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**Experiencing Dialysis:  
A Descriptive Phenomenological Study of Nurses and  
Patients in Dialysis Satellite Units**

Mark Thomas Bevan

Submitted in accordance with the requirements for the  
degree of Doctor of Philosophy

University of Huddersfield

2007

The candidate confirms that the work submitted is his own and that appropriate credit has been given where references have been made to the work of others

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## List of Abbreviations

CKD: Chronic Kidney Disease
COREC: Central Office of Research Ethics Committees
CRF: Chronic Renal Failure
ESRF/D: End-Stage Renal Failure/Disease
DoH: Department of Health
DSU: Dialysis Satellite Unit
LREC: Local Research Ethics Committee
MU: Main Unit
NHS: National Health Service
NMC: Nursing and Midwifery Council
QoL: Quality of Life

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## Abstract

### **Experiencing Dialysis: A Descriptive Phenomenological Study of Nurses and Patients in Dialysis Satellite Units**

Dialysis satellite units (DSU) have been a method of treatment delivery in the UK since the 1980s. Units were developed to expand dialysis provision and serve a number of patients from specific geographical areas.

There is a dearth of research related to satellite unit dialysis. Most research related to haemodialysis usually incorporates satellite unit patients in their findings. Available research is related to measurable parameters of medical treatment. At the start of the research there was no research related to nursing experience on satellite units. Nursing experience was examined generally and specifically around aspects such as stress. Research relating to patient experience is based upon methodologically accepted approaches such as measuring stress, coping, compliance and quality of life. These methods frequently reduce experience into statistics that, while they have a range of application, often miss the depth of meaning related to experience.

Patients express a great deal of satisfaction about their experiences of satellite units and are reluctant to return to a main unit for treatment. This expression of experience stimulated the research question '*What is the experience of patients and nurses in dialysis satellite units?*' The research aims to examine the subjective experience of both nurses and patients. The research will aim to describe structures of experience to shed light upon expressions of satisfaction and reluctance.

The means for examining subjective experience required the use of a qualitative research method. The descriptive phenomenology of Husserl was chosen for its distinct structure and theory free approach to studying phenomena of the Lifeworld.

The method of data collection was provided by a novel phenomenological interview structure which incorporated the use of imaginative variation. Observation as a method of data collection was also used because it provided aspects of experience that would remain hidden through interview method alone. Spradley's (1980) descriptive matrix was used to guide observations. A combination of both methods increases phenomenological adequacy. Three DSUs provided the field of study. A total of twenty five patients and twelve staff members were interviewed. Ethical approval was obtained for the research.

Data analysis was undertaken with a modified version of Giorgi's (1985) phenomenological method of data reduction by meaning units and generalization. Imaginative variation was applied for structural clarity and structural coding was applied for adequacy.

Four general structures of experience were synthesised to provide a constitution of phenomena.

1. Experiencing Illness. Illness is context structure that gives meaning to dialysis. Minimalization of illness is structured through the absence of doctors, not seeing illness and distancing illness by referral to the main unit.
2. Time Saved. Time is saved for the patient through fewer patients for dialysis, time distraction, and absence of illness. Staff save time through preparation and planning and making time available for patients.
3. Feeling Safe: Repetition, routine, familiarity, predictability, nearness and closeness, being known, knowing others and not thinking of illness all provide an experience structure of feeling safe.
4. Freedom to Practice: Making a difference. Feeling isolated and an awareness of responsibility leads to decision thoughtfulness. Thoughtfulness enhances decision making giving a sense of autonomy, confidence and freedom to practice. These facets of experience enable nurses to make a difference to patient care.

The findings of the research identify the patient desire to avoid experiencing illness improves coping ability. Satellite unit nurses develop enhanced skills and expertise that enables quality patient care. The experience of nurses is congruent with other nurse-led units. Implications for practice are the development of autonomy and responsibility which would enhance service provision for patients. An innovative application of phenomenology involving observation and imaginative variation can produce accurate descriptions of structure of experience.

# **Chapter One**

## **Introduction**

## **1.0 Introduction**

This dissertation is an examination of the experiences of nurses and patients from dialysis satellite units. It reflects an amalgamation of specific interests, personal experience, observation, and comments by others about the nature of dialysis satellite unit life. The decision to undertake the study is grounded in my personal experience and that of others and because of this it is qualitative in nature. My interest in human beings, their experiences, their lives, accomplishments and troubles provided me with a reason to pursue this venture. From the outset I acknowledge that human life is communal, intersubjective, and interpretative, that it creates its own culture which is historically orientated and has meaning. I see that each person is embodied in that they live their lives in through their bodies immersed in community and culture. It is living an embodied life that brings people to the consciousness of nurses. Illness of the body focuses attention and requires treatment and care by nurses. Living with a chronic illness such as end-stage kidney failure means that people will frequently and regularly come into contact with nurses for a variety of needs such as dialysis. It is this convergence of nurses and patients that has interest for me.

A nurse is trained to watch and listen to people, to hear their concerns and observe their corporality. I use the word corporality to emphasise not only the body but the bodily existence of the person. In this sense this study is an extension of nursing practice of watching and listening to people living in illness. It is also an exploration of nursing in action, of people being nurses and of what it means to manage people who need haemodialysis. I do not aim to answer the unanswerable question of “what is nursing?” but to shed light on unseen or shaded aspects of nursing.

At first glance at a dialysis unit one could be forgiven for presuming dialysis nursing is highly technical and machine orientated. It is not clear if this truly is the case or whether what we gaze at provides an accurate interpretation of what dialysis nurses do. When looking into a

dialysis unit is our attention is drawn to the wonders of medical technologies that sustains life and in doing so our interpretations may be dominated by machinery. This domination or, as I prefer to call it, bright aspect of appearance, hinders our ability to see other aspects. Indeed I have expressed such concerns of technologically dominated view in that past (Bevan, 1998). This study is not intended to investigate this question outright but it does highlight the importance of appearance. What I mean here is the importance of appearance that is more adequately presented to the viewer. Dialysis is a technological venture for both the patient and the nurse; it is living with life sustaining technology, dependency and implementation respectively. This is an intersubjective, co-experienced and communal convergence. It is this convergence that interests to wonder how nurses and patients experience haemodialysis. Naturally convergence occurs in buildings and the demand for these centres is increasing. As I shall explain, in more detail later, the traditional regional or main centre model for dialysis facilities could no longer sustain demand This inability to sustain demand was a catalyst for the development of satellite units. Satellite units are poorly researched, as I will show, and are almost entirely nurse-led units. What they offer is a unique opportunity to explore nurse and patient experience.

My study investigated the nurse-patient intersubjective experience of satellite haemodialysis units. In order to do this it is important that the background is fleshed out in more detail than what I have alluded to above. The background information will show the reader what the renal setting is about and the development of dialysis satellite units as a treatment modality. Here the reader will also find more information regarding the aim and outline method of the study. Following on from this I shall examine what evidence there is regarding the experiences of patients and nurses in the dialysis setting. The evidence of experience will draw upon a range of literature to provide a picture of how things are and what this means. Moving on the reader will be taken through the ethical issues related to this study. Not only will the ethical section discuss the practicalities associated with the study but it will show how the approach I used i.e. Phenomenology is foundational for ethics.

I am aware that I have introduced the term “Phenomenology” for the first time here without providing a definition. I can assure the reader that this will be dealt with in great detail following the section regarding how I recruited participants. Phenomenology will be analysed including some nursing influences. There is a strong philosophical basis to phenomenology and this will be reflected in the discussion, however, this is translated into the practicalities of data collection methods and analysis used during the investigation. The findings will be displayed for the reader and will include not only narrative text but also findings from observations. Finally, if that isn’t enough, there is a discussion showing what it all means with particular reference to the nursing discipline, patient care and further research. I hope the journey for the reader is not overly arduous, considering the size and volume, but is interesting, stimulating and sheds light onto shaded aspects of nursing and patient co-experience of dialysis.

## **Background to the Study**

### **1.1 Kidney Disease and Kidney Failure**

The first known written knowledge of the function of the kidney and its relation to urine production were expressed by Rufus of Ephesus in the 1<sup>st</sup> century AD and Galen in the 2<sup>nd</sup> century AD (Cameron Stewart, 2005). Rufus of Ephesus described scarred kidneys and the symptoms experienced that are now attributable to kidney failure. This early knowledge influenced understanding of the kidney for several hundreds of years until the 16<sup>th</sup> and 17<sup>th</sup> centuries, when interest in human body function became part of the new science of the renaissance. However, it was not until 1827 when Richard Bright linked specific symptoms to the failure of the kidney. This was significant because until this point symptoms were seen as diseases in their own right. (Cameron Stewart, 2005). The recognition that kidney failure was linked to elevated levels of urea (a by product of protein metabolism in the body) in the blood led to the term uraemia (which literally means urine in the blood) being used. The speciality

of nephrology did not develop until much later in the twentieth century when dialysis and transplantation became realistic treatment options for what was a terminal disease.

The kidney is responsible for maintaining the body's normal internal physiological chemical balance. The kidney has many functions and includes maintaining water balance; electrolyte (e.g. sodium, potassium, chloride) balance; removal of waste, toxins and drugs; control of blood pressure; activating vitamin D; acid balance; and production of red blood cells. When the kidneys fail the functions stated above lead to a deranged state whereby water, electrolytes, waste, toxins and drugs cannot be removed and thus accumulate in the body. Accumulation in the body presents as fluid overload, dangerous levels of potassium (may cause cardiac arrest), and the effects of systemic poisoning such as headaches, nausea, vomiting, itching, cramps, weight loss, tiredness, cognitive impairment, and insomnia to name just a few. The person will also suffer from severe anaemia, iron deficiency, acidosis, and vitamin D deficiency (causing bone disease such as fractures).

A decline in kidney function can occur over a number of hours, as in acute kidney failure, or months to years in chronic disease (depending upon the nature of the cause). Chronic kidney disease (CKD) is irreversible and in many instances leads to end-stage kidney failure (ESRF). If kidney failure is not treated then the person will gradually deteriorate into a coma which is swiftly followed by death (Swan & Keane, 2001).

## **1.2 The Causes of Chronic Kidney Disease**

The causes of chronic kidney disease are multiple and can be primary (initial disease is in the kidney) or secondary to a systemic disease such as diabetes mellitus. The commonest cause of ESRF in the developed world is diabetes mellitus (20-40%) followed by high blood pressure (5-25%) and a chronic inflammation of the kidney called glomerulonephritis (10-20%) (Goddard, Turner, Cumming & Stewart, 2006). The incidence of CKD is three times that of

ESRF. The incidence of ESRF has increased over recent years which has led to increasing numbers of people being accepted for dialysis. The acceptance rates increased during the 1990s from 67 people per million population (pmp) in 1991 to 82 pmp in 1995 and 92pmp in 1998 ( The U K Renal Registry, 2003). It is forecast that the acceptance rate will increase and should reach an estimate of between 120-130pmp.

### **1.3 Who Gets Chronic Kidney Disease?**

There is data that shows that CKD is predominantly a disease of the elderly. The median age of patients receiving dialysis is 64.8 years with 22.3 % being older than 75 years old (The UK Renal Registry, 2003). In addition to this there is a higher proportion of males to females (6:1) especially in the over 40 age group (The Renal Association, 2002). There is a disproportionate incidence of ESRF in ethnic groups for example 422pmp for Indo-Asians and 374 for Afro-Caribbean (The Renal Association, 2002). The reason for this relates to increased risk and incidence of cardiovascular disease, hypertension and diabetes mellitus within these groups. The Renal Association (2002) also report that those from low socio-economic classes, which include many ethnic minority groups, have a high incidence of ESRF and a high mortality rate from renal failure.

### **1.4 Treatment for Kidney Failure: Haemodialysis**

Dialysis is a term coined by Thomas Grahame in 1850 to describe diffusion of solutes through a semi-permeable membrane. Grahame had the vision to state that dialysis had the possibility of removing substances from the blood (Cameron Stewart, 2005). Further developments of dialysis as a possible treatment (but not initially for kidney failure) were carried out in the early 20<sup>th</sup> century. It was theorized that waste substances and toxins could be removed from the blood across a semipermeable membrane (dialysis) and thus preventing death from kidney failure. Early attempts at dialysing humans in the 1920s ended in death for all the patients. Treatments were hampered by limited technological advancement such as plastics. Not until

1945 did Willelm Kolff, in Nazi occupied Holland, manage to use dialysis to successfully treat a patient with acute renal failure. This proved to be a major breakthrough. Dialysis developed slowly again limited by slow developments in technology. Not until the 1960s did dialysis begin to be applied to ESRF patients when the means of permanent vascular access was developed. Dialysis remained a relatively experimental treatment during the 1960s however it gained significant public attention and demand to increase its availability. During the 1970s there was a moderate increase in dialysis mainly centred at teaching hospitals that acted as regional centres and restricted treatment to younger patients without significant co-morbidity. The main form of dialysis at this time was haemodialysis and undertaken at either the hospital or increasingly at home (Cameron Stewart, 2005).

### **1.5 Development of Satellite Units**

During the 1980s there was increasing demand for dialysis. This was partially met by the introduction of an alternative form of treatment called peritoneal dialysis; though this was not suitable for many patients. Dialysis units began to expand and it was about the mid-1980s that the first minimal care units were developed; later to be known as satellite units. These units were developed to manage the increasing demand for dialysis, and to treat a geographically located critical mass of patients (Renal Registry, 2002). Satellite units were nurse-led but still remained linked to main units for all aspects of treatment and medical decisions. A change in government health policy in 1994 saw a marked increase in the number of satellite units through additional funding. In 1993 there were thirty six units; by 1995 this had increased to sixty; a further increase in 1998 to seventy three. By 2002 there were one hundred and seventeen units (including twenty nine units commercially managed for the NHS) treating five thousand seven hundred and three patients (The UK Renal Registry, 2001, The UK Renal Registry, 2003). A further forty seven satellite units were being planned (The UK Renal Registry, 2003).

By 2002 satellite units accounted for 47% of dialysis stations in the United Kingdom which accounts for a 79% increase in the number of patients dialysed. Hence satellite units are a

significant treatment resource for kidney failure and will continue to grow as the demand grows.

### **1.6 Identifying the Research Problem**

My involvement with kidney failure began as a student nurse where I had my first exposure to patients suffering from the disease. My experience was one of frustration because I found that no one seemed to understand how to care for them, which, in my mind, led to inappropriate nursing care. This experience stimulated a desire to get involved in the kidney speciality to ensure that at least I could provide appropriate care. I started working in a dialysis unit at a large teaching hospital in 1985. I quickly became involved haemodialysis and witnessed the early establishment of two satellite units in about 1987. As a charge nurse I had frequent contact with the satellite unit staff and patients. My involvement with satellite units increased when I became a nursing teacher for renal nursing. I frequently visited the satellite units, which numbered seven at one point, to ensure students were well supported and to ensure they were adequate student teaching environments.

During my visits to the units I would talk with patients and staff and observe activities and events. One comment that was often mentioned by patients was that they no did not want to return to the main unit. This comment stuck with me for several years until the opportunity arose to consider it for research. The reason it stayed with me was because it seemed to point to something going on that was interesting and possibly reflected satellite unit culture.

There is a general acceptance in the literature of the existence of dialysis units as a homogeneous mass with no real acknowledgment of their potential for mediating psychological responses of patients. Dialysis treatment is also perceived as an isolated event not immersed in a social environment. However, patients live in the social world of the dialysis unit and beyond, which will invariably have an impact upon their psychological perception and reaction. Nurses work in these units, in isolation from the main unit, which invariably meant that their experience was different from those at the main unit. Therefore, it

was important to understand how patients responded in different dialysis units. This is of particular importance due expansion of dialysis services where nurse-led satellite units are increasingly the norm. Until fairly recent times there was no research relating to satellite units. This research is retrospectively descriptive statistical in nature such as those cited above from The Renal Association.

It was presumed that what occurred in the main unit applied to satellite units too. Whilst some of this may be true, my experience appeared to identify a different kind of environment. I began to think about what was happening at a satellite unit that made patients not want to return to the main unit, appear satisfied with treatment and be emotionally stable. Clearly the patient's experience was significantly different to warrant examination. In view of the fact that satellite unit numbers will increase it also seemed important to understand what was happening which may inform future developments. Whether this observation are true or not is not the focus of the research but it was these observations that made me as the initial question *"What was going on in dialysis satellite units?"*

### **1.7 The Research Question**

Once I had identified a particular attraction there was a need to become somewhat focussed and reflect my interest in the intersubjective nature of experience. Therefore, the initial question was restated to the following *"what is the experience of patients and nurses in dialysis satellite units?"* Here is a more focused question that identifies the realm of my study: the nurse-patient experience. Having identified this focus the overall aim of the study is to *explore how nurses and patients experienced dialysis satellite units*. Posing the initial question and aim in the above manner means that a broad scope for investigation is envisaged. Adopting this approach is not unusual in qualitative research and quite often the single aim or question is sufficient for the investigation to progress (Munhall, 1994, Munhall & Oiler Boyd, 1999). The rationale for this approach is that the study is exploratory and open to whatever appears to the researcher. It also means there are no preconceived ideas to be

forced upon the phenomenon under investigation which is congruent with phenomenological method (Munhall, 1994). In order to achieve my aim one of the objectives was *to describe experience as it appears*. Stating this is important because it relates to how things are, not how they could be or how they should be. This objective is a commitment to illuminating shaded aspects of experience. There are also two words that are important, describe and appear. To use the word “describe” positions me in a particular orientation to phenomenon. It means that I aim to describe a thing and not explain it in relation to cause and effect. Description is also not seen as a low level cognitive skill but a disciplined approach to presenting clarity in meaning and interpretation. The relationship to the word “appear” is important because it means that whatever is described has to relate to what appears as it appears. By adopting this objective I am placed into a descriptive phenomenological orientation which is about the study of the appearance of things to consciousness.

According to Husserl (2001) as soon as experience is expressed through language it becomes thematic. Therefore the objective, stated above, also indicates another important issue which is about making sense or meaning. In order to make sense or meaning is to articulate it, or in this instance it is appearance of experience, it must become thematic. This is not to say that themes will be placed at the outset, but that themes will emerge in some manner. A theme indicates some form or structure or organisation that has meaning for a thing or state of affairs. I acknowledge that experience is structured or organised in some form or other. Therefore the next objective will be to *describe the structures and meanings of experience of patients and nurses on dialysis satellite units*. To describe structures *and* meanings will help make sense of experience.

To recap what I have just discussed, the aim of the study is to *explore how nurses and patients experienced dialysis satellite units*. The objectives of the study are: 1.*To describe experience as it appears and 2.To describe the structures and meanings of experience of patients and nurses on dialysis satellite units*.

To help achieve these objectives and provide more detail I developed the following subsidiary questions:

- *What experiential structures constitute a dialysis satellite unit for nurses and patients?*
- *What are the interactions between the nurse and patients?*

As I have already stated, by asking questions in this manner, the research is identified as exploratory. It also identifies that the focus is upon gaining access to personal experience which is an examination of subjectivity; an insider perspective (Giorgi and Giorgi, 2003, Holloway and Wheeler, 1996). In essence the questions aim to clarify situations of the everyday lifeworld of satellite unit patients and nurses. Lifeworld is a phenomenological term that describes the world in which we live and find meaning. There is no desire on my part to reduce experiences into a limited amount of convenient variables or numbers. That is not to say that quantitative methods would not yield some interesting figures of frequency or distribution of phenomena. For example, I was well aware of quality of life scores and depression frequency which have their uses. However, I wanted to enter the research from the perspective of exploring experiences, events and activities, and not assuming a certain proportion of patients will be depressed. In essence I was concerned to describe experience rather than make explanations in order to avoid inappropriately fixing meaning to them (Henwood & Pidgeon, 1993).

By expressing these concerns I was able to clarify my philosophical/ontological position which was to remain throughout the research. This critical self analysis early in the process is important to provide a position that is conducive to effective research (Mason, 2002). My concern was for detailed accounts of experience that makes sense of their lived world and ensures vividness of experience remained present. The adoption of a phenomenological orientation to research will provide a number of benefits to nursing. Because phenomenology is the study of lived experience as it appears it aims at understanding the meaning of that experience. This is a direct contact with experience of the world (of patients) rather than distancing brought about by theoretical abstraction. The study of experience is a study of

experience (of nurses and patients) brought to consciousness and reflected upon which means that experience is made sense of and may be articulated. Making sense is interpreting experience which can be described accurately which in turn can provide structures of experience that may be idiosyncratic or may have a more general application. Phenomenology is systematic and scientific with a focus upon being self-critical, thoughtful, explicit, as well as focused upon a concern for the subject matter of the lived human world (Munhall, 1994). This means phenomenological research will help nurses understand what it means to be a nurse or a patient in a given situation or experience; which is about what it means to be human. So, for nurses, phenomenology offers the opportunity to understand experience and in doing so appraise how to proceed in their endeavour to care for patients. By understanding patient experience as well as theirs nurses can provide a care that is understood and intersubjectively converged in a more effective manner.

In summary, dialysis satellite units are a form of patient treatment that is increasing but has not been researched in any depth. It is a form of treatment that is predominantly nurse-led and offers a field of study that could describe the intersubjective nature of experience in this setting. The dearth of research in this area means that an exploratory study is needed and because of the intersubjective nature of experience it would need to be qualitative. Phenomenology provides a means for studying human experience in a systematic manner that is scientific and thoughtful. Phenomenology is also congruent with nursing ideology of understanding patient experience in order to provide patient-centred care. This dissertation is an account of the investigation of dialysis satellite units which examines the literature, the ethical concerns, recruitment of participants, the data collection methods and methods for analysis as well as what the findings are and mean in relation to patient care and nursing in general.

# **Chapter Two**

## **Literature Review**

## **2.0 Literature Search Method**

One of the important aspects of phenomenological method is the explication of known theory and knowledge so that it may be put in abeyance when examining a phenomenon. In view of this it is important to examine the literature in order to explore my research problem to see if it has already been tackled in any particular manner to avoid unnecessary duplication. Therefore a search of the literature was undertaken. Key words for the search were identified as follows: haemodialysis; dialysis units; dialysis nursing; nephrology nursing; quality of life; psychological reactions; depression; anxiety; stress; coping; non-compliance, and patient experience. The literature search was undertaken in electronic data bases and included Medline; Cinhal; Sociological Abstracts; PsychMethods; Social Sciences Citation; and Embase, as well as manual searches in university libraries.

Literature was chosen on the basis of its application to experience of dialysis and dialysis units. It became apparent that there was no clear unified policy for undertaking research on people's experience of kidney failure which provided a plethora of approaches, methods and psychometric tools. There was also very limited research about renal/nephrology nursing experience. Most research is retrospective or exploratory and usually on small sample sizes which is not unusual in healthcare research. Occasionally psychological research of patients was subsumed by quality of life studies often in relation to a medical intervention. The discussion that follows is an analysis of the literature search and is a synthesis of the varied methods presented in the many studies.

### **2.1 Introduction**

The introduction of haemodialysis (HD) in the early 1960s as a form of maintenance treatment heralded a new era in the management of chronic renal failure (CRF). Prior to this anyone with CRF would find himself or herself with a terminal disease. Scribner's development of a vascular shunt made long-term treatment possible, but also brought with it

additional problems, such as patient selection and long-term coping and rehabilitation (Fox & Swazey, 1973). Demand for dialysis clearly outstripped availability something of which still has not been overcome in the present climate (Kidney Alliance, 2001). This led to a means of selection that, from the outset, identified psychological issues and problems of the individual and their ability to cope with HD. Very early on Eschbach et al (1967) identified the development of excessive dependence upon spouses in the home dialysis situation which appeared to negatively affect adjustment. Psychiatric evaluation of patients for suitability for dialysis occurred in only 25% of the centres that Katz and Proctor (1969) investigated indicating that this was not a widespread activity. It was felt by many units that patient evaluation was an important aspect of selection for treatment and hopefully positive long term adaptation (Sand, Livingston and Wright, 1966). Limited availability of treatment at this period in time, and patient selection, became an impetus for psychological research on dialysis patients.

## **2.2 Haemodialysis and Stress**

From the early days of dialysis and patient selection it became increasingly clear that being a HD patient was linked to psychological problems that affected the patient's outcome. Wright, Sand & Livingstone (1966) undertook a prospective study of twelve patients commencing dialysis to identify the kinds of stress, coping reactions and adaptation. The researchers interviewed patients prior to treatment and at follow up interviews between 6 and 33 months after commencing treatment. Additional psychometric examination was undertaken with a battery of tests: Welcher Adult Intelligence test; Thematic Apperception Test, Rorschach, Rotter Sentence completion, and Minnesota Multiphasic Personality Inventory. The kinds of stressors identified were centred on the theme of the threat of loss: the threat of loss of body parts or function, loss of group membership, changes in the way of living, and loss of home, possessions, occupation, and financial status. The perceived or actual feelings of threat of loss were linked to uncertainty about the future (Wright et al, 1966). Indeed the inability to plan

for the future affected the partner of the HD patient demonstrating that HD had implications beyond the individual alone. Other identified common stressors related to dietary restrictions; bone and joint pain; duration and frequency of treatment; dialysis cannulae; decreased energy and physical activity; and a reduction in sexual potency. The reactions to the stress of dialysis presented in a number of ways and included denial, projection, and depression, where depression is of particular concern and may be present in any patient (Wright et al, 1966). Identification of stressful events in the patient's experience is deemed to be an important area in understanding coping and adaptation to dialysis.

Treatment related stress has been divided into physical and psychosocial stressors indicating a range of potential stressors (Baldree et al, 1982, Bihl, Estwing Ferrans & Powers, 1988). Physiological stressors also rate high in the perception of stress by patients (Baldree et al, 1982, Gurklis and Menke, 1988, Bihl, Estwing Ferrans & Powers, 1988, Everett et al, 1995, Lok, 1996, Welch & Austin, 1998, Welch & Austin, 2001, Mok & Tam, 2001). A list of identified stressors can be found in table 1 below. There is some disagreement in the classification of physiological or psychological stressors. Lok (1996) felt that a review of the classification was necessary because of the need to reflect patient experience more accurately. He argues that 'Limitations of physical activity' should be reclassified as a physiological stressor rather than a psychosocial stressor as first mentioned by Baldree, Murphy and Powers (1982).

Baldree, Murphy and Powers (1982) aimed to develop a dialysis specific tool for identifying stressors and the level of stress due to what they felt was the reliance upon many indirect psychometric tools. They developed the Haemodialysis Stressor Scale (HSS) with a 32-item scale rating the incidence and severity of stressors including physical and psychosocial subscales. This was coupled with the Jalowiec Coping scale (JCS), a 40-item list of coping methods, used for patients to rate on a scale of 1 (least helpful) to 5 (most helpful). Thirty five patients were assessed. The findings demonstrated that both psychosocial and physical

symptoms affect the patient equally. Baldree et al (1982) found that fluid restriction ranked the highest psychosocial stressor above uncertainty of the future and limitation of food. The top physiological stressor was muscle cramps followed by fatigue. The highest ranked coping method was trying to maintain control over the situation, ahead of maintaining hope, prayer and worry. They also found no relationship between stressors and coping methods used. Baldree et al (1982) concluded that patients tended to use problem-orientated approaches to coping particularly maintaining optimism and controlling the situation.

<b><u>The Most Commonly Reported Haemodialysis Related Stressors</u></b>	
<b>Physiological Stressors</b>	<b>Psychological Stressors</b>
Muscle cramps	Limitation of fluids
Fatigue	Uncertainty about future
Feeling tired	Limitation of food
Itching	Decrease in social life
Presence of vascular access	Cost factors
Stiffening of joints	Boredom
Nausea and vomiting	Limited in styles of clothing
Feelings related to treatment	Changes in family responsibility
Insomnia	Limitation of time and place of vacation
	Frequent hospital admissions
	Transportation
	Loss of body function
	Fear of being alone

**Table 1**

Bihl, Estwing, Ferrans and Powers (1988) used the HSS to examine the stress in eighteen peritoneal dialysis (PD) patients and eighteen haemodialysis patients. The haemodialysis patients identified fatigue and routine to be the highest ranked stressors. The PD patients ranked uncertainty and limits to time and place for vacation as the highest ranked stressors. Both group's levels of stress were lower than those found in the Baldree et al study. The overall stressors were similar to those stated by Baldree et al.

Gurklis and Menke (1988) undertook a replication study of the Baldree et al study. Gurklis and Menke had a sample size of sixty eight that was more culturally diverse with more black

patients (29 in total). This issue was concluded to be important because the major coping method was found to be prayer, as opposed to maintaining control in the Baldree et al study. Prayer was especially important amongst the black participants suggesting ethnic sensitivity rather than universal similarity. They found that physical stressors ranked higher than psychosocial stressors. Feeling tired was the highest stressor followed by cramp, with limitation of fluid being the highest psychosocial stressor above limitations of food and physical activity. As with Baldree et al they found that blaming others, taking drugs and/or alcohol were the least reported methods of coping. They also found that patients used a combination of problem-orientated and affective-orientated coping strategies in equal manner. In addition to this they found that the length of time on dialysis was related to stress: higher stress was reported in patients who had been on dialysis a shorter period of time. The researchers also found additional stressors that patients had identified themselves and weren't on the original stressor scale such as being 'tied to the machine', 'dependence' and 'loss of time at home' which indicates a need for further development of the tool. What this implies is that not only is dialysis stressful but an ability to come to terms and adapt over time will allow a more positive adjustment.

Welch and Austin (1999) interviewed a convenience sample of 86 North American patients aged between 20 and 82 (mean age 55) twice, at three month intervals, and use of the HSS to see if there was time altered perception of treatment-related stressors. In this study the highest ranked stressors related to life style changes at both interview one and two. The stressors identified by the patients included time lost while on dialysis, the inconvenience of unit dialysis and the inability to participate in valued activities. The second ranked stressors were fatigue, feeling sick, and an inability to travel freely. The third ranked group of stressors were related to vascular access problems such as inexperienced staff, bleeding, pain and miscannulation. Mean stress appeared to reduce over time for 19 out of 27 items, however, the percentage of patients experiencing stress went up over time in 23 out of 27 items. Welch and Austin also found that older patients suffered from more physically related stress than

younger patients but the stressors identified were different. For example, older patients suffered from joint stiffening whereas younger patients were more concerned about changes in body image. Interestingly patients who were better educated (at least to high school level) appeared to suffer more stress than those less well educated. These stressors included uncertainty, dependency, treatment cost and transportation. The researchers also found, unsurprisingly, that those patients new to dialysis (less than 6 months treatment) suffered more stress especially related to treatment such as cramp. Caucasian patients appeared to experience more stress than African American patients initially but this evened out over time. Welch and Austin's study raises issues perhaps not identified in previous studies. These issues are that stress changes with time not only the intensity but the total number; gender differences of stress perception occur; education may influence stress perception; age-related variance in physical orientated stress; ethnic variance; and newness to treatment is more stressful. A more complex picture is described in this study highlighting the life-changing effect of dialysis and stress associated with treatment. Burns (2004) used Roy's Adaptation model to study coping strategies in 102 Black Americans. Burns (2004) found, like other studies, that physical problems such as fatigue and muscle soreness were frequently reported. Burns also found that the more problems a patient identified the less well they adapted to treatment. It was also found that prayer and trust in God was the most used coping strategy by this sample of patients indicating ethnic specificity similar to the Bihl et al study.

More recent studies have identified physical symptoms such as fatigue, itching, cramp, sleep disturbance, tiredness, and length of treatment were all found to play a part in the physical stress associated with treatment (Lok, 1996, McCann & Boore, 2000, Mok & Tam, 2001). A recent Canadian study, by Logan, Pelletier-Hibbert and Hodgkins (2006), aimed to assess stress and coping in the over 65 year old age group. Using the HSS and the JCS a sample of 50 dialysis patients were assessed. The highest ranked stressor was identified as limits on time and place for vacation ahead which was ahead of feeling tired, decrease in social life and limitation of fluid. Limits on time and place for vacation was not a stressor identified in the

other studies which may demonstrate changes in population expectations, social differences between age and ethnic groups as well as changes in dialysis treatment such as improvements in the treatment of anaemia leading to less tiredness. Interestingly they found that length of time on dialysis was the lowest ranked stressor which was a different finding to those found in similar studies mentioned earlier. The highest ranking coping strategies were keeping a sense of humour, looking on the good side and thinking positively demonstrating an optimistic orientation. Logan et al found that as a group the elderly were fairly homogenous in relation to stressors. Older patients used a fewer number of coping methods and often found them to be of limited value. What this implies is that older patients may not cope as well as younger patients and should be targeted for additional support.

The Logan, Pelletier-Hibbert and Hodgkins (2006) study contrasts differently to another Canadian study undertaken in 2005 by Harwood et al. In the Harwood et al study qualitative interviews were undertaken in eleven patients with ages between 61 and 89 years. The physiological stressor identified as most troublesome was 'feeling sick' followed by insomnia and psychological stressors tied for top place were 'being a burden on the family', financial stress and transportation. Four patients stated they felt little or no stress. Whilst this was a small study it does highlight the important issue of patient identified problems and researcher produced items. In the latter case the patient is forced to make a judgement against set criteria which may not relate to their experience. The fact that some patients stated that they felt little or no stress is important because it is quite plausible that this is the case and thus makes individualised care more of an imperative rather than generalizations.

The cultural or ethnic perception of stressors is an important issue. For example in Mok and Tam's (2001) study of 50 Hong Kong dialysis patients limitation of fluid was identified as the highest stressor. They put this down to the social functioning within families and friends where the taking of Chinese tea is an important social interaction. Yeh and Chou (2007) found that dependence on medical staff and vascular access problems rated highest as

stressors in 2642 Taiwanese patients. This indicates treatment orientated stress and is different to the culturally similar sample found in Mok and Tam's study. Lok (1996) examined the stressors of 58 Australian dialysis patients and found that limitations on activity and fatigue were the highest ranking stressors. Lok found that Australian patients used problem-solving orientated coping at a higher level compared to North American studies where affect-orientation coping was more dominant. The studies point to the need for cultural sensitivity because it cannot be assumed that everyone will perceive stress in the same way.

Physical effects of illness play a major part in the perception of stress though what is not clear is the distinction between illness stressors and treatment stressors (Logan, Peletier-Hibbert and Hodgkins, 2006). For example fatigue is present in patients during the pre-dialysis stage of treatment for CRF, but is also present during the dialysis stage of treatment indicating a need for clearer distinction between stressors. Increased age would appear to influence the perception of physical stressors ranking them higher than psychosocial stressors, which is possibly due to age-related physical limitations and increased comorbidity (Gurklis & Menke, 1988, Lok, 1996, Logan, Pelletier-Hibbert and Hodgkins, 2006).

There are early signs that renal nurses are attempting to gain a deeper understanding of illness/treatment-related stressors. For example the commonly cited stressor of fatigue is examined by McCann & Boore (2000) and Lee, Lin, Chaboyer, Chiang and Hung (2007). Using a phenomenological approach Lee et al (2007) based in Taiwan, interviewed 14 patients. The findings were categorised into physical, affective and cognitive fatigue. Physical fatigue was experiencing fatigue in physical situations such as regular dialysis; uraemic symptoms (such as headache, pain, cramp, and dizziness); insufficient energy to do anything; and suffering disturbed sleep. Affective fatigue was experienced as detesting long-term treatment (a sense of helplessness); perceiving depression with mood changes; and feeling exhausted which is an overwhelming experience of feeling out of control. Cognitive fatigue was experienced as regretting lost cognition (loss of memory and attention); intentional

isolation due to apathy decreased interest and motivation; and coping with fatigue which amounts to developing strategies to control and adapt to fatigue. This study could be criticised from a phenomenological perspective of falling back onto traditional scientific terminology to explain patient experience rather than phenomenological terminology such as temporality, embodiment, and being-with-others. That aside, it gives useful insight into fatigue. The study shows that overall fatigue was stressful because it thwarts attempts to live an ordinary life and shows that a single stressor is itself multidimensional.

The earlier McCann and Boore (2000) study aimed to describe how fatigue was described by patients. A complex data collection approach was employed using the Multidimensional Fatigue Inventory (20-item); symptom assessment; physical health status; sleep disturbance; The Hospital Anxiety and Depression scale; interviews; and physiological data. Thirty nine patients were assessed. The mean age was 46.5 years and ages ranged from 18 to 65 years old. The findings showed that all patients suffered fatigue and reduced activity. Patients experienced a range of symptoms (such as joint pain, weakness) numbering from 2 to 10 per person, with a mean of seven. The severity of the symptoms varied but there was a correlation between measures of fatigue and the number and severity of symptoms in that where patients had more and severe symptoms fatigue was higher. Poor health also correlated with high measures of fatigue with a strong correlation between the measure of fatigue and depression. Poor sleep was also associated with fatigue. McCann and Boore found that 51.4% of their sample had depression and a further 40.5% were suffering from anxiety. No links were found with fatigue and biochemical variables including anaemia which would naturally be assumed to be a major factor. In this study McCann and Boore begin to demonstrate correlations between fatigue and other aspects of illness experience. By doing this they add to the understanding of fatigue in haemodialysis patients as a stressor and thus enable the opportunity for better interventions and personalised care.

Tsay (2004) attempted to investigate how fatigue could be improved in dialysis patients by the use of acupressure massage. In this pre-test post-test randomized control study 106 Taiwanese patients were assigned to an experimental group (acupressure) a placebo group (sham acupressure massage) and a control group (usual unit care). Massage was undertaken three times each week for four weeks. Fatigue was measured by the Piper Fatigue scale, a Visual Analogue Scale for fatigue, the Pittsburgh Sleep Quality Index, and the Beck Depression Inventory. The findings showed no difference in fatigue between the experimental group and the placebo group with both groups having significant improvement compared to the control group. The author state that the results show that fatigue is improved by acupressure massage. However the placebo group had almost similar improvement which indicates that massage (of either type) will be helpful at least in the short-term, or a there is a Hawthorne effect. Tsay fails to discuss the effect on depression which was only measured post-test other than to say that it correlated strongly with fatigue.

As indicated above stressors also influence the coping and adjustment of HD patients. The perception of psychosocial or physiological stress is identified by patients in the shape of restrictions upon fluid and food intake, uncertainty about the future, bodily appearance changes, dependency, frequent hospital admissions, and limitations in physical activity to mention a few (Baldree et al, 1982, Gurklis & Menke, 1988, Lok, 1996). Treatment orientated stressors appear more generalised to lifestyle rather than specific to the treatment. This appears unusual but may be due to the stress assessment tool's lack of sensitivity or specificity to stressors. Specific treatment related problems such as cannulation difficulties; vascular access failure; hypotension; and dialysis machine failure are omitted, under stated or added by patients themselves as stressors when interviewed (Welch & Austin, 1999). It may be wholly acceptable that these are omitted from the patient's perception in that they are dealt with as and when they occur in dialysis units rather than those issues that affect more patients globally. However, there may be some doubt in this as Mitra et al (1999) appear to identify a

relationship with preparation for dialysis and stress. Mitra et al found that there was an over estimation of hypertension when blood pressure was taken before dialysis. Mitra et al attributed this to a phenomenon known as “white coat hypertension” where an individual’s blood pressure can be highly elevated in the presence of healthcare professional or in clinical settings. White coat hypertension is thought to be emotionally motivated by some form of perceived stressful event such as becoming hostile to others (Raikkonen et al, 1999). Using blood pressure as an objective measure of emotional response to dialysis it would seem evident that some dialysis patients find the thought of dialysis treatment itself to be stressful. Nichols and Springford (1984), in a study of 36 patients and spouses training for home haemodialysis, appear to add support to this notion by finding that more than two thirds of their patients (67%) consistently worried about having trouble with their fistula prior to dialysis. They also found that patients felt anxious before going on the machine, and before going to the unit. These anxieties improved but did not disappear after the training period. A note of caution is needed with this study because it is about patients learning to adopt dialysis treatment skills normally undertaken by nurses and quite understandably would cause anxiety. However, pre-treatment related anxiety or stress would appear evident whether undertaken by a nurse or the patient themselves.

The perception of whether something is stressful or not can relate to the mood of the individual (Knapton, 1988, Devins, 1989, Knapton, 1990). Knapton (1988, 1990) performed a prospective study of mood and its relationship to dialysis-related symptoms. Ten patients new to treatment were followed for 12 weeks using a Profile of Mood States (POMS), diaries to note feelings, and a symptom record that included cramp, restless legs, headache, nausea, vomiting and faintness. Knapton’s study found that symptom severity or mood change can occur due to physical events such as cramp or headache, and non-physical events such as handling by staff, family related problems and consecutive difficult dialysis sessions. The first six weeks of treatment appeared to be a crucial period where mood and psychological stability were influenced by the positive or negative experiences of treatment. A negative

experience during this period appears to influence mood and appraisal of stressors. This clearly has implications for nurses in relation to making initiation of treatment and future treatment as stress free as possible for the patient. In addition to this it was found that a low level of affective distress appeared to relate to supportive home circumstances. The inclusion of the family and/or partners in the process of patient care would appear to be a helpful supportive intervention for new starters.

Negative moods correlate with the degree of perceived intrusiveness of the illness (Devins, Binik, Hutchinson, Hollomby, Barre & Guttman 1983/4). Devins, Binik et al (1983/4) constructed a model of adaptation based on the patient's perception of illness intrusiveness and limited control into their daily lives. Devins, Binik et al examined the illness intrusiveness in 70 patients of which 35 were haemodialysis patients and the others were transplant or PD patients. The mean age was 41 indicating a very young sample. A battery of psychometric tools were used including the POMS, Beck depression inventory, Rosenberg self-esteem scale and the Bradburn 11-point rating of life happiness. Intrusiveness was rated on a 7 point (not very much - very much) scale on the basis of whether the illness interfered with other aspects of his/her life. Perceived control was rated using a similar scale. The findings demonstrated that lower levels of perceived control and high perceived levels of intrusiveness correlated highly with high negative and low positive moods. Transplant patients had significantly higher positive moods than any of the dialysis patients. If the individual construes the illness to intrude significantly into their daily lives then there is an increase in negative mood (Devins, 1989). Intrusiveness is related more to illness and treatment not necessarily to dialysis alone (Devins, Binik et al 1983/4). Indeed Devins (1989) found that patient participation in dialysis does not necessarily contribute to psychosocial well-being even though they did perceive greater control over dialysis because it did not reduce illness intrusiveness.

The idea that more general aspects of illness are related to illness intrusiveness was followed up by Musci, Molnar, Rethelyi et al (2004). In this study the authors were concerned about the impact of sleep disorders and the perception of illness intrusiveness particularly when problems such as insomnia have already been identified as a major stressor for dialysis patients. Musci, Molnar, Rethelyi et al studied the prevalence of sleep problems that included insomnia, restless legs, periodic limb movement and sleep apnoea in 78 patients. The study found that in their sample 65% of patients reported at least one sleep related disorder. Insomnia was the most common problem with 49% followed by sleep apnoea at 32% and restless legs syndrome at 15%. The researchers also found that these patients reported higher levels of illness intrusiveness and worse self-perceived health. Sleep disorder was found to be an independent predictor of illness intrusiveness indicating its importance and the need for active assessment and intervention to help patients. Reducing sleep disorders will enable patient to cope and adapt to dialysis in a more positive manner.

One example of an intervention approach can be found in the study by Tsay and Chen (2003). In this randomized control study Tsay and Chen (2003) aimed to assess the effectiveness of acupressure and the quality of sleep. The study was undertaken in four hospitals in Taiwan where 98 patients were randomly assigned to an acupressure group, a sham group and a control group. The acupressure intervention was in the form of a 14 minute acupressure (three-point) massage three times per week for four weeks. The sham intervention also involved massage for 14 minutes three times per week for four weeks but the massage was not allowed to be in areas where acupressure points were known to exist. The control group received routine unit care. The quality of sleep was measured by the Pittsburgh sleep quality index along with a daily sleep log which used a likert-scale method in a pre-test post-test manner. The study found a significant improvement in sleep in patients who had undergone the acupressure massage. The quality of sleep improved with time only in the acupressure group. This was thought to be due to the stimulation of serotonin at acupressure points which relaxes the body and promotes sleep (Tsay and Chen, 2003). The sham group also improved

the quality of sleep but not as much as the acupressure group. What this shows is that massage helps relaxation but is not as effective as acupressure massage. Tsay and Chen believe that acupressure massage can be taught to patients easily and would enable relaxation and improved sleep. The research also appears to show that some dialysis patients live in a constant state of stress.

The view that enabling patients to relax improves psychological affects is supported by Alarcon, Jenkins, Heestand, Scott and Cantor (1982) who found in an experimental group of 38 patients that self-instructional progressive relaxation techniques (an instructional video) reduced anxiety levels significantly when compared to a control group. It appears clear that techniques for helping patients to relax which can be taught to them will aid their coping and adjustment

The impact of the perceived intrusiveness of illness would appear to be moderated by age and self-perception (Devins, Beanlands, Mandin & Paul 1997). In a study of illness intrusiveness, self-concept and age in 49 haemodialysis patients and 52 transplant patients (with a mean age of 43) individuals who perceived themselves as 'kidney patients' had higher levels of distress, whereas patients with high levels of intrusiveness but who did not construe themselves like 'kidney patients' demonstrated low levels of emotional distress (Devins, Beanlands et al, 1997). The researchers used a similar battery of psychometric tools to the previous illness intrusiveness study along with the Illness intrusiveness scale and a new self-concept as a kidney patient scale which used semantic differential technique. The self-concept kidney patient scale uses typical clinical and social features such as headache, cramp, social isolation and employment to allow patients to self assess 'myself as I am now' against this criteria. In relation to age Devins, Beanlands et al (1997) found in younger patients illness intrusiveness compromised psychosocial well-being when they construed themselves dissimilar to kidney patients. Older patients had decreased well being when they construed themselves as 'like kidney patients' as illness intrusiveness increased. Therefore the ability to perceive oneself as

like a kidney patient will moderate distress in relation to illness intrusiveness. It would appear that increasing illness intrusiveness in the elderly caused distress possibly due to the perception of decreased control (Devins, Beanlands et al, 1997). Interestingly younger people were better off if they adopt the kidney patient role but worse when they perceived themselves as dissimilar. This could be related to a younger person's need for developing their own identity and independence.

The degree of illness and control over the treatment has been seen as stressful and contributing to depression (Eitel, Hatchett, Friend, Griffin, Wadhwa, 1995). Eitel, Hatchett and colleagues (1995) found that individuals who had high illness intrusiveness and high behavioural control (for example with peritoneal dialysis or home haemodialysis) coped less well and had higher levels of depression. This was felt to be in part due to the interference of illness and treatment in social relationships. To add to this problem it was also thought that reduced interaction with medical personnel and high expectations from medical personnel added to the burden of the patient. The intrusiveness of the treatment into the everyday life not only of the patient but of family members is thought to contribute to a patient's depression (Eitel Hatchett et al 1995). This would seem to support Devins's earlier statement that adopting control over treatment aspects doesn't necessarily lead to better coping and adjustment.

## **1.2 Haemodialysis and Coping**

The effect of stress and the perception of stressors clearly impacts upon the reaction, coping and adjustment ability of the haemodialysis patient. The psychological effects of haemodialysis upon patients are often presented in two manners: coping and emotional (psychiatric) reactions. Coping has been described as the cognitive process of managing external and/or internal demands that are perceived as taxing or exceeding an individual's resources (Lazarus & Folkman, 1984). Coping relies upon how a situation is appraised in

relation to the perception of what can be done. As stated above Gurklis and Menke (1988) found that patients coped by using affective methods and/or problem solving strategies. Psychosocial stressors tended to be dealt with by problem-solving and affective strategies whereas physiological stressors were managed by affective coping methods though there appears to be ethnic variation (Gurklis & Menke, 1988, Baldree et al, 1982, Lok, 1996). Affective methods of coping included prayer and trust in God, hoping things will get better, worry, try to put things out of mind, and laugh it off. Problem solving coping methods included trying to maintain control, looking at the problem objectively, and accepting it as it is (Gurklis & Menke, 1988, Baldree et al, 1982, Lok, 1996).

Coping methods for dealing with specific stressors have not been identified and therefore continue along the general life approach. However many of the strategies discussed could easily be applied to specific stressors. Klang Bjorvell and Cronqvist (1996) studied the coping strategies and sense of coherence in 48 patients with a mean age of 58. The researchers used the JCS and the Sense of Coherence Scale to look at whether coping was confrontational, emotive or palliative. Confrontational coping is where the person tries to meet a problem head on such as changing the situation. Emotive coping use emotional responses such as becoming angry, worry or getting nervous. Palliative coping is a means of displacing a problem using strategies such as laughing it off, withdrawal from the situation and situation resignation. Klang Bjorvell and Cronqvist (1996) found that confrontational (problem-solving) coping strategies were the most commonly used such as maintaining control or finding more about the situation and emotive strategies the least used. It appears that patients want to deal with problems head on which seems a practical approach because it would seem to reduce stress. Most patients appeared to demonstrate some degree of worry (83%) and nervousness (71%) especially in the pre-dialysis patients probably due to situated uncertainty. Men used more confrontational strategies than women. It was also found that patient's coping strategies changed over time probably in response to changes in the nature of stressors (Klang Bjorvell and Cronqvist, 1996).

In a descriptive-correlational study of the coping strategies of 30 male haemodialysis patients Cormier-Daigle and Stewart (1997) concur with the findings stated above. In this study male patients tended to use problem-orientated approaches especially seeking support by gaining information probably as a means to gain control over the situation. The desire to speak to someone, including gaining professional help, over a stressful event was less preferred by patients. Escape-avoidance (palliative) methods were little used indicating, with problem-orientated strategies, a positive psychological state for this group of patients. These men also noted the amount of social support as being important in helping them cope but also stated a high level of conflict occurred in which case they used escape-avoidance coping strategies. This probably reflects a perception of their illness being the cause of the problem in the first place and male's natural reluctance to share emotions (Cormier-Daigle and Stewart, 1997).

These studies identify a number of coping strategies employed by dialysis patients that are classified into three categories: Problem-orientated, Emotive, and Escape-avoidance (palliative). The studies collectively indicate that patients cope well with treatment and illness when using problem-orientated methods. However, when problems are less defined or non-illness focused coping becomes less easy and escape-avoidance strategies are employed, perhaps unsuccessfully. Positive coping ability will enable a patient to adjust and adapt to dialysis.

**The Most Commonly Reported Haemodialysis Coping Strategies**

- Trying to maintain control
- Prayer
- Trust in God
- Hope things will get better
- Look at the problem objectively
- Try to find meaning in the situation
- Accept the situation
- Find out more about the situation
- Put it out of your mind
- Worry

**Table 2**

## **2.4 Reactions and Adjustment to Haemodialysis**

Reactions to dialysis have been summarised as denial, projection, anxiety, regression, repression, aggression, displacement, reaction formation, depression, and isolation of affect (Kaplan De Nour, Shaltiel, & Czaczkes, 1968, Wright et al, 1966, Malmquist et al, 1972, Yanagida et al, 1981). One of the earliest studies into the reactions of dialysis patients was undertaken by Kaplan De Nour, Shaltiel, Czaczkes (1968). In their research 9 patients were studied for a year. At this stage of development, dialysis units were small with limited patient populations and therefore it is not unusual for studies to have small samples. What this meant was that researchers could use more detailed approaches to studying their patients. Patients in the sample had two psychiatric interviews and halfway through the study a battery of psychometric tests that included Taylor's Manifest of Anxiety Scale, Barron's Ego Strength test, sentence completion test and Rorschach. The results found patients to have good emotional equilibrium. Psychiatric symptoms were rare such as paranoia, anxiety and irregularly found depression at different stages. Patients developed defensive behavioural patterns. Denial was the major defence employed by patients and included denial of dependence, illness, of the kidney machine and complete denial of emotional problems. Patients also frequently demonstrated displacement (of their feelings about dialysis) by talking about vascular access and performed meticulous care of it. Patients also dealt with problems without demonstrating any feelings, though feelings were shown through projection onto others such as no one understanding what the patient is going through. Kaplan De Nour, Shaltiel, Czaczkes (1968) found that patient defences were generally brittle causing frequent changes in intensity and combinations of defences resulting in ever changing behaviour. Patients endeavoured to maintain normal behaviour but frequently found it difficult to sustain due to stressful events. The major problem that appears to manifest in defence reactions is due to the dependency and aggression that it provokes. Kaplan De Nour, Shaltiel, Czaczkes (1968) go on to conclude that aggression must be controlled and suppressed because of the

dependency situation and that defences against aggression must be mobilized which in effect is a double-bind for the patient (Alexander, 1976).

Yanagida, Streltzer and Siemsen (1981) found that denial was a positive adaptive process in those patients who were compliant with treatment requirements. Their study investigated attitudinal variables of denial in patients who were compliant with treatment and those who were not. A battery of psychometric tests was used including the Beck depression Inventory and the response to illness questionnaire. They found that patients who used high levels of denial also reported lower levels of depression and expressed a lower level of dependence upon the dialysis machine and staff. Denial appears to act as a stress buffering role therefore allowing patients to adapt to dialysis with less fear and anxiety.

The prolonged stress of dialysis will make the individual adopt a tendency to withdraw from active coping using defence mechanisms such as denial, passivity, aggression, and a negative self-perception that can make a patient present as someone who looks depressed (Shanan et al, 1976). This can be misleading in that the patient may be treated for depression rather than looking to manage or reduce stress and improve coping strategies. As identified by Kaplan De Nour, Shaltiel, Czaczkes (1968) a major manifestation of dependency was aggression which is a predictor of poor adjustment (Malmquist et al, 1972, Malmquist, 1973, Hagberg & Malmquist, 1974). Malmquist performed a prospective study on 23 patients to explore factors for prediction of adjustment to dialysis (Malmquist, 1973). Patients underwent psychiatric assessment 3-4 weeks prior to commencing treatment and then again at 6 and 12 months after commencing treatment. The assessment included psychiatric interview, psychological tests and intelligence tests (however, the author fails to specify which tests). What Malmquist found was if patients had begun to accept lifestyle changes before starting dialysis they were usually better adjusted than if they had not and were more likely to be back at work. Those patients that worked had more social contacts and reported fewer psychiatric symptoms (anxiety, mood swings, tension), feelings of dependence or irritability compared to patients

who were not at work. It was also found in an analysis of pre-treatment assessment that patients who, prior to commencing treatment, had an inflexible attitude towards changes in lifestyle were more readily rehabilitated because of the desire to maintain normal lifestyle (Hagberg & Malmquist, 1974). Hagberg & Malmquist, (1974) also found other positive signs that predict good adjustment included maintaining regular social contacts, positive expectations of rehabilitation, defence mechanisms other than isolation and an adequate reaction to kidney disease. Negative signs were found to be the opposite of positive signs especially when a patient relies upon isolation as a defence mechanism. What Malquist identifies here is the beneficial effects of a positive outlook, a desire to maintain a sense of normality, and socialisation in the prediction and maintenance of good adjustment to treatment.

The beneficial effect of a positive attitude is supported by a more recent study by Gilbar, Or-Han and Plivazky (2005) who found that patients who displayed a 'fighting spirit' will use problem-focused coping strategies and demonstrate less psychological distress and better adjustment. They also found that younger patients displayed more distress because of threats to their life, independence, and their social role. Patients who had a fatalistic attitude and anxious preoccupation used emotion-based coping and demonstrated high levels of psychiatric distress and poor adjustment.

The idea of a fatalistic attitude to life or maintaining a 'fighting spirit' can be linked to the notion of locus of control. In an earlier study by Poll and Kaplan De Nour, (1980) patients appeared to develop an external locus of control when they commenced dialysis suggesting dependency upon powerful others or a kind of regression in behaviour. Such regression or a change to an external locus of control indicates poor adjustment whereas, those who maintain positive expectations for themselves and an inability to shift personal goals or way of life was a positive prognostic factor for good adjustment (Hagberg & Malquist, 1974). More recently Gencoz and Astan (2006) examined the relationship between locus of control, social support

and depression in 104 haemodialysis patients. The researchers used the Beck Depression Inventory, The Rotter Locus of Control Scale, Multidimensional Scale of Perceived Social Support, and the Satisfaction from Receiving Support Scale. What they found was that patients with an internal locus of control who perceived an availability of social support saw a reduction in depressive symptoms. Patients with an external locus of control who received social support also had reduced depressive symptoms. What this indicates is that for the 'fatalistic' patient the need for actual help is required whereas the 'positive outlook' patient appears only to need to know that it is available suggesting an option available when a problem arises (a problem-solving approach). It also points to a sense of control as being important for patients. There is also evidence to suggest that social support ameliorates stress and depressive symptoms and appears to improve health-enhancing behaviour (Lewis and Rook, 1999).

The ability for patients to control their lives would seem to be important in the coping with dialysis and its treatment. This appears to be related to how individuals perceive their ability to control their situation. Attempts at developing skills in patients for coping with the stressors of dialysis have been reported (Leak, Friend & Wadhwa, 1999; Tsay, Lee, & Lee, 2005). Leake, Friend and Wadhwa (1999) attempted to improve patient coping by helping patients present a positive image of them self. The study took a 3 X 3 approach with an experimental group (structured coping interviews), problem disclosure group (structured disclosure interview) and a control group (usual treatment). What was found was that the experimental group demonstrated fewer depressive symptoms, felt less depressed, and were more able to cope when compared to the other groups. Coping was found to be a significant predictor of adjustment. Better patient coping leads to better adjustment due to a sense of control.

Tsay, Lee & Lee (2005) undertook a two group randomized controlled trial to assess the effects of an adaptation training programme on 57 patients with end-stage renal disease. The

adaptation training programme (ATP) lasted 8 weeks and was a 2 hourly session where patients were enabled to develop coping skills through stress management, problem-solving and cognitive behaviour modification. The control group received the usual care on the unit. The HSS, Beck depression Inventory and Medical Outcomes SF36 were used for measuring patient response. What the researchers found was that the ATP was effective in decreasing stress and depression levels and improving quality of life in these patients when compared to a control group. The patients felt more capable of dealing with disease-related stressors and that illness was manageable. This supports an earlier randomized controlled trial by Tsay and Huang (2004) who found that developing empowering skills in patients improves their ability to cope and experience less anxiety and depression symptoms. All these studies suggest that patients can be helped to gain control in aspects of their experience that enables them to cope positively with illness and dialysis and in doing so have better adjustment.

Interestingly, according to Yeh, Huang, Yang, Lee, Chen and Chen, (2004) anxiety is assessed and treated far less in haemodialysis patients than depression. Patients who demonstrated a generalised anxiety disorder had more psychiatric distress than patients with depression alone and showed worse adjustment to dialysis. However, what they also found was that anxiety was more readily treated with anxiolytics and this group of patients demonstrated less depression symptoms than patients with depression alone following treatment. They conclude by stating that more attention should be given to assessing and treating anxiety in dialysis patients especially when it appears to respond well to treatment.

The above research studies point towards a number of relationships that influence the ability to adjust to haemodialysis. The number of stressors, type of coping strategy employed, ability to cope, perception of illness intrusiveness, social support, positive or fatalistic outlook, and control over treatment all influence well-being and whether a patient suffers from depression. Psychiatric reactions to dialysis such as depression are indicative of poor adjustment and may affect survival (Kimmel et al, 1993, Kimmel et al, 2000). Approximately 10% of patients

admitted for dialysis have a concurrent psychiatric disorder of which depression is the most common (Kimmel et al, 1998). Mollaoglu (2004) found 87(62%) patients out of a sample of 140 were depressed and had a significantly lower quality of life. Mollaoglu (2004) found a correlation between depression and (low) haemoglobin level which perhaps relates to symptom of fatigue. Diagnosis of depression is difficult as many of the physical symptoms of depression such as insomnia or fatigue are also symptoms of uraemia. Kutner, Fair and Kutner (1985) found somatic symptoms appeared to yield exaggerated depression or anxiety scores. They found 45% of patients demonstrated clinical anxiety and 52.3% demonstrated depressive symptoms or depression. Therefore diagnosis would appear to need to be made on the affective dimension such as negative self image, thoughts of death and suicidal ideation which are all absent in the non-depressed uraemic patient rather than on physical symptoms (Craven et al, 1987). The level of depression a patient experiences would appear to relate to pre-illness psychiatric history whereby a pre-dialysis history of depression makes it more likely to occur when treatment begins (Malmquist, 1973). The perception of illness, like illness intrusiveness, rather than illness itself is also associated with depression. The more one perceives illness to be worse the more a person will be depressed (Sacks et al, 1990). The effects of perception of illness as having an impact can be supported by McCann and Boore (2000) who found that 51.4% of patients who perceived them self to be fatigued were also depressed. However, the impact of actual physical illness cannot be underestimated, for example the correction of haemoglobin with erythropoietin leads to less fatigue, less depression and improved quality of life (Canadian EPO Study Group, 1990, Foley et al, 2000). An international multicentre study involving 12 countries and 9382 patients studied screening for depression and found that physician-diagnosed depression prevalence was 13.9% (Lopes, Albert, Young, et al, 2004). The study also found that these patients were more likely to be hospitalized, withdraw from treatment or die. It also found that depression was under diagnosed and under treated among dialysis patients.

There appears to be an association with depression and poorer one-year survival and that a stressful event that precipitates depression may have harmful mortality consequences (Kimmel et al, 2000). In a study that examined the quality of life mental health and survival of new patients to dialysis Valdes, Garcia-Mendoza et al (2006) found that poor mental health at the third month of dialysis was an independent predictor of short-term survival. For each point positive adjustment of mental health the relative risk of death decreased by 4%. This also appears to support the earlier discussed study by Knapton (1990) relating to mood and coping in dialysis patients. What this implies is the effect of depression upon dialysis patients is stated as having the same magnitude as medical risks thus making it essential that depression is identified early and promptly treated (Kimmel et al, 2000).

The importance of depression in dialysis patients is that it can lead to suicide in which Neu and Kjellstrand (1986) suggest that there was about a 15 times greater risk than that of the general population. However it would seem that haemodialysis is a less risk factor for suicide than peritoneal dialysis where Ford and Kaserman (2000) claim that there would be 141 fewer suicides per 1000 patients if patients were transferred to haemodialysis. This possibly relates a perceived excessive burden of illness management in the PD patient. One problem associated with identifying suicidal behaviour in dialysis patients is what actually constitutes that behaviour. Overt self-harm may be one method of suicide but the dialysis patient has at his or her disposal more subtle ways such as dietary or fluid restriction and non-adherence or non-attendance for treatment (Kimmel, 2001). A recent review of crude suicide rates in the United States dialysis programme by Kurella, Kimmel, Young and Chertow (2005) found that between 1995 and 2001 the rate of suicide was 24.2 suicides per 100,000 patient years. This was an 84% higher rate than the general public. However, whilst greater than the general public suicide in haemodialysis patients is still relatively rare. The mean age for suicide was 63 and the mean age for withdrawal from treatment (which is often construed as suicide) was 71 years. Males were more likely to withdraw (81.1%) from treatment or commit suicide (85.2%) than females. Other characteristics of patients who committed suicide were that they

were younger, more likely to be non-black, have mental illness, recent hospital admission, be uninsured (for health care), have alcohol or drug dependency, non-ambulant, have diabetes, have congestive heart failure or previous stroke (by Kurella, Kimmel, Young and Chertow, 2005). These results indicate that males have poor adjustment and often concurrent (mental) health problems that may go unchecked. How this transfers to other cultures is unclear but would be useful to know to help identify those at risk and support them.

