis, renal replacement therapy results in a way of life that, in contrast to their expectation from the dominant discourse, is limited in its 'normality'. Certain complex difficulties that are characteristic of living on dialysis are represented in the concerns of the client discourse.

According to the dominant discourse dialysis is supposed to remove the symptoms associated with CRF. The first concern outlined in this chapter shows that from the client perspective people living on dialysis, despite excellent treatment, continue to suffer from the symptoms of CRF and also renal replacement therapy. Dialysis is supposed to be fitted into a person's lifestyle without a great deal of disruption according to the dominant discourse. The second concern shows that from the client perspective negotiating the requirements of dialysis to integrate it into their lifestyle involve significant limitations and even require some modification of the therapeutic regime itself.

According to the dominant discourse dialysis is supposed to become part of their normal lives over time. The third concern shows that from the client perspective there is a

continuing tension between their normal lives and the requirements of their therapy, manifested in a sense of the ongoingness and uncertainty of life on dialysis, that they cope with through their hope of a transplant. Self-care dialysis at home is supposed to enhance personal independence according to the dominant discourse. The final concern outlined in this chapter shows that from the client perspective living on dialysis results in an altered interrelationship between autonomy and dependence that is manifested in several different ways in their experience.

Together these make up the renal client discourse, a response to the dominant discourse they have been socialized with, that models the common perspective from their shared position within the renal context, underlying each of their individual accounts of their experience of illness and therapy. It is the chronicity of the condition and the therapy required to manage it, neglected in the dominant discourse, that shapes the client perspective. By delineating four concerns of the renal client discourse I have outlined the characteristic features of the client perspective, obscured in the renal setting by the dominant professional viewpoint, that influence the individual experience of living on dialysis for these men and others in a similar position.

The outline in this chapter, representing the position of people living on dialysis who are using a haemodialysis machine at home, represents one form of the client discourse in the renal context. For other groups of people living on different modalities of dialysis therapy, CAPD or in-centre haemodialysis, there would be different forms of the renal client discourse. There would be another for transplantation. The generic nature of the formulations for people living on home haemodialysis in this chapter suggests that people living on other dialysis modalities are likely to have the same general concerns, because they will all represent their common position in the renal setting as people with CRF dependent on renal replacement therapies. They might be articulated somewhat differently, as variants of the client discourse presented here, reflecting the distinctive character of each of these particular treatment modalities.

For example while people living on CAPD can experience symptoms from the treatment, they have a different, less aggressive, character than on haemodialysis. They do not go 'flat' at the end of treatment or have the potential to bleed profusely, as on

haemodialysis, but they can suffer from fluid underload of more subtle onset or symptoms of peritonitis. Negotiating dialysis to fit into their lifestyle and the resulting limitations also involve distinctive issues for people living on CAPD, given its contrasting therapeutic pattern to haemodialysis, requiring a relatively brief routine four times every day in contrast to an intensive thrice weekly treatment. Likewise in-centre haemodialysis, with its rigid schedule, extensive time commitment and transportation issues, contrasts with the relative freedom of home haemodialysis.

The impact of the ongoingness and uncertainty of life on dialysis is different for people living on CAPD, using a simple but very repetitive technology with distinctive complications and also a limited duration of viability, than for people living on home haemodialysis, a relatively complex technology requiring a range of skills for self-management with its own particular complications and longer term problems. Likewise for people living on CAPD the altered interrelation of autonomy and dependence is influenced by the distinctive character of CAPD therapy, the combination of relative simplicity and constant repetition that it requires. For people living on in-centre haemodialysis, whose reliance on the professional staff to actually perform their treatment is reiterated in complex variations at every session (for example a delay causing them to have to wait before commencing a session, or an inexperienced staff member having difficulty cannulating their fistula), the interrelationship of autonomy and dependence has a different character than for people managing their own haemodialysis at home.

The delineation of the client discourse in the renal context in this chapter raises the question of how these common concerns relate to the accounts of each of these Pakeha men using self-care haemodialysis at home. How do the aspects of the renal client discourse enable an understanding of their individual experience of living on home haemodialysis as set out in their accounts? Having abstracted the renal client discourse underlying the set of accounts, in the next chapter I will show how this relates to the individual's interpretation of their experience of renal illness and therapy.

Chapter 9. Living on home haemodialysis and the renal client discourse

In this chapter I will show how the individual experience of living on home haemodialysis can be understood in terms of the concerns of the renal client discourse. Having abstracted the various aspects of the renal client discourse from the set of accounts in the last chapter, representing their common perspective in the renal context that is obscured by the dominant professional viewpoint, I will now consider the relationship between the renal client discourse and the individual's experience of renal illness and therapy.

After suggesting that their individual experiences reflect the interaction of the renal client discourse with the various influential dimensions of their own personal social location, I will outline four of these that are significant in this study. I will then specifically consider the influence of gender and ethnicity, elements in the dimension of their current social status, to suggest how being Pakeha men influences their lives on dialysis. Finally, very briefly returning to each of the men's individual accounts, I will illustrate how, by highlighting its distinctive contours, the client discourse enables an understanding of his experience of living on dialysis.

Further reflection on the men's accounts, after having abstracted the renal client discourse from them, suggests that an individual account of the experience of renal illness and therapy can be critically interpreted as resulting from the interaction of their common position as people living on dialysis with various dimensions of their own personal social location. Their common position as people living on dialysis itself results, in terms of the critical sketch of the renal setting that orients this study, from the interaction of the influential dominant renal discourse that they have been socialized with, and the renal client discourse that is a response to it, reflecting their shared

perspective in the renal setting. Given that the influence of the dominant discourse is reflected in the renal client discourse that is a response to it, the experience of the individual living on dialysis can be understood as resulting from the interaction between the aspects of the client discourse, reflecting their common position in the renal setting, and the dimensions of their personal location.

In contrast to the aspects of the client discourse, constituting them as clients in the renal context, the dimensions of their personal social location comprise a matrix of factors influencing them as individuals. These include their social status, their current experience of dialysis treatment, their own history of renal replacement therapy and their personal style of response to having to live on dialysis. How significantly an individual's experience of living on dialysis is influenced by the various aspects of the renal client discourse depends upon the interaction of these common concerns with the different dimensions of their personal social location that I will now briefly outline.

9.1 The dimensions of their personal social location

The first dimension of their personal social location, their social status, includes a range of variables that define their present life circumstances, such as their marital and employment status. A man like Chris, living with his wife of twenty years with their children having left home, is in a different location from a younger man with a dependent child like Paul, whose partner has left him. For the former living on dialysis is made easier by having his wife with him and an adult child nearby, whereas for the latter living on dialysis prevents him from having an intimate relationship and complicates his care of his child.

As a younger man who is a solo parent and unemployed, Paul is in a different social location than Keith, a financially independent retired man with adult children. For the former his already difficult situation is worsened by dialysis, whereas for the latter his comfortable situation facilitates coping with dialysis. A man like Mark who is working full time is in a different location than a retired man like Owen. For the former a key issue is fitting dialysis in to his work schedule and the loss of leisure time activities. For

the latter dialysis can be easily fitted into his daily life, but having to do so thwarts his expectation of a relaxed free retired lifestyle.

Other elements of their social status, referred to by Tell et al. (1995) as the effects of the "social environment," can include gender and ethnicity. In the renal setting Brunier and McKeever (1993), as discussed above, have demonstrated how socially structured gender roles have influenced the development of renal services. Reiss et al. (1986), also noted above, have speculatively used ethnicity to explain differences in outcome of groups of patients from different social settings. The specific influence of gender and ethnicity in this study of Pakeha men are reviewed below. These various elements of their current social status, one dimension of their personal social location, influence these men's accounts of their experience of renal illness and therapy through their interaction with aspects of the renal client discourse.

The second dimension of their personal location, their current experience of dialysis refers to their personal feelings of physical wellbeing resulting from CRF and renal replacement therapy. Several of the men in this study, Chris and John, with few relatively minor symptoms, reported that they felt very well on dialysis. By contrast Paul, despite lengthy treatment and few significant specific symptoms, had a very poor general sense of wellbeing due to tiredness limiting his capacity for any activity. For another man, Mark, his sense of wellbeing was fragile, readily disturbed by minor changes in his dialysis regime causing significant symptoms. The other men, Owen and Keith, reported that they were generally well living on dialysis but acknowledged some symptoms of their CRF or its complications despite good treatment.

Other aspects of their general physical wellbeing, associated with or exacerbated by the CRF and its treatment, are also influential in their current experience of living on haemodialysis. John's joint pain and immobility not only limited his capacity to perform his own treatment, but also limited many other activities in his current life on dialysis. Although none of the men in this study were affected in this way, visual impairment, a common complication associated with CRF for people with diabetes, limits capacity for self-care in dialysis and other activities. Likewise angina is a not uncommon disabling symptom for people living on haemodialysis. Poor short-term memory can be influential

for the elderly. Their current experience of dialysis, one dimension of their personal social location, influences these men's accounts of their experience of renal illness and therapy through their interaction with aspects of the renal client discourse.

A third dimension of their personal social location is their own renal history, the whole set of experiences they have had of renal replacement therapy, that contribute to their understanding of life on dialysis. Chris, who initially had a very difficult experience on CAPD for reasons beyond his control, but was now very successfully managing since changing to haemodialysis which he believed was a better form of treatment, had a very positive view of his current life on dialysis. John, who had been on dialysis for less than two years with an uncomplicated history that has not radically disrupted his lifestyle, also had a positive view of his life on dialysis. However his difficult experience, during the period of discussions for this research, radically undermined his optimistic view.

Owen, whose transplant had allowed him a normal life for many years but finally resulted in complications due to long-term immunosuppression, contrasted that with the constraints of his current life on haemodialysis. From his extensive renal history he was aware of the limitations of all forms of renal replacement therapy. Mark, having found living on haemodialysis for a number of years very restrictive while waiting all that time for a transplant he had expected that had not eventuated, took a guarded view of his life on dialysis. Paul's renal history of several alternating periods of dialysis with a transplant enabled him, despite his current problematic experience, to look forward to yet another positive change in a further transplant. By contrast Keith's renal history of increasing health problems despite successfully dialyzing himself, interrupted by a complicated unsuccessful transplant, had made it difficult for him to remain hopeful about the future. The pattern of their past experience of renal replacement therapy, one dimension of their personal social location, influences these men's accounts of their experience of renal illness and therapy through their interaction with aspects of the renal client discourse.

Their personal style of response, a fourth dimension of their personal social location, refers to their particular attitude in approaching the situation of having to live on dialysis. Keith, a pragmatic active person, viewed his CRF and dialysis as a set of

practical issues to be managed and solved by medical expertise. John, laconic and stoic in his general approach to life, accepted life on dialysis as yet another problem in his life that he had to address himself and work through.

Several men, Chris and Paul, took a positive view of their prospects, confident that they would in the not too distant future receive a transplant. For Chris this optimistic view accorded with a generally positive view of his life, whereas, for Paul, his hope was a way of coping with the misery of his current life on dialysis that he could not alter. Several naturally reflective and sensitive men, Owen and Mark, aware both of the limitations of their lives on dialysis and also the uncertainty of receiving a transplant, focused on attempting to appreciate the possibilities available while living on dialysis. They attempted to deal with their CRF philosophically as they did the rest of their lives.

The attitude of their family toward their illness and therapy is also an influential element in this dimension of their personal social location for some of the men. The acceptance and active support of several of the men's wives positively influenced their life on dialysis. In particular Keith's capacity to continue to cope on home haemodialysis was dependent upon his wife's support with the treatment process. For Chris his family's anxiety about his life on dialysis, contrasting with his own confidence in his ability to cope, added a stress to his life on dialysis, increasing his desire for a transplant. Paul's problems with his partner's attitudes to his treatment had ultimately led to him living alone while on dialysis. Their personal style of response to their situation of having to live on dialysis, and also their families' attitude, one dimension of their personal social location, influences the men's accounts of their experience of renal illness and therapy through their interaction with aspects of the renal client discourse.

The four different dimensions are interrelated, together constituting their personal social location. Their current experiences of life on dialysis are shaped in part by their renal history. The events of their renal history have different meanings depending on their style of response, as do their current experiences. Likewise their social status and current experiences affect one another. Together these different dimensions of their personal social location shape their individual experience of renal illness and therapy, through their interaction with the different aspects of the renal client discourse,

reflecting their common position as people living on dialysis. The individual contours of each man's account of living on dialysis in this study reflects the significance for him of different aspects of the renal client discourse in terms of his personal social location.

9.2 The influence of gender and ethnicity

How do gender and ethnicity influence the experience of living on dialysis? A few papers in the renal literature suggest that women and people from ethnic minorities on dialysis may respond somewhat differently to the experience of dialysis (Owen, 1995; Reiss et al., 1986; Somer and Tucker, 1992; Tell et al., 1995; Wolcott et al. 1988; Williamson, 1992). The social structuring of gender roles in society may also mean that the family of a man on dialysis, especially his partner, respond differently than the family of a woman on dialysis (see Brunier and McKeever, 1993; Soskolne and De Nour, 1989). In terms of the framework of this study gender and ethnicity, for example being a Pakeha man, are elements in the dimension of social status in their personal social location, influencing their experience of living on dialysis through its interaction with the various aspects of the client discourse.

The limited literature available about the characteristics of the experience of being a Pakeha man (belonging to the dominant 'white' culture descended from the European colonists) suggests they may include a cluster of distinctive qualities. Phillip's (1987) study of the history of Pakeha masculinity around the stereotype of the 'bloke', expressing a social discourse prevalent in the New Zealand context, presented a traditional image of the Pakeha male. Characteristically self-sufficient, uncommunicative, unexpressive, hardworking, providing for his family but also sharing a distinctive ethos of 'mateship' (centred on the pub and rugby), the author considered this image was now being broken down. A feminist analysis has interpreted male culture in New Zealand as attempting to reconcile archetypal 'man alone' (epitomized by the book of the same name by Mulgan, 1939) with 'family man', recognizing a similar matrix of qualities as Phillips (1987) but involving some innate tensions (James and Saville-Smith, 1989). More recent writing suggests that the hegemony of this image obscures a diversity of male experience, of "masculinities" in New Zealand (Laws, R.,

Campbell, H. and Schick, R., 1999). The complexity of the well-known personal reflection, *Being Pakeha now* by the historian Michael King (1999) about his own experience as a Pakeha man, supports this view.

This New Zealand writing appears to represent a variant on some general themes in writing on male identity, as characterized by autonomous rationality in contrast to affective interrelatedness (Seidler, 1989). In his recent research Watson (2000), viewing gendered identity as "a way in which social practice is ordered" (quoting Connell, 1995, p. 71), found male "embodiment," men's experience of the body in everyday life, to focus around gender roles of husband, father and worker. For the men in his study 'health' was not conceptualized independently but was rather a bodily state that enables a man to fulfill these roles whereas illness limits his capacity to fulfill them.

Reflecting the centrality of work to the identity of the New Zealand male in the literature, the interpretation of their experience of living on dialysis by the men in this study was structured according to their employment status, as either working, unemployed or retired from work. For those who were working, Mark and John, maintaining their employment was the key goal that oriented their lives on dialysis. Although negotiating dialysis into the pattern of their lives while working fulltime limited any other leisure activities, this did not matter greatly to them because maintaining their work was so important to them. John revealed the centrality of work in his life by describing his dialysis therapy and the dialysis machine in terms of work several times. *"It's there to do a job just like I am. I'm the boss, the [dialysis] machine has its job to do. It's like a working relationship. Driving a truck, the truck does its job for you, if it breaks down you get pissed off with it. It's another work tool, there for my health rather than my pocket. It doesn't chirp into life until I turn it on."* Likewise commenting on his worry about unexpected machine failure Mark said *"to work I need this [the dialysis machine] to work."*

For those unable to work because of their dialysis, this shaped their lives, one, Chris, adopting the househusband role, another Paul the solo parent role. Keith and Owen, retired, both noted that they doubted that they could have continued to work given the demands of their dialysis regime. In fact Keith had retired early because of the effects of

his dialysis regime. While these two did not face the difficulty of integrating dialysis into their working lives, the need to accommodate dialysis into their lives was still perceived as restrictive, because it destroyed their sense of freedom from schedules around working that they had expected to characterize their retirement. For these Pakeha men the aspect of negotiation and limitation in their lifestyle involved in being in the position of living on haemodialysis centred around how the dialysis regime affected the pattern of their lifestyle, defined as working, unable to work because of dialysis or having retired from work.

Their financial security, an outcome of their work history and a key signifier of autonomy, particularly in terms of their capacity to provide for their family, was specifically mentioned by most of the men at some point, suggesting its importance to their sense of wellbeing. With one exception, despite living on dialysis they were financially secure. For John being able to provide for his family through his work was of central importance in his life. Mark had set buying a home as an achievable goal, while living on dialysis, that he had reached. While Keith had been forced to retire early, because of dialysis, this had no financial impact on his family because of his superannuation.

For the one unemployed man, Paul, lack of financial security and reliance on the welfare authorities was an ongoing problem. Although he was concerned at his inability to provide properly for his son, he considered he could manage on his limited benefit if it was not periodically arbitrarily altered by the authorities. Having to deal with the welfare officials, as a person dependant on them treated as a "*dole bludger*," was humiliating. He noted "*I can make my life better when I get work after I get a transplant.*"

Chris was also unable to work because of his dialysis, despite his best efforts, but, in contrast to Paul, was still financially secure because of his wife was working. He had adjusted to this situation, through adopting the househusband role, in order to maintain some sense of making a worthwhile contribution to the household. His comment "*I don't feel as though I'm useless*" suggests the significance to him of not being able to work. His wife, though she enjoyed her good job, felt constrained by having to work

because he could not. Chris saw the chance to be employed again as one of the benefits of a transplant. These Pakeha men dealt with several aspects of the renal client discourse, both that of negotiation and limitations in their lifestyle, and also the altered relationship of autonomy and dependence involved in the position of living on dialysis, in terms of their financial security and ability to provide for their family, an outcome of their work status.

Reflecting the New Zealand male stereotype of the 'family man', these men talked of their family relationships, in relation to their life on dialysis, in terms of continuing to provide support to their families. Chris was keen to get a kidney transplant in order to relieve his families' concern about his wellbeing on dialysis, although he did not personally share it. Paul was confident that receiving a transplant would enable him to care better for his son. John was relatively satisfied with his life on dialysis because he could manage it without interfering with his role of supporting his family. The older men were aware of the impact of their dialysis on their wives and, though personally unconcerned when thinking of their own possible deaths, were concerned to ensure that their wives would manage without them.

However, while they were oriented to continuing to look after their families, generally household activities had actually been adapted to accommodate these men's dialysis treatment, almost either as an adjunct or an alternative to their work, around which the household pattern had normally been oriented. Typically men and women's roles had become more defined following the onset of dialysis, Chris who became the househusband being the one exception. However in contrast to the normal character of men's work, that typically allowed women their own free time when he was at work, the women tended to be in the house while the men were dialyzing, resulting in their own independent activities being somewhat curtailed. Their household role had effectively been extended to include a supportive role in their partner's dialysis. While appreciative of the help of their wives these men had difficulty explicitly recognizing the rearrangement of their households to support them, because of their view of themselves as providing support their families.

Relationships beyond the family, important for half of the men in the study, had been difficult to sustain. The central ritual of 'mateship', drinking beer down at the pub with the boys, is difficult to participate in without problems when living on a limited daily fluid intake on haemodialysis. As Paul said *"I chose to stay away from them. They're embarrassed because I can't fit in."* Living on dialysis had tended to undermine these relationships that were part of their identity as men. In general these Pakeha men dealt with three aspects of the renal client discourse, negotiation and limitation, ongoingness and uncertainty and the altered interrelationship of autonomy and dependence involved in their lives on dialysis, through seeking to maintain the character of their family relationships despite changes to their other relationships.

Reflecting the self-sufficiency identified as characteristic of the New Zealand male in the literature, for the men in this study their conception of themselves as controlling their therapy was an important expression of their independence. All saw themselves as managing well on treatment even though their objective physical conditions varied significantly. Despite various difficulties in the past all were confident in their own competence to manage their treatment at home, it was *"second nature"* to them now. They were all comfortable with the technology suggesting that they had, as John put it, *"an aptitude for that sort of thing."* Mastery of the machine was an expression of practical self-sufficiency.

For John, most recently on dialysis, managing his own treatment was explicitly a new focal point for manifesting the strong independence that was characteristic throughout his life. He coped with life on dialysis by being in control of the machine. Chris emphasized his independence on the machine by several times noting that he was more confident of his ability to manage the machine than his family were about him managing it. Despite some anxieties about the tendency of his machine to malfunction, Mark was clear that he did not want a helper but preferred to dialyze alone. For both Keith and Owen their specific worry about the uncertainty of potential future complications, despite assiduously complying with the treatment prescription, was, they stated, because they wondered if they would be able to continue to independently manage their own dialysis at home. The local version of the dominant discourse, promoting self-care

dialysis, was congruent with the self-sufficiency characteristic of their Pakeha male identity.

Even those who had significant help from their partners in the dialysis process, Keith and Owen, did not view themselves as dependent on their wives. While the women generally helped with the treatment this was described in terms of "*partnership*", language that disguised any increased dependence in the relationship associated with the performance of the dialysis procedure. These men tended to stress their control of the process even if their wives helped significantly. However a number of the men recognized that working together on their dialysis and the help they had received from their wives had enhanced their lives together.

The men's alterations to the dialysis procedure, especially when a conscious rejection of professional advice, were expressions of their autonomy against the dependence implicit in life on dialysis. Keith stated bluntly "*whether it's right, wrong or otherwise it's my technique*". Paul spoke of "*a happy medium between what I feel is good and what the docs say. Nurses can't tell you what it's like dialyzing, you need to alter it to suit yourself. I know I should do what he says but I'll go with what I know and how I feel.*" John was also direct. "*I do it how I want within the guidelines of the system. No one knows how a person feels except the person themselves. I know how I feel myself, I'll dictate what I can do. Certain things you keep to yourself. I don't want to offend people. They do their best for you. Now it's passed over to me I'm doing the best for me.*"

The underlying dependence on the dialysis process itself, when acknowledged, most poetically by Mark as being "*entwined*" with the machine, and most graphically by Owen as being "*tethered*" to the machine, was always viewed as problematic, as limiting their capacity to live their lives independently. The universal reference to their limitations on travelling, especially for holidays, a contemporary signifier of autonomous self-expression, was an obvious reflection of discomfort with dependence implicit in life on dialysis. Several men, Keith and Owen, did suggest the dialysis machine itself as "*isolating*", perhaps even the burden of their autonomy in treating themselves at home. In general as Pakeha men they coped with the altered interrelationship of autonomy and dependence in their lives on dialysis by asserting their

autonomy through controlling the process, while having difficulty acknowledging the dependence involved in living on dialysis.

9.3 The different experience of women and Maori living on dialysis

Given the suggestions in the literature set out above (for example Reiss et al., 1986; Tell et al.; 1995, Wolcott et al.; 1988, Williamson, 1992) women and Maori (indigenous people who constitute the major alternative ethnic group on dialysis in New Zealand) may respond somewhat differently than Pakeha men to living on dialysis. In terms of this study, a different gender or ethnicity, as elements of the dimension of social status in their personal location, will, through their interaction with the different aspects of the client discourse, contribute to a distinctive quality in their experience of CRF and renal replacement therapy. Being a woman and/or Maori may be influential in various ways in their lives on dialysis in comparison with Pakeha men.

Perhaps, in contrast to these men, for women their sense of identity might not be so narrowly focused in autonomy expressed through their work status, providing for their families or control of their dialysis therapy. Women, somewhat differently socialized, may tend rather towards a diversity of activities in their lives, not only work but also household and community roles, viewing themselves more as interrelated with others, autonomy and dependence as being complementary aspects of their experience (see Gilligan, 1982). As a result their relationships beyond the family may not suffer as dramatically as for many men on dialysis. However other issues, irrelevant for these men, in particular distortion of their body image through surgery necessary for dialysis access, as a threat to the expression of their sense of femininity, may be significant for women (Appel and Campbell, 2000).

Haemodialysis may more readily fit around the traditional male role than the female role. The man may view haemodialysis treatment, whether self-care or in-centre, as an additional form of work. Women may support their husbands by becoming dialysis helpers for them as part their domestic activities in the female role, as Brunier and McKeever (1993) suggest. By contrast self-care dialysis for a woman at home may be

viewed as disruptive of her normal domestic activities (see Anderson and Elfert, 1989; Soskolne and De Nour, 1989), and undermining of their relationship as it also requires support from her partner that is alien to his normal role. In general two aspects of the renal client discourse, negotiation and the limitations of dialysis therapy and the interrelation of autonomy and dependence, through their interaction with the element of gender in the dimension of social status in their personal social location, may give rise to somewhat different experiences of living on dialysis.

In contrast to the Pakeha focus on the nuclear family that is relatively self-contained, as manifested by these men, Maori may focus on the extended family group, the *whanau*, involving an extensive range of relationships (Rangihau, 1975). This can have a number of implications for people living on dialysis. In general for Pakeha independence through self-care in all aspects of one's life, including health therapies, is highly valued according to the dominant individualistic ethic. For Maori, more collectivist in orientation, valuing rather more their interrelatedness with one another, family help may be normative in healthcare. When older Maori are living on dialysis younger relatives are often involved in various ways in assisting the person on treatment. This is the expectation in their community, both on the part of older and younger people. Reiss et al. (1986) speculated that the better outcomes of a group of people living on dialysis consisting primarily of poor black people, compared to those of a group consisting mainly of middle class white people, could reflect their better social support systems, based on a more collectivist community, in contrast to the dominant nuclear family orientation. The experience of Maori and Pakeha living on dialysis may be somewhat different because of the different character of their family support.

These Pakeha men all referred to the inability to travel as problematic, but always did so in terms of the optional leisure activity of taking holidays away from home. For Maori this limitation on travel may rather be critical in preventing them from fulfilling important family obligations by restricting access to important *hui* (meetings), especially *tangi* (funerals), with their *whanau*, often held in distant rural areas that are the *turangawaewae* (homebase) of the tribe. From their point of view, this may require sudden irregular variations in their therapeutic regime to enable them to carry out their essential social roles at gatherings of their *whanau*. Their social obligations arising from

their family interrelationships may cause complexities in their experience of life on dialysis.

For Maori their relationships with health professionals may have a distinctive character compared to those of Pakeha because of their different cultural assumptions (including a somewhat different view of health), the cross cultural nature of these relationships with health professionals who are generally Pakeha, and also the monocultural institutional contexts in which these professional interactions take place. Maori may find it more difficult to express their views on matters which are important to them, may feel intimidated and misunderstood, reacting by initially assiduously following the treatment prescription only to then reject it completely (see Polaschek, 1998). For Maori the character of their relationships with health professionals may influence their experience of life on dialysis.

As with gender above, in general the aspects of the renal client discourse, negotiation and the resulting limitations, the altered interrelationship of autonomy and dependence, and also perhaps the ongoingness and uncertainty involved, and maybe even the residual symptoms of CRF and dialysis, may, through their interaction with the element of ethnicity in the dimension of social status in their personal location, give rise to somewhat different experiences of life on dialysis.

These speculative thoughts about the possible influence of being a woman and/or Maori on the experience of CRF and renal replacement therapy throw into relief the distinctive features of the experience of the participants in this study as Pakeha men, work-oriented, focussed on their own nuclear family and individualistically autonomous. They suggest the distinctive influence of gender and ethnicity, as elements of one dimension of their personal social location, on the experience of living on dialysis via their interaction with aspects of the renal client discourse.

9.4 Understanding the men's accounts in terms of the renal client discourse

Having now outlined the influential dimensions of their personal social location, briefly reinterpreting each of the accounts of the six men in this study, in terms of the interaction of these with the aspects of the renal client discourse, illustrates how, by highlighting its distinctive contours, the renal client discourse enables an understanding of the experience of living on dialysis.

For Mark, maintaining his employment, the key element in his social status, by negotiating his dialysis regime into his lifestyle, results in a very tight weekly schedule with significant limitations in his social life and relationships. Because he is personally sensitive to the symptoms of CRF and dialysis in his current experience of life on dialysis, he finds that any deviation from his defined routine causes him to suffer from symptoms that negatively affect him, most importantly in impairing his work performance.

As an analytical person his own history, of having waited for a number of years for a transplant that he expected but he had not yet received, has led him to reflect on the ongoingness and uncertainty of his future life on dialysis. Aware of the altered relationship between autonomy and dependence in his life, not only having to use the dialysis machine to stay well but also the possibility of disruption to his life by factors beyond his control despite careful dialysis, he copes through his personal attitude of stoic determination. Mark finds life on dialysis demanding and his wellbeing fragile, but he is able to maintain control of what is most important in his life, his work. Although concerned about his life on dialysis, he seeks to live in the present while hoping for a better future.

Chris feels very well in his current experience of life on dialysis, not suffering from any significant symptoms. His personal history of having moved from CAPD, when he did not feel well, to haemodialysis that he believes is more effective, underlines his current sense of wellbeing. He has been able to successfully negotiate dialysis into his life, given his stable social status as married with a working wife, and also an adult daughter who provides him with support as necessary. He accepts the limitations of being unable

to maintain employment as he would prefer and not being able to travel as he used to, having adapted to his situation through taking on the role of househusband.

Chris manages the ongoingness and uncertainty of life on dialysis, specifically manifested for him by his periodic vascular access problems, through his characteristic optimistic attitude to life. However he has been unable to allay his families' concern about his future on dialysis. Although aware of the altered interrelationship of autonomy and dependence in his life, for example through his changed role in the family, Chris is not troubled by this. He remains positive, able to suppress any concerns, because of his successful adaptation to life on dialysis and his confidence that he will receive a transplant.

In his current experience of living on dialysis Keith is crippled by a range of symptoms. However, despite this, he feels he is managing reasonably well because his social status as comfortably retired with a supportive family means he has been able to negotiate the requirements of dialysis into his lifestyle without any limitations interfering too greatly with his wide range of leisure activities.

Keith has coped with his life on dialysis through his pragmatic attitude, expecting that his problems will be solved through medical expertise and technology. His history of gradually increasing physical problems while living on dialysis, punctuated by an unsuccessful transplant (where medical expertise failed him), have increased his sense of the ongoingness and uncertainty of life on dialysis. Recognizing his increasing dependence on his wife to manage dialysis as his physical deterioration continues, and the failure of the health system to offer him another transplant, he is beginning to lose confidence in a medical solution to his problems.

In his current experience of dialysis Paul has significant symptoms of lack of energy and tiredness that affect the rest of his life. Negotiating dialysis into his weekly lifestyle in order to stay reasonably well, when combined with the influence of his residual symptoms, has destroyed the key elements of his social status, causing him to lose his employment, social life and personal relationships.

Paul understands the ongoingness and uncertainty of life on dialysis from his own complex renal history, but his memory of his past transplant gives him hope for the future. Acutely aware of the altered interrelationship between autonomy and dependence in his life, only able to passively endure his current experience of living on the machine, especially his status as a welfare beneficiary, Paul copes through his attitude of optimistic fatalism. He is confident that he will receive a transplant shortly to enable him to escape his current difficult life on dialysis.

John feels very well with almost no symptoms in his current experience since commencing dialysis, which contrasts with his memory, in his brief renal history, of his life before he began dialysis, when he had symptoms that interfered significantly with his lifestyle. Although the negotiation required to integrate his dialysis regime into his lifestyle creates a tight weekly schedule he does not find this very limiting because he is able to maintain the key elements of his social status as self-employed and supporting his family.

John, with a strongly independent attitude, copes with the altered interrelationship of autonomy and dependence inherent in living on dialysis by maintaining control of the process. He became aware of the ongoingness and uncertainty of life on dialysis from his unexpectedly difficult surgical experience during the interviews. He now stoically accepts life on dialysis, in the expectation of a transplant, as long as he can continue a life he considers worth living.

Although he suffers from a range of symptoms in his current experience of living on dialysis that periodically affect him, Owen considers he is managing reasonably well. His social status, as comfortably retired with a supportive wife, facilitates the negotiation of the requirements of the dialysis regime into his lifestyle, but Owen is very conscious of the limitations it causes in his weekly activities, in particular the inevitable unexpected variations that he finds frustrating.

From his long history of the range of renal replacement therapies and their complications Owen is fully aware of the ongoingness and uncertainty of living on dialysis. While accepting his current level of dependence in his life on dialysis he

recognizes the possibility of gradual deterioration that would increase his dependence, and also the decreasing likelihood of receiving a transplant to prevent this. He copes through an attitude of philosophical detachment about his own situation.