## **2.5 Adherence to Treatment**

One area of concern to health professionals relating to patient behaviour is their adaptation to treatment regimens. End-stage renal disease and dialysis require alterations in diet and fluid allowances, frequent hospital attendance for treatment and much modification when changes are needed. Consequently it is not surprising that some patients do not adhere to the complex prescribed treatment regimens. The issue of non-adherence is of major concern to health care professionals because it can seriously affect the treatment efficiency and more importantly lead to premature death (Rao et al, 1994, Saran, Bragg-Gresham, Rayner et al, 2003). Saran, Bragg-Gresham Rayner et al (2003) studied data from an international multicentered haemodialysis study and found that non-compliance increased the risk of death, and increased hospitalization due to complications. They also found that where a dialysis unit was large there was an increase in the occurrence of non-compliance which amounted to more than 10 patients per shift or a dialysis population greater than 60 for a unit. Interestingly the researchers also found that there was an 11% decrease in the likelihood of skipping for every 10% increase in highly qualified staff, lower non-compliance when a dietitian was present and where there was increased contact with a doctor. What can be derived from this is that patients respond better when they have closer contact with staff which may be a beneficial outcome for smaller facilities such as satellite units.

Whether non-adherence or non-compliance is a reaction to dialysis remains unclear because it is not apparent whether psychological distress causes non-adherence or not (Kimmel, 2001). It is not clear if depression is a predictor of non-adherence. Whether non-adherence is a response to depression rather than a predictor is also not clear however, some patients who are depressed appear to be very compliant with their treatment (Everett et al, 1995). Kimmel, Peterson, Weihs et al (1995) found that 25.5% of their sample who were non-compliant was depressed.

There has been some attempt to identify factors that are associated with or predict non-adherence and include the following. Ifudu et al (1996) identified that young male patients new to dialysis were more likely to be non-compliant due to the increased threat of dependency than older patients. Kutner, Zhang, McClellan, and Cole (2002) carried out a multicentre study to identify psychosocial predictors of non-compliance. The study included collecting data such as missed or shortened dialysis, fluid level and biochemical markers (phosphate, potassium) from 119 haemodialysis patients and 51 PD patients. The study reported that one third of haemodialysis and PD patients were non-compliant on at least one indicator. They also identified that young patients, smokers and a perceived negative effect of dialysis upon daily life were predictors. The researchers found smoking to be a marker of priority of health in patients; smokers viewed health as low priority which is supported by Leggat et al, (1998).

Pang, Ip and Chang (2001) examined the correlates of fluid compliance in 92 Chinese dialysis patients. They found Chinese patients tend to be more compliant than is found in western studies. Where non-compliance occurred it was related to low family income, co morbidity and low satisfaction with social support and in this case appears to be a response to other (non-illness) factors (Pang, Ip, & Chen, 2001). Daily stress and major life stress was linked to non-compliance in that the more stress perceived or a sudden event would influence a patient negatively (Everett et al, 1995). Brown and Fitzpatrick (1988) found non-compliance,

according to their criteria (biochemical results and fluid levels) to be present in 58% of their sample. They found that the patient's (negative) perception of control over broader aspects of their life and poor acceptance of limitations made them more likely to be non-compliant (Brown & Fitzpatrick, 1988).

In a series of studies Christensen and colleagues examined personality factors that may influence non-compliance. Christensen and Smith (1995) examined the concept of conscientiousness and adherence in dialysis patient. They found that conscientiousness in an individual significantly correlated with adherence to medication regimens but not with dietary regimen adherence. Christensen, Weibe, & Lawton, (1997) examined the role of cynical hostility and powerful others (locus of control) and its relation to predicting non-compliance. They found that high hostility was linked to dietary non-compliance and that this hostility was grounded upon the expectation that adherence would result in an expectation of immediate improvement in health. This is useful in that it gives an indication of expectation and how realistic patients perceive actions can be. Christensen, Moran, Stallman, Voigts, and Lawson (1997) examined the monitoring attentional style of patients and their adherence to a medical regimen. Contrary to intuition whereby patients who monitor themselves would show more compliance to regimen, it was found that high self monitoring patients demonstrated higher interdialytic weight gain and poor dietary adherence. This did not seem to apply to medication. The rationale for this was suggested that high monitoring patients tended to over-estimate the severity of their illness and show greater distress during stressful events which was thought to be due to a perceived sense of low control and a form of displacement.

To support this finding Christensen (2000) examined the patient-by-treatment context relationship to adherence to treatment comparing home dialysis and in-centre dialysis. Christensen concluded that a vigilant and active style of coping is associated with more favourable compliance only in those undertaking highly patient directed home dialysis. Those patients receiving hospital based dialysis a less vigilant passive coping style is associated with

favourable adherence to treatment. Christensen and colleagues indicate that non-compliance is complex and relates to patient's self perception of control, fulfilment of (unrealistic) expectations, self-monitoring style, vigilance and coping style.

What is clear is that non-compliance is a complex event, which may have more to do with perception of illness and treatment, attitudes, beliefs, and control rather than sociodemographic variables such as age (Kimmel et al, 1995, Sensky et al, 1996). Sensky et al (1996) argue that research should focus upon cognitive factors rather than pure sociodemographics and this would be more helpful; in other words find out what the person is thinking rather than how old s/he is or what ethnic background they are. It does point to the need for individualised care rather than a generalised approach and that staff should be aware of their own theoretical prejudices towards non-compliance when working with patients. One problem with compliance/adherence studies is that they assume that people are by and large compliant with or adhere to the rules, regulations and laws of society and the social world. It is not unreasonable to consider that each and every one of us does not adhere to some rule at some point in the day no matter how minor. What compliance studies may be more indicative of is the inflexibility of treatment regimens and their limitations.

## **2.6 Quality of Life**

Attempts at finding a global measure of the impact of haemodialysis upon patients has led to the use of quality of life (QoL) investigations. As with most of the research examining psychological responses to dialysis there is a plethora of different tools used such as the Kidney Disease Quality of Life (KDQOL), SF36, Karnofsky Performance Scale, Illness Effect Questionnaire or the Beck Depression Inventory (BDI) being the most common examples (Mingardi 1999). This makes consistency a problem but equally provides data that is available on similar or same topics but from different approaches. Hence the pluralistic approach can be seen to add depth of understanding. However, Unruh, Weisbord and Kimmel

(2005) argue that it is important to measure QoL because of its association with health care utilization, morbidity, and mortality. It is often used to assess the efficacy of interventions and to make decision about patient treatment. Health related quality of life has been shown to be a predictor of important outcomes such as survival but has yet to become integrated into routine dialysis treatment (Unruh, Weisbord and Kimmel, 2005).

Unsurprisingly, when compared to the general population end-stage renal disease patients experience a lower quality of life with dialysis patients reporting a lower QoL than transplant patients (Evans et al, 1985, Simmons & Abress, 1990, Gudex, 1995, Waiser et al, 1998, Fujisawa et al, 2000). Gudex (1995) identifies many factors that influence QoL including anxiety, pain, lack of energy and depression. Additionally there appears to be ethnic variation in QoL perception where Indo-Asian patients reported lower QoL than white Europeans (Bakewell et al, 2001). Why this ethnic variance should occur is not clear but it may be due to lack of QoL tool cultural specificity.

However, what is not clear is whether a poor QoL makes the individual depressed or whether being depressed provides a perception of a poor QoL. As already stated by Mollaoglu (2004) depression is common in dialysis patients and is associated with low quality of life. Martin and Thompson (2000) also add to this in a study of 72 patients using the KDQOL and the Hospital Anxiety and Depression Scale (HAD) by concluding that depression and anxiety are strong determinants of a low quality of life. They also found that a significant proportion of patients suffered from psychological distress: depression was 23% and anxiety 39%. Low quality of life is linked to mortality in that those who started with a low QoL had a rapidly declining QoL and often died (Maruschka et al, 1999). In an international multicentre study of QoL, using the KDQOL, involving 17, 236 patients it was found that patients who have a low quality of life have a risk of death 93% higher than those with a higher recorded QoL (Mapes, Lopes, Satayathum et al, 2003). These researchers also found that the same group of patients had a 56% higher risk of hospitalization and these results correlate well with low serum

albumin levels as a predictor of death. A significant finding is the level of QoL relates more to physical functioning rather than mental functioning and is not age related (Singer et al, 1999, Maruschka et al, 1999, Painter et al, 2000, Lamping et al, 2000).

The issue about age as a factor for QoL when initiating or discontinuing is a constant clinical debate. McKee, Parker, Elvish et al, (2005) in a one year prospective study examined the significance of age and quality of life in 58 patients who had received treatment continuously for 6-12 months. McKee, Parker, Elvish et al (2005) were concerned that many of the current QoL scales do not focus upon the needs of the elderly and as a consequence rate older patients as having a poor quality of life. Participants were asked to nominate important quality of life domains and then reassess these as treatment progressed. What the study demonstrated that different age groups place values on different domains. For example older (>60years) patients placed more value on family rather than leisure activities as identified by younger (<60years) patients. Patients of different age groups nominated completely different domains of life. Younger patients highlighted finances and work whereas older patients nominated religion. Domains would change as duration of dialysis progressed and the QoL scores improved during this time. In view of these differences the authors conclude that there was no difference in QoL between different age groups because they have different life foci. In support of the age factor issue Rebollo, Ortega, Baltar, et al (2001) had also earlier found that when accounting for age related differences older people reported a higher QoL than younger patients. They found that older patients recorded better physical functioning, less pain, and a better general health perception. Rebollo, Ortega, Baltar, et al (2001) also found in their cohort that older patients recorded fewer hospital admissions and shorter stays than younger patients. This appears to contradict the notion that older patients will naturally require more care and treatment. This is felt to be important because it emphasises how generic QoL tools can lack specificity and lead to discrimination and stereotyping of patient groups.

Quality of Life is an important concept that is complex and cannot be pinned down to one specific issue. It is worth noting that the importance of good physical functioning is important in the perception of quality of life. This has already been noted in studies looking at stressors and how much it influences perception. However therapeutic interventions can make a difference such as is demonstrated by the introduction of erythropoietin (EPO) for the correction of anaemia. Here, patients' QoL is improved when they are administered EPO increasing haemoglobin and therefore increasing their, appetite, physical functioning, sexual activity, and cognitive function (Nissenson, 1989, Haines, 1990, Canadian Erythropoietin Study Group, 1990). These areas are involved in the perception of well-being and will influence QoL. What this indicates is the complexity of patient experience and that no one thing can be attributed. One point of consideration is that QoL studies can be construed not necessarily as measuring patient's QoL but the effectiveness of treatment and they may not provide useful understanding of the patient's experience of life on dialysis. Quality of Life studies can be as misleading as relying upon clinical data such as Kt/V or biochemistry to assess patient health; they only offer a limited dimension.

## **2.7 Patient Experience**

Many of the previous studies into the patient's response to dialysis adopt a psychometric approach to their investigations. Psychometrics is useful in that they can provide a consistent way in measuring specific phenomenon indicating its prevalence and incidence and thus providing useful statistics (Banyard & Hayes, 1994). However, these studies miss the important aspect of patient experience, that is, what it is like to suffer or endure dialysis. Attempts to gain insight into the patient experience have seen a growth in qualitative approaches that aim to interpret the patient's experience. There are many themes which researchers identify regarding the patient's encounter that appear to describe the existential experience. For example patients work at maintaining a sense of hope and optimism for the future, which is a way of minimising the ever-present threat of death, overcoming illness and

finding meaning in illness (Rittman et al, 1993, Hagren et al, 2001, Caress et al, 2001). Additionally patients strive for control of their altered lives and have a desire to return to a normal life (Lindqvist et al, 2000, Hagren et al, 2001, Caress et al, 2001, White and Grenyer, 1999 Gregory et al, 1998, Smith, Flowers & Osborn, 1997). Hagren, Petterson, Severinsson, Lutzen, & Clyne, (2001) undertook a study to explore the experiences of patients suffering end-stage renal disease. Fifteen patients with a mean age of 62 years and at least 3 months dialysis experience were interviewed. The themes identified the dialysis machine as a lifeline which involved a loss of freedom, and dependence upon caregivers. Dependence upon caregivers was a struggle to be seen as an individual, be made welcome and be managed by someone who knew what they were doing. Other experience saw the disruption of family and social life which put strains upon relationships. Patients expressed the experience of living in the constant threat of death and tried to deflect this by remaining optimistic about their life. They also felt it important to be involved in decisions about their treatment and care to gain control and responsibility for their life. Hagren and colleagues argue that haemodialysis patients experience a struggle against dependence and sustaining personal autonomy within the limitations imposed by the illness. Hagren and colleagues developed this study by examining how illness and treatment encroached upon time (Hagren, Petterson, Severinsson et al, 2005). Forty one dialysis patients with a mean age of 67.5 years and a minimum of three months on dialysis were interviewed. The findings found that dialysis was about 'not finding space for living' (Hagren et al 2005, p296). This theme described the intrusiveness of illness and treatment making personal life having to compete with treatment for time. Social and personal experiences were being squeezed out of their lives by dialysis. Dialysis was time consuming and thus restricting. Patients also expressed the need for accessibility of staff and personal attention and as such felt vulnerable and misunderstood. Clearly patients experience a struggle to live a normal life and need assistance from staff to enable them to manage their situation.

In a similar study Polaschek (2003) interviewed six dialysis patients and found that patients struggled to manage symptoms of illness and dialysis on a daily basis. Lack of energy is identified as the most significant problem and supports studies of stressors mentioned earlier. Patients found it hard to live with constant variation in feeling well or unwell. Equally important was the adjustment they had to make in their lives particularly with managing time, limitations and uncertainty. Patients also expressed a need to be in control of their treatment and to develop a relationship with healthcare professionals to constantly elicit treatment orientated information.

Patients also have to balance the everyday function of their lives with the effects of illness such as feeling fatigued or having a headache. Continual management of physical changes and body failure affects the biographical understanding that patients have of themselves (Corbin and Strauss, 1988). The failing body effects how patients can perform for themselves, for others and in front of others. Not being able to undertake simple activities such as shopping or washing up serves to reinforce the feelings of failure and dependence. Having end-stage renal disease means living with dependence upon machinery, their partners, and health care professionals and is something patients struggle with, which requires a redefining of their existence (Rittman et al, 1993, Gregory et al, 1998). The enforced dependence of dialysis makes patients grieve for losses, a wish for normality and independence, and struggle with uncertainty (Gregory et al, 1998, Lindqvist et al, 2000, White and Grenyer, 1999). Thus haemodialysis patients appear to have to reconstruct their lives, their taken-for-granted view of themselves of being-in-the-world struggle with the intrusiveness of treatment and loss of personal time to treatment as well as keeping death at arms length.

## **2.8 The Dialysis Unit and Unit Staff.**

Many of the emotional responses of patients to renal failure identify either the dialysis its self or stresses of altered life activities such as working as being the focus of (mal)adaptation. Few

studies have attempted to address the effects of the dialysis unit alone as influencing patient response or outcome, however some evidence suggests that dialysis unit staff do in fact influence patient outcome (Kaplan De-Nour, 1980). Polaschek (2003) found patients needed to negotiate with staff to elicit information and Hagren et al (2005) identified how accessibility to staff influenced how they felt about their situation. Kaplan De-Nour, Czaczkes, and Lilos (1972) in a study of medical teams (including nurses) and opinions about their patients identified that the expectations of staff and their consensus of opinion influences patient outcome. Kaplan De-Nour, Czaczkes, and Lilos (1972) suggest that where there is a realistic consensus of opinion patients are more likely to comply with treatment. Where there was a lack of team opinion there was lack of satisfaction not only among the patients but also with the staff. For example where of the opinion by the staff was that they had the 'wrong' patients there would be inconsistency in expectations of patients with differing regimes from different team members presenting with behaviour such as scolding patients. Kaplan De-Nour and Czaczkes (1974a) found that where doctors use less denial in the estimation of patient adjustment, patients fared better overall. Therefore it seems evident that the psychological reactions of staff affect the adaptation and adjustment of patients. Overly high expectations of staff may militate against the perceived positive coping of individuals (Kaplan De-Nour & Czaczkes, 1974b).

Nurses, as with doctors, appear to influence patient adaptation by identifying acceptable patients and those who are rejected (Kaplan De-Nour, 1975, Kaplan De-Nour, 1980). Patients who appear well behaved; grateful and well adjusted were accepted by nursing staff whereas those who were adjusted but ungrateful, or ungrateful, or maladjusted were rejected. Also unrealistic expectations by the team would influence the adjustment of patients. What this suggests is that there is a mismatch between what staff perceive as appropriate behaviour and adjustment and what the patient perceives as acceptable (Huber and Tucker, 1984). It also identifies inflexible stereotyping of patient types and behaviours. Huber and Tucker suggest a need for constructive dialogue between nurses and patients to gain consensus in patient-

agreed (realistic) goals to aid positive adjustment. Adoption of a blanket policy to patient care appears inappropriate to positive patient adjustment (Huber & Tucker, 1984). Polaschek (2003) believes individualised care is possible by nurses providing they are aware of dominant discourses within the unit, such as the biomedical discourse, and mediate it to provide a more patient orientated approach.

Herron (1985) found there was a tendency for the unit he studied to be authoritarian in approach to patient care. Herron also found poor compliance, frustrated expectations, and the capacity to tolerate less than optimal results led to patient isolation and staff withdrawal. Staff withdrawal was felt to be a means of dealing with frustration brought about by patients unable to attain unrealistic expectations. It would appear that staff behaviour and attitude clearly influence the atmosphere of the dialysis unit and the resultant adjustment of patients (Kaplan De-Nour, 1980) Interestingly Kaplan De-Nour (1980) reports that even when an explanation of patient behaviour was made by a psychiatrist to improve staff understanding there was no change to staff attitudes. Additionally group discussion resulted in aggressive acting-out behaviour that was detrimental to the whole unit. This suggests that the social complexities of dialysis units are not linked solely with patient behaviour but include staff adjustment, attitudes, expectations, and possibly working practices.

As has been stated nurses can influence patient outcome and is something that patients state themselves (Hagren et al, 2005). Dialysis nurses tend to undervalue their role (Lewis, Bonner, Campbell, Cooper and Willard, 1994). Dialysis nurses found their job stressful often lacking coping strategies to deal with long-term management of the chronically ill patient. This stress was found to present as emotional exhaustion, a sense of burnout and poor coping (Nichols, Springford & Searle, 1981; Lewis, Bonner, Campbell, Cooper and Willard, 1994). To add to this Wertzel, Vollrath, Ritz and Ferner (1977) analysed nurse-patient interaction in 13 nurses and 28 patients. They found that dialysis nurses viewed themselves as depressed and very anxious. It was found that this was due to frequent and repeated contact with dialysis patients

whereby nurses identify with the fears of the patients such as sudden death. This would explain nurses' rejection of 'bad' patients because of the emotions they create. Nurses also avoided patients who evoked the greatest emotions causing a sense of guilt and aggression. Aggression was caused by patient attitudes of ambivalence, complaining, lack of gratitude and demanding attention (Wertzel, Vollrath, Ritz and Ferner, 1977). Patients also viewed themselves as depressed. The authors also found patients to be highly reluctant to communicate and have higher feelings of aggression. What this points to is the complex interaction between nurses and patients where emotional responses of one group can influence another. It would seem that unit managers need to pay close attention to the social structure of units; the way individuals and teams function and react in these stressful environments.

The above research focuses upon central units and does not include satellite units. It has already been stated in the introduction that research of satellite units has focused upon the clinical outcomes of patients only and certainly not of the nursing aspects. Nephrology nursing is poorly researched and where research is undertaken it is often clinically orientated. There are exceptions as already stated by Lewis et al (1994) and Polaschek (2003). Bonner (2003) undertook a qualitative research study of 17 registered nurses on a dialysis unit to examine nephrology nursing expertise. Through observation and interview Bonner constructed a description of expertise that consisted of recognition of expertise involving being trusted, being a role model for others, and teaching others. These results stated that nurses demonstrated expertise when nurses and patients increasingly trusted their judgement in a whole range of conditions. Being a role model for others involved leadership skills; dictating acceptable and good practice boundaries; responding to situations quickly; acting as a resource; and preceptorship of new staff. Expert nurses also were teachers of other staff, patients, and families. The teaching role was a major role and involved a great deal of time. The nephrology nursing expert role is one that is located in individual behaviour but recognised by others and appears to hinge upon trust. Bonner (2003) extended this research in

a study of six expert nurses and eleven non-expert nurses. Using semi-structured interview, participant observation and document review Bonner found that only expert nurses practiced in the realm of blurred boundaries such as medication prescribing and medical investigation. Some of this blurring was formal as in medication prescribing and other blurring was informal such as working extra shifts and in different nephrology specialist areas such as transplantation (Bonner, 2003).

Bonner and Greenwood (2006) identified that expert nephrology nurses differed from experienced non-expert nephrology nurses by a number of characteristics. As stated by Bonner expert nurses are recognised by others as experts but also demonstrate an obligation and commitment to and have motivation and enjoyment for nephrology nursing. Expert nurses demonstrated a commitment to high quality patient-focused care. Expert nurses possessed extensive knowledge and vast experience, which enabled them to be self-directing and to blur the boundaries of their practice. Bonner and Greenwood also explain that experienced non-expert nurses had become competent through routine and repetition of their work. These nurses were able to integrate routine work with more sophisticated work such as prioritising unit work; however, they did not demonstrate the expert nurse characteristics mentioned above. In addition to this it was noted that these nurses tended to remain within the rules and boundaries of practice they had been taught. These studies highlight the differing levels of nursing practice available in nephrology nursing and link closely with Benner's 'Novice to Expert' conceptualisation (Bonner and Greenwood, 2006). Furthermore this also hints as to the possible level of expertise required at a nurse-led unit such as a satellite unit.

Harwood, Wilson, Heidenheim and Lindsay (2004) examined the effect of advance nephrology nurse practitioner and nephrologist team compared to nephrologist only approach to patient care in a dialysis unit. Using clinical data from patients to compare outcomes it was found that the advanced nephrology nurse practitioner-nephrologist team worked more efficiently than a nephrologist alone. Whilst there was no statistical difference between the

two groups in terms of clinical outcome there were more decisions about patient treatment in the team approach to achieve outcomes more quickly. The team members also expressed increased satisfaction and the perception of a higher standard of care. Perhaps what this study does show is that a collaborative approach demonstrates closer working and communication as well as easing the burden of the workload.

The importance of these studies in relation to satellite units is the need for nurses to work in a capacity where medical care is not immediately available. Hence nurses will need to be able to practice in a manner that is different from a main unit. A lack of evidence to support developed practice in nephrology nursing means that it may be useful to look elsewhere in the nursing profession to find further insight. The satellite unit is in effect a nurse-led unit of intermediate/continuing care. Nurse-led care has been gaining momentum in recent years (Griffiths, 2006). Nurse-led care came to prominence in the late 1980s and 1990s in the area of intermediate care. The Burford and Oxford Nursing Development Unit developed nursing beds where the admission and discharge was on the basis of nursing care/need (Pearson, 1988). Pearson argued that a new approach to nursing was needed that involved primary nursing which in essence is about case management in which a nurse accepts responsibility for the planning and administration of care (Pearson, 1988; McMahon & Pearson, 1991). Its implementation was founded upon the need for more flexible ways of practicing that required educated professionals and a move away from traditional task allocation methods. This has become more important with changes in health service management (Griffiths, 2006). Griffiths (2006) adds that evidence relating to the effectiveness of nurse-led care is scarce however, and adds that there were only 10 controlled trials of intermediate care in nurse-led units. Griffiths, Edwards, Forbes Harris, Richie (2004) in a meta-analysis of research of nurse-led units showed there was no statistical difference in mortality between nurse-led units (NLU) and usual inpatient care. It was found that patients discharged from NLUs had a better functional status and least likely to be discharged to a nursing/care home. Patients at NLUs tended to have longer stays and were more costly but may have medium-term benefit for

patient outcome. Griffiths, Harris, Richardson et al (2004) also found that patient experience showed good satisfaction and minimal concern about the lack of medical input. Many patients perceived the NLU to be conducive to recuperation or rehabilitation though there were concerns that they were a 'dumping ground' from acute wards (Wiles, Postle, Steiner & Walsh, 2001).

Wiles, Postle, Steiner & Walsh, (2001) interviewed nurses in a 10-bedded NLU post-acute unit in the south of England. Their findings showed that increased autonomy and responsibility over their work which was highly positive. The acceptance of increased responsibility was daunting initially but was soon adjusted to. There was recognition of the need to develop enhanced skills such as identifying when to call for medical assistance. The nurses were able to work more directly with other members of the medical team and improve their teamwork approach. Nurses were found to have greater satisfaction from being able to provide holistic care, skill development and being involved in innovative nursing. Nurses were found to be resistant to the idea of taking on more medical activities which would threaten the nurse-led concept. Many medical staff felt that these nurses should adopt some medical tasks that would enhance the patient care, such as prescribing medication, to free them for other duties. This view demonstrates the conflict of discourse between nurses and doctors where nurses do not want to adopt medical tasks only at the behest of medical staff when they have found these tasks an inconvenience. Many of the senior staff felt there was opportunity to adopt some tasks that would in fact enhance the nurse's role and make them less dependent upon medical staff, like prescribing medication. The NLU provided opportunities for enhanced working and job satisfaction but needs to be managed effectively with appropriate support measures (Wiles, Postle, Steiner & Walsh, 2001).

Rosen and Mountford (2002) examined the development of extended roles in 9 NHS walk-in centres in London. In this study it was found that the development of extended roles was both challenging and stressful. The adoption of many medical skills such as clinical examination

and diagnosis was also stressful due to doubt over their diagnosis and treatment plans. Rosen and Mountford found that nurses were not prepared appropriately to work in walk-in centres and developed skills on the job. What appeared to occur was that nurses were being given autonomy without adequate support. They concluded that a coherent training programme is necessary for nurses to work in unsupervised conditions.

A qualitative study of nurses' lived experience of a nurse-led chemotherapy day unit by Mcilpatrick, Sullivan & McKenna (2006) found that nurses viewed their experiences as both positive and negative. They found the experience positive in that they could get to know patients well, challenging in developing new skills such as administering sophisticated cancer treatment, developing expertise, and moving away from task orientation. Negative experiences were focused upon stress and constant pressure of not feeling that holistic care is given. Some nurses found they could not develop close relationships with patients because it was a day clinic and this left them feeling dissatisfied. In addition to this nurses also felt they were nursing the chemotherapy clinic rather than the patient because of focus upon technical skills such as intravenous drug administration.

A similar study of outpatient breast cancer chemotherapy users and providers by Fitzsimmons, Hawker, Simmonds et al, (2005) found that nurses felt they had more time to listen and talk to patients. They felt there was continuity of care but were resistant to adopting additional medical tasks. The nurses were concerned about a lack of patient focus if new tasks were adopted. Patients viewed the nurses as skilled and as complementary to doctors. Many patients were resistant to the idea of a nurse-led unit because of concerns about appropriate nurse training and education to take on the role. This study highlights the need for educational preparation for staff and clearly defined roles so that optimal care can be given.

What these studies identify in nurse-led care is that it is a viable option for patients and nurses. From a nursing perspective nurse-led care offers an increase in autonomy and

responsibility and enhanced clinical skills such as deciding when intervention is needed. There appears to be better job satisfaction due to control over workload and a closer relationship with patients. However, there is some friction regarding the adoption of medical tasks particularly when staff feel this will threaten their nursing role and contact with the patient. These studies also highlight that nurses need to be prepared for their role in nurse-led units so that care can be optimised by developing decision-making and technical skills. Nurse-led care appears to be effective but is not necessarily a cheap alternative to medical treatment and therefore should be considered with much care (Griffiths, 2002).

## **2.9 A Summary of Findings from the Review**

In summary, the patient's experience of dialysis there is a great deal of stress involved in their lives which requires the use of coping strategies such as denial. Patients need to cope with the uncertainty of their lives, which provides a high level of anxiety. Depression is a major response to the changes that a life on dialysis brings but this appears to be dependent upon the illness severity or intrusiveness perception by the patient. Dialysis requires many changes in normal living activity such as dietary and fluid restrictions that may prove difficult to manage over the long term. Patients on dialysis can maintain a reasonable quality of life, though this is by no means on a par with those who have received a kidney transplant or those without renal failure. Their quality of life is affected by depression and the number and severity of physical symptoms. There are major efforts at maintaining a normal life and hope for the future which plays a large part in the day-to-day experience of the dialysis patient. In view of the psychological experience of the dialysis patient I find it surprising that patients manage to cope at all. However there must be credit given to the patients themselves for their ability to live in the face of long-term adversity.

I also found that many of these studies do not address the fact that dialysis is about the individual in their world. That is to say that the social world of the patient's interaction with

the dialysis is not addressed in their perception. The use of stressors appears to act as a surrogate concept to explain interaction at one level such as stress associated with cannulation but remains limited in scope. Differing methodologies and theoretical underpinnings of these studies offer me a fragmented image of experience that is often superficial in informing practitioners what the person is living through. The fact that someone is stressed doesn't let me appreciate how they feel when they are stressed. Because of this it has not been unusual in my clinical experience to encounter healthcare practitioners who, because of research statistics, presume all patients are depressed and non-compliant and treat them accordingly.

There is a general acceptance of the dialysis unit including dialysis satellite units as one homogeneous mass with no real acknowledgment of its potential for mediating psychological responses. There is no differentiation between main units and satellite units particularly when it comes to clinical research. Research about satellite units has been limited to typical medical measurable factors such as blood biochemistry levels. Whilst satellite units provide treatment as good as main units there is no evidence regarding patient experience (The UK Renal Registry, 2001). However, the patient lives in the social world of the dialysis unit and beyond, which will invariably have an impact upon his/her psychological perception and reaction (Kaplan De Nour & Czaczkes, 1974a, Kaplan De Nour & Czaczkes, 1974b, Kaplan De Nour, 1975, Kaplan De Nour, Czaczkes, & Lilos, 1972, Kaplan De Nour, 1980). Therefore it is important to understand how patients respond in different dialysis units particularly because of an expansion of dialysis services where nurse-led satellite units are increasingly the norm.

This has implications for renal nurses in that they must, in the current climate, be able to provide evidence of their practice and how it has benefits for patients. Understanding how dialysis unit experience is structured can point to how it can be manipulated to aid a better experience and would be one of many useful strategies nurses can undertake in practical terms. Further to this there is also limited research about dialysis nurses in their work. Kaplan De Nour's many studies only intimate the interrelatedness of staff and patient experiences but

again these are focused upon specific outcomes such as rehabilitation or 'goodness'. Understanding nursing experience has the possible implications for developing practice and working environments as well as the effect upon patients.

In view of the dearth of literature regarding satellite units as nurse-led units and dialysis nursing per se it appears appropriate I examine them as phenomena in their own right. Evidence from Bonner and others point to good skills development by dialysis nurses with opportunities for expert or advanced practice. The skills identified by Bonner and Greenwood are consistent with those found in nurse-led clinics in other areas of nursing. The development of skills that push the normal boundaries of care appears essential so long as they are tempered by a strong nursing philosophical attitude for maintaining nursing and not becoming 'mini' doctors. Nurse-led clinics appear to offer great job satisfaction for nurses but need appropriate training to cope with increased responsibility and stress found in dialysis units.

Because of the dearth of information about satellite unit experience it would seem prudent to undertake an exploratory descriptive investigation. This approach would allow exploration of activities, events and personal experiences that goes up to make a unit what it is. Therefore a phenomenological descriptive study of subjective experience is warranted in order to add the nature of evidence and understanding of those who use satellite units. Phenomenology is best suited to exploring the subjective experience of the Lifeworld. However before actual investigation can begin the area to be studied must be identified, permission obtained and access gained all acting under an ethical premise.

# **Chapter Three**

## **Ethical Issues**

### **3.0 Introduction**

Research is a human scientific endeavour that is controlled by a range of guidelines, protocols, methods and legislation. The rationale for such control is grounded in historical development of science (Feyerabend, 1993; Kuhn, 1996). Control in science is important from the point of view that methodological rigor can be applied so that it may be trustworthy as a whole. One particular area of strict control is the ethical management of those who partake in research. The Nuremburg Code was developed after World War 2 to provide safety standards for future scientific research on humans and stipulated that voluntary consent of individuals was essential (Pellegrino, 1997, Cassell and Young, 2002). The Declaration of Helsinki goes further by clearly identifies the duty of researchers to protect the life, health, privacy and dignity of human participants (WMA, 1964/2004). These guidelines have provided the basis for medical and social science research practice however the researcher needs to be aware of profession specific standards and codes of conduct that may impact upon their approach such as those for nurses (NMC, 2004). Additionally there is a need to be aware of the legislation such as the Human Rights Act (1998), Data Protection Act (1998) and Research Governance Framework for Health and Social Care (2001).

Each set of the guidelines aims to protect the individual involved in research from harm and to ensure professional practice. These guidelines are focused upon the rights of individuals that reflect a move towards a rights based society (O'Brien & Chantler, 2003). There are several guiding principles common to guidelines (see table 3) that a researcher must integrate into the study (Holloway and Wheeler, 1996).

Participants are free from risk
Informed consent
Voluntary participation
Right to withdraw or refuse involvement
Confidentiality
Anonymity
Dignity
Privacy
Fidelity and truthfulness
Conflicts of interest

**Table 3: Ethical Principles for Guiding Research**

### **3.1 The Approval Process**

Any research that is to be undertaken in any governmental health or social care setting must seek approval from the local ethics committee. The recent formalisation of the process of application has seen a stricter control and database recording that aims to ensure research applications are of an acceptable scientific standard (DoH, 2001). Applications are now made through a central government internet based system (Central Office of Research Ethics Committee, [COREC], 2001).

My application for ethical approval was undertaken prior to the implementation of the Guidelines for Research Governance was published. However, this did not mean that the ethical principles identified in table 1 were not considered. An outline of the time line for ethical approval can be found below in table 4. Ethical approval was sought from local research ethics committees as well as gaining approval from potential participating units. Approval was granted after a protracted affair of modification to the participant information sheet. Additionally a detailed account of the approval process can be found in appendix one.

<b>Unit 1 &amp; 2</b>	
October 1999:	Approach nursing and medical managers of units 1 & 2.
November 1999:	Meeting with nursing managers and proposal submission to medical director
December 1999:	Unit 1 & 2 Medical and nursing management approval awarded.
January 2000:	Advice sought from NHS trust research & development unit
February 2000:	LREC application submitted.
March 2000:	Approval in principle awarded subject to information sheet modification
May 2000:	Modified information sheet submitted
June 2000:	LREC reply requiring additional information sheet modification
August 2000:	Resubmission of modified information sheet
September 2000:	Final approval confirmed from LREC
<b>Unit 3</b>	
June 2002:	Initial enquiry with unit senior nurse
July 2002:	Meeting with unit senior nurse and submission to medical director and director of research
August 2002:	NHS trust approval
January 2003:	Honorary contract awarded

**Table 4: Ethical Approval Timeline**

### **3.2 Examining the Phenomenological Perspective and its Relationship to Ethical Issues**

The research process requires significant thought about its ethical implications. This also includes an active application of these principles throughout the actual study. These principles are numerous and include consent, power, responsibility, accountability, and freedom. What are acknowledged in these principles is the vulnerability of research participants (even where animals are concerned) and the duty of the researcher to recognise it and not exploit it. Therefore these principles are foundational for the implementation of all research no matter what type is undertaken.

Because of these issues, I am forced to consider ethical implications of phenomenology and its method. Phenomenology provides an interesting debate with its relationship to ethics. There is a degree of congruency between research ethics and phenomenological method. Both approaches aim to minimally impact upon the lifeworld of the person. Indeed research ethics

aims to preserve the individuality of the person including the cultural aspects (Robson, 1993). Phenomenology also aims at not changing the person but to retain the individuality of experience (Levinas, 1979). At the same time the phenomenological approach requires the researcher to treat each person or their experiences as equal (Spinelli, 2005). The phenomenological method of horizontization is precisely this stance that posits an ethical approach of making no judgements regarding hierarchical, ordinal, cultural or social importance. Each experience is to be analysed on its own merits and is, I feel, a demonstration of an ethical responsibility towards experience and method.

However, in the first instance it is important to note that phenomenology is without ethics. That is to say ethics is not a theoretical consideration in the application of phenomenology (Husserl, 2001, Levinas, 1979). This is part of the radical notion of phenomenology in that all theoretical disciplines (amongst other modes of knowledge) that produce normative theory are excluded from the method and includes ethics (Husserl, 2001). Husserl's point of view is stated from a philosophical stance that can easily exclude ethics in its analysis, but when applied to human subject research it does raise an issue of its application. Phenomenological method application highlights two clear areas of concern regarding ethics. Firstly the method requires a particular stance whereby the researcher uses no knowledge or belief and is committed to this stance. Secondly the 'atheoretical' approach is directed towards other people and objects whereby no ethical judgements are to be made. These two points are the same parts of a direction in that the first part is the 'I' and the stance I adopt and the second part is how I use this stance to examine the phenomenon.

When I adopt the epoché I am placing myself in a position whereby I cannot use my beliefs, knowledge or theories including any moral or ethical position I may possess. My suspension of these forms of knowledge is a kind of freedom from binding to the everyday world and a rebinding in an unfamiliar and uncomfortable positing. Whilst it frees me from my socially constituted ways of thinking it also binds me to the phenomenon I wish to examine. I must

focus on that given object, but I must also be aware of the requirement to sustain an ethical research approach. This ethical approach is within my horizon of experience but must take a back seat. The congruency between ethics and phenomenological approach allows me to proceed and because the world remains ever present I can act ethically in my approach.

The whole phenomenological research enterprise presumes a certain a priori existences of others that require examination. According to Levinas (1979), this a priori existence posits a fundamental ethics. When I embark upon an interview or observation in a phenomenological manner I intuit activities, acts, speech acts, objects and so on of the other. From this I see that I have a directional orientation to the other that is 'I-Other'. This 'I-Other' orientation is grounded in my experience. I experience the Other as actually existing as an object but not as a mere physical thing like a rock or a tree (Husserl, 1960, Husserl, 1964). The Other has a privileged status in my experience of the world. I experience the Other as an object but also at the same time I experience them as a subject for this world (which is also my world), and because of this they will experience me too; they are co-experienced. I cannot apprehend the Other's inner world of thinking and emotions in the same way as I apprehend my own. However, I apprehend the Other's body or more precisely their bodily presence which allows me to see associations; a unity of similarity with myself and is described by Husserl (1960) as pairing. Pairing provides me with a sense of the Other with coincidences and the ultimate (but unlikely) limit having complete likeness to me. When I see the Other I do not see them as a duplicate of myself but as experiencing the Other as there. This has two dimensions, it recognises the existence of the Other as 'being-there' and that I could see the world as they see it if I were in the Other's position; a spatial existence. Here we see a connection that establishes a relationship with other people at a fundamental level of experience. This experience is a 'pairing' which allows me to see the others as embodied and perceiving. I also understand the outward conduct of the other, such as anger, through my own circumstances. The understanding this generates is known as empathy (Husserl, 1960). The term empathy is not to be used in the common or specifically psychological usage as described by Rogers

whereby 'one person is capable of taking on the role of the other' (Rogers, 1948, p348). Empathy, in the phenomenological sense, is fundamental and arguably existential in that it recognises the 'I' it understands other persons and accepts them as ego subjects like myself and related to the world. Their world and my world are the same (Husserl, 1960).

Empathy is a meaning giving act of experiencing Others as other than me and that my experience is intersubjective. Phenomenology is a conscious attempt to understand Others. The Other is seen as an ego like myself and not an alter ego (Levinas, 1979). This recognition of the Other as embodied ego, establishes the fact that the Other may suffer as I suffer, have concerns and experience happiness as I do. And yet I can chose to be inattentive or indifferent to the other and let the other not matter to me. But even as I do this the Other is never reduced to a mere object remaining an embodied ego. To add to this the Other is never a single subject but is acknowledged as being in a community of others.

The experience with the Other is made more emphatic by the face-to-face encounter. The face of the Other moves me from identifying the other as an embodied ego like myself to being 'someone' (Levinas, 1979). The face reveals to me the sameness and difference of the Other and requires an attentiveness that shows the Other matters. This identifies a crux of ethical importance to phenomenological research directed to Others. Once I engage face-to-face with the other I become bound to them because the face establishes a relationship and invites me to speak. Speaking is an appeal for discourse which binds me to maintain the relationship on equal status (Levinas, 1979). Face-to-face encounter matters because it reveals a 'someone' brought about by the empathic recognition of the embodied ego which establishes meaning and meaning matters. Hence phenomenological human research has a fundamental ethical orientation because of attentiveness towards Others.

I have an underlying ethical basis from which phenomenological research is undertaken. In undertaking phenomenological research I deliberately encounter embodied egos of others on a

face-to-face basis, even when I am doing observation. The face-to-face encounter establishes a relationship through my appeal for others to speak and my attentiveness towards them. Here I am able to give the experience of others a voice through meaning. The ethical basis does not end there because my face-to-face encounter bears witness to lived experience of the Other. According to Naef (2006) bearing witness is ethical because the researcher deliberately establishes the relationship with the Other and in doing so creates a responsibility. This responsibility is not to negate the Other by inaccurate descriptions or interpretations and neither should it make or claim constructions that are not evident (Naef, 2006). My responsibility is to remain authentic to the Other which is a truth of representation and retaining the essence of experience.

Having established a fundamental ethics of phenomenological research in my face-to-face encounter, attentiveness, speaking and bearing witness I must examine this in action. A vital requirement of phenomenological method is to undertake the epoché. The epoché has the possibility of treating other people unethically such as I can resist the ethical knowledge of my professional orientation. Additionally, my aim to identify general structures of experience may despoil the 'face-to-face' encounter through the loss of the 'someone' being present. This may be the case if my intention was to find universal essences, as in the case of transcendental phenomenology, but this is not what I intend. I aim to grasp meaning (categorical intuitions) through description grounded in the experience of Others and because of this they remain present and not lost. The face-to-face encounter leads to a revealing of lived experience. The lived experience is always contextual and related to the world which is phenomenologically ethical. To abstract this experience runs the risk of decontextualisation and loss of the 'someone.'

In practical terms an example may demonstrate the point. During one of my observations at satellite unit one I witnessed many nurse-patient interactions. This particular incident occurred during the initiation of dialysis stage of the morning treatment session. It was not

unusual in comparison to other days with much nurse-patient interaction, humour and dialysis related activity. During this episode a patient who was receiving dialysis on a regular basis at the unit, in a four station area, made loud comments to a nurse that was of a sexual nature. The nurse responded to the situation by immediately and publicly angrily berating the patient. The patient did not apologise and sat looking at the nurse. The nurse then carried on with her business. Later she returned to the patient to undertake required monitoring activity. The nurse later stated to me that she felt the patient was not to speak to her or other people in that manner.

This situation is analyzable from a whole range of theoretical perspectives. For example, I could adopt the nursing professional perspective which is grounded in religious idealism towards others and the intent that the nurse should intend no harm to the patient: the patient always comes first (Kuhse, 1997). Equally I could analyse it from the Nursing Midwifery Council standards of practice which requires the nurse to “behave in a way that upholds the reputation of the profession” (NMC, 2004, p7). From this perspective I could argue that the nurse is behaving unprofessionally and as such unethically. I could also use psychological theory to explore personalities, abnormal psychology or traits. I could even apply social theories of power and agency (Morrow, 1994). I could also feel empowered to speak to the nurse and question the way she managed the situation so publicly without thought of consequences. What I would be doing is making a judgement in terms of right and wrong behaviour against some form of normative theory. However, the epoché denies me the use of these forms of knowledge, so instead I must describe it as it is. Describing it phenomenologically sustains the interaction of the face-to-face encounter and the people of the experience. They are not abstracted to a theoretical level. Instead the episode is described to explicate meaning. In this instance given the context of the findings of the research the episode is described within the structures of experiences that include the following: routine and repetition of experience, nearness and closeness, being known and knowing others, and not being valued.

The routine and repetition of experience establishes closeness to one another. Closeness enables the people in the unit to know others, be known and provides a sense of community. In this community people are not strangers and interaction is more personal and individual. Comments are made in an atmosphere of mutual respect revealed by the face-to-face encounter. The patient appeared to despoil the 'someone' of the nurse to which the nurse took offence. The offence required the nurse to redress the balance by emphasising her 'someone' status publicly and not being negated or reduced to a mere object (not being valued). The communication was immediate and at a personal level the nurse acted ethically in order to sustain her own integrity and that of the unit community. The incident enabled both the nurse and the patient to move on to other activities. This brief description of one of my observations of experience has shown that ethical issues that are immediate and lifeworld oriented can be explicated by phenomenology. I can sustain an approach that is true to the participants and as such remains ethical.

Phenomenological human research has an ethical underpinning found in the face-to-face encounter. It is also ethical from the point of view that it is about exploring the research participants lived experiences of the lifeworld and bearing witness. Reporting the lifeworld of research participants must remain contextual and truthful and as such I find it ethical.

### **3.3 Applying Ethical Principles 1: Patient Information**

Informed consent is the cornerstone of ethical research (MRC, 2000, Cassell & Young, 2002, RCN 2004). An essential element of informed consent is the quality of information that is provided to potential participants. An information sheet was a mandatory requirement for LREC application and approval which is in accordance with research governance standards (DoH, 2001). The importance of this is undoubtedly to ensure participants understand what is involved in the research in order for them to make a decision whether or not to take part. From a nursing perspective, whether as a clinician or as a researcher, the nurse is required to gain consent for any aspect of the nurse-patient relationship where care or treatment is

required (NMC 2004). This consent includes eliciting personal information which is also covered by the Data Protection Act (1998). In view of this it was important to develop a patient information sheet that meets the ethical principles identified in box 1 above.

The patient information (See appendix 2) sheet was initially adapted from Trumbull's information sheet found in Moustakas (1994) but also included areas omitted by Trumbull but to be found in Corec (2001) information sheet guidelines. Structurally Trumbull's information sheet is provided as a letter. The first part of the sheet identified who the researcher was and the reason for undertaking the study. I also felt it important to state that the research was for a PhD so that participants would know where the research is situated, that it did not belong to the main unit, but linked to an academic institution. As with Trumbull's approach, the information adopted a personal tone in an attempt to appeal to the individual. The tone demonstrated an appreciation of the personal nature of being involved and what that means to the researcher. To add to this it was important that the information sheet acknowledged the commitment of the participant including the time, energy, and commitment involved. The importance of this approach was to give potential participants an idea of what participation meant and that it was appreciated by the researcher.

The next part of the information sheet was constructed to inform a potential participant of what aspect of their experience the research is interested in and how it is hoped their involvement will help answer the question(s). The importance of this statement was to give participants a focus for what aspects, such as feelings and behaviours, will be examined. I felt it was important, at this point, to state that there are no tests of any kind involved. Whilst this may appear trivial at first glance it was important because dialysis patients are, by the nature of the treatment, exposed to a great number of tests such as blood tests, X-rays, and experimental or therapeutic research. In view of this, it was also felt that it would reduce any potential threat from a physical perspective that may have inhibited involvement.

The next area covered by the information sheet informed the reader of what I wanted to do to collect data. It was important to state that I would be present in the unit for several weeks and that data collection will include making notes, talking to people and recording the interviews. This emphasised the fact that the research will take place on the unit. It also states that people will be invited to be interviewed. I felt this statement was important to emphasise the autonomy of participants in that they will be asked and not assumed they will participate once the I was in place. This section also highlighted the manner of the interview including an estimate of the time commitment and areas of interest. What it did omit was where the interview would take place. This was a genuine omission and did not assume any hidden agenda in where interviews should take place. In fact all interviews took place on the units even though participants were offered to suggest when and where they would like to be interviewed.

To follow on from the data collection method it was important to stress the consent aspect of the participant and to stress that the information will be recorded in two ways. Trumbull's information sheet omits an area that is essential and a requirement by COREC (2001). Trumbull omits any consideration of confidentiality however it was include in this information sheet. The reason for inclusion is to ensure that an individual's right to privacy is maintained and that the data will remain safe (Data Protection Act, 1998, RCN, 2004). The information sheet does not state how and where the information will be stored, however, this was mentioned to potential participants on a personal verbal level.

A further omission of Trumbull's is a reminder of participants' personal autonomy. This important area was included in the information sheet in the form of a statement of acknowledging the person's right to refuse with no alteration in their treatment (Behi, 1995) and is an aspect particularly emphasised by COREC (2001). To support individual autonomy, further there was a statement enabling direct questioning via contact numbers in case someone wanted to speak confidentially to me.

Upon reflection the information sheet did omit an area included in the COREC guidelines. This omission again was not intentional but should have highlighted any advantages or disadvantages for participating in the research. Whilst I thought there was minimal risk to participants and no personal advantages in relation to treatment, there are issues that may be disadvantageous (Haverkamp, 2005). An example of a disadvantage could occur when being interviewed on the unit which may compromise their right to privacy by being observed and or overheard by others.

### **3.4 Applying Ethical Principles 2: Informed Consent and Voluntary Participation**

Gaining consent from individuals is essential prior to any research can be undertaken (Pellegrino, 1997, Cassell and Young, 2002, MRC, 2005). This consent must be voluntary and informed in order for the research to be trustworthy in any manner (Behi, 1995, Haverkamp, 2005). Informed consent presumes that the informed component is adequate, clear in meaning, and truthful. What is not clear as to what amount of information will dictate informed (Kvale, 1996). It is undoubtedly the role of the principle researcher and the ethics committee to ensure that important information is made available in a manner that can be accessed by potential participants such as an information sheet, tape recording or appropriate language (Behi, 1995, DoH, 2001).

Potential participants were informed by information sheet and a personal explanation by me. Consent forms were provided to the each person on all the units and a sample can be found in appendix 2. The reason for this was to assess any potential issues regarding the observational aspect of the research. Some may not want to be watched or their actions and comments recorded. Others may be happy to be interviewed but not observed whereas others may be happy to be observed but not interviewed. To illustrate this issue on unit one there was a patient who had experienced some tragic personal circumstances and was suffering from

depression. This person declined to be interviewed but was happy to be observed and have any non-personal information recorded. What this person meant by non-personal was any discussions related to her private life. This was acknowledged but did prove to be delicate to manage. Decisions were made to discuss situations that occurred with the person involved to gain approval. This approach was adopted to build a relationship of trust and confidence, though it may be viewed as a form of censorship where unflattering material could be objected to by the person. I was fortunate that this situation did not occur. Another example involved a patient on unit three who had been involved in some clinical research. The research involved modifying an alternative form of treatment. The person believed the research resulted in the need for dialysis and that risks associated with the treatment had been omitted from initial information. Consequently this person refused to be interviewed but was happy to be observed and comments recorded. The refusal to be interviewed was respected as an individual demonstrating their right not to be involved.

Gaining consent from the patient group was important for the reason that they are a vulnerable group. The vulnerability lies in their dependence upon dialysis and being attached to a dialysis machine for about four hours three times each week. They are quite literally a captive group. Therefore it was important that every effort was made to gain consent that was voluntarily given.

One issue that was not explicit as could have been on the consent form was an explanation of what would happen to the analysed data. When consent is given it is propositional, that is to say an assertion of what will happen (O'Neill, 2003). This assertion assumes that all events and acts will follow as presumed but does not include variations that occur when situations change. For example a patient may give permission to be observed and interviewed and that information will provide information but not realise that the information may be published in academic journals. There was an assumption that people would know that a PhD involved publication of findings to which academic papers may be additionally

published. In view of this lack of clarity such issues were discussed prior to commencement of the interview with participants.

### **3.4.1 Right to Withdraw or Refuse Involvement**

The right to withdraw is an essential requirement (WMA 1964/2000) and was made explicit on the information sheet and verbally reinforced at the time of the interview. It was fortunate that no patient withdrew their consent during the research. Had such an incident occurred no questions would have been asked because accepting an individual's decision and right to withdraw would preclude such an approach. There was no overall refusal to be involved other than refusal to give interviews by a number of staff and patients. All participants appeared more at ease with the observation than the interview.

### **3.4.2 Participants are Free from Risk**

There was an evaluation of the data collection method and a conclusion that there was minimal risk of harm to potential participants. One potential risk identified was that patients may become distressed when recounting their experience, especially if there had been some particularly difficult times. One example of patient distress occurred in unit one when a patient recounted an event that led to amputation of a limb. The patient began to cry and stated worries for the future. This episode was managed through a previously used strategy of asking the person if they would like to discontinue with the interview either completely or temporarily. In addition to this, an opportunity to sit and discuss any issues was offered using professionally gained nursing experience. In this one incident the patient insisted that the interview should continue and apologised for the behaviour which was not really necessary. Emotional support and assurances of confidentiality were also offered. A potential risk is that negative comments or controversial descriptions by participants make their way to managers which may cause some institutional disharmony. In an attempt to prevent this, assurances of confidentiality and privacy where applicable were ensured.

### **3.4.3 Confidentiality, Anonymity, Dignity, Privacy, Fidelity and Truthfulness**

Researchers are not immune from the Data Protection Act of 1998. In addition to this, a nurse researcher is bound by the NMC code of professional conduct which required the nurse to maintain patient confidentiality and protect confidential information (NMC 2004). The information elicited from individuals is a personal account of their experience. In the first instance it is important that the researcher is aware that the data can only be used for the purposes stated when consent is given. It is the responsibility of the researcher to have adequate and relevant but not excessive data for the purpose(s) they are required. Therefore the method applied in this research did not warrant the need to gain information regarding such as types of dialyser used or blood specimen results. This information would not inform the nature of the research or the results and therefore was not collected. Any information collected was kept by the researcher alone in a secure filing cabinet on a separate site from the research sites.

All personal information that could potentially identify an individual was removed when used as case examples or vignettes within the data analysis. Interview transcripts and initial coded transcripts kept the individual's name only to enable me to remember whom the individual was in order to remain context related when analysing data. This information was not transferred to latter stages of analysis. All interview participants were given a copy of their transcript in order to make sure they were aware what was recorded, to be analysed and for accuracy and fidelity. This is an important point for research trustworthiness because it sustains accuracy. It is also important from a phenomenological perspective because it retains its closeness to the phenomenon.

Ensuring privacy was a challenge when undertaking interviews with patients. When patients agreed to be interviewed they were offered options of where to be it could be performed. All

patient interviewees stated they wanted to be interviewed whilst on dialysis. The patients stated that this would not be a problem to them. The reason for this was that they did not want it to occur before dialysis as this may delay them getting on or to wait after dialysis as this would delay their transport home. They also did not want to have the intrusion into their home. In view of this, where practicable, it was agreed they would be placed in areas where privacy could be more or less achieved without compromising their safety. However, the communal nature of satellite units often made ultimate privacy difficult and interviewees often spoke with fellow patients during interviews.

Ensuring privacy was easier for staff interviews as in all but two cases the interviews were undertaken in staff rooms or offices. The two who were not interviewed in the office were interviewed in the main clinical area but on both occasions there were no other staff or patients present.

### **3.5 Conflicts of Interest**

All potential participants were informed of my professional background and experience. There was emphasis of the neutrality stance of not having any attachment to the units. I did explain that with unit one and two there was a professional link in relation to educational liaison when students were present or access to educational courses. With unit three there was not link at all. Funding for the research was through the researcher's employer who was not the hospital trust to which the units belonged. Nurses were informed that refusal to take part would have no influence upon potential application to courses run by myself or university where I worked.

### **3.6 Reflections**

The examination of the phenomenological relationship to ethics has allowed me to proceed with the study. This is because I can feel assured that the method is ethically sound. In view

of this I was able to proceed with identifying the research participants. The phenomenological stance allowed me to accept all participants as they presented themselves. Interestingly, I found this remarkably easy. This was partly due to the fact that I had no clinical responsibility; I didn't have to worry about making the place work. It was also easy because I was focused upon how they presented rather than how I wanted to see them. The epoche enabled me to be free from my natural attitude of ethical or moral judgement making. It was, in fact, quite liberating not to view nurses in this way or that way. I found this freedom of judgement allowed me to look at actions, activities and events in a fresh way. The epoche enabled me to question people about their experience without prejudice. The example provided earlier, relating to a nurse's response to a patient's comment, enabled me to ask what the event was about and what it meant in a way that was without professional bias. The fact that I may use this information without prejudice was also liberating. I did not have to judge whether this event was professionally ethical; it was examined apohantically: on its own merit.

The phenomenological method required me to remain close to the phenomenon when describing it. I found this is a profoundly ethical requirement because it means being truthful and accurate. My findings would be providing a voice to the participants. In order for me to provide a voice I must recognise my 'I-Other' phenomenological relationship. Participants are not mere objects; they are like me and exist in my world as much as I exist in theirs. My request to speak to them meant I not only had to listen, but report their experience because it was my beckoning. Truthful and accurate description must be free from judgements based upon any theoretical stance. I could not interpret the findings in any particular manner. Ethically, I was governed by what appeared and not what could or should be. A phenomenological ethical approach is congruent with research ethics.

In summary the ethical analysis has enabled me to demonstrate that phenomenology has a strong ethical perspective that is at a fundamental ontological level. It is congruent with

research ethical principles because it means acknowledging the existence of the other as being equal to the researcher. There was also a practical application of these principles that were obligations in order to proceed. All these facets meant that the phenomenological thread ran throughout all aspects of the research including ethics. Having this ethical basis meant that the recruitment of participants could proceed. The recruitment of participants will follow on from this chapter.

# **Chapter Four**

## **The Research Participants**

## **4.0 Introduction**

The ethical approval necessary for commencing my research was received which enabled me to recruit participants. In this section I will outline the decisions made to identify participants in the research of dialysis satellite units. I will explain the rationale behind the decisions made throughout the stage of identifying dialysis satellite units. I will also outline any problems that were encountered and explain any solutions employed to overcome them. The characteristics of the participants will also be presented including any issues raised at the time of the study.

### **4.1 Identifying the wider context of the research participants**

In order to gain the appropriate source of experience for this research there was a need to consider the research questions posed at the proposal. The questions identify several areas such as describing a general structure of satellite units, and what are the experiences of both patients and nurses. The focus on the general structure of satellite unit experience gives direction for the research. Clearly the research has to involve both satellite unit nurses and patients. However, it was important to clarify the location of satellite units in the broader context in order to have meaning for the wider world (Mason 2002).

Satellite units, as we have seen, are part of a broader picture in the world of treatment for end-stage renal disease. As such, people with end-stage renal disease may or may not experience satellite unit treatment. All satellite unit patients will have experienced other treatment experiences, such as becoming ill and being on a main unit. Satellite unit treatment is an option available to some patients in the wider world of patients with renal failure. The satellite unit can be examined in isolation to an extent, but its link with the main unit must remain present for it to maintain part of its reality context; its horizon. From a phenomenological perspective the satellite unit is seen as an independent piece but inextricably linked to the whole.

Whilst the position of where a satellite unit is situated in the wider context is made clear, the practical activity of which satellite unit(s) staff and patients to be approached to take part needs to be explained. I found information on how to choose appropriate research participants for phenomenological research was absent from the usual qualitative research textbooks. Literature relating to phenomenology is focused upon phenomenological method and appears to assume that sampling will not be a problem. A phenomenological researcher would need to examine general qualitative research literature to follow any kind of strategy.

Qualitative research sampling strategy is usually described as purposive and not concerned with demonstrating statistical significance or generalization (Robson, 1993, Holloway & Wheeler, 1996). Indeed it is concerned with depth and richness of experience which points to choosing those participants who can provide this kind of information (Kuzel, 1992). There is also a general acceptance of a relatively small number of participants on the basis that this number will provide a great deal of information, which takes time to analyse (Miles & Huberman, 1994; Smith, 2003). What is not clear is the number of participants is small or large enough to gain sufficient information for the analysis. There appears to be an arbitrary limit of participants providing the researcher can justify this decision. The lack of clarity does leave a researcher with some important decisions to make and justify, which can be a source of anxiety.

I found a way to overcome this methodological anxiety in the philosophical background to phenomenology. This phenomenological perspective argues a described structure will be incomplete because phenomena are experienced in manifold, which is to say, from many aspects (Sokolowski, 2000). Accepting incompleteness is acknowledgment of a post-modern approach to knowledge and narrative tradition (Polkinghorne, 1992). I accept, from a phenomenological perspective, that any number of participants will provide a limited manifold of experience and as such an incomplete description. The problem here was at what number will be deemed appropriate for an adequate description. For a discussion about

adequacy, see section 4.3 below and the following chapter about phenomenology where it is discussed in more detail. This dilemma is the proverbial ‘how long is a piece of string?’ question. Clearly if there are multiple aspects then the more experiences that can be explored the better.

## **4.2 Identifying and Accessing Satellite Units**

The focus of this research was the structure of satellite unit experience which provided a decision to study at least one satellite unit. However, one satellite unit would provide one aspect of the phenomenon and whilst it may provide some elements of structure, it would be more incomplete than if more units were studied. Without doubt, I encountered a feeling of going round in circles with this conundrum of how many is enough, but a practical analysis provided a solution that appeared acceptable for the research. My analysis of the problem explored the possibility of attending more than one unit with the time available for someone in full-time employment. The time available for research was one day per week for about a three month period. It was negotiated that three, three month periods would be made available to attend three separate satellite units. This was a practical solution that made the possibility of doing this research a reality. I finally made the decision to attend three satellite units within the given time, meaning each unit would be visited for a three month period one day per week.

The choice of satellite units was also undertaken in a practical manner. In view of the fact that no unit’s experience was more important than another (Phenomenological horizontalization) it made no real difference as to which units were chosen. However, I recognised that the choice of which unit to study may not wholly be mine. Access to units is governed by their managers who act as gate-keepers, and even though there was ethical approval access was not guaranteed (Burgess, 1984). I arranged to present my research proposal at a monthly meeting

where satellite unit managers attend. I was able to discuss the proposal and answer any questions. As a consequence a number of unit managers expressed an interest to be involved.

Choosing the first unit was based again on a purely practical reason and that was my ability to get to it. At this point in time I did not possess a car and used public transport for most of my travelling. I chose the nearest unit because I could get there easily by bicycle from home. Whilst I recognised this was an arbitrary decision there was a need for pragmatism, and the willingness of the staff also influenced my decision (Burgess, 1984). Phenomenological horizontalization also provides a legitimate reason to choose the unit. The first unit was approximately five miles from the main unit within the same city boundary.

The second unit was chosen when the unit manager expressed an interest to be involved. The manager expressed no particular concerns and was just pleased to help. I was happy to accept the offer from the manager because it removed an access barrier. I was aware of a potential for personal agenda from the manager but found none when I attended the unit. The second unit was attached to the same main unit as the first but was approximately ten miles from the main unit and at the opposite side of the city. By this time I had moved house and acquired a car that enabled me to access units further away from the main unit.

The choice of unit three occurred through opportunity and practical reasons. I had moved house some distance (100miles) from the original city where the research began. I had heard that a satellite unit had opened at my local general hospital. I saw this as an opportunity to access a unit not attached to the first two units. The reason for this was to expand participant inclusion beyond one main unit and as such perhaps to increase phenomenological adequacy. The unit was also not linked to unit one and two and as such would provide an additional dimension to experience. The unit was within driving distance from my home and was within a separate city to the main unit to which it belonged.

In reality, units one and three were convenient for travelling and as such determined my choice of which unit. This decision is hopefully balanced by the fact that unit three was in a different part of the country to the other two. Convenience, in this instance, is acceptable because of the notion of 'horizontalization' (Spinelli, 1989) and accepting the qualitative research philosophy of not attempting to demonstrate statistical representativeness and generalisability (Sandelowski, 1986). Nevertheless by using three units, differences and similarities may become present that may help clarify structures of experience and phenomenal.

### **4.3 Phenomenological Adequacy and Sample Size**

The issue of adequacy and sample size played a lot on my mind because it was deemed a serious point to which no answers had been provided by phenomenological or qualitative researchers. Adequacy is a fundamental issue within phenomenological research because it is a matter of trust for the reader. The trust lies in the belief that the researcher has established a range of information that is sufficient to provide an adequate description of a phenomenon. This has implications for research trustworthiness and is something I found not discussed in any clarity by phenomenological researchers. It is true that the richness and depth of information is important for qualitative research however, there need to be sufficient participants to allow for differing experiences (variants) and not those that just confirm the researcher's ideas (Shipman, 1988).

One possible solution is to look to Husserl (2001) who sees that there are different levels of fulfilment. Husserl means that there are low levels of adequacy where evidence is limited and high levels of adequacy where evidence is in abundance. What this implies is that a phenomenological researcher must be aware that a small sample, such as four participants, provides a lower level of adequacy and as such limited fulfilment. Therefore a larger sample will provide increased adequacy and more fulfilment. What the phenomenological researcher

must bear in mind when considering a sample is that the end description must demonstrate manifold of experiences fused to provide a presentation of a single appearance that has adequacy and a sense of being fulfilled (Husserl 2001).

In this study to sample from one unit would only provide a low level of fulfilment because there would only be a limited number of aspects of experience. To include additional units and participants raises the level of fulfilment and thus adequacy by increasing the experiences. Therefore a larger sampling strategy from multiple sites becomes essential for establishing a higher level of adequacy in this phenomenological research. In view of this, a decision was made to interview ten patients and ten staff members from each unit in order to provide, what I considered, a sufficient number for attaining a level of adequacy and parity between the units.

#### **4.4 Gaining Access to Participants**

I made no distinction between patients and staff when considering access. I viewed both patients and nurses as individuals who need to be treated with equal ethical concern. The ethical approval procedure followed local requirements and was prior to the NHS requirements of COREC guidelines. Access to each unit was negotiated with the unit manager and in the instance of unit three additional ethical approval was sought. I negotiated with each unit manager that access would be one day per week; though they were happy to accommodate more than one. The day of attendance was negotiated on a week-by-week basis due to various work commitments. Further to this, it was important to be able to access each cohort of patients during the week to ensure as broad a sampling of the unit time as possible. Satellite units provide treatment to two cohorts of patients three times each week, half during the morning and the other half during the afternoon. It was important to be able to access these times for adequacy. I alternated the days of attendance each week to cover the patient cohorts. For example, some patients dialysed on a Monday, Wednesday, and Friday morning

and some on the same days but afternoon. The other group of patients were split between Tuesday, Thursday and Sunday or Saturday mornings and afternoons. It is to be noted at this point that Saturday or Sunday was not sampled due to personal home commitments. Gaining access to staff seemed easier because there were a limited number who worked flexibly and would be present at some point during the period of the study.

#### **4.5 Deciding Who to Interview**

Choosing who to interview was difficult. The qualitative philosophy requires the inclusion of those best suited to provide the experience under investigation (Munhall & Oiler Boyd, 1999). The desire to gain a general structure means that a large sample was necessary. The large sample is not aimed at being representative but providing an opportunity to gain information from as many people as possible to increase phenomenological adequacy. It also demonstrates engagement in the phenomenological concept of manifold of appearance of identity: satellite units can be experienced in different ways.

A decision was made to include, where possible, people from ethnic minorities. Clearly the inclusion of one or two individuals from ethnic minorities does not mean they are representative of that group of people in the same way as inclusion of females is not representative of this gender group (Allmark 2004). However, as stated above, their inclusion does help move towards structural adequacy. The issue of including people from ethnic minorities is a thorny one and something that healthcare qualitative researchers must consider when the government insists on cultural inclusiveness (Department of Health 2001). Allmark (2004) suggests that a way to help researchers is to consider the issue of fairness when thinking of a research sample. Allmark asks the researcher to think whether or not it would be fair to exclude someone who may benefit from the outcome of the research particularly if it influences healthcare policy. Exclusion would be deemed unfair when one considers that, whilst acceptance rates are regionally variable, ethnic minorities account for 15% of new

patients and account for 18% of the dialysis patient population; a population which is expected to rise (Renal Registry. 2002).

One practical issue that came into consideration when deciding who to interview was, as highlighted by Morse (1991), the ability to communicate. Morse (1991) states that research interview participants should be articulate, capable of reflection and able to communicate effectively. These points are important and may exclude not only those from ethnic minorities but those where English is not their first language. Language interpretation was not available and I could not afford to pay for an interpreter so this in itself excluded some people. This was not ideal but practical given the limitation of resources and something that needs considering in future research. In view of these criteria I decided to assess an individual's ability to communicate before approaching them for interview. What this meant was to observe their communication with others and talk to them myself. This was a useful exercise because it quickly became clear who may be a suitable candidate however, it does highlight the problem of excluding those who may have something valuable to say but may have some difficulty expressing it. I found this a dilemma but decided that I would invite those individuals who I thought were suitable in relation to the stated criteria (see table 5 below). I applied these issues to both patients and staff but at the time of the research there were no members of staff who were from an ethnic minority.

<b>Criteria for Inclusion</b>
Effective communication ability
Articulate
Capable of reflection
Ethnic minorities
Gender: male and female
Well enough to take part
Consent
Experience of satellite unit dialysis
Experience of main unit dialysis

**Table 5**

The following criteria were not used for inclusion: time since starting on dialysis; frequency of dialysis; biochemistry and haematology levels; dialysis adequacy; type of dialyser;

experience of other forms of dialysis; and kidney transplantation. The reason for not using these criteria is because there is no effort to make correlations with them. Phenomenology aims to describe experience not correlate experience with biochemical markers or effectiveness of dialysis, which presumes a theoretical basis for such a linkage.

#### **4.6 Problems in Recruiting Interview Participants**

Each person on the units had received an information sheet and a consent form which can be seen in appendix 2. Interestingly everyone signed the consent form, however not everyone wished to be interviewed but were happy to be observed. Staff members were more reluctant to be interviewed than patients. Indeed some staff members became very coy and avoided my contact. This was particularly obvious in unit three. Why this occurred is unclear but it may be that I was better known in units one and two. The low numbers of nurses who were interviewed has implications for phenomenal adequacy. It means the subsequent findings have a limited level of adequacy. I found this quite startling at first because these members of staff were happy to discuss anything in my presence but refused to be interviewed. They provided no reason and though feeling frustrated at not achieving my desired number I did not pursue them on the ethical basis of right to refuse (Holloway and Wheeler, 1996). I did not start interviewing patients or staff until I had attended six times and interviewed staff after patients.

The target of ten staff and patients seemed reasonable, given the number of patients and staff available at the units, but proved to be more difficult than I expected. Some individuals stated that they did not want to be interviewed but were happy to talk 'off the record'. One can only speculate on the reasons but one reason for this may have been that those patients who agreed to be interviewed did so whilst on dialysis and as such compromised their privacy and confidentiality: they could be seen and heard. All participants were offered the opportunity to be interviewed in private of whom only three staff members accepted; the rest were happy to

be interviewed on the unit. The total number of participants interviewed and refusals can be found in the table 6 below.

There were instances where staff members insisted that I speak to certain patients because they felt they would give a good account. This provided a dilemma because staff felt they were being helpful and yet I did not want to offend them. To get around this problem I thanked the staff and spoke to the patient later. The reason for this was to have time to assess the patient's communication and behaviour. This approach was useful, for example, in one instance a recommended patient turned out to be psychologically distressed and at times incoherent. When I discussed this with the staff they said that they thought he would be a good candidate to show psychological problems: clearly I had some work to do to re-explain my research purpose.

In summary the recruitment of participants included gaining access to three satellite units. Two units were in the same city and linked to the same main unit. The third unit was in another city and not linked in any way to the first two. Following ethical approval access to the units was negotiated with my attendance one day per week for three months. Ten patients and ten staff members from each unit was decided as the sample size in order to provide some phenomena adequacy. This was not achieved due to participant refusal for personal reasons. A total of thirty seven participants were interviewed. There were fewer nurses interviewed than patients.

A concern for sustaining a phenomenological approach was evident in the sampling process in that a concern for adequacy was central. This phenomenological orientation means that a level of consistency is sustained. This consistency is further addressed in the following chapter which examines the philosophical phenomenological basis for its application to the practical activity of human experience research.

The overall numbers and characteristics of the research sample can be seen in tables 6, 7 and 8 below.

	Total Approached (%)	Total Interviewed (%)	Refused	Total Number of Females/unit (%)	Number of Females interviewed (%)	Ethnic Minority Total/unit (%)	Ethnic Minority Interviewed (%)
<b>Unit 1</b>							
Number of patients (Total 43)	16 (37)	10 (23)	6	10 (23)	2 (20)	3 (7)	1(33)
Number of Staff (Total 11)	8 (72)	5 (45)	3	10 (90)	4 (40)	0	0
<b>Unit 2</b>							
Number of patients (Total 18)	10 (55)	7 (38)	3	5 (28)	1 (20)	5 (28)	2 (40)
Number of Staff (Total 7)	7(100)	4 (57)	3	6 (85)	3 (50)	0	0
<b>Unit 3</b>							
Number of patients (Total 28)	12 (42)	8 (25)	4	6 (21)	1(16)	0	0
Number of Staff (Total10)	6 (60)	3 (30)	3	8 (80)	3 (37)	0	0
Total Number of People (107: 79*: 28#)	59 (55)	37 (34)	22	45 (42) 21(26)* 24 (85)#	14 (31)	8 (10)*	3 (37)*

\*Patients; # Staff

**Table 6: The Profile of Interview Respondents per Unit.**

Staff	Age (yrs)	Gender M/F	Qualification	Designation	Time at DSU
<b>Unit 1</b>					
1	31	F	RN	Sister	9 months
2	34	F	RN	Staff Nurse	10 months
3	40	F	None	Healthcare assistant	4 months
4	48	M	RN	Staff Nurse	4 months
5	46	F	RN	Staff Nurse	3 Years
<b>Unit 2</b>					
1	42	F	RN	Staff Nurse	2 year
2	43	F	RN	Sister	2 year
3	28	F	RN	Staff Nurse	9months
4	49	M	RN	Staff Nurse	1½ years
<b>Unit 3</b>					
1	54	F	RN	Staff Nurse	1 year
2	46	F	RN	Staff Nurse	1 Year
3	38	F	RN	Staff Nurse	1 year

RN: Registered Nurse

**Table 7: Characteristics of Staff Member Interview Respondents for each unit**

Patient	Age	Gender F/M	Ethnicity	Renal Disease	Time on HD (years)	Other ESRF treatment	A/V access
<b>Unit 1</b>							
1	73	F	Afro-Caribbean	Diabetes	12	None	Fistula
2	66	M	Caucasian	Unknown	15	Home HD (12 yrs)	Fistula
3	59	M	Caucasian	Renal cancer	1	None	Fistula
4	50	M	Caucasian	Diabetes	2	None	Graft
5	69	F	Caucasian	APKD*	4	None	Fistula
6	66	M	Caucasian	APKD*	3	None	Fistula
7	50	M	Caucasian	Nephritis+	1	None	Fistula
8	50	M	Caucasian	Unknown	1	CAPD (2yr)	Fistula
9	76	M	Caucasian	Diabetes	2	None	Fistula
10	84	M	Caucasian	Obstructive Uropathy	8	None	Fistula
<b>Unit 2</b>							
1	67	M	Caucasian	Diabetes, High BP	2	None	Fistula
2	78	M	Caucasian	High BP	2	None	Fistula
3	49	M	Caucasian	Renal Artery stenosis	3	None	Central Line
4	56	M	Asian	High BP	2½	None	Fistula
5	69	F	Caucasian	Atrophic Kidneys	3	None	Fistula
6	57	M	Asian	Diabetes, High BP	3	None	Fistula
7	81	M	Caucasian	Unknown	1½	None	Fistula
<b>Unit 3</b>							
1	25	M	Caucasian	Wegener's†	3	None	Fistula
2	46	M	Caucasian	APKD*	3	Kidney Transplant (9yrs)	Fistula
3	57	M	Caucasian	Diabetes, High BP	2	None	Fistula
4	30	M	Caucasian	Congenital Obstructive Uropathy	3	CAPD (1½ yr)	Fistula
5	66	M	Caucasian	Aortic aneurysm	1	None	Fistula
6	22	F	Caucasian	SLE‡	3	CAPD (1yr)	Fistula
7	72	M	Caucasian	High B P	6	Kidney Transplant (2 days)	Fistula
8	63	M	Caucasian	Obstructive Uropathy	2½	None	Fistula

\*APKD: Adult Polycystic kidney Disease; +Nephritis: IgA Nephropathy

† Wegener's Granulomatosis; ‡ SLE: Systemic Lupus Erythematosis

HD: Haemodialysis; CAPD: Continuous Ambulatory Peritoneal Dialysis

A/V: arterio-venous, ESRF: End-stage renal failure

**Table 8: Characteristics of Patient Interview Respondents for each unit**

# **Chapter Five**

## **Research Method**

### **An Analysis of the Fundamental Concepts of Descriptive Phenomenology for the use in Health Science Research**

## **5.0 An introduction to Phenomenology**

In this chapter I will examine phenomenology and its application to research. I have already alluded to phenomenology in the introduction as the study of experience brought to consciousness. In this chapter phenomenology will be examined with its operational concepts that are necessary for application to practice. As an approach to research phenomenology is not one of the easiest particularly as it is heavily grounded in philosophy. There are many variations each of which is dependent upon its author. The current dominant method in nursing is the interpretive approach that follows Heidegger's hermeneutics found in his treatise 'Being and Time.' However, in nursing phenomenological research there appears much methodological confusion often with sources being third or fourth hand interpretations. In view of this, I felt it was important to return to the foundations of phenomenology (the thing itself!) and understand the methodological intricacies from that basis. By undertaking this exercise I would avoid the multitude of interpretations available in the nursing literature and clear up any misunderstanding. The phenomenological method that is explained in this chapter is the descriptive approach describe by Husserl.

The examination of phenomenology and in particular Husserl's descriptive approach will cover the important areas such as the confusion surrounding phenomenological reduction, bracketing, and epoché. Following a brief introduction there will be discussions about Husserl's terminology such as 'intentionality', 'natural attitude', 'lifeworld', 'identity as manifold', 'wholes and parts', 'constitution', and 'adequacy'. There will be particular attention paid to the contentious issues of the phenomenological reduction and imaginative variation. This is because they are believed to be essential parts of phenomenological research and yet nurses appear to have either altered them or over looked their use (Crotty, 1996). One further reason why I chose to return to Husserl is because of his desire to provide an approach to examining experience that was methodological and explicit.

Edmund Husserl is identified as the founder of phenomenology (Kockelmans, 1994; Moran, 2000). Husserl was a mathematician who was instructed in philosophy by Franz Brentano which provided the seeds for the growth of phenomenology. Husserl was attracted to Brentano's project of 'Descriptive Psychology' and his account of mental acts as intentional structure with an intentional relationship with an object (Moran, 2000). Husserl's involvement in psychology saw him develop a stance against what he called psychologism. Husserl was not against psychology but psychologism which was the use of natural science methods (naturalism) as a model for examining psychological phenomena in a positivistic objective manner. Psychologism had no room for exploration of human entities such as meaning or subjectivity (Spiegelberg, 1971). Husserl was not against natural science, but believed that psychological phenomena could be examined in a rigorous manner that required a new method that reflected the phenomenon under investigation. Husserl became increasingly interested in being, though not the being of being as such, but the fact that there are beings in the world that are aware of themselves and of others (Spiegelberg, 1971). It was this awareness that intrigued Husserl and directed him towards the subjective experience of human beings. Husserl was keen to shed light on subjective experience in a scientific manner but was at pains to separate his method from pure introspectionism or solipsism. Husserl saw the wonder of subjectivity as providing meaning for reality or the world of experience (Husserl, 1967). The subjective experience had validity, could offer insight into meaning and could be examined in an 'objective' manner.

Phenomenology was Husserl's method for examining subjective phenomena that provides meaning. In his desire to provide a rigorous science of subjectivity Husserl developed phenomenological methodology comprising the adoption of description and concepts such as intentionality (which is consciousness is always directed towards an object) the epoché (the abstention of use of knowledge and beliefs), lifeworld (the world as experienced by each person) intuition (things present for examination) and imaginative variation (variation of structural components of experience). To examine subjective experience from Husserl's

perspective is to become fully immersed in phenomenological method. In order to do this it was important that I examine phenomenology in depth so as to understand and apply phenomenology accurately to the research process.

## **5.1 Intentionality**

One of the important fundamental concepts of phenomenology is the notion of intentionality. Intentionality is the term used to describe consciousness. Intentionality is seen as an essential characteristic of psychological being and living (Husserl, 1967). Psychological life is a life of consciousness which is always a consciousness of something. Husserl adopted the term and idea of intentionality from his mentor Franz Brentano who had explained intentionality as a 'reference to a content, the directedness toward an object or the immanent object quality' (Cited by Spiegelberg, 1971, p 39). Husserl appropriated the term and transformed it into something more than what Brentano intended. The term was altered to mean consciousness is always directed towards an object and avoided using contents as the sole means of describing consciousness or some 'inner' state. Instead of pure content of a thing, there was concern for the experience of those contents because it is experience that makes the contents real in any manner or form. It is what goes on within such experiences, (the acts), that are of concern (Husserl, 2001).

The act of being conscious of something is pre-reflective which is to say it is an unreflective apprehending of a thing. In this manner the person doing the apprehending is focused upon the thing and not how s/he apprehends the thing. The implication of this is that at the moment of perceiving or apprehending a thing, which could be something real such as a car or something such as a memory, we appear unaware of *how* we perceive it (Valle, King, & Halling, 1989). What can be seen from this is that consciousness of something is correlated with the way it is perceived. This correlation is the structure of consciousness in that we

perceive a thing in a particular way or manner; however, the way in which a thing is perceived can only be accessed after the event through reflection (Ihde, 1986).

The correlations of the experience of consciousness are named 'noema' and the mode of being conscious is the 'noesis' (Husserl, 1967). Noema (Noematic) is the object correlate of intentional experience; the thing itself. Noesis (Noetic) is the manner in which the object is experienced. The meaning of a thing is to be found in the noetic correlate of consciousness (Husserl, 1967). The noetic manner of an experience is made up of an individual's cognitive biases, beliefs, values and knowledge which are grounded in natural attitude (Spinelli, 1989). There are different ways of intentionality, for example perceptual intentions are seen in a different way to the way a word is intentionally dealt with. For example, a picture is seen as a picture as opposed to something that isn't a picture. Additionally, the picture is experienced as something more than a combination of colours or a piece of paper: it is a picture of something. The noetic experience of the picture is layered (sedimented) with all these ways of experiencing it to provide meaning (Sokolowski, 2000). Therefore experiencing a phenomenon, such as a dialysis satellite unit, is layered in a way that provides meaning which makes it different from something else like a main unit.

Intentionality is therefore at the centre of the examination of a person's experience, it demonstrates the consciousness of something. The examination of intentionality enables the researcher to use reflective accounts of experiences or situations as a means of discovering the meaning of those situations and the processes that generate them (Wertz, 2005). Therefore an account of a person's experience of a dialysis unit will provide information regarding that individual's way of seeing the dialysis unit and the way s/he sees it is its meaning. The experience of the individual is the experience of that person in the natural attitude and how it is to be examined, as a description, by a researcher is to use the phenomenological method which includes the phenomenological reduction.

## 5.2 The Natural Attitude

The natural attitude plays an important part in phenomenological research as it is this that is precisely under investigation. The natural attitude is unthematic in that one experience appears to merge logically and seamlessly with another and accepted quite naturally as such (Luft 1998). The natural attitude is pervasive, dominant and something of which the individual is unaware of being in. The very fact that a person is unaware of being in the natural attitude is precisely why it is natural; it takes no effort. Therefore to the person engaged in every day life natural attitude is hidden (Luft, 1998).

In the natural attitude things are given (presented to consciousness) to us because we deal with them. The way things are given to us in natural attitude is based upon the basic structure of intentionality: the thing and how we experience it. A thing that is given to a person in natural attitude is always given as something, such as a car is given as something to drive or to get to work thus making things a nexus of meaning (Luft, 1998). The person is engaged in projects of everyday life which includes things like cars, pursuing goals, feeling pain, or in the case of a dialysis patient, preparing for dialysis. These projects are the interests of people and as such people are never passive but actively involved in a life of interests: the existence of things either actual or virtual. For the person in the natural attitude active life is carried out in a certain attitude or attitudes that shift without being noticed, such as the attitude of being a nurse to the attitude of being a parent (Luft, 1998). These attitudes are important in that they make certain things valid, for example; arithmetic is available only when in an arithmetical attitude or whether the two straight lines of the Muller-Lyer's optical illusion are the same size only matters when adopting a quantification attitude (Merleau-Ponty, 1962, Husserl, 1990).

The individual is immersed in the natural attitude with its multiple attitudes which allows the individual to see things. Each of these things is set against a background called a horizon or

lifeworld. The lifeworld is a field of multiple attitudes such as job attitude, holiday attitude, shopping attitude that the individual is at home in and is known as a homeworld (Luft, 1998). The homeworld of the individual is lived with a set of beliefs and opinions that are accepted but not necessarily true. The acceptance of beliefs, whether in the attitude of work or leisure attitude, is known by Husserl as naïve and this acceptance is dogmatic (Husserl, 1967). Naive belief is not to be seen in a negative light, rather it demonstrates the belief in existence of things from aspects and perspectives but they are open to alteration. Homeworld is an intersubjective experience that occurs in a kind of casualness of going about life with things and others and is a practical (and not theoretical) enterprise. Attitudes that are not homeworld attitudes are known as alienworld. An alien attitude can be integrated into an individual's natural attitude and only then will it become homeworld. An example may be demonstrated whereby an individual who is previously well enters the alienworld of dialysis when s/he is diagnosed with end-stage renal failure. Dialysis only becomes homeworld natural attitude when it is integrated along with its beliefs, myths and opinions.

The conclusion is that the style of understanding in the natural attitude is biased and presumptuous and continues in concordance with the familiar. All that is familiar to the individual is accepted as reality, it is not questioned as such and because of this it is taken for granted. Therefore, the individual is at home in natural attitude which includes beliefs, attitudes, opinions, religion, myths, knowledge, and understanding which is cultural, social, scientific, and prejudicial.

To examine the natural attitude and make it thematic (understandable chunks of subject matter) requires a shift that moves the researcher into the phenomenological attitude (Husserl, 1964; Husserl, 1967). The researcher to stands outside natural attitude and in doing then becomes transcendent; a term that may not sit too easily with many researchers because of its philosophical and metaphysical linkage. In phenomenology transcendent simply means to stand outside the natural attitude. The phenomenological reduction requires the researcher to

put aside or bracket contents of his or her natural attitude so that the natural attitude of others may be examined (Spinelli, 1989). A detailed discussion of the phenomenological reduction can be found further in this chapter.

### **5.3 The Lifeworld**

Lifeworld has briefly been discussed earlier but further discussion is needed for clarification. Husserl introduced lifeworld in his work “The Crisis of European Sciences and Transcendental Phenomenology” as a response to criticism of the idealism of transcendental phenomenology (Spiegelberg, 1971; Moran, 2000). These criticisms were aimed at Husserl’s view that the individual could completely withdraw him/herself from the world and as such fall into the Cartesian dualist trap. Here (inside the body) the pure ego and consciousness resides, out there is the world. Later, Husserl saw this was an error because by bringing the pure ego into view it passed over all the meaning content of the lifeworld: without the lifeworld consciousness is empty (Moran, 2000). Husserl was accused of pure idealism and a lack of relation to the world. To counter these accusations Husserl provided an explicit account of the notion of lifeworld in Crisis” to demonstrate the relationship of the person to the lifeworld. However, it is worth noting there is evidence of Husserl’s application of method to everyday objects of life throughout his various works including Cartesian Meditations and The Idea of Phenomenology (Spiegelberg, 1971).

The introduction of the lifeworld into phenomenology has been very influential for subsequent phenomenologically orientated research. Such research is aimed at explicating the lifeworld through the investigation of lived-experiences (Crotty, 1996). The importance of lifeworld in relation to phenomenology and research is what it means. Lifeworld is derived from what Husserl calls ‘horizon’ (Husserl 1970). Horizon is a correlate of the consciousness of the world and the objects or experiences within it; it is context. For example, the consciousness or perceptual experience of a house always stands out or against a background of other houses or trees etc. The house object is perceived within its perceptual field or

context; its horizon (Husserl, 1970; Ihde, 1986). An important point to note here is that the object (house) comes to have meaning through the background (perceptual field). This perceptual field is the horizon and is a correlate of the unity of thing/experience and background. The horizon is not the focus of attention but provides the backdrop to human projects; it is the context of experience (Keen, 1975). What this means, for my research, is that I am focusing upon a particular experience of people in dialysis satellite units who have horizons that provide meaning. For example, a patient will undergo dialysis treatment in a satellite unit but this is against a backdrop of the main unit, home life, illness and wellness. Satellite unit dialysis has meaning because it is a correlate of the lifeworld horizon.

The horizon is always pre-given for people and is a referential point for every person and every experience at the same time. It is from the horizon that each person must ultimately be understood: here is where meaning and sense can be found (Kockelmans, 1994). A horizon is, at one level individual, but at another level a communal experience and therefore intersubjective. It is within this communal experience that there is a constant alteration of validity of experience. Individual aspects of perception or experience are altered through the being with others and an acknowledgement that they provide additional aspects or perspectives, such as other people's opinions and experiences as well as an experiencing of others (Husserl, 1970). What individuals already know is that, within their horizon, they live within the horizon of others. An individual horizon or background is known as a lifeworld which already exists for that person. The lifeworld provides the ground for a person's life and is transformed through communal re-interpretation (Kockelmans, 1994).

Each experience of a person, such as a dialysis patient, is set against a horizon or lifeworld of their various experiences which may include, for example, not being ill, being ill, sensing time, and being with others. All these experiences will provide context for experience, a distinction between experiences, and a distinction between objects (Stewart & Mickunas, 1990). Therefore one experience is distinct and set against another, such as dialysis in a main

unit and dialysis in a satellite unit. Implicit within the lifeworld is past, present and future; a spatiotemporal world (Husserl, 1970, Moran, 2000). The lifeworld is one of anticipation of the future that continues from the past. This historical aspect is important in the provision of meaning within the lifeworld and experience. Therefore a dialysis patient lives anticipating a future (such as more dialysis or transplantation) knowing their past has brought him or her to this point.

All lifeworld experience occurs in the natural attitude with all its mundanity; the pre-reflective engagement in projects of life. An experience within a lifeworld becomes a theme for understanding the larger context. Investigation into these experiences enables a thematic meaning of lifeworld experience which would provide broader understanding (Stewart & Mickunas, 1990) The method for examining the phenomena of natural attitude of the lifeworld is, according to Husserl, by phenomenology and the phenomenological reduction (Husserl, 1970). Phenomenological research must retain the background context of the lifeworld in order for it to provide meaning.

#### **5.4 Identity as Manifold**

Objects of consciousness or experience are not experienced in a single unchangeable. These objects of consciousness can be experienced in many ways and are not limited to an individual alone (Sokolowski, 2000). An individual person can experience a thing, like a chair, from different angles and with different shades of light and at different times. Each of these experiences adds to the experience of the chair and thus adds to its meaning. In addition to this a thing, such as a chair, can be presented in many ways such as shapes, sizes and colours but the meaning can remain the same. What occurs is that the meaning of a thing, like a chair, becomes its identity. The experience of a thing does not need to remain an isolated experience. The experience of others allows seeing objects from a view point that a phenomenologist does not share. It is this sharing of viewpoint that adds to the meaning and thus identity of a thing or experience (Sokolowski, 2000). The sharing of viewpoint

emphasises the intersubjective nature of lifeworld experiences and how they can be altered and interpreted.

### **5.5 Wholes and Parts**

The additional experiences of others offer aspects that are hidden from view and in doing so make the experience or thing more complete and therefore increases its adequacy. An increase in the adequacy of a thing or experience makes it more indubitable increasing the number of dependent parts that go towards constituting the whole (Husserl, 1967). Experiences can be related to each other as wholes to parts or as a series of parts of a whole (Husserl, 2001). A whole has two types of parts: pieces and moments. Pieces are parts that can be presented by themselves and can therefore be independent. For example in the experience of being a dialysis patient the experience of an actual dialysis session can be presented as an independent part that describes the actual process. However, independent parts must not be separated from wholes when considering the meaning of the whole. The reason for this is because the meaning of being (on dialysis) requires a unity and becomes incomplete without it (Husserl, 1967).

Moments are inseparable parts of the whole and thus non-independent. For example, an aspect of the experience of being a dialysis patient may include fear of dialysis. This fear is a moment that cannot be removed from the whole because it is an essential part of the experience and links with other moments and blend to make the experience complete (Sokolowski, 2000). A moment, as an experience, such as fear of dialysis cannulae, can be talked about but only as attached to the experience of dialysis. When it is discussed as separated from the whole it becomes an abstraction or an ideal.

## **5.6 Constitution**

Constitution is one of Husserl's operative concepts which mean they are used rather than clearly defined. Constitution refers to how an object of consciousness has a sense of being that it has and how subjectivity gives the object that sense (Moran 2001). The purpose of phenomenology is to not only describe the relationship between the knowing act and known object of consciousness but also to explain how an object of knowledge is constituted in our knowing acts (Kockelmans, 1994). In other words, it's about bringing a thing into light or to articulate how a thing is meant (Sokolowski, 2000). For example, a dialysis satellite unit will have meaning to those who use it and it is the role of the phenomenological researcher to 'bring to light' the constitution of that meaning; the articulation of relationships between parts and wholes in order to provide a synthesis of unity. Constitution does not mean that the unity of a thing is constructed in a piecemeal manner or with aspects stuck together. Neither does it mean that an object can be made to mean anything, rather it will offer itself in a certain way for articulation (Sokolowski, 2000).

## **5.7 Adequacy**

Adequacy is a term used by Husserl in an attempt to come to terms with the extent of fullness of presentation of a phenomenon (Husserl, 2001). The direct presentation of phenomena (sensorial intuition) has varying gradients of fullness. The aim for a phenomenological investigator is to move along these gradients to know things better (Husserl, 2001). There are occasions where phenomena are vague and barely recognisable and occasions when a thing is instantly present in clear and full form. To see a thing directly in front, such as a dialysis machine, is to have its meaning intention fulfilled by its bodily presence. This fulfilment, by bodily presence, is seen as an act of 'adequate self-presentation' which is a corresponding synthesis unity of signified meaning that direct intuition enables its recognition and knowing (Husserl, 2001). A signified meaning is when a thing, such as a dialysis machine, is imagined, spoken or reflected upon and its image signifies the intended but not present thing. Husserl

(2001) calls this an 'inauthentic intention' because the thing is not presented in its fullness but symbolic in nature. However, a signified meaning does link to something that is meant: a representation. Hence reflective accounts of experience are 'inauthentic intentions' and as such do not provide complete adequacy however, they do signify a phenomenon. It is this relation to phenomena that is important. What is important about this is that the sign or signified meaning, which is a representation, amounts to an interpretation. Hence, in Husserl's view, a representation is an interpretation (Husserl, 2001). This is an important point for the researcher because it means that when an interview is undertaken the participant is engaged in making a representation which is an interpretation which has meaning. It is these representations (interpretations) that can and are to be described.

Husserl recognises that the sensuous means of 'seeing' a thing fails to include 'seeing' of ideal things and states of affairs such as grasping of a situation. Husserl calls this form of 'seeing' categorial intuition (Moran, 2000). For example, a categorial intuition grasps the essence of a thing such as immediate 'seeing' that 'dialysis consumes time' and is a higher order intuition (Moran, 2000; Husserl, 2001). Therefore interviews provide phenomena that are founded on immediate experience and an ideal (signified, representation or interpretation) of that experience that can be 'seen' (grasped) in a categorial manner. The categorial intuition is constituted through relationships that only become apparent when a part is removed for scrutiny (Husserl, 2001).

In view of this discussion adequacy, for the phenomenological researcher using interview data, can be achieved through explicating multiple parts and their relationships to describe the essential structure of a thing or experience. Where possible the phenomenological researcher should be aiming for clearer gradients of fullness. Adequacy is improved by increasing the aspects of experience and their relationships by, for example, the use of multiple interviews. The researcher can further increase adequacy through direct presentation of the phenomenon such as attending dialysis units and observing patients undergoing dialysis and nursing staff.

In this instance the phenomenon is present in 'adequate self-presentation' offering aspects of experience for examination. A synthesis of unity of the adequate self-presentation and categorial intuition that provides a description of real phenomena will offer a sense of adequacy. It is this union which is established through phenomenological method that enables the description of structures of experience.

### **5.8 The Phenomenological Reduction & Epoché**

The phenomenological reduction is a complex technical method essential for phenomenology. Husserl strove to clarify the method over his life and subsequently provided several different descriptions (Moran, 2000). Moran (2000) states there are eight descriptions alone of the phenomenological reduction in the book 'Crisis of European Science.' As a consequence there is much confusion regarding the method which only adds ammunition to critics of phenomenology and makes it difficult for the novice phenomenologist.

The phenomenological reduction is the means for examining intentionality of consciousness which is related to things such as tables, houses, people, and psychological phenomena such as remembering, imagining, and planning (Husserl, 1970). It is also the means for examining the natural attitude of lifeworld experience. The psychological phenomenon that Husserl was concerned about initially focused upon the experience of the individual phenomenologist however, in his later writing, he was concerned that the process should be focused upon the lifeworld in order to keep it grounded and refute criticisms of idealism directed at him on the basis of his Transcendental Phenomenology (Husserl, 1970). Contrary to his critics Husserl was concerned about the realism of the lifeworld and the experience of it. Husserl was in fact a realist. It is the lifeworld that phenomenological reduction is aimed at because in the 'lifeworld we also find human beings, with all their suffering, living in common in the world-horizon in their particular social interrelations and knowing themselves to be such' (Husserl, 1970, p146). It is the pre-giveness of the lifeworld where subjective experience will provide meaning. However, the process of the phenomenological reduction aimed at the experience of

lifeworld is commonly explained in a simplistic manner such as 'bracketing' and making explicit and documenting personal knowledge. Indeed this is a common practice in nursing phenomenology (Crotty, 1996). This explanation views the process as a simple identification of knowledge but fails to explain the complete and sustained attitudinal shift necessary for the phenomenological reduction.

### **5.8.1 The Reduction in Phenomenology**

The reduction remains one of the most contentious aspects of phenomenology. Those nurse researchers such as Leonard (1994) who criticise the reduction tend to adopt a position emphasised by Heidegger in that reduction to pure ego is impossible (Seeberger, 1975). The criticism is aimed at Husserl's idealism and claims that complete reduction is impossible because each person remains inherently involved with the world at all times and therefore cannot step outside of that involvement (Merleau-Ponty, 1962, Seeberger, 1975). This constant involvement in the world would appear to make the reduction a flawed process and yet even Husserl's sternest critic, Heidegger, found the reduction a necessity for his exposition of being in *Being and Time* which only works against a background of phenomenological reduction (Merleau-Ponty, 1962, Gadamar, 1989). Heidegger (1962) explains the reduction in terms of phenomena being covered up, not yet known, buried over through deterioration which leaves the experience of things as a 'naiveté of haphazard immediate and unreflective beholding' (p61) or what Husserl would call natural attitude. The way to phenomena is to move back towards its givenness, a leading back or what Heidegger calls 're-duction' (Heidegger, 1988). Whilst Heidegger and Husserl may have a different focus for their projects (being and consciousness respectively) it is important to note that even those who aspire to be hermeneutical in their phenomenological approach adopt the use of the reduction. Heidegger is not the only interpretative (hermeneutic) phenomenologist who utilised the reductive method. Hermeneutic phenomenologist Paul Ricour found 'bracketing'

essential in his work *Freedom and Nature* to enable experience to become thematic and thus and intelligible (Ihde, 1971).

The importance of this cannot be overstated as the misrepresentation of the use of the reduction has led to a dominant phenomenological research in nursing to what Crotty calls nursing phenomenology (Crotty 1996). These researchers have adopted interpretive phenomenology on an interpretation of Heidegger's *Being and Time* by Dreyfus, often via Benner. This group of researchers, such as Crist and Tanner, omit the need for the reduction or utilise it as a means to make explicit their knowledge and explicitly use it in the analysis of research data; but not in the way it was intended (Crist and Tanner, 2003). Indeed, these researchers use the term 'interpretive hermeneutic', which surely is tautological, and appears to demonstrate a lack of clarity at the least. This approach has led to confusion in method and understanding (Horrocks, 2000).

This confused approach is not isolated to nursing phenomenology. Smith and Osbourn's (2003, p 51) Interpretative Phenomenological Analysis (IPA) is described as a means to 'explore in detail how participants make sense of their personal and social world.' Though Smith and Osbourn argue this process is phenomenological there is no mention or evidence of use of the phenomenological reduction. Their approach would not be called phenomenology on the basis of an absence of the reduction. The adoption of the reduction is essential to undertake phenomenology; it is a central feature of the process and imperative for the reflective attitude (Farber, 1943, Gurwitsch, 1955). According to Giorgi (1997), from a phenomenological psychological perspective, no work can be considered to be phenomenological without the use of the phenomenological reduction. Those researchers who chose not to undertake the reduction need to be cautious in how they describe their research approach. Whilst they may claim the individual cannot be reduced to a pure ego they fail to note that Husserl was at pains to emphasize that the reduction, and especially the psychological reduction remains grounded in the world (Husserl, 1970, Ashworth, 1999). The

reduction remains important even for interpretivists, as well as existentialists, in enabling a temporary breaking from pre-reflective activity to a critical reflective attitude that enables a bringing of the world to light with its meaning through language (Merleau-Ponty, 1962, Ashworth, 1999).

### **5.8.2 The Phenomenological Psychological Reduction and the Transcendental Phenomenological Reduction**

Husserl identifies two main reductions, one being the psychological phenomenological reduction and the other being the transcendental reduction. The transcendental reduction stands hierarchically above the psychological reduction and is the realm of the philosopher interested in pure essences. Whilst the main attention of this discussion will focus upon the psychological phenomenological reduction; it is important to explain both methods and their realm of application. The reduction in phenomenological psychology is a bracketing of the world but not the empirical subject (Giorgi, 1997). It enables the researcher to examine the natural attitude of the person, to make it experienceable and thematic in its mundanity (Husserl, 1970, Giorgi, 1997). Within the phenomenological psychological reduction the research participant is not expected to adopt the reduction only the researcher should (Giorgi, 1997). The phenomenological psychologist must place in 'brackets' all his or her existential convictions and judgements concerning the subject under examination. In doing so the psychologist must become a 'disinterested observer' of him/herself as well as other subjects. However, the psychologist (the phenomenological psychologically reduced ego) remains a mundane ego, which is to say, of the world and not transcendent in the form of the transcendental reduction.

The reduction in transcendental phenomenology enables the philosopher to be 'above his own natural being and above the natural world' (Husserl, 1970, p152). Essentially the transcendental reduction not only brackets the world but also the individual in order to examine the object as purely given without elements of the natural world infiltrating into the

examination process. The philosopher becomes an ego above his own being and the natural world. The transcendental reduction attempts to make the philosopher a pure ego and stand outside of experience (Ihde, 1986). Criticism of this approach emphasises it to be too much like Cartesian doubt leading to a pure mind which then sets out an idealism not connected to reality (or the body). Many subsequent phenomenologists including Heidegger could not adhere to this idealist notion (Ihde, 1986). As already mentioned earlier Husserl was at pains to correct the idealist interpretation by admitting the transcendently reduced ego lost all meaning when detached from the very thing that gave it meaning: the world. The transcendental reduction will not be used in this research because the aim is not to find pure essences but to make explicit the structures of experience of the dialysis satellite unit.

### **5.8.3 The phenomenological Attitude: The Epoché**

The phenomenological reduction is not to be confused with reductionism. Reductionism is the attempt to simplify phenomenon by showing that it can be reduced to another phenomenon. The phenomenological reduction is the focusing upon a phenomenon as it appears: a return to the thing itself. It is also a stepping back in order to describe apparent existential experience as a presence (Giorgi, 1997). Despite the differences of approach between the psychological reduction and the transcendental reduction there are fundamental processes that remain the same. The first thing the phenomenologist must do is to adopt the phenomenological attitude. The phenomenological attitude is what makes phenomenology possible and is the part of the reduction known as the epoché (Zaner, 1975). The epoché is to be seen as a critical-position taking attitude that requires the phenomenologist to adopt and accept a resolve to take nothing for granted. Only through the epoché does the phenomenologist engage in the resolve to perform the reduction (Zaner, 1975). Hence, the epoché is an attitudinal shift that is directed at moving the phenomenologist out of the natural attitude and to adopt a critical stance. The critical element requires the phenomenologist to question his or her position regarding the phenomenon under investigation. Critical self questioning is a reflective process that remains

self-conscious. Self-consciousness requires a critical view of knowledge that includes beliefs, knowledge and attitudes that present themselves in relation to the phenomenon.

The phenomenologist is required to undertake the phenomenological reduction and in doing so 'put out of play' any mode of validities of knowledge, beliefs, or values about the phenomenon (Husserl, 1970, p 237). A mode of validity of a thing is when it has certain differentials that make it as it is. For example, the mode of validity of a dialysis unit is different when compared to, let's say, a transplant unit. The bracketing of knowledge, beliefs, values and attitudes is akin to the mathematical process of putting formulae within brackets so that it may be dealt with discretely. Husserl uses many terms to explain what is meant by bracketing including 'putting out of play' as well as an abstention, abandoning, inhibit the positing of the object, put it out of action, and refraining from judgement (Husserl, 1967; Husserl, 1970; Moran 2000). Husserl adds that knowledge including scientific knowledge is not to be made use of and in doing so not a single proposition is to be appropriated or act as a foundation regardless of the nature of the evidence (Husserl, 1967). The resolve to undertake this process is to become what Merleau-Ponty (1962) calls a perpetual beginner not taking for granted what is known.

#### **5.8.4 Bracketing and Doubting**

It is important to explain that bracketed knowledge within the phenomenological reduction is not doubted in any manner. Despite Husserl alluding to the Cartesian doubt (perhaps inappropriately) as part of the method he adds that it is only a device of method (Husserl, 1967). The notion of doubt in the phenomenological reduction is a means of attempting to get across the idea of Descartes of suspending belief in order to get a clear perception of a phenomenon. Doubt is a possible mode of consciousness within the natural attitude but not within the reduction (Williams, 1958).

However, when undertaking the phenomenological reduction the phenomenologist is not required to doubt the existence of the world or the bracketed knowledge; there is no doubt for the phenomenologist that the world exists. The reduction does not undermine or doubt the truth of what is given (Levinas, 1998). Bracketing is simply the suspension of use of taken for granted knowledge of the natural attitude so a phenomenon may present itself without the clutter of everyday life experience (Williams, 1958). The phenomenologist adopts a pre-suppositionless stance but does not disbelieve the existence of the phenomenon in any way.

### **5.8.5 Reduction and Error**

The adoption of the reduction whether by psychologists, nurses, or phenomenologists appears to be undertaken without criticism. There are those, such as Heidegger and Merleau-Ponty, who state that complete reduction is impossible and in general terms this has been accepted to a greater or lesser extent. Merleau-Ponty (1962, p xiii) supports the use of the reduction by stating that “the only way to become aware of our being-in-the-world is to suspend or activity of our relationship with the world.” However, the question of whether error in the act of phenomenological reduction can occur remains relatively unchallenged (Farber, 1943, Winthrop, 1949). According to Farber (1943) Husserl admits that there can be errors in the case of phenomenological seeing but argues this is no different to from ordinary external perception.

There is a sense in some (Giorgi, 1985, Husserl, 2000) that the solution to possible error is in accurate and adequate description of the experience of phenomena. However, the definition of the term adequate is not so evident. Heidegger’s response to the possibility of error was to state that phenomena should be examined in an apophantic manner. What this means is that the givens of a phenomenon, such as the experience of others, should only be judged upon how it presents itself to the examiner rather than by comparison. This is because, Heidegger felt, comparison obscures the thing being examined (Heidegger, 1988, p209). However

Winthrop (1949) claims that errors in the reduction will be upon apophantic judgements with respect to synthetic propositions. What this means is that when the researcher is required to perform the reduction it is only s/he who makes a judgement based upon self what s/he decides is sufficient or adequate in order to provide a thematized description. Therefore from the perspective of an external scientific methodological audit the process is unclear and lacks a standardised technique for eliminating error (Winthrop, 1949). Winthrop goes on to argue that this would lead to disagreement between two or more phenomenologists suggesting ambiguity.

It would be easy to disregard Winthrop's argument on the basis of his stance being from an empirical-logical perspective whereby evidence must be scientifically reproducible. Husserl would argue that Winthrop has not engaged in the phenomenological orientation to phenomena: he has a fixed methodological orientation and as such will find phenomenology of no help (Husserl, 1967). To construe something as error means there is either an explicit or implicit agreement that a phenomenon is already known in its completeness in order for it to be judged against. The phenomenological response to this problem would be on the basis that experience of phenomena are never completely presented in full, they present in manifold, are inexhaustive and therefore require constant modification and refinement through additional research (Moustakas, 1994). This would seem to imply that phenomena can never be truly known and suggests on that basis why research should be undertaken at all. However, Moustakas (1994) believes, implicitly, that error can be overcome by a detailed description of experience beginning with the epoché, returning to the thing itself, making explicit recognised qualities and linking thematized constituents of the experience.

Methodologically speaking, one potential solution would be the demonstration of descriptive coding during data analysis rather than interpretative or explanatory codes. It is precisely this methodological problem Giorgi (1985) endeavours to overcome by keeping original text in close proximity to the phenomenological psychological description. This process shows the

maintenance of the reduction and consistency in process. The proximity of original text ensures the end description has allegiance to it and is present for all to see. Giorgi's (1985) method is more transparent than other's such as Colaizzi (1978). The importance for the minimising of error in the reduction would appear to be by remaining descriptively close to original experience.

### **5.8.6 Phenomenological Reduction as Self-Critical Reflection**

The phenomenological reduction is attitudinal and an orientation in the manner in which the phenomenon is to be examined and this manner is ultimately reflective (Husserl, 1967). The conscious experience of things is only brought to light through reflection. Reflections themselves are experiences themselves that may lead to further reflections. It is possible that, should the phenomenological researcher follow this process, they may come to the conclusion that only their own experience and knowledge exists. This problem is avoided from a phenomenological psychological research perspective by remaining focused upon the experience of others and the fact that their existence is not doubted in any manner. Husserl (1970) notes that others (people) are experienced as real and united parts of the world. Additionally, others are experienced experiencing the same world the phenomenologist experiences. The world is experienced as an intersubjective world there for each individual (Husserl, 1964). However, it is equally true that each phenomenological reflective act belongs to the person performing it.

The reflective process is a self-critical process used to examine the difference between what is experienced, what is noted and modifications that come through the act of apprehending. It is a form of self-interrogation of interests (Colaizzi, 1978). Colaizzi (1978, p56) notes that the phenomenological psychological researcher must investigate and interrogate his or personal interests, personality, personal inclination, hidden gains, use of scientific knowledge, political and religious interests as well as economic, ethical and moral interests. This reflective process

is important because phenomenologically modes of validities are sedimented and used unconsciously. In view of this sedimentation the self-aware critical reflection is in effect self-surveillance. Bracketed knowledge remains in existence and has to so that it becomes a point of reference in the act of the reduction. Referencing requires the phenomenologist to perform a self-surveillance questioning his or her own descriptions of the phenomenon. It is a resolve to not accept the taken for granted and is a to and fro activity between what is given and what is known.

### **5.8.7 Reduction as Dynamic Process**

The phenomenological reduction is therefore far from being a simple process it involves a commitment and determination that goes beyond simple explication of knowledge often found in nursing phenomenological studies. The reduction is seen in nursing phenomenology as something that occurs at the beginning of a research study whereas methodologically it continues throughout the whole process of phenomenon apprehending and analysis. One additional point to note about the reduction is that it removes all hierarchy due to no position being taken by the researcher. Every aspect of the phenomenon under investigation is treated as equal. The reduction is not a static process; it is dynamic and requires dynamism from the user to ensure its effectiveness.

### **5.9 Imaginative Variation**

Imaginative variation is a particular activity applied to the phenomenological method. The activity is known by a number of different terms each of which is used to varying degrees by Husserl (Kockelmans, 1994). For example in 'ideas' Husserl (1931/1967, p198) uses the term 'free-fancy' and in Cartesian Meditations he uses the terms 'essential' or 'eidetic analysis' (Husserl, 1960, p70) and 'phantasy' appears with equal frequency (Kockelmans, 1994). The lack of clarity and adoption of a single term does not help the novice researcher in the understanding of phenomenological method. Such lack of clarity leads to problems of

misunderstanding and misrepresentation making phenomenology an easy target for those who criticise its abundance of jargon. However, irrespective of what term Husserl uses to explain the activity, he is providing an important process of phenomena clarification. For Husserl the adequacy of an essential structure of whatever is being examined is of vital importance and this method helps achieve adequacy.

Husserl argues that ‘free-fancies’ hold high status over perception in helping to provide the grasping of what is being experienced (a form of truth) through consciousness (Husserl, 1967/1931). To claim that imagination hold such a high status in identifying ‘truth’ or essential structures of experience would undoubtedly leave the phenomenologist open to ridicule from positivist and logic-based researchers on the basis of the improbability of imagination being truth. However, what imaginative variation aims to do is expose the elements of the reality against a range of possibilities, to make it stand out, and thus demonstrate its existence (Levinas, 1998). Employing imaginative variation enables an infinite number of possibilities for use during the thematization of conscious experience. The relationship between imaginative variation and clarity of the experienced is such that it can be seen as a means of clarifying the original conscious experience (Farber, 1943). The modification of the original consciousness (through imaginative variation) enables a reflection back upon the original in a way that emphasises features that are unchanging and remain present (Farber, 1943).

### **5.9.1 Imaginative variation as thought experiments**

The method of imaginative variation may initially appear simple but further examination demonstrates its complexity for the user. Indeed it is not unlike a natural scientist imagining an experiment between two substances such as chemicals. The imagining of adding one chemical to another may cause a reaction and change the initial chemical, and if so how does the new substance present itself that is different from the original? Husserl (1960) describes

the method in a straight forward manner using the example of a table. Here Husserl asks the reader to imagine a table and then with the table-object in mind to freely vary and ‘fictively’ change aspects of it such as shape or colour quite arbitrarily. The culmination of the multiple variations should enable the researcher to locate the essential structure of the table, that is to say what remains constant or invariant. What is happening here is a form of mental or thought experimentation that implicitly requires the researcher to abstract the real phenomenon as a kind of universal or example of the thing being examined (Mohanty, 1989). This does not mean that the researcher becomes lost in idealism or a kind of essentialism, claims often directed towards Husserl (Idhe, 1986; Mohanty, 1997), but rather it allows for clarity. This is not a simple process; the researcher has to have this example in mind in a deliberate manner and maintain this process. For example, following the analysis of a dialysis satellite unit (DSU) experience of the patient, a mental abstraction of its reality must be held in mind. Once this abstraction is apprehended the researcher must abstain from locating it in any one reality and then variations can be made. It is the abstaining that frees the researcher to explore the possibilities and locate the invariant structure of experience (Sokolowski, 2000).

The approach is believed by some to be essential in that it enables the researcher to gain radical insights into the taken-for-granted phenomenon (Ihde, 1986, Farber, 1943). This approach is what Idhe (1989) calls ‘Experimental Phenomenology’ an important element for increasing the adequacy of the description of the phenomenon which in turn will lead to and increase in apodicticity (true or provable) of the phenomenon.

Naturally, the researcher needs to feel comfortable performing these thought experiments. There is a need for the researcher to push the boundaries by removing parts from the abstraction or by adding parts to it and feel comfortable whilst doing this. It is important that as many variants as possible are imagined and any possibility is permitted a kind of ‘no holds barred’ approach (Moustakas, 1994). This in itself is a challenge to the researcher as it

appears to remove the reality away from the experience; however the abstraction must remain grounded in reality that is to say the reality from whence it came.

One problem that exists with the method is to do with the actual altering of the essential structure itself. How does the structural substance present itself to the researcher when it has been changed? For example, if the dialysis satellite unit is moved into a park, how does that present it self and how does the researcher make sense of it? Husserl (2001) argues that the intuitive act, that is to say the dialysis satellite unit image, is bestowed with meaning. To see the dialysis satellite unit is an act of seeing something with meaning and has a particular set of meaning expectations projected upon it. Every object (noema) of our consciousness has content and that content is meaning which refers to the object (Husserl, 1976). The set of meaning expectations, the dialysis satellite unit in this instance, is what Husserl (2001) calls 'Auffassung' (p291) or interpretation. It is the interpretation that endows the dialysis satellite unit with an objective sense as a thing (but not reified) and for Husserl the differences of interpretation are descriptive differences. Hence changing an aspect of a dialysis satellite unit potentially changes the description of the dialysis satellite unit which would alter the interpretation. The 'new' interpretation is compared with the original to see if the meaning has altered in any way. So to return to the 'dialysis satellite unit in the park' example, if the situatedness of a dialysis satellite unit is an important structure then does the change of situatedness alter the meaning of the unit? This may mean, for example, issues such as access to medical back up or provision of food for the staff and patients may have a strong influence upon the original meaning of the dialysis satellite unit, and change of situatedness to a 'park' significantly alters that meaning. For Husserl (2001) this is when a thing, like the dialysis satellite unit, is bestowed with a meaning and therefore is a fulfilled-intentionality. Interpretation of the object links the parts piece by piece and thus would give full meaning to a greater or lesser extent (Husserl, 2001). It is through examination by imaginative variation that description provides adequacy of interpretation: its meaning. Therefore the abstracted

thing being examined is never lost in some form of idealism or essentialism but is clearly grounded in reality.

### **5.9.2 Problems with the process**

Imaginative variation requires the positing of possibilities upon an abstracted reality to attain clarity of general structure. However, what is not clear is how many variations are enough, that is, when does the researcher stop the application of the method and demonstrate adequacy? Indeed variations can be produced indefinitely for as long as the researcher wants to continue or runs out of imaginable variations (a true limit of possibilities) (Levin, 1968; Mohanty, 1989). Levin (1968) argues that as a method imaginative variation is flawed in terms of adequacy because whenever variations are terminated there will always be a faint image of the object because it will be incomplete. However, this faintness is dependent upon which level of structure the researcher wishes to describe. To enter into the philosophical level to which Husserl describes as transcendental and have an essential structure (eidos) that is universal is not necessary for the examination of day-to-day experience (Giorgi, 1985). The psychological researcher is not looking for the particular but for the general or the typical that is context related (Giorgi, 1985). The incompleteness of a general structure represents a particular way of interpreting the experience that is manifold and as such all experience is unknowable in its totality (Sokolowski, 2000). In view of this the researcher offers an adequate description that is always open to modification should more evidence become available.

Levin (1968) highlights another problem concerning the applied invariants questioning whether they are themselves some form of unexamined focus of interest. For example, the use of absurd variants by the researcher may be a 'quick fix' method of presuming adequacy of general structure. To place a dialysis satellite unit in a cow shed is clearly a possibility but absurd in relation to the reality because the content to be interpreted sets limits through

similarity and exact likeness; that is, its specific substance (Husserl, 2001/1900). This would mean, for example, that an underlying necessity for asepsis in clinical procedures would exclude dialysing in a cow shed.

The procedure presumes that the researcher will remain in the phenomenological attitude which means a disciplined approach throughout the application of variants. Additionally, grasping of adequacy of the general structure after a limited number of variants would seem to need some form of insight development (Levin, 1968). The insight would presume that sufficient variants have been made and that what is presented has certainty of proof. Therefore, the grasping of the general structure should have knowledge of which variants are really possible variants of the general structure and that by adding any more variants would not alter it. The problem with this debate is that when viewed in the manner of Levin it adopts the point of view of traditional logic which eventually would lead us to Cartesian doubt and wondering how anything can be proven to exist. This is not helpful to the researcher who needs to demonstrate validity and truthfulness of evidence. However, the phenomenological researcher adopts an attitude not of the Cartesian doubt manner but one in which the world already exists and is lived through (Merleau-Ponty, 1962).

The general structure is the means to understanding the experience of the world and whilst what is in front of the researcher is self-evident it can never be totally adequate because things have different modes of appearance (Palermo, 1978). The justification of not applying variations ad infinitum is that the process of imaginative variation provides a general structure that means a thing. However, it is not the actual thing in time and space because it is a thought experiment process and as such the invariants of the general structure are not nullified by the variation (Palermo, 1978). In other words not all imaginary options are possible only those that can be inserted within the boundaries of the specific experience and in this way absurd variants are negated (Spinelli 1989).

### **5.9.3 Imaginative Variation and Induction**

The method of imaginative variation has a strong link with induction. Induction is the development of generalisations or theories from specific empirical examples (Barker, Pistrang and Elliott, 2002). Indeed imaginative variation, in the realms of psychological research, aims to produce generalisations from specific experiences. However, difference lies in that induction requires actual examples to extend the generalisation and is thus limited by what is available, whereas imaginative variation is about clarification through the use of possibilities and thus can proceed (Levin, 1968).

### **5.9.4 Imaginative Variation and Phenomenological Psychology**

Imaginative variation is seen as an important part of phenomenological psychological research; it is essential for the method of pure psychology as access to the pure psychic (Heidegger, 1970). The pure psychic for Heidegger (1970) is the a-priori experience of consciousness as it is lived. The application of imaginative variation to phenomenological psychological research is variable. Giorgi (1985), a Husserlian phenomenologist, discusses the application of imaginative variation in his study of the phenomenological psychology of learning. He applies the notion of developing generalities, not universals, from interview data which is moderated by the original context. The original context is the link to reality which provides a limit to how imaginative you could be.

For Giorgi the application of this method occurs in the transformation of the analysis of 'meaning units' (units of text transformed in to psychological language) to a general structure. There is an interrogation of the general structure relative to the context which keeps it grounded in reality. The questioning is one which adopts a manner that tries to make sense of the theme or structure of experience. Hence it moves from specific experience(s) to a general structure. The importance of imaginative variation for phenomenological psychological research is that it provides a form of validation for the findings that does not need to be

externally verified by another person (Giorgi, 1989). Here Giorgi (1989) argues that the method excludes the need for an external judge on the grounds that the judge then becomes a primary researcher who may interpret the data in a wholly new way. This would then require the judge to convince the researcher of the new interpretation. However, it is not clear if the judge has undertaken the phenomenological approach to examining the data; which would be essential. What occurs here is a paradox in that on the one hand Giorgi is concerned about accurate descriptions of other people's experience to provide meaning and yet he is not prepared to accept the meaning or interpretation of a judge who is involved in the intersubjectivity of being in the world with other people. What Giorgi appears to be concerned about is that the external judge's role is not to correct the understanding of the data which assumes there is an already known correct interpretation, but to ensure due process has been applied. The external judge, in the case of one being used, should only be concerned with method and not interpretation of the data (Giorgi, 1989). Giorgi and Giorgi (2003) only briefly state the process of imaginative variation in their description of phenomenological method by explaining that structure is gained by determining 'constituents that are typically essential' (p 45). This description lacks detail and as a practical guide is unhelpful to the novice researcher.

Colaizzi is frequently cited as a source for phenomenological methodological application in nursing research (Crotty, 1996). Colaizzi (1978, p59) is unclear in his description of phenomenological method and certainly would not help a novice researcher when he states the researcher '...is involved in that ineffable thing known as creative insight; he must leap from what his subjects say to what they mean.' This form of description of method is ambiguous, lends a sense of the mystique, leaves the researcher with a totally free reign for interpretation, and assumes the researcher is capable making this creative insight. Use of the word 'ineffable' ('something that can not be spoken') is unsatisfactory for those qualitative researchers who aim for clarity of process or want to adopt Colaizzi's method. Colaizzi does offer some advice when undertaking the creative insight activity in that the researcher should

never sever all contact with the original text or meaning units when formulating meaning. Here he remains true to phenomenological method which helps keep the 'insight' grounded in reality.

Van Kaam (1969, p326) offers some guidance in his method whereby the researcher must compare 'the different elements and different descriptions in which they are used.....to determine those elements that might probably be said to be constituents of the experience....' Those elements that are not thought to be inherent in the structure are to be eliminated from the description and subsequently lead to a hypothetical description that requires further comparison with initial examples to assess if further revision is required. This approach is also supported by Moustakas (1994) in his method of searching for examples that illustrate the general structure and thus provide depth of description. The reflecting back of the general structure upon original text or transcripts is apparent in all these methods. This is important because it is the stability for maintaining contact with what is real that is to say the individual experience and thus maintaining validity or in qualitative research terms 'truthfulness' and credibility (Robson, 1993). Reflecting back is the process of maintaining contact with context and grounding and thus positing it clearly within experience.

### **5.9.5 Nurse Phenomenological Researcher Misinterpretation of Imaginative Variation**

Many nurse researchers who use phenomenology have tended to not utilise Husserlian method. Instead they have adopted what they call interpretive phenomenology or Heideggerian Hermeneutics (Leonard, 1994; Crotty, 1996; Benner, 1984; Oiler Boyd, 1999). Descriptions of the interpretive method do not mention the practice of imaginative variation as essential but talk about using vignettes or exemplars to demonstrate the interpreted experience (Leonard, 1994). These nurse researchers appear to reject the Husserlian notion of phenomenology for the 'Heideggerian' method without fully understand what Heidegger meant. Heidegger (1962) gives an account of his use of phenomenology in *Being and Time*. In

it he states that the very meaning of phenomenology is to describe the 'thingness' of what we encounter to give it scientific definiteness (Heidegger, 1962, p39). He adds that the meaning of phenomenological description lies in interpretation (Heidegger, 1962, p61). Interpretation is grounded upon meaning and here Heidegger agrees with Husserl that essences are understood by their meaning (Heidegger, 1962, p187) For Heidegger essence is the being of something and his approach was to provide the meaning of being-in-the-world through description of its essential structure. Heidegger sees the possibilities of a description of the essential structure of Being (Dasein) as providing the basis for further study of things that appear not to have the same character as Being (Heidegger, 1962, p62). Here Heidegger is offering a general structure of being for imaginative variation with other entities for clarification. Heidegger is indebted to Husserl for the method of phenomenology including imaginative variation and utilises it throughout *Being and Time*.

Imaginative variation is evident in the Heidegger's manner of describing essential structures of Being (Dasein). For example, Heidegger considers the notion of being-with others and concludes that Being can never be alone. This conclusion is derived through experimenting with the notion of can Being truly consider itself alone when others are already part of its world? Heidegger (1962, p157) considers the structure of being-with others and being alone and states that being alone is a 'deficient mode of Being-with: its very possibility is proof of this.' What this means is that Being cannot even consider the idea of being alone because that could not occur without already being-with others. Therefore to try to imagine a person or one's self being alone without any notion of other humans is unobtainable. Clearly Heidegger is using imaginative variation to clarify essential structures of Being in his book *Being and Time* and in his method of phenomenology. Heidegger is not attempting to develop some super ego that transcends even the self, something at which he was at odds with Husserl, but he is attempting to describe the basic structure of everyday experience of being-in-the-world. Therefore nursing research appears to have not fully grasped the methodological aspects of

imaginative variation as an important element but has interpreted its own version of phenomenology with this element omitted.