Reflecting on the men's accounts in these terms, as the product of the interaction of the dimensions of their personal location with the concerns of the renal client discourse, highlights their distinctive features, illustrating how the renal client discourse enables an understanding of the experience of renal illness and therapy.

9.5 Conclusion: understanding the client experience

In this chapter I have suggested that an individual's experience of renal illness and therapy can be critically interpreted as resulting from the interaction of their common position of living on haemodialysis, described in the aspects of the renal client discourse, with the dimensions of their own personal social location. I have outlined the various significant dimensions of the personal social location of the individual living on dialysis. I have considered the influence of gender and ethnicity, elements in the dimension of their current social status, through reflecting on the experience of the men in this study in terms of some relevant literature and by contrasting it with the experience of women and Maori.

By briefly reviewing the accounts of the six men in the study I have illustrated the capacity of the renal client discourse to clarify the meaning of the individual's experience of renal illness and therapy. The concerns of the renal client discourse, the characteristic features of life on dialysis obscured by the dominant discourse in the renal context, enable an understanding of the experience of living on dialysis.

In terms of the critical interpretive approach developed for this study the accounts of the third section presented each man's interpretation of his experience of renal illness and therapy. The renal client discourse of the fourth section, produced through a critical reflection on these accounts as a set, offers an understanding of their shared experience of living on home haemodialysis. In this chapter I have shown how the renal client

discourse enables an understanding of the individual experience of each man in his account. Integrating the client discourse, produced through critical reflection on their collective experience of the set of accounts, with the individual interpretation of their experience in their hermeneutic accounts, demonstrates the coherence and transferability of the outcomes of the study, supporting its trustworthiness.

Personally I found that through the interviews I discovered a great deal more about the men in the study than I had learned through my clinical practice. Reconsidering their accounts of their experience in the light of the concerns of the renal client discourse enabled me to make sense of their lives on dialysis in a way that I had not been able to before. As a renal nurse it was my sense of the difficulty of living on dialysis that it is not easy for health professionals to understand, reflected in the dissonance between the professional and client viewpoints, that initially motivated this study. Delineating the aspects of the renal client discourse in contrast to the dominant discourse in the renal context, through the analysis of the fourth section, has clarified for me the character of this dissonance between renal health professionals and people living on dialysis. The concerns of the renal client discourse provide a way of understanding the complexity of living on dialysis for people with CRF.

In ward meetings about people with CRF I can now understand in a different way health professionals' comments about their patients, especially in using the ubiquitous language of non-compliance to interpret the actions of people living on dialysis that are problematic from professional viewpoint oriented to therapeutic outcomes. The professional language makes perfect sense in terms of the dominant discourse but this behaviour can have a very different meaning in the light of the client discourse. Likewise comments from people living on dialysis about their situation, difficult to understand or apparently irrational from the professional point of view, are often now meaningful to me in terms of concerns of the renal client discourse. The renal client discourse, a product of the critical distance between the men and myself as nurse researcher, has enabled me to hermeneutically engage with renal clients more closely than before.

In the next chapter I will consider one important implication of this understanding of the experience of living on dialysis set out in the last two chapters. Interpreting the experience of renal illness and therapy in terms of contrasting client and dominant discourses in the renal context provides the basis for a reflection on the character of nursing work in the renal setting utilizing my own experience as a renal nurse. Given renal health professionals' difficulty discerning the distinctive experience of living on dialysis, an initial assumption of this study, this discussion will suggest the potential of the nursing role in the renal setting.

Chapter 10. Negotiated care: Nursing practice in the renal context.

This chapter discusses one important implication of the understanding of the experience of renal illness and therapy developed in this study, an interpretation of the meaning of nursing work in the renal setting. The initial assumptions of this study were that the distinctive experiences of people living on dialysis are not easy to discern because they are obscured by the professional viewpoint that is dominant in the renal setting. The dissonance between the professional viewpoint and the client perspective, reflected in tensions in interactions between nurses and people with CRF, raised a question about the role of nurses in the renal setting. While nursing work could be idealistically viewed as helping to bridge the gap between the professional viewpoint and the client perspective, in practice the nurse in the renal setting can often simply operate as a technician (see Thompson, 1987, p. 272) who implements and enforces the dominant professional viewpoint, undermining any distinctive nursing role in the renal setting.

From the critical view of the renal setting articulated in the second section of this thesis I have, in this fourth section, developed an understanding of the experience of one group of people, Pakeha men at home on haemodialysis, in contrast to the dominant professional viewpoint. This interpretation of the experience of renal illness and therapy provides the basis for a discussion, utilizing my own experience as a renal nurse, about the meaning of nursing work with renal clients. This chapter will suggest that, given their intensive ongoing involvement with people living on dialysis, nurses working with them have the opportunity to recognize and engage their personal experiences of living on dialysis. Interpreting nursing work in terms of the understanding of the experience of renal illness and therapy developed in this thesis indicates its potential in the renal setting.

In this chapter I will outline a view of nursing work in the renal context as negotiated care. I will indicate how the idea of negotiation is more appropriate to interpret the interactions between nurses and renal clients than the notion of compliance currently ubiquitous in the renal setting. I will clarify the meaning of 'care' within negotiated care by using some critical commentary on this word that is prevalent in current nursing literature. I will then specifically consider the meaning of negotiated care in relation to one aspect of the renal client discourse, the altered interrelationship between autonomy and dependence for the person living on dialysis. Through this reflection, based on my renal nursing experience, I will illustrate the potential for nursing work in the renal setting in terms of the model of negotiated care. In conclusion I will suggest this understanding of nursing work in the renal setting can contribute to the humanization of contemporary medical technologies such as renal replacement therapies.

10.1 Different understandings of the response to renal replacement therapy

The difference between the dominant viewpoint and client perspective in the renal setting is epitomized by the gap between the professional expectation and the actual practice of people living on dialysis. This is a source of the sense of dissonance between health professionals and people with CRF that was an initial motivation for this study. The response of the person with CRF is generally understood in terms of compliance with the therapeutic regime by health professionals, in accord with the ideology of the dominant discourse, that therapy is efficacious if the patient adheres to the professional treatment prescription (see above Bame et al., 1993; Levy, 1995; O'Brien, 1990; Reiss, 1990; Wright 1998). Viewing people living on dialysis in terms of patient 'roles' or 'careers' supports this understanding of their response to therapy (see above Artinian, 1983, 1990; Gerhardt, 1990; Hardiker et al., 1986; Morgan, 1988). In these terms compliance, necessary for a beneficial outcome, is rational. The prevalence of non-compliance by patients, mystifying to health professionals, has been the subject of a great deal of study, but almost all of it, as has been noted, according to the professional premise of its irrationality (Thorne, 1990, p. 66).

This study has shown that from the point of view of the person living on dialysis their experience of illness and therapy reflects the interaction of their own personal location with their position as a person living on dialysis outlined in the client discourse. Their response to therapy is influenced by the various aspects of the client discourse described in this thesis, including the symptoms of CRF and dialysis they experience, the negotiation and limitations involved in integrating therapy into their lifestyle, the ongoingness and uncertainty associated with having to live on dialysis and the altered balance between autonomy and dependence in their lives caused by living with CRF. This study had shown that behaviour that is simply labeled as irrational noncompliance from the dominant viewpoint in fact makes sense for them as a result of their response to the complex experience of illness and therapy.

The management of fluid balance, an integral element in a therapeutic regime involving haemodialysis that can only be controlled by the person with CRF, illustrates the difference between the professional viewpoint and client perspective. In the professional view it is presumed that the necessity for fluid intake control is not difficult to understand, as the person no longer passes a normal volume of urine and excess fluid is only removed during dialysis. The patient will comply with the daily limit to fluid intake is set by the doctor, a simple figure easily translated into a particular number of drinks because it is beneficial for their health. From this perspective significant variation from the professional prescription, measurable in terms of weight gains between treatments, is labeled non-compliance (Wright, 1998).

Despite this professional logic it is well known that adherence to their daily fluid allowance is problematic for many people on dialysis (Bame et al., 1993; O'Brien, 1990). In one study it was found that dialysis patients in general 'managed' their daily fluid restriction by simply ignoring it (Welch and Austin, 1999, p. 334), reflecting renal nurses' experience that many people on dialysis gain many litres between treatments. O'Neill and Glasgow (1991), noting in their study the shared acceptance of the importance of adhering to their daily fluid allowance by staff and clients, showed the different evaluation of the significance of barriers to fluid intake control, even the simplest such as thirst, between these two groups. The six men in

this study actually managed their fluid balance by accepting the daily fluid prescription as a recommendation that they varied according to their own experience of living on dialysis. Their experience, confirming the literature, suggests that, from the point of view of people living on dialysis, managing the limitation in fluid intake required is not as simple as the professional view assumes.

The reasons why people living on dialysis do not meet the demands of the therapeutic regime are complex. Despite the professional assumption they may not fully understand the different aspects of fluid intake control involved in renal replacement therapy. Their response to the demands of the therapeutic regime may be influenced by their perspective, from their position in the renal context as people living on dialysis, described in this study as aspects of the client discourse. They may find, as did some of the men in this study, that in fact they suffer from symptoms at their target weight after treatment, leading them to modify the professional prescription, altering their pattern of fluid intake or their target weight, in order to manage these symptoms. They may find that the negotiation required to integrate the requirements of the therapeutic regime, such as a daily fluid intake limit, into the normal pattern of their lives, results in significant limitations for their lifestyles. Drinking, epitomized by the beer at the pub, the coffee at the cafe or the cup of tea at home, is an integral aspect of social ritual that had to be abandoned or significantly modified by these men. Others may not be willing or able to make this adjustment.

They may find that the routinization of their lives, epitomized by daily fluid intake control, reflecting the ongoingness and uncertainty of life on dialysis, may itself undermine the self-control required to manage their daily fluid intake. For example having to maintain such careful discipline indefinitely, always to some extent distorting the normality of their way of life, becomes more difficult at points where other stressful uncertainties, undermining their normal routine, impinge. Periodic problems with fluid intake control in people who normally manage well are often associated with some sort of personal crisis such as loss of employment or a relationship breakdown. Finally the requirement for fluid intake limitation, as a key feature of the therapeutic regime that has a global influence on the normal pattern of their lives, limiting their capacity to drink when they want to, may become a focal

point for the expression of their autonomy in certain circumstances, reacting against the dependence required by life on dialysis. This may be one reason why some people often drink a surprising volume, beyond the typical amount for people without CRF, between treatments.

In general the adherence of people living on dialysis to specific therapeutic requirements, such as fluid intake control, may be undermined by their experience that, despite assiduous compliance, the general outcome of treatment for them is not as beneficial as was predicted, in terms of the dominant discourse, by renal health professionals (see Thorne, 1990). They may simply find, despite their best intentions, that the demands of the therapeutic regime are too difficult to manage in terms of their own lifestyle, or they may personally decide that the costs of meeting these demands are too high in terms of the necessary alteration to their lifestyle. In either case their behavior, labeled as noncompliance by health professionals, is viewed, this study suggests, very differently from the perspective of people living on dialysis. Their response to the demands of treatment is part of their complex experience of renal illness and therapy.

10.2 The renal nursing role as negotiated care

In the light of these contrasting professional and client perspectives on the response to renal replacement therapy, what is the role of the nurse in the renal setting? As her role is constituted by it, the nurse in her clinical work inevitably participates in the dominant discourse. However, while nursing practice is related to, indeed an integral aspect of "the structure of the work environment" (Wellard, 1992, p. 956) in the renal setting, it does not simply and inevitably follow that "nurses endorse the dominant construction of chronic illness" (Wellard, 1998, p. 54). Although the nurse in her activities supports the requirement of the therapeutic regime, in accord with the dominant discourse, she also has the potential, through her intensive ongoing interaction with the person living on dialysis, to recognize and respond to their experience of living on dialysis.

Health professionals in other disciplines in the renal context, whether medicine, physiotherapy or medical social work, have very limited opportunities to do this. Reflecting the character of contemporary healthcare contexts, they are specialists who are intermittently involved with the person with a health need, addressing particular aspects of the disease process or its effects through specific assessment and therapy. Medical consultations, brief interrogations of the patient oriented to diagnosis that conclude with an authoritative pronouncement, epitomize this pattern, tending to contradict any open responsiveness and dialogue (Mechanic, 1995, p. 1207; Mishler, 1984, p. 10; Morris, 1999, p. 251). As Barnard (1988) notes “for most of medicine’s modern history physicians have distrusted patient’s views of their own experience” (quoted in Thorne, 1993, p. 104) because of their orientation toward objective evidence as necessary for scientific diagnosis, negating the value of their subjective opinion. In the context of this form of interaction the patient is like a prisoner, “one who is seen but does not see, he is an object of information, never a subject of communication” (Foucault, 1977, p. 200). Other specialized health professionals have a similar pattern of intermittent interactions oriented by a defined purpose, the diagnosis and treatment of particular elements of a health problem. In a specialized healthcare context the nature of these interactions, reflecting the hegemony of the dominant discourse, actually contributes to the difficulty in the ‘voice’ of the person living with CRF being ‘heard’ by health professionals.

By contrast nursing work involves intensive and ongoing interactions with people receiving therapy that are not oriented to one specific therapeutic outcome, but rather involve a range of activities that include support in their ordinary daily activities. On the basis of various therapeutic activities, meeting some objective health needs in accord with the dominant discourse such as dialyzing patients or teaching them about dialysis, the nurse, through her ongoing interpersonal relationship with the client, has the potential to engage their subjective experience of illness and therapy.

The various clinical management activities become distinctive as nursing (beyond the specific technical functions also performed by renal technicians or aides) when they contribute to the development of a relationship enabling the nurse to respond to their experience as a person in this particular healthcare setting. The nurse has the capacity to do this on the basis of her nursing orientation of openness to the client’s

expression of their experience, her own experience of working with many other similar clients over time and her experiential knowledge of the concerns of people in this position in the renal setting, together creating a sensitivity to the situation of the individual she is working with. One nursing study has obliquely alluded to this in showing that the longer dialysis nurses had been employed, and thus the more experienced they were, the more attuned they were to the needs of families of dialysis patients (Wagner, 1996, p. 23).

From the perspective of the dominant discourse the nurse is purely a functionary implementing its requirements through the authoritative performance of specialized activities like dialysis. The institutional configuration of her operational role may discourage the nurse from envisaging any contribution in her work beyond this definition. Nurses' own unreflective use of the language of the dominant discourse, in particular of compliance, may also prevent them from understanding any further potential of their work in this chronic healthcare context. Allen (1985, p. 63) has pointed to the tendency for nursing to unthinkingly replicate the medical model in its self-definitions. "Our current definition of nursing as a science that diagnoses and treats parodies objectifying medical language." This has resulted in "scientistic" thinking ubiquitous in nursing (Thomson, 1983, p. 271). Nursing roles are readily co-opted to participate in power relations characteristically expressed in terms of professional authority in the healthcare context. "The idea of professionalism hides monopolistic, territorial imperatives under an ideology of service and quality care" (Allen, 1985, p. 63; see Thompson, 1983, p. 278). In a specialized context, involving complex and rigorous requirements of technological therapy, the nurse can become merely a technician enforcing compliance with the therapeutic prescription (Bevan, 1998; see Thompson, 1983, p. 271).

However the nurse working in this chronic care context can also understand herself as performing these activities as one aspect of her role of responding to the experience of the client. Although the current nursing role, like all other roles in the renal context, is shaped by the dominant discourse, it can be understood as, potentially at least, also engaging the client discourse. The relative obscurity of this

potentiality in the nursing role in the renal setting is a reflection of the hegemony of the dominant discourse.

The work of the nurse can be conceptualized as negotiated care, facilitating the client's attempts to integrate the requirements of the therapeutic regime, reflecting the dominant discourse, and their own situation, reflecting the interaction of their personal social location with their position as a person living on dialysis, outlined in the client discourse. Through her relationship with the client the nurse responds to their situation, on the basis of her nursing experience that has sensitized her to the different aspects of life on dialysis here delineated as the concerns of the client discourse. This enables her to engage their experience, informing her relationship with the client in supporting them in managing to continue to live as fully as possible on dialysis in their own situation.

Thus nursing work in the renal setting has an authoritative aspect, manifested in clinical activities in accord with the dominant discourse, but it also has a responsive aspect, manifested in response to the experience of the individual client that reflects the client discourse. Negotiated care, facilitating the client themselves to negotiate the requirements of the treatment regime into their own lifestyle, involves a dynamic between these two aspects of the nursing role, positively characterizing the potential in the relationship between the client and the nurse as both the expression of the dominant discourse and also a response to the client discourse.

While the nursing role in the renal setting can be viewed as a function of the dominant discourse the critical interpretive approach in this study illuminates another possibility present in renal nursing practice, through nurses seeking to respond to the client perspective. Although her functional role, determined by the dominant discourse, initially positions the nurse within the renal context at a distance from the person with CRF, the distinctive character of her work with clients, expressing the potential of the nursing role within a chronic healthcare setting, shifts her position near to that of clients in the renal context. The nursing role is situated between the professional and client poles in the renal context. Such positioning contributes to

ambiguity about the professional character of nursing work in terms of the discourse dominant within healthcare services.

However as Allen (1985, above) suggests the colonization of the understanding of the nursing role by such ideologies of professionalism obscures the distinctive contribution of nursing work in healthcare services (see also Thompson, 1983, p. 278). Nursing is paradoxically positioned in relation to the language of professionalism, at once participating in its affirmation, both of its positive and negative dimensions, but also, through practice in terms of its potential outlined here, critiquing the limitations inherent in the concept. One could say that the expert nurse in a contemporary chronic healthcare context, while obviously a class of health professional, is distinctive because of her characteristic responsive closeness to the client, in contrast to the objective distance from the patient typical of other health professionals.

Nursing work is an “in between” role (Bishop and Scudder, 1990, p. 171), not simply in liaison between doctor and patient but rather, precisely, in mediating between the dominant and client discourses for a person living in this chronic healthcare context. The distinctive character of the nursing role is the capacity to ‘hear’ the client ‘voice’ that is easily lost in the specialized health context of renal replacement therapy, in Foucauldian terms the ‘subjugated knowledge’ representing the perspective of the renal client counter to the dominant professional ‘gaze’ (Foucault, 1980, pp. 81-96; Lupton, 1997, p. 99). The nurse has the potential to address the dissonance arising from the difference between the professional viewpoint and the client perspective in the renal setting.

10.3 Beyond compliance to negotiation

The dominant discourse promotes dialysis as enabling a reasonably normal life, and also individuals taking responsibility for their own treatment as enabling autonomy

that enhances such

clients that neglects the professional prescription, in attempting to maintain features of their own way of life that are normal to them, is labelled non-compliance. The dominant renal discourse, by affirming the efficacy of therapy while negating the client perspective in accord with the acute curative paradigm of biomedicine, produces to this contradiction because it is incongruent with the chronicity of renal illness and therapy, the basis of the client perspective that gives rise to 'non-compliant' behaviour.

While compliance with the treatment prescription is necessary, the ubiquitous nature of this concept in the renal setting makes it difficult for the person who is receiving therapy to express their experience, especially where it does not accord with the dominant viewpoint. The affirmation of "normality" (see Gerhardt, 1996) as achievable through renal replacement therapy in the dominant discourse disguises the inherent abnormality characteristic of the experience of chronic illness (Thorne, 1993, p. 76). People who live on dialysis, finding they are unable to discuss difficulties in living on renal replacement therapy with health professionals in the context established by the dominant discourse, have to discreetly adjust the prescribed regime to fit with the pattern of their own lifestyle, trading off health professionals' recommendations against the loss of features of their way of life which make it worth their while to undertake the treatment in the first place.

The tension between the requirements of the dialysis regime and their desired lifestyle are personally negotiated by the person who is living on dialysis. In this study one aspect of the client discourse, the negotiation necessary to integrate the requirements of therapy into their lifestyle, included personally altering aspects of their therapeutic regime as one element in this process. These decisions, what might be called a "covert caring for the self" in Lindsay's (1997) phrase, are made in accord with their own understanding of health and general wellbeing, including attitudes about autonomy and dependence in illness, which may differ from those of health professionals who are working with them. The men in this study confirmed that professional attitudes, reflecting the dominant discourse, inhibited them from discussing any such changes to the therapeutic regime that would be discouraged and labeled as non-compliant. The tensions in interactions between nurses and their

clients, focused on 'non compliant' behavior, reflect the dislocation between professional and client perspectives summarized here as the contrasting dominant and client discourses.

Several studies have noted the importance of client attitudes toward therapy, in particular beliefs about its efficacy, as affecting outcomes on treatment, while others have shown that compliance with the professionally prescribed therapeutic prescription does not necessarily correlate with positive outcomes (Horne and Weinman, 1994; O'Brien, 1990; Reiss, 1990; Reiss et al., 1986; Ruggiero et al., 1992). Obviously, if their own views can be more influential in the outcome of therapy than strict compliance, people with CRF can reasonably question aspects of the treatment prescription. Further if people do not believe that careful compliance with aspects of the treatment prescription makes any difference to their well-being they do not have a strong incentive to be compliant. Given the debate about the actual correlation between compliance and outcomes for people living on dialysis, the insistence on assiduous compliance on the basis that therapy is efficacious is clearly an ideological construct of the dominant discourse.

From the point of view of the person living on dialysis, reflected in the client discourse, the chronicity of renal illness and therapy make it difficult to maintain a reasonably normal life. In particular the demanding nature of the obligatory regime contradicts their autonomy, contributing to the altered relationship between autonomy and dependence for the person living on dialysis that is one aspect of the client discourse. Although a considerable degree of compliance with the therapeutic prescription is necessary, given the limitations and uncertainties associated with renal replacement therapy, the lack of clear correlation of compliance with clinical outcomes, and also the difficulties associated with living on dialysis delineated in this study as the concerns of the client discourse, some degree of autonomous variation to enable a reasonably normal life for the person on dialysis is itself reasonable, and often, from listening to renal clients, necessary.

In a setting such as the renal context shaped by the dominant discourse it is easily forgotten that the client has the right to decline medical advice (Wright, 1998:36).

While the professional goal is a positive objective clinical outcome for the patient this may not have as high a priority for the person with CRF as other goals in their life. Dines (1994, p. 329) makes the point that nurses need to avoid "healthism with its assumption that health is the only goal in life which ought to be pursued. Nurses working in health promotion need to respect other goals, for example economic, intellectual or hedonistic that individuals have the right to pursue." The experienced renal nurse does not simply implement what is best for the patient from the professional viewpoint but also seeks to facilitate what the client considers is best from their own point of view.

Several papers, considering compliance, attempt to stretch the meaning of the concept in order to understand the behavior of people living on dialysis. As noted above Thorne (1990) explicates the concept of 'constructive non-compliance' through a typology of the relationship between people with chronic healthcare problems and health professionals. Likewise above O'Brien (1990) characterizes non-compliant behavior positively as 'reasoned' compliance. Both these papers, while reflecting the hegemony of the concept of compliance in chronic healthcare contexts, also implicitly recognize its inadequacy in understanding the relationship of health professionals and clients in chronic healthcare settings.

By contrast several writers have suggested the idea of negotiation or even partnership as an alternative to compliance in understanding the relationship between people with chronic illness and healthcare professionals. Kleinman (1988) in *The Illness Narratives*, from a medical viewpoint, characterizes the relationship between the health professional and client with a chronic illness as one of negotiation, saying "care for chronic illness is (or should be) more like a negotiation among therapeutic allies than action the physician takes on behalf of the patient" (Kleinman, 1988, p. 242, footnote 4). Thorne (1990) also speaks of achieving an alliance through negotiation, language echoed by Sloan (1999, p. 504). Other writers speak of achieving a shared understanding (Toombs, 1992, p. 89) or interdependence (Luckenbaugh, 1990, p. 140).

However references to negotiation or partnership as enabling autonomy, found in recent nursing publications (for example Challinor and Sedgewick, 1998, p. 45; Christensen, 1990; Webb, 1996), can involve a neglect of the limitations and dependence inherent in chronic illness (Bevan, 1998; Thorne and Paterson, 1998). Simply contrasting partnership with compliance (for example Coates and Boore, 1995, p. 636) ignores both the necessity for compliance with therapy, and also the difficulties in achieving partnership, given differences in power between health professionals and clients in specialized healthcare contexts. By contrast the concept of a "guarded alliance" between patients and healthcare providers, applied by Sloan (1999) to the renal setting, describes the complex relationship with healthcare professionals that the person living on dialysis manages by using one of several styles. Implicit in this characterization of the client perspective is the recognition of the asymmetry in the relationship.

Formulations of the idea of partnership or negotiation, while positive in recognizing need for open communication, can fail to recognize the difficulties inherent in such communication in a specialized healthcare context. Instead of idealizing this relationship by assuming a non-problematic equality between health professionals and clients, this study, from the sketch of the renal context as constituted by the dominant and client discourses in the second section, has shown the need to acknowledge the asymmetry in the relationship between healthcare professionals and their clients. The conceptualization of nursing work as negotiated care, recognizing the difference in knowledge and power between them, acknowledges that open communication can in practice be inhibited by the character of contemporary specialized healthcare contexts.

Meaningful negotiation can most readily be achieved on the basis of some understanding of the contrasting perspectives of healthcare professionals and clients, enabling recognition of the distinctive concerns of people living on dialysis. It is the nurse, on the basis of her extensive interaction with them, in contrast to the sporadic interactions of other health professionals with the patient, who has the potential to develop a relationship with the person living on dialysis that enables her move beyond simply enforcing compliance to engaging in a negotiation with them that

supports them in their own negotiation of the requirements of renal replacement therapy into the pattern of their own lifestyle.

In particular the conceptualization of nursing work as negotiated care developed in this chapter does not downplay the necessity for compliance. Rather it recognizes the nursing role as attempting to help the person living on dialysis balance the clinical requirements of therapy from the professional viewpoint with considerations from the client perspective reflected in the client discourse. Nursing work as negotiated care does not gloss over tensions inherent in interactions between nurses and the clients. Rather it recognizes nursing interrelationships with clients as attempting to work through these tensions that are inevitable, given the character of the specialized renal setting as constituted by the dominant professional discourse. The nursing role has the potential, through its expression of the dynamic of its contrasting authoritative and responsive aspects in an ongoing relationship with the client, to mediate the tension between the client and professional perspectives, outlined in this study as the dominant and client discourses in the renal context.

Understanding nursing work as negotiated care enables a clarification of the character of the form of nursing research in this thesis. A study such as this involves an interaction with people living on dialysis in which the two aspects of the nursing role are utilized differently than in nursing work. While a typical clinical nursing interaction with a client has both a responsive and an authoritative aspect simultaneously, an interaction in interviews in this form of nursing research involves an interrelationship that seeks to be responsive to the experience of participants through bracketing the authoritative dimension of the nursing role. A skilled effort is needed to achieve this given the difference in knowledge and power between the health professional and client in a specialized healthcare context such as the renal setting. Analysis in this form of research involves a reflection about these interactions in interviews with participants, by employing the information available from the authoritative aspect of her role.

The different utilization of these two aspects in the clinical nursing role and the nursing researcher role creates the complexity I described in my experience of

interacting with the men in this study. However it also creates the possibilities for this sort of study that requires the insights of both the personal client perspective, derived from the responsive aspect of the nursing role, and the objective professional viewpoint, derived from the authoritative aspect of the nursing role.

10.4 Practising negotiated care

Nursing practice as negotiated care involves open discussion seeking to discover the client's experience of illness and therapy, and also information sharing with them about their condition and therapy, to assist them in making informed choices in terms of their own situation. Such an approach explicitly accepts their role in making such choices in relation to their therapy. It also allows the nurse to indicate to clients the limits of clinical support available given certain choices. In the context of such negotiation people living on dialysis are able to openly discuss and review their choices on the basis of their experience if they so choose. Recognizing that behavior labeled as 'non-compliant' represents clients' discreet attempts to integrate the requirements of therapy into their own lifestyle, in a context where the dominant discourse simply requires compliance, such an approach, seeks to make this an explicit negotiation in order to make it more informed.

Considering the example of fluid intake management, the experienced nurse has an awareness of the complexity of the issue of fluid intake control for people living on dialysis, that has been articulated in this study in terms of the client discourse. She knows that symptoms related to dialysis may influence their fluid intake control. She understands that the person living on dialysis may find the requirement to control their fluid intake interferes with their way of life, especially their pattern of social activities, making them feel excluded, even alienated, from the important social rituals where drinking is central to participation. She is aware that the impact of the chronicity of renal failure and the routinization of their lives required by the therapeutic regime may be reflected in problems with fluid intake control, especially if they face some other personal stresses in their lives. She recognizes one reaction of

the person living on dialysis to their sense restrictiveness and limited control in their life may be manifested in drinking beyond the professional prescription.

The nurse, in an empathetic and responsive manner, seeks to discover from the client their normal pattern of drinking and how this fits into their social life, the cup of tea with the neighbour next door in the afternoon or the glass of beer at the bowling club with friends on Friday night. She also discerns any other relevant information, for example how they feel when they reach their target weight, finds out how their pattern of fluid intake relates to their salt intake in their diet. In the light of the pattern and meaning of drinking in their normal lifestyle, the specific stresses associated with fluid balance management for them and the more general influences from their life situation, the nurse can offer suggestions about ways in which fluid intake may be managed that recognize their sensory needs and the significance of important social rituals where drinking is integral to their participation. This may involve some suggestions about their diet or their target weight. Through such an open dialogue she can encourage compliance in the interests of the person's health while recognizing the tension with their personal capacities and social needs, supporting the person to negotiate, in the best way possible for them, the necessary fluid restriction into their daily pattern of living.

The experienced nurse does not blame the person for their fluid overload, recognizing that fluid management is their responsibility and also acknowledging that careful fluid control is very demanding, that some people may generally be unable to regularly maintain a very limited fluid intake. She does not simply insist on fulfillment of the requirements of the therapeutic regime. Rather she seeks to understand the client's point of view in order to discuss possibilities for their own management of the therapeutic requirements in terms of their own lifestyle. She recognizes their right to determine their pattern of cooperation with the treatment regime. If, for example, an elderly person indicates that limitation of their daily fluid intake requires a radical alteration to their life pattern that is so difficult from their point of view that they are not willing to make it, even if it makes their treatments difficult or shortens their life, then the nurse accepts this outcome of their

negotiation. She may also indicate the limits of clinical support available in response to the decisions of the client in relation to fluid intake control.

Negotiated care in fluid management involves an open dialogue enabling the person living on dialysis to determine how to manage this requirement of the therapeutic regime in terms of their own capacities and their lifestyle as they see fit. In general the experienced nurse who practices in terms of negotiated care, having explained the necessity for fluid intake control, supports their success in self-management while accepting the inevitable limitations in achieving control of fluid intake as a consequence of the client's choices.

10.5 Caring

Given nursing work as a negotiation as described above, what does 'caring' within negotiated care mean? 'Caring', an empathetic orientation of the nurse towards her client, while often understood today as characteristic of nursing practice (Benner and Wrubel, 1989; Bishop and Scudder, 1990; Gadow, 1985), is a concept that has also recently been critiqued. Armstrong (1983) suggests that 'nursing care', formerly primarily physical 'cares', was reconstructed as 'caring', inventing a relationship between the nurse and her client, reflecting a reconceptualization of the person with a health need as simply the 'patient,' in response to a psychological current that had become prevalent in contemporary society. Mulholland (1995) considers that the humanist discourse prevalent in nursing, epitomized by discussion of the centrality of 'caring', rests on an unexamined "assumed underlying consensus model" of understanding (Mulholland, 1995, p. 445). The view of the person with a health need is presumed to be congruent with that of the nurse who is attuned to their needs through her skilled care. In a more radical perspective Walker questions the discourse of 'caring' prevalent in nursing, a product of liberal humanism, as in fact a "technology of gender" that subjugates nurses and women to the "dominant social order in health care" (Walker, 1997, pp. 751, 752).

Allen notes that through “power imbalances” often disguised under a professional “ideology of service and quality” (Allen, 1985, p. 63), nursing participates in what he characterizes as “the American illness non-care system” (Allen, 1995, p. 180). While referring specifically to the role of nursing in healthcare institutions, this can be translated into recognition of the power differential in the individual encounter between the nurse and the person with a health need. Based on her expert knowledge and the dependency created by an illness requiring therapy, in terms of this study reflecting the dominant discourse in a specialized healthcare context, the nurse is in a powerful position in relation to the sick person she is working with, that can be obscured by an ideology of ‘care’.