### **5.10 Phenomenology and Description**

Phenomenology is generally divided into two main streams; descriptive and interpretive. The interpretive approach has become more popular than the descriptive approach since the works of Heidegger and Gadamer (Giorgi, 1992). Indeed the interpretive approach has become very popular in nursing qualitative research particularly influenced by the work of Benner (Crotty, 1996). However, Husserl developed Phenomenology with a view to it being a descriptive science that will provide foundation for sciences including psychology (Husserl 1970). The importance of description for Husserl was influenced by Brentano in his attempt to make psychology rigorous science that was not reliant upon natural science methods (Husserl, 1970).

Description does not replace explanatory methods; it provides the concepts or themes for explanatory theory to work upon. However, for Husserl (1970), phenomenological psychological description is not analogous to the descriptive natural sciences because of the phenomena of human experience cannot be modelled upon the natural sciences. According to Husserl phenomenological psychological description is to be modelled upon its subject matter i.e. human experience. The description of human experience is to provide clarity from what actually presents (intuition) itself to the researcher and not, in Husserl's words, through 'empty word-concepts or move in the sphere of vagueness' (Husserl, 1970, p233). In Husserl's (1970) view, description is to be of human experience in the life-world whether it is the experience of the body or 'psychic' in nature. This view should not be seen to support Cartesian duality because Husserl is at pains to emphasise the embodiment of humans (Husserl, 1970).

In order to undertake a phenomenological description the researcher must only describe what is directly given to intuition (in the phenomenological sense of the word: directly presented to consciousness in its original state [Moran, 200]). Phenomenological description requires the suspension of knowledge, theories and beliefs (natural attitude) through the epoché so that the thing is described without influence of competing knowledge. It also requires the use of imaginative variation to gain precision through identification of invariant structures.

Husserl provided few examples of the phenomenological description, perhaps his best being the phenomenology of internal consciousness however; there is an example to be found in Cartesian Meditations. In this example Husserl explains the perceiving of a die and describes how it presents in that it is ‘given continuously as an objective unity in a multiform and changeable multiplicity of manners of appearing’ and that these appearances have a temporal flow that are a ‘unity of a synthesis’, such that in them “one and the same” is intended in appearing (Husserl, 1960, p39). Here Husserl is describing that the multiple appearances of the die has a collective unity that must demonstrate the same die. This collective unity is a synthesis and as such has a synthetic structure (Hammond et al, 1991). What is seen here is the way in which a phenomenon can be described ‘which from different perspectives’ has a manifold of appearances that each makes up the one thing being examined. Each way of appearing can be described in the manner in which it appears to the onlooker and how that appearing is experienced. Hence aspects such as colour, shape and texture can be described with spatial proximity and temporal flow in actual presence and as well as psychological acts such as remembering. The key to this is whether the thing being described is present or whether it is described from memory its synthetic structure remains.

The rule of description is to avoid explanation. This may at first glance appear easy but in practice can be difficult (Spinelli, 2005). Spinelli believes, following Merleau-Ponty, that total phenomenological description is impossible because no description is ‘free of explanatory components’ (Spinelli, 2005, p21). For example, when questioned, a patient state

that's/he is depressed the natural consequence may be to ask 'why?' This is because the desire to have a cause and effect (positivistic) reason, especially in clinical care, is ingrained into practice from the very beginning. However, Spinelli, pragmatically or conveniently, solves his dilemma by arguing that explanations run on a continuum with concrete descriptions at one end and abstract analysis at the other. Regardless of this one important rule is to avoid asking 'why?' or questioning the possibility of a thing being what it is (Mohanty, 1989)

### **5.10.1 Description and Interpretation**

Husserl's descriptive phenomenology (which is a tautological statement but for the purpose of this discussion differentiates it from interpretive approaches) has received much criticism not least from Heidegger. Heidegger believed that description was an inappropriate method for making sense of human existence and claimed that the correct method was of phenomenological description is interpretation (Heidegger, 1962). This means that the correct way to describe a phenomenon is to interpret it. Interpretation occurs because humans are thinking historical beings that already understand their situation in an unreflective manner; they are self-interpreting beings (Heidegger, 1962). Husserl was not against interpretation and saw it as important for making sense. Indeed Husserl recognises that interpretation is evident when expressions are made that signify some form of meaning (Husserl, 2001). Therefore interpretation is evident and recognised by Husserl but what he aims to do with phenomenology is show these interpretations of experience in as much clarity and precision as possible. Therefore descriptive method does not deny interpretation as a fundamental basis for making sense it aims to describe them as they are.

The human experience is verbal and language is the medium of explaining human experience (Gadamar, 1989). Language is a medium for interpreting and expressing experience. Our ability to express experience is limited by language and words. Whilst this may be the case Giorgi (1992) argues that these interpretations still can be described which is congruent with

Husserl's view. Heidegger's argument is that everyday experience hides the true meaning of human being and this must somehow be cast aside to reveal the truth. This approach is called the hermeneutics of suspicion (Ashworth, 2003) and is also congruent with Husserl's view that phenomena can be seen more clearly once natural attitude is withheld.

Delius (1953) takes issue with Heidegger's approach feeling that description is the only way to examine phenomenon through phenomenology. Delius (1953) argues that phenomena are presented to us on the same horizontal level. If a thing is hidden by another thing (indicating a vertical relationship) then in order to uncover this thing we must already have this thing presented to us. However, Delius feels that if one thing is related to another we cannot perceive it without at once perceiving it as related which must be at the same level i.e. horizontal. Therefore things can only be seen to be related if the relationship is seen also. In order to get around this issue Heidegger states that the way to access this hidden thing is through a referent such as a guiding idea (part of the hermeneutic circle) meaning that we already have experience of the phenomenon which hides another 'true' phenomenon. Again Delius takes issue and argues that Heidegger asserts that we do not usually have any perception of those deeper hidden phenomena. If this is the case, he argues, how does interpretive analysis occur without resorting to guesses or ideas?

Heidegger's interpretive approach (for which he provides no method) appears to allow for the fitting of phenomena to personal ideas or theoretical concepts and even suppressing those that perhaps don't fit as well as would be liked (Delius, 1953). This reason is perhaps why Husserl's desire to describe only what is given in *the* way it is given becomes more important in terms of research trustworthiness. To add to the effectiveness of this argument it is worth noting that Heidegger constantly refers to agricultural crafts and traditions in his existential approach as examples of authenticity of being. However, Heidegger is a willing participant in the powerful Heimat (Homeland) culture that occurred in the late nineteenth century and revived in the decades leading up to the Second World War. Heimat culture was romanticism

of rustic life that was exploited by German 'high' culture, successive governments, including the Nazi party to provide an image of anti-technology, purity and authentic being (Blackbourn, 2003, Adorno, 1973). Knowing these were some of Heidegger's guiding influences offers an alternative insight into his interpretations. The point is that Heidegger did not make explicit his method of interpretation or his guiding influences which leaves subsequent 'Heideggerian' Phenomenology like those cited in nursing research in some what of a vague situation.

Descriptive phenomenologists such as Giorgi and Mohanty do not deny that interpretation exists and that there is a place for it in the examination of phenomena. What they do feel strongly about is the need to state that descriptive phenomenology should not be judged by an interpretive model in the same way that qualitative method should not be judged by quantitative methods (Giorgi, 1992, Mohanty, 1989). In defence of descriptive method Giorgi (1992) identifies several areas that are important to clarify to understand the differences. For example Giorgi believes all meanings even if ambiguous can be described; interpretation occurs to make clarity when ambiguity occurs. Interpretivists believe interpretation is necessary to go beyond the data to account for gaps in what is given (Giorgi 1992). However, for the purpose of description there is no need to go beyond data, things can be described in their incompleteness or contradictory status. Another criticism states that description uses language which is deemed to be theory-laden and is therefore interpretation. Mohanty (1989, p23) replies to this statement by arguing that 'language serves as a condition of the givenness of things in a precise manner in which they are given' and thus providing a 'phenomenal identity of the expression and the experience' that are amenable to description. Language can be used to describe experience but in doing so must remain located within the range of that experience and not beyond to remain valid. Gadamar (1989) supports this notion regarding the importance of language and words. Gadamar (1989) is concerned that to employ the etymological line to get to true meaning is an error and a fallacy. Heidegger used this method to get to the root meaning of being claiming only Greek and German languages were suitable

for this approach (Heidegger, 1962). Words change their meaning and this event reflects the changes in things such as the word 'Gay' which has changed in popular usage from an adjective describing presentation and attitude to that of a noun labelling a type of person i.e. homosexual.

Husserl was well aware of the need for scientific precision which is why he went to great lengths to clarify phenomenological method. The adoption of description was an attempt to avoid possibility of ambiguity and vagueness of phenomena. Husserl was equally aware of the use of language and its meaning conveyance (Husserl 2001). Husserl (2001, p104) sees words, amongst other things, as indicative signs from which the individual identifies meaningful signs to what Husserl calls 'expressions'. For Husserl all expressions in communicative speech function as indications of the thoughts of the speaker which is the sense giving of inner experience. Sense is made through the correlation of experiences on the side of the hearer that is s/he interprets it (Husserl, 2001). For a more detailed explanation of this refer to Husserl's Logical Investigations, Investigation One: Expression and Meaning (Husserl 2001). Perhaps the reason why there may be so much antipathy towards descriptive phenomenology is because description is perceived as low level knowledge and cognitive skill as well as falling victim to the seductions of 'grasping meaning' through the interpretative argument. The argument for interpretation is seductive particularly when there is shift in attitude in what constitutes knowledge (Habermas, 1984).

Husserl acknowledged the fundamental position of interpretation in understanding phenomena (2001). Phenomena are given to us whereby the appearance of objects and the properties presented by their contents is constituted in interpretation. However, even at this fundamental level where interpretation is present there is a restriction upon processes. According to Husserl (2001, p323) we are not free to interpret content in various forms because content sets limits by the nature of its substance. It is the contents and their relatedness to each other that links to interpretation. In this instance phenomenology is about

describing the contents (essential relations, patterns or structures) of interpretations as they are uncovered (Mohanty, 1989). The process of describing invariably involves reflection and analysis but avoids the use of deduction and preconceptions. Mohanty (1989) identifies four elements necessary for phenomenological description. Mohanty states that a phenomenological description must have an underlying sense of apodicticity or to use his words “This is indeed so” (Mohanty, 1989, p57). For something to be phenomenologically descriptive it must, (a) be about essence or essential structures or about meaning or meaning structures; (b) it must be “self-consciously free from unacknowledged presuppositions”; (c) it must relate essence or meaning to the intentional act which constitutes it, and (d) must be about a correlation structure (Mohanty, 1989, p57& 58). What this means is in the instance of this research is that my descriptions must show essential or meaning structures of experience that relates to how it is perceived or reflected upon and how they relate to each other. Phenomenological description provides implications and meanings to consciousness that allows further analysis through interpretation but always on a horizontal level. In the same way interpretations can be described to provide further analysis. In this view phenomenological description and interpretation are complementary and not in opposition. Hence the strict delineation of descriptive or interpretive phenomenological method is simply to state what will be undertaken in the analysis and the limitations of the method. Neither method is superior to the other; they have closely related but different intentions. Therefore, when adopting a phenomenological approach it is important to stress whether it is descriptive or interpretive as in the case of Giorgi’s descriptive method.

### **5.10.2 Giorgi’s Descriptive Method**

Giorgi (1992) is keen to stress the importance of description in his method of phenomenological psychology. However close examination of his method reveals some lack of clarity of description. Giorgi (1985) stresses that a phenomenon under investigation in his approach remains descriptive throughout the phenomenological analytical method. Giorgi

goes on to claim that naïve descriptions are transformed into general psychological categories by ‘going through the concrete descriptions and not by abstraction or formalization, which are selective according to the criteria selected’ (Giorgi, 1985, p17). Several problems arise with this account of description. Giorgi (1985) claims that a subject’s everyday expression is transformed into psychological language however, to transform something is fundamentally to change it, that is, it moves from one thing to another thing. To have something transformed means that there must be a referent for change. In this case the referent is psychological language and therefore to move from a naïve description to a psychological description requires an understanding of two sets of language i.e. the everyday and the psychological. The psychological transformation between languages can only be brought about through an interpretation of the naïve description. In this case interpretation is the transformational device and if this is so then Giorgi is an interpretivist which would provide him with dilemma of no longer being a descriptive phenomenologist. In addition to this, Giorgi (1985, p 17) does not help his case by stating that ‘transformations are necessary because the descriptions by naïve subjects express in a cryptic way multiple realities’. This statement clearly indicates that something is hidden in a cryptic manner and thus needs to be made present, something not unlike Heidegger. One possible solution to Giorgi’s dilemma is perhaps brought about by Delius’ (1953) idea of horizontal presentation of phenomena.

What Giorgi is perhaps not doing is stating that a certain phenomenon is really something else. What he is stating is that it is obscured but once unobscured it is the same as a phenomenon expressed in psychological language. In this instance Giorgi remains on a horizontal level of description because he is not attempting to change the fundamental structure of the phenomenon and not stating that is really something else. However, in this instance one must know that the thing that obscures means the same as the thing obscured just in a different way. If this is the case, then this too requires some form of interpretation. It also means the relationship between naïve expression and psychological expression must be known.

Giorgi's method infers a link between two similar expressions of phenomenon which needs to be made explicit. The answer to the inferring is brought about, by a hermeneutic catalyst; a naïve descriptive account is interpreted into psychological language. Therefore it is possible that Giorgi remains descriptive but only through the use of a hermeneutic device which is a link between the two. The hermeneutic device acts as a bridge between the two (naïve and psychological) expressions of the intended phenomenon.

Description in phenomenology is aimed at identifying the structure of phenomena from which meaning can be expressed and does not pretend to be anything else. There is room for both forms of phenomenology one to provide descriptions of experience and the other to make sense of phenomena. It may be necessary to accept that description is also brought about by interpretation especially when there is some form of transformation applied. Importantly for a phenomenological psychological investigation the description of the other's experience is one of their natural attitude; their interpretation of experiencing of the world.

### **5.11 Summary**

Phenomenology offers a very complex but structured approach to examining subjective experience. Phenomenology, though based in philosophy, has a practical application that can lead the researcher in an attempt to find clarity in qualitative subjective experience that would allow explication of its meaning. Phenomenology is ideally suited to examine the experiences of those who attend dialysis satellite units in a qualitative manner and through description shed light upon aspects and structures of that experience. Phenomenology, in the descriptive orientation, acknowledges interpretation as fundamental but aims to describe experience in its modes of appearance, by limiting attention to the thing that is presented and withholding external influences. It is important to translate the philosophical basis of phenomenology into a practical method for empirical research. The method acknowledges the fundamental basis of

interpretation but also must include the key elements of the approach which are the phenomenological reduction and epoche, horizontalization, description, imaginative variation, lifeworld, adequacy, and identity as manifold. The next section will explain the application of these elements to empirical research of the experience of patients and nurses in dialysis satellite units.

## **Chapter Six**

# **Descriptive Phenomenology Applied to Collecting Research Data**

## **6.0 Data Collection Methods**

In this chapter I will explain the process of data collection which, as already stated, is aimed at providing description of experience. It builds upon the idea of exploring the lived experiences of those involved in dialysis satellite units. This chapter is the implementation of a descriptive phenomenological approach that is not limited to interview in the way that it is frequently applied in nursing phenomenology, but include observation. I have stated that phenomena need to be examined from as many perspectives as possible to provide adequacy. Indeed it goes without saying that interviewing many people will provide important perspectives and lighten shaded aspects of experience. However, interviewing alone limits our understanding of experience simply because too many aspects remain shaded from view. What this calls for is a combined approach whereby not only experiences (as aspects) brought are in to light so must context and behaviour. This combined approach is important not only for methodological consistency, but also for phenomenal adequacy.

Snygg and Combs (1949) identified, a then radical idea to psychology, that human behaviour can be observed from two points; the insider and the outsider (which was dominant ideology of the time). The insider is naturally the person who from whom we want to know about their lived experience. The outsider is another person observing them who in this instance was me. Snygg and Combs (1949) imply by this approach that phenomena are co-experienced between the insider and outsider in a way that indicates a unified intersubjective experience. This approach is congruent with Husserl's explanation of intersubjectivity as co-experiencing through empathy, which provides meaning. In accepting this position of intersubjectivity and co-experience, I intended to use a combined approach of phenomenological interview and observation: insider-outsider accounts.

### **6.1 The Interview Process for Eliciting Experience**

My interest in interviewing and phenomenology stems from to my undergraduate dissertation. At that point I undertook initial steps to understanding phenomenology applied to research. I interviewed ten patients who had abruptly become ill with renal failure and commenced dialysis as a matter of urgency. This study provided the opportunity to explore interview technique and interaction with people during the method. I recognised the immediate interaction and involvement of both parties and that the interviewer is never divorced from the interview context. Additionally, the interview context is something which is constructed for the research and as such not a natural interaction. The dissertation also provided me exposure to phenomenology though at that point in time it was heavily influenced by the nursing Heideggerian method.

Additional experience with interview occurred whilst undertaking a Masters degree. I undertook a module in qualitative interviewing which helped highlight methodological dos and don'ts as well as good technique. This was put into practice in my dissertation which used personal construct psychology as a basis of exploring how dialysis nurses construed patients perceived to be non-compliant. The dissertation allowed me to explore an alternative, though fundamentally phenomenological, approach based upon Kelly's 'credulous approach' (Kelly, 1991).

Both experiences provide me with the sense of the importance of interviewing as a method and also with the emphasis upon the person being interviewed rather than my self. I also learned to live with the anxiety of silence during interviews when I frequently felt that I should be asking something or anything. These experiences have aided me in my research by making me aware of the holistic meaning of the interview context.

## **6.2 Recognising an Epistemological Position**

The natural attitude explains the way in which each of us is involved in the lifeworld (Husserl, 1970). Natural attitude takes no effort and is the normal mode of being engaged in the world. For phenomenological psychological research it is precisely the experience of the lifeworld in natural attitude that is under investigation (Giorgi, 1997). Therefore as a researcher I am interested in describing a person's experience in the way they experience it and not from some theoretical standpoint.

The questions I identified at the outset of the research were aimed at finding out what it means to be a patient or nurse on a dialysis satellite unit. Asking the question in this manner demonstrated a position in terms of the nature of knowledge and as such my epistemological stance. The research question poses the issue of the place of experience in generating knowledge, how that knowledge is obtained, and its truth value (Henwood et al 1993). The use of interview as a method for collecting experience data is both epistemological and practical. My epistemological perspective is essentially post-modern by recognising that human experience is complex, is grounded in the world which is experienced intersubjectively, is contextual and has meaning (Mason, 2002). This approach tacitly recognises that those people to be involved in the research are not passive vessels of knowledge ready to spew it forth upon demand. On the contrary, respondents are viewed as real, active, interpreting, and will intend to find meaning in experience including the research interview (von Eckartsberg, 1986, Holstein & Gubrium, 1995). Implicitly the above explanation does not exclude me as the researcher and interviewer. Indeed the very question was generated from my experience of dialysis satellite units and a desire to find out about the experiences of nurses and patients in these units. Therefore, I am actively involved in the research regardless of the design. The practical aspect of this approach is grounded in an assumption that the best way to find out about someone's experience is to ask them; they may tell you (Kelly, 1991).

The method for analyzing phenomena in the phenomenological tradition is reflective (Husserl, 1967, von Eckartsberg, 1986). In philosophical phenomenology it is the philosopher who reflects upon the givenness of a thing, whereas in the phenomenological psychological approach initial reflection is by the person who has undergone a particular experience. It is through the verbalization of this reflected experience that we gain access to the thing experienced and its meaning. Accepting the supposition that vocabulary is shared through culture and a linguistic community whereby experience is identified and named in a consistent manner, interview is an appropriate means of explicating experience (von Eckartsberg, 1986).

### **6.3 Phenomenological Interview Method**

Interviewing is by far the most common data gathering method in qualitative research and specifically dominant in phenomenological research (Mason 2002). However, despite this dominance there is very little instruction as to how it should be undertaken. There is a dearth of advice or instruction in how to undertake phenomenological interviewing. Typically there is an assumption that general qualitative interview method will suffice for subsequent phenomenological analysis to commence. For example in Moustakas's (1994) book about phenomenological research methods there is a minor discussion about interviews where it assumes that it will be used. Moustakas (1994) provides a list of areas to consider for interview but offers no explanatory discussion. Moustakas's (1994) book is mainly concerned with phenomenological theory and analysis of data.

Giorgi (1997, p245) offers minimal advice to questions stating that '....questions are generally broad and open ended so that the subject has sufficient opportunity to express his or her view point extensively.' Giorgi (1997, 1989) also appears to differentiate descriptions from interviews whereby a description from an interviewee provides content for the interview which is a probing and expansion of the initial description. Here Giorgi is implying that his

approach is a two tiered method; obtain descriptions followed by interview. Giorgi appears to imply that a description is not part of the interview process however the initial description is obtained from an interview method which seems to add some confusion to his approach. However, there is no advice as to how the subsequent interview method should precede other than 'broad open ended questions'. Giorgi appears to use description of experience as a heuristic device to get to detail from his second stage 'interview' method.

In relation to questioning, Benner (1994) offers some advice for phenomenological researchers by recommending that questions be asked in the vocabulary and language of the interviewee. Whilst this may be useful it does assume that the researcher knows the language and vocabulary of those to be interviewed and if s/he doesn't then a major barrier to continuation exists. In Benner's (1994) view this approach is to gain access to the interviewee's perspective unencumbered by theoretical terms such as 'emotion' which appears to imply a form of phenomenological reduction. Benner (1994) does highlight an important point by advising the researcher to listen actively which should lead to areas for clarification and probing.

Colaizzi (1978) provides some indication of application of phenomenological theory by stressing the importance for the researcher of uncovering and interrogating his or her presuppositions which implies the use of the phenomenological reduction. However, for Colaizzi, the presuppositions are not laid aside but provide a thematic basis for question development moving from one's personal experience and leading to broad themed questions. In this manner Colaizzi's method is interpretivist from the outset.

The evidence for developing a method for phenomenological interview is sketchy and varied if viewed from the above mentioned authorities. The thorough reading of these authors left me with a sense of frustration in terms of how best to proceed. There are elements of phenomenological method mentioned by these authors but there is no apparent structure to

interviewing which leads to a lack of clarity leaving phenomenology open to criticism. The generally accepted thesis for phenomenological interviewing is one of flexibility related to the issue under investigation. Whilst flexibility is a necessity, a problem with this approach is that it leaves it open to abuse whereby any approach can be labelled phenomenological as a means to justify a lack of structure without the research necessarily being phenomenological. It also flies in the face of what Husserl was trying to achieve; a scientific approach to examining phenomena which is methodical.

General qualitative interviewing method provides a useful guide to undertaking interviews. These interviews are generally deemed to be semi-structured or unstructured (Holloway & Wheeler, 1996). Holloway and Wheeler (1996) feel that structured interviews are predominantly the domain of quantitative research and should be avoided by qualitative researchers. However, Mason (2002) feels that even this view is inaccurate because even the most unstructured interview will have some underlying structure in order to remain focused upon the phenomenon under investigation. Indeed it is this underlying structure that I feel needs to be made explicit to demonstrate method for the purpose of trustworthiness. The arguments against semi-structured interviews is based upon a positivistic notion that standardisation is reliable and is able to control interviewer effect (Mishler, 1986). Mishler (1986) argues convincingly against the claim of standardisation whereby the interviewer has an important effect upon the process such as verbal intonation or context. In this instance standardisation is not fully achievable because it does not control the complexity of human interaction and would cast doubt on reliability for the positivists. Mishler (1986) is arguing a post-modern attitude where all knowledge is relative and where there is no one privileged viewpoint (Polkinghorne, 1992).

One author above others provided me with some helpful structure to phenomenological researching and interviewing is the little known Seidman. Seidman's method has been used to explore lived experience in a number of different areas such as breast cancer (Thomas-

MacLean, 2004); conceptions of teachers as researchers (Reis-Jorge, 2007); suffering and well-being in life threatening illness (Mount, Boston, & Cohen, 2007); Learning to read in a violent society (Hurley & Wooden, 1994); and living with blood pressure (van Wissen, Litchfield, & Maling, 1998). Seidman (1991) provided one of the most detailed descriptions of phenomenological interview method. Seidman's method is based upon Schutz's interpretation of Husserl's phenomenology, and follows a specific structure that is more implicit rather than explicitly expressed. However, I found Seidman's approach useful because having been immersed in phenomenology I recognised his implicit phenomenological method. In Seidman's method there are three interviews per person where the first is a focused life history, followed by an interview that aims to reconstruct the experience, and finally an interview that gets the interviewee to reflect upon the meaning of their experience. Here, Seidman is carefully trying to construct context because, for Seidman, meaning enables behaviour to be put into context (Seidman 1991). There is a vague statement alluding to the phenomenological reduction by stating that the interviewer should recognise that it is not his/her ego that is important, but to stay focused upon the person being interviewed. Additionally he recommends the use of open-ended questions that develop from the context building process and if a guide is used it should be done so cautiously and flexibly.

Structure does not need to mean the narrow definition to which Mishler alludes where the researcher imposes his or her world on the interviewee (Rubin & Rubin, 1995). Structure does not need to mean that there are a series of pre-planned questions that follow a specific pattern based upon a pre-given theory or perspective. Structure can mean a broad outline of how an interview is undertaken and in this instance it was to be grounded in phenomenological method. Therefore, for me, structure is a basis for which the method of collecting data is built upon.

#### **6.4 Phenomenological Structure to the Interview Process**

I felt that phenomenology provided sufficient structure to examine an experience through interview in an explicit way provided it was applied flexibly. I also felt that it needed to be applied authentically and avoid the usual primary focus of the method upon data analysis. The intention was to remain faithful to phenomenological method but attempt to keep it practical. This is also important for maintaining methodological consistency and increase trustworthiness. Structure in phenomenological method is provided by the following key areas: description; natural attitude; lifeworld; identity as manifold; phenomenological reduction, and imaginative variation. It has to be remembered that phenomenological method is a total method in that one has to become immersed in it from the start and not at the point of data analysis. Taking these key areas and points identified by earlier mentioned authors I translated phenomenological method into a structure for phenomenological interviewing consisting of three main domains: contextualization (Natural attitude and lifeworld), apprehending the phenomenon (Identity as manifold, natural attitude), and clarifying the phenomenon (imaginative variation). For an outline see table 9 below.

It is important to note that each of these three structural interview domains is undertaken in the phenomenological reduction on the part of the researcher. The reduction, as previously stated, is the means of examining people's conscious experience of phenomena (Husserl, 1970). What the phenomenological reduction requires the researcher to do is abstain from the use of personal knowledge, theory or beliefs in order to become a perpetual beginner (Merleau-Ponty, 1962). The method required me to become aware of my own natural attitude, immersion in my lifeworld, and how I take this all for granted (Merleau-Ponty, 1962). What this amounts to is at one level a dialogue with my self, to become reflexive when asking questions. Questions are posed with self-consciousness and avoid asking questions such as *'does that make you stressed?'* which is a tacit acknowledgement of the quality of life concept of stress. However, should the person respond to questions and talks about feeling stressed I need to respond with questions that elicit descriptions of the person's experience of stress.

What this approach does is acknowledge their use of words like 'stress' to describe their world and does not try to reinterpret their experience into some other language. By doing this I tried to remain faithful to the descriptions of experience of the people I interviewed and accepted this was how they described their world which maintains a level of validity.

For the purpose of the interview an experience must be made evident to the researcher in order to examine its modes of appearing. The means for doing this is to ask questions of people who have undergone that particular experience in a way that brings the experience to consciousness. Consciousness of a particular experience must be made present to the intuition of the researcher through the use of words which is in itself a meaning-making process (Seidman, 1991). For the researcher this is particularly important because it is about keeping focused and concentrating in the direction of the phenomenon (Spiegelberg, 1971).

#### **6.4.1 Providing Context**

As the interviewer, I acknowledge that the person is immersed in their lifeworld of objects and experiences of which I am a part; that is to say intersubjective. Objects or experiences of the lifeworld stand out against a backdrop (horizon or context) which provides meaning to that object or experience (Husserl, 1970). Therefore in order to examine a person's particular experience I must consider the context from which the experience gains meaning. In this instance my questions could not proceed directly to the experience of the satellite unit because this would isolate it from its context and render it meaningless (Seidman, 1991). Instead the interview developed from the point of providing context in which the experience is situated. The fact that a patient has kidney failure provides context for their experience of dialysis and being at a satellite unit. Therefore I felt it was important that context was made explicit through the asking of descriptive questions about such things as becoming ill and how they came to be dialysing at the satellite unit. The method provided some degree of narrative which gave context but also highlighted areas for further questioning. This method is

congruent with Giorgi's (1989) description and interview process and Seidman's (1991) focused life history. The transcription below offers an example of context from a patient's experience (from unit three) of becoming ill.

*Interviewer*

*Can you describe to me about becoming ill with kidney failure?*

*Patient*

*Aye, well I was going to the hospital and they were taking the blood and that and they said that there was something up with my kidneys but I wasn't on dialysis and in about a years time I will have to start dialysis. I went home on the weekend and I was lying in bed and it was like (Makes a gasping sound) and I couldn't breathe you know, it was terrible. So I got up and opened the window and still couldn't breathe and I've got like a button for the care and they came out and said right back in to hospital. They phoned for an ambulance and took me to the renal unit, the main one and put me on oxygen. They said 'you will have to start dialysis tomorrow' and I said 'oh well' and I done it.*

*Interviewer*

*Can you describe how did you felt?*

*Patient*

*Well I wasn't really bothered you know, so long as I was going to feel better, you know. They took me up and put like a neck line in you know. That was alright but I had problems with that later on like. It came out of the chest. I got blood poisoning from it so they took that one out and put one in my groin. Never again, that was agony. The doctor said it was a fifteen minute job; I was down 2 hours (having the line inserted). They couldn't get it in I was all cut and bruised. They said we will leave it today and put another one in tomorrow and I said if you think that you are going to put another one in there tomorrow you have got to be joking. He said oh no we'll try the other side and they were still having bother and the consultant came in and he got it in. I've never sworn so much in all my life. I called him all the names under the sun.*

The transcript describes becoming ill and the experience of having vascular access inserted.

The description of experience demonstrates what the patient went through that provided context for his dialysis. In this instance it would appear that inability to breathe and the vascular access episode are important contextual elements.

Whilst illness is one aspect of context attending the satellite unit is another. The following transcript is from a patient's experience (from unit one) and how he came to be at the satellite unit. The transcript shows how descriptive context questions are used. The method also requires flexibility from the interviewer to develop questions that are relevant to the individual.

*Interviewer*

*Would you describe how you came to be here?*

*Patient*

*Well I were er told well, I wouldn't like to say whether he (senior nurse) told me or whether he asked me, I wouldn't like to say, you know (laughs). He said you'll be going, he used these words, "you'll be going to the satellite unit in so and so and we've made arrangements for a couple of days time." There were an opening I suppose. Like I say, with it being unknown you tend to worry a bit don't you?*

*Interviewer*

*Can you describe your first day here?*

*Patient*

*I can, yes, well I came in and they introduced me to all the staff that were on on the day. I was worried about it, and I was still on the line as well, not the fistula. I was worried a little a bit about it. The first couple of times I was worried but I got to know staff and they seem pleasant and nothing's changed and this is how I feel about it.*

*Interviewer*

*You said you were worried, can you describe what you were worried about?*

*Patient*

*Well the actual procedure was the same as the main unit. I just got sort of settled to the procedure at the main unit after about three months. I knew what would happen straight away and coming here was it going to be the same? I didn't know that you see: turned out it was nothing different. If you're an anxious person it would help to have some information. I realised that it was exactly the same as the main unit and the people coming were exactly were more or less the same people. I got to know people and staff. Staff were more or less the same people coming in er, it helps you.*

It is important that as an interviewer one doesn't start analysis however, notes can be made of issues or elements that may be useful for clarification questioning later. For example, when using the above transcript it may be that one can use the issue regarding how the patient came about attending the satellite unit: if he had been asked rather than told. It is important that I remained in the phenomenological reduction and focused upon the participant's experience. I cannot ask the participant to describe how they coped with starting anew at the unit but I can, as in the above example of being worried, draw on what the participant says to describe in detail their experience.

One of the points highlighted above is the need for description. Description provides structure in that it requires the researcher to adopt a particular mode of questioning. Explanatory questions are not required and the researcher should refrain from asking 'why?' (Spinelli, 1989). This means questions were structured along the lines of '*please describe your experience of becoming ill*'. The process was to enable the person to reconstruct their experience. 'Grand Tour' questions (Spradley, 1979) were used to elicit further descriptions

of a person's experience by asking them to describe the satellite unit. 'Grand Tour' questioning is a method that Spradley uses to obtain descriptive accounts of places or events that provide context for participants. For example, I would ask a nurse to show me around the unit and describe what happens in different rooms or spaces and who does what. These questions provide a participant's account of spatial and contextual aspects of experience.

#### **6.4.2 Apprehending the Phenomenon**

Phenomenological method posits that the identity of a thing or experience has modes of appearance and is experienced in many ways (Sokolowski, 2000). For example, a patient may experience a satellite unit in many ways such as for the first time, taken for granted or when feeling ill. The experience is not limited to one person but each person experiences the satellite unit and thus we find the unit is experienced in many ways by many people. In view of many modes of appearing my interviews needed to consider exploring many experiences. The implication here is that a single question is inadequate to present the many aspects of an experience and therefore I was prepared to ask more questions. In qualitative research parlance this is known as probing but preferably further exploration is a better term, however, the questions should remain descriptive. An example of this kind of question would be *'describe a typical day for you at the satellite unit'* or *'describe what happens when you enter the unit at the start of your session?'*

Whilst the goal is to get participants to describe experience one cannot control how people choose to express their experience. It is not unusual for people to describe experience in terms of a narrative account; to use analogy or significant events. These expressions are interpretations of experience that assumes immediate understanding on the part of the listener. In this descriptive approach I cannot accept these interpretations at face value though this is not to negate their existence. There is no doubt these interpretations are meaningful but this approach means I am focused upon the structure of the interpretation. Therefore I was duty

bound to investigate these interpretations to elicit clarity. In order to achieve this goal descriptive questions were supplemented with structural questions which aim to show how individuals structure their experiences (Spradley, 1979). An example of this descriptive structural questioning could be ‘*what do you do to prepare for dialysis?*’ When an interpretative statement is offered by a participant then a structural question is used to unpick what is meant by it. The following example demonstrated how the method works in practice. The example is from a nurse on unit one who describes her interpretation of her “concern” for patients. The first question is descriptive which is then followed by structural questions in order to illuminate the aspect under inspection.

*Interviewer:*

*You mentioned that you had a concern for your dialysis patients could you please describe what you mean by concern?*

*Nurse:*

*Yeah, I think as a nurse in dialysis you have a responsibility to look after them (patients) to the best of your responsibility and you provide the facilities for dialysis. You provide the extras such as advice. You provide a service basically and that to me is, is, if you have done your job right and the patient walks out with a smile on their face saying ‘see you in two days’, ‘see you after the weekend,’ and leaves well (not ill)..... if they leave well or you are walking through a bay and everyone is nodding (sleeping) or watching TV but someone doesn’t look very well I think it is my responsibility to say ‘are you all right?’ They might be feeling fine or they might be going off (hypotensive episode) but not wanting to say anything or frequently the buzzer doesn’t work (laughs). It is just thinking ‘they’re alright or they’re quiet what are they up to?’ Just thinking ‘you don’t look very well’ and ‘are you all right?’ and some times patients just don’t complain even if they have got chest pain or they are feeling like they are going off but they don’t want to bother you because you are busy. And I think that they should feel that if they are not feeling unwell, even if it is unfounded and their blood pressure is fine then it is our concern while they are here. From walking through that door until they go out that door again. That is our responsibility*

The nurse describes a concern for the health of the patient during the dialysis treatment but added that there was more to her ‘concern’ in the following description.

*Interviewer*

*Can you describe what sort of concern you mean?*

*Nurse*

*Erm, I think feeling about them because you get to know them well and you get to know bits about their family and things. They might have outside pressures, people who have family, husbands or wives who aren’t perhaps well. One of my patients’ husband was poorly near Christmas and it didn’t take two minutes to ask ‘how is your husband?’ and she said he was a lot better and that they were going to do his operation on such and such and within that week the chap had had his operation and was a bit sore but she said he was feeling great. And that is all it took that little bit of*

*empathy really, compassion. It affects your patient because they are sat there for four hours, they have got to come for treatment; how is so and so doing at home, are they all right? And I think that doesn't take much to show interest in them as a person.*

Here the nurse expands her description of concern by stating that in addition to treatment related concern she has concern about the person as an individual. She describes that she has an awareness of how the treatment affects patients and that she makes the effort to show an interest in patients as a person. However, the nurse then moves on to describe what other aspects she means when she talks about 'concern' but also uses it in conjunction with being 'enthusiastic'.

*Interviewer*

*You mentioned that you were concerned and enthusiastic about the patients; can you describe what you do when you are concerned and enthusiastic?*

*Nurse*

*Em, I enjoy what I do, silly things like having a laugh and joke with the patients, being serious when you need to, making the place comfortable for them and being approachable so that they can say 'can I have a word?' whether it is your patient or not, whoever is on that shift. I take that as a compliment if a patient can confide in you and I don't find it trouble if I find some says would you mind getting me a blanket or can I have an extra cup of tea, you know it is part of their comfort so long as they are not drinking gallons of tea and haven't got twenty five blankets and everyone else has got none. I think it is part of caring, the little things as much as the big things. You don't just connect them up and say 'hi and bye' and leave them for four hours you have got one eye out and thinking yeah, feel alright feel okay. They have got to be able to say that they don't feel well. I enjoy my job, I have enjoyed it since I came into nursing but in the last ten months I have really enjoyed it and thought this is my niche. I love haemodialysis, the patients we have on a regular basis, I quite like that, you have got time to have a relationship with them. They become a bit like family, friends but with a barrier as they are patients. But you say 'did you have a good weekend,' 'what did you do,' 'how is your little boy?' or.....*

*I like to think I'm a people person. I like to think to be, you know, I like to feel people are comfortable with me. And if people come out and say to me 'do you mind doing such and such?' for me and don't feel afraid of asking me for things then, you know, I take that as yeah, you know, I'm doing my job, that is what I am here for. What ever the problem is big or small, it may be massive to them but small to me. And if they feel comfortable to say 'would you mind getting me a glass of water, I'm thirsty?' I say 'yeah' and know that they are not going to get (grumpy voice) 'oh get a glass of water, hmmmppf'. There is no point nobody benefits from that. At the end of the shift they say thanks for that and a simple glass of water can make them comfortable. That is what nursing is all about.*

Here the nurse offers several descriptive aspects of 'concern' and 'enthusiastic' and concrete examples such as comfort. She finishes off by attributing these aspects to nursing. The nurse provided a wealth of information for later analysis. It is not required at this point of the discussion to enter into data analysis but to demonstrate how the use of structural descriptive

questions enables detailed apprehending of the phenomenon. It would have been easy to accept the word 'concern' at face value particularly as I have a nursing background where concern for patients is an important value. However, this would be accepting my interpretations, as valid as they may be, and not showing commitment to the phenomenological method: the epoche. Descriptive and structural questions provide a basis for maintaining the phenomenological reduction as well as a configuration for examining experience and avoiding explanatory questions on the part of the researcher.

### **6.4.3 Clarifying the Phenomenon**

Clarification of the phenomenon is undertaken with the use of imaginative variation. Imaginative variation is not normally used in the interview process. Imaginative variation is normally a process used in the analysis of interview data in its transcribed format (Giorgi, 1985). The imaginative variation requires that when the researcher intuits a structure of experience it is then put through the process of imaginatively varying its structural components to uncover invariant parts and thus clarifying its structure (Husserl, 1960). The rationale for placing the imaginative variation post data collection is to methodically place it as part of data analysis as a form of phenomenon reduction (in relation to removal of variants) and phenomenon clarification. It appears that the post interview placement of imaginative variation has become a given without rationale. Spiegelberg (1971) places the imaginative variation earlier in the process of examining a phenomenon. Spiegelberg's reasoning for the early placement is that it provides 'stepping stones' for the 'apprehension of the general essences' (Spiegelberg, 1971, p677).

My concern for the late placement of the imaginative variation is that it reified the analysis process more like a cookbook method rather than the dynamic process I believe it should be. The phenomenon is actively examined, according to Husserl (1967) which includes the use of imagination. In view of the need to actively examine phenomena my intention was to

introduce imaginative variation into the interview structure thus rendering it more active. I was immediately aware that this was a novel approach to phenomenological research but felt justified on the basis that each person's experience is an experience in its own fullness (though not complete). It also adds consistency to method in the examination of phenomenon. This means each person's experience can be examined for modes of appearance and clarification. An advantage to applying imaginative variation at this point is that it remains grounded in context and avoids the quick and 'cheap' use of obscure or absurd variation and remains close to the original experience. An additional advantage is potentially important in relation to validity claims. If the phenomenon is varied with the interviewee then the structure remains real and context bound from the perspective of that person. By taking the person through the imaginative variation (in their lifeworld experience) they provide adequacy of structure. Additionally they remained grounded in their experience. The process would have the added benefit of explicitly demonstrating questions of structural variation.

One of my concerns was how to implement imaginative variation in the interview structure. Reflection upon the phenomenological method meant I could not impose predetermined variations because that would presume answers and content on my part. The answer appeared to be one generated from the interview itself. The generation of variation questions would be developed from the participant's descriptions of experience through active listening and a reflexive approach. The method required the person to describe his or her experience which must be grounded in context (for meaning) and would enhance claims of trustworthiness (Seidman, 1991). I felt that context and experience description would provide suitable material for variation because it is context that provides meaning for the experience. In order to achieve this it was decided that the horizon of lifeworld (as stated previously) became increasingly important.

The process is active for the interviewer and the interviewee. The interviewer must remain focused and attentive (Seidman, 1991). The interviewer must listen to what is being said

however it does require that a judgement is made to identify an aspect of structure of experience for clarification. The method proved fruitful; for example, patients described the fact that in their experience doctors were present on the main unit but not on the satellite unit. Once this distinction was identified variation questions can be asked such as ‘*describe how the presence of a doctor on the satellite unit would change the unit?*’ Questions can be asked in this manner because they aim to make the person identify invariants by describing how the experience would change. Clarification of phenomena should occur after contextualisation and after apprehending the phenomenon because it provides the back drop for meaning and only against this back drop can meaning be altered in any way.

The following example demonstrated how variation questions can be applied from context description. Using the frequently cited issue by participants about the absence of doctors on the satellite unit the following question can be asked.

*Interviewer*

*If there was a doctor here all the time would that change the unit?*

*Patient (unit 3)*

*No not really, if he was like a friendly doctor, even if he came round say once a week just to say hello, you know. The senior nurse is good, he is very good. Doctors are alright for the procedures but they can't tell you that much different than the senior nurse. I never used to see the doctors there anyway*

There is no guarantee that a complete structure would be elicited but this is not the aim of phenomenological method rather it is adequacy that is important. The method appears to provide a grounded level of adequacy. The adequacy is borne out of real experience that is verified by the person him or herself and as such adds to trustworthiness of the method. Individual structures can then be compared with other individual structures to provide an intersubjective structure. The structure is not developed to provide ‘correct’ results or predetermined outcomes but helps in the streamlining of analysis and understanding. The practical application of the method is, in my mind, a form of experimenting with phenomenon to identify invariants. The method is not unlike Ihde’s (1986) approach of using hermeneutical devices to alter phenomenon to identify invariants. This method, I believe, is dynamic, practical and would form part of what is called experimental phenomenology (Ihde,

1986, Gallagher & Sorensen, 2006). Experimentation is with the experience in situ with the person present rather than removed to a transcript and idealised by abstraction.

The interview method and structure is constructed in a broad sequential manner made up of parts (see table 9). The initial starting point is contextualisation, to describe the immediate context of the experience. The method was piloted on some willing patients and nurses (with consent) at a separate satellite unit. I found the method to be very active and concentration intensive. The need for a reflexive approach was important because there were times when I slipped effortlessly into natural attitude and found my self asking questions such as what coping methods were used. During the study I found that if I was tired I would not undertake any interviews because tiredness made the self-dialogue and active listening difficult and slippage into natural attitude effortless. I did begin one interview but soon terminated it because of tiredness on my part. I also realised not to interview if patients or nurses looked particularly tired or distressed in any way because I soon found out that they would become irritated and would then provide limited answers. I also had to clarify to patients that I wasn't trying to catch them out in any manner. At the outset I began explaining that I may ask some clarification questions. Interview duration on average ranged between forty five minutes and one hour.

The method was active and dynamic provided full attention was given. I felt that it reflected phenomenological method but in a practical and flexible way that was not perplexing for the interviewee. The phenomenological interview approach has a structure of contextualisation (lifeworld) which requires descriptive context questions followed by the structure of apprehending the phenomenon which has descriptive and structural questions; and lastly the structure of clarifying the phenomenon (imaginative variation) with questions that aimed at varying structure. The interview questioning is undertaken in a semi-structured manner in order to remain flexible so that a phenomenon can be examined (See sample interview schedule in appendix 3).

Phenomenological Attitude	Researcher Approach	Interview Structure	Method	Example
Phenomenological Reduction (Epoché)	Acceptance of Natural attitude of participants	Contextualization (eliciting the lifeworld)	Descriptive/narrative context questions	‘Tell me about becoming ill’ or ‘Tell me how you came to be at the satellite unit’
	Reflexive Critical Dialogue with self	Apprehending the Phenomenon	Descriptive and structural questions of modes of appearing	‘Tell me about your typical day at the satellite unit’ or ‘Tell me what you do to get ready for dialysis’
	Active Listening	Clarifying the Phenomenon	Imaginative Variation: varying of structure	‘Describe how the unit experience would change if a doctor was present at all times’

**Table 9: A Structure of Phenomenological Interview**

### 6.5 Observation as a Data Collection Method

This section of the chapter will outline the method of data collection through the use of participant-observation. The method will be explained and describe particular issues raised in the process. Observation as a method of data collection in nursing research has maintained a low profile (Morse, 2003). The use of interview particularly through nursing phenomenology has seen that method become dominant (Mulhall, 2003). Whilst it is not fully clear why this should be the case there is without doubt influence from the interpretivist epistemology. A nursing pre-occupation with interpreting the patient or nurse experience is influenced by the works of Heidegger through researchers such as Benner. Interviewing from this perspective is linked to a post-modern epistemology whereas observing behaviour can be seen as positivistic behaviourism of modernist epistemology. However, this is not to state that observation may not be post-modern with clear examples, such as the work of Goffman, where such an approach can make a significant difference in how experience is made sense of.

### **6.5.1 A Rationale for Using Observation: Increasing Adequacy**

To summarise, the use of participant-observation in a phenomenological study is required to add context and content to reflected accounts, it sheds light onto shaded aspects of experience and increases adequacy. My decision to use observation as a data collection method is grounded in phenomenology. In phenomenology an object, event or activity is intuited. What this means is that a phenomenon is brought to the presence of consciousness through acts of intuition. The presence of a phenomenon can be intuited in a variety of ways such as remembering (re-presentation), imagination (fantasy), and perception (presentation) (Levinas, 1998). The interview can provide a phenomenon to consciousness through re-presentation which is a re-presenting of something meant or signified such as a particular incident or event. The event or incident is meant through the words used to describe it. However, the event or incident in this instance is not present but is instead an empty intention re-presented or signified (Levinas, 1998, Sokolowski, 2000). Therefore an interview is known as a signifying intuitive act which aims at the object, event or activity but the thing is not actually present and therefore the intention is empty.

Observation offers aspects of experience that may not be evident in the re-presentation of experience. A reflection or re-presentation is context bound which is where meaning is grounded. Observation offers a visibility of context features and aspects of experience that may not be available through interview re-presentation. Observation makes present elements of experience that participants undergo. For example, a nurse may talk about getting ready for the patient but not include how s/he uses time to move between several dialysis machines. Observation, in this instance, demonstrated a preparation of machines so that they did not complete preparation in unison but rather in a manageable sequential manner. Observation is important because it brings to consciousness taken-for-granted aspects of experience which increases phenomenal adequacy.

A phenomenon intuited through perception gives something of the thing itself; a sense of fullness, which is a privileged case of intuition (Levinas, 1998). Therefore an object, event or activity that is perceived has an immediate given that allows its apprehending. The characteristic of a perception, for Husserl, is that it has the thing before you in ‘flesh and bones’ as it were (Levinas, 1998, p70; Moran 2000). Having the thing before you makes perception a primary intuition that gives being. Reflection upon the act of perception leads to the seeking of the concept of being (Levinas, 1998). When an object is presented it does so with evidence of a full mental seeing of something in itself (Husserl, 1960). It is worth noting that perception described in this manner does not mean that observation has a special status over other forms of intuition because if it did imaginative intuitions such as new ideas would have no status unless they could be observed. Therefore observation offers an aspect of phenomenon that is presented in fullness with immediacy and in doing so provides additional adequacy.

The method of observation offered me a means of being conscious of a satellite unit right there in front of me for examination with its modes of appearing and aspects. The use of observation allowed the exploration of physical objects, events and activities that occur in experiencing a satellite unit. An interview alone reduces access to a person’s social world through reflection whereas including observation would add context and aspects to verbalized experience (Seale, 2004). Observation would also provide an opportunity for increasing adequacy by providing context. Providing context, modes of appearing and aspects would enable description of experience with a sense of fullness. Fullness is not to be confused with completeness. Completeness is where all aspects and boundaries of a thing are known whereas fullness is where all aspects are not necessarily known but sufficient are present to provide an adequate description of experience.

The phenomenon under investigation always appears in a context of fluidity which means there is always something happening (Snygg & Combs, 1949). To add to this the observed

object or situation has form and content that is always organised, though this may vary from person to person and time to time (Snygg & Combs 1949). This organisation always has meaning and is in reference to the self and his or her interests. Therefore observation offers access to meaning in the form of content and organisation of the experience of individuals and where these overlap with others.

I recognise that the use of observation is not a means of confirming truth in what is said by individuals (Maggs-Rapport, 2000). Further to this observation is not used as a means of identifying correlations particularly in the sense of causal relations. Correlations presume theoretical knowledge of a link between phenomena and this is not the aim phenomenology. Phenomenology does look for relationships and examines them but cause and effect are not within its scope. What observation, in this sense, would provide is convergence of aspects of experience, should it occur, and add adequacy to descriptions of the phenomenon (Maggs-Rapport, 2000).

The use of observation as a data collection method recognises the issue of whose experience will be verbalized (Savage, 2000). Indeed it will be my observations of other people's activities, actions and events. The basis for such a concern is grounded in a positivistic paradigm where there is a determination to separate subjectivity and objectivity. The positivistic view is a desire to exclude the researcher's subjective involvement (such as personal observation) which is seen as a source of data contamination. This approach denies the fact that essentially it is the researcher who asks the question and determines the nature of the research. Whether the researcher is purely observer or a complete participant, descriptions come from the researcher. What this demonstrates is that both the interviewees and the researcher provide a multi-vocal joint product when research is undertaken in a participant-observation approach (Ashworth, 1995). This is a tacit acknowledgement of the intersubjective nature of the Lifeworld (Hegelund, 2005). The involvement of my self assumes that I shall be active and reflexive throughout the process (Mason, 2002).

## **6.5 2 Participant-Observer Role**

The decision to be a participant-observer rather than a pure observer was not taken lightly. A major issue for me was the ethical treatment of the patient or the nurse. To act as a detached observer was unfair on those being observed by lacking the human interaction that builds trust. This, for me, was a potential barrier to developing relationships necessary for later interviews (Hammersley & Atkinson, 1995). Neither could I accept the role of complete participant with a concealed identity because I did not want to mislead anyone, as that could be disastrous for relations and the research (Burgess, 1984, Hammersley & Atkinson, 1995). Participant-observation offered the opportunity for open and honest relationships. In addition to this it provided me with access to a blending-in with everyday activities and events and unobtrusiveness through being involved and causing minimal disruption (Burgess, 1984, Bogdewic, 1992).

Being involved in the events and activities of the unit acknowledges researcher involvement and potential researcher influence on the behaviour of individuals (Hammersley & Atkinson, 1995). However, in reality it is highly unlikely that a single observer in a unit is going to change custom, routine and practice built up over a considerable period of time (Frankenberg, 1982). My very appearance did arouse interest with numerous questions regarding the nature of the study and why their lives should be of interest. Some individuals would ask how my research was progressing and what had I found so far. My response was always truthful and stated that I didn't have enough data at that moment in time. This response deflected any further questions about findings and avoided 'on the hoof' analysis by myself or the participant.

One important concern regarding my role was the potential conflict between being a researcher and a professional nurse. The nursing professional regulatory body requires nurses to ensure patient safety, privacy and confidentiality. I was concerned that I may witness

practice deemed unsafe or inappropriate by colleagues. There was potential for conflict within myself which would undoubtedly jeopardize the research. However, it is clear for me that patient safety comes first and this would take priority over the research. Whilst I did not encounter any problems it is prudent to be prepared for possible conflict when a professional enters a familiar area of practice (Boyle, 1991). Another aspect of role conflict as a nurse researcher was the sense of kinship that is felt in practice. What this meant was there were times when I found it difficult to stand back and not become immersed in the work and forget about being a researcher. It would have been very easy to 'go native' but inappropriate for my research. I did struggle at times but managed to come to terms with the problem by dividing my time. I would participate (researching) during busy periods such as the start of treatment and use quieter periods of the day to make notes, observe from afar, or interview people. Besides, patients actively told me to stop standing around and get them on or off dialysis once I had gained their trust. I did not refuse to help when asked but by establishing this pattern of work it enabled a productive relationship between patients, nurses and my self.

Bogdewic (1992) recommends that the researcher be unobtrusive and unassuming in approach. In view of this advice wherever possible I withdrew to the periphery of the unit to observe or write field notes. I offered information about my self when questioned and refrained from offering advice. I did offer limited self-revealing information that would benefit social interaction and relationship building such as limited aspects of my family, where I lived and my obsession with running. However, there were three occasions when nurses asked my advice about educational aspects. I provided what advice I could on the basis that I felt there needed to be a reciprocal arrangement which would engender a harmonious relationship and maintenance of marginality (Hammersley & Atkinson, 1995).

In relation to level of participation I undertook the role called 'acceptable incompetence' by Lofland & Lofland (1984, p38). In this role I acted 'ignorant' of the unit and its processes. I did not know how to use the specific dialysis machines on the unit which meant I needed to

be taught by a member of staff. Whilst I knew in general how the dialysis machines worked the need for teaching meant that I could adopt a novice approach rather than take activities for granted, and access activities that required someone to describe and show them to me. The role is congruent with phenomenology whereby I was able to put in abeyance my knowledge of the situation.

I arranged to work shifts that covered different dialysis sessions and days. This approach provided access to a variety of events and activities. I initially started working on the morning shift arriving at the same time as the staff and participated in the opening of the unit and the preparation phase. These times allowed staff to teach me activities and established rapport. I also worked to put patients on dialysis and take them off as well as the preparatory in-between phases when not taking notes or interviewing. Explicit working with staff and patients was beneficial because it helped build up a strong relationship, rapport and importantly trust. I was trusted to put patients on dialysis not only by the staff but also by the patients themselves. This in itself is a sense of achievement because patients do not do this lightly. My sense of involvement and good relationships was demonstrated when staff invited me out on social occasions and on one occasion bought me a Christmas present.

### **6.5.3 Observational Data Collection Method**

In order to remain in the phenomenological orientation a phenomenological approach identified by Bruyn (1966) was used to examine satellite units. The approach provided a procedure for data collection, management, and analysis. Bruyn (1966) provided a clear structure for undertaking phenomenological observation. Bruyn's procedural rules follow that of Herbert Spiegelberg's description of phenomenological method which is a Husserlian approach (Bruyn, 1966). Bruyn's procedural rules begin with the investigation of phenomena without preconceptions of their nature. Here Bruyn is advising the observer to adopt the epoche and phenomenological reduction; to be aware of your own prejudices and their

influences upon how you intuit phenomena. Bruyn emphasises the need for the suspension of prior conceptions about phenomena to continue throughout the procedure to remain consistently phenomenological. The next stage of the procedure is to observe the phenomenon as it appears to consciousness. This means to have the phenomenon such as the satellite unit, nurse or patient directly in front of you. Naturally this acknowledges the sensuous nature of observation but does not award it any higher status than re-presentation.

The third rule is to examine phenomena for similarities, identify essential structures and relations. What Bruyn requires the observer to do here is apply the imaginative variation to the data in order to refine the phenomenon to its essential structure of appearance which is an analytical method. The fourth rule requires the observer to examine how the phenomenon presents itself. Here Bruyn asks the observer to look at modes of appearing. For example, on a satellite unit it required me to make observations at different times of the day and/or week or to observe nurses doing different activities. In this way aspects of the phenomenon can be made available to consciousness and thus help in showing how it is constituted. The final stage requires the observer to bring all these stage together to elicit meaning from the phenomena and describe it. Description and not explanation is required in order to remain phenomenological and related to the lifeworld and not theoretical. Clearly this last stage is the analytical aspect of the method and is congruent with Giorgi's data analysis method which I intend to use for this research.

It is clear from Husserl (2001) and Bruyn (1966) that the phenomenon to be observed should be directly experienceable by the researcher where ever possible. However, entering the field leads one open to an infinite amount of observational opportunities that may be overwhelming to say the least. Bruyn (1966) advises proceeding with a series of "objective standards" that remain sufficiently broad enough to function within a phenomenological orientation. These objective standards lead to adequate subjective descriptions of experience that can cross all theoretical bases such as psychology, sociology and philosophy. Objective standards are

sufficiently fundamental to observing experience and include terms like “event,” “act,” and “experience” (Bruyn, 1966). What Bruyn is identifying here is the description of form, content and organisation advocated by Snygg & Combs (1949).

**Phenomenological Observation Procedural Rules (After Bruyn, 1966)**

1. Investigate particular phenomena without definitive preconceptions of their nature
2. Observe in phenomena that which appears immediately to consciousness
3. Look for similarities in phenomena as given to consciousness; distinguish their essences and essential relations intuitively.
4. Explore how phenomena constitute themselves in consciousness while continuing to suspend prior conceptions of their nature.
5. Examine what concealed meanings may be discovered through the application of conceptions of reality.

**Table 10**

I found that Spradley’s (1980) ethnographic method provided an approach that appeared congruent with Bruyn’s phenomenological approach. Maggs-Rapport (2000) feels there are commonalities between ethnography and phenomenology. Maggs-Rapport (2000) lists the similarities as; the use of the researcher as a data collection tool; the need for a self conscious approach; use of interviews; open-ended and structured questioning; and finding meaning in narrative. Spradley’s approach aims at making explicit culture by being involved in that culture. This approach is concerned with what people do, what people say, what people make and what they use. Whilst culture is not something I aim to describe, Spradley’s objective standards provide adequate descriptors of subjective experience broad enough for the phenomenological approach. Further to this the phenomenological congruency with Spradley’s approach is that he espouses a descriptive method. Spradley requires the observer to avoid using personal knowledge, theory or particular questions but rather to ask the question ‘what is going on here?’ (Spradley, 1980, p73). Here Spradley is requiring the observer to approach the event or activity with no preconceived ideas so that what is observed

can be seen for what it is and is in essence the adoption of the phenomenological reduction. Observations are to remain descriptive and at a general level which may lead to focused observations at a later date.

Clearly one dilemma is to establish what to observe when and how. Spradley's descriptive approach was helpful because it maintained the phenomenological reduction by entering the research setting as if a new experience (and quite often it is). The starting point of what to observe was identified as Spradley's 'Grand Tour'. The grand tour is as its name suggests to be taken on a tour around and have the unit described by someone from within a unit. The grand tour is important for providing context or in phenomenological words horizon elicitation. Questions that were used in this process by the observer remained descriptive along the lines of 'what happens in this room?' and 'who is in this room?' Spradley observes that these questions lead on to 'mini tour' questions such as 'what happens at a dialysis space?' or 'what activities occur at the nurse's station?' The structure of these descriptions is supported by what Spradley calls nine dimensions of social situations (which is congruent with Bruyn's objective standards) and includes space, activity, event, object, act, actor, time, goal, and feeling which provides form, content and organisation (Spradley, 1980, p78). The nine dimensions were used as a guide to loosely structure observations whilst in the satellite unit setting.

The nine dimensions are constructed in a descriptive question matrix (see table 11). The matrix demonstrates interrelatedness such as what happened where, who was present, and in what chronological order did it occur. The matrix does not stipulate in what order to make observations but provides themes to observe. The themes are general enough not to identify any particular activity or event but it is recognised that the matrix does provide a preconceived structure that may not appear phenomenological. However, the themes offer a means of examining aspects of experience and modes of appearing. For example, in my normal natural attitude as a nephrology nurse I would enter a dialysis space focused upon

getting the patient ready for cannulation and dialysis. The descriptive (phenomenological) observation approach enabled me to identify the dialysis space (form) in the first instance followed by whom and what was present (content), in what capacity, at what time (organisation) and so on. It also enabled the description of objects and the physical unit itself which would take a background or horizontal form. What was useful about this approach is that it allowed me to access behaviour I would have normally taken for granted such as preparing a dialysis machine for the next patient.

One objective standard that Spradley (1980) does not include but remains phenomenologically important is known as a “sign.” Husserl finds “signs” as phenomenologically important because of their fundamental meaning. Signs or “signitive” acts are acts of meaning, sense-giving factors attached to expressions (Husserl, 2001). Signs of expression of meaning must have a communicative relation to another human. A sign can be a physical object that is bestowed with communicative meaning which may be universal or context related such as a set of scales in a dialysis unit signifies fluid balance measurement. A signitive object is known for what it is because it is given in its intentional intuition (Husserl, 2001). This means we know what an object means because of our experiencing of it is found in context; in its horizon. Signitive acts can be verbal expressions or a recognition of relationships between aspects and parts such as found in sequences of behaviour. Therefore the sign is an important objective standard for finding meaning and relatedness in experience. In view of this I decided to add signitive acts and signs to the dimensions I had adopted from Spradley’s as a guide to observation.

## **6.6 Participant-Observation Method**

All observations were made into notebooks as near the time of occurrence as possible. The content of these observations were descriptions of mundane activities and events, verbatim comments and discussions, personal reflections and feelings, and memos to my self. No

attempt was made to analyse the observations. All notes were made with a date and time attached to them.

Observation began by agreeing a start date with the nurse in charge of the unit. There was no problem with this and it amounted to me informing the unit when I would begin and what days I would be present. I had one day per week to undertake observation. As to which day was appropriate was left fluid due to personal work commitments and importantly to enable access to different patient groups and nurses. Satellite units are open for treatment on six days each week. The day the unit is closed is either Saturday or Sunday. Unit one and two were closed on a Saturday and unit three was closed on a Sunday. I was unable to attend weekend dialysis sessions due to personal home commitments which may have limited the adequacy of the findings. However, in order to overcome this limitation I attended dialysis sessions which covered the same patient groups during the week. This was possible because patients were allocated to a dialysis time slot or session. Dialysis sessions were on alternate days such as Monday, Wednesday and Friday morning or afternoon, and Tuesday, Thursday and Saturday (or Sunday) morning or afternoon. For example a patient may be allocated to dialyse on the morning of Monday, Wednesday and Friday. Access to patients who dialyse at the weekend was undertaken by attending on Tuesday or Thursday. In order to maximise adequacy through exposure to patients and staff, I organised to attend at least once every day (Monday to Friday) over the total observation period. All three satellite units opened at 7 am and closed 8pm. When at a unit I attended for a full day (7am-8pm) in order to cover a complete experience for that day. There were variations in these times for example at unit one I found certain members of staff turned up earlier or would leave later. Consequently I found that sometimes I needed to arrive earlier and leave later in order to cover these variations.