In the light of these questions about the meaning of ‘care’ in nursing practice what does care within ‘negotiated care’ mean? In a chronic healthcare setting like the renal context ‘care’ can be understood as indicating first that the nursing role is focused on the person with CRF, enabling them to manage to live as fully as possible with their condition and its necessary therapy. Rather than an objectively successful clinical outcome, in accord with the dominant discourse, nursing work is oriented to the general wellbeing of the client as a person in their own situation. Second ‘care’ indicates that nursing work seeks to achieve this through the quality of the relationship between the nurse and her client, involving a responsiveness by the nurse to the personal situation of the client. This is based on a recognition of their personal social location and also an awareness of their position as a person living on dialysis, derived from some sense of the asymmetry in their relationship, that the nurse has developed from her nursing experience. In this study this awareness, generally not explicitly formulated by the experienced nurse, is delineated as the aspects of the renal client discourse. It is the quality of ‘caring’ developed in the relationship that enables an effective negotiation facilitating the client in managing to live as fully as possible on dialysis.

Caring can no longer simply be viewed as a characteristic of nurses or the nursing role in our postmodern context. Rather in a chronic setting it can be understood as a quality that a nurse seeks to realize in her relationship with a client, in as great a degree as possible, by overcoming the inherent limitations and difficulties inevitably

involved in such a relationship. These include the personal limitations, of both the nurse and the client, that inhibit openness to another person in a particular situation. Some of the complexities in this relationship derive from the fact that the ways in which people respond to the experience of illness and therapy are not determined by the nurse, even though they may be influenced by the nurse. The nurse's capacity to create a relationship with a client is variable, for, whatever her attitude, the client can ultimately determine the shape of the relationship.

The limitations on the possibilities in the quality of the relationship, suggested by the idea of care as negotiated, also include the character of the specialized healthcare context, shaped by the dominant discourse, in which the nurse inevitably participates. Renal nurses work in a setting where the influence of dominant discourse tends to negate the client perspective, obscuring the concerns of people living on dialysis. This is a source of the tensions manifested in interactions between nurses and their clients, commonly focussed on the issue of compliance with the therapeutic regime. In such a setting it can be difficult for the nurse who seeks to maintain a balance in the dynamic between the authoritative aspect of her role, reflecting the dominant discourse, and the responsive aspect of her role, seeking to address the client discourse. Other effects of the institutional configuration of her work, for example high staff/client ratios causing fatigue or 'burnout', can also limit possibilities for the quality of the relationship with the client.

The experienced nurse seeks to develop a relationship, supporting the client to integrate the therapeutic regime into their own situation, through the dynamic of the authoritative and responsive dimensions of her role. In practice negotiated care can be complex and even ambiguous. For example in the renal setting a nurse may exert professional influence on a client, during the early phase when he is orienting to the therapy, to encourage him to adopt a higher degree of self-care in his therapy than he may feel he is capable of at that point. She does this because she knows from her experience that he does have the capacity for it and will ultimately benefit from such independence. In this case the nurse is 'forcing' a person to try to perform certain aspects of their own therapy, from the authoritative aspect of her role, because she understands, through her relationship with him, from the responsive aspect of her

role, that it is in his best interest, even though he does not recognize or acknowledge it.

In another common situation that occurs in the renal setting a nurse may decide to lengthen the treatment hours of a person who regularly arrives for treatment at the dialysis unit very fluid overloaded. While explaining this on the basis that it is necessary because of the large volume of fluid that needs to be removed during the treatment, the nurse generally also highlights the importance of compliance with their daily fluid intake restriction that will permit shorter treatment hours in the future. This scenario can be ambiguous depending on how it is played, either an encouraging learning experience to assist the client in managing this element of the requirements of the therapy, or a punishment for behavior viewed as problematic by the nurse because it tends to complicate management, making her task more difficult. In the former case, maintaining a balance between the authoritative and responsive aspects of the nursing role, such an episode can contribute to the development of a relationship as negotiated care. In the latter, the balance has been lost and the nursing role is reduced to the implementation of the dominant discourse.

The initial cannulation of a fistula by the renal nurse, prior to the first dialysis treatment, epitomizes the complexity of the nursing role in the dialysis setting. This event is freighted with significant emotion for the client, not only around the procedure of needling the vessel itself for the first time but also as a signifier of their new status of dialysis dependency. Ideally the nurse appears authoritative, inspiring confidence in the client that she can objectively manage the therapeutic event, yet also sensitive to the concerns of the individual for whom this is a unique experience. Maintaining these polarities, the authoritative and the responsive, both integral to the nursing role, in a dynamic tension, establishes the possibilities for the relationship that will develop. If one negates the other in her work the nurse becomes either an 'uncaring' technician or an unprofessional sympathizer. In either case she becomes unable to respond effectively to the personal needs of the client. Both are held in a creative tension in skilled nursing practice as care that is negotiated.

Limitations created by the character of a specialized healthcare context can reflect wider social influences than the dominant discourse itself. For example a cross-cultural relationship between nurse and client in a monoculturally oriented institution may have inherently limited possibilities for negotiated care (Polaschek, 1998). If the client finds the setting itself alien and intimidating, specific practices within it culturally offensive and the therapeutic regimes inimical to the social habits of their ethnic group, then the individual attitudes of the nurse are unlikely to be able to overcome this negative influence of the institutional context. In fact such a context will tend to negate any such efforts, inhibit sensitivity to clues to the client's different cultural perspective, rather facilitating and reinforcing any residual monocultural attitudes in the nurse. However, such is the complexity of these inter-ethnic interactions, that a person from a different minority culture may have the expectation that the nurse will adopt an authoritative role and become confused, suspicious or anxious if, in specifically seeking to overcome the monocultural bias inherent in the clinical situation, she attempts to work with the client in a collaborative manner.

Nursing work, as care that is negotiated, seeks to respond to the experience of illness and therapy through the quality of the relationship that the nurse develops with her client, overcoming limitations, personal, institutional and cultural, in order to enable a negotiation through which she can assist them to live as fully as possible on dialysis.

10.6 Engaging the altered relationship between autonomy and dependence

Nursing work as negotiated care explicitly engages one aspect of the client discourse, the altered relationship between autonomy and dependence for the person living on dialysis, because this is manifested in the relationships with healthcare professionals that are created by their condition and its associated therapy. Involvement with renal healthcare professionals is a new form of relationship a person needs to accommodate as one aspect of the process of continuing to live on dialysis in their own situation. Their response to CRF and renal replacement therapy includes their

relationships with healthcare professionals who manage the condition by providing the therapy.

The altered relationship between autonomy and dependence for the person living on dialysis can have a range of manifestations. These can include compliance as the expression of dependence, or non-compliance as the assertion of autonomy. In the context of CRF and dialysis a pattern of ritualistic adherence or demanding particularity by the client can be contrasted with fatalistic indifference or cavalier denial. At the deepest level 'ritual' compliance (in O'Brien's language, 1990) may result in worse outcomes because people are living in order to dialyze, while so called non-compliance, or more positively 'reasoned' compliance, may result in better outcomes because they are dialyzing in order to live. Rather than judging some of these as pathological manifestations, Hardiker et al. (1986) note that they are better simply understood as different ways that people cope with having to live on dialysis (see also Littlewood et al., 1990; Sloan, 1999). The character of their developing relationships with healthcare professionals reflect their general approach in managing to live with CRF in their own situation.

Nursing work as negotiated care does not simply reflect the dominant discourse by promoting the possibility of autonomy for the client while paradoxically requiring compliance that demonstrates their dependence on the therapeutic regime. The experienced renal nurse recognizes the powerful position of healthcare professionals in their relationships with clients. Encouraging the autonomy of the client in coping with CRF and dialysis while also contributing to the implementation of therapies requiring compliance, she recognizes their dependence on therapy. The nurse's relationship with the client is oriented towards facilitating the person to find a new equilibrium, given the altered relationship between dependence and autonomy inherent in their position of living on dialysis in their own situation. The nursing dynamic of authority and responsiveness in her role, manifested in the relationship between nurse and client, mirrors the complex interrelationship of dependence and autonomy involved in living on dialysis.

Ultimately the nursing relationship with the person with a chronic healthcare need is for that person one manifestation of the complex interrelationship between autonomy and dependence in their lives caused by their experience of illness and therapy. Within the dynamic interplay between these polarities, the need to accept limitations involved in their situation while actively striving to overcome them, they relate to the nurse who seeks to respond to their experience. Skilled nursing work involves a recognition of limitations that need to be accepted and possibilities that can be enhanced for the person with a particular healthcare need. The ambiguities in the life of the person who is the subject with CRF, reflecting the aspects of the client discourse in the renal context, influence the relationships between clients and health professionals involved with them, creating challenges that the experienced nurse seeks to respond to through negotiated care.

For example the situation can occur where a young man living on home haemodialysis is brought into the dialysis unit unwell. While claiming to have been dialyzing normally at home he is found to be underdialysed from his serum creatinine blood results, indicating he has been significantly shortening his treatment hours or missing treatments. He then blames staff for failure to respond adequately to his telephone queries about his treatment. Viewing this event as simply a failure to comply with the treatment prescription, this situation could be managed by requiring him to change to in-centre treatment in an attempt to enforce compliance. Alternatively it could be managed by informing him that, capable of treating himself at home, his failure to comply, and the consequent risk of serious illness or death, is his own responsibility.

However the experienced nurse understands that failure to dialyze adequately at home by younger people, and misrepresentation of their treatment to health professionals or anger at them, is a manifestation of the tension between their natural orientation to the assertion of autonomy and their actual dependence on renal replacement therapy, in terms of this study as reflecting one aspect of the client discourse. On this basis, recognizing the difficulty in maintaining the discipline required by renal replacement therapy, she attempts to discover from the young man any issues from his perspective about his current situation of living on dialysis,

reflecting aspects of the client discourse, that healthcare professionals can address in order to support him. From this responsiveness to his experience she can encourage him in making any decisions about altering his therapy, as an active expression of his own autonomy, in order to manage life on dialysis, while accepting the difficulties he may have in successfully achieving this.

One possible dimension of the nursing role as negotiated care, in engaging the relationship between autonomy and dependence for the person living on dialysis, is representing the client's right to actively negotiate their treatment with the group of healthcare professionals working with him. Often the nurse may need to react against the tendency of the specialized health experts, in accord with the dominant discourse, to prescribe management that the patient is simply expected to comply with. This can require a presentation of the situation of the client as person, based on the nurse's interrelationship with them, including their difficulties with managing therapy within their own lifestyle. It can also require representation of their right to be fully informed about their diagnosis and involved in any decisions about their therapy, even to modify aspects of the therapeutic regime or decline them in order to optimize their lives on renal therapy from their point of view.

Nursing work seeks to mediate between the professional viewpoint, based on the dominant discourse that nurses themselves participate in, and the views of the person living on dialysis, reflecting the client discourse. This can even mean critiquing the dominant discourse, as manifested in particular institutional practices, at points where it does not take account of the client perspective as the nurse understands it. From her experience the expert nurse is able to understand the situation of the person living on dialysis, characterized in this study as the various aspects of the client discourse, in particular the altered relationship between autonomy and dependence, by representing the client perspective to the other members of the healthcare team.

The experiences of the six men in the study support this understanding of nursing work as negotiated care. A number of them positively described their interactions with the nursing staff as analogous to other interpersonal relationships. Chris said, *"It's not like a nurse/patient relationship. Were friends. I've known some since the*

first day I was sick." Paul said it felt *"like one big family. More friendly than clinical ...they're interested in how you are."* These comments indicated that for these men the key feature of nursing work with them was the ongoing nature of these relationships and their supportive character, rather than the necessary technical expertise that they tended to take for granted. Their analogy with personal relationships suggested the quality of the relationship that the nurses had been able to create in these professional interactions. This reflects the view of nursing work in this chapter as based on a response to the experience of illness and therapy outlined in the client discourse.

In referring to the difficulties in their interactions with nursing staff their comments suggested a sense of the limitations in the ongoing supportive character of these relationships. Mark said that nurses *"often seem under pressure"* [with little time to talk or respond]. Owen said of a trip to the dialysis unit *"I was efficiently connected to the dialysis machine but there was no communication."* John noted about his hospitalization *"the nurses are busy, they can't be tied up with emotional problems.... At certain times you're eventually forgotten."* Generally the men indicated they could not talk with the nurses about the alterations that they made to their treatment regimes. These comments reflected the limited or even diminished quality in the relationships created by some nursing interactions in contrast to the men's expectations. Here nursing work has become simply a function of the dominant discourse.

A number of the men made comments indicating that in their view healthcare professionals could not really understand their experience as people living on dialysis. These were generally in the context of explaining their deviance from the professional therapeutic prescription. For example Paul said *"nurses can't tell you what its like dialyzing."* John noted *"they don't now how I feel, only I know how I feel."* These comments reflected their sense of the distance between staff and themselves created by their different positions in the renal setting. The positive quality of their relationships with the nurses who supported them in general, despite their limitations and this sense of distance between them, demonstrates the potential

of nursing work in mediating the dominant and client discourses for the person living on dialysis in the renal setting.

10.7 Conclusion: humanizing therapy

This chapter has considered one important implication of the understanding of the experience of living on dialysis developed in this study. In undertaking this project I was initially motivated by my recognition, from a nursing perspective, of a dissonance between the professional and consumer perspectives in the renal setting. However, from my own experience, I was also aware that nursing work, by expert practitioners, had the potential to address wider issues, beyond the objective condition and therapy itself, that were the source of this dissonance. The delineation of the concerns of people living on dialysis as aspects of the client discourse in this thesis has enabled a clarification of the possibility for the nursing role in the renal setting. Demonstrating the relevance of the understanding of the experience of renal illness and therapy developed in this study, by clarifying the meaning of nursing work in the renal setting, supports the trustworthiness and significance of this study of the concerns of Pakeha men living on home haemodialysis.

Nursing work can be understood as negotiated care. On the basis of specific therapeutic activities in accord with the dominant discourse, the nurse, through her ongoing relationship with the client, is able to respond to their experience of illness and therapy. Through her work as negotiated care she can facilitate the client's attempts to integrate the requirements of the therapeutic regime, reflecting the dominant discourse, and their personal situation, reflecting the interaction of their own personal location with their position as a person living on dialysis, described in the client discourse. Aware of their difficulties, in particular the complex interrelation of autonomy and dependence involved in living with a chronic illness, the nurse, through her relationship with the client, seeks to contribute to the client's own ongoing effort to manage to live more fully on dialysis in their own situation.

The nursing role in this chronic healthcare setting is best understood in relation to the clients that nurses work with. In the contemporary situation it is difficult to affirm

any feature, whether any specific activities or an attitude such as 'care,' as inherent in nursing work. No definitive meaning for 'nursing' is possible in the postmodern milieu. Given the contemporary healthcare situation dominated by biomedicine, this chapter has suggested that the most important feature of the nursing role, in a chronic healthcare setting such as the renal context, is in a relationship, an intensive ongoing involvement based on responsiveness to the experience of illness and therapy, that can assist the client in managing to live with CRF. The concerns of the client discourse delineate the characteristic difficulties in the experience of people living on dialysis that expert nurses address, formalizing the experiential knowledge they develop from their practice.

While nursing work is in a sense an 'in-between' role, in Bishop and Scudder's (1990, p. 171) phrase, it is not simply liaison or even advocacy. Rather nursing work is a distinctive contribution to healthcare services based on a process of discerning a client's needs in terms of their experience of illness and therapy in order to assist them in meeting them. As one aspect of this the nurse can share her understanding of the client's experience with the group of health care professionals. This nursing view, generalist and holistic, can then perform an important function of ensuring that the specialized activities of the various other health professionals in the health care team are all integrated to ensure that the healthcare services cooperate with the client themselves in meeting their health needs, and thus contributes to their wellbeing as a person. Such an 'in-between' role for nursing can be delineated by forms of nursing scholarship with a critical dimension that themselves manifest "in betweenness" (Thompson, 1987, p. 27), such as a critical interpretive approach.

Although renal nursing activities are defined by the dominant discourse that constitutes the renal context, tending to reduce her role to that of a specialized technician, through her ongoing interrelationship with the client, characteristic of nursing work in a chronic healthcare setting, the renal nurse also has the potential to engage their subjective experience of illness and therapy. Nursing work in the renal setting can be significant in bringing a humanistic orientation to a highly technological context, recognizing potential distortions in the lives of clients produced by the dominant discourse itself and addressing the dissonance between the

professional and the client perspective. This study has attempted to clarify what is implicit in expert nursing practice in the renal setting, its potential for humanizing renal replacement therapy.