Observations occurred at two ways. Firstly there were observations made from a distance. What this means is that I was not involved in the event or activity being observed. These opportunities often allowed me to write running commentaries of what was happening as they

happened. I was often able to sit at a convenient but unobtrusive vantage point to make notes as I observed. These observations were 'real time' observations. The second level of observations followed my involvement in acts, activities or events on the unit. At a convenient time on the unit or later at home I would write my observations maintaining a descriptive method. My notes also included a section of my own personal experience and reflections related to each day of attendance. I was aware that occasionally I was visible during making notes by both patients and staff. Visibility meant I was open to questioning or comments. I frequently received humorous comments from individuals such as 'make a note of this' and 'did you see that?' and 'can you write down that the nursing staff are wicked towards us'. I was also aware that I may be altering behaviour such as patients acting in a particular way when I was around. However, my close involvement with dialysis activities, regular attendance and familiarity appeared to militate against such behaviour.

When I was involved in activities with staff and patients I initially adopted the role of a novice as mentioned earlier. This allowed me to employ a naïve attitude and ask very simple and basic questions about objects, events, and activities such as why certain activities occurred at certain times and what happens next. Whilst in reality I was familiar with the dialysis machines I pleaded ignorance so that I could have nurses describe the machine and the various functions and activities to me whilst showing me how to use them. The novice approach also worked with patients in that they were happy to help and divulge what they knew to someone who appeared to know little. The method enabled practical application of the phenomenological reduction. This approach was beneficial but it is of limited value, in some instances, because staff and patients expected me to know certain things after being told or shown a number of times. This is a key practical point because as I soon found out participants begin to question my ability to continue if I remained completely naïve in certain circumstances such as cannulating a fistula. I also did not pursue descriptions of objects or events once I felt I had an adequate amount of aspects covered. For example a thorough description of a dialysis station in one dialysis space was pretty much the same as another in

the same unit though differences in activities and events were noted. In instances such as this differences were identified like the absence of a television or nearness to the nursing station.

### 6.6.1 Spaces

My observations were structured around the objective standards mentioned earlier by Spradley (1980) and Bruyn (1966). I began with observing spaces in the unit. A space is a physical place such as the satellite unit where actors, objects and activities occur. I observed spaces from my perspective and also from those who used them such as patients and staff. This is where “grand tour” and “mini tour” exercises helped. These exercises provided me with their descriptions as well as relationships between spaces, objects, actors, and activities. For example, in unit one I identified the patient waiting area as multifunctional. It wasn’t just the patient waiting area it was also where patient transport drivers waited; where staff held their breaks and had meetings; and where the Christmas party was focused. Interview alone may miss information or aspects of activities within spaces. The full range of spaces I observed is listed below.

<b>Observed Spaces on Dialysis Satellite Units</b>	
Entrance to the unit	Spaces outside the unit
Car parking	Corridors
Patient waiting areas	Nurse’s Station
Dialysis treatment rooms	Dialysis stations
Sister’s office	Staff rooms
Patient changing area	Staff changing areas
Kitchens	Clinical rooms
Toilets	Technician’s rooms
Dialysis machine preparation rooms	Sluice rooms
Patient examination rooms	Store rooms
Water treatment rooms	Cupboards

Please note that left and right sides of the examples are listed and are not meant to indicate any relationship.

**Table 11**

### 6.6.2 Objects

Objects are physical things that are present in spaces. Objects were described in the space they were found and what activities they were associated with. Objects were described for the spaces listed above where they were situated. For example, there were objects found in the

dialysis space such as the dialysis machine, treatment chair, buckets, nurse call buttons, television, headphones, blankets, and pillows to name a few. Each object was involved in some form of activity whether it was treatment orientated or patient comfort or safety. Some objects were permanent features like the nurse's station, other objects were semi-permanent like dialysis machines which could be move if needed, and others were transient such as the refreshments trolley.

Objects and the activities they were involved in were described in observation notes. The list of objects was extensive but easily linked to spaces and activities. For example a simple object like a bucket would be found in a dialysis space next to a machine for use during preparation and cessation of treatment. The same bucket may also be found in the sluice where it is emptied and cleaned before being returned to the dialysis station. The weighing scales could be found in different rooms in different units. In unit one and two it was situated in the main dialysis room whereas in unit three it was situated in the patient waiting area. What appears a trivial observation had an impact upon activities as was found in unit three where all patients immediately weighed themselves when they arrived and waited for admission to the treatment room. In unit one and two the patients had to wait until admission to the treatment area which then meant congestion around the scales and delay getting on to treatment. There was an instance where an object, that is, the nurse's station is also a space. The nurse's station as an object is a physical thing such as a desk or table (as in unit two) but it is also a space where nurses congregate to undertake certain activities.

The following example describes an object which, in this case, is a dialysis machine from unit one.

*The dialysis machine is relatively slim and moveable when a brake is released. All wires and pipes exit the machine from its rear and enter their respective inlets and plugs on the wall behind the patient's chair. These include dialysis solution inlets, effluent outlets, and electricity supply. The machines are a pale cream colour and stand about five feet high. They have an array of buttons, flashing lights, pumps and nozzles. The machine has the current electronic visual display in green and others in orange and red. There areas of measurement and monitoring that have labels such as venous pressure, transmembrane pressure, and conductivity. All appear meaningless unless the observer/user understands their purpose and meaning. In the main the*

*machines function relatively quietly with silent movement of the blood pump and silent flickering of lights on the display. The blood tubing shudders from time to time in relation to the movement of the blood pump. Occasionally the machine emits an alarm and stops pumping the blood. This alarm alerts a member of staff to immediately attend to a problem identified by the machine. (Code 2, Code 260)*

### **Example of Objects Observed on the Dialysis Satellite Units**

#### **Dialysis Space**

Dialysis machines (SP)	Blood tubing (T)
Artificial kidney (T)	Treatment chair (SP)
Needles (T)	Dialysis packs (T)
Clamps (SP)	Buckets (SP)
Angle poise lights (P)	Television (P)
TV remote control (P)	Nurse-call button (P)
Adjustable table (SP)	Pillows (T)
Blankets (T)	Sheets (T)
Books & magazines (T)	Radio (P, T)
CD player (T)	DVD player (T)
Curtains (SP)	Oxygen supply point (P)
Emergency call button (P)	Fluid pipes (P)
Electrical sockets (P)	Personal electric fan (T)
Newspaper (T)	Clothes (T)
Pens/pencils (T)	Dialysis prescription sheet (T)
Saline replacement fluid (T)	Vomit bowls (T)
Cups (T)	Food & drink (T)
Kermode (T)	Urine bottle (T)
Blood specimen bottles (T)	Trolleys (T)
Plastic apron (T)	Washbasin (P)

*P: Permanent, SP: Semi-permanent, T: Transient*

Please note that left and right sides of the examples are listed and are not meant to indicate any relationship.

### **Table 12**

#### **6.6.3 Events**

An event is a set of related activities that people carry out. These are easily identifiable by their content of acts and activities that occur at given times or situations. For example, the very nature of dialysis and its activities meant that there was manifest repetition and routine such as machine preparation time, “putting on” time and “taking off” time. There were also spontaneous events such as patient hypotensive episodes, events of patient bleeding, and visitors to the unit. Events that included patients and nurses had a mirror image structure to them. For example, a dialysis preparation event meant that nurses undertook a certain collection of activities like machine preparation and patients undertook a different set of

activities such as personal comfort and chair preparation. However these activities often converged at given points in order for the next activity or event to occur such as cannulation of vascular access followed dialysis preparation. Events could occur independently, sequentially or simultaneously. For example, the Intradialysis event included food events or patient hypotensive events. A description of an event is provided in the example below.

**A hypotensive episode**

*One patient asks for a nurse’s assistance stating that she feels unwell. Two nurses attend to her. One nurse lowers the back rest to make the patient lie flat. The other nurse applied a blood pressure cuff and measured the blood pressure. She also attended to the machine and reduced the ultrafiltration pressure. The patient stated she felt sick and was ‘all sweaty’. She apologised profusely for being a nuisance and showing herself up. One nurse spoke to her and stated that she was not a nuisance and that she was not showing herself up. A vomit bowl was brought just in case. The two attending nurses discussed their options. They maintained a presence at the patient’s side. They asked about any other symptoms such as chest pain to which the patient concurred. The staff members changed their disposition and became more serious in manner and actions. A decision was made to terminate dialysis. One nurse phoned the A&E department to inform them that they were bringing the patient over. The patient became more apologetic for being “a nuisance” and wished she had not said anything.*

*The event changed the mood of the unit for a while. The atmosphere became quieter and ‘serious’ with much less discussion and the staff getting on with work in a quieter manner. The unit returned to its light-heartedness by the time lunchtime came around which coincided with taking off time. (Code 128)*

<b>Example of Events Occurring on Dialysis Satellite Units</b>	
Unit opening and closing	Dialysis preparation
Cannulation	Intradialysis time
“ Putting on”	“Taking off” event
Hypotensive (“Going off”)	Food events
Patient transport	Christmas
Patient admission	Emergency events
Unacceptable patient behaviour	Medication events
Unit visitors	Patient treatment withdrawal
Staff shortage	Cleaning
New patients	New staff
A distressed patient	

Please note that left and right sides of the examples are listed and are not meant to indicate any relationship.

**Table 13**

**6.6.4 Acts & Activities**

An act is a single action that a person performs and activities are a set of related acts that people do. Acts and activities provide the contents of events such as the act of act of laying a sheet on a dialysis chair is part of the activity of preparing the patient treatment space which

is part of the dialysis preparation event. When undertaking observations in this nature I found the necessity to observe activities frequently in order to be able to describe the range of acts and activities. The observation of activities amounted to a deconstruction or reconstruction process by identifying individual acts and how these linked to others to make activities. Observation identified a large number of acts that were subsumed in activities. This also meant that acts and activities were naturally thematic; they belonged and as such provided meaning. An example of an activity and the acts it contained can be found below. Activities were wide spread and included the following: dialysis commencement; dialysis cessation; preparation; cannulation; food and drink; humour; communication; time management; nurse-patient sharing activities; nurse's station; cleaning; technical; safety; Christmas; hypotensive episode; entertainment; and comfort. Below are examples of an act and an activity. The first is of an act undertaken by a nurse prior to cannulation. The second example demonstrates an interaction activity between two female patients and a nurse sharing experience.

Act

*The nurse observes the patient's fistula for signs of 'sucking' [jargon for where the pump sucks the blood vessel wall thus occluding the needle] or 'blowing' [jargon for a collection of blood under the skin due to punctured blood vessel]. (Code 7)*

Activity

*One patient brought her wedding photos in. the wedding was a long time ago. The patient was keen to share in the experience with the staff and comments on clothes. The staff made comments of interest such as 'look at the clothes' and 'you looked lovely', and took time to look at the pictures. There was also referral to another patient who had also brought in some pictures and that she had a mini dress on. (Code 26)*

<b>An Example of Activity: Hypotensive Episode (“Going off”) Activity (Acts)</b>	
Attend the patient	Communication act
Blood pressure measurement	Lay the patient flat
Touch the patient	Speak reassurance
Provide a vomit bowl	Turn off ultrafiltration pressure
Infuse saline	Act of waiting
Mouthwash	Provide tissues
Turn on ultrafiltration pressure	Recommence treatment
Terminate treatment	Observe from a distance
Reassess fluid loss	Clean any mess

Please note that left and right sides of the examples are listed and are not meant to indicate any relationship.

**Table 14**

### 6.6.5 Goals and Feelings

Goals identify what people were trying to accomplish during the activities and events. Feelings identify the emotions people were feeling at the time of activities. These observations were made during activities and interaction with patients and staff. Often these observations were made evident by actors themselves such as a patient explaining that he brought himself “in for dialysis so that he can finish quicker and get home sooner because he disliked dialysis.” Other times it required that I asked what was going on such as the instance when a patient was withdrawing from dialysis. The staff wanted to continue to provide the care as long as they could because they felt they had a good relationship with him and his family. They also felt that if they could provide continuity of care, the patient was ‘their’ patient whom they felt was important. The example below explains why a nurse (from unit 3) feels she provides the goal of good quality of care through the use of time:

*You do have more time with them that is probably why the quality of care is....it is probably what you can pick up with the time. Every day we sit with them and ask them what’s new or a problem. We just chat to them but they usually come out with something that is quite important. That is probably why the care is good, not just the care that is given is different; it’s not. It is because we can talk to the patients more and listen. (Code 384).*

### 6.6.6 Time

Time relates to the sequencing of events and activities over a time period. Time is one of the fundamental relational standard objectives cited by Bruyn. Time links all activities (e.g. cannulation) and events (e.g. putting on) often providing meaning only at specific times. For example in the previous section the nurse explains that she feels she can provide good quality care only because she perceives more time is available. Hence when the nurse undertakes this activity it fits into a time frame of many events and activities such as after medication has been dispensed but before staff break time. In this way she feels she has time for patients and this has significant meaning of personal satisfaction. Time also related to the routine of the unit’s activities as well as signitive acts and behaviours. Time was observed in terms of clock-time (what happened at what time and how long it took) and temporally (how people acted

over time). Temporal observations allowed the construction of patterns through related events, acts and activities.

### **6.6.7 Signs & Signitive Acts**

As stated previously signs are acts, expressions or objects that indicate related meaningfulness. My immediate concern is the potential on my part to place my meanings onto signs or identify signs where they may not be present. These would be acts of careless interpretation something which I am to abstain from in my investigation. Therefore I observed events, acts, activities and actors to identify signs or signitive acts that demonstrated meaningful relationships. For example, I identified a signitive act performed by patients that involved the patient adopting a seated posture with their vascular access arm out stretched upon completion of their dialysis preparation. This seated posture signified a readiness to commence treatment. Nurses would state that the patient was “ready” for cannulation (or “needling” to use their terminology) and patients would complain that they had been “ready” in this position for a while and it was their turn now. These descriptions of experience by the actors provided their meaning to a signitive act that did not require my interpretation. The seated posture meant something; readiness to commence.

There were many visible and audible signs within a dialysis satellite unit. There were mechanical signs such as those the dialysis machine produces, nurse call alarms and door bells. The dialysis machine was a significant producer of mechanical signs. It produced audible signs such as alarms and visible flashing lights to attract attention of the nursing staff because there may be a problem. Signs or signitive acts could be more subtle than an alarm and may manifest itself in an activity, an act, event or expression. Signs or signitive acts heralded the beginning or end of an event or set of activities. An obvious example would be the sign of a patient expressing that they felt dizzy. The signitive act of expression of dizziness meant altered activities of nurses who would attend the patient and assume

treatment for a hypotensive episode. It is important to state that a signitive act or sign is not a cause of behaviour change but rather it meant something to the interpreter of it. For example, I noticed nurses would look around the unit towards the end of the putting on event and given that no patient was waiting to commence treatment they would undertake a new set of activities. The sign of all patients on dialysis, or about to, meant a change in activities such as food and drink or medication dispensation activities.

Events and activities acted as signs that had meaning and would see a change in behaviour. For example, in the case offered above relating to the hypotensive episode event and provided again below it can be seen that there are signitive acts that indicates a change in the unit atmosphere.

*.....The two attending nurses discussed their options. They maintained a presence at the patient's side. They asked about any other symptoms such as chest pain to which the patient concurred. The staff members changed their disposition and became more serious in manner and actions. A decision was made to terminate dialysis. One nurse phoned the A&E department to inform them that they were bringing the patient over. The patient became more apologetic for being "a nuisance" and wished she had not said anything.*

*The event changed the mood of the unit for a while. The atmosphere became quieter and 'serious' with much less discussion and the staff getting on with work in a quieter manner. The unit returned to its relaxed atmosphere by the time lunchtime came around which coincided with taking off time. (Code 128)*

Clearly the patient's condition required a change in attitude and management by the staff. This change in attitude and patient management signified something different from the normal; seriousness. This seriousness has meaning which is recognised by those present (including other patients) with an alteration in the way they went about things. It was also noted that another event (taking off) provided another sign that there could be a return to the usual activities.

Signs could be located temporally in that they orientated to time. This was also important because it was meaningful. An example of a temporal signitive act was identified with the early morning opening of the dialysis treatment room door for patients. The treatment room

door opening occurred at a given time and only when it was open at that time did it mean that patients could enter. If the door opened before the given time patients had to be beckoned in by staff or else they asked if it was okay to enter. Signitive acts play an important role in intuition by providing fulfilled meaning intentions. By this it means what is intended displays its meaning clearly (Husserl, 2001).

<b>Examples of Signs &amp; Signitive Acts</b>	
<b><i>Mechanical/Objects</i></b>	
Dialysis machine alarms	Dialysis machine lights
Telephones	Door bell
Door bell	
<b><i>Expressions</i></b>	
Dizziness	Illness expressions
Humour	
<b><i>Acts</i></b>	
Ready position	Treatment room door opening
Patient wearing headphones	Sleeping patient
<b><i>Temporal</i></b>	
Refreshments	Event changes
Deliveries to the unit	

Please note that left and right sides of the examples are listed and are not meant to indicate any relationship.

**Table 15**

### **6.6.8 Actors**

Actors are those people who are involved in the activities and events that occur in the dialysis satellite unit. Actors include mainly nurses and patients but less frequently they include doctors, relatives, dialysis machine technicians, domestic cleaning staff, portering staff, drivers, and hospital maintenance staff.

### **6.6.9 Sensuous Intuition: The Visual**

It was undoubtedly helpful to be present in the units but I could not be present all the time. Having the unit visually presented to me enabled me to be sensitive to the context and I was concerned to sustain this impression. I decided that one way of keeping my observation of objects, acts and activities visible was to take photographs (with consent). Photographs were

used to capture spaces, objects and activities. I used a digital camera that had a quiet mechanism that would be audibly unobtrusive. Photographs offer a mediated visualization a kind of detached involvement. I also recognised they must be used with caution. A photograph is visual, not verbal and is not passively received by the viewer (Schwartz, 1989). Photographs trigger actively constructed meaning and can be polysemic (Schwartz, 1989). In view of this I felt it important that they were used sparingly and illustratively. When I took photographs I described the context and reason for taking them to keep them connected. Therefore when I used photographs they were to be used as visual reminder of the phenomenon and a visual illustration of the thing itself. The use in the presentation of findings is there to provide a visual 'snap shot' representation of the thing. It aims to make the thing present. I use photographs with caution aware that the observer may place their own interpretations upon them. In view of they will have context information with them.

## **6.7 Summary**

This chapter has explained the methods of data collection I used. There has been a deliberate attempt to use phenomenologically orientated approaches that are congruent with the research question. The interview method allowed an open-ended questioning approach that employed a structure to capture the phenomenon in context and its meaning. The interview method provided an aspect of experience for individuals that are reflections. To add to this visible aspect and provide phenomenal adequacy participant-observation was used. The participant-observation approach was phenomenological and structured around what Bruyn calls "objective standards" which are broad categories of human experience. The combined methods allowed depth of experience to be made explicit. Rather than relying upon one dimension (a description of reflected experience) the approach offered an additional sensuous dimension; a lightening of shaded aspects. The multi-method approach is not about proving what participants say but about adding context to meaning in order to provide an adequate description of experience.

The data collection method explicitly applies key phenomenological concepts identified in the previous chapter which includes the phenomenological reduction and epoche (focus upon the participant's experience and upon the satellite unit), lifeworld (context elicitation and description), identity as manifold (multiple interviews and observations to provide different aspects ), wholes and parts (experiences and parts of experiences), horizontilization (same attention to oral and visual data collection), imaginative variation (clarification of phenomenon questioning), and adequacy (multiple interviews and observations). The data collection method sustains a descriptive approach including the descriptions of participant's interpretations for it to remain in the descriptive phenomenological orientation. The data collection method has demonstrated methodological and philosophical consistency with descriptive phenomenology. The next section will show the analysis of the collected data that culminates in a descriptive account of dialysis satellite units. The analysis will continue in the phenomenological approach adopted for this research and continue methodological consistency.

<u>SPACE</u>	<u>SPACE</u> Can you describe in detail all places?	<u>OBJECT</u> What are all the ways space is organised by objects?	<u>ACT</u> What are all the ways space is organised by acts	<u>ACTIVITY</u> What are all the ways space is organised by activities?	<u>EVENT</u> What are all the ways space is organised by events?	<u>TIME</u> What spatial changes occur over time?	<u>ACTOR</u> What are all the ways space is used by actors?	<u>GOAL</u> What are all the ways space is related to goals?	<u>FEELING</u> What places are associated with feelings?
<u>OBJECT</u>	Where are objects located?	Can you describe in detail all the objects?	What are all the ways objects are used in acts?	What are all the ways objects are used in activities?	What are all the ways objects are used in events?	How are objects used at different times?	What are all the ways objects are used by actors?	How are objects used in seeking goals?	What are all the ways objects evoke feelings?
<u>ACT</u>	Where do acts occur?	How do acts incorporate the use of objects?	Can you describe in detail all the acts?	How are acts part of activities?	How are acts part of events?	How do acts vary over time?	What are the ways acts are performed by actors?	What are all the ways acts are related to goals?	What are all the ways acts are linked to feelings?
<u>ACTIVITY</u>	What are all the places activities occur?	What are all the ways activities incorporate objects?	What are all the ways activities involve acts?	Can you describe in detail all the activities?	What are all the ways activities are parts of events?	How do activities vary at different times?	What are all the ways activities involve actors?	What are all the ways activities involve goals?	How do activities involve feelings?
<u>EVENT</u>	What are all the places events occur?	What are all the ways events incorporate objects?	What are all the ways events incorporate acts?	What are all the ways events incorporate activities?	Can you describe in detail all the events?	How do events occur over time? Is there any sequencing?	How do events involve the various actors?	How are events related to goals?	How do events evoke feelings?
<u>TIME</u>	Where do time periods occur?	What are all the ways time affects objects?	How do acts fall into time periods?	How do activities fall into time periods?	How do events fall into time periods?	Can you describe in detail all the time periods?	When are all the times actors are "on stage"?	How are all goals related to time periods?	When are feelings evoked?
<u>ACTOR</u>	Where do actors place themselves?	What are all the ways actors use objects?	What are all the ways actors use acts?	How are actors involved in activities?	How are actors involved in events?	How do actors change over time or at different times?	Can you describe in detail all the actors?	Which actors are linked to which goals?	What are the feelings experienced by actors?
<u>GOAL</u>	Where are goals sought and achieved?	What are all the ways goals involve objects?	What are all the ways goals involve acts?	What activities are goal seeking or linked to goals?	What are all the events are linked to goals?	Which goals are scheduled for which times?	How do the various goals affect the various actors?	Can you describe in detail all the goals?	What are all the ways goals evoke feelings?
<u>FEELING</u>	Where do the various feeling states occur?	What feelings lead to the use of what objects?	What are all the ways feelings affect acts?	What are all the ways feelings affect activities?	What are all the ways feelings affect events?	How are feelings related to various time periods?	What are all the ways feelings involve actors?	What are the ways feelings influence goals?	Can you describe in detail all feelings?

Table 16: Descriptive Observation Matrix

**Space:** The physical place or places

**Actor:** the people involved

**Activity:** a set of related acts people do

**Object:** the physical things that are present

**Event:** a set of related activities that people carry out

**Time:** the sequencing that takes place over time

**Goal:** the things people are trying to accomplish

**Feeling:** the emotions felt and expressed

**Act:** single actions that people do

(Spradley, 1980)

# **Chapter Seven**

## **Data Analysis**

## **7.0 Analysis of Data**

In the last chapter I outlined the method of data collection. I explained the method of interviewing grounded in Seidman's strategy and Husserl's (descriptive) phenomenology. I also explained my observational method which utilised "objective standards" (such as acts and activities) derived from Spradley's ethnographic approach and Bruyn's phenomenological observation approach. In this chapter I will explain how the data were analysed in the phenomenological orientation to sustain consistency and trustworthiness. I will show how Giorgi's descriptive phenomenological method was used as a guide to analysis of interview data. I will also show how observational data were analysed in a phenomenological orientation. Following this there will be a discussion about how the two types of data were combined to provide one overall description of experience.

### **7.1 Managing the Data**

All tape recordings were transcribed by me. The reason for this was due to previous experience during my MSc, where listening to taped interviews would mentally transport me back to the event. This mental placement helped me keep the feel of the context as I transcribed. It also meant that I had control of the process to ensure that the same method was used throughout. Transcriptions usually occurred within a week in order to keep as close to the event as possible. I had completed nearly all transcriptions when my house was struck by lightning. The lightning strike caused all the wiring and electrical appliances to burn out including my computer. All my transcribing was lost due to hard drive failure and I hadn't been cautious enough to make a back up. This was undoubtedly a dark moment for me because I could not face re-transcribing all the interviews. I found this particularly disheartening and could have happily stopped my PhD at that point. After a short break I regained my motivation and began transcribing again. I learned from this episode to back up my work in as many places I could and use the experience to alert colleagues of the potential for 'acts of God' (the insurance company's term).

Interviews were transcribed verbatim in order to maintain the actual way people spoke and to ensure that no change was made. This posed some challenges in trying to ensure local ways of speaking were maintained. Transcribing was difficult because people do not speak in the same grammatical way as the written word (Kvale, 1996). It was difficult to decide where to place commas or full stops and maintain coherence. The process of transcribing is in itself a form of interpretation where judgments are made on the basis of meaning from one language presentation (spoken word) to another (written word) (Kvale, 1996). A decision was made to keep the transcribing convention as simple as possible so that it could be replicated easily during the process. I made this decision in full understanding of the theoretical complexities of transcription convention, language and different approaches (Silverman, 1993, Kvale, 1996). Transcriptions are conversations that are decontextualized or abstractions of experience and therefore must be treated in a way that is mindful of the context of the research and the participants (Kvale, 1996).

Transcription was in the first instance into a Word document (Microsoft) using the following conventions:

\*I: interviewer

\*R: Respondent

..... : Pause

(.....): Missing words

(Clarification of a word or term to maintain context or coherence)

All transcripts were edited to ensure anonymity and any names cited are changed to maintain integrity. Each transcript was filed in relation to the unit where it belonged. Each participant received a copy of the interview transcript. This was undertaken in order to ensure accuracy of transcription and to allow any feedback on what was said.

Observations, reflections and memos were transcribed verbatim into separate files. Each transcribed observation was kept in a file that located it to the unit from where it was made. Dates and contexts of observations were made. Transcription in this instance was easy because it was a matter of copying the written language which was mine. Care was made not to reinterpret what was written down, though there was an occasional clarification of statements so that they made more sense. All transcriptions were made into word processed documents (Microsoft Word) and stored in a dedicated file on four separate data storage devices (two USB memory sticks and two computers).

## **7.2 The Use of QSR NVivo 2.0 for Data Management and Analysis**

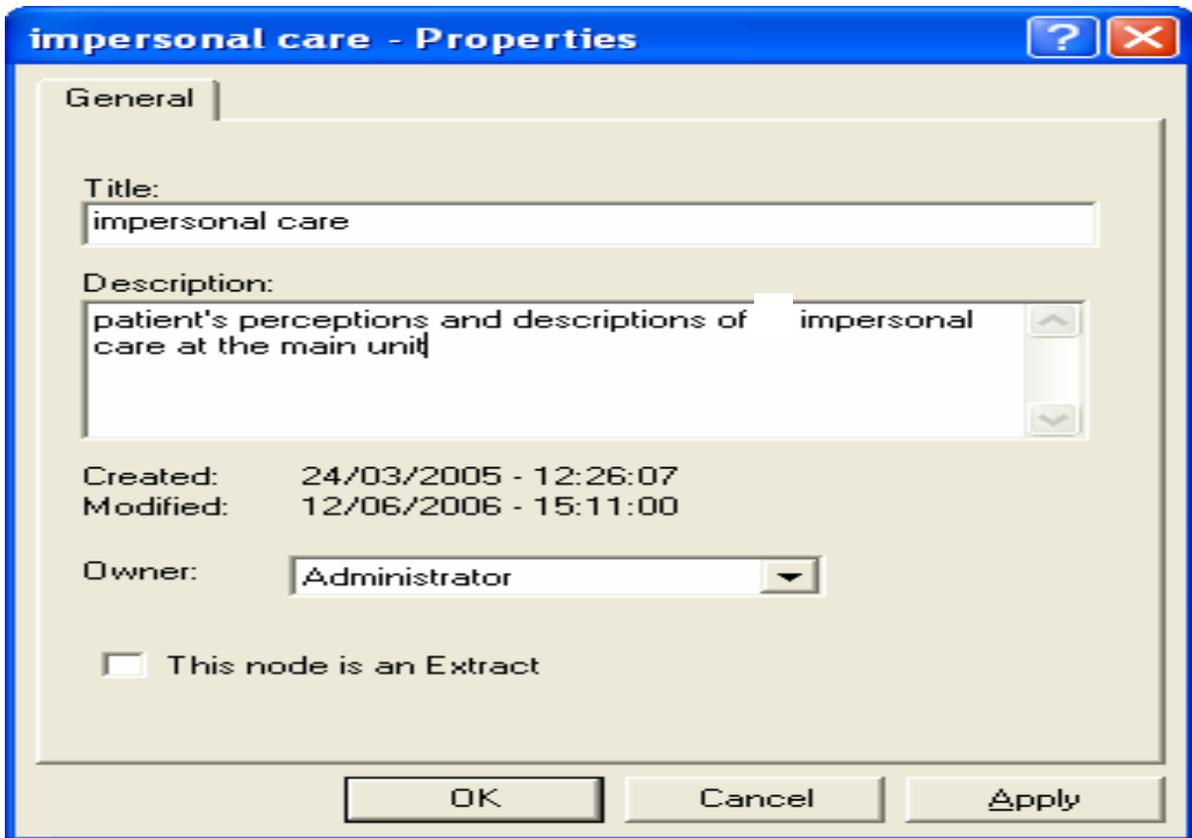
My undergraduate experience of manual management of qualitative data made me reluctant to use this method. The huge amount of data that occurs from qualitative research can be difficult to manage when confronted with piles of paper. Therefore I decided that data analysis management would be undertaken with the use of computer software designed for managing qualitative data. There is an increasing number of computer software packages for analysing qualitative data each with their own specific qualities (Dey, 1993; Coffey & Atkinson, 1996, Richards, 2005). In view of this, the preference of software is a complex choice of method. I had used software previously (The Ethnograph) and found it very useful for managing and retrieval of data; however found it limited for helping to structure ideas. I also had experience of NUD\*IST and had decided to use this for its ability to structure data. However, this software was no longer available to me but NVivo was. This software was examined in relation to its suitability for data structuring which I found to be appropriate. NVivo allowed visible multiple coding and modelling which helped demonstrate links between meaning units. One of the benefits of using computer assisted qualitative data analysis is that it enables the handling of large amounts of data. This in turn allowed for the potential of larger sample sizes, though this is not necessarily one of the main

criterion for qualitative sampling. The projected sample I aimed for meant a large amount of data would be produced that needed to be managed.

I was mindful of the fact that the use of computers was not a substitute for careful thinking and actual analysis. The importance of this issue was not to become over-reliant upon the technology and to keep in touch with the data itself (Miles & Huberman, 1994; Gibbs, 2002). NVivo has a tendency towards grounded theory in its method for handling data; though it has sufficient flexibility for phenomenological method (Gibbs, 2002). This is an important issue because it is a matter of underlying personal philosophy about qualitative research. I do not lean towards a 'purist' orientation whereby computers are seen to be taking over the very essence of qualitative analysis and theorising (Dey, 1993; Richards, 2005). If I was not aware of this concern then it may have meant that my analysis was potentially confined by what the computer could do. A computer programme may limit the way in which I think about data purely because of the way it is presented on screen, or by its inability to perform certain tasks. An inability to perform certain tasks may inhibit the development of creative analysis methods by being hooked into a mechanistic approach: the code and retrieve approach (Dey 1993; Gibbs, 2002). There may also be the possibility of analysing data that should not be analysed in the systematic manner provided by the computer. This mechanistic approach may also allow the manipulation of data in such a way that there is detachment from its source; a loss of grounding. However, I agree with Gibbs (2002) when he states the meanings of texts are not understood by computers; meaning requires the researcher to interpret the data. The computer does not decide what portions of text to code and how to attribute codes and description to the text. NVivo has the benefit of being able to retrieve chunks of coded text that is highlighted but nested in its context.

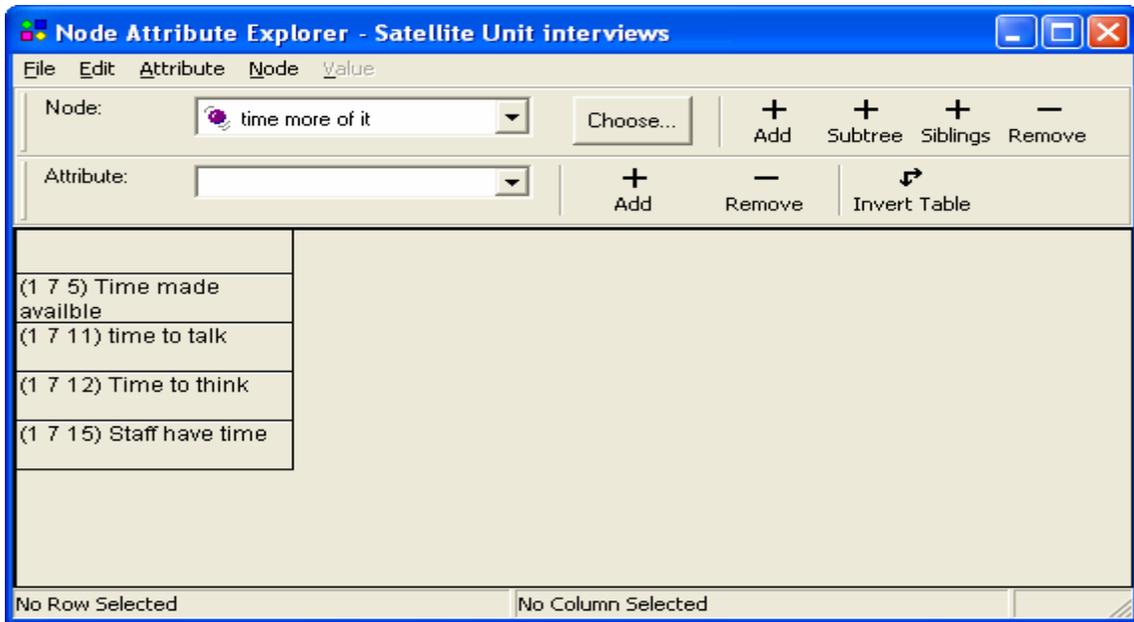
Though NVivo offered much there were times when I had to revert to physical piles of paper. I found reading from a computer screen for too long caused me to have headaches and was tiresome to my eyes. I also found the physical piles of paper easy to read, add notes and comments to, and reorganize where necessary. I found there was something more tangible about piles of paper spread about the floor that helped see relationships.

Word documents were converted into rich text format for use with NVivo and saved in an NVivo project I constructed. This allowed immediate access rather than the need to move between programmes. NVivo was useful because it allowed the indexing of data into lists which made retrieval easier. These lists were initially based on interviews but as analysis proceeded additional lists were added. Indexing were lists of nodes, groups of linked nodes and structured groups that constituted key themes. NVivo allowed the moving, swapping, linking, and building of data. Codes were constructed using NVivo by the reading of text. Chunks, portions or meaning units of text that were significant for the description of experience were identified and coded. For example, during the examination of observed data I came upon my description of a nurse assessing a patient's vascular access, this was coded as *Act- access assessment*. All codes had words attached to them that described what was occurring. Each code also had a definition attached to it that described what was meant by the descriptor. The image below taken from my NVivo "free node" index provides an example of a code with a description of what it means.



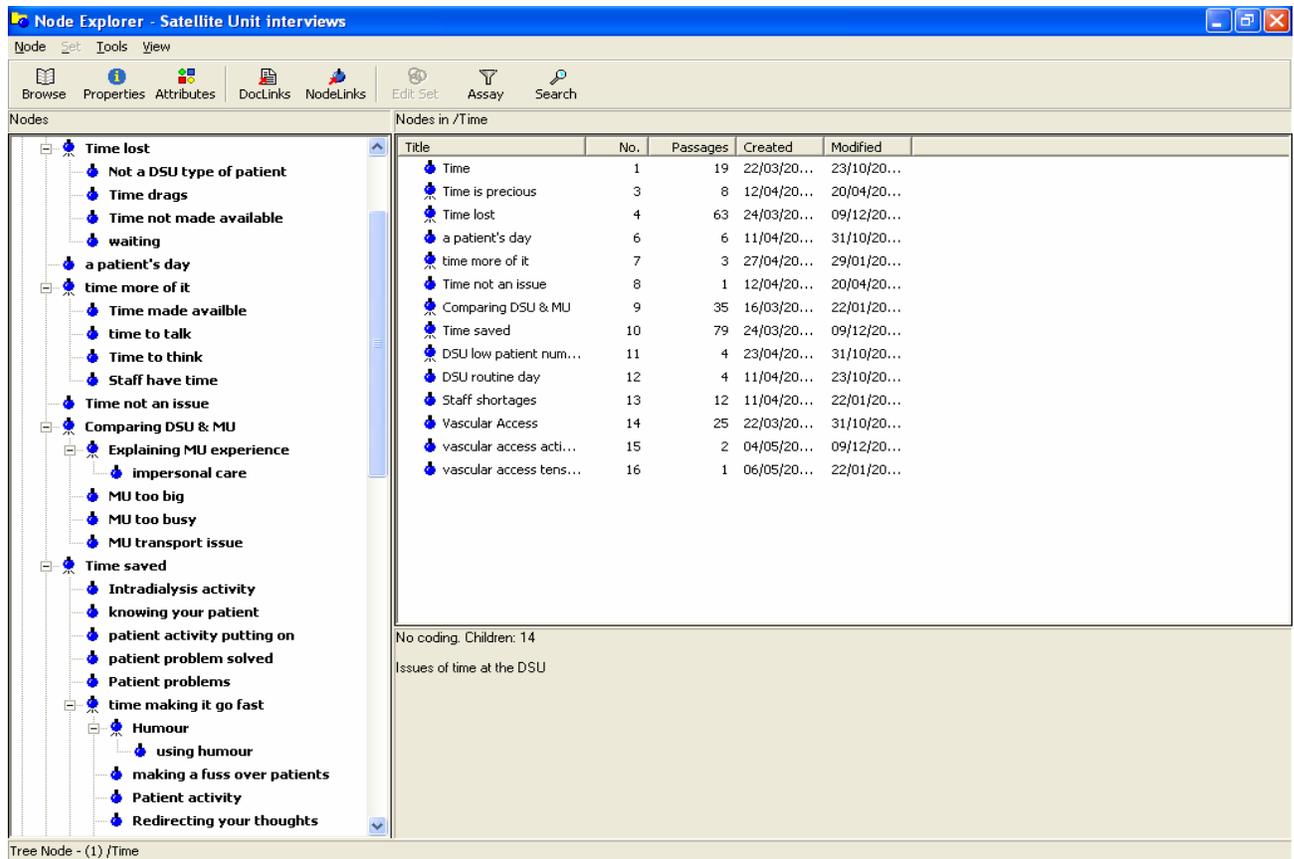
**Figure 1: Example of a code and its descriptor**

Following initial coding of data, analysis brought about linking of meaning units to construct initial themes for further analysis. These linked codes were either subsumed under single codes or descriptor themes (general meaning units). Codes were constructed to house related meaning units or codes. The image below demonstrates the meaning units (codes) attributed to a theme named *Time: more of it*. Each of the meaning units in this theme describes examples of patients' experience of having more time.



**Figure 2: Example of an initial theme with attributed codes**

Further analysis of the data saw the merging of related themes (or general meaning units) to provide a theme that had multiple aspects of appearing. Relationships were made on the basis of their appearing and grounding found in the original text. For example, issues relation to time as described by participants such as those of nurses' or patients' and observations were linked together as shown in the example below.



**Figure 3: The above image demonstrates the relationships that developed during analysis to construct themes (general structures of meaning).**

Themes (general structures of meaning) were analysed to consider their relation to other themes and to retain a sense of the experience of the participants. An example of ‘modelled’ relationships can be found at the end of this chapter (Page 215). These general structures of meaning were examined to produce a description of experience that is called a categorial intuition.

### 7.3 Data Analysis

A data analysis method was identified in advance of the research as that described by Giorgi (1985). Giorgi’s method is a process of data reduction and transformation into general essential structures of experience (Giorgi, 1985, Giorgi, 1989, Giorgi, 1996, Giorgi & Giorgi, 2003, Kvale 1996). The process requires the researcher to maintain the phenomenological reduction and epoche throughout the analysis in a sustained manner, as previously discussed in the chapter

regarding phenomenological method. Here, I reflected upon my knowledge and experience about dialysis and renal failure and made explicit areas of interest that may be influential in my thinking about the data. Examples of areas of interest that I put in abeyance (phenomenological reduction) included those identified in the literature review such as stress, coping, quality of life, depression as well as themes such as health promotion, therapeutic relationships and nursing theory. I also put in abeyance my knowledge and experience of renal care which included specific diseases, dialysis techniques, and illness management such as bone disease and anaemia. In addition to this I also suspended my feelings and beliefs in what I thought about satellite units, their patients and the staff, of which some were colleagues. I also found that as the research progressed areas of knowledge that I took for granted emerged into my awareness (such as my beliefs related to the main units and my own views on how techniques should be undertaken) required me to add these to my growing list. On a practical basis there was a great deal to suspend which may have proven difficult to remember. I found that I needed to make reminder comments of my thoughts in my observation recording book. I would read through these comments and refresh my phenomenological attitude before entering the unit and prior to any interview as well as during data analysis. I quickly realised that a proactive self-critical attitude was needed in order to keep myself focused. This meant reflecting upon how experiences and objects were presented. For example, in my natural attitude as a dialysis nurse the focus of my attention would be upon things that would enable the treatment to progress such as vascular access patency, machine preparedness or patient physical symptoms. By examining my natural attitude I was able to look at the activities and experiences of dialysis in a way unencumbered by this particular way of seeing treatment. What occurred was an opening up that allowed me to see, for example, the activities patients undertook in preparation for dialysis in order to make their time appear to pass quicker.

Naturally, I was not able to put my interests completely aside but their presence alerted me to slippage in to natural attitude. I found that natural attitude slippage would be a sudden realisation. For example during a coding session I found my self using the term ‘stress’ to describe patient experience which was very annoying but a salient reminder. It seemed so natural to apply these terms and at first sight did not seem out of place. However, I realised that I had to return to the transcript and re-read it in order to ensure that phenomenological reduction was maintained. I found that I had to question my notes and coding frequently just to satisfy my anxiety for not placing my established knowledge on the transcriptions. It was time consuming but nonetheless rewarding.

### **7.3.1 Data Reduction: Developing Meaning Units**

Prior to commencing data analysis and reduction the researcher must treat all data equally through a process called horizontilization. Horizontilization means that no data has precedence over another and there is no hierarchical structure to it. This includes interview and observation data. Data reduction is a method of data simplification or abstraction where key meaning is located and extracted from the main transcript (Miles & Huberman, 1994). Reduction does not mean that data is stripped from context but reduced into manageable chunks. The decision to undertake data reduction only occurred after transcripts were read in full to gain a sense of the experience (Giorgi, 1985).

All original interview transcriptions were read through and analysed individually to maintain their sense of individuality, context and linear connection (Giorgi & Giorgi, 2003). Reading a transcript to gain a sense of experience appeared easy but I found the desire to start looking for patterns and themes and leap immediately ahead was strong. Any immediate themes or patterns were noted and added to my list of possible influential factors.

Once a transcript had been read and a sense of experience was noted the next stage of analysis commenced. This step is Giorgi's data reduction from original description to a 'meaning unit' (Giorgi, 1985). A meaning unit is a constituent of the whole sense of experience and is context laden (Giorgi, 1985). A meaning unit is also a correlate of experience of what the person believed happened and what it meant, and is not taken as an objective truth (Giorgi, 1985). However, should a section of transcript be independent of context then it is, in Giorgi's terms, an element. In phenomenological terms this is a piece of the whole. Deciding what counts as a meaning unit was based upon identifying an extract from a transcript that appears to demonstrate some form of meaning related to the phenomenon. A meaning unit does not exist independently except in the phenomenological attitude of the researcher. In this instance it was I who decided that certain words, sentences or paragraphs held meaning. The identification of a meaning unit is not an arbitrary decision rather it is a process of thinking about what is being said or presented (Giorgi, 1985). A meaning unit presents the original experience in concise manner that retains context but is written in the third person. This step is a linear movement towards providing general descriptive statements; it is abstracting the personal to the general. When undertaking this process I was mindful of the movement away from the original transcript and endeavoured to maintain context. This reductive process is analytical that required a judgement of what is meaningful and remains within the phenomenological reduction.

### **7.3.2 General Descriptive Units and Provisional Thematic Structures**

Meaning units were read and examined for structures of experience. Structures were identified as those aspects of experience that appeared to matter to the meaning unit and make sense. Once structures were identified they were made explicit in generalised form and called general description units. A general description unit is a description of experience in a condensed meaningful but non-individualized form. General description units must still capture experience and context. This process was repeated with all transcripts. All general description units were

then examined and provisional thematic structures identified. Provisional thematic structures are the merging of general description units to produce a fuller picture of experience. They are called provisional because at this stage their independent status is tentative and may disappear later in the analysis process. This is not a process of looking to fill in any gaps of experience but the placing together of units that produce aspects that make a collective synthesis of a unity of experience. It is possible that aspects of experience are missing. However, complete descriptions are not what are being sought here rather general descriptions of structures of experience.

### **List of Provisional Thematic Structures**

- Illness
- Time saved
- Nursing experience of dialysis satellite unit
- Patient experience of dialysis satellite unit
- Problem solving
- Community
- Communication
- Humour
- Feeling safe
- Relaxing
- Main unit experience
- Certainty
- Taking off activities & events
- Putting on activities & events
- During dialysis activities & events
- Patients feel 'cared for'
- Imaginative variation themes

### **7.3.3 Crisis of Representation**

At this point of the analysis I became worried about being able to demonstrate the horizontal movement between descriptions from individuals and an overall general structure. I had what Mason (2002) calls a crisis of representation regarding my end description and initial data and how they held together. I wondered how I could show the link explicitly in some tangible way rather than subsumed through a series of abstractions. I used the provisional thematic structures as templates to return back along the linear process to original transcripts. This process was a matter

of thematic expansion by returning to original texts, via meaning units, to code original meaning statements relevant to the provisional thematic structure. Examples of interview imaginative variation process were also coded for application to the general structure. These were to be used later in the analysis for adequacy.

This process was repeated for every transcript. I was aware that it was counter to Giorgi's method however I felt that too much qualitative research has to be accepted at face value and with my internal crisis I felt a 'belt and braces' approach necessary, at least for my peace of mind. Coding was descriptive in that the identified extract was given a title that described its contents (See appendix 4 for a full code list).

Once the coding was undertaken it was assigned to their respective provisional thematic structures. NVivo was very useful in managing data and the coding of transcripts. I was able to assign coded meaning extracts to provisional thematic structures and then demonstrate the complexity of this in diagrammatical form (see diagram of 'Time Saved' below).

#### **7.3.4 Clarification of Structures: Imaginative Variation**

Structures were clarified by applying imaginative variation method. Taking examples from the interviews as invariant structures the provisional thematic structures were analysed as to their adequacy. For example, patients often mentioned the low numbers of patients at satellite units as important. The notion of low patient numbers was applied to the structures by asking questions such as 'if there were more patients what would that do to the structure?' in this instance, for example, by adding more patients the unit would get busier, there would be more people to get to know, there would be more to do for the staff, there may be more delay getting on and off dialysis and ultimately time would be lost. A list of invariants taken from the interviews and applied in imaginative variation is listed below.

### **List of Imaginative Invariants Derived from Interviews**

- Small unit/large unit
- Fewer patients/more patients
- Presence/absence of doctors
- Peacefulness
- Being listened to
- Quick on & off dialysis
- Ill people
- Being able to relax
- Personal
- Know each other
- Responsibility
- Nearness

Throughout the analytical process it was evident there were no clear borders between thematic structures. What this represented was the complexity of satellite unit experience and the relationships between structures. It was clear that provisional thematic structures could not remain static because of much overlapping and that they should inform the overall description of experience. The next stage was to provide a description of a general structure of (verbal) experience of a satellite unit. General description units that made up provisional thematic structures were re-read to get a sense of the experience. Following this, general thematic structures were described by linking provisional structures to experience taking into account overlapping and similarity. This process is not a matter of subsuming provisional themes but more about using them in a horizontal manner to provide general structures or an act of constitution (Husserl, 2001). For example, whilst the general structure 'Feeling Safe' has the same title as a provisional theme it provided a salient description but included the provisional theme along with themes such as community, certainty and relaxed.

General thematic structures are those where a sense of experience and context is sustained but provide a description of a particular experience such as 'Time' or 'Illness'. General thematic structures are complex and in Husserl's view should demonstrate constitution. However, at this

stage of analysis these general thematic structures have limited adequacy because of reliance upon interview data alone. Constitution is the phenomenological term used to explain how things constitute themselves to our consciousness; in other words how a thing is 'crystallized' to provide meaning.

#### **7.3.4 Analysis of Observed Data**

The analysis of observations follows the phenomenological method by firstly remaining in the epoche. By this I mean that I refrained from using theory or knowledge to make descriptions. However, as already stated in the data collection methods chapter, it is recognised that some form of organisation has already been forced upon the data by accepting Spradley's (1980) dimensions of social situations and Husserl's "signitive acts" as a structure for observation. These dimensions are congruent with Bruyn's (1966) "objective standards" which are descriptors such as 'events' or 'activities' that are broad enough not to dictate what kind of event or activity. What these dimensions do is enable the description of form, content and organisation of the observed.

The analysis began by reading through observation field notes from each unit in turn. These notes were then transcribed into a textual format in a word processor programme (Microsoft Word). Each of the transcriptions was filed under each unit number for initial ease of retrieval. Each transcript was re-read and then indexing codes were applied based upon the structure of observation stated above. This means that observational field notes data were placed into the following categories: spaces, objects, goals, actors, acts, activities, events, time, feeling, and signitive acts. For example, an observation of a specific act was coded firstly as an act, then an additional descriptor added to discriminate it from other acts such as *act-attach artificial kidney*. Each category was examined independently as an aspect of experience and then similarities were identified to distinguish essential structures of experience. The coded data were added to the index list of codes which was essentially a list of unrelated descriptors. Descriptors were applied

to codes (as described earlier in this chapter) with a statement of definition. Each code was retrievable with its original context still intact so as not to lose its grounded relationship.

Notation about spaces was read and examined in terms of what they constituted. This meant textured (e.g. rooms, colours, shapes, sounds) aspects that demonstrated similarity and variance between spaces from each unit were described. Here I found many similarities which became essential spatial structures. Spaces were also identified as spatial horizons in which the lifeworld is played out. Whilst some units had more spaces than others the essential spatial structures were as follows:

Waiting space	Storeroom
Weighing space	Kitchen
Dialysis treatment space	Sluice
Nurse's station	Sister's Office
Preparation space	Technician's room
Toilets/changing room	Water treatment area

There were a few spaces that did appear but not on each unit such as a clinical room and an identified isolation space for suspected infection (unit 3) and were deemed not essential for a general structure. This is not to say that these areas were not important, but they were not found in each unit. What these spaces identified was variation for possible activities but demonstrated no additional activities from those found in the other units. All of the spaces identified above represent areas where activities and events occur that are important to the satellite unit lifeworld. Spaces could be actual rooms with their own textures like walls, ceilings and objects (such as the sister's office or storerooms), or they could be an area within a larger space or room where specific activities occur. A typical example of a space within a space would be attributed to the nurse's station which was often located in a central region of the dialysis treatment space. These spaces within spaces could have well defined boundaries where boundary limits could be defined

by the objects within; such as in a dialysis station with a machine, a chair and screening curtains. Alternatively, they had no clearly defined boundary but were areas where an activity occurred or an object could be found. These spaces may also be defined by objects such as a table, chairs and a computer found at the nurse's station space or the weighing scales.

Each space was analysed for things within them. This included objects such as a dialysis machine and chairs, and actors such as nurses and patients. For example, a dialysis station space has objects such as the dialysis machine, dialysis patient's chair, table, television and remote control, nurse call button and so on. The actors who could be found in this area were mainly patients and nurses but also included doctors, technicians, maintenance staff, other health care professionals such as dieticians, and cleaning staff. Each group of actors could be found in spaces depending upon their activity or event. For example nurses had global involvement in a dialysis station, whereas a patient would be limited to the chair, TV, table, comfort objects, and limited intentional machine activity such as machine placement.

The analysis of spaces and objects was linked to acts, activities and events. To use the example of the space 'dialysis station', it was here that nursing clinical acts, activities, and events occurred such as blood pressure measurement during the activity of patient assessment that occurred during the "putting on" event. Hence the dialysis station had a clinical focus (e.g. doing things to or with patients or by proxy through the dialysis machine), whereas the nurse's station had predominantly administrative activities such as writing notes or using the computer. These acts, activities, time, goals, signitive acts and events were analysed in relation to the range of their contents. This is not unlike Spradley's (1980) taxonomic analysis where an identified item subsumes other items that have relationships. For example, communicative activity would have information giving acts, sharing acts (where staff and patients shared personal information about each other), attention seeking acts, helping acts, and humorous acts.

The range of contents shows relationships between groups of acts, activities and so on. The next stage was to make explicit the relationships so that the phenomenon would begin to make a fuller picture. In a phenomenological sense this is a move from parts (both independent and non-independent) and moments towards the whole. The example provided below demonstrates how coded observations of objects, acts and activities were clustered together through relationships. It has to be noted that it would be absurd to take these acts and activities out of context; their relationship is context bound and indeed the context is responsible for acts or activities. For example, the object chair is present (for the patient for dialysis) and has the function of allowing the patient to lie down, which is what the nurse does to the patient when s/he is “going off”. This cluster is a subgroup for a larger theme of “going off”.

**Activity- “going off” Nurse**

*Object dialysis station-chair:* present and involved related to *Activity helping:* the nurse helps the patient to lie down

*Act- vomit bowl for patient:* in case the patient vomits during going off is related to *Doing care for the patients:* such as washing the patient (as defined by the nurse)

*Object-dialysis machine:* present and involved is related to *Nurse dialysis machine activity:* what the nurse does to the machine which is related to *Activity-dialysis monitoring:* monitoring the machine during the episode.

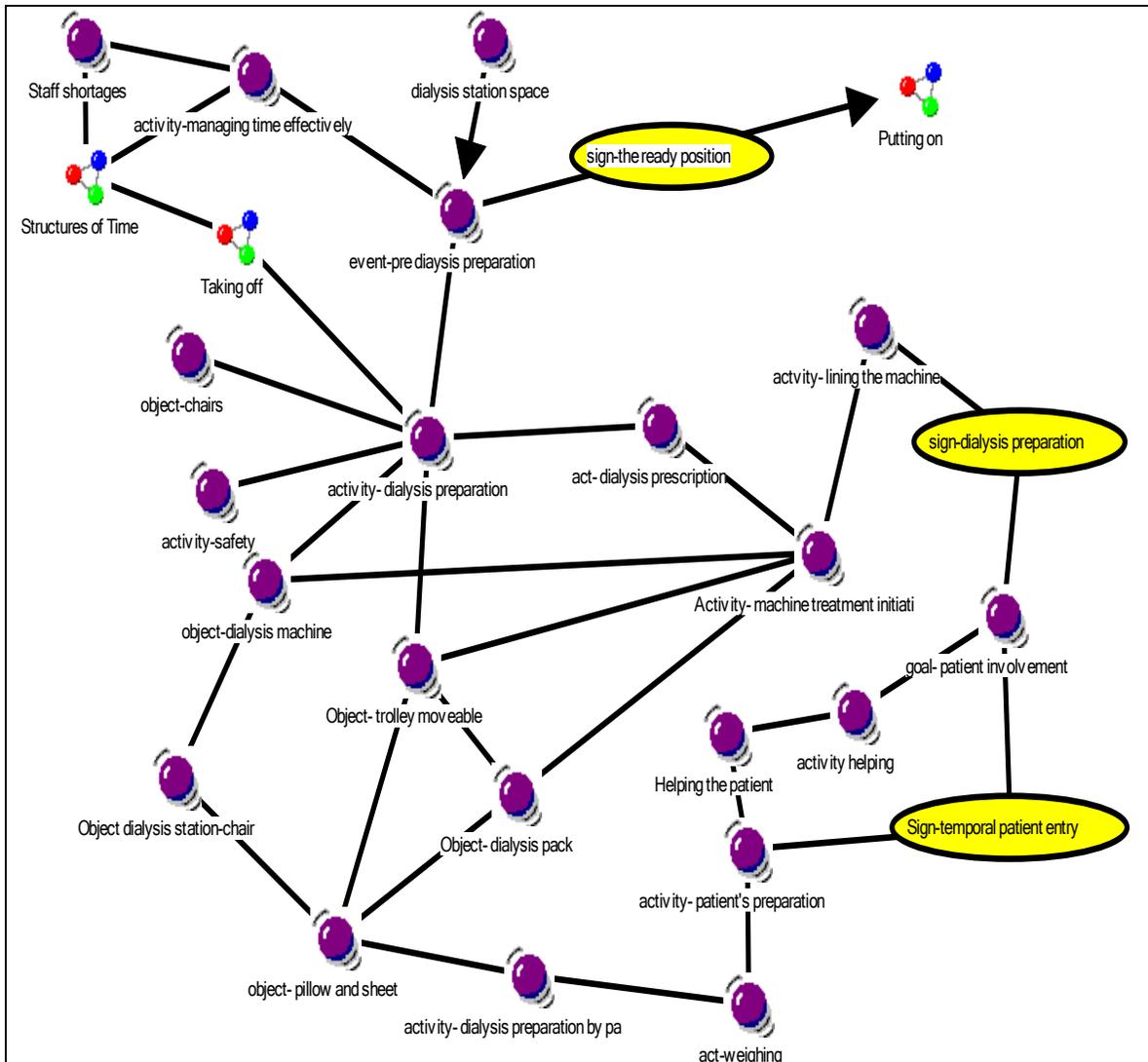
*Safety activity:* what the nurse does to make sure the patient is safe from harm is related to *Activity-assessment:* assessment for improvement or worsening and each of the above groupings

Descriptive themes of activity are constructed on the basis of these analyses. To use the “going off” activity example cited above the following sample description is formed from the nursing activity:

*During a “going off” event a nurse undertakes a number of activities which have the goal of returning to patient to a stable condition. A nurse will behave in a speedy manner during this event. A nurse will assess the patient by undertaking blood pressure measurement and questioning the patient how s/he feels. A decision is made to lay the patient flat for air way safety. A nurse assesses the dialysis machine and makes an alteration to the treatment to enable the patient to recover. An infusion of intravenous*

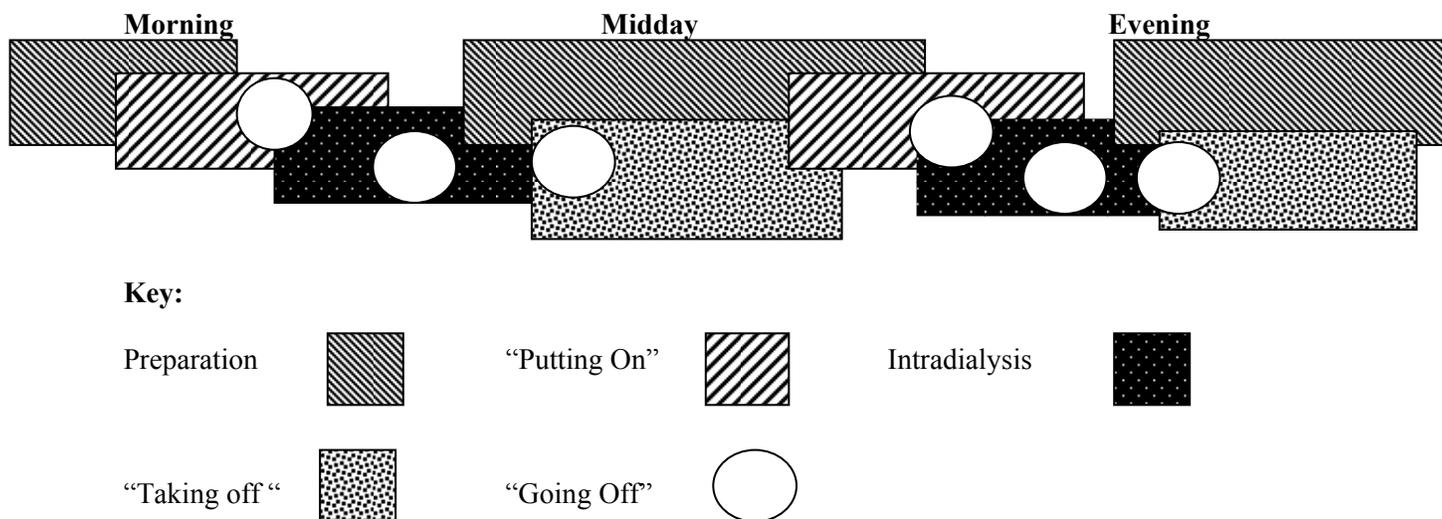
*fluid is undertaken by the nurse via a drip fed directly into the blood tubes on the dialysis machine. Blood pressure measurements are undertaken as a monitoring activity to assess the patient's condition. A nurse will make reassuring statements to the patient and attend for as long as s/he considers necessary.*

It is worth mentioning here, that just because an act or activity is a subgroup it by no means indicates a hierarchical structure but rather a clustering of closely related observations with the same level of importance (horizontalization). Another example can be seen in the activity of preparing for dialysis where there are parallel patient and nurse activities. In this instance a nurse performs machine preparation activity whilst the patient prepares the dialysis chair for comfort. These activities may overlap whereby a nurse may prepare the chair for a patient or a patient may open a dialysis pack for the nurse in readiness. To continue with this example, nurse activities and patient activities converge to make a preparation event which occurs in a time frame and is orientated towards the goal of initiating treatment, or in local jargon “putting on”. I had decided to adopt local jargon words for some aspects because they appeared universal to all units studied, and because it maintained a strong relationship to the original context. A visual example is provided below (figure 4) in the ‘modelled’ image of the preparation event. This modelling was enabled by NVivo to show relationships in a visually explicit way. It allowed for coded data to be moved around until relationships are made that relate distinctly to the context and retain their coherence and meaning. Modelling also enabled a non-hierarchical presentation which is important for a phenomenological perspective of horizontalization.



**Figure 4 Diagram showing the relationship and overlap between acts, activities, events, signitive acts etc. and relationships to other themes for dialysis preparation from an observational data perspective.**

The analysis also identified that these acts, activities etc. were clustered at specific times to produce a coherent picture in the following general structural themes: Preparation, "Putting on", Intradialysis, "Taking off", and "Going off". These general themes of activity were repeated throughout the day starting and finishing with preparation. The diagram below provides a visual demonstration of the overlapping relationship between the general themes of activity experience that occur in a 24 hour period. This overlapping relationship occurs in a cyclical manner repeating each day.



**Figure 5** Diagram showing the overlapping relationship between general themes of activity experience

Each of these general themes of activity experience involved a whole range of different activities and the like. There were occasions when acts or activities were difficult to place. One example was the act of the nurse sitting with the patient. The difficulty was with the act itself. Taken as a simple performance act it could be categorized as such. However, this act occurred at different times and at different events or activities. Therefore ‘sitting with the patient’ had to be contextualised for it to make sense because it could be found in conjunction with other activities such as providing information, sharing, or helping. It was important to retain the context of meaning and be careful not to interpret this in some manner such as a nursing theoretical concept of caring. Sitting with the patient could easily be construed in this way such as a caring being an act of closeness but that would be slippage into natural attitude. Therefore these acts, activities etc. had to remain context bound with no interpretation placed upon them. At this stage there emerged a descriptive account of general structures of activity experience. Meaning could only be attributed to these activities and events when both data sets are merged.

The list below is an example of the content of the theme “Taking Off” with its theme number (12) and the sub-themes e.g. (12 1)

### “Taking Off”

(12 1) act-information giving (12 2) activity helping (12 3) activity- patient cleans chair (12 4) activity-dialysis discontinuation (12 5) activity-humour (12 6) activity-managing time effectively (12 9) activity sharing (12 11) Dialysis event taking off (12 12) Dialysis object (12 13) dialysis station space (12 14) act- attending to the patient (12 15) event- taking off (12 16) goal- patient involvement (12 17) goal-taking off (12 18) Object- dialysis pack (12 19) Object dialysis station-chair (12 20) object- pillow and sheet (12 21) Object- trolley moveable (12 22) object- weighing scales (12 23) object-chairs (12 24) object-dialysis machine (12 25) sign-taking off time (12 26) space-weighing area (12 27) vascular access activity (12 28) Dialysis activity taking off 2 (12 29) Dialysis event taking off 2 (12 30) act- providing information

### **List of content of Taking Off**

### **A Summary of the Data Analysis Process for Observed Data**

1. Field notes were transcribed via word processor and transferred into NVivo .
2. Coding and indexing (via NVivo) into “Objective Standards” categories: Actors, Acts, Activities, Events, Objects, Goals, Time, & Signitive acts.
3. Each category of standard was analysed for its content e.g. content of acts, activities etc.
4. Examination and establishing relationships on the basis of content and clustering of activity. Descriptive themes constructed. Modelling used to produce a visual image of relationships.
5. Merging relationships into descriptive general themes of activity experience.

The list below shows the major themes prior to triangulation

(1) Time (2) Illness (3) satellite back up (4) Problem solving (5) A community (6) communication (7) Humour (8) Feeling safe (9) Relaxing (10) Main Unit Experience (11) Certainty (12) ~Taking off~ (13) patient care (14) ~going off~ (15) Nursing activity (16) Patients Feel 'Cared For' (17) Imaginative variation (18) Patient experience of DSU (19) Nursing Experience of DSU (20) Preparation (21) The intradialysis (22) Putting on (23) Patient activity

### **7.3.5 Combining Interview and Observational Data**

During the development of the research method I explored the literature regarding the merging of data. I examined Spradley's work which I thought was important considering I was using aspects of his method. However, as with much of the discussion regarding merging or combining data sets, Spradley was not clear how he discriminated between them. Different types of data did not appear to be a problem for Spradley (1980); he assumes that what is said and what is observed are of the same order and of the same phenomenon regardless of the source of the data (e.g. self reports, participant interviews etc). Indeed, Spradley used the data to build up a multidimensional picture of complex social situations rather than to address validity. Farmer, Robinson, Elliott and Eyles (2006, p 377) hit the nail on the head when they state "there is little direction in this literature (*about triangulation*), however, regarding the nature and shape that this analytical process should take." They are also critical of authors such as Risjord, Moloney and Dunbar (2001) who comment on triangulation with a preoccupation with philosophical debate, but fail to explore or explain the practicalities of application. I concur with this view in that such authors appeared concerned with epistemology or the need for the collection of rich and contextualized data, which is undoubtedly important, but do not add to the techniques. Triangulation is a term often used to describe the process of data analysis. Interestingly this is a term derived from navigational language which compares several measurements of a geographical area for more

accurate mapping. Other words have also been offered to explain the combining of data sets such as integration, merging and interpolation. Interpolation is a word that may be used to explain the uniting of data sets, but this is an unsatisfactory term because it is a mathematical term. What interpolation means is to estimate values from known ones in the same range: it is the adding of something (Concise Oxford Dictionary, 1991). In order to do this, one must go beyond the data to suggest something. Further to this, to estimate is to approximate or more plainly put to guess. To guess is not something Husserl wanted in his method, he was looking for adequacy of description. To guess would set up another question or a hypothesis which would need to be proved or disproved, which is something that is quite possible but not the intention here. There is one further point, the use of quantitative or positivistic language to explain or describe qualitative methods is incongruous with the idea that each approach should use its own terminology to explain itself and would remain in an apophantic domain.

This research has been about appearances and experiences of a phenomenon. The study is an attempt to shed light upon aspects of a phenomenon and therefore it is a clearing of vision that is brought about by the uniting of experiences: observed and reflected. Therefore the combining of data sets in a phenomenological sense is to embody: to give form and meaning. There are two very different types of information. Both are textually presented but one is gleaned from interviews (reflection) and the other is derived from observation (intended). The objective was to give form and meaning to the verbal and the visual. The first point to consider is the nature of the phenomenon being examined. The interviews describe experience of satellite unit experience and the observations describe actors, activities, and events that occur in the same units. So, firstly I have two sets of data that relate to the same phenomenon. What each of these data sets offer is information relating to aspects of that phenomenon: they are already related.

A summary of the data combination method can be found below in table 17 . In order to embody (give form) to these two data sets I began by arranging these two sets into observational data and interview (patient and nurse). The findings of prior analyses were examined. I examined the observational data themes and then examined the interview data themes. I looked for what was said by participants about these events. I also reversed this activity by looking at what was being said by participants and seeing what this was related to in the observational data themes. This back and forth process meant that I was covering all aspects of the data. The method was not an attempt to back one type of evidence up with another but to use the data to give form.

There were opportunities to identify links between experience and observation where clear relationships existed. It also meant the opportunity to identify aspects that were unique or atypical. They were unique in that they may have been stated but nothing similar was found in the observed data themes (and vice versa). These unique data aspects did not detract from the analysis it just meant that particular aspects of the phenomenon were not developed in as full a form as others. One example was found where two patients acknowledged the benefits of a satellite unit, but would have preferred to stay at the main unit. That particular experience stood out against the majority of patients who preferred the satellite unit to the main unit. It was unique and offered an aspect that was not fully illuminated.

<b>Stage</b>	<b>Analysis Activity</b>
1. Arranging	Findings arranged into observed and interviews (patient, nurse) data. Contents of arrangement examined for themes
2. Complimentarity	Findings are examined and compared to each other. Themes are examined for complimentarity (relationships). Unique situations identified and included
3. Variation & Invariation	Themes are examined for variation and invariation to identify general structures.
4. Fullness	Findings examined to develop a full description of experience.

**Table 17: Summary of Process for Giving Form (Triangulation) to Data**

It was important to examine the data with no sense of hierarchy (horizontalization) between them. The reason for this was to ensure that no one set of data excessively influenced the overall description. What follows is an example of methodological triangulation used in the analysis. The patient related meaning unit from unit 2 is found in the theme “Feeling Safe” and the sub-theme of “Control.” This meaning unit is also linked to the theme “Being Known”. The meaning unit describes a patient’s explanation on how she felt more in control of her situation at the satellite unit. The meaning unit is used to maintain a sense of context.

At the satellite unit A gets to know information about her treatment in detail, such as blood results and effectiveness of treatment. A finds this gives her a sense of control and allows her to manage aspects of care such as dietary regulation.

Examination of observation themes identified a relationship to the theme “intradialysis activity”. This theme has an activity sub-theme of “Activity-Nurse intradialysis” which includes “Nurse-patient –interaction” which involves “activity-communication” where observation coded data called “Staff providing information to patient” is nested. The example below provides evidence of the kind of coded data of nurses providing information. It also demonstrates the importance of information giving activity that is context bound.

The sister spent 30 minutes sitting with a patient and talking about an operation he was to undergo. She listened and clarified issues. She explained what was involved, where he would go and what to expect. She offered reassurance about not losing his dialysis slot at the satellite unit and that it would be here upon his return. This appeared to please him. The sister gave him her full attention during this period apart from one interruption by the HCA.

There is a relationship between the feeling of control and receiving information that appears to enable a sense of control. This kind of relationship is complimentary to each other; they show complex activities and interactions. The provision of information that means control to the patient is complimented by the following sample of data. This sample is taken from the theme “Time, more of it” and is an extract from an interview from a nurse and is situated in the sub-theme of “time made available”. The extract links the patient experience, the observation and the nursing experience through an orientation to time.

You do have more time with them that is probably why the quality of care is...it is probably what you can pick up with the time. Every day we sit with them and ask them what's new or a problem. We just chat to them but they usually come out with something that is quite important. That is probably why the care is good, not just the care that is given is different (*to the main unit*); it's not. It is because we can talk to the patients more .and listen.

In this instance the nurse identifies that they have more time with patients that allows issues to be recognized and discussed. The themes that these samples are taken from provide a basis for describing experience. In this instance, the relationship between nurses describing the allocation of time to be with patients can be linked with the observation of a nursing activity of spending time to provide information, which links with the meaning unit of the patient experience of feeling in control. The aim in this example would be to describe this relationship, as it is presented, in a manner that captures the context and meaning that a satellite unit affords staff more time to inform patients about their care. This is a patient experience of control over treatment; something not experienced in the main unit. It is also a description of nursing activity that occurs in a satellite unit which in turn enables a sense of control. This is a demonstration of the process that is on a horizontal level but was undertaken throughout. As the analysis continued, more relationships emerged and a fuller description of experience was developed.

I refrained from interpreting the findings into abstract concepts and remained grounded in the phenomenon in front of me. Invariants and variants of experience were identified to provide a general structure. Variant (atypical) structures were identified and acknowledged as important but held to one side as an incomplete aspect. For example one variant was found with the voicing of a need for medical staff to be present by two patients and one member of staff. The presence of medical staff was described as a reassuring aspect for the nurse and patients. Because this was not a common experience it was thus deemed a variant. However, it did not mean that it was less important and would be suitable question for further study. It is included in the description of experience to highlight a divergence in contrast to convergence.

These relationships began to show a form that constitutes experience. These experiences provide a fuller description of satellite unit lifeworld. The multiple relationships between the verbal and the visual provide multidimensional aspects. From a phenomenological perspective this is known as a categorial intuition. A categorial intuition is where something appears as actual or self-given; a sense of fullness (Husserl, 2001). Categorial intuitions are acts where the object of consciousness cannot be grasped all at once (Levinas, 1995). Categorial intuitions are related to sensuous acts such as those undertaken during observation. Their manner of appearance is determined by this relationship to the sensuous and can only be shown by this relation. A categorial intuition recognises relationships, parts and wholes, the part is in the whole and its appearance is given as the whole, not the part. It is as Levinas (1995, p83) describes, a “state of affairs”, or an understanding of the thing as a whole. The analysis process saw the development of themes that leads on to a fuller sense of understanding of the “state of affairs” of the experience of the satellite dialysis unit. The satellite unit is understood as a category of experience, as a whole, and is presented as such in the findings.

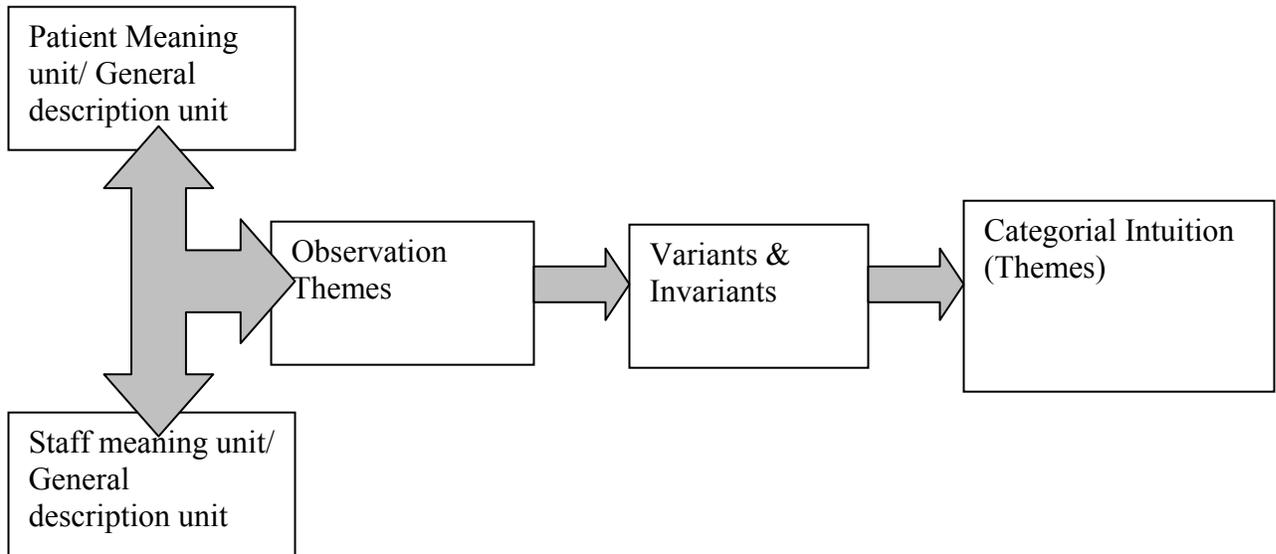
In order to present the content of categorial intuition of the experience of dialysis satellite units, general thematic structures of experience were identified. The general thematic structures provide form for content and are as follows: Experiencing Illness; Feeling Safe; Time Saved, and Freedom to Practice. General thematic structures offered a way of verbalising experience in a coherent and unified manner. Following this, copies of the general thematic structures were distributed to the satellite units for staff and patients to examine to demonstrate participant voices are being expressed. I was aware of the issue was viewed as contentious by some people (Mason, 2002, Richards, 2005). The intention of respondent validation is an attempt by researchers to be transparent and have their interpretations confirmed by those who took part. The problem with this approach it may look like a ‘quick fix’ of proof of interpretive for validation of findings (Mason, 2002). Mason goes on to argue that it cannot be assumed that the respondent holds the

same epistemological standpoint as the researcher, and if they do how can a researcher demonstrate this? Giorgi (1992) also highlights this point, though from an external examiner perspective, that it is difficult for an external person to come to the same interpretation without undertaking phenomenological reduction and having all the evidence available for scrutiny. The problem with these arguments is that it denies a reader the ability to interpret what they see and identify if it has a sense of fullness, coherence and truth. It does not mean that an apophantic approach to judgement needs to be adopted, but neither does one have to compare the findings. It is for the respondents to see if what I produced makes sense of their world.

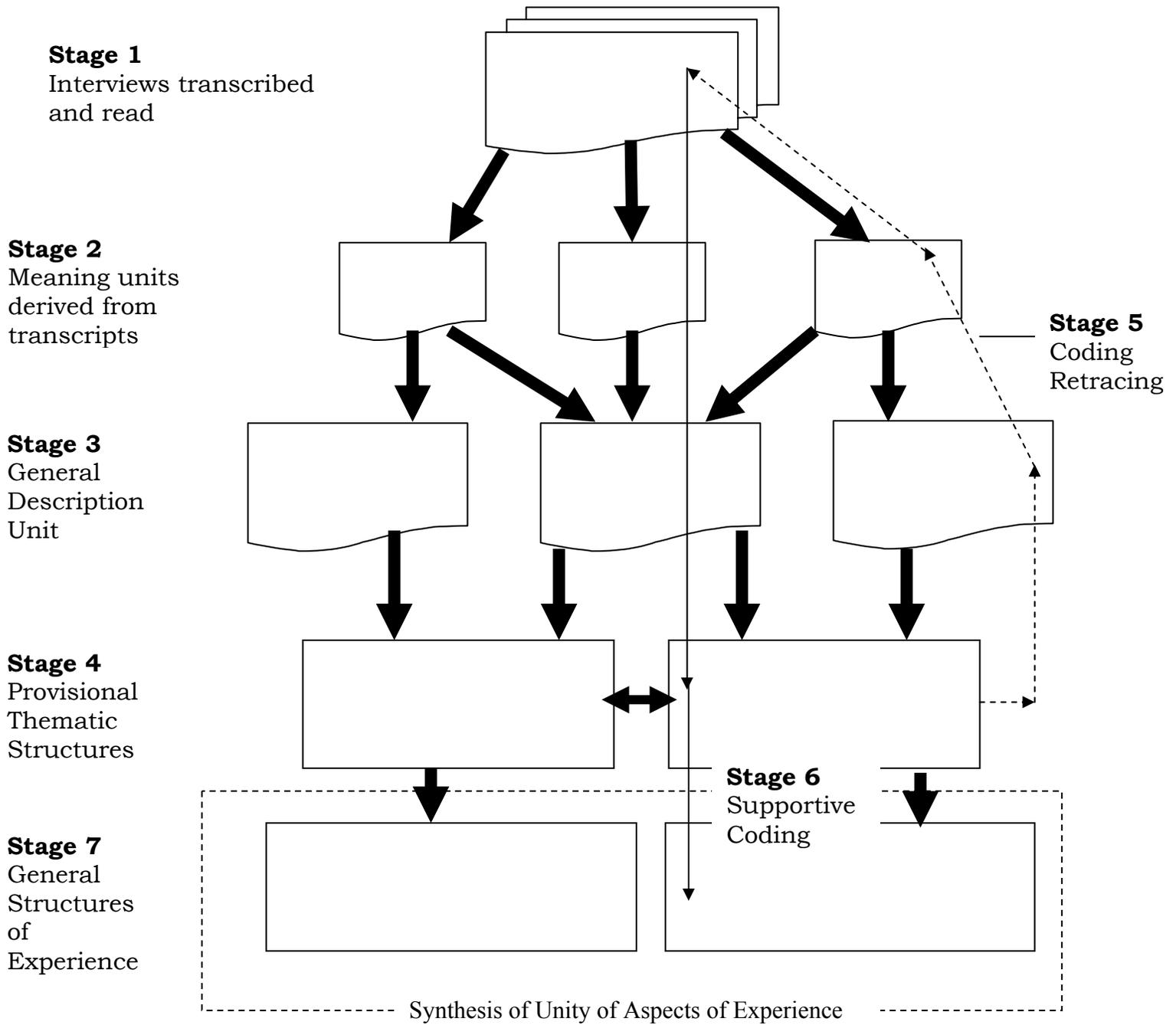
My rationale for returning to the units was to provide feedback to those involved as to what I had produced as a sharing process. I always felt a strong sense of reciprocation between myself and the nurses and patients. I felt I had a moral responsibility to these people to show them what I had produced and offer them the opportunity to comment upon it. Time was provided to allow for feedback which was positive and supportive when it occurred. The feedback was positive but naturally unit members identified specifics that were relevant to their own unit and not mentioned in the structures. However when I explained the purpose of the research they were happy to accept the description of general structures and felt it to be accurate. I was grateful for their honest and supportive feedback. An example of an email responding to the general structures from a staff member can found in appendix.

In summary this chapter has outlined the methods for analysing both interview and observation data and how they were combined to provide form and content. The analysis shows the complexity of multi-method approach but also adds depth to findings. Findings from the data analysis are presented in the next chapter. They are presented in a way as to show form of that lifeworld with its aspects of horizon, activities and experience.

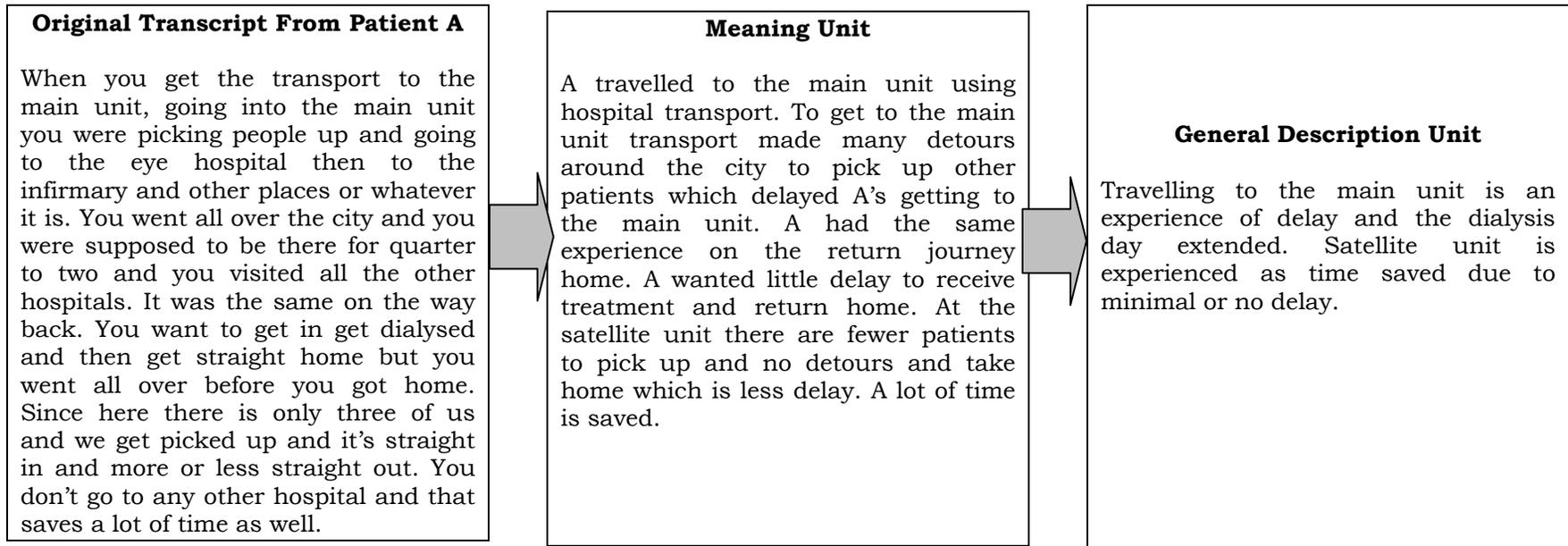
**Figure 6: Diagrammatic Representation of the Combining of Data sets: Data Embodiment**



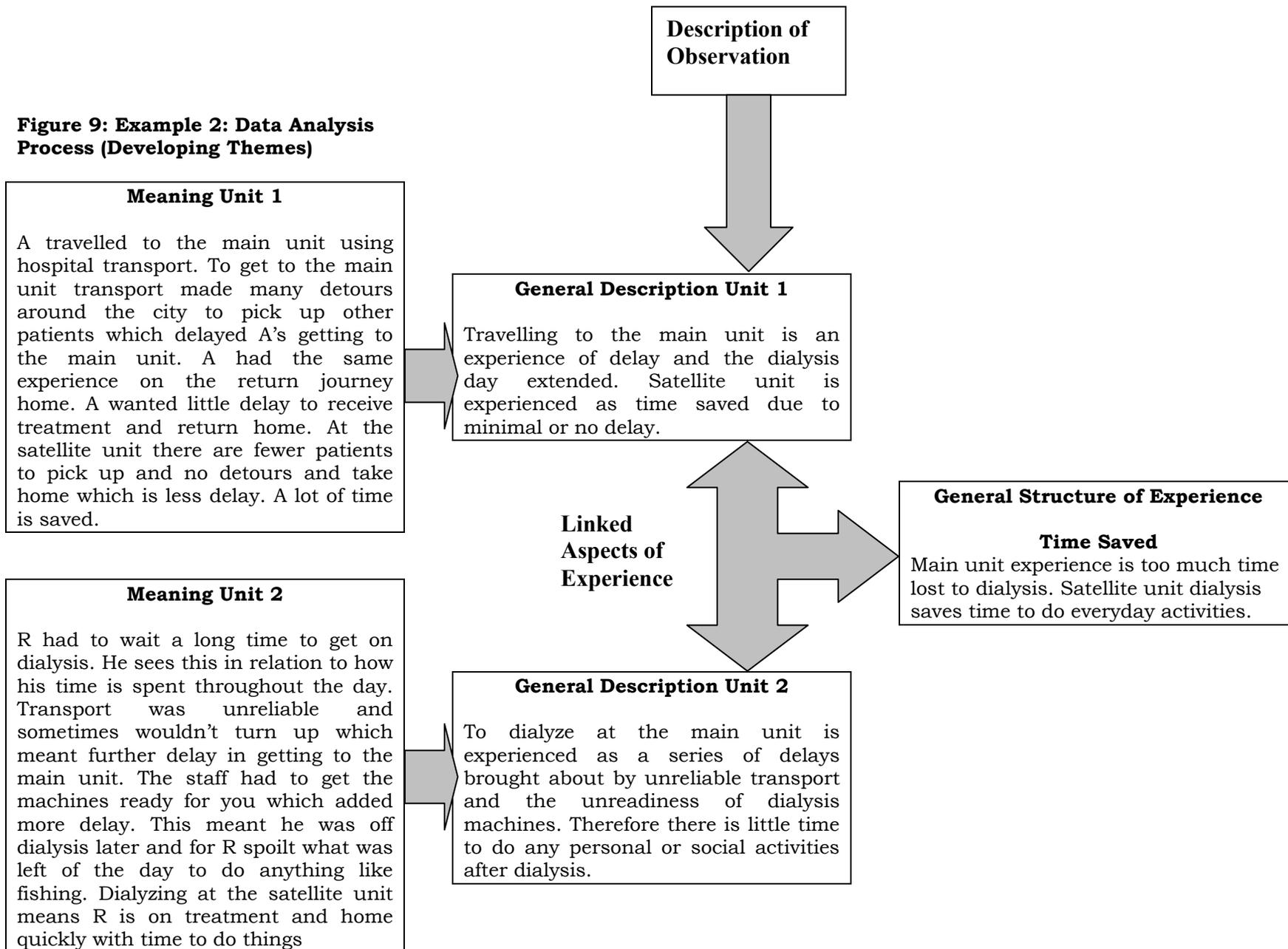
**Figure 7: Diagram Summarizing the Data Analytical Process for Interviews**



**Figure 8: Example 1: Data Analysis Process (Data Reduction)**



**Figure 9: Example 2: Data Analysis Process (Developing Themes)**





**Chapter Eight**  
**Research Findings**  
**Descriptions of the Units**

## **8.0 Descriptions of the Satellite Units**

In the previous chapter I explained how the data were analysed. There was a combination of interview and observation data to produce form and content of satellite unit experience. This form and content has been called a categorial intuition because the complexity of experience makes it difficult to grasp as a whole. A categorial intuition is a 'state of affairs' that recognises wholes, part and their relationships. It must be remembered here that a categorial intuition is built upon sensuous intuitions which are already constituted in appearance. In following the idea of categorial intuition, I will present the visual (sensuous) descriptions of satellite unit experience which is the basis for complex phenomenon. This section will describe the satellite units (textures) and then structural elements that are invariant features despite the varied locations and physical building and layout. Schematic plans of each unit can be found in appendix 6. This section will begin with descriptions of the textures of each unit. The reason for describing physical textures is due to the need to place experience in its horizon which includes the physical objects found in the world. It would be remiss of me to omit this very important basis for describing experience. The units each have different layouts but provide the same function; however the overall experience for patients and staff remains similar. There will follow a description of invariant aspects of satellite unit structure.

### **8.1 Description of Satellite Unit One**

Unit one is situated on the western side of a hospital grounds on the eastern side of the city. It stands alone and is accessed through a small link corridor from a main corridor that allows access to the main hospital. External access (see figure 11 below), at the time of the research, is locked due to demolition of nearby buildings in order to minimise spread of airborne infection. The entrance for patients is through a door on the small link corridor. There is limited parking due to the building work. The main door has a keypad lock system to monitor access and limit unwanted guests. The main door is out of the line of vision from the main ward and therefore cannot be monitored by staff.



**Figure 11: External Space: External Entrance to Unit One (Link to main hospital to the right). The picture is from the staff and patient car parking area. The window to the left of the door is of the main treatment room.**

The entrance lobby (See figure 12 below) is a short corridor leading to a waiting area. On the immediate right is a storage cupboard. Further along on the right is a short corridor leading to two offices on the right, the staff toilet directly ahead, there is a kitchen is on the far left, and staff changing room on the near left. The main lobby waiting area has a large hexagonal fish tank with six large gold fish. The main seating area has five seats and a coffee table. This area is used for waiting by patients and transport drivers and for staff breaks. The offices and waiting areas are places where staff can go to escape clinical demand. On the coffee table are some magazines and some health information. The reading material is general such as celebrity gossip magazines and geared towards the patients. There are some doors that link to another ward but are locked and no access is allowed.



**Figure 12: Waiting Room Space: Patient Waiting Area (Entrance to the treatment area is on the left behind the fish tank). Staff rooms and kitchen is to the right. The doors at the rear of the picture are locked but link to an unused ward area. The waiting area was primarily for patients but used for many other activities such as staff discussions and refreshments. Objects are visible. This picture was taken prior to patients entering the unit.**

Entering the main unit on the right there is a corridor that leads to two dialysis stations on the near right. In relation to the main treatment area these two dialysis stations appear remote but can be seen through partition windows. This area has a cavernous feel especially when the lights are low due to its high ceiling and limited content of objects. The corridor also leads to some utility rooms. The first of these rooms on the left is a clinical room which has a window facing onto the main treatment area. This room houses medications, dressing packs, a fridge for drugs, and other clinical material. It is used minimally, to prepare drugs or retrieve objects such as dressing packs. It is used to have private discussions by staff without leaving the main unit, and without losing visual contact with patients because of the link window. The next room on the left is known as the “techs” room. This room is used for preparing machines. A

medical physics technician attends the unit from the main unit to undertake machine repairs within this room. The room is used to get spare machines ready as a standby. At the end of the corridor is a storeroom that is full of boxes, packs and packets. It used mainly to retrieve objects. It is used more frequently by healthcare assistants in the role of unpacking and stacking supplies.

The main thoroughfare is from the lobby entrance. To the left is the nurse's station (NS). Here there are two telephones, the front door intercom, and a computer. There are many papers, storage holes, draws and information sheets around the station. Qualified staff frequent the NS seated behind it to discuss issues, have handovers, make and receive phone calls, access the computer, fill in blood forms, complete patient records, and have social conversations. The nurse's station faces onto the main treatment area where patients can be seen at all times. The nurse's station also makes nurses present and visible when not attending to patients.

There are two four stations bays on the right (See figure 13). Each bay is identical in layout: the only difference is that the furthest bay has a window facing outside. Each bay has four dialysis stations. There is a chair and a dialysis machine at each station. There is also an adjustable table for patients to put things on. The chairs are large and grey and on wheels for movement. The chairs have the ability to be controlled and articulate electrically by a remote control handset. This allows the patient to recline or lay flat if needed. The chair control handset is on the arm of the chair and is self positioning. Nursing staff have access to the same control that becomes important in situations of sudden hypotension episodes.



**Figure 13: Space: Main Treatment Area (unit entrance is at the far right of the picture). This is where the majority of activities and events occur. The picture shows objects present in the dialysis space such as treatment chairs, dialysis machines, televisions (suspended above the patients) and trolleys. The picture was taken during the Intradialysis time. This period of time is where patients and nurses undertake parallel activities that converge at specific points such as hypotensive events or patient education.**

Above each station is a television (see figure 13 above) that can be controlled by the patient through a remote control handset. No sound comes from the TV because each station has an ear phone set through which the TV sound is transmitted. Televisions keep the attention of the patient, which means there are frequent times of little speaking between patients. There is a radio constantly playing at an unobtrusive but audible level. A local radio station is the station of choice that provides local news, travel and weather information and a balanced selection of music not geared to any specific age group. It is not clear for whom the radio is

on. The patients wear earphone sets, watch TV or sleep and therefore do not appear to listen to it

There is an extra dialysis chair at the end of the nurses' station. This is like the other dialysis stations but it does not have the benefit of an overhead TV. All patients rotate into this chair at some point to maintain 'equality'. Patients do not have a set dialysis station.

At the end of the main treatment area there are the patient changing rooms and toilets, the water treatment room (where water is purified for dialysis) which are separated by an emergency exit door.

## **8.2 Description of Satellite Unit Two**

Unit two is situated on the north side of a specialist treatment hospital to the north of the city of the main unit. The unit is an old 'portacabin' type building that has been upgraded for use as a satellite unit (see figure 14 below). The unit is very compact. Upon entering the front door into the main corridor there is a small patient waiting area on the left. There are four chairs and a table with some reading matter which is patient education material and a few magazines. The main corridor bisects the building down the centre with the treatment rooms on the left side and utility rooms on the right.



**Figure 14: Space: Entrance to Unit 2. The unit is housed in a temporary and old building. The main hospital buildings are on the right of the picture. The picture was taken from the patient and staff car park. The main treatment room is on the left side of the building and looks out onto the road and some trees.**

Further along the corridor just after the patient waiting area, on the left, is the staff room. This is an 'L' shaped room that has many comfortable chairs, a coffee table with a variety of magazines, both professional and general interest, and staff lockers. The room is used for changing and for break times for the staff. On the right side of the corridor and directly opposite the staff room is the sister's office. This is a large square shaped room. It is used for management issues such as confidential talks or where the person in-charge does necessary paperwork or telephone calls.

Following the corridor further along the right side and after the sister's office is a room for storage of clinical material such as dressing packs and syringes as well as the refrigerator for

drugs. This room is used for preparation of medications and retrieval of clinical equipment. Next to this room is the “tech’s” room. This room is used by a visiting technician from the main unit to fix malfunctioning machines. They also visit to ensure their own supplies remain stocked up. The next room on the right is the water treatment room for water purification and is rarely entered apart from the occasional access to assess the system by the technician.

Towards the far end of the corridor, on the right side, is a small rectangular kitchen. It has a small refrigerator on the left, some kitchen cupboards, a dishwasher, a sink unit, and a microwave machine. This room is frequently used by staff to prepared food and drinks for the patients and themselves and to keep refreshments stored. At the end of the corridor on the right are the patient and staff toilets and a sluice area for waste. Patients rarely use these facilities which are mainly used by staff. The end of the corridor has an emergency exit.

After the staff room on the left side is a large store room for dialysis material supplies. This room is only used for stocking up and retrieval of necessary equipment.

The main treatment area is entered through a door on the left immediately after the store room. The room is wide and rectangular in shape with windows facing out on the left side. There are six dialysis stations. There are four in line on the right side within the main room (See figure 15 below). These stations have an outlook on to a higher level road, trees, grassed area and a rose bed. There are two stations in a room at one end which is at a right angle to the main unit. This area has widows on the left side.



**Fig. 15: Space: Main Treatment Room Unit 2. The picture was taken during the Intradialysis period. It shows objects, how objects are situated and activity of a patient receiving treatment. The dialysis chairs face the windows looking out of the window.**

Each dialysis station has a chair that mechanically articulates to provide various positions via a hand control. Additionally to the chair and the dialysis machine is a table with a portable television upon it (See figure 15). On the left side of the main treatment room near the far end is the nurse's station. This comprises of a large table with chairs and a smaller table upon which a computer stands. The nurse's station is visible to all patients and within easy talking distance. The nurse's station is where staff undertake administrative activities.

### **8.3 Description of Satellite Unit Three**

Unit three is situated in the grounds of a recently built general hospital in a different city to the main unit about 20 miles away. The unit is an 'L' shaped building with the small limb of the 'L' being the area for access and linking onto another ward. The entrance (See figure 16

below) to the unit leads into the waiting area (See figure 17). To the immediate left are a small corridor and a set of double doors leading to another ward. Access through this door is limited to cleaning staff activity. Directly ahead is the sister's office used for private conversations and administrative activity. Access to the treatment area is directly to the right upon entering the waiting area.

In the waiting area there are 11 chairs, 12 large lockers and 12 small lockers for patients (See figure 17 below). There are two sets of weighing scales; one for standing and one for sitting, used by patients for pre and post dialysis weighing. A small coffee table is in the centre with magazines and a bowl of pot pourri. On the wall is a notice board, a dialysis station allocation board and some patient information leaflets in holders. There are two doors to toilets one for staff and one for patients. The waiting area is very clean, tidy and an area of little activity.



**Figure 16: Space: Entrance to Unit 3 taken from the patient and staff car parking area.**



**Figure 17: Space: Waiting Area (Entrance to the treatment area is to the right of the picture). The room at the rear is the sister's office and there is a link corridor to another ward on the left. The picture shows objects found in the space including the seated weighing scales in the lower right corner. The picture was taken during the morning dialysis preparation period.**

The waiting area is where each cohort of patients waits prior to commencing dialysis. Patients do not enter the dialysis treatment area until invited to do so by staff. Patients weigh themselves and inform staff of their weight when they enter.

The treatment area is entered via double doors to the right of the entrance to the unit. The area is rectangular with eleven treatment stations placed around the sides of the room (See figure 18). Immediately on the right is the nurse's station. There is a computer, a printer, folders with patient files, a whiteboard with patient cohort dialysis time allocation. This is the area where nursing staff return to during quiet periods of the day. Record keeping, telephone calls, computer updates and discussions occur here.



**Figure 18: Space: Main Treatment Area (Entrance to the left of the picture). The picture was taken during the “putting on” event. The picture shows objects such dialysis machines, chairs, sheets, televisions (above), and trolleys. The picture has people present, patients seated and nurses are visible busy with “putting on” activities.**

The first dialysis station is on the immediate left behind a short waist high wall which acts as a barrier between treatment space and access to the entrance. The remaining stations spiral clockwise from the first station around the room at regular spaces. Station eleven is behind the nurses’ station and is separate to main treatment stations and is used to provide extra privacy for patients when needed.

At the right side of unit is a small corridor from which there is access to utility areas. On the left is the kitchen which includes a fridge, microwave, kettle, kitchen units and sink. The next room on the left is the staff room which has a TV, four chairs and a book shelf unit and a coffee table. The rooms on the right are a sluice for waste disposal, a ‘Tech’s’ room where dialysis machine technicians visit nearly daily from the main unit; and a clinical supplies store room. At the end of the corridor is an emergency exit.

## **8.4 Descriptive Structural Aspects of Satellite Units**

The satellite unit has many structural aspects that make up the whole perception. This next section describes essential structural aspects of dialysis at a satellite unit. These structural aspects are located in phases where specific events and activities occur. Many of these structural aspects provide the routine of the unit such as 'putting on' as well as a consequence of the routine (nursing station activity).

### **8.4.1 The Preparation Phase**

The beginning of the day is an early start for all the units. Staff enter units from around 6am to 7am in order to be ready for the patients. Preparation for the morning occurs at the end of the previous day's dialysis session where equipment is made ready for individual patients.

The day starts by staff entering the unit and switching the lights on. No patients are present at this time. Staff begin to prepare the machines as soon as they have entered the unit. Machine preparation means the blood tubing is removed from their packets and placed upon the machines in the relevant areas. Care must be taken to avoid dropping the tubing on the floor and causing contamination. The artificial kidney is attached to the clamp which holds it in place at the side of the machine. The blood tubing is primed (filled) with one litre of saline.

Through necessity of limited staff numbers, experienced staff have learned to prime several machines at once. Hence there is a constant flitting between machines as various alarms ring or saline is completely used up. The need to be multi-skilled is important due to the limited number of staff available. There is an urgency to have the machines ready for when the patients appear for dialysis. Patients appear on the unit from about 7am though time is variable. Each member of staff is given an area to prepare and machines to prime. There is a need to manage the work load and hence a division of labour occurs. This allows for effective accomplishment of required tasks. The preparation is an essential routine that occurs in a

smooth manner. Beginning the day highlights the structural parts of early preparation, immediate activity, development of the ability to multi-skill, and a division of labour to achieve outcomes.

The presentation of patients for treatment heralds the next phase of the activity which is preparation for treatment initiation. Patients enter the treatment area only when given permission by the nursing staff. Permission is a signitive act that is either verbal or non-verbal such as an opening of the treatment room door. Patients prepare their dialysis station for personal comfort for the time on dialysis. The preparation routine or ritual ranges from simple arrangement of pillows and hand sets for the TV, chair and nurse call set to elaborate reorganisation. For some patients preparation is an extensive activity which requires covering of the chair with sheets, careful placement of pillows. Strategic placements of blankets occur so that they may be put on or taken off with one hand at any time.

Further strategic placement includes reading material, sweets, pens, TV channel changer, earphones and the nurse call button. The chair can be placed in a way to improve viewing of the TV, windows or staff. The chair is adapted to suit the sitting position such as the backrest reclined and the leg support elevated. When the area is prepared the patient retires to it and rarely moves from it waiting for a nurse to attend for needle insertion. Preparation also includes the movement of the dialysis machine from one side to the other so that blood lines do not cross the body. Some patients appear more confident in what they can do in arranging the dialysis area. Some patients will also write their weight on dialysis prescription sheet

When a patient has finished their preparation they adopt a 'ready position' (see figure 19). This position is a signitive act and an indication for the nurse to put the patient on dialysis. The patient sits in his/her chair with the arm with the fistula extended and exposed ready to have the needles inserted. Those with a central venous catheter have it exposed ready for staff to attend to it.

Nurses undertake parallel preparation activities. They may assist the patient to get weighed and prepare the station for them. Staff will examine the dialysis machine for its readiness. They will calculate fluid removal to be entered into the machine. Anticoagulation is prepared for administration to the patient. The dialysis pack will be opened on a moveable trolley and solutions poured into small pots found in the pack. Patient specific dialysis needles are placed onto the open pack. The pack and needles are treated in a way so as to prevent contamination. Preparation occurs at the prior to initiation of treatment and as such can overlap with the intradialysis and “taking off” phases.



**Fig. 19: Signitive Act:** The picture shows how a patient is seated and ready to be put on dialysis. This act is the ‘Ready’ Position (but in this instance with cannulae [needles] already inserted and ‘put on’) and informs staff of readiness to be cannulated. The picture was taken during the “putting on” event.

### **8.4.2 Commencing Treatment ('Putting On') Phase**

When the patient is ready the putting on phase commences. This phase will last until all patients have commenced dialysis. Nurses and healthcare assistants will be focused upon this phase in order to minimise time wastage. The patient is then put onto dialysis through an activity the nurses call 'needling' whereby large hollow bore needles are inserted in to the large blood vessels in the patient's arm (see picture 19 above). The process of 'needling' is a complex activity that occurs at each session. Putting on can be done by one or two people. It requires the ability to 'needle' a fistula and use a dialysis machine. If there are two members of staff then the division of labour is clear; one for the patient and one for the machine. The nurse has the responsibility to assess the patient prior to commencing dialysis. This includes general features; BP, fluid removal, anticoagulation, ensuring the prescription is correct, the need for blood specimens and checking if the machine is ready. Additionally there is the assessment of vascular access (line, fistula, graft). Most patients have a fistula that is assessed by a glance and the occasional feel for vascular patency. The assessment is looking for infections, bruises, previous 'needling' sites and patency. The feeling for patency involves the touching of the arm with the intent to 'needle'.

Local anaesthetic is applied to the areas for 'needling'. The person who does the 'needling' prepares the cannulae by priming them with saline via a syringe. The purpose of this activity is to prevent the accidental injection of air into the patient. The needles are inserted and assessed for patency and secured with adhesive tape (See figure 20). The patient is then attached to the machine using the needles and the blood lines.

Alarm limits are set automatically by the machine. The ultrafiltration (fluid removal) pump is started to remove any excess fluid from the patient during the session. The heparin (anticoagulation) pump is started. The machine is checked for all parameters being set correctly before the nurse leaves the patient. The patient is made comfortable and any

additional needs are met such as moving a table nearer. The dialysis area is tidied and the trolley is removed to be cleaned. Used material is put in the bin and any sharp objects such as needles are placed in the ‘Sharps’ bin. Patient dialysis record documentation is completed, only then does the nurse moves on to the next patient. This process is repeated until all patients have commenced dialysis. The whole event will take between one to two hours. The “putting on” phase is a building up for treatment. A sign for nurses to commence other activities is identified when all or most of the patients have commenced dialysis: this signifies the intradialysis phase.



**Figure 20: Act: ‘Needled’ Fistula.** The picture shows the fistula arm of the patient with cannulae inserted and connected to the dialysis machine. The picture was taken during the Intradialysis period.

#### **8.4.4 The Intradialysis Phase**

The intradialysis phase is initiated by the sign that most or all patients have initiated dialysis. There is a change in the type of activities that occur. The convergence of activity that occurs

during the putting on phase suddenly diverges. Nurses assess the situation and decide what activities follow the “putting on” phase. Each nurse assumes an activity that may be administrative, clinical or concerned with unit day-to-day functioning such as stock-taking. Whilst there may be minor variations about specific activities or use of equipment, broad structures are observable and as such describable. These are unit management activities such as preparing for the next session, communicating, administering medication, stock-taking, administration, or teaching. There are also patient related activities such as checking medication, monitoring patients, making people comfortable, and treatment alterations. The Intradialysis phase allows some staff to gravitate towards the nurse’s station as a centre for administrative activities. Other staff are located in other spaces such as treatment room or sister’s office. Nursing staff move about the unit performing these activities until they have a refreshment break after which they will recommence the activities. Health care assistants are involved in activities that are called “house-keeping” such as tidying. They are often involved in commencing preparation activities. They are missed if absent because the work must be shared out amongst the nursing staff.

A preparation phase for the next session of patients begins during the intradialysis phase. It involves making ready the dialysis blood tubing, artificial kidney and prescription sheet. It is placed in a position ready for easy distribution as soon as the incumbent group of patients leaves the treatment space.

For patients this is a quiet time usually a period of sleep or dozing, watching TV, listening to music or reading. Reading appears to be the least undertaken pass-time. What is read is generally a newspaper, rarely a book. Patients also monitor each other by asking how they feel. They monitor for the event known as “going off” which is a sudden reduction in blood pressure. They ask each other how they feel or attract nursing staff if a fellow patient appears to be “going off”.

Verbal interaction is often down to a minimum. Those patients who are verbal may make comments to passing staff or other patients. Staff interact with patients by either impromptu comments, questions from patients, something topical is visible on TV, or treatment/care related information needs. All spontaneous interactions are short-lived lasting about 5-10 minutes. Humour continues to be the major interactional method for initiating contact or extending interaction. Patients are confined to their chair and therefore limited in what they can do over four hours. Other communication interaction activities occur that often lasts much longer than the spontaneous type. One example is a communication activity that is treatment or health related and involves providing information, clarifying issues and teaching. Nurses can spend quite some time undertaking this activity which will require sitting near to the patient. Another example is attending patients who are distressed. In this instance there may be more than one nurse attending. They attend until they feel satisfied the patient's distress has improved.

Nurses undertake monitoring activities that requires visual inspection of the patient, vascular access and dialysis machine. Fluid removal levels are checked and alterations are made where appropriate. The patient's blood pressure is measured. Importantly, the patient is always asked how they feel. This is a surveillance question for the "going off" event. The "going off" event can occur at anytime from initiation to termination of dialysis. It is most likely to occur during the intradialysis phase.

#### **8.4. 4 "Going Off"**

"Going off" is the term used by both nurses and patients to describe a hypotensive event. It is a typical example of a common patient related activity. The patient may complain of feeling dizzy, nauseated, have blurred vision, vomit, get leg cramp, cold sweating, or even become unconscious. The patient remains connected to the dialysis machine. The nurse(s) acts quickly. Fluid removal by the machine is switched off. An infusion of fluid replacement is

given of approximately 200mls of 0.9% saline to the patient. Other fluid replacements may be given. The goal is to elevate the patient's blood pressure to a normal level so that they may feel better and continue treatment. The blood pressure is checked, by a nurse, at the start of the event and rechecked as necessary. Fluid removal is recommenced when the patient feels better. Dialysis may be discontinued if the patient is at risk of severe illness or it is near the patient's finishing time.

Nurses undertake comforting measures for the patient when s/he is 'going-off'. A sympathetic approach is evident. There is also a demeanour of being in control. Focus is upon patient recovery and the patient's experience. There are many questions such as 'how are you?' and positive statements like 'you are looking better'. There is physical touch in that the hand will be placed on the patient's forehead or arm. This appears to be a comforting and supportive act. The nurse attends throughout the event until the patient and nurse are satisfied that there is good recovery. Supporting and comforting words are used throughout. The nurse will also undertake an assessment of the patient's experience to see if this has become a trend that may indicate a need for some alteration in the treatment options. Recommendations may be made later to a doctor or nurse in reviewing the patient's condition.

#### **8.4.5 Completing Treatment: 'Taking Off' Phase**

Completion of treatment is the termination of this aspect of structure which is to be repeated for the next cohort of patients. Completion of treatment is known as 'taking off'. 'Taking off' is a busy period where dialysis is terminated; it is an event where all staff get involved. "Taking off" is a re-convergence of focused nurse-patient interaction. All activity is focused upon taking the patient off dialysis. "Taking off" begins with signs such as the ringing of completion alarms set on the machine at the start of dialysis. Another sign is patient behaviour which sees them sitting up and collecting their personal possessions together. Some patients may even go so far as to begin removing adhesive tapes used to secure blood tubing. Staff members move to open dialysis packs that have gauze and cotton wool balls in them. These

objects are used to help apply pressure on the needle puncture site and for dressing it when complete. The activity is the reverse of the “putting on” activity: it is an undoing of what has been built up. Staff move from patient to patient. Needles are removed whilst another manages the machine. Some staff perform both acts of removing needles and managing the machine. Patients cooperate by apply pressure on the removed needle sites until the bleeding has stopped. Patients are expected to participate by applying pressure to the puncture site. They also undo what they prepared at the start by removing sheets and pillow cases and washing down the chair. Patients weigh themselves and have their BP checked. This is a busy period with staff and patients walking around. The “taking off” phase is relaxed though busy. Staff know what to do but it does not appear frenetic or overtly stressful. Preparation for the next patient cohort commences as soon as the current patient leaves the dialysis station.

#### **8.4.6 Preparing for the next patient**

##### *Preparation Activity*

When the machines are stripped of the blood tubing and artificial kidney and cleaned they are then made ready for the next patient. New blood tubing, dialyser and bags of saline are attached ready for priming. The machines automatically internally rinse clean themselves. When patients leave the dialysis area staff prime the machines again. Trolleys are prepared for access insertion. There is usually an overlap between patients leaving and patients coming in. The machine is lined and primed when it is ready. The ‘one-off-one-ready’ process means that machines are prepared on the go as soon as a patient is finished, maximising the efficient use of time. It avoids en-mass preparation and makes the process manageable. This would appear to prevent delay and allows for staff to go for lunch breaks.

Where the completion of treatment is at the end of the day staff prepare for treatment in the following morning. Each dialysis station is prepared with all that is needed for the next patient. The blood tubing and artificial kidney are not attached until the next morning.

Records are updated and general tidying occurs. The unit is left clean and ready for the next session.

The completion of treatment is the conclusion of a cycle of events and activity that is repeated twice daily and for each patient three times each week. The repeated cycle of dialysis provides the descriptive structure of the satellite unit of Beginning the day; Preparation; 'Putting on'; Intradialysis Activity; 'Taking off' and Preparing for the next patient.

### **The Nurse's Station Space**

The nurses' station is used by all staff (See figure 21). This is a central focus for nursing communication. It acts as a focal attraction point. Staff sit or stand here to undertake administrative activities unless called on to do some kind of task, such as dealing with a patient or machine alarms. The nurse's station is the informational focal point. Record keeping is undertaken here. Records are written up or altered. Information is retrieved from or put into the computer. Information is sought by telephoning the relevant people. Decisions are made and plans are developed in managing various issues through discussion and information review.

The nurse's station provides constant access to the computer to review treatment aspects such as medications and blood results. There is much treatment related discussion and problem-solving. There is also personal discussion about home life or work life and in equal proportion. Patients are not ignored they are allowed to sleep or have a quiet time but staff will see to patient's needs as and when the need arises. The nurse's station is located in a position whereby staff are visible to patients and patients are visible to staff. There are frequent acts of visual surveillance of patients by staff. The nurse's station is a structural focal point for staff and patients in that it is the informational centre for the treatment of patients.



**Figure 21: Space: The Nursing Station (from unit one). The nurse's station faces the dialysis bays and shows its proximity to the patients. The picture shows a nurse seated at the station undertaking a telephone communication activity. Many objects are present both clinical and non-clinical (a pot plant!).**

This section has described general texture and activity of satellite unit experience. The idea is to provide a basis for combining the sensuous with reflected accounts of individuals who attend them. Therefore the next chapter will describe the categorial intuition of dialysis satellite unit experience. It will include the sensuous and the reflected to produce themes of structure.

**Chapter Nine**  
**Research Findings**  
**Structures of Experience**

## 9.0 Structures of Experience

This chapter will describe the structures of experience of both patients and nurses. The analysis of experience of those who attend dialysis satellite units has been synthesised to provide general thematic structural descriptions: an act of constitution. This act of constitution is essentially a categorial intuition: a grasping of understanding of a complex phenomenon. Articulation of any phenomenon is done so by making it thematic and comprehensible. The description of each structure of experience begins with a summary of a general structure before attending to detail. The rationale for this is to remain committed to phenomenological method and produce statements of general structure. Further to this a summary of general structure will provide the reader with an overall sense of experience at a glance. Examples of typical statements made by patients and nurses are used to demonstrate important structural aspects of experience. These examples are drawn from all the units but were chosen because of their typification and conciseness of description of experience.

### 9.1 Experiencing Illness: The Lived Experience Context

#### **Summary of General Structure of Experience**

Illness is the background to the experience of dialysis. People become ill in a variety of ways with kidney failure and need dialysis. Becoming ill with kidney failure is an independent part of the patient's experience at the dialysis satellite unit because it stands out in its own right. Becoming ill prior to commencing treatment remains part of their whole experience and is their horizon for meaning. First exposure to dialysis is at the main unit where the experience is of illness. The satellite unit offers the experience of not seeing ill patients as a reminder of how ill they are. An absence of doctors provides a situation of 'wellness' which is not being ill enough to need to be at the main unit. Absence of doctors is an invariant. A constant presence of doctors would alter the autonomy of nursing staff and patient experience of illness. Patients and nurses endeavour to maintain the experience of wellness by making decisions to make it illness distant by treating it promptly and preferably on the unit or by removing illness to the main unit.

The existence of dialysis is grounded in disease and illness. The fact that each patient has end-stage renal failure (ESRF) is the reason why they need dialysis. This is accepted as reality and is not doubted. Becoming ill and needing dialysis is part of a patient's experience and consequently context to their experience of a dialysis satellite unit. Illness is a given within the dialysis satellite unit because the unit would not exist without it. Each patient knows that

it is because of illness that they are at the dialysis satellite unit. This fact is mirrored by the nursing staff whose role is determined by ESRF and dialysis.

Becoming ill with renal disease is an occurrence in the patient's past that is relevant to their current experience (Code 100). The nature of the disease that caused the kidney failure can be different for each individual. For some patients the initial disease that caused the kidney failure is no longer active whereas for others the initial disease remains active even after the kidneys have failed. Both groups of patients experience the problems associated with ESRF which may include high blood pressure, tiredness, bone and muscle problems as well as dietary and fluid restrictions. Those whose illness continues following ESRF have the added problems associated with their underlying disease. For example, a patient with diabetes mellitus who has ESRF may have visual impairment, altered bowel function, neurological problems such as numbness and poor circulation. Regardless of the cause of kidney failure all patients' health will deteriorate quicker than people without kidney failure, though for some it may be slow and for others a sudden illness.

Becoming ill with kidney failure is an aspect of patient experience. Whilst not immediate or imminent it is one that remains important all the same. The experience of becoming ill is an absent experience. An absent experience does not mean that it does not exist, rather it is an aspect that is out of view but known to exist and is fundamental to a patient's experience. Patients become ill in a number of ways. There are those who had a vague and unknown illness, those with a sudden illness, and those where illness is known.

### **9.1.1 Describing Illness Horizons: Vague and unknown illness**

Those patients who presented with a vague illness described themselves as feeling generally unwell. Illness was nothing they could pin down but felt tired, nauseated, had no appetite and lost weight (Code 100). Individuals attempted to make sense of their physical feelings by

attributing them to functional aspects of their life such as overworking, warm environment or insufficient sleep (Code 100). Additional symptoms of illness such as nausea and vomiting were associated with other potential causes such as a 'bad pint of beer' or a lingering virus. Weight loss provided much concern for patients and many were anxious or fearful that they may have cancer. The fear of having cancer is a common experience and is described by one patient when asked to describe becoming ill:

Patient 3; Unit 2

*"Er, it all started when I started losing a lot of weight. I did lose a lot of weight I must have lost 3.5-4 stone 'cause I was massive me. I never went to the doctors because I was frightened it was something else(Cancer). One day I had no choice, I got home from work, I worked days then, I got home about twenty past five, by half-past six I was in the hospital; I had collapsed totally. It started with vomiting a lot and nose bleeds and things like that. I thought it was the big C (Cancer). to be honest. The weight was just falling off me everything I ate just came straight back and it frightened me so I just never went to the doctors. I know I was a fool because they might have been able to do something. I was in intensive care for three or four days."*  
(Code 100)

Here the patient summarised the experience to highlight the important features of being ill, sensing that something serious was wrong. His thoughts orientated towards cancer and wanted to avoid encountering it as a reality. The association of weight loss with cancer provides a fear of its possibility which delayed accessing medical help.

The deterioration in a person's health leads to a point when they can no longer continue as normal (Code 100). This may have been because they were too tired or in many people they collapsed requiring the need for urgent medical care (Code 100, Code 107). The example provided below typifies an attitude of carrying on with an expectation of illness being transient but ultimately leading to collapse.

Patient 7; Unit 1

*"It happened over a period of say six weeks. I caught flu, this is how I found out I caught flu and I were at work and I were getting tired, you know, during the day. Well I'm a wagon driver and at dinnertime you stop for your break and I'd have something to eat and then sleep for a while, you know, because I was really tired. I had cold and that knocks hell out of you any way, I were like that for a week or so. I thought 'take a couple tablets shake it off' kept on working and working and I couldn't shake it off. And then I came home from work..... well I got into the yard (work) and I was feeling rough and the boss just said to me 'get yourself home and get yourself sorted*

*out' you see. So I went home and I went to the doctor's and I told him I weren't feeling well and he said it's just a bit of cold you've got, so he sent me home. Now the same day about half eleven at night I couldn't breathe, fluid were building up inside, I didn't know it were fluid building up at the time, but I couldn't breathe. So wife phoned for an ambulance and rushed me into hospital and they did some tests on me when I was there and that's when I found out it were my kidneys that were failing."* (Code 100, Code 107)

The vagueness of the illness makes it difficult to determine a cause which the patient's doctor also failed to identify. The culmination of symptoms leading to a critical situation is a repeated in many patients' accounts of becoming ill (Code 100, Code 107).

### **9.1.2 Sudden Illness**

Some patients become ill quite suddenly. One day they are well and the next they are ill which may be life threatening (Code 107). The condition may not initially be kidney failure but may lead to it as a secondary event as demonstrated in the example provided below. The situation is met with relief that they are alive but also with disbelief of where they are now with a permanent illness. The extract below outlines one patient's sudden transition from wellness and normal everyday activity to a critical condition then to a chronic illness.

Patient 5; Unit 3

*"Er, I was a very fit and active feller. I played cricket into my late thirties and then I took up golf and played golf to a good standard, not high but good because I took it up so late..... Until eventually I played golf in a corporate event in a late September and I was going well up to thirteen holes and after that I could hardly walk from one hole to the next. Then I went back to the doctors and he sent me for an x-ray on my lower back on the Friday and then on the Monday the doctor, which is always a bad sign, came to the house and said they wanted me in hospital immediately and I was brought in as a life and death situation. They discovered that I had an aneurysm (potentially fatal weakening of the main blood vessel through the body) which was twelve centimetres long. It was a big thing to save my life, and they saved my life and I went through the operation, they had to clamp my kidneys off and they didn't kick back in again. From being fit and well I became a hospital patient. It was a hell of a shock to the system, hell of a shock, a big shock. But I am lucky to be here I know that, well I'm lucky and unlucky, I survived the operation."* (Code100).

Description of the pre-illness life provides a grounding from which they have moved to where they are now (Code 100). This is the life that was left behind but is very much part of who they are. It is important as a personal measure for their return to wellness.

The extent of the illness had not entered the mind of the patient until the patient had improved when they had time to reflect (Code 390). The transition from wellness to illness is traumatic in this instance and takes some considerable time to overcome. The experience is lived with a sense of insecurity. Some patients need constant reassurance by the presence of medical staff 'just in case' they become ill again (Code 390). Transfer to the dialysis satellite unit leads to an experience of great trepidation and worry (Code 213). There is concern for their health and a desire for frequent contact with a doctor at the satellite unit (Code 6).

Patient 9; Unit 1

*It would be better if a doctor was here to check up and ask how you were over the last 28 days, you know what I mean, has everything gone alright? It's alright they take your blood figures and for example I wasn't on iron for three or four months and then all of a sudden I've back to three days a week. Why has it dropped, why have my figures dropped? I ask but you can't be asking every time. I want to know everything it's my bloody body, I might be dead next year, you know what I mean. And this is all I'm trying to say is you get feedback, if there was a doctor, what's causing this? Why aren't... you know what I mean. (Code 6)*

The absence of medical staff proves to be a challenge to a limited number of patients. They frequently voiced the desire to see a doctor (Code 6). The challenge is expressed in the view that a satellite unit is about being 'put out to pasture' no longer of any use. A satellite unit experience is an unsatisfactory one in this instance (Code 384).

### **9.1.3 Known Illness**

Another way that people became ill and eventually developed ESRF is that they knew they had kidney disease (Code 100). These patients attended specialist doctors who monitored their kidney function over a period time. This time could be several months to several years as in the case of one patient who had had kidney disease since childhood. There comes a point when the patient needs to start dialysis due severely deteriorated kidney function. There is much variation as to when a patient would start dialysis; but for many it was a culmination of symptoms for which dialysis gave relief. The extract below describes one patient's experience

of suffering increasing symptoms of illness that eventually culminates in dialysis and symptom relief, but is typical for this group of patients.

Patient 5; Unit 2

*'Well it will be about five years ago. I knew my kidneys were small. I came to see the doctor and he said 'you are alright you don't need to go on dialysis for a while'. Well about three years ago he said well that I will need to go on dialysis. I was being sick and couldn't keep anything down. So I went to the main unit and had dialysis there. I liked it there that was one thing and I have been on about three years, three months now. I have been here (Satellite unit) just over eighteen months. I am quite well when I am on dialysis, I couldn't have managed without it because I was that sickly, I couldn't eat anything. I have been okay ever since. I was ill feeling sick and couldn't eat anything. I had diarrhoea and this was about six months before I came on dialysis really, but they kept telling me I was alright. I said I was not then they rang me up and said can you come on Monday for dialysis for a couple of hours. So I came and that was it I was on for ever then. As soon as I came on I began to feel better the, I was alright' (Code 100).*

Whilst dialysis may have provided the patient with physical relief from symptoms, starting dialysis still causes emotional distress; not unlike that of the patients in the other groups. There are feelings of despair and an inability to control what is happening to them; their destiny is no longer their own. This can be seen in the example provided below (Code 390, Code 391, Code 433).

Patient 5; Unit 3

*(Being told he needed dialysis it was) Terrible absolutely terrible. I couldn't believe that my life could be interrupted three times a week. I didn't know how I would cope with that. It more or less interrupted with my social life, my whole life that I had come to an end. That was difficult to take. Even going away for long week ends, that was stopped, but I got round it another way. (Code 391)*

Starting dialysis can be a relief with the sense of relief came from something positive occurring to manage the slow decline in health (Code 433). Dialysis makes the patient feel better than they did. Relief from pre-dialysis symptoms alone makes the patient feel better (Code 433).