The critical interpretive approach developed in this study has enabled this understanding of the role of nursing work to healthcare services, beyond simply supporting medical diagnosis and treatment. The potential of nursing practice is somewhat obscure in the present healthcare setting where even the views of the recipients of healthcare services tend to be neglected in favour of the perspective of the specialized experts who manage treatment, characterized in this text in terms of the dominant discourse. Benner bluntly states 'nursing's invisibility and devaluation is due to society's ambivalence toward care and preference for technical fixes' (Benner, 1990a, p. 16). It is because of the hegemony of the empirical analytic paradigm epitomized by scientific technology in our contemporary culture, the objective and cerebral aspect of the human, that other aspects, the subjective, affective, esthetic or spiritual tend to be negated. It is these dimensions of human reality that nursing work in the chronic healthcare setting can respond to, complementing the technical management of the health specialists in order to provide more balanced, fully human healthcare services for people.

This discussion suggests the potential of nursing work to contribute to the realization of a broader view, in which the 20th century modernist model of services such as renal replacement therapy, based on the acute curative paradigm of biomedicine, will be superseded, in a postmodern setting, by a more comprehensive model of chronic management in the biocultural paradigm (see Morris, 1999). The dominant discourse in the renal context, reflecting the biomedical paradigm, can be transformed in the different context of the biocultural paradigm. Focusing on efficacious therapy the dominant discourse tends to obscure the client perspective. It is the experienced nurse who has "ears to hear" and can "listen", in terms of the traditional quote that began this reflection, to the quiet voice of the client not easily heard amidst the expert health talk in a contemporary health context shaped by dominant discourse. Mediating between the dominant professional discourse and the client discourse,

through her relationship with the client, the renal nurse can assist people with a chronic illness requiring a complex therapy to live as fully as possible.

Chapter 11. The significance of this study

The experiences of people living on dialysis are characterized by some common concerns. These are not easily discerned because they are obscured by the professional viewpoint dominant in the renal setting. This is the cause of the dissonance between the perspective of renal clients and renal health professionals, epitomized by the ubiquitous professional language of compliance with the therapeutic prescription, which was an initial motivation for this research project. By listening to the 'voice' of the six participants in this study I have delineated the concerns that characterize the client perspective in the renal setting for people living on one form of renal replacement therapy. This has enabled me to articulate an understanding of the experience of one group of renal clients, Pakeha men living on home haemodialysis.

11.1 A critical interpretive approach

Given that the views of people living on dialysis are not easily discerned I needed a methodology for this study through which I could recognize and understand the 'voice' of the six participants from the renal setting. An approach based in the interpretive paradigm, rather than the empirical analytic paradigm that is dominant in the renal setting, was necessary in order to hear what they were saying about their experiences. For this study I developed an alternative synthesis of the hermeneutic and critical traditions, in contrast to critical hermeneutics advocated by some nursing researchers, that I named a critical interpretive approach. This enabled me to discern the interpretations of the participants, but then reinterpret them from a critical stance, recognizing that they could be most fully understood by contextualizing them.

Such a critical stance is necessary for the researcher to identify and locate various different interpretations, some of which may be obscured by the dominant ideology, within a social setting. It also enables the researcher to consciously position himself in relation to the setting and participants he is researching. Through developing critical standpoint for this study I was able to contextualize the interpretations of the participants within the renal setting and also the study itself. The methodology developed for this study offers a powerful way to undertake interpretive research seeking to understand individual experiences in terms of the interplay of several contrasting interpretive perspectives within a social setting.

After producing accounts of their individual interpretations of their experiences in this thesis I have presented an interpretation of their collective experience through an analysis of the accounts as a set from my critical standpoint. By modelling the common perspective underlying their individual accounts this thesis offers an understanding of the 'voice' of people living on dialysis that is obscured by the dominant professional viewpoint in the renal setting. While critical hermeneutics would be a helpful methodology to outline contextual influences on the understanding of individuals in a social setting, the critical interpretive approach provided a useful way to understand the experience of one group of people in this social setting that is shaped by a dominant ideology.

The critical interpretive methodology developed to address this research topic is one example of the creative possibilities for research methodologies within the "arc" (Thompson, 1990, p. 242) of the interpretive turn. I consider that it has enabled me to produce an understanding that models the meaning of the experience of one group of people living on dialysis in a trustworthy way. In my view, beyond this study, it has the potential to be useful in other contemporary healthcare settings, especially those created by chronic illness.

11.2 A Foucauldian sketch

To create a critical standpoint for this study, an alternative to the dominant professional viewpoint in the renal setting, I used some ideas derived from Foucauldian thought. I sketched the renal setting as a specialized healthcare context constituted by several interrelated discourses, primarily the dominant professional discourse but also several others, in particular a client discourse. The different discourses reflect contrasting interpretive perspectives from the different positions of various groups, health professionals, people living on dialysis, companies marketing dialysis equipment or others, within the renal setting.

The dominant discourse represents the professional viewpoint, based on the body of specialized renal knowledge, which is ubiquitous within the renal setting. Although the understanding of every individual is influenced by their socialization with the dominant discourse, there can also be a client discourse representing the interpretive perspective of people living on dialysis within the renal setting. Underlying individual interpretations of their experience of illness and therapy, the client discourse contrasts with the dominant discourse, but is related to it as a “resistant” (Foucault, 1977, p. 27; 1980, pp. 95, 96) response to it. The renal client discourse is made up of several different ‘concerns’ representing the characteristic difficulties involved in living on dialysis.

Employing Foucauldian thought within the critical interpretive approach was valuable for this study because it established a useful critical view of the renal setting. By conceptualising the renal setting as a specific social context, constituted by dominant and client discourses that are interrelated, the Foucauldian sketch offered a way of viewing this chronic healthcare setting that facilitated a delineation of the distinctive client perspective within it. In particular, it made clear that the concerns of the client discourse are most fully intelligible as a response to the dominant discourse in the renal context. Through using this critical lens I was able to analyse the accounts of the participants in the study in order to understand the experience of people living on dialysis.

Often the critical approach employed in nursing studies has been derived from the modernist critical meta-narrative. This sketch, orienting this study, is an example of the use, within the 'arc' of the interpretive paradigm, of a contemporary form of critical thinking that is congruent with our postmodern situation, in a nursing research project reflecting on a contemporary healthcare context.

11.3 The concerns of the renal client discourse

In this study I have presented an understanding of the experience of living on home haemodialysis. The Foucauldian sketch of the renal setting suggested their common perspective could be viewed as a client discourse constituted by several concerns, the characteristic difficulties involved in living on dialysis. By reflecting on the set of accounts of the six participant's interpretations of their experience of renal illness and therapy, contextualizing them in terms of the critical sketch of the renal setting, I have delineated four concerns of people living on home haemodialysis in this thesis.

Living on dialysis they continue to suffer from some symptoms caused by CRF and also renal replacement therapy. Integrating dialysis therapy into the pattern of their lives requires a process of negotiation that results in some limitations on their normal lifestyle. Having to maintain their dialysis therapy indefinitely leads to a sense of ongoingness and uncertainty that they cope with through their hope of a transplant to allow them to escape from dialysis. Continuing to live using renal replacement therapy causes a complex alteration in the relationship between autonomy and dependence in various aspects of their lives. While, according to the dominant discourse, dialysis offers a reasonably normal life, the men's own focus on normality, epitomized by one of the participants, Mark, noting that he had "*forgotten what normal is,*" suggests that for them their lives were less than normal, because they are distorted by the concerns of the renal client discourse.

The concerns of the renal client discourse, in contrast to the dominant discourse, model the distinctive perspective from their position within the renal context. In the accounts of the men's interpretation of their experience I have listened to the client 'voice'

easily lost in the expert health talk that dominates the renal setting. Through delineating four concerns of the renal client discourse this thesis has articulated an understanding of the experience of people living on home haemodialysis that is obscured by the dominant professional viewpoint in the renal setting. These concerns of the renal client discourse facilitate an understanding of the individual experience of living on dialysis.

The dominant discourse in the renal setting is framed in terms of an efficacious therapy solving the objective problem of replacing lost renal function. Through using the critical interpretive approach this study has identified the characteristic difficulties, underlying six men's interpretations of their experience as people living on dialysis, in contrast to the dominant professional viewpoint. Understanding these men's experience, through delineating the concerns of the renal client discourse in this study, I have presented an alternative view of the renally replaced life that offers a "challenge directed to what is" (Foucault, 1981, p. 13).

In general this thesis has shown how the experience of a chronic illness can be most fully interpreted in terms of its relationship to the dominant professional viewpoint within a contemporary healthcare setting. This study of the concerns of Pakeha men living on home haemodialysis is an example of the possibilities that nursing research can offer in extending understanding of the experience of living with chronic illness.

11.4 Negotiated care

One important implication of this study is an understanding of the potential of the nursing role in the renal setting. The renal nurse, on the basis of her extensive involvement with the renal client, can respond to their experience of renal illness and therapy. Through her work as negotiated care she can develop a relationship with the person with CRF, supporting them in integrating renal replacement therapy into their own situation. It is the renal nurse with "ears to hear" who can "listen" to the 'voice' of the person living on dialysis. Such an understanding moves beyond the language of compliance with the therapeutic prescription reflecting the dominant professional

discourse. Rather, through negotiated care, mediating between the requirements of the dominant discourse and the concerns of client discourse, the nurse can support people with this chronic illness requiring a complex therapy to live as fully as possible.

More generally in this study I have suggested that, despite naming it as chronic renal failure, the optimistic ideology of the dominant discourse downplays the difficulties inherent in living on dialysis. Renal replacement therapy is a classic instance of an efficacious contemporary healthcare technology. However by 'curing' a formerly terminal condition, it has actually created a chronic illness. The dominant discourse in the renal setting, expressive of the acute curative paradigm of biomedicine, is incongruent with the chronicity inherent in the experience of renal illness and therapy. This is the source of the dissonance between the professional and client perspectives that is delineated in the concerns of the client discourse in this study.

A more holistic approach, in contrast to the hegemonic biomedical paradigm, that has been named 'biocultural' (Morris 1999), can overcome the dissonance between the professional and client perspectives in the renal setting. In offering an alternative view of the renally replaced life this study is of value because, by understanding the experience of the subjects of this chronic illness, it critiques the current orientation of renal services and points a way forward. It argues that nursing practice as negotiated care, by responding to the concerns of the person living on dialysis, can humanize this highly technological therapy. Such a revaluing of the role of the renal nurse, based on an appreciation of the client experience their work addresses, can contribute to the reconceptualization of renal services within a biocultural paradigm, enabling a more comprehensive service that better meets the needs of the person living on dialysis. It suggests possibilities for reflecting on other chronic healthcare settings within such a biocultural paradigm.

11.5 The value of this study.

However its initial formulation has limited this research project. From the beginning I focussed on one specific client group, Pakeha men, because the experience of living on

dialysis could be different for women and people of other ethnicities. Likewise I focussed on one modality of renal replacement therapy, home haemodialysis.

In the study gender and ethnicity are interpreted as elements of one dimension of their personal social location that interact with the aspects of the client discourse to produce their experience of renal illness and therapy. I have commented, in the light of some clues from the literature, on the possible influence of their masculinity and Pakeha ethnicity on their experience of living on dialysis. Clearly further study of other groups living on dialysis, women or people of different ethnicities, would test the value of the interpretation of the influence of gender and ethnicity in the experience of living on dialysis presented in this thesis.

The renal client discourse presented in this study is recognized as one of several variants that reflect the different modalities of renal replacement therapy. However the generic formulation of the concerns of the client discourse suggests they are common to anyone living on renal replacement therapy, reflecting their common position as recipients of therapy, whatever their modality of treatment, in the renal setting.

Studies of people using other modalities of renal replacement therapy, in-centre haemodialysis or the various forms of peritoneal dialysis currently available, could further develop the analysis of this study. They could refine the formulations in this thesis by showing any differences in the concerns of people living on these different forms of treatment. By means of comparison they could delineate clearly the distinctive features of each variant, and hence establish their generic base, reflecting the common position of people living on dialysis whatever their modality of therapy. Likewise research in other renal units, in New Zealand or elsewhere, could clarify the local 'dialect' of the client discourse delineated in this study, particularly around the hope of a transplant as a way of escaping dialysis, another possible extension of this study.

In general the design of the study, as reflected in the shape of the thesis, has sought to demonstrate its coherence (Koch, 1996, p. 178) to support its trustworthiness. The analysis of the fourth section of this thesis, interpreting the experience of the men in the study in terms of the interrelationship between the dimensions of their personal

social location and the aspects of the renal client discourse, and in particular the generic formulation of the concerns of the client discourse delineating their common position as people living on dialysis, presents an understanding that can be employed in further studies of different groups of people living on dialysis. This transferability (Emden and Sandelowski, 1998; Koch, 1996, p. 179) of the understanding of the experience of living on dialysis in this study supports the trustworthiness and significance of this study. Chapter ten, discussing one important implication of the study, the meaning of nursing work in the renal setting, suggests the relevance (Altheide and Johnson, 1994, p. 493) of the understanding of the experience of renal illness and therapy in this thesis, supporting the significance of the study.

Finally the trustworthiness and significance of this study as qualitative research will be judged by critical review, not only by other researchers, but by renal peers and even perhaps by renal clients themselves (Altheide and Johnson, 1994, p. 448). The findings of this study are being made available to the community of renal nurses and associated healthcare workers through presentation at professional forums. They will also be shared in an appropriate form with the local renal client support group for whom they should have particular relevance. The value of this work will be demonstrated if it helps to stimulate further reflection on practice in the renal setting among the health professionals who work there, perhaps even in a changing understanding of people with CRF.

11.6 A renal nurse researcher

In terms of critical interpretive approach it has been necessary for me, throughout the thesis, to “account” (Altheide and Johnson, 1994, p. 493) for myself in terms of my own “interest” (Thompson, 1990, p. 228) in this work. This has involved articulating my experience as a nurse, from my sense of the dissonance between the perspectives of renal clients and renal health professionals, to the ambiguity in the nursing role in the renal setting. It has also required positioning myself in relation to the participants in the study, not only acknowledging and addressing my professional power in relation to

them, but also recognizing that both the accounts and the analysis in this study, while attempting to respond to their experiences, are my production as researcher.

Finally I have undertaken this particular study of the renal setting, attempting to understand the experience of people living on dialysis, because I, as researcher, am a professional insider, distinctively positioned within the renal setting as a nurse. From the perspective of my role as a nurse, reflecting the dominant discourse but engaging the client discourse, I have completed this particular research project. This has both given me insights into the optimistic character of the dominant discourse in the renal setting, and also allowed me to respond the 'voice' of the men in the study. Combining researcher and nursing roles in this particular setting, in Foucauldian terms as a modest type of "specific intellectual" (Foucault 1980, p.126), has enabled me to produce an alternative view of this specialized healthcare context.

Given the potential of nursing work suggested above, this study demonstrates that nursing research, in the setting of a chronic illness like renal failure, can delineate the characteristic features of client experiences that nurses can address in their work. Studies of the type presented in this thesis can not only support the development of nursing expertise, but also to make clear the distinctive contribution that nursing work can make to the wellbeing of people living with chronic illnesses in these settings.

My involvement with the group of men in this study has enriched my work with people with CRF. In the discussions with the participants in the study I was able to learn more fully than is possible in clinical practice about the experience of several individuals living on dialysis. By reflecting on their experience through the critical interpretive methodology I have been able to articulate my own sense, from my clinical practice, of the difficulty inherent in continuing to live with this chronic illness while dependent on a specific health technology, in an understanding of the client experience in a coherent way as the four concerns of the renal client discourse.

While in the dominant professional viewpoint dialysis is an efficacious therapy enabling a reasonably normal life by replacing renal function, for the person continuing to live on dialysis involves certain characteristic difficulties and losses. The four

concerns of the renal client discourse delineate the client perspective that is difficult to discern in the renal setting shaped by the dominant discourse. Through this study of the concerns of the Pakeha men living on home haemodialysis I have been able to appreciate more fully the experiences shared with me by renal clients whom I encounter in my work. I hope it will be helpful for other nurses in the renal setting, contributing toward the development of an understanding of the experience of this chronic illness and, ultimately, a better service to people living on dialysis.

Appendix 1. The chronology of this research study.

1. This study was commenced as a thesis for MA examination in April 1997.
2. The project was supervised within the Department of Nursing and Midwifery of Victoria University of Wellington.
3. Ethics Approval for the project was obtained from the Central Regional Ethics committee in July 1997.
4. Interviews for the project were completed from October to December 1997.
5. The process for transfer from MA to PhD examination was conducted through the department in December 1998.
6. The study has been completed in April of 2001

Appendix 2. Ethics Application

NATIONAL APPLICATION FORM FOR ETHICAL APPROVAL OF A HEALTH RESEARCH PROJECT

PART I : BASIC INFORMATION

1. Full Project Title

The concerns of Pakeha men on Home Haemodialysis: An interpretive study.