The need for dialysis makes the patient recognise the implications for their life (Code 390, Code 391, Code 211, Code 212). The dependence upon a dialysis machine and staff is acknowledged by patients; whilst they may not want to attend for dialysis, attend they will.

There is no choice, in their view, but to attend for dialysis. The alternative to dialysis (death) is known but not spoken about in explicit terms. Not to attend is not an option; it is something they must do (Code 391). An appreciation of the situation a patient finds him or herself is typically expressed in the extract below.

Patient 3: Unit 2

*I just accepted it and thought if that is the case that is the case and there is nowt I can do about it really. I were a bit taken aback because they explained there was a lot of things I couldn't do and that I would have to go to hospital three times a week for four hours and I thought 'Well I have to do it or I die' and if I don't they said I would only last a week or two at the most. So there were no choice really. (Code 391)*

The need for dialysis exposes the patient to pain quite often for the first time. Pain is not a frequent experience of their initial illness until access to their blood supply is needed for dialysis (Code 107). Gaining access to the blood supply frequently means experiencing pain as demonstrated in the example below.

Patient 3; Unit 3

*'They took me up and put like a neck line (Temporary access) in you know. That was alright but I had problems with that later on like. It came out of the chest. I got blood poisoning from it so they took that one out and put one in my groin. Never again, that was agony. The doctor said it was a fifteen minute job; I was down 2 hours. They couldn't get it in I was all cut and bruised. They said we will leave it today and put another one in tomorrow and I said if you think that you are going to put another one in there tomorrow you have got to be joking. He said oh no we'll try the other side and they were still having bother and the consultant came in and he got it in. I've never sworn so much in all my life. I called him all the names under the sun.'* (Code 483)

Pain occurs in the nature of temporary and permanent access procedures. Temporary access insertion is a painful ordeal to be endured generally on more than one occasion (Code 246). Permanent access creation causes initial temporary pain followed by intermittent pain with the insertion of two dialysis needles at each treatment. Temporary access causes delay and frustration because of problems such as blockage of the tubing. Delay and frustration caused by temporary access is demonstrated in the extract below.

Patient 3; Unit 2

*It's difficult now because I have a line and it is not working properly and they have to fill it with urokinase( to dissolve the blockage) and wait for half an hour. So I'm here*

*walking around and then I'm not on 'til quarter to eight. I'm sort of first here but last off you know, sometimes it peeves me off but there is nowt I can do about it. If I could use my fistula then I would be first on. Me and him come together at the same time but he'll be going home half an hour before me, but when I was using the fistula we both used to go together (Code 483).*

Permanent access insertion alters the status of the patient to one of stability, relief from the access ordeal and quicker commencement of treatment (Code 483, Code 485).

#### **9.1.4. Presence and Absence of Illness**

Dialysis patients worry about being ill (Code 107). The satellite unit is a place of wellness which appears as a paradox considering they have chronic illness. Patients who become ill with kidney failure will require dialysis which will initially occur in a main unit. At the main unit they will have vascular access organised and inserted. Their condition will be stabilized and show some improvement in health. The length of time the patient is at the main unit is variable depending upon the seriousness of their illness and availability of space at the satellite unit (Code 212). The experience of the main unit has many aspects and illness is one of them. The main unit has patients with a range of illness from 'well' to seriously ill (Code 283). Many of the satellite unit patients begin their experience being seriously ill with memory of the initial stage of illness as a vague experience, a blur that denies focus (Code 283). Improvement in health brings clarity of experience. Clarity of experience brings about the realisation of recent closeness to death (Code 107). The example below serves to demonstrate the place of illness in others as a reminder of a person's own illness experience. It emphasises the fragile state their current health condition is considered to be in.

Patient 3; Unit 1

*If you see some body poorly or having a rough time; it makes you wonder am I going to be like that. A lot of the poorly people at the main unit had after effects regular, regular, know what I mean, regular away (Unconscious) through the dialysis. No fault of the staff, but it may have been their(the patient) fault over indulging and things like that. I didn't like seeing that; people being sick and vomiting, passing out more or less. I went through it myself at the beginning 'til your body gets used to it the process of dialysis. I think everybody will go through the same sort of symptoms. I feel more stable now, touch wood I'm not ill as regular (Code 204).*

Images of illness witnessed on a daily basis precipitates fear and retreat to self experience not concerned with others (Code 238). Every experience is related to their own illness experiences and the desire to be secure from it. This desire abates through realisation that death is no longer proximal to the patient; death becomes distant (Code 304). Distancing of death heralds a new focus for experience. The patient is no longer like those that are confronted on a daily basis at the main unit: their illness has altered. Improvement is a move away from closeness to death, but the potential for its return is presented to the patient every day they attend for dialysis on the main unit (Code 238, Code 279)

Main unit experience is one of illness where there are many ill patients to be seen (Code 283, Code 285). The ill patient provides recognition of the patient's own situation, one they would rather not be reminded of (Code 304). The 'well' patient does not want to sit next to or opposite an ill patient or even see one. The experience is profoundly disturbing with sympathy and worry as expressed in the example below.

Patient 5; Unit 3

*Like I explain you can have someone who is very ill. There was one wheeled in on a bed very ill but you don't see that here.*

*\*I*

*Does not seeing ill people being wheeled in and out make a difference?*

*\*R*

*It does with me. If you see somebody who is ill and you have been that way yourself then you just have sympathy for them. You look at them and go 'oh' it reminds me of being ill and I was at my lowest then.*

*\*I*

*You would like to be reminded?*

*\*R*

*No that is for sure, for sure..... I was sick of being told that I was lucky to be alive. You see in here there isn't anybody like me. The rest, the kidneys just failed or got diseased, but my kidneys weren't diseased. At the main unit it is all doom and gloom. I don't break down easy but they made me break down, all doom and gloom I hated it. (Code 304)*

The patient does not want to be reminded of being ill; which is something that the dialysis satellite unit provides. The dialysis satellite unit is an absence of serious illness. Seriously ill patients are not present to experience. Illness does occur but not as experienced on the main unit. Illness presentation can occur through the effects of dialysis treatment or other illness

such as infection (Code 147). Dialysis treatment illness can be dealt with quickly by staff. Such experience does not evoke the same fear as experienced in the main unit. Staff members attend patients in a concerted effort to enable the patient to recover (Code 9, Code 227, Code 58, Code 68). The patient experience is one of feeling safe or apologetic for causing a disturbance like becoming unconscious during dialysis (Code 144, Code 147).

Non-dialysis related illness is potentially serious and may evoke fear of returning to the main unit (Code 338). The main unit is recognised as the place where serious illness occurs; to go there means the patient must be seriously ill. Additionally' it is recognised that the main unit is the place to be made well. The potential of returning to the main unit brings illness and death proximal to the patient which evokes memories of their own illness. The fear of the main unit experience is described in the following observation of a patient. The patient is to be transferred to the main unit due to possible lack of blood supply to his foot.

#### Observation Unit 1

*Arrangements were made for him to be admitted which meant ensuring a bed was available on ward \*\* and arranging transport. The patient was informed. Staff members continued to see the patient and offer more concrete supportive statements now they too knew what was involved.*

*The patient was still anxious about the possibility of losing his leg. He stated that the other leg had begun in a similar manner. He was tearful again. He explained that he would only go to ward \*\* because they knew how to look after renal patients. He also said that the surgical wards have bad memories of his previous amputation. He then stated that the nurses on the satellite unit are the best. He would have preferred to have stayed at the satellite unit but understood why he couldn't. He stated that the staff at the main unit were good 'everyone of them' but he got better looked after in the DSU. (Code 204, Code 188)*

The transfer to the main unit for the patient carries the threat of not returning to a dialysis satellite unit due to serious illness, health instability or death. Patients seek of reassurance that their space at the dialysis satellite unit remains available in their absence. They have intent to return and this illness is construed as temporary and wellness will return. A patient's place is held available (Code 62). Communication is maintained by staff contacting the main unit to

enquire upon their patient's health status and likelihood of imminent return to the satellite unit (Code 22, Code 36, Code 127).

Illness is to be avoided and this means that surveillance is required by both staff and patients. This is a required task for nursing staff but is a task that is adopted by patients. Those patients who have become accustomed to the satellite unit, are 'more well' than others, adopt the role of watching the 'not as well' patients (Code 76, Code 29, Code 248, Code 275). The role of patients watching fellow patients is adopted when they feel comfortable about their own health. This is demonstrated in the extract below.

Patient 7; Unit 1

*It (The satellite unit) relaxes you, you're relaxed more. It's like if I'm sitting here and look at Pete (another patient opposite) and he's not looking good and say 'are you all right Pete?' and if he doesn't answer I can press buzzer and I can get them (the nurses) right quick because you get to know them. (Code 204, Code 72)*

Patients know each other, which allow changes in another patient's behaviour or demeanour to alert them for signs of illness which may go unnoticed by nursing staff. Surveillance adds to a sense of security experienced by dialysis satellite unit patients. It is only through a sense of security that patient illness surveillance occurs (Code 203, Code 204). Only by feeling relaxed and secure from illness can a patient observe others for illness (Code 388). Feeling secure is created through relationships that develop between patients and staff and patients alike. Evidence of illness arouses other patients to question an afflicted person and brings this to the attention of the nursing staff when they are not present (Code, 72, Code 204).

Illness alters the mood on a unit. Normal talk changes to whispers becoming serious in nature (Code 135). The content of talk alters from humorous banter to statements of concern, questioning and support for the ill person (Code 82). The mood only returns to the earlier light-heartedness when there is recognition of improvement or a sign that the situation has changed for the better (Code 401). The sign may come from the change in mood and talk from staff or from the ill patient themselves or when the illness episode has been displaced

from the satellite unit. Displacement of illness from the unit brings a sense of relief whereby patients are no longer exposed to illness either visually or knowing that it is present on the unit (Code 4, Code 304, Code 398). Illness is an absent aspect of dialysis satellite unit experience with only occasional exposure to it.

### **9.1.5 Absence and Presence of Doctors**

The absence of doctors is a variable experience for patients. Patients on the main unit are accustomed to medical staff being present and having almost immediate access to them. Immediate access is reassurance against the presence of illness and death. The fear of death brings constant seeking of medical reassurance which is demonstrated in the interview extract provided below.

Patient 7; Unit 1

*I came round and thought I'm ill as well and I can't just look..... Sometimes you, er, find yourself a bit selfish in yourself; you think there is no other one bar you, like. Then gradually my mind started working well, I can understand why they're in the same boat as me like you know, maybe some are a lot worse than me, and that's when I started thinking like well, just calm down and things will come right. That's how it was at the beginning, all I thought was I wanted attention straight away; I didn't seem to look at anyone else. Like if I clicked my fingers, I wanted attention (from doctors). Then it gradually wore off; I think I was frightened basically I thought I'm on my way out (to die) here. (Code 100)*

Presence of a doctor signifies an issue with illness. The desire to see a doctor is necessitated by an alteration in health stability. There is an aversion to attending the main unit to see medical staff unless the patient absolutely necessary. The absence of medical staff, on a day-to-day basis, provides little concern to most patients. However, this is contradictory because some would like to see a doctor from time to time for reassurance. Patients recognise that being at a satellite unit means s/he is not seriously ill and does not warrant constant medical attendance (Code 6). Having health problems met by the unit staff is preferable and emphasises the non-serious nature of illness

Patient 1; Unit 2

*\*I*

*Do you see the doctors up here?*

*\*R*

*It doesn't make any difference. Honestly it doesn't bother me. I only want to see a doctor when I need one. That is all I can say really (Code 6).*

Patient 6; Unit 3

*I don't know, I mean if you are through here it means you are not as ill as the other ones who are poorly at the minute. I think the nurses have to spend more time with the ones who are really ill, do you know what I mean, they seemed to be always rushing about through there (The main unit). You do see the staff but I mean they are trying to care for the ones that are really sick at the moment aren't they? But if there is something the matter with somebody they would still do the same here but it's because we're pretty fit but, do you know what I mean. With being on here we don't need to see the doctor all the time. (Code 6)*

Unit three has a nurse consultant who undertakes the role of medical assessment of patients.

The nurse consultant provides a conduit for health management and referral to medical staff (Code 187). The intermittent presence of the nurse consultant provides a sense of security that illness problems are solved without attending the main unit. Only serious problems are referred to the main unit (Code 187). The absence of a nurse consultant on units one and two had no affect upon the sense of security provided by the nursing staff (Code 203, Code 204). The perceived ability of nursing staff to deal with illness promptly and successfully allows relaxation of the patient and illness distancing. Patients know they can see a doctor should they need to.

The total absence of a doctor is not a fully acceptable situation. Both patients and nurses feel the need to have medical support; though not a constant presence. The absence of medical staff is only a partially hidden absence that is veiled by the physical distance from the main unit. Medical presence can occur through request or spontaneous visit or the transferral to the main unit. Absence of illness security requires reassurance something the patient desires. The occasional reassurance visit by medical staff even to confirm no change in health status is absent and despite feeling safe it is felt to be a necessity by both patients. Illness is managed and minimised to ease the patient experience.

## 9.2 Feeling Safe

### Summary of General Structure of Experience

Treatment at a satellite unit is one of feeling safe. Repetition and routine brings an experience of familiarity, certainty and predictability. Feeling safe means a sense of nearness. Nearness is the close physical proximity of the unit to home. Nearness is also the physical closeness of the nursing staff and other patients that provides a feeling of togetherness. Togetherness is a psychological closeness that means being known and knowing others. Being known and knowing others removes emotional distress from treatment establishing a sense of relaxation. Being known by the staff, such as how to use their vascular access or being given information about their treatment, makes the patient feel safe. Patients feel safe knowing they will see the same staff and can predict how they will be during and after treatment. Knowing others and being known in a small unit with few patients is belonging to a community. Satellite unit experience means patients can relax and make no effort with relationships. Feeling safe is not thinking about illness being present.

### 9.2.1 Routine & Repetition

Kidney failure brings to a patient's consciousness uncertainty about everyday life. However, kidney failure also brings certainty for the need for dialysis which in turn sustains life and the very uncertainty of having kidney failure. To escape from the uncertainty of dialysis is to receive a kidney transplant; this is equally uncertain. A kidney transplant represents a return to normal everyday life of wellness (Code 234, Code 466). Normality is thought of as a life without illness, not having to see ill people and of personal illness. The prospect of returning to a life of wellness is felt as something that sustains patients as described in the extract provided below.

Patient 3; Unit 1

*Well the thing is wondering if you are ever going to be right (well) is one thing. I've got to try and be positive that one day I maybe lucky enough to get a transplant and be normal again. You've got to think positive all the time. If I thought I wasn't going to get well again or some thing like that like some of the patients that come this is going to be the rest of their lives. At times I wouldn't want to come. I'm lucky in that I've got a little bit of light at the end of the tunnel (Code 234).*

Transplantation sustains the individual to endure dialysis by offering a future of time not lost to dialysis. Time lost to dialysis is time lost in its repetition of routine (Code 451, Code 452). Routine and repetition involves activities and events such as preparing for treatment, watching the same programmes on television, eating the same food, placing the vascular access arm in a certain position, and talking to the same people (Code 25, Code 247, Code

470, Code 402, Code 42). The repetition and routine of attending for treatment is imposed upon the person and is essential to carry on. Attending a dialysis unit on a routine and repetitive basis bring with it accustomedness to experience. There is a grasping of what is to occur and what may be predicted with some degree of certainty (Code 25, Code 121, Code 377). Dialysis is an experience of routine and repetition that creates an expectation of what will happen within the routine. Other people, activities and events assume a chronological order and an expected existence (Code 4). Routine means a predictability of life arranged around dialysis. The extract below describes one patient's typical day arranged around dialysis. The extract identifies important chronological aspects of preparation, waiting, and recovery. Interestingly dialysis treatment is omitted.

Patient 7; Unit 2

*\*I*

*What is your typical day on a dialysis day?*

*\*R*

*I Get up, get ready wait for transport. I get up at half-past five because I can't rush about. I have my breakfast and I need my inhaler. Then I wait for transport and then come here. I go to the toilet a couple of times to make sure nothing happens while I'm here (at the unit). I go the foyer but not too early (to wait for transport). When I come home it is quiet and have a sit down and have my dinner and a drink then a read or a sleep then go to bed about ten and sleep pretty well (Code 4).*

### **9.2.2 Nearness & Closeness**

Nearness and closeness are structural aspects of proximity. Proximity is the psychological and physical presence of important aspects of satellite unit experience being at hand. The decision by patients to attend the satellite unit is one that brings them nearer to home (Code 124, Code 386). The nearness of a satellite unit is consciousness of its physical position near to a patient's home or what they regard as local. Whilst for most patients the satellite unit was near to home, for one or two it made no difference in distance whether they were at the main unit or satellite unit. What these patients gained was quicker access to the unit which saved time and provided a temporal experience of nearness (Code 386).

Nearness is important not only because it saved time, but because it provided opportunities perceived absent at the main unit. Consciousness of unit nearness allowed patients to think freely of doing things for themselves. These opportunities were perceived as not available at the main unit, such as driving themselves to and from dialysis. Other patients considered the possibility of using public transport whilst one or two were able to walk to the unit. This opportunity is described by a patient in the example below (Code 386).

Patient 6; Unit 2

*They said why not go to the satellite unit it is only walking distance from your home if you are having all these problems (with transport). So, it opened in the January but I said I will continue (at the main unit), but when all the problems (at the main unit) started I thought that I would have a look. So I walked here and cut across and timed my self and it only took ten minutes. So I came here and they reassured me every thing was fine.. (Code 386).*

Nearness is a convenience that makes life easier and less of an ordeal (Code 263). A unit's nearness allows the convenience of attending on non-dialysis days for whatever purpose; such as collecting medication. Nearness to home posits the unit in an area that is known to them enabling them to feel 'relaxed' and safe (Code 388).

Feeling near is not confined to the proximity of the satellite unit but includes other aspects of experience. There is consciousness of the nearness of other patients who can be spoken to and seen (Code 123). In the example below a patient describes his experience of the importance of the nearness of other patients.

Patient 1; Unit 3

\*R

*The main unit wasn't too bad, but you could only talk to who ever was nearer to you. Here it is all tight (all in the same room) and you can talk to everyone and see everyone from where you are sat. You can talk to anyone form any seat. I like to have a joke and a chatter but everyone knows that if you want a sleep then you can (Code 123)*

The nearness of other patients provides a basis for communication with them which is felt to be important. Nearness of others who can be talked to and seen removes feeling isolated and

distressed: as experienced at the main unit (Code 123). The same patient as above elaborates upon his experience.

Patient 1; Unit 3

*I've always liked the closer group. It is more spread out (at the main unit) but there were patients there who I didn't get on with and that used to upset me. So when you have a smaller group you can talk and help each other out as well (Code 123).*

Nearness is also consciousness of the close physical proximity of the nursing staff at the satellite unit. Like other patients, the staff are visible and at hand. The sense of proximity occurs through the nursing station being physically situated in the area where the patients are treated (Code 310, Code 312). Nursing staff are visible and present which enables patients to relax. The nearness of nursing staff is reassuring and enhances the feeling of being able to relax (Code 388, Code 486).

Closeness is a term used by patients to describe experience of being at the satellite unit. The word closeness is often used interchangeably with nearness but specifically is used to describe a psychological experience. Closeness is an awareness of an emotional relationship between patients and between patients and nurses brought about by nearness, routine and repetition (Code 123). Closeness is a feeling of being understood, not being isolated, and being able to talk at a level beyond simple day-to-day social niceties through knowing others and being known: a sense of togetherness (Code 3, Code 365).

### **9.2.3 Being Known, Knowing Others and Knowing What to Expect**

Frequent exposure to repetition and routine creates familiarity with the unit as a whole. Familiarity between patients and between patients and staff does not hold the negative meaning of easy going or carelessness. Familiarity is experiencing things and people that have become well known to the patient: a close acquaintance (Code 121). Familiarity between nurses and patients provides a situation for knowing the other person and being known. For the patient, being known is the recognition of being an individual (Code 174). Being

recognised as a person and an individual on the satellite unit is a different experience to that of the main unit. At the main unit there was no sense of individuality, rather a feeling as if being a commodity or being on a processing line in a factory (Code 239). An experience of lack of individuality is briefly described in the below extract. The brevity of the extract was is not uncommon: patients found it difficult to describe and used analogy.

Patient 7; Unit 1

*You're just in big rows down at the main unit, like a conveyor belt sort of thing.....That's one thing at the main unit I didn't get to know any of them. You are in you got your dialysis and you were away (Code 239).*

Being known is more than having the patient's name known; though this in it self is important. Being known by name helps create a sense of the personal. The name of the patient has meaning and identity and a tacit knowing of that person (Code 108). Being known by name attracts attention to the patient such as being greeted when entering the unit or knowing that such a person requires a certain kind of food or treatment (Code 108, Code 369). The extracts below show the significance, for the patient, of being known by name and what this means. Being known by the nursing staff establishes an absence of effort on the part of the patient in their approach to treatment. The absence of effort is a feeling of being 'relaxed' (Code 388). Patients use the word 'relax' to describe their dialysis experience at the satellite unit.

Patient 1; Unit 3

*Like at the main unit and places like that they don't really know you, you are just a patient. Whereas here they are personable, you know it is Pete and they'll come and sort things out and fill in things for you. You walk in and the other patients say 'hello' and the nurses all know you. It's not like you feel like it is somewhere where you don't want to go really (Code 108)*

Patient 5 Unit 2

*\*I*

*You said was more personal up here.....*

*\*R*

*Yes, one to one.*

*\*I*

*What sort of things do the nurses do?*

*\*R*

*Well it is difficult to put that in to perspective. When you walk in the door you it's 'You're number five John' and within minutes there is somebody there to put you on.*

*You are not sat out, I'm here early in the morning, I'm here at seven and I read my paper and they say 'come in'. (Code 369).*

Patient 3; Unit1

*You feel more relaxed about it. You know exactly where they are going to do it and how they are going to do it, relaxed. Unless it's me, I'm a sensitive sort of person and things like that affect me, you know what I mean. I don't know every patient may not worry about things like that, I do. I know that they're going to treat me exactly the same every time I'm quite happy (Code 388).*

To relax is not to have to think or worry about dialysis. To relax is not having to make the effort normally required by patients of making themselves known to the staff. Making yourself known to staff may include informing them about their vascular access, treatment or aspects of their life. This all takes effort causing worry about uncertainty. Initiating dialysis is easier and saves time through already being known; as does terminating dialysis. Patients are known, such as those who will take longer to stop bleeding or what dialysis prescription they are on, without referring to the prescription sheet (Code 257).

Being known includes knowing about personal aspects of a patient's life such as family members, personal history or holidays. Additional to this is being noticed. Being noticed is where staff notice changes in the patient which may be health related, but may also be simple things such as a new pair of shoes and commenting upon it (Code 257) Being known in this manner is being known in depth and being paid attention (Code 467).

Being known is not experienced in isolation but along with knowing others. Knowing others includes patients and staff of the satellite unit. Other patients are known by name and talk to each other (Code 255). Knowing other patient's involves personal information which often includes partner relationships and health problems (Code 255). Knowing other patients involves talking, sharing and humour aimed at each other, themselves and the nursing staff (Code236, Code 479). The knowing others provides the background to enable humour to be used. Humour helps create the patient's 'relaxed' approach to dialysis in that they know what to expect from the other patients or staff and feel confident to think of other things (Code 388,

Code 479). For example, in the extract below a patient describes the effect humour has upon the dialysis experience.

Patient 2; Unit 3

*\*I*

*You mentioned about having a laugh is that important?*

*\*R*

*Definitely, when you come in here and you have to go on these machines to start with and you're sitting there miserable all day. It makes it a lot better, it makes you feel easy and relaxed with the nurses having a joke on with you. You come in here all miserable it will make the day even longer. Like I say most of them is all right, they like a joke (Code236).*

Knowing staff members is about knowing what to expect. Staff are known by their names. Name personalises them opening up aspects of their lives which become known about; such as their family. Knowing the staff occurs through routine and repetition as well as seeing the same staff each time. At the main unit staff are experienced as strangers who perform treatment and leave (Code 256). Main unit staff are busy, there are more of them, on many different shifts and may not be seen for several days or weeks at a time (Code 235). Patients do not know who to expect and how the nurses will perform. New nurses or nurses covering staff shortages at the satellite unit do not allow the patient to relax until patients know what to expect (Code 108). Knowing the staff is knowing how they will perform which in turn gives confidence in their ability. Having confidence in the staff enhances the relaxed approach of the patient towards dialysis and how they will feel during and after treatment. Not knowing who will be present and how they perform provides a feeling of uncertainty from which the patient cannot predict how they will feel (Code 473).

Patient 8; Unit 1

*At the main unit it was different staff and different faces at times, swapping and changing all the time, because at the main unit they are mainly ill people compared to here, but well I'm ill but. I mean they were older and they had more symptoms than I had and needed more looking after and that. (Code 473).*

Knowing others and being known is a background of certainty for the patient. Certainty for the patient is knowing what to expect. Knowing what to expect is related to the absence of illness. The absence of illness removes busyness, illness activity and an uncertainty of not

knowing what to expect. This in turn provides a calm and quiet environment. Knowing other patients are well means that the patient does not have to think about or see illness. Patients know that staff time is not consumed by illness and its activity, which is time available to spend with the patient. Knowing these features of certainty enables the patient to predict their experience and be 'relaxed' about dialysis (Code 377, Code 121). Feeling certain about what to expect is emphasised in the whole experience including when transport will be available, how problems will be dealt with and how vascular access will be managed. This feeling of certainty is described by a patient as a typical example what being known by staff members means. Being known is being looked after.

Patient 3; Unit 1

*What everybody's fistula would be like or everybody's line and know treatment and what's gone on before. I mean, erm, when they come to me they know how exactly my fistula is like. They know how to put it in with care, with out accidents. When they go to a certain patient and they've been treating them for so long they know exactly how to treat their fistula or their line. It gives you more confidence, makes you feel more relaxed about it. They know how to look after you. I think it is a big thing is that. If there are different people every time when they come to connect you up, if they've never done it before, I mean never done you before er, they don't know the little pit falls sort of thing. (Code 377)*

Dialysis experience at the main unit is one of uncertainty. Not knowing the staff and not being known by them means a patient does not know what to expect. Time is not made available and the patient is uncertain how things will be done and how they will feel (Code 128). Knowing what to expect provides the patient with a feeling of being in control (Code 136, Code 377). For a patient to predict that dialysis will be uneventful and he or she will feel well afterwards establishes an ease with life towards dialysis. Knowing there will be no problems has a feeling being looked after by the staff (Code 118, Code 103, Code 174).

#### **9.2.4 Being in Safe Hands**

Satellite unit dialysis is experienced as feeling safe by being in safe hands. Being safe occurs through interaction with staff and observation of unit activity. Dialysis may cause problems during the treatment: commonly a sudden reduction in blood pressure and cramp. A drop in

blood pressure may make the patient become unconscious or suffer cramp which will cause pain. These experiences are disliked and provide a feeling of not being in control and shame at losing control (Code 147, Code 279). Not being able to predict when these events will occur makes the patient feel insecure.

Knowing that a nurse is present, visible and ready to act establishes a background of feeling safe (Code 486, Code 302). Main unit experience is an absence of nursing presence and visibility creating a sense of abandonment whilst receiving treatment. Episodes of low blood pressure may go unnoticed by staff (Code 1279, Code 280). Feeling insecure about treatment is an absence of relaxation and distraction away from treatment time. Observing ill patients and associated illness activity causes concern about their own condition and how it will be managed (Code 203). The patient experiences a paradox whereby to be ill consumes time and attracts attention and yet they do not want to be ill to attract attention related to illness. Being a non-ill dialysis patient in a main unit is a feeling of not being safe and abandonment.

Staff visibility is essential in order to feel safe (Code 486). The large size of a main unit meant that staff could disappear from view (Code 434, Code 239, Code 280). Visibility is not just being able to see staff but also being able to talk to them whilst they are visible (Code 279). Visibility of the staff is evident at the satellite unit. Staff are visible all the time and are always present (Code 204, Code 407). Staff members get involved in conversations and ask how a patient feels. Being asked about health throughout treatment is reassuring to the patient. Reassurance for the patient is knowing that they are being observed and present in the minds of the nursing staff (Code 369, Code 489).

Additional feelings of safeness are experienced at the cannulation time. Cannulation time at the main unit is associated with problems of pain and delay (Code 16, Code 32). Pain and delay is experienced as not being in control and knowing that this lack of control is to be expected. A satellite provides feelings of safety and expectation by knowing cannulation will

be uneventful and is performed in a manner the patient expects (Code 108). Cannulation or dialysis access is immediate, quick and with minimal or no delay (Code 489). Here, the patient does not have to think about cannulation to the same degree of pain and uncertainty as experienced in the main unit.

A patient feels in safe hands when they receive immediate attention when feeling unwell. Problems are dealt with promptly, thoroughly, on a continuous basis and are patient focused (Code 369, Code 349). Patients know there is someone there who will sort their problems as soon as they occur and to their satisfaction (Code 380).

Feeling safe for patients is knowing what is happening to themselves. Patients feel safe about how they can deal with their treatment by knowing what is happening to them (Code 223). Being given information by staff about treatment, such as blood results, is a feature of feeling safe (Code 425). Time is spent with patients providing information and clarifying treatment issues. Spending time with a nurse is reassuring and establishes a sense of trust and openness between the patient and nurse (Code 102, Code 109). A patient feels he or she can talk to the nurse about their treatment and they will be listened to which helps them 'relax' and feel cared for: something not experienced at the main unit (Code 109, Code 163).

### **9.2.5 Experiencing Community**

Feeling safe enables 'relaxation' about dialysis and as such provides space and time for talking about subjects other than treatment. The content of talk is varied ranging from treatment related aspects to family and personal issues (Code 135). A number of features makes interaction more personal and includes unit size, fewer and closer patients, staff visibility and presence. (Code 249, Code 404, Code 405, Code 207). Involvement between staff and patients alters relationships to one that is highly sociable. There is an effort to get on well with each other by staff (Code 406). Staff are aware of their influence upon patients and

modify their behaviour to present one that is friendly, helpful and not confrontational (Code 176). The extract below demonstrates the importance of maintaining relationships in order to keep a relaxed unit. Nurses are sensitive to their own behaviour and that of colleagues and how it affects patients.

Nurse 2, Unit 1

*..... If you have got an issue you have got to tackle it straight away to sort the problem and to keep a friendly atmosphere as well. The patients pick up things quite easily. Like last week one of our nurses was in a bit of a mood and the patients picked up straight away and they become quiet and careful. How you behave does impact upon patients. You are quite close to them in there, you can't escape as such so how you are and your behaviour will affect the patients so you have to sort it out before the patients come in. On the main unit they wouldn't pick it up so easily (Code 176).*

Knowing the staff is a form of friendship. This friendship is reciprocated by the staff though they must maintain a professional aspect to their role (Code 357). Staff ask about a patient's home life and experience and continue this on each treatment day. Staff friendliness is clearly identified as being different from that of main unit. Patients feel they can have a bit of fun with the staff and talk to them about almost anything. Staff are seen as more than nurses but friends in themselves. A friendship with staff establishes over time and they are people whom they trust (Code 216, Code 217). This friendship is a closeness which is described as a community or a family (Code 1, Code 3, Code 161, Code 199). Each person gets to know how each other, what they like and dislike. The feeling of community means patients do not have to work at relationships. Attending the unit is done so with ease. This sense of ease is demonstrated in the extract below.

Patient 6; Unit 3

*\*I*

*Is there more of a community here?*

*\*R*

*Oh aye, everybody is friendly, everybody knows what is happening.*

*\*I*

*What difference does that make?*

*\*S*

*Why it is a big difference because you can relax. You are not, er, going to a unit where you are isolated like, you know what I mean. If you want to talk to somebody you can, if you don't you don't, you know (Code 1).*

The above extract highlights the importance to patients of not being isolated but being part of something. The sense of community or family is one where there is a feeling of belonging where they all have something in common. The feeling community provides a feeling of safety not experienced at the main unit: it is a feeling of being normal. (Code 128, Code 197).

This experience is typified in the extract below.

Patient 7; Unit 1

*You're just in big rows down at the main unit, like a conveyor belt sort of thing. To here you get swapped about and you get to know the patients, get to know them by their names. That's one thing at the main unit I didn't get to know any of them. You are in you got your dialysis and you were away. Here it's like a little family, I know everybody by their first names and there is always some part of the day you have a good crack with them.*

*\*I*

*Is that important?*

*\*R*

*Well, er, you're more relaxed then, er, just everything about you, er, more relaxed, its kind of hard to say but yeah more relaxed. They're good company, you can have a good laugh with them. You can talk about dialysis like er, how are you feeling today? Sort of thing, you can say well I've had a bad night or, sort of thing, you can talk and it gives you reassurance it is not just you; there's other people going through things just the same as you. Like at the main unit you didn't do owt like that, you went in, you went onto your machine and never spoke, four hours you just lay there and tried your best to go to sleep and here you can have a.....*

*\*I*

*You mentioned about having a laugh is that important?*

*\*R*

*I do, it takes other things off your mind. You think you're back to kind of normal kind of thing. You're not lying worrying or thinking what goes through your mind. It takes all that out of you. That's what I think (Code 166)*

Feeling safe in this community is a sense of normality. Satellite unit community is being “back to normality.” Being involved with others is feeling safe and means relaxation.

Staff and patients interact in non-medical manner not only in the unit but often beyond the unit. Staff arrange events that are not illness or treatment related such as a Christmas meal at a restaurant or birthday and Christmas celebrations (Code 1218, Code 194).

Nursing staff feel it is part of their role to make patients welcome, to try to make them happier and show them how the unit functions. Knowing what to expect for the patient helps a nurse maintain the calm environment that enables relaxation for the patient. Additionally it helps the

staff appear relaxed, from the perspective of the patient, which enables them to feel they are making a difference to patients (Code 270). Staff feel a duty to establish this kind of environment and relationship as described by a nurse in the below extract.

Nurse 1; Unit 3

*I think it is more the patient is happier and they don't mind so much coming here for dialysis. You have got to make a difference, I mean they are here for four hours and we chat to them. Sometimes we do a quiz on the odd occasion; it helps pass the time away. And they all have their own televisions here. I think they are made to feel a little bit more special. At the main unit they had to share like one between three (Code 269).*

Normalizing patient experience away from an overtly treatment dominated experience is important for nursing staff. This is a feeling that necessitates staff to entertain patients which enhances distraction of consciousness away from dialysis treatment (Code 270, Code 179) and shows life can be normal. This personal view, which is shared amongst staff, is for the patient's benefit. They make great effort to arrange events such as a Christmas party (Code 343). Nurses also endeavour to develop trust in patients. This is so that they will feel comfortable when they attend for treatment and enable better interaction (Code 351, Code 468). Trust helps develop a community or family feeling that patients experience. Trust is felt to be essential to create the relaxing experience where staff view patients as being settled, gain physical weight and talk about personal aspects of their lives (Code 356, Code 360). The example below offers a nurse's account of a patient being settled in satellite unit life.

Nurse 2; Unit 1

*\*I*

*How do you know somebody has settled in?*

*\*R*

*Their manner, they come in, they usually come in with a smile. They'll come in and find out where they will sit down and they will chat, they will be bright. To me they will be they feel relaxed and to me that speaks volumes. They are not afraid to come in to the unit, you know not thinking with dread. They usually start putting weight on because they start eating better because they are quite settled in the routine. We usually find with patients that within three months they have had to have their weight increased. I take it that if they are eating well then they are feeling well and they are feeling settled. To me it is also a sign that we are doing our job well, dialysing them well and we are doing our job properly. One woman said she was frightened to come here but after coming here she didn't know why she should be so scared. They come in saying hello and become communicative I think, you know with the same staff and the same patients, so the faces are familiar, the unit is familiar, they don't think 'oh I*

*don't know where I am sitting and who is putting me on'. Erm I think that has a positive affect upon them (Code 356).*

These experiences create an environment for the patient that makes them feel safe, secure, and certain about treatment. Nursing staff establish a community environment through a belief in minimising the medical and re-establishing a normal feel to a life on treatment.

## 9.3 Time Saved

### Summary of General Structure of Experience

Dialysis is time consumed from the normal everyday life of the patient. Time is saved, in the satellite unit, by shortening the full duration of dialysis time experienced. Fewer patients, absence of illness, direct and short travelling shortens dialysis time. Time lost is experienced at the main unit where dialysis time expands due to delay in travelling to and from home and starting and finishing treatment and the presence of illness. Time is saved through managing time by preparation and planning but is a delicate condition where problems may limit amount of time saved. Managing time enables it to be available for staff to talk and spend time with patients. Time spent with patients enables the planning and management of patient problems.

### 9.3.1 Dialysis Time

Dialysis is time consuming. The patient's everyday life time is consumed by the need to attend for dialysis. This involves treatment three times per week for approximately four hours each on each occasion. Everyday life is a life of normal activities, such as shopping, that is away from the dialysis unit. To have end-stage renal failure is to recognise a need for dialysis. To dialyse is to recognise the need to give time, from everyday life, over to dialysis time (Code 452). Dialysis time is accepted as a necessity: something that is to be done to sustain everyday life, not to dialyse is not to live. Everyday life is life also has an intermittent absence of dialysis. Absence of dialysis provides its distancing: its abeyance. Distancing is the physical and mental distance put between the patient and dialysis. Dialysis time is a partial losing of everyday life, something which the satellite unit partially restores by shortening dialysis time (Code 460). For the patient there is an urgent desire to get back to every day life as soon as dialysis is finished. Patients recognise the choices they have to make and the difficulty they have in the day-to-day challenges they pose. Being on dialysis is time given over to the possibility of a normal life through transplant. In the extract below a patient describes the situation of being a dialysis patient.

Patient 7; Unit 1

*(The satellite unit helps) It does because at the end of the day, you come here you want to get on and you want to get off and get out because four hours is long enough. You don't look forward to it but at the end of the day we've no choice in the matter unless you want to end it. Like you say well I'm cutting this out today, I might go*

*tomorrow or the day after and you're gradually going down the next thing is you're away (Dead) aren't you? So I think I've a bit more to live for. Some times you do get depressed don't get me wrong, it does get you down but the quicker you're down the quicker you have to pick yourself up. Don't let yourself go down that much because if you do you're on the slippery road, you know. I do get down now and then but I'm not long snapping out of it, I don't let my self get that bad, no way. Now with my sister (possible kidney donor) and that I've got to look after myself for that precious kidney it's like gold, get that and hope to get back to something normal, you know. Because life at the moment is, you know, you are tied, you can't go here. I used to be very active; I used to go here there all over the place. Until I get kidney that's that stopped you know. Oh aye it's a big thing, a big change in my life, terrible, but what can you do? They do their best here at the satellite unit (Code 273).*

Dialysis time is a reminder of how illness distances the preciousness of normal everyday life (Code 451). Dialysis time is a slow stretching out from and towards everyday life; it is a hiatus or an interlude in everyday life that is to be endured. Dialysis time is an invariant of patient experience and is structured by three parts; 1) time leading towards treatment; 2) treatment time; and 3) time leading towards everyday life. Time leading towards dialysis involves waiting at home for the time to leave, travelling time and time at the unit waiting for treatment. Treatment time involves preparation time, cannulation time, on time, 'clotting' time, and tidying time. Time leading towards everyday life involves waiting to go home, travelling time, recovery time, and experienced as time returning to everyday life.

The desire to reach the end of each dialysis interlude in everyday life is experienced as a dragging out or a slow creeping towards its end. Each hour is noted along with start and finish times (Code 450). Dialysis treatment time is described by a patient in the extract below.

Patient 2; Unit 3

*\*I*

*Is that one of the hardest things about being on dialysis, the time?*

*\*R*

*Aye, it never seems to go very quick it always seems to drag. Some people do five hours. I used to do three hours and that was great and now I do four and that's steady away now like. Between five and six (Hours), oh murder (laughs). (Code 450)*

Reaching the end of treatment time is made endurable by distracting consciousness of treatment time towards other things. Distraction of consciousness, away from treatment time, is an attempt to lose consciousness of this time in order to make the end of treatment time

appear nearer (Code 387). Losing treatment time in this manner is the filling up of consciousness with activities that distract (Code 248). The most efficient distraction is sleep. Sleep occurs intermittently during treatment time for many patients and as such loses treatment time consciousness in fragments. Further distraction occurs through reading of books or newspapers brought by patients. Listening to music through personal music players also distracts through the removal of audible reminders of treatment. The extract below shows the patients struggle to quicken the perception of treatment time.

Patient 2; Unit 3

*Mind I have got a CD as well. If I cannot get the Tele cause of an awkward (where it is positioned) chair I can listen to a CD. It is surprising how time flies when you are watching the television. If not you are sitting and time drags and it is boring, it bores you. If you are sat over there you watch the clock all day and that makes it worse. Some of them go to sleep and it flies over then (Code 454).*

Watching television offers much distraction (Code 91, Code 470). The ability to choose what is watched and listened to via headphones isolates intentional focus. Television distracts and loses time. The inability to watch television or to share a television and not lose time, limits distractional shift and is a disliked experience (Code 454). Engaging in talk and humour shifts the focus of consciousness of treatment time and fills in time. Humour shifts consciousness of treatment time towards others, away from illness worries (with its sense of time extension) and makes treatment time endurable (Code 236, Code 479). Humour's ability to help quicken time is explained below.

Patient 4 Unit 1

*\*I*

*You mentioned about having a laugh is that important?*

*\*R*

*I do, it takes other things off your mind. You think you're back to kind of normal kind of thing. You're not lying worrying or thinking what goes through your mind. It takes all that out of you. That's what I think (Code 479).*

Patient7; Unit 2

*It is more friendly you can have a joke with the staff. It is more light hearted. That makes a difference because if you weren't light hearted we would all be down and any light hearted talk would stop. Light hearted talk between patients passes the time unless you are asleep (Code 479).*

Spending time on treatment is more time than enough and should be minimal. Everyday life is precious time that is to be used as much as possible. If more everyday life that can be retained is time not lost to dialysis time it is saved time.

### **9.3.2 Time Saved**

Time spent on the dialysis satellite unit is experienced as time saved from dialysis time. This is because time experienced at the main unit is unacceptable time lost (Code 286). Time saved is also a reduction of dialysis time and a growth of precious everyday life. Time allocated to receiving dialysis is set by clinical prescription and therefore rarely changed. Erosion of dialysis time is a change that occurs when a patient is dialysed at the satellite unit. Time is saved in the period leading towards dialysis, through later transport pick up time. Later pick up time allows more time to spend in bed in the morning or to the self in the afternoon. Travelling to the satellite unit saves time by being shorter and direct (Code 182, Code 190). The opportunity for saving time increases a sense of confidence that enables some patients to bring themselves into the unit. This saves additional time as seen in the example below.

Patient 6; Unit 3

*I'm using my own transport. So with using transport I used to get picked up at about seven o'clock in the morning, well now I set off at ten to eight. So there's fifty minutes(saved). When I come off I used to have to wait at least half an hour whereas now I go straight home so there's an hour straight off the journey (Code 460).*

Shortening dialysis time can occur by increasing the availability of the self to be flexible to dialyse when an earlier treatment session becomes available. This has the added benefit of helping the nursing staff be efficient with time. The extract below provides a patient's description of a reason for early attendance.

Patient 7; Unit 1

*I mean, I can help them(nurses) out by coming in early and I help them out by coming off early and that is one less to take of at a night time. If I'm off here, this machine at three o'clock I can guarantee I'm at home at ten past. And that's walking up to the car park into the car and home in ten minutes (Code 460).*

Directness of travelling improves emotional preparedness towards dialysis time (Code 182). Emotions expressed as 'stress' and 'worry' are not at the front of a patient's thoughts about satellite dialysis. It is often expressed as feeling 'relaxed' (Code 388). Waiting time at the satellite unit is minimised (Code 488). There is reduced time spent waiting to enter the treatment room with more often than not immediate admission (Code 400).

Treatment time begins with self-preparation time. Self-preparation time aids the speed at which a patient can commence treatment and allows for treatment time distraction (Code 25). Self-preparation involves information elicitation for nursing staff by getting weighed and calculating fluid volume to be removed (Code 25, Code 42). Blood pressure measurement is undertaken as well as providing information regarding changes in health status. This in turn limits the time staff members will take to assess a patient's condition and treatment options during preparation time (Code 341, Code 342, Code 148). Self-preparation time is essential to enable distraction of consciousness of treatment time (Code 79). It begins with the preparation of the dialysis chair for personal comfort. Sheets, pillows and blankets are positioned in personal preferential manner and the chair is positioned to amplify distraction (Code 25, Code 79, Code 145, Code 321). Comfort is foundational for distraction of consciousness of treatment time (Code 104). Preparation for distraction of treatment time consciousness requires the placement of tools for distraction, such as books, television controls and radio or CD player, in a position that is convenient for treatment time (Code 341, Code 342, Code 148). Time spent undertaking this process is variable depending upon the individual but each person has specific activities to follow through. Completion of self-preparation time is demonstrated through the adopting a position of readiness (Code 87). This position is a signitive act that informs the nurse of a patient's readiness to progress to the next stage. The 'Ready' position is demonstrated by the arm for cannulation or central line being exposed whilst the patient is sat in his or her chair (Code 148, Code 402).

The sooner the patient adopts 'Ready' position, signifying their intent, the sooner the patient begins treatment (Code 44, Code 45). Initiating access is important in that delays at this stage will delay treatment and increase dialysis time. Avoidance of delay is established by not distracting a nurse during the activity. As soon as treatment is initiated distraction from consciousness of treatment time begins (Code 484, Code 485).

Termination of treatment time is a period of anticipation of restarting everyday life. Time is saved by the patient assisting the nurse wherever possible by applying pressure to removed needles to stop the bleeding: clotting time (Code 80). This is followed by further information elicitation such blood pressure measurement, weight and any health or treatment related symptoms. Rapid clearing of tools for distraction enables the patient to enter into the time following treatment. This time is directedness towards home with minimal waiting and travelling detour. Recovery time differs amongst individuals but is the period at home following treatment when individuals re-establish themselves into everyday life (Code 4, Code, 451). The extract below describes how dialysis fits into everyday life and the need to keep busy away from dialysis to maximise time.

Patient 6; Unit 2

*When I am on dialysis, I finish my job about five(am) I sit in the canteen down there for an hour then leave at about half six and get here for ten to seven. Then I have my dialysis, then I go home, make a sandwich, have a shower and in to bed. Get up about half five and start work at half seven. I'm always on the go and I think you need to be, I think you really do (Code 4).*

Time saved is an invariant of dialysis time at the satellite unit. It is experienced by all patients even for those where travelling to the main unit or the satellite unit made no difference. The main unit is experienced as time lost (Code 452).

### **9.3.3 Time Lost**

Time lost is the experience of losing time associated with everyday life. Dialysis time is time lost. However dialysis time at the satellite unit is time saved in relation to dialysis time at the

main unit (Code 452, Code 460). This experience is not one in opposition to but in relation to dialysis at the main unit. This means that it is experience in reference to previous experience and is a filled intention, that is to say, its contents are full and present. Each of the three structural parts of dialysis time 1) time leading towards treatment; 2) treatment time; and 3) time leading towards everyday life are lengthened at the main unit for almost all patients. Time leading towards treatment means an early rise in the morning or an early start for afternoon treatment (Code 452). Added to this, was a long journey to the unit picking up several people then followed by a long wait to get on treatment. This point is explained by a patient in the following extract.

Patient 1; Unit 2

*\*I*

*Did you wait a long time to get on dialysis at the main unit?*

*\*R*

*Yes, quite a while. I try and put it in terms of how you spend the time of day. I've been sat there an hour. They have all the machines to get ready before you can go in, it takes ages. The transport was bad. It would take ages. Sometimes it wouldn't turn up. I would ring up and ask if they were still coming or had they missed me and they would say it's on its way and that was half-past eight, quarter to nine. He'd come pick you up, take you down, nine o'clock and all the other people were on the machines then. Then you come off at one o'clock, taxi driver would be there at half-past one, two o'clock. It spoilt the day, always so late (Code 452).*

The above extract describes a common experience erosion of everyday life due to delayed treatment. This occurs due to slow machine preparation and transport delays. Time leading towards treatment is waiting time; waiting for transport, waiting to get to the main unit, waiting to get on treatment (Code 279, Code 488). Time leading towards everyday life at the main unit is waiting time; waiting for other patients waiting for transport, waiting to get home and waiting for recovery (Code 289, Code 488). Time lost to dialysis makes the patient feel worse than they already do through the importance attached to everyday life. This point is succinctly put in the following brief extract

Patient 7; Unit 3

*\*I*

*Is time important?*

*\*R*

*Well yes it is because the longer the day is on dialysis the worse the day feels. You want to get in get straight on and get off (Code, 447).*

Treatment time was also time spent waiting. When on dialysis, in the main unit, distraction of consciousness of treatment time is difficult due to the environment. The busyness of the main unit with many patients including several who were ill which delayed commencing treatment but also inhibited distraction (Code 162, Code 86, Code 36). Treatment time at the main unit is an inability to relax, a sense of being on edge all the time.

Patient 4; Unit 2

*\*I*

*Would you be calm and relaxed at the main unit?*

*\*R*

*No because there is too much noise from the machines or sometimes banging and people walking around and dropping things. It is too big a place that is why (Code 279).*

The above extract describes the experience of being at the main unit and inability to be distracted. Main unit time dragged and time availability was limited and brief. Staff availability was experienced as fleeting moments and waiting for these fleeting opportunities (Code 285, Code 129). Illness demanded time and those who were ill experienced more available time (Code 161, Code 36).

### **9.3.4 Time Made Available**

The satellite unit patient endeavours to shorten dialysis time. Distraction from the consciousness of dialysis time provides a means for enduring treatment time. However, treatment time opens up time not only for distraction but to have 'time spent with.' 'Time spent with' is time available with the nursing staff (Code 453). To have time to talk with nursing staff is different from the main unit. Time availability on the main unit is brief and hurried (Code 458). Main unit brief and hurried time experience is described by a patient in the following extract.

Patient 4; Unit 1

*Well, at the main unit they don't seem to have much time to talk to you and what have you. They are always busy but I'm not saying that they are not busy here but they*

*always seem to be buzzing around down at the main unit where here they seem to take it in their stride, you know what I mean. But I like it here (Code 452)*

Time made available on the main unit is brief and hurried and as such is time of unfulfilled need and expectation. The briefness of time is against a background of busyness. There is more illness, more patients and larger treatment space (Code 279, Code 284, Code 285). The limit of time made available for patients, on the main unit, is a disconnection from those providing treatment. The disconnectedness of time not available at the main unit is experienced as being a commodity to be processed (Code 239), which was felt personally and often with anger. Disconnectedness means impersonal care.

Patient 1; Unit 2

*R*

*..... It is impersonal down there, you are just a number.*

*\*I*

*How is it impersonal?*

*\*R*

*Well there's too many people as against the nurses, just impersonal. Here it is more one to one (Code 239)*

Patient 8; Unit 1

*You're just in big rows down at the main unit, like a conveyor belt sort of thing (Code 239)*

Patient 7; Unit 1

*We all named it the 'meat factory' (laughs) just a nickname the meat factory..... 'Next?' (Laughs) (Code 239)*

The last statement is a patient analogy to interpret their experience as akin to inanimate objects: disconnected. Time made available on the satellite unit is not brief time, it is fulfilled time (Code , 9, Code 11, Code 67). Needs are fulfilled by attendance listening, talking and humour (Code 236, Code 60). Fulfilled time is time made available for what is needed to sustain wellness, clarify and feel 'relaxed' with a connectedness to those providing the treatment (Code 388, Code 463). The impact of having time made available is typically described by a patient in the following extract.

Patient 6; Unit 3

*\*I*

*What difference does having more time make?*

*\*R*

*Why they have, you can talk to them and they have more time to explain things like.*

*\*I*

*Does that make a difference?*

*\*R*

*Oh yes because I like to ask all sorts of questions, very inquisitive.*

*\*I*

*Being able to talk to them and ask questions, how does that make you feel?*

*\*R*

*Better because you are helping with your treatment, you know what I mean. You are involved in your treatment. Whereas you normally you don't get to find out if you are at the doctor's and that they don't get to tell you nowt. Whereas here if I have had any tests I get to talk about it and ask any questions, talk about it and see how I feel (Code 453, Code 463).*

Shortening of dialysis time is made possible by the absence of illness (see illness experience) and fewer patients present at any one time (Code 207). Fewer patients are less distraction for the nursing staff. Patients experience almost immediate attention with a reduction in the time waiting to initiate treatment (Code 168). Fewer patients makes more time available for patients (Code 207).

## 9.4 Freedom to Practice: Making a Difference

### Summary of General Structure of Experience

Nursing experience of working on a dialysis satellite unit is initially grounded in a sense of isolation with no immediate back up. This isolation brings awareness to the nurse of the nature of their responsibility towards ensuring safe and effective treatment. Awareness of responsibility leads to a sense of cautiousness that is not reluctance, but an enhanced thoughtfulness about decision-making. The ability to make enhanced decisions provides an experience of freedom to practice: a sense of autonomy. Freedom to practice is a presence which is absent at the main unit. Autonomy gives a feeling of confidence greater than that experienced at the main unit. Knowing the patient is an involvement that sensitizes nurses to the patient experience. Autonomy establishes a feeling of pride and ownership of the unit, patients, and the care they provide. Freedom to practice means making a difference to the patient.

### 9.4.1 An Opportunity to Practice

The context for nurses to work in a satellite unit is variable. Many have experience of working at a main unit but made a conscious decision to begin working at satellite unit. The impetus for moving to a satellite unit was a desire for change. Nurses had reached a point whereby a feeling of significant frustration regarding their practice had developed (Code 427). Frustration was borne out of an inability to control their practice. Large unit size, great numbers of staff and many ill patients meant they were busy. This busyness meant an unsatisfactory way to practice and impersonal. A nurse describes her conclusion about her work on a main unit in the following extract

Unit 2; Nurse 3

*On the main unit I came to the conclusion that patients are managed like a conveyor belt; they come in and get them on to dialysis, do what you have to do while they are on then get them off ready for the next lot of patients (Code 282).*

This busyness meant a lack of focus and fragmented care. Main unit experience was a feeling of nebulous responsibility. Nurses often identified a deficit in their practice that could be fulfilled at a satellite unit. This deficit may range from management skills to simple clinical procedural techniques. For example, a nurse, in the following extract, describes the need to develop a clinical skill by moving to a satellite unit in spite of what colleagues warned against (Code 427).

Unit2; Nurse 4

*I wanted to master my needling because to come out here there may be no one else to fall back on to, so it comes down to your needling skills. If you screw up with a fistula then that patient is in serious trouble and has to be sent to a main unit. My confidence has grown over three years and I thought that I would like to try the satellite unit even though the manager at the main unit had said "it was a backwards step and you are just going for the easy life, the soft life" (Code 427).*

A satellite unit also offered a promise of managing a group of patients on a regular basis and decision making (Code 427). This point is made succinctly by a nurse in the following extract.

Unit 2; Nurse 1

*\*I*

*What got you interested in coming to a satellite unit?*

*\*R*

*What is was on nights you had your own group of patients to look after on a regular basis. You got to know them really well and on days I didn't feel that I had that same experience with patients. I felt that I wanted my own group of patients again and I felt the satellite unit would do that*

*\*I*

*Had you been to a satellite unit?*

*\*R*

*Yes I had done a few shifts and I felt it was more autonomous as well. You can make your own decisions to a certain extent without having to check with other people all the time. (Code 427).*

A satellite unit was perceived as a place of opportunity to be exploited for patient benefit.

The experience of a satellite unit is contrasted to main unit care. It offers nurses the opportunity to fulfil nursing ideological practice. The concept of holism is important to this group of nurses. They believe in this concept and its achievement at a satellite unit. The following extract emphasises the attraction of working at a satellite unit and the opportunity to practice holistically. The nurse emphasises some important structural aspects of experience that makes her holistic nursing possible

*I enjoy the smallness of the unit. It is friendly, erm it is very personal. It is an area which you can feel quite relaxed, you don't feel over stressed. You don't have someone breathing down your neck. You're given a lot of autonomy which is nice as you don't get a lot of that in nursing. You have got your own group of patients. You can look after them from coming in for their dialysis session, organising holidays, chasing up out-patients. Erm, basically you can care for them quite holistically which is nice because it is such a small unit you can have a lot of contact with them (Code 162).*

Clearly small unit size, friendliness, being relaxed, autonomy and a named case load are important features for successful satellite experience. These are features that have already been mentioned from the patient perspective which demonstrates a mirroring of experience between nurses and patients. Achieving a sense of holism provides job satisfaction even when there difficult times such as staffing shortages. This point of job satisfaction is demonstrated in the following extract.

Unit 3; Nurse 1

*I think I have gained job satisfaction and more confidence because there is only a few of us, sometimes there is only three staff, and you have got to make your own decisions. Where at the main unit there were doctors there and a lot more staff and you tended to seek advice even when you could have thought about it yourself (Code 251).*

A satellite unit has provided many opportunities and benefits to practice in a manner that appears to satisfy both nurses and patients.

#### **9.4.2 Isolation, Caution and Responsibility**

Satellite unit nursing provides an opportunity to practice in a way that is experienced differently to that gained on the main unit. Satellite unit experience is one of freedom to make decisions and autonomy. Commencing work at the satellite unit takes some time to get accustomed to. Satellite units are quiet environments, not busy like main units, with limited people in attendance. Satellite units are physically near to or parts of other buildings, such as hospitals, but contact with the people within them is very limited. An immediate feeling of beginning work at a satellite unit is one of isolation: of being on one's own as the example below highlights (Code 250, Code 417). This experience of isolation is described by a nurse in a typical manner in the following extract.

Nurse 1; Unit 2

*\*I*

*What do you mean isolated?*

*\*R*

*We are here and there is nobody near us, the rest of the hospital has nothing to do with us. Nobody comes in and out and it is so quiet. I was used to the discharge suite*

*where there are so many people coming from all over the place. Nobody is here, just us. It was strange at first. I was so used to the main unit and had been in that environment for so long that that it was just quiet (Code 250).*

The feeling of being isolated is 'scary'. Scarieness is an acknowledgement of no immediate source for referral, should problems arise, to other staff such as a senior nurse or doctor (Code 250, Code86). An inaccessibility of immediate referral to others is a grasping of the context that patient management is solely the responsibility of who ever is in charge (Code 416). The example below demonstrates the link between isolation and no immediate and direct access to help.

Nurse 2; Unit 2

*\*R*

*Er, the main difference is the isolation that you feel as opposed to the main unit where everything is on tap. Quite often if you have a problem and ring up you don't get in touch with the person you want straight away. On the main unit you have direct access to sort things out (Code 416).*

This experience is recognition of immediate responsibility that a nurse is confronted with and has to assume charge of. Responsibility like this can be absent, deflected or hidden from on the main unit. Absence of responsibility in the main unit is occurs through the management structure whereby senior staff assume total responsibility. Also it occurs where there are increased numbers of staff a nurse can hide or be lost amongst the numbers. This recognition is, as one nurse puts it, knowing that 'the buck stops with you' especially when a patient's life is at risk (Code 423). Acknowledgement of responsibility leads to an approach known as being 'cautious' especially about decisions (Code 423). Cautiousness is not a reluctance to make decisions, but thoughtfulness in greater depth and breadth than experienced at the main unit. This thoughtfulness enables a nurse to be clear of what is needed with this understanding and who is held accountable (Code 423). The experience is outlined by this respondent who contrasts main unit experience with satellite unit experience to demonstrate the need to assume responsibility.

Nurse 4; Unit 2

*\*R*

*On the main unit you have always got somebody else to fall back on and er, on a satellite unit the decision comes down to you. Now if you make the wrong decision and decide go ahead and dialyse the patient even though they are unwell and something serious happens on dialysis the repercussions will come fairly and squarely back to me. So the decisions that are made are very final and they stop here. I can't go to a higher grade and ask what shall I do or see a manager. I can contact the doctors which I do make use of. It was clear today that (a patient) needed to go straight away (to the main unit) by ambulance because he was so unwell (Code 423).*

Responsibility is not limited to patient care, unlike the nurse's experiences of the main unit, but expands to include the management and maintenance of the satellite unit in total (Code 432, Code 27, Code 47). In this instance the nurse has to consider issues such as cleaning, kitchen function, hygiene, ordering supplies as well as dialysis machine function and preparation. These responsibilities are undertaken by different people on the main unit leaving the nurse to focus upon patient treatment (Code 432, Code 169, Code 170). These indirect patient care aspects all have an impact upon the day to day function and routine of the satellite unit (Code 175). Problems with indirect patient care aspects may disrupt the smooth running of the unit in a minor or a major way. For example, a dishwasher failure means nurses washing dishes which consume time, or failure to order supplies may mean one or more patients cannot dialyse until replacements are acquired. These aspects are the responsibility of the satellite unit nurse.

Nurses express this responsibility for patients as a measure of patient satisfaction or wellness. Nurses measure their success by how well patients are during treatment. When patients are well, without symptoms or problems then nurses are satisfied. However, when there are problems, more often than not beyond their control, then they feel responsible for what is occurring. This failure of responsibility means they are not doing their job properly and limits satisfaction. This responsibility is emphasised in the following extract.

Unit 1; Nurse 1

*Sometimes I do sometimes I don't it just depends on how it is. If the patients are all poorly you think 'oh what am I doing to this patient?' Some times you do think what are we doing...er, what are we...er, we are very.....er sometimes we are not getting any job satisfaction. But on the other hand when they are always doing right like we have one gentleman, he came here, transplant failed, you just felt really gutted for the*

*bloke, he'd had a transplant for fifteen years and he came here and he was always, always poorly on dialysis. Now he is wonderful and that gives you job satisfaction that you have got him over that period when he has lost his transplant. And then he started feeling unwell on dialysis and now from whatever we have done for him. He dialyses well. So that gives you satisfaction. But when everything is going wrong you think 'oh what am I doing to this patient, I am not making his life any easier' (Code 439).*

Nurses see patients as improved through their behaviour. This is a recurrent aspect of satellite unit experience. Patients who deteriorate and require referral to the main unit represent failure. This failure means not being valued as competent. These nurses appear to have unrealistic expectations of what they can achieve. This feeling is compounded by comments made by staff from the main unit. Satellite unit staff feelings of enhanced confidence and autonomy in managing patients is not appreciated or understood by main unit staff (Code 281). Nurses only refer patients to the main unit when they are not in a position to solve the problem. However, not being able to solve the problem makes satellite nurses worry about how they are viewed. Satellite unit staff experience negative views and comments directed to them by main unit staff that infer their job is an 'easy life.' This is because they have fewer patients, it is not busy, no ill patients and it is quiet in comparison (Code 281). Satellite unit staff feel undervalued and criticised by main unit staff when a patient is referred back to the main unit (Code 205, Code 281). They are conscious of sending a patient back to the main unit because it stirs feelings of an inability to cope or failure to manage the patient correctly: in the eyes of the main unit (Code 205). The feeling of not being valued or appearing incompetent is expressed by a nurse in the extract below.