2. Short Project Title (lay title)

The concerns of Pakeha men on Home Haemodialysis.

3. Principal investigators Name and Position

Nick Polaschek
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Department of Nursing and Midwifery
Victoria University of Wellington

Charge Nurse
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4. Department/location of Principal Investigator (All correspondence will go to this address)

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5. Co-investigators Name and Position:

NA

6. Supervisors Name and Position (where this is supervised work):

Assoc Prof Cheryle Moss
Department of Nursing and Midwifery
Victoria University of Wellington

7. Proposed Starting Date:

1 August 1997

8. Proposed Finishing Date:

1 April 1999

9. Duration of Project:

20 months

10. Proposed Number of Participants:

Six

11. Is this a multicentre project?

No

12. Do you request a fast track procedure?

No

PART II : PROJECT SUMMARY

1. MULTICENTRE PROPOSALS

1.1 Is this a multicentre study?

NO

1.1.1 If yes, please provide name and address of the principal investigator in New Zealand, if any, and local contact name and address

NA

1.1.2 Please list all other New Zealand centres involved in the study

NA

1.2 Has the protocol been reviewed by any other Ethics Committee in New Zealand?

NO

2. FUNDING

2.1 What is the proposed source of funding?

Self funding.

A small sum of up to \$500 may be applied for towards research expenses from Victoria University funds available for this purpose.

2.2 Give name(s) of proposed funder(s) and date when result of funding application will be known

NA

3. SCIENTIFIC ASSESSMENT

Has this project been scientifically assessed by independent review?

YES

If yes:

By whom?

Department of Nursing and Midwifery Victoria University Research and Ethics meeting.

Dr Allison Kirkman
Department of Sociology
Victoria University

4. SUMMARY

Give a brief summary, not more than 200 words, of the study

Chronic Renal Failure, a fatal condition without treatment, is managed by Renal replacement therapy, including a fluid, dietary and drug regime and regular ongoing dialysis treatment by either haemodialysis or peritoneal dialysis.

While many studies attempt to assess the quality of life of patient populations with renal failure, they often recognise the complexity of patient adherence to prescribed treatment regimes (O'Brien 1990, Reiss 1986, Hoothay 1990). There are only a few studies which attempt to discover the dialysis patients' perspective on their situation (Rittman 1993, Hardiker 1986).

Recognising that renal patients have a different perspective than health care professionals because they are in a different position, this study involves intensive interviews with a small group of Pakeha men on self care haemodialysis at home, in order to discover their concerns as dialysis patients. Their concerns are those

changed aspects of their lives which have become important to them since they have been living on dialysis.

Participants' reports will be analysed in terms of a pattern of potential concerns, derived from the literature, reflecting the nature of renal care. By understanding the meanings of this group of patients' experience in terms of the context of renal care the study will reveal the concerns underlying their experience as haemodialysis patients.

PART III : PROJECT DETAILS

A SCIENTIFIC BASIS

1. AIMS OF PROJECT

1.1 What does the project aim to investigate ?

This study aims to investigate the experiences of a particular group of renal patients. Rather than objectively assessing their quality of life on dialysis it attempts to discover their perspective as patients on dialysis.

It seeks to elicit their view of their lives on dialysis through intensive interviews. It will then analyse their view of their lives on dialysis by comparing it with the understanding of their situation as described in the literature.

This will enable a description of the concerns underlying their experience as dialysis patients, the changed aspects of their lives since they began dialysis.

It will show the relative significance of various aspects of their lives as dialysis patients which may concern them. These include not only residual symptoms or losses from the normal lifestyle but also the impact of the monotony caused by the dialysis regime on their lives or the conflict between autonomy and dependence created by the treatment programme.

1.2 Is it based on specific hypotheses (if so, state them briefly))

No

1.3 What is the potential significance of this project for improved health care for the community, and for the advancement of knowledge?

By discovering the important issues in their care from the patients' perspective the study will stimulate discussion on the current pattern of practice in the Wellington Renal department in the care of this group of patients.

It may also suggest issues that may have a wider applicability to the general dialysis patient population. It will help facilitate reflection to improve the provision of care according to the patients needs.

As this study attempts to use an interpretive approach to illuminate patients' experiences of care, it may contribute to the development of this approach to studying illness and health care practices.

1.4 Is this project to be used to formulate policy ?

No

2. RESEARCHER QUALIFICATIONS

2.1 What experience do the researchers have in this type of research? (Please include a brief curriculum vitae, and details of recent publications.)

The researcher is not experienced in this form of research. He is nurse with 15 years renal experience specialising in Haemodialysis.

He has reviewed research and undertaken small scale survey research as part of his undergraduate degree (BA economics) and Post Grad Diploma (Soc Sciences Sociology, distinction).

This research is being undertaken under the supervision of an experienced academic researcher.

3. RESEARCH METHODS

(The following 2 sections should be described in lay terms)

3.1 What is the method of analysis? If this is (wholly or partly) quantitative research, please give the following:

Not Quantitative.

3.2 If the research methods are (wholly or partly) qualitative, give a brief description of their theoretical basis:

Hermeneutic or interpretivist approaches to research are a family of methods of investigating human experience. Based on the writings of thinkers like Heidegger and Gadamer, they suggest that all human understanding (from the religious to the scientific) is an interpretation from a particular position within a given social context or world. In this anti-foundationalist view all forms of human understanding are recognised as expressed in a specific "language" which is situated within a particular social "horizon". Research using the interpretivist approach attempts to understand "lived experience", to illuminate the meaning of their lives for particular groups of human beings (see Dreyfus 1991, Palmer 1969, Warnke 1987, Van Manen 1990).

Where nursing work is understood as a practice involving the phenomenon of illness and caring (Benner 1994, Bishop & Scudder 1990), nursing research attempts to understand the interpretation of the participants' lived experience in the context of the given meanings of their particular health care setting. In terms of such an approach in the renal setting, the understanding of the person with renal failure results from their experience of their illness and the practices of renal care,

especially dialysis. A person learns the language of the renal world in order to interpret their experience of living with renal failure.

Within the interpretivist approach critical thinking recognises that different groups within a social setting have different positions which reflect differences in power and are expressed in different discourses. A writer like Foucault recognises that the ideology of the dominant group, which is produced in a particular context, may give rise to resistant counter discourses. "Normalization" of social groups through surveillance and discipline, in accord with the dominant scientific discourse, is characteristic of modern society (Rainbow ed 1984, Smart 1985, McHoul & Grace 1993, Kincheloe & McLaren 1994).

In health care a critical approach questions the assumption of consensus commonly embodied in research (Mulholland 1995). It rather recognises the different "locations" of patients, health care professionals and other groups of actors involved within a health care setting. It attempts to discern the "conditions" which can give rise to a range of different discourses within a specific health care context (Allen 1985, 1995). In terms of such an approach in the renal setting the formal renal discourse, through the surveillance and discipline of diagnosis and treatment, normalising the experience of the person with renal failure, defines the subject as patient. However dissonant elements of the patient's experience, resulting from their position in the renal world, may give rise to a distinctive perspective which is difficult to discern.

This research will use concepts derived from interpretivist and critical thinking as a basis to study the experience of Pakeha men living on home Haemodialysis. The research process itself, from the development of a conceptual framework of potential concerns from a reading of the literature, through the collection of data, to the analysis of the texts produced from it, will be in accord with assumptions and practices congruent with this form of thinking. Through the adoption of this approach the study will seek to illuminate the concerns of Pakeha men on home haemodialysis.

3.3 Describe the study design. Include diagrams and charts to illustrate if necessary.

Initially in this research project a conceptual framework of potential patient concerns of haemodialysis patients will be developed from a survey of the literature, both of renal and of other sources. The pattern of postulated concerns will range from obvious aspects like residual symptoms to more subtle aspects such as the influence of monotony through the dialysis regime on the lives of patients.

Next a small group of six patients will be interviewed in their homes on three occasions about their life on dialysis. These will be in depth interviews, having the character of discussions, in which participants will be encouraged to give their views about their experience in a range of areas.

Finally an analysis of the participant interviews will be made in terms of the conceptual framework. The researcher will make an interpretation of the participants views of their experience in terms of the pattern of postulated concerns. The participants' understanding will be located within the contours of the renal context.

The primary source, the text derived from the taped conversations, with any secondary sources from the interviews shared by the participants, will be interpreted with the aid of the researcher's notes around the interviews, substantive, procedural and methodological, using the conceptual framework developed from the literature. During this process, which may involve clarification of the significance of their texts with patients and/or modification of the conceptual framework, the dimensions of the dialysis patients' concerns will be recognised.

This research design clearly distinguishes between the conceptual framework of the researcher (embodying his assumptions, reflections and reading), the transcripts of the participants' reports (their own views of their experience) and the interpretive analysis (their reports in terms of the conceptual framework). Such clarity is helpful in this study where the researcher works for the renal department which supports the renal patients in the study ie where the context of the researcher and those being researched to some extent overlap.

The results of the analysis will be a description of the pattern of concerns of this group of haemodialysis patients, through discerning, evaluating and articulating thematic elements in the primary and secondary texts. The findings of this study will seek to illuminate the concerns that underlie their experience as dialysis patients

4. PROCEDURES

- 4.1 What procedures will be carried out? Include all tests to be carried out on samples.

NA

- 4.2 How many visits/admissions of participants will this project involve? Give also an estimate of total time involved for participants.

This research will involve a total of three hours of participants' time in three one hour interviews.

- 4.3 Describe any interview methods involved and attach copies of any questionnaires being used.

These interviews will not be formally structured but have the character of discussions with participants on a range of topics related to their life on dialysis. This will enable the participants to state their views on their life on dialysis rather than simply respond to questions on a pattern determined by the researcher.

See topics in appendix

- 4.4 If blood, tissue or body fluid samples are to be obtained, state type, use, access to, frequency, number of samples, total volume, means of storage, length of proposed storage and method of disposal.

NA

4.5 Will any drugs be administered?

NA

5. RISKS AND SAFETY

5.1 Who will carry out the research procedures?

NA

5.2 Where will the research procedures take place?

NA

5.3 Is there scientific evidence of any physical or psychological risks?

NA

5.4 What arrangements will be made for monitoring and detecting adverse outcomes?

NA

5.5 Will any potential toxins, mutagens or teratogens be used? If so outline the justification for their use.

NA

5.6 Will any radiation or radioactive substances be used?

NA

Note: *If any form of radiation is being used please answer the following:*

5.6.1 Under whose license is the radiation being used?

NA

5.6.2 Has National Radiation Laboratory (NRL) approval been sought to use radiation in this study?

NO

If *yes*, please enclose a copy of the approval, and contact name and phone number.

If *no*, please explain why:

NA

5.7 What facilities are there for dealing with emergencies?

NA

B BUDGET AND USE OF RESOURCES

6. BUDGET

6.1 Please supply a budget for this study, including a description of all financial support to be received by the researchers, such as fees or expenses.

Library borrowing costs	\$300
Transcription costs	\$1000
Travel to interviews	\$ 300
Tapes, paper, discs etc	\$ 800
Student fees	\$4800
TOTAL	\$ 7200

6.2 Does the researcher, the host department or the host institution, have any financial interest in the outcome of this research?

No

6.3 Will there be payments according to the number of participants recruited? If so, please specify.

No

7. RESOURCE IMPLICATIONS

7.1 Does the study involve the use of healthcare resources?

No

7.2 What effect will this use of resources have on waiting list times for patients i.e., for diagnostic tests or for standard treatments?

None

7.3 What are the likely benefits to participants?

It is hoped that through the research process the participants will find it helpful to be able to express their perspective on their life on dialysis to a researcher who is knowledgeable about their situation. It is considered that their sense of being supported by the department of Renal Medicine will be enhanced through contributing to research that shows an interest in their views.

By describing the concerns of this patient group cared for by the renal department the study may suggest which aspects of the service best meet patient needs and which aspects are not so well oriented to patient needs. This may lead to changes which could benefit many patients including participants in the study.

C PARTICIPANTS

8. SAMPLE

8.1 How will potential participants be identified?

Suitable potential participants will be identified by nursing staff caring for them.

8.1.1 Where will potential participants be approached? For example in an outpatient clinic? (If appropriate describe by type e.g. students.)

Potential participants will initially be sent a letter at their homes. If they indicate a willingness or consider participation a further discussion will take place with them in their homes or at another location suitable to them.

8.1.2 Who will make the initial approach to potential participants?

The initial request to participate will be made by letter from the researcher.

8.1.3 What relationship, (if any) will participants have to the researchers?

The researcher works for the renal department which cares for the participants. He is known to them but does not directly care for them currently and has not done so for at least a year.

8.2 How many participants is it intended to recruit?

Six.

8.3 What are the inclusion/exclusion criteria?

Participants will be Pakeha men who have been on Home haemodialysis for at least one year. They will be assessed by nursing staff caring for them as physically well, fully rehabilitated according to Karnovsky score from ANZDATA assessment (see Disney 1995) and managing well on dialysis. They will not have dialysed in the Hospital unit for one year.

Pakeha men are defined as men born in or permanent residents of New Zealand who are not of Maori, Pacific Island or Asian ethnicity as defined by themselves.

This specific group has been chosen because research from overseas (Reiss 1986, Wolcott 1988, Brunier 1993, Tell 1995) suggests that dialysis patients who are women or from ethnic minorities may have somewhat different concerns from white men from the dominant culture.

This probably results from the intersection of their experience as dialysis patients with broader societal issues relating to gender and ethnicity. While the concerns of women and Maori warrant study as much as Pakeha men, this

initial exploratory study will clarify the concerns of this one specific group, perhaps as a prelude to some more comprehensive study.

8.4 How will participants be recruited, e.g. advertisements, notices

Potential participants will be recruited initially by being sent letters from the researcher at home to request they consider participating in the study.

If they indicate their provisional willingness by telephoning the researcher as requested, they will be invited to meet the researcher at their home or a place convenient to them. At this discussion he will give them full information about the study and answer their questions to enable them to decide whether they wish to participate.

A week after this discussion they will be rung by the researcher to check whether they agree to participate.

If they agree to participate they will sign a written consent form at the beginning of the first interview.

9. FINANCIAL COSTS AND PAYMENTS

9.1 Will there be any financial cost to the participant? Give examples.

No

9.2 Will the study drug/treatment continue to be available to the participant after the study ends? If yes, will there be a cost?

NA

9.3 Will any payments be made to participants or will they gain materially in other ways from participating in this project?

No

If yes, please supply details:

9.4 What are the additional benefits to the participants from participating in this project?

None

10. COMPENSATION OF PARTICIPANTS

Is this a clinical trial as defined in the ARCIC Guidelines?

NO

If yes, please answer the following:

- 10.1 Is the trial being carried out principally for the benefit of a manufacturer or distributor of the drug or item in respect of which the trial is taking place?

NA

- 10.2 a) If the answer to 10.1 is NO please complete Statutory Declaration Form A (and provide participants with an explanation of the ARCIC requirements for and level of compensation)

NA

- b) If the answer to 10.2 is YES, please complete Statutory Declaration Form B and answer questions 10.3, 10.4 and 10.5.

NA

- 10.3 What type of injury/adverse consequence resulting from participation in the trial has the manufacturer or distributor undertaken to cover:

NA

- 10.4 What type of compensation has the manufacturer or distributor agreed to pay?

NA

- 10.5 Exclusion clauses:

- a) Has the manufacturer or distributor limited or excluded liability if the injury is attributable to the negligence of someone other than the manufacturer or distributor? (such as negligence by the investigator, research staff, the hospital or institution, or the participant).
- b) Has the manufacturer or distributor limited or excluded liability if the injury resulted from a deviation from the study protocol by someone other than the manufacturer or distributor?
- c) Is company liability limited in any other way?

NA

11. INFORMATION AND CONSENT

- 11.1 Who will explain the project to potential participants?

The investigator will explain the project to potential participants.

- 11.2 Is there any special relationship between the person explaining the project, or any of the investigators and the participants (e.g. teacher/student; doctor/patient)?

The investigator works for the Renal department which cares for the participants. He is known to them but has not been actively involved in their care for at least a year.

After the investigator has explained the project to potential participants, making clear they have the choice not to participate, he will later ring to confirm the willingness of those approached to participate.

11.3 When and where will the explanation be given?

At the potential participants house, or at another place of mutually agreed convenience.