Nurse 1; Unit 1

*Erm..... sometimes I get the feeling when you speak to the nurses on the main unit they will, well you hear comments like 'they don't know how to do a dry weight assessment'. You are a bit conscious of sending someone to the main unit because they might think they (DSU staff) have let his weight pile on and not assessed him properly. I take that as being our fault rather than a fault of the system really being that they are not assessed as well as they are at the main unit. There is a doctor on site (at the main unit) and if you are unhappy with someone then you get them assessed. We can't they have to wait for clinic, you know they don't see the patients are going off all the time and you might have to put the weight up you see, are you with me?*

*\*I*

*Yes*

\*R

*You kind of sometimes get the feeling that it is 'oh the satellite unit they can't cope or deal with things like that'. It is not all the time, the odd occasion you do get some funny vibes, but nothing has ever been said outright (Code 205).*

To add to this experience of not being valued by the main unit is the feeling of being a staff resource for filling in for staff shortages elsewhere in the renal services. Additionally there is a feeling that their own staff shortages are frequently ignored (Code 428, Code 205). This feeling is compounded when main unit staff are provided as temporary cover for satellite unit staff shortage. These staff feel they are being sent to the unit as punishment of some kind (Code 281). Temporary cover staff are called by one nurse 'magazine flickers' because of their obvious lack of involvement and would prefer to read magazines.

### **9.4.3 Illness and nursing**

Nurses working on the dialysis satellite unit know their patients have illness. Knowing the illness experience enables these nurses to be sensitive to patient care. However, the sort of patient they expect to care for should be stable and not someone who has serious illness (Code 472, Code 294, Code 297). Experiencing serious illness is a potential but should be absent in order for the patient to be at the satellite unit. A unit structure is not one for seriously ill patients. When describing satellite unit patients the expectation of 'stable' patients is dominant. Patients should meet a certain type which is expressed by two nurses in the extracts below.

Nurse 4; Unit 1

*Well they are fitter than normal, they are not acute and we don't have facilities for acutes (seriously ill patients). So there is a certain level of fitness, so our role is to make a normal life as they can really. (Code 472)*

Nurse 2; Unit 1

*(Laughs) 'patients have' .... basically lots of problems, but stable on dialysis as in they don't drop their blood pressure. They can tolerate dialysis; they can tolerate their prescription without being symptomatic and without being unwell each time (Code 472).*

Managing a satellite unit requires planning that enables its efficient running. Patients who are ill or demanding alter the efficient running of a unit and as such are not satellite patients (Code 300, Code 297). Illness increases workload making the unit busier. This works counter to the accepted view that a dialysis satellite unit is a place of stability and control. Illness exposes the nurse to a sense of isolation which is felt proximally, but does become partially distant with experience. Medical assistance is remote and not immediate. Whilst medical staff may be accessible via telephone to the main unit, delay in receiving such help adds to the feeling of isolation (Code 250). Isolation is immediately felt upon starting work at the satellite unit and takes some time to get accustomed to. The extract below demonstrates the sense of isolation experienced by satellite unit staff from the start.

Nurse 2; Unit 2

*\*I*

*Can you remember your first day here?*

*\*R*

*Erm, yeah, it was strange, it wasn't like the main unit no coming and going. It was strange and I felt a bit isolated.*

*\*I*

*What do you mean isolated?*

*\*R*

*We are here and there is nobody near us. The rest of the hospital has nothing to do with us. Nobody comes in and out and it is so quiet. I was used to the discharge suite where there are so many people coming from all over the place. Nobody is here, just us. It was strange at first. I was so used to the main unit and had been in that environment for so long that that it was just quiet. (Code 250).*

Isolation provides a need for dependence upon rehearsed procedures and emergency services for extreme or critical illness. The support of the emergency services is comforting but not ideal because of delay. Waiting for help adds to the sense of isolation. Nurses develop a pragmatic approach to this issue as shown below.

Nurse 4; Unit 1

*\*I*

*What is involved in patients going back to the main unit?*

*\*R*

*Well usually they become ill on the machine and we have certain procedures that we go through. We have got crash trolley and all that lot. If they get to crashing stage we ring an ambulance because the hospital team has nothing to do with us as we are the main unit's and we just do CPR and call an ambulance. (Code250).*

The decision to contact medical staff or use emergency services forces nurses to expand self-reliance and sense of autonomy (Code 139, Code 140). This, in turn, provides a sense of increased confidence. Confidence is felt through decision-making that occurs when managing ill patients. Illness focuses thoughts upon what needs to be done and how to best to do it. Acceptance of the responsibility for making decisions grows through the absence of direct medical referral; there is no choice.

Nurse 1; Unit 1

*\*I*

*Is that different to working on a main unit?*

*\*R*

*Yeah to a certain extent I think, what it was you weren't capable of making the decisions you asked the doctor's advice because they were there. Whereas here you have to make that decision, you have got no choice in the matter. Obviously I am not talking about life threatening decisions; we're talking about small decisions. You know if someone was unwell you would ring up the doctor and say 'is it okay if we take them off?' but you could have made that decision your self. We have to do that here. You know sometimes you did rely on the doctors that little bit more (Code 140).*

Decisions relating to illness are about life threatening conditions, such as acute chest pain, serious infection, or minor illness issues. Illness is recognised to affect patients and is to be corrected so as to maintain a quiet, stable and controlled unit. The nurse establishes a presence and talks to patients as a collective. The presence of a nurse initiates talking between patients (Code 178, Code 247). The nurse endeavours to provide an environment of normality without illness.

#### **9.4.4 Presence of Autonomy**

Isolation, responsibility and cautiousness establish autonomy of practice and decision-making. Autonomy is a freedom to practice, a kind of liberty from the structures imposed on the main unit. Autonomy enables the nurse to adopt responsibility to do more for the patient than they are able to at the main unit (Code 98, Code 139). The ability to do more for a patient enhances a feeling of satisfaction about what they do (Code 251, Code 113). Autonomy in the satellite unit posits the nurse in the situation whereby s/he is free to make decisions without a

constant need to explain to a superior; as demonstrated in the example provided below (Code 98).

Nurse 2; Unit 1

*\*I*

*Is it a kind of freedom?*

*\*R*

*Yeah, you are not constantly, er, you are accountable but you don't have to explain yourself all the time to anybody else. That is nice because you can use your own judgement. You can always ask advice from your colleagues. This particular fellow was having his hand dressed and I saw it and said 'have you been to the doctor?' and another nurse said 'oh yeah, I never thought of that'. I don't mind, I wouldn't mind, I try to think rightly or wrongly that I have got quite a lot of common sense and if someone said to me 'what about this?' I would happily take the advice from others, if I wasn't sure. But other nurses, (like the senior nurse) who have got more experience in renal and it was something renal, er, if it was something general health wise, er, one of the ladies came to me and said 'give me some tablets for thrush I've been getting some backache' and I said 'might it be that you have got a water infection as well?' So I gave her an MSU (Urine specimen) bottle, toddles it back and yeah UTI (urinary tract infection). Then it was where is the best way to get a some antibiotics. Friday evening, ring the GP tell the story and, and the receptionist said yeah the doctor can do that, if not can she come in the morning (Code 98).*

The liberty experienced by satellite unit nurses is freedom to use knowledge and skills and a freedom to try ideas (Code 137, Code 139, Code 140). There is freedom to chose to do things; freedom to contact medical staff directly rather than referring to senior nursing staff, and freedom to use their own judgements (Code 86).

The freedom experienced by satellite unit staff is a presence of a different way of practice which is absent from their main unit experience. Freedom is experienced by the staff as a freedom to make decisions. Whilst in many instances the nature of the decisions may appear small or trivial they do enhance the ability of the nurse to function in an independent manner (Code 140). Increased decision making includes the ordering investigations, contacting the patient's GP and managing the patient's blood levels in order to minimising anaemia. By having an increase in decision-making the structure of independence of the satellite unit is enhanced and sustained (Code 423).

This liberty in their autonomy provides a responsibility to their self through a self-awareness and evaluation of their situation. Freedom to make decisions has accountability attached to it. Decisions and ideas are discussed with colleagues to assess outcome and success (Code 98, Code 420, Code 441). This freedom to practice and discuss issues with colleagues is a basis for improving confidence to practice more independently (Code 242). Increased confidence is a tangible feeling but is tempered by an awareness of their situation as expressed by this respondent below.

Nurse 4; Unit 2

*\*I*

*Has that (freedom to make decisions) altered how you function as a nurse?*

*\*R*

*Oh yes, it has and I am much more confident in my decisions than I ever used to be on the main unit. That can be a false confidence in a way because you have got nobody there to say that you shouldn't have done that. You haven't got anybody there to correct you necessarily right away. The good news is that I do feel confident about my decisions. When I reflect about certain actions I feel okay about it and if I am not happy about it I try to improve it (Code 242).*

A growth in confidence in personal practice appears to be a universal experience of all nurses on satellite units. Nurses feel confident in their ability to manage the unit, manage the patient, work with colleagues and communicate with the main unit. Confidence is also gained through being involved in the mundane but essential activities of the unit such as ordering supplies (Code 242, Code 170, Code 274). The extract below is from a nurse who describes her increase in confidence since working at the satellite unit

Nurse 3; Unit 2

*We do ordering, I work out the transport, I did the Christmas transport last year, that was okay. All these things, you are not left on your own, you just have to get on and do them. I.....my role I'm like an associate nurse to the E grades and not left in charge but there to assist them. I have extended my role in some ways like I say I have got my own patients, I do ordering, erm, you know, general things. Even my needling (Cannulation of vascular access) skills have surpassed really. When I left the main unit I didn't like needling grafts, I had an awful fear of needling grafts, and the sister who was my mentor at the time said 'don't be frightened of grafts, they are easy to do'. When I came, the first patient I had to needle had a leg graft and I thought 'Oh God I don't want to do it' but you know I found it quite easy. It was like a fear that I wouldn't be able to needle (Code 98, Code 169, Code 170).*

Being involved in this manner brings about an awareness of the requirements of the unit and the responsibility to make it continue to function: it has got to be done.

Confidence to manage the patient occurs through practical treatment and management decisions (Code 274). Such decisions may include whether or not to contact a doctor, refer the patient to the main unit or how best to manage a patient's vascular access. Being confident about patient treatment establishes the freedom to move into the personal and social aspects of patient care and know the patient better (Code 242, Code 120).

Communication with the main unit or patient's GP increases decision-making confidence by developing skills and strategies to deal with problems. This is of particular concern when communication is difficult, unsatisfactory or problems need to be solved (Code 278, Code 127, Code 22). Reasons for communicating with the main unit are based around issues of patient illness and treatment, machine problems, or seeking and providing information. The people contacted at the main unit are nursing staff, of the various subunits such as the transplant unit, doctors, dieticians, technicians and managers (Code 22, Code 127). Communication with the main unit is pro-active on the part of satellite unit staff in order to gain information needed to manage the unit and patients. This pro-activity is a response to the main unit not providing the satellite unit staff with the information as quickly as the staff would like. Such information is varied but is mainly to do with patient-related problems or information, such as admission to the main unit, or discharge home (Code 128). Pro-activity is borne out of a responsibility to ensure the unit continues to run smoothly.

#### **9.4.5 Nursing Time: For the patient and treatment**

Experience of a satellite unit is a unity of synthesis of aspects (a categorial intuition) which includes nurse's experience of interrelatedness with patient experience. Nursing staff are aware of time and how they can utilise this time. Dialysis time is limited on the satellite unit

requiring efficient use of time. Dialysis is a repetition of events and activities that allow for efficient use of time. Repetition involves knowing what is to come: it involves preparation for treatment, treatment, finishing treatment and starting again (Code 175). Nursing time is time to turn around to start anew. Turn around time includes preparation time; which requires the constant thinking and planning ahead (Code 374). Planning ahead involves an anticipation of events and activities. Preparation time is managing time for the future so that it may be used efficiently (Code 175, Code 465).

Efficient use of time, by preparation, enables patients to get on and off dialysis quickly and be ready for the next group of patients (Code 151). The routine of dialysis allows the knowing what is to be done and the active looking ahead at what is to be done and what may happen. Knowing what may happen is grounded in knowing the treatment and knowing the patients (Code 257). These factors enable the efficient use of time which establishes the 'time saved' experience of the satellite unit.

The experience of the nurse is directed to the future and focused upon the patient. Management of time remains directed upon what is to be done to make time available for patients. Each member of staff has a tacit understanding of what needs to be done when undertaking activities of preparation (Code 151). Each individual of the nursing team (such as sister, staff nurse or health care assistant) undertakes specific tasks. For example, the healthcare assistant is involved in preparing equipment for the completion of dialysis treatment whilst treatment is in progress (Code 231). Preparation and looking ahead makes time available to talk to the patient and spend time with them. Time spent with the patient makes knowing a patient easier and to assess for current or potential problems (Code 349, Code 350).

Staff shortage influences the efficiency of time and preparation with an increase in activity and speed of work. Staff members undertake activities normally performed by others such as

that of the healthcare assistant or another staff nurse. Members of staff work to limit potential time lost by using time made available through preparation time, though as the extract below demonstrates there may be a loss of time made available.

Nurse 1; Unit 1

*I think when you are short staffed and you haven't got the staff, you are just putting on and you are not giving the patients anything else. You are literally putting them on and taking them off and doing whatever you have to do and you very rarely get time to do anything else (Code 428).*

Staff shortages can influence 'time saved' by lengthening time going on treatment. There is activity to limit delay. The experience of looking ahead is a delicate one should there be a problem. Should something interfere with looking ahead then tension and urgency grows. For example the 'cannulation time' of getting a patient on to treatment is a crucial stage in saving time and should there be difficulty then it will cause delay elsewhere in the routine. Difficulty or delay of 'cannulation time' establishes tension for future activities, preparation and 'time saved' (Code 485). After delay or difficulty there is an attempt to re-establishing routine and preparation through catch-up. Catch-up attempts to place activities and events in order within routine in relation to time, though order may occur time placement may not. Patients whose problems provide recurrent delay or difficulty require referral to the main unit either by transfer for treatment or consultation to re-establish the routine (Code 297).

Nurses make time for patients. Efficient use of time makes it available to know patients. Knowing patients is important because this is where satellite nurses feel they can make a difference. Knowing a patient means they can be sensitive to that patients needs. For example, the following extract describes one nurse's reason for knowing patients

Unit 2; Nurse 4

*It is because sometimes a lot of the renal patients are elderly and so there spouses are elderly and you get to know more about the problems they encounter than you do on the main unit. For instance, there is one patient here whose husband has been getting problems with walking recently and it has been coming on quickly and he is no longer able to drive her to work and pick her up. Knowing what is going on in her life and how frustrated she feels and how exhausted she is running around after him has some bearing on the way she dialyses. In another case, when a patient was burgled you*

*knew he was going to have a rubbish dialysis because he was still in the trauma of being burgled. He came home from shopping and they had smashed the front door in and taken all the Christmas presents and turned the house upside down. He had to come in for dialysis the following day and was still shaken up; the police hadn't had time to get over there. We knew his blood sugars would be all over the place because he is a diabetic and even though he felt okay you knew there was a lot of trauma going on underneath (Code 257).*

This extract describes the depth of knowing that nurses become involved in. Knowing the clinical aspects of the patient is bound to knowing personal life (Code 257). This extract describes sensitivity towards a patient's experience that enables them to tailor care appropriately. Knowing the patient extends into their family life. As identified, in the above extract, the theme of extended knowing is important in understanding a patient's experience. Appreciating a patient's whole experience, through knowing, means being able to provide holistic care. In the following extract a nurse describes how extended knowing works in practice.

Unit 1; Nurse 2

*You get to know them well and you get to know bits about their family and things. They might have outside pressures, people who have family, husbands or wives who aren't perhaps well. One of my patients' husband was poorly near Christmas and it didn't take two minutes to ask 'how is your husband?' and she said he was a lot better and that they were going to do his operation on such and such and within that week the chap had had his operation and was a bit sore but she said he was feeling great. And that is all it took that little bit of empathy really, compassion. It affects your patient because they are sat there for four hours, they have got to come for treatment; how is so and so doing at home, are they all right? And I think that doesn't take much to show interest in them as a person (Code 257).*

The nurse calls application of extended knowing compassion and empathy. The point made about empathy is one of nursing's conceptual underpinnings however; it has allusions the fundamental phenomenological empathy discussed in the ethics chapter. As this nurse describes, her empathy is a fundamental beckoning to the patient. Indeed, this kind of knowing provides both the nurse and the patient with feelings of satisfaction. Knowing patients is important for satellite unit nurses (Code 257). They know even the little things that make a difference, such as how much sugar in tea.

Unit 1; Nurse3

*Like I say you get to know your patients here. Like three times a week and you get to know all the patients individually, you know and you know exactly what they want, if*

*you know what I mean. I even know down to how many sugars they take in their tea because you go round and do it every time and you sort of get to know from them (Code 257).*

Knowing patients builds up relationships that provide a means of establishing trust which enables a sense ease for patients. This ease with nurses means patients approach them with personal problems. Sexual problems are a common problem for dialysis patients but they do not discuss it openly. Satellite unit nurses found that patients begin to discuss these sensitive personal problems when they are at ease.

Unit 3, Nurse1

*Erm, sometimes they talk to us about their sex life. One of the patients, when we were doing the single assessment document, one of them said he didn't want to talk to people about that sort of thing when it was in a big room, it was too impersonal (at the main unit). Here they have told us more because there is only a few of us and they tend to see us more (Code 468).*

Extended knowing is places the nurse in a privileged relationship which means making a difference to the patient.

#### **9.4.6 Ownership**

Nursing staff experience a sense of pride in their unit. They have a sense of ownership of the unit and the patients (Code 340). Patients are expressed as 'their patients' or specific satellite unit name patients rather than generic dialysis patients. Satellite unit staff take pride in knowing their patients and their treatment. They feel this has been possible to achieve because of freedom to practice and manage their care. There is a keenness to make sure the patient receives the best care they can provide even if transferred back to the main unit (Code 340). The nurse aims to manage the whole experience of the patient to minimise discomfort or delay. The extract below outlines this concern for patients not being known and ensuring the delivery of optimal care.

Nurse 2; Unit 2

*\*I*

*And if a patient goes to the main unit?*

*\*R*

*You tend to ring across and find out how they are. You have to know because they are your patients and you have a sense of ownership. They are my patients and I want to know what is happening to them and you think you are giving the best care. It is not that you think that they are not good enough, it is just that you want the best care. You need to follow through to see how they are doing and when they are coming back. You have to manage the transport and the dialysis machine for their return. Also you need to know for when they return as you can't just rely on their version of things. There may be things peculiar to them or changes to their treatment that needs managing (Code 205).*

Ownership of patients is founded in the application of the 'named nurse' concept. Nurses take pride in the fact that they have responsibility for a case load of patients. Ownership means deliberate investment of time and involvement in patient care. The named nurse case load approach ring fences a specific group of patients for a nurse: they become her patients. An individual patient or group is expressed with a pronoun: my patients or our patients.

#### Unit 3; Nurse 3

*We all have our own patients: the named nurse. So you do the monthly reviews, the bloods and I find our patients have opened up more. We found a lot of things that were upsetting, worrying the patients that they didn't tell you about. I don't know if it was bigger and more impersonal. They have come to know us more being here and we do all day shifts so we tend to see our patients more than we did at the main unit because we only have the one shift. At the main unit we had three shifts so if the patients were in on a morning and you were in on a twilight you might not see them for three weeks. We see our patients at least once a week (Code 205).*

This sense of ownership may not be an unusual occurrence for nurses, but it is meaningful for the satellite unit nurses. They have invested themselves in knowing their patients and as such want to ensure they get the best care they can. Ownership can cause a satellite nurse much frustration particularly if a patient is at the main unit. As demonstrated earlier, staff frequently call the main unit to establish what is happening to their patient. Frustration also occurs with care other aspects of care. The following extract is taken from a description of a patient care situation on unit 2. It is based around a dying patient who normally dialyses at the satellite unit.

*A patient is to withdraw from treatment due to liver failure. Currently, he is dialysing once a week but why is not clear. Staff would prefer him to dialyse at the DSU whilst he is capable. He is drowsy but welcomes familiar faces. His wife is happy to continue at the DSU but would like him to die at home. There is a lot of palpable tension due to communication problems. Decisions are apparently becoming confused as other agencies become involved. The vicar is*

*apparently being very 'heavy' (a unit nurse's word) about how everyone feels. The staff appear frustrated over a lack of decision and support from medical staff. There appears no clear strategy for management. The senior sister wants to provide a service but knows what her boundaries are. She is possessive about her patient 'if he goes to the main hospital he will be shut in a side room and that will be the sum of his contact and he will not have familiar faces around him'.*

The sister voices her ownership through concerns for the patient. The patient is one of her patients and would prefer him to stay. This episode also demonstrates one of the unique variant episodes of experience where illness (and death) is not rapidly removed from the unit. It is positively retained on the basis of patient familiarity experience overriding illness.

The nursing experience on a satellite unit is one of enhanced practice, managing illness, confidence, knowing the patient and autonomy that provides a sense of satisfaction. It is not without its down sides such as staff shortages, but it provides a background by which professional ideological approaches to care can be aimed at.

# **Chapter Ten**

## **Discussion and Conclusions**

## **10.0 Discussion**

The findings of the research have been presented in a descriptive manner congruent with descriptive phenomenology. The findings described the categorial intuition of dialysis satellite unit experience. Articulation of the categorial intuition is presented in thematic form in order to make it understandable. From this description meaning has to be made explicit along with the implications for research and practice. This section will discuss meaning as well as implication for practice, research and provide conclusions. Whilst both nursing and patient experience are derived from different perspectives their convergence provides an experience that has positive meaning for each group. Understanding experience leads to possibilities for care improvement and career development.

### **10.1 Making a Difference: The Satellite Unit Nurse**

This research has been an investigation into the experiences of nurses and patients in three dialysis satellite units. The impetus for the study was grounded in experience; my experience. Patients had expressed a sense of satisfaction in the experience of being at a satellite unit and a reluctance to return to their main unit. An interest in satisfaction and reluctance experience gave impetus for me to think about this as a problem: what is the experience of a satellite unit for patients? Because patients have nurses involved in their management it became important to include the nursing aspect. The inclusion of a nursing aspect assumed a nexus between what patients experienced and what nurses experienced. This nexus is recognition of co-experiencing the lived world. Life is lived with and in relation to others and therefore they are part of lifeworld context.

Context, or horizon, is an essential means for understanding the lifeworld of others. This is because context is lifeworld: the point from which experience derives meaning. The lifeworld of a satellite unit, for nurses, proved to be important and influential. The context in which a nurse practices is important because it will provide meaning for themselves and in particular

their nursing identity. Satellite unit lifeworld, in a nursing context, was a form of liberation; a freedom from previous constraints. A reflective appraisal by nurses had demonstrated unhappiness with his or her current position and a satellite unit was an opportunity to redress it. The opportunity perceived inherent in a satellite unit was to practice with a sense of freedom. This freedom to practice is a welcomed acknowledgement of responsibility. However, responsibility is not an empty responsibility but one that is full with possibility of making a difference for the patient.

Main unit experience represented practice unfulfilled. The busyness on main units was an unintentional but frustrating distancing from patients. Being distanced from patients is an important issue for nurses; it goes against basic nursing ideology of patient-centredness. Patient-centred care has been influential within nurse education for some time. For example, Kenworthy (2001) maps out some basic concepts of patient-centredness for student nurses in a foundational text. In his mapping, Kenworthy (2001, p216) mentions a need for nurses to “willingly accept increasing levels of responsibility” as part of this role. Patient-centred care is also known as individualised care: responsibility for care catered to an individual’s needs (Binnie & Titchen, 1999). Patient-centred care or individualised care is not a new idea; it has been around for a number of decades. North American nursing has been influential in its development to provide a distinct area of focus for nursing practice (Binnie & Titchen, 1999). Patient-centredness is influenced by humanistic psychology and in nursing that is particularly by Carl Rogers. The Rogerian mantra of “unconditional positive regard” is an important foundational concept for patient-centred care. In essence it amounts to a ‘phenomenological bracketing’ of personal knowledge to avoid making judgements about someone. Here is an important point that relates to the main unit experience of satellite nurses. It is a fundamental existential philosophical approach: recognition of another human like me. Removing the possibility of judging a person opens up a possibility of connecting with the person. Being able to connect with the person at this level is directing attention on that individual: nursing gaze is patient-centred.

Satellite unit nurses disliked main unit experience because of it distanced them from patients (others like me) who are the focus of their practice. Connecting with patients is a fundamental pre-requisite in patient-centred care, but nurses experienced a disconnection. Disconnection is a loss of relatedness to what is important. The busyness of a main unit means practicing without relatedness, due to many patients, illness and lack of time. What occurs here is what Heidegger would call “technological enframing” (Heidegger, 1993, p332). Technological enframing means that something has become a resource to be used as a result of technology. Because of the busyness of the unit a nurse is busy managing dialysis treatments of the many; the nurse is enframed by the dialysis machine and it assumes a primacy over patient connectedness (Heidegger, 1993). This kind of nursing (enframed nursing) is an empty busywork (Bevan, 1988). For satellite unit nurses, main unit experience became an enframing one where they lost their relatedness to the patient. This loss of relatedness occurred due to limited time availability and a loss of continuity. Nurses were not alone to experience technological enframing, patients suffer as a consequence. Patients experience loss of relatedness by feeling like a commodity in a factory processing line; depersonalised, isolated and fearful.

A Satellite unit offers an opportunity to escape from the empty busy work of a main unit. An opportunity exists to reclaim the dialysis nurse’s relatedness to patients: nursing identity is reclaimed. A satellite unit offers nursing that is identity-constituting (Edwards, 2001). Identity-constituting nursing is nursing (and caring) that recognises that people are constituted by their concerns, which includes illness and its symptoms. The experience here is double sided in that by working on a satellite unit a nurse is able to not only constitute the identity of the patient but also her own. Satellite nurses can reclaim their professionally and socially constructed identity of being patient-centred. Satellite unit nurses identified patient connectedness as an important feature of their experience. Patient connectedness is an important feature of patient-centred care (Currie, Harvey, West, McKenna, Keeney, 2005). It appears that when a nursing environment is busy, there is a lack of time and nurses cannot

address fundamental needs of patients such as addressing patients' anxiety and concerns (West, Barron, & Reeves, 2005). Nurses are aware of this problem and feel it compromises quality care. Satellite unit nurses were sensitive to this problem and aimed to change their practice in order not to compromise their nursing identity. These nurses exchanged their place of work despite unsupportive comments from their colleagues at the main unit. This demonstrates a high level of commitment to reclaiming their nursing identity. However, the spectre of empty busywork looms nearby when staffing shortages exist. Indeed, when there were staff shortages, the primacy of treatment recurred much to a nurse's frustration which challenges the notion of holism. This is a problem replicated in other nurse-led units as Mcilpatrick, Sullivan & McKenna (2006) found in a chemotherapy unit.

Satellite nurses show a commitment to patient-centred care. They espouse and practice the named-nurse concept. The named nurse concept first saw light of day in the UK in the Patient's Charter of 1991 (Dooley, 1999). Named nursing is primary nursing by another name and is means of organising care by allocating a case load of patients to a nurse or nurses. The named nurse concept is enshrined in legislation and therefore had to be implemented into practice (Dooley, 1999). Implementation was variable with many areas paying lip service to the requirement. However, nurses appear to like the idea because it provides an explicit boundary for responsibility (Binnie & Titchen, 1999). This can and is problematic for nurses when they are busy and short staffed because it then becomes an unrealistic goal. An unachievable goal becomes a heavy weight of unmet expectations and a sense of frustration and failure. Indeed this is what drove many nurses to change their practice; they could not meet what was required.

Satellite unit nursing appears to demonstrate many of the concepts of patient-centred care identified by Hook (2006) such as autonomy, and close relationships. Satellite unit nurses demonstrate a commitment to the primacy of the patient. This commitment is demonstrated in the management of treatment. Nurses work to make time available for patients. Making time

for patients in a highly technological environment demonstrates a valuing of the patient as a person. The patient does not have to interrupt nursing activity to gain time; it is freely available. Valuing the person is a central feature for nursing, not just patient-centred care, but it also emphasises another concept and that of shared power (Hook, 2006). Nurses make time available not as an empty gesture to ideals but as a recognition of understanding the patient experience. They understand the patient's illness, with its symptoms and restrictions, which means they know patients will encounter problems. Making time for patients is a kind of presencing: an acknowledgement of availability for the patient. The nurse's time does not have to be used it just needs to be available. There is proactive involvement to prevent patient problems. Nurses think ahead in anticipation for the patient. This thinking ahead is much like Benner's expert nurse 'future think' activity (Benner, 1984, p102). This future think activity is sensitivity to the temporality of the dialysis patient. Nurses have seen ill patients and know what path this chronic condition may lead to. They try to minimise the possibilities of negative impact. This thinking ahead includes examining the blood specimen results for possible problems. Satellite nurses look to anticipate patient care needs in order to work with them in partnership: skill attributed to expert nurses (Benner, 1984).

Thinking ahead, for the satellite nurse, is not a paternalistic orientation but a means of sharing information. Patients frequently expressed that they knew more about their condition and treatment than at the main unit. This is because nurses informed patients about their treatment. Nurses would attend to patients, sit with them and explain what ever was needed. This activity was not a one off but a standard form of practice. Knowledge is shared with the patient because nurses recognised the patient's competence to look after his or herself. The knowledge obtained from blood specimens or other investigations is the patient's knowledge that is interpreted for them by the nurse. Providing this information for patients demonstrates the power sharing and power generating attributes of these nurses. They are not frightened to empower patients to question what is happening to them; they positively encourage it. This power sharing enables a mature relationship to develop whereby treatment and care can be

negotiated. Sharing power through information giving is a dominant attribute of patient-centred-care (Mead et al, 2002).

What was evident in satellite unit patients was their sense of ease or 'relaxation' (to use their term) with attending for dialysis. Patients felt safe and this feeling was generated by nurses. Nursing competence at managing illness was commended by patients. Nurses showed sensitivity to patient experience by minimising the occurrence of illness. Patients welcomed clinical competence and the predictability of seeing the same staff on each occasion. Nurses also demonstrated visibility which is reassurance through presence. Visibility enabled confidence in the nurses that they will be available: being present. Knowing this presence of nurses was evident and not absent. Actual visual sight was not wholly necessary, knowing the nurse was a hand was enough: the nurse had a presence in the mind of the patient. Nurses developed a safe environment in a clinical sense as well as a communicative one. Patients were free to speak with nurses and other patients and it was positively encouraged. The safe environment enabled people to get to know each other and establish a sense of community. The development of a community is an empowering feature by creating a medium for bonding and generating concern for others. The nursing activity to support a community provides a medium for sharing experience. Sharing experience eliminates feeling isolated. Community is friendliness and an acceptance of equality of status between patients and nurses and patients which means a feeling of normality. When examined in this light satellite nursing activity has a therapeutic component to it; it enables change and makes a difference to the patient (Ersser, 1991, Binnie & Titchen, 1999). Like any community it is owned by its participants and this is a prominent feature of satellite nursing; they own the care.

Central to the ability to practice patient-centred care is an ability to practice autonomously. Physical distance from the main unit means usual inhibiting restraints are lifted. Absence of medical staff and senior management is liberating but also stimulating. Liberation is found in the need to think for themselves and have the courage of their convictions. Liberation opens

up possibilities which are a daring to think beyond the norm. Creative activity occurs to solve problems and improve patient care within the realms of the unit. Creativity occurs in various instances such as developing an anaemia surveillance tool, or flexible dialysis shifts to assist patients having a long weekend break. Autonomy is accepted with its responsibility for owning your actions. Whilst initially daunting, the willingness to decision-making skills and accept responsibility is relished. Decision-making is focused upon doing what is best for the patient: a benevolent orientation. Patient focused decision-making is a collaborative affair between nurses alone (where appropriate) and nurse and patients. It is evident in the way many patients ended up at a satellite unit; being told and sent without consultation. Satellite nurses consult with patients as to which is the best way to proceed. This adds to a patient's feeling of involvement and partnership. Autonomy for a satellite unit nurse is freedom to practice to make a difference. This does not mean that satellite unit nursing is an easy option. On the contrary it is time consuming and emotionally draining. The nursing commitment means nurses frequently lost their day off to ensure care was provided.

Satellite unit nurses demonstrated many attributes of patient-centred care as well as those found in other nurse-led units. The experience was similar to those identified by McIlpatrick, Sullivan & McKenna (2006), a positive experience, knowing patients better, expertise development, and patient-focused. The study supported the findings of Fitzsimmons, Hawker, Simmonds et al, (2005) examination of a nurse-led chemotherapy unit. Nurses had more time to talk to patients. This was evident on the satellite unit but nurses additionally organised activities to ensure it was available. Satellite units demonstrated many skills that Benner attribute to expert nurses such as building a therapeutic community, managing patient crises, being present and anticipating patient problems. It is disappointing for these nurses not to receive the credit that is due from their peers at main units. Instead they are treated like poor relations that can't stand the heat of busyness. There is a perverse snobbishness in this attitude that remains dominant. Satellite unit nurses rapidly adapt to their environment and develop skills of flexibility that provides a high quality patient-centred service.

The research has implications for nursing knowledge. The knowledge derived from this study is empirical. It is derived from experience through a systematic process of enquiry. The systematic process offers a means of contributing to a nursing epistemology. Rather than grand theorising, these findings demonstrate knowledge for nursing derived from practice. The generation of knowledge from practice helps provide a sense of realism to a practice-based profession. It also provides power of agency by being able to explain what nursing is about. The finding of this research can be linked to other findings. As already identified, the findings link with the experiences of other nurse-led units. Importantly they lend support to a middle-range theory of caring. Removal of context to a level of abstraction identifies a number of themes. These categories can include decision-making, patient involvement and being available (see table 18 below). These categories of nursing activity support the middle range theory of caring described in a phenomenological study by Swanson (1991). The nursing activities of this study meet the middle-range criteria by being narrow in scope and encompass limited number concepts of aspects of the real world (Fawcett, 1995). Each of these concepts is linked to the other and only finds meaning in this way. The findings are interactional in nature demonstrating the human process of nursing which is ontological. Swanson (1991) described five categories of caring that provided structure for her theory. Although empirically derived from studies in neonatal intensive care units, the categories can be generalised. Swanson's five categories are: knowing, being with, doing for, enabling and maintaining belief. Whilst there is difference in category terms the contents show similarity (see table 19 below). For example, Swanson describes 'doing for' as comforting, anticipating, performing competently and skilfully, protecting, and preserving dignity. Similar findings can be found in a phenomenological study by Forrest (1989) Forrest (1989) found themes such as 'being there', 'closeness', knowing them well, touching and holding, respect, feeling with and for, and picking up cues. In addition to this Benner, (1984) and Benner and Wrubel (1989) identify many of the same themes in their writing. Indeed Benner's work of 1984 has been highly influential in understanding nursing activity. The contents of these studies overlap with many of the findings in this study. This study contributes to the understanding of nursing

activity when caring for patients. What this demonstrates is a move towards clarity of construct of caring in nursing. General themes of caring in nursing may be constructed out of these kinds of research to provide knowledge for further research and education.

<b>Category</b>	<b>Descriptor</b>
<b>Communicating</b>	Open and reciprocal sharing of information between the nurse and the patient
<b>Involving patients</b>	Partnership development and power sharing
<b>Decision-making</b>	Freedom to choose what is best for the patient and how it is implemented. Anticipating patient needs.
<b>Community</b>	Establishing relationships, knowing, sharing and a sense of normality
<b>Clinical Competence</b>	Efficient and safe treatment delivery and illness management
<b>Being Available</b>	Visibility, being present to the patient, and time present-to-hand
<b>Trust</b>	Establishing an environment of mutual trust
<b>Commitment</b>	Placing the patient at the centre of care

**Table 18**

<b>Bevan (2007) Category</b>		<b>Swanson (1991) Category</b>	
<b>Community</b>	Establishing relationships, knowing, sharing and a sense of normality	<b>Knowing</b>	Avoiding assumptions, seeking cues, engaging the self of both Centring on the one cared for
<b>Involving patients</b>	Partnership development and power sharing	<b>Enabling</b>	Informing/explaining, supporting/allowing, focusing, generating alternatives, thinking it through, validating, giving feedback
<b>Clinical Competence</b>	Efficient and safe treatment delivery and illness management	<b>Doing for</b>	Comforting, anticipating, performing competently/skilfully, protecting, preserving dignity
<b>Being Available</b>	Visibility, being present to the patient, and time present-to-hand	<b>Being with</b>	Being there, conveying ability, sharing feelings, not burdening
<b>Commitment</b>	Placing the patient at the centre of care	<b>Maintaining Belief</b>	Believing in/holding in esteem, maintaining hop-filled attitude, offering realistic optimism, going the distance.
<b>Communicating</b>	Open and reciprocal sharing of information between the nurse and the patient		
<b>Decision-making</b>	Freedom to choose what is best for the patient and how it is implemented. Anticipating patient needs		

**Table 19**

What is also of importance here is that phenomenological approaches appear demonstrate sensitivity towards the human activity of nursing. If, as may be the case, findings continue to show a sense of consistency then phenomenology will have done a great service to nursing.

How this adds to nursing empowerment is problematic. These findings are qualitative in nature and may prove to be difficult to measure. In the current climate of outcomes based healthcare, their lack of measurability may disadvantage claims that nurses make a difference. The power that these finding have is that they are patient responses, and in that sense they are outcomes. This does provide power for nurses particularly in the recent shift in government policy for user and carer involvement and satisfaction. Whilst, as a profession we should not have to rely on the verbalisation of nursing from patients; it does recognise an altogether different outcome basis for nursing. Being able to get this kind of outcome demonstrated and accepted is a possibility for future research.

These contents overlap with clinical competence, decision-making and commitment. What this demonstrates is a move towards clarification of a construct of caring in nursing. Whilst this speculation is interesting and stimulating research needs to demonstrate its pragmatic side to show validity (Kvale, 1986). The next section examines the patient context and practical implications necessary to meet Kvale's measure of validity.

## **10.2 Understanding Experience and Implications for Clinical Practice**

### **Dialysis, Time and the Patient**

The discussion of the structures of experience is essentially about meaning. Whilst description offers aspects of experience as constituted, it will be necessary to offer an interpretation to provide meaning (Spiegelberg, 1971). It is worth noting that Husserl did not encourage the use of interpretation but neither did he wholesale reject it, he found it important for understanding (Spiegelberg, 1971). The experiences described of those patients who attend

for dialysis represents a conscious struggle with time. It is interesting to note that the patient's struggle with time really reflects the whole problem dialysis has with time. Time is a foundational concept for the quantification of dialysis. The very delivery of dialysis treatment is bound by time (Tattersall, Farrington & Greenwood, 1998). The earliest success of treatment was founded upon incremental time exposure of the patient to dialysis. Indeed it was noted that when patients were treated about three times per week they suffered fewer uraemic symptoms and survival increased. The idea of thrice weekly gained uncritical support and became the standard regardless of whether or not it was appropriate. Time associated with each dialysis session has altered as improvements in technology have allowed better metabolic waste and toxin removal. Over the years, dialysis times per session has reduced from an initial ten hours or more to the current approximate four hours (Tattersall, Farrington & Greenwood, 1998). The drive to reduce dialysis time even lower was witnessed in the United States with catastrophic effects of high mortality (Locatelli & Manzoni, 1999). Where dialysis duration has remained at four hours or more (8 hours in some units) patient survival has improved (Locatelli & Manzoni, 1999). Time is therefore an important factor that is required for the method of prescribing treatment known as dialysis adequacy. In an interesting parallel with phenomenology, adequacy remains a controversial concept within the field of dialysis where what is deemed adequate treatment remains unclear.

The use of time, as described in the above context for dialysis, is what Husserl calls 'external time' (Husserl, 1964). External time is associated with clocks and calendars and is also known as objective time. External time allows for events to be organised into a linear manner: a timeline. Indeed the dialysis patient organises his or her life around events organised in external time. For example, satellite unit patients arrange which day and what time they will receive dialysis and how long it will last. Dialysis has made external time stand out against other aspects of experience. Patients attempt to alter the perception of external time by slowing it down between dialysis sessions and speeding it up whilst receiving treatment. External time is one level of time experience that is used between individuals to make sense of an

intersubjective world. However, external time is insufficient to explain the importance of time to patients in this study. Clearly time is important for these patients with a desire to save as much as possible. It is the importance attached to time that makes it significant. Husserl (1964) provides an analysis of time experience beyond external time which he calls internal time. Internal time is the subjective experiencing of time that includes the sequence of mental acts (such as remembering) and experiences as well as its duration (Sokolowski, 2000). What is important about this is that internal consciousness of time is never independent from experiences and indeed is foundational for experience though not bound by external time (Husserl, 1964). Like intentionality, internal time cannot exist independently of objects and the experience of these objects. Therefore being conscious of dialysis is being conscious of time. Time provides form and this form is found in individual objects. The form of an object is presented in its enduring manner. Therefore the duration of an object or experience is its form which makes it concrete (Husserl, 1964). Each object or experience is given as it is because it possesses this concrete form which in turn gives it a temporal location (Kockelmans, 1994). Therefore time is a relationship to things (Merleau-Ponty, 1962). In terms of dialysis its duration (time) is the basis of patient experience which makes it into something concrete. Dialysis has a form that extends beyond simple use of needles, blood tubing and external time. The concrete form of dialysis (for a patient) is its time and a consciousness of it which is the loss of personal time. Everything associated with dialysis; transport, a dialysis unit or cannulae, represents a relationship to dialysis time: an almost unbreakable enslavement to time consciousness. Being a dialysis patient means constant consciousness of time.

Consciousness of internal time is an awareness of what presents itself as a 'now.' However, a 'now' only exists against a horizon of what has been present and trailing off (but retained) and an anticipation of something coming into presence (Husserl, 1964, Kockelmans, 1994). Therefore, experiencing dialysis is a temporal flux; a synthesis and a continuation. Under normal everyday experiences a person is engaged in the projects and activities of the lifeworld

unaware of internal time consciousness (Fuchs, 2006). What this means is that the past and future do not stand out in any manner; they are submerged in our temporal flux. For the person with kidney failure, illness and dialysis impacts upon the consciousness of time. The way internal time is experienced is altered. In the first instance illness is experienced in an unreflected embodied temporal manner (Toombs, 1990). So, for example, feeling unwell is endured but has no external time point. Secondly, a reflection upon bodily alteration, such as vomiting or cramp, provides meaning that something is not right which then becomes illness suffered in internal time; which brings the body to consciousness as a psychic object (Toombs, 1990). Symptoms and treatment brings the body to consciousness that is temporally located in dialysis: it has duration. For the patients in this study illness represents a temporally located experience that has a past but equally has a future. Illness makes the 'now' stand out against what has been and what is not yet. The 'now' is a clear experiencing of treatment and a brutal reminder of their life in illness. An anticipation of the future based upon their current experience is one that they would rather not consider unless it includes an escape through kidney transplantation (Kieran & Maynooth, 2001). Patients frequently speak of living day-to-day avoiding looking to the future (Kieran & Maynooth, 2001). Their future is one of consciousness of failing health and proximity to death. Therefore patients turn away from this future projection to a nearer and less anxiety provoking future: home and the familiar. The desire to be well and away from treatment provides a realistic escape from the temporal location of their concrete experience of illness (Polaschek, 2003). Being at home represents submersion in familiar everyday life and an opportunity for temporal flux to resume its normal unreflected state. Reminders of dialysis and consciousness of time can be put in abeyance: at least temporarily.

Time experienced during dialysis is experienced as going slow and focused upon the self: "how long must I endure?" This experience of internal time is contrasted with the external time of treatment: its duration appears magnified. Fuchs (2006) argues that these experiences occur when a gap between experiencing the present and past or the future. The gap for the

patient is between experiencing the present (dialysis and illness) and the immediate future: being home. The gap interrupts the normal imperceptible temporal flux and the patient becomes conscious of the duration of treatment. For the dialysis patient returning home appears as a conscious 'not yet', an unfulfillment, which is experienced as impatience and time pressure made obvious by clock watching. Experiencing the 'not yet' forces attention upon the self and the duration of treatment. The repetition of dialysis exposes the patient to the disquieting reoccurrence of experiencing 'not yet' and the frustration of time going slowly. The patient attempts to overcome time frustration by being immersed in activities that tries to normalise their temporal experience. Attempts at temporal normalisation include activities such as watching television, reading, listening to music, sleeping, and conversation.

To add to this the dialysis patient yearns for a return to a normal existence of what has gone by in the past. In this experience a gap emerges between the past and appears as something irretrievably lost (Fuchs, 2005). This experience presents itself for the dialysis patient, as time moving on relentlessly and uncontrollably and mourning for what is lost. Normal existence is an absence of illness and dialysis where life is not explicitly governed by a consciousness of time experience (Kierans, 2005). The loss of living a normal existence is an unacceptable loss leading the patient being in a situation of trying to retrieve as much time as possible in order to become re-immersed in it. What emerges for a patient is a life where s/he chases after an experience of not being conscious of internal time by negating or minimising that very consciousness. To need dialysis is to endure. The satellite unit offers a means of time retrieval and a partial submergence of consciousness of internal time.

A patient's struggle with time is also grounded in the presentation of illness. Illness represents a whole range of fears and anxieties made present to consciousness. The consciousness of these fears and anxieties is the consciousness of time or more precisely time lost of an unreflective engagement in the world. This consciousness of health or illness is consciousness of a temporal flux; it is time filled out and concrete (Husserl, 1964). Consciousness is of time

tangibly given over to dialysis. Hence the patient's lived-experience is a consciousness of time consciousness (Husserl, 1964). Experiencing illness and dialysis subsequently becomes an important locus for managing time consciousness.

### **10.2.1 Fear of Illness and the Observation of Illness in Others**

Mortality in renal failure remains high and is predominantly a disease of the elderly with a median survival of three and half years for the over fifty five years old (The Renal Association, 2002). Dialysis units have high patient turnover due high mortality and morbidity. This is especially noticeable in the elderly, which means that a patient can frequently witness serious and often fatal illness in others. This means seeing illness, symptoms and death can become a frequent occurrence. This research supports the work of Noyes Hartz, Doebbeling et al, (2000) regarding fear of illness. Fear of illness and death is a common concern in the general population with an increased incidence in those with a medical condition such as kidney failure (Noyes, Hartz, Doebbeling et al, 2000). Noyes, Hartz, Doebbeling et al (2000) found that seeing an injured or dead person coupled with prospects of illness, injury or death in the self significantly increased distress in people with a medical condition. To add to this, Goldsteen, Counte & Goldsteen (1995) found that for someone with a medical condition observing illness or death in a relative or friend affected their sense of control over health. Further to this Goldsteen, Counte & Goldsteen (1995) found that a patient's locus of control over health is grounded in their own experience of illness and reinforced by the experiences of others. These patients also had a poor locus of control of their health and suffered psychological distress. This research supports the work of Goldsteen, Counte & Goldsteen (1995) in that patients felt a lack of control over illness experience particularly at the main unit but not so at the satellite unit. This increased sense of control at a satellite unit extended to others where patients monitored other patients to prevent them becoming ill so as not to witness it. The satellite unit offered control over illness experience that was not available at the main unit. Being able to do something about illness in others provides a sense of control.

Illness fear including injury, illness and death is increased with age (Agras, Sylvester & Olivean, 1969). Additionally illness fears were increased in the elderly with chronic conditions such as kidney failure possibly indicating a response in those considered vulnerable (Agras, Sylvester & Olivean, 1969). Patients on the satellite units in this research were mainly elderly (mean age 59 years) and reflected these fears and anxieties. The incidence of anxiety is common in dialysis patients and is linked with depression and mortality (Alarcon, Jenkins, Heestand et al, 1982; Tossani, Cossano & Fava, 2005; Valdes, Garcia-Mendez, Rebollo et al, 2006).

Experiencing actual or perceived control over a situation has been identified as significant in the development of positive health behaviours and perceptions of quality of life in dialysis patients (Covic, Seica, Gusbeth-Tatomir et al, 2004). How an illness is cognitively represented by a patient is related to quality of life: a poor representation is related to a poor quality of life (Covic, Seica, Gusbeth-Tatomir et al, 2004). To add to this, Devins et al (1997) found if a patient construed him/herself as a 'kidney patient' (with all the implicit meaning of illness) they suffered more emotional distress. Self construal as a 'kidney patient' appears to be linked to a negative self-representation of illness. Covic, Seica, Gusbeth-Tatomir et al, (2004) also found that dialysis patients who had a higher sense of control and understanding of their illness had lower emotional responses to it.

Undoubtedly Satellite unit patients get to know each other well and seeing a fellow patient being ill affects them. Main unit dialysis treatment provides exposure to illness in fellow patients which may reinforce a sense of illness. Patients in this study expressed feeling safe by not witnessing or experiencing illness which allowed them to relax and not spend time consciously thinking of their own health. Nurses can help patients to have a realistic view of themselves by supporting positive and healthy behaviour such as effective management of fluid limitations to prevent hypotensive episodes whilst having dialysis or recognising that not

all illness (such as colds) is linked to their kidney disease. By extracting some aspects of illness not related to kidney disease and giving patients active strategies to deal with them, nurses can offer some control to the patient. For example, simple procedures or skills for managing colds, accessing their GP, or consulting about medication may prove helpful. A means of altering the illness impression of main units would help patients cope with the prospect of possible return by satellite unit patients. Main units need to be sensitive to illness experience and where possible avoid treating well patients with those who are very ill and require much nursing or medical intervention.

My research findings show that satellite unit patients clearly know they are burdened by symptoms and treatment. They also recognise that an increase in repetition or the number of symptoms is not a good sign which adds to the burden of illness; which is high in dialysis patients (Weisbord, 2003; Davison et al, 2006a, Eitel et al, 1995). The findings also show that satellite unit patients recognise that becoming ill and returning to the main unit is a cause for anxiety and overall distress of mental health. Symptoms of illness have already been identified as causing stress in haemodialysis patients and the patients in this study appeared no different (Lok, 1996, McCann & Boore, 2000, Mok & Tam, 2001). To add to this there is evidence that supports that multiple symptoms are related to low quality of life in dialysis patients (Weisbord, 2003; Unruh, Weisbord & Kimmel, 2005; Davison et al, 2006a; Davison et al 2006b, Eitel et al, 1995). The relationship between the burden of symptoms and quality of life has increasingly been linked to depression; which is an independent indicator of mortality (Tossani et al, 2005; Kimmel & Peterson, 2005). Satellite unit patients considered themselves to have a better quality of life and a more positive outlook than when at they are at main unit.

Wherever possible a patient's health should be stabilised to a healthy stable state as soon as possible. By stabilising a patient's health staff can establish a platform of certainty for the patient. It is recognised that the complexity of disease and individual response makes stability

difficult in some patients. However, nurses can minimise the symptom burden through proactive intervention such as preventing dialysis-related hypotension. Nursing care is not only to be directed towards providing treatment but also the minimisation of exposure to illness and symptoms which would help minimise an adverse psychological state of the patient and potentially for early death.

The main unit dialysis nurse can provide realistic time for the patient as demonstrated by the satellite unit nurse. By providing time for the patient, in the manner undertaken by the satellite unit nurse, a condition is set for interaction and mutual understanding. Establishing this condition offers opportunity that both the patient and the nurse know what is to be expected; time for listening and understanding. It would also remove the sense of isolation that patients feel when they are at the main unit.

What this study identified was that satellite unit patients felt less anxious and more relaxed. Dialysis patients are presented with the possibility of their death being near on a daily basis. Anxiety presents a person with their Being as a being towards its end (Heidegger, 1962). In order to avoid the anxiety this invokes a dialysis patient attempts to 'flee' into everyday activity such as talking, shopping or watching television in everyday life (Heidegger, 1962) and attempts to become absorbed in it. To flee is not denial or doubting but turning away from anxiety and putting some distance between the person and confrontation with their death. This absorption in everyday life is a normal way of existing and making death distant and non-personal which in turn makes it manageable (Heidegger, 1962). Therefore whatever the nurse can do to help the patient to 'flee' from anxiety into normal activities will help the patient cope when death is omnipresent. The recovery of time (time saved), for satellite unit patients, is important to help them in this 'fleeing' into normal everyday life and distancing of death. The ability of staff to minimise time lost becomes important as well as the ability for

treatment time to go fast. Here the nurse can help patients by developing strategies to maximise the use of time.

Being able to relax and avoid situations and thoughts that stimulate anxiety is undoubtedly a major benefit of a satellite unit. Being able to relax decreases negative psychological reactions, particularly in those who claimed to be anxious before they began treatment (Alarcon, Jenkins, Heestand et al, 1982). Relaxation enables patients to think of things not related to illness and interact more effectively such as using humour or asking questions. Humour was very obvious in each of the satellite units especially when patients were on dialysis. Humour played an important role in distracting focus from treatment and illness. Staff and patients often found humour in treatment and illness experiences which helped change the unit atmosphere. Indeed Logan, Pelletier-Hibbert and Hodgins (2006) found that being able to maintain a sense of humour was a helpful coping strategy to diffuse the stress of dialysis.

In a study that included education and counselling to deinstitutionalise a dialysis unit, Tucker, Mulkerne & Ziller (1982) found that they could develop a sense of enjoyment in dialysis patients by providing an entertainment programme. They found that patients experienced a less depressing time at the unit with an increase in self esteem and satisfaction. Tucker, Mulkerne & Ziller (1982) also found that patient morale improved which altered the unit atmosphere to a positive one for patients and staff. There was also more patient interaction and enthusiasm for work amongst staff. This study supports work that found staff attitude can affect patient outcome (Kaplan De-Nour, 1972).

In this study of satellite unit experience it was observed that staff actively entertained patients with games such as 'Bingo' and arranged trips out to the coast, for a meal and to a disco. There was a lot of emphasis by satellite unit staff on remembering patient's birthdays and planning celebrations such as Christmas. What this implies is that by personalisation of

experience and demonstrating this individuality through normal experiences on a day to day basis the dialysis nurse can help patients establish normal activities into their lives. Establishing normal activities and interactions in the unit will help distance anxiety and thoughts of death. The importance of this for practice is that for many patients they become socially isolated and illness becomes the focus of their attention. The satellite nurses demonstrated a relaxed interactive approach showing interest and concern for patients. The appropriate use of humour was important for the atmosphere and seemed to help normalise experience by moving beyond the seriousness of illness. This does not mean that the patient's illness is denied or even made trivial but to provide balance and perspective.

Satellite units, by their nature, do not have medical cover and are best placed to de-medicalize experience within the limits of the treatment. The Renal Association (2001) found only nine (28%) of satellite units had permanent daytime medical cover. Where medical cover occurred units were more likely to accept patients for their first treatment and have an out patient clinic. What this means is that medical cover complicates the experience of a satellite unit by accepting patients who have not been stabilised at a main unit and thus with symptoms and possible vascular access problems. Medical cover brings medicalization, a disease focus and illness anxiety for satellite unit patients. Medicalization may also be a threat to how satellite unit nurses develop, perform and gain confidence by making immediate referral for assistance easier. In many ways this would be a retrograde step for the satellite unit experience.

The nurse can help patients by providing a deinstitutionalised setting by de-medicalizing the environment. This can be done by introducing normal activities in to the normal day to day running of the satellite unit. The fact that many patients are old and live alone means that dialysis offers a possibility of important social interaction to further aid distancing of illness anxiety. Nursing staff could aim to get a balance between medical necessity and normal social interaction. In the current climate of increasing role specialisation and reduction to pure clinical tasks (such as the 'vascular access' nurse or anaemia coordinator nurse) important

human experience needs to be emphasised to maintain a balance. This may mean that nurses could consider setting up some kind of ‘social secretary’ type of role to influence this kind of activity. Nurses could work collaboratively with patient groups such as the Kidney Patients Association to provide some form of entertainment schedule as suggested in the study highlighted above by Tucker and colleagues. A social interaction approach could be adopted in the main unit to help with the transition onto dialysis. Naturally this may need to be moderated by clinical demands.

<b>Key Practice Implication Points</b>
<ul style="list-style-type: none"> <li>• Develop an understanding of the individual’s temporal experience of dialysis</li> <li>• Develop patient skills for managing non-renal illness</li> <li>• Increase staff awareness of the impact of patients observing illness.</li> <li>• Develop patient skills to minimize impact of their own illness</li> <li>• Rapid health stabilization is essential</li> <li>• Establish a sense of wellness and positive self-perception</li> <li>• Develop a sense of certainty and prediction as soon as possible</li> <li>• Rapid symptom avoidance and/or removal</li> <li>• Patients should know they are likely to be transferred to a satellite unit as soon as they are stable.</li> <li>• Pragmatic de-medicalization of clinical settings</li> <li>• Establish a balance between clinical and normal behaviour</li> <li>• Explore means for ‘entertaining’ patients</li> <li>• Involve patient support groups</li> <li>• Establish normal interaction including appropriate humour</li> <li>• Establish normal activities such as celebrations</li> <li>• Enable patient relaxation</li> <li>• Establish a relaxed environment for staff and patients</li> <li>• Provide a calm, relaxed and good humoured environment</li> <li>• Provide time for patients</li> <li>• Establish a sense of mutual understanding</li> </ul>

## **10.3 Satellite Unit Management Implications**

### **10.3.1 Providing Control & Autonomy**

Satellite unit staff expressed satisfaction with their work. Close patient interaction, unit management, development of clinical skills, and confidence provided a sense of accomplishment. A sense of personal accomplishment coupled with low depersonalisation and low emotional exhaustion is less likely to cause burnout (Lewis, Bonner, Campbell et al, 1994). Satellite units are a more stable environment, more predictable and as such

controllable. What can be identified from this is that if an environment can be developed to provide a sense of control over the workload, whether related to patient care or unit management, then dialysis nurses can experience job satisfaction brought about by a sense of coherence (Lewis, Bonner, Campbell et al, 1994). Brokalaki (2001) identified that dialysis nurses felt more stressed when they had no participation in patient care decision-making, had a lack of knowledge coupled with increased responsibility. This would appear to emphasise that where nurses have responsibility, knowledge and ability to make decisions, such as the satellite unit, they are likely to feel less stressed and more in control. Being able to make independent decisions has already been identified by Moore (1972) as important in developing confidence in dialysis nurses. Satellite unit nurses thoughts of returning to the main unit were linked with perceptions of not knowing what was happening coupled with a drop in confidence. Feelings of frustration were experienced by satellite unit nurses when they were not in control, such as not being able to contact medical staff or a lack of information from the main unit. Clearly increasing communication between the main unit and the satellite unit needs to be efficient and effective. The allocation of a named doctor for referral and contact during treatment hours may be helpful.

### **10.3.2 Encouraging Creativity and Quality**

By being in control of their environment nurses were keen to construct quality care based upon ideals such as individualism and holism. Though there were occasions of frustration quality of care was something that staff found difficult to explain but knew they experienced it. Examples of created quality were expressed more easily by patients, such as flexibility, humour, and proficiency. Created quality is an aspiration within limitations found in the context of nurse-patient relationships (Polaschek, 2003). Whilst a satellite unit has limitations placed upon it, they appear not too limiting whereby staff were able to provide an environment that patients were satisfied with and very reluctant to leave. The freedom of practice exhibited by satellite unit staff is an empowerment to create a quality environment

they could not achieve at the main unit. Clearly what can be learned from this experience is professional quality care can be provided by nurses when the right conditions are present. Freedom to operate in a less managerially restrictive manner appears to enhance the professional skills of the nurse. Additionally, it enables nurses to combine clinical requirements of treatment with a more person centred experience for patients. It would be beneficial to both patients and nurses if this kind of situation could be replicated throughout the care of renal patients. It may certainly influence the prospects of recruitment and retention of nurses in renal services.

The clinical development that occurs can be exploited to enable nurses proceed rapidly along Bonner's (2003) continuation of expertise. Satellite unit nurses are generally competent to perform dialysis by the time they start working there and could be described as experienced non-experts (Bonner & Greenwood, 2005, Bonner & Greenwood, 2006). From this perspective a nurse is competent and can get through the day with a reasonable degree of referring to other nurses for assistance. However, the satellite unit experience pushes a nurse beyond this level to develop expertise that is recognised among each other. Recognition of expertise by others is an important facet for nephrology nursing expertise (Bonner, 2003). How much this expertise is recognised is of concern because many satellite unit nurses feel undervalued by the main unit. Harwood et al, (2004) demonstrated that nurse-led nephrology services, a term which can be applied to satellite units, can provide improved care and patient satisfaction. Harwood et al (2004) also found that the patients trusted the independent decisions made by nurses. This experience was certainly reflected in the comments of satellite unit patients whereby they clearly trusted the nursing staff. Being trusted is one of the key features of nephrology nursing expertise (Bonner, 2003).

One important implication to improve expertise would be the training in nurse prescribing of medications and medical clinical assessment. The rationale for this would be that time delays brought about by an inability to contact medical staff can be reduced. These skills would

enable a more confident nurse who can have skills to make effective illness management decisions that can enhance patient trust. Additionally, these skills may alleviate anxiety in those patients who feel the need for medical cover.

The satellite unit experience shows that they are good environments for developing nursing expertise. Main units could potentially use satellite units for training staff. The relaxed environment is more conducive to learning and appears less stressful. However, it should be noted that this may provide stress to the satellite unit staff and should be undertaken with care. Clinical and patient management skills can be developed and assessed by expert nurses to establish quality practitioners.

Time remains an issue at the centre of treatment for renal failure. Time attributed to treatment has reduced over the decades from sixteen hours per session in the nineteen sixties to three or four hours currently. The issue of time has mainly been focused around its role in prescribing dialysis treatment (Locatelli & Manzoni, 1999). Time is one of three variables used to dictate the efficiency of dialysis. What has become evident around treatment debates is that patients need more dialysis which can be achieved by more time on dialysis (Locatelli & Manzoni, 1999). This appears at odds with the patient experience in the satellite unit. Patients resented time given over to dialysis but found satellite dialysis more palatable than main unit care because of the reduction in time lost. What can be learned from the study is that nurses have a major influence upon the treatment time. Nurses new to dialysis can be trained to become efficient in the use of time for patient and unit management but maintain that balance with patient interaction. Whilst in-service programmes rightly focus upon clinical tasks, such as cannulation, they fail to include skills needed for the management of the unit. These management skills are developed in an informal manner that may be effective but equally can be variable. An application of a structured approach that develops staff beyond clinical skills would undoubtedly benefit not only satellite units but also main units and ultimately patient

care. As was described in this study satellite unit nurses felt more involved and confident when they understood the whole unit management process and were actively involved in it.

Enhancing active involvement, as found in the satellite unit, would be helpful to overcome the potential for mindlessness found in the repetition of dialysis treatment (Langer, 1989, Bevan, 1998). In many instances these individuals can become known as ‘mindless experts’ who may become dangerous practitioners. Langer (1989) argues that mindlessness limits control by preventing intelligent decision making. This, perhaps, emphasises what satellite unit nurses stress when they find a new freedom to practice because they are able to make decisions for themselves which provides a sense of control and mindfulness. This being the case, by implication is a means of developing nurses to establish control over their workload through a structured management programme. This kind of programme should begin early and not just be limited to those in authority: which is generally the case. Indeed this is what a modern health service should be aiming for.

To help establish effective patient care there needs to be improvement in the sense of isolation that satellite unit nurses experience. Whilst isolation may be the making of these nurses the initial anxiety it provokes should be prevented by improving communication and support with the main unit. This is important because the main unit should recognise that the satellite unit staff are communicating not because they are incompetent but because they need something. It is in essence the need for recognition of expertise and in a different context that has different demands. It may be useful for main unit staff to rotate to satellite units to gain an appreciation of experience and learn unit management skills. An additional benefit to this exercise would be to patients in that they would encounter familiar faces at the main unit. This would which help with reducing anxiety related to attending it. However, staff stability at the satellite unit is essential for patients to feel safe and relax.

<b>Key Practice Implication Points</b>
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- |  |
|--|
| <ul style="list-style-type: none"><li>• Improve unit to unit communication</li></ul> |
|--|

- Provide conditions for improving decision-making ability for staff
- Rotate satellite unit and main unit staff
- Recognise satellite