11.4 Will a competent interpreter be available, if required?

NA

11.5 How much time will be allowed for the potential participant to decide about taking part?

A decision will be asked for after one week. The interviews will not take place for several weeks after this during which time potential participants can reconsider and withdraw.

11.6 Will the participants be capable of giving consent themselves?
- If not, to whom will the project be explained and who will give consent?

Yes

11.7 In what form (written, or oral) will consent be obtained? If oral consent only, state reasons why.

Written consent.

12. CONFIDENTIALITY AND USE OF RESULTS

12.1 How will data be handled to safeguard confidentiality (both during and after completion of the research project)?

Participants' anonymity will be promoted by the use of pseudonyms in all written reports of the research materials.

Participants will be informed that they have the right to withdraw at any time if they do not want information they have given used in the study. In this case their data will be returned to them. They have the right to exclude any information given from publication.

Access to the data during and after the research process will be controlled by the researcher and limited to specific persons who will agree to be bound by a confidentiality agreement in terms of this application.

The researcher guarantees that he will not share any information derived from the study with any clinicians caring for the participants. He will advise participants to share such information with their clinicians themselves if he considers it will benefit them to do so.

- 12.2 How long will the data from the study be kept and who will be responsible for its safe keeping?

The data will be destroyed when the study is presented. The investigator will be responsible for its safekeeping.

- 12.3 Who will have access to the raw data and/or clinical records during, or after, the study?

Only the researcher will have access to the tapes during the study. If a transcriber is employed s/he will be required to sign a confidentiality agreement.

No one else will have access to this data.

- 12.4 If recordings are made, will participants be offered the opportunity to edit the transcripts of the recordings? Yes

Participants will be invited to comment on the accuracy of their statements made in the interviews through the summary sent to them as part of the research process. They will be specifically invited to review any taped statements intended to be directly quoted in the final report in order to modify or veto it. If they wish they will be able to review a full transcript of their interviews. They will be able to edit any statement to more accurately reflect their views or delete material they do not wish used. They can decide to withdraw from the study if they are unhappy with the content of their interview.

- 12.5 What will be done with the raw data when the study is finished? If audio or video tapes are used how will these be stored and disposed of?

Tapes and transcripts will be destroyed.

- 12.6 Describe any arrangements to make results available to participants, including whether they will be offered their audio tapes or videos.

Participants will be given a summary of their interviews as part of the research process. They will be offered a copy of their tapes. They will be given a summary of the results of the research. If they wish they will be given a copy of the full report.

- 12.7 Is it intended to inform the participants' GP of the results of the investigations, if the participant consents? If NO, outline the reasons.

If issues arise during the interviews, which it would benefit the participants themselves for their clinicians to be aware of, they will be encouraged to discuss these issues with their clinician.

- 12.8 Will any restriction be placed on publication of results? If yes, please supply details.

No, other than those noted above.

13. CULTURAL ISSUES

13.1 Are there any aspects of the research which might raise specific cultural issues?

The group of participants are Pakeha men. This group has been chosen because it is recognised in the literature (Reiss 1986, Wolcott 1988) that dialysis patients of different ethnic origins, such as Maori, may have different concerns than those from the dominant white culture. Rather than treating all dialysis patients as a homogeneous group, Pakeha men have been chosen in recognition that the experience of dialysis for Maori may be distinctive, both as a result of their specific cultural background and as a result of their position in the dominant white culture.

Maori men and women, as a significant proportion of the dialysis population in New Zealand, certainly deserve to be studied as much as Pakeha men. Researching with Maori would best be done by a person with considerable knowledge of Maori culture.

It is hoped that dissemination of this study throughout the renal community will stimulate further research which will include work with Maori patients.

13.1.1 The following checklist has been devised to assist researchers complete their research proposals where Maori participants/resources are party to the process:

1. Does your project impact on Maori Health?

NO

2. If the response to Question 1 is NO, outline the reason to support this.

It only involves Pakeha patients.

3. Outline the consultation process undertaken prior to methodology being consolidated.

NA

13.1.2 Does your research involve other ethnic or cultural groups?

NO

14. OTHER ETHICAL ISSUES

- 14.1 Do you see any other ethical issues arising from this project, other than those already dealt with in your answers?

The relationship of the researcher to the participants, as a member of the health care team caring for them, has the potential to exacerbate the ethical problems involved in the study. The design of the study has specifically addressed this issue in an attempt to minimise this potential.

Philosophically it is considered that this relationship will be advantageous to the research process and the research itself to the relationship between the department and the participants. It is hoped that, given the ethos of openness and trust that prevails in the Wellington department of Renal Medicine, participants will be more willing to freely, honestly and fully share with the researcher who works there.

Explicitly addressing issues of confidentiality in the context of such a positive ethos should enable a greater insight than would be possible with a researcher unrelated to the participants at all.

Thank you for your assistance in helping us assess your project fully. Please now complete the declaration's page (Part IV) and then enclose a completed Drug Administration Form (if applicable), and ARCIC Declaration (if applicable)

PART IV: DECLARATIONS

1. DECLARATION BY PRINCIPAL INVESTIGATOR

The information supplied in this application is, to the best of my knowledge and belief, accurate. I have considered the ethical issues involved in this research and believe that I have adequately addressed them in this application. I understand that if the protocol for this research changes in any way I must inform the Ethics Committee.

NAME OF PRINCIPAL INVESTIGATOR (PLEASE PRINT):

SIGNATURE OF PRINCIPAL INVESTIGATOR:

DATE:

2. DECLARATION BY THE HEAD OF THE DEPARTMENT OR SERVICE MANAGER IN WHICH THE PRINCIPAL INVESTIGATOR IS LOCATED**

I have read the application and believe it to be scientifically and ethically sound. I approve the Research Design. I give my consent for the application to be forwarded to the Ethics Committee.

NAME OF HEAD OF DEPARTMENT OR SERVICE MANAGER (PLEASE PRINT):

SIGNATURE OF HEAD OF DEPARTMENT OR SERVICE MANAGER:

DATE:

****** (NOTE: WHERE THE HEAD OF DEPARTMENT IS ALSO ONE OF THE INVESTIGATORS, THE HEAD OF DEPARTMENT DECLARATION MUST BE SIGNED BY THE APPROPRIATE DEAN, OR RELEVANT SENIOR OFFICER)

3. DECLARATION BY THE GENERAL MANAGER OF THE HEALTH SERVICE IN WHICH THE PRINCIPAL INVESTIGATOR IS BEING UNDERTAKEN (IF APPLICABLE)

I have reviewed the proposal for cost, resources, and administrative aspects and issues regarding patient participation and staff involvement. The proposal has my approval subject to the consent of the Ethics Committee.

NAME OF GENERAL MANAGER (PLEASE PRINT):

SIGNATURE:

PART IV: DECLARATIONS

1. DECLARATION BY PRINCIPAL INVESTIGATOR

The information supplied in this application is, to the best of my knowledge and belief, accurate. I have considered the ethical issues involved in this research and believe that I have adequately addressed them in this application. I understand that if the protocol for this research changes in any way I must inform the Ethics Committee.

NAME OF PRINCIPAL INVESTIGATOR (PLEASE PRINT):

NICK POLASCITEK

SIGNATURE OF PRINCIPAL INVESTIGATOR:



DATE:

18/6/97

2. DECLARATION BY THE HEAD OF THE DEPARTMENT OR SERVICE MANAGER IN WHICH THE PRINCIPAL INVESTIGATOR IS LOCATED**

I have read the application and believe it to be scientifically and ethically sound. I approve the Research Design. I give my consent for the application to be forwarded to the Ethics Committee.

NAME OF HEAD OF DEPARTMENT OR SERVICE MANAGER (PLEASE PRINT):

Peter Hatfield Clinical Academic Renal/Urology

SIGNATURE OF HEAD OF DEPARTMENT OR SERVICE MANAGER:

PETER HATFIELD

DATE: 18.6.97

** (NOTE: WHERE THE HEAD OF DEPARTMENT IS ALSO ONE OF THE INVESTIGATORS, THE HEAD OF DEPARTMENT DECLARATION MUST BE SIGNED BY THE APPROPRIATE DEAN, OR RELEVANT SENIOR OFFICER)

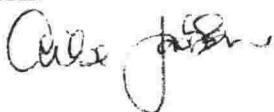
3. DECLARATION BY THE GENERAL MANAGER OF THE HEALTH SERVICE IN WHICH THE PRINCIPAL INVESTIGATOR IS BEING UNDERTAKEN (IF APPLICABLE)

I have reviewed the proposal for cost, resources, and administrative aspects and issues regarding patient participation and staff involvement. The proposal has my approval subject to the consent of the Ethics Committee.

NAME OF ^{Service} GENERAL MANAGER (PLEASE PRINT):

Aileen Jacobson

SIGNATURE:



VICTORIA UNIVERSITY OF WELLINGTON
Te Whare Wananga o te Upoko o te Ika a Maui



19 June 1997

Alison Douglas
Chairperson
Wellington Ethics Committee
Wellington Hospital
Private Bag 7902
Wellington South

Dear Alison

**Re: Nick Polaschek
The concerns of Pakeha men on Home Haemodialysis: An
interpretive study**

This proposal has been reviewed by the Department of Nursing and Midwifery Research Committee and meets our approval for submission to your Committee for ethical consideration.

Yours sincerely

Maralyn Rowley
Senior Lecturer



Assessment of Proposal for MA Thesis in Nursing Studies

Project Title

The Concerns of Pakeha Men on Home Haemodialysis: An Interpretive Study

Researcher

Nick Polaschek, Masters Student, Department of Nursing and Midwifery, Victoria University of Wellington

This research proposal focuses on the experiences of pakeha men who are on home haemodialysis. The researcher is particularly concerned to show the world of the person on home haemodialysis from their own perspective as opposed to the perspective of nursing or medical personnel. There are several features of this proposal which warrant comment and which justify research of this nature.

Viewing the world from the perspective of the person living the experience is now a well accepted and important methodological approach within many social science disciplines. In this study a qualitative methodology is imperative if the experiences, feelings, and views of this group of men are to be explored. While this research intends to focus upon those men undergoing home haemodialysis the findings of the research may also shed light on the experiences of people living with chronic illnesses which require an adherence to specific routines or therapeutic regimes.

The researcher brings to this research a long experience in renal nursing, but is distanced sufficiently from the proposed respondents to allow for this type of interviewing to be carried out. That is, he is not immediately responsible for their care and the attendant ethical issues which would arise in this situation.

The researcher is also male and intends to interview male pakeha on home haemodialysis. There are definite advantages in men interviewing men (and women interviewing women) in that gender does provide a shared experience, and assist with the development of rapport. This rapport will be also aided by the proposed three interviews with each respondent - this allows for an in-depth account to be obtained. The other quality that contributes to the similarity between the researcher and the respondents is that of ethnicity, and this helps to reduce the gap between the researcher and the researched. The rationale for selecting pakeha men for this study is elaborated in the proposal.

The research topic has merit on another level, that of the focus on men's perspectives on their own health. Research into men's health is currently gaining attention from a wide range of commentators, and research in this area will contribute greatly to the sparse literature which is presently available.

I look forward to reading the completed study, and recommend that it be approved.

A handwritten signature in black ink, appearing to read 'Allison Kirkman', followed by a long horizontal line.

Allison Kirkman (Dr)
Lecturer in Sociology

18 June 1997

WELLINGTON ETHICS COMMITTEE

CENTRAL REGIONAL HEALTH AUTHORITY

9 July, 1997

Mr Nick Polaschek
Department of Nursing and Midwifery
Victoria University
PO Box 600
WELLINGTON

Dear Nick

97/52 - The concerns of Pakeha men on home haemodialysis: An interpretive study.

Your application for Ethics Committee approval for the above study was considered by the Ethics Committee at its meeting on 8 July 1997. The Committee expressed its appreciation of the very comprehensive nature of your proposal, noting that it addressed the various ethical issues in considerable depth. The only issue to which the Committee wished to draw your attention was the importance in a study where there are only six participants, of the need for caution in ensuring that the participants remain non-identifiable in the final write-up of the study.

This study is approved. It is a condition of Ethics Committee approval that you provide a brief progress report no later than July 1998 and at the completion of the study a copy of any report/publication for the Committee's records. Please notify the Committee if the study is abandoned or changed in any way.

We wish you well with your research.

Yours sincerely



 Sharron Cole
CHAIRPERSON



Appendix one

The concerns of Pakeha men on Home Haemodialysis

Researcher: Nick Polaschek, Charge Nurse, Haemodialysis Unit tel 3855980

Request for participation / Information sheet

Dear

I am writing to ask you to consider being part of a research project I am doing for my thesis for an MA in Nursing Studies at Victoria University. This letter gives you information about the project to help you decide whether you wish to be involved.

My study attempts to find out the concerns of men on Home Haemodialysis. At present there is little work done on how people actually feel about their life on dialysis or trying to discover what the issues are that concern them about it.

The results of the project will help us to reassess how effectively our service meets the needs of Renal patients as they see them. It is hoped that it will contribute to improving the life of people on dialysis.

My research will involve working in some depth with a selected group of about six patients, men who have been on dialysis for over a year. In the interviews participants will discuss different aspects of what life on dialysis is like for them.

Participating in the research would involve three interviews, each of about an hour, at your home, talking about how your life has changed since you have been on dialysis. The interviews would be taped. The second, which would take place while you started a dialysis session at home, would specifically discuss how you found the process of dialysis. At a third you would be able to comment on a written summary of the first two interviews which I would have given to you beforehand.

You will be given a pseudonym (false name) for the project which will be used in research reports to ensure your anonymity. No material that could identify you will be used in the reports.

At any time during the research you could withdraw your participation if you wished to. How much you say about any subject is entirely up to you. Anything that you say that is to be included in the final report you will be able to review and modify or

exclude if you wish. When the whole project was completed you would get a summary of the results or, if you prefer, a copy of the full research report.

While the research is based on patients' views I will interpret these in my work. Any conclusions from my work will be open to review as they will be shared with the Wellington Regional Kidney Society to allow their comment and with professional groups for their critique. The project will be completed in 1999.

The project is being supervised by members of the Department of Nursing and Midwifery at Victoria University. It is supported by the Department of Renal Medicine. It had been audited by the Ethics Committee of the Central Regional Health Authority.

Thank you for considering being involved in this research. If you are interested in being part of this research project please give me a ring in the next week at 3855980 day or 3897583 evening. I can arrange to meet you if you wish to discuss any matter of concern to you about it to enable you to make a decision. If for any reason you do not wish to participate that's fine. I only need a small group of people who are happy to discuss their lives on dialysis

yours sincerely

Nick Polaschek

VICTORIA UNIVERSITY OF WELLINGTON
Te Whare Wananga o te Upoko o te Ika a Maui



RENAL MEDICINE

Appendix two

The concerns of Pakeha men on Home Haemodialysis

Researcher: Nick Polaschek, Charge Nurse Haemodialysis Unit, Phone 3855980

CONSENT FORM

I, consent to participate in the study by Nick Polaschek on "The concerns of Pakeha men on Home Haemodialysis".

I agree to Nick Polaschek coming to my home to conduct three interviews with me which will be recorded on audiotape.

I agree that any information I give, including my own words, may be used in the study report.

I agree that the tapes of my interviews and computer diskettes of any transcripts of these will be stored safely in accord with normal academic practice for five years.

I have read the information sheet about the project and discussed all issues of concern to me with the researcher. I understand what the study will involve for me. I have had sufficient time to decide whether I wish to take part.

I understand that my participation in the study is confidential and that no material that could identify me will be used.

I understand that my participation in the study is voluntary (my choice) and that I have the right, without giving a reason, to withdraw at any time during the study.



The concerns of Pakeha men on Home Haemodialysis

CONSENT FORM (continued)

I understand that I will be given the opportunity to review all the information that I supply and can require that any part or all of it be excluded from the study if I choose.

I understand that any information supplied by me will be kept separate from my clinical care information. It will not be discussed with my clinicians unless I specifically request it. I understand that my participation will not affect my clinical care in any way.

I understand that use of the information I have given, other than the study report, will be discussed with me, any potential identification problems explored, and my permission explicitly sought to use the material, any of which I may exclude if I so wish.

I know that if I have any concerns about any aspect of study before, during or after my participation, I can discuss these with the Wellington Ethics Committee, telephone Wellington Hospital 385-5999 ext 5158.

PATIENT SIGNATURE:

WITNESS SIGNATURE:

DATE:

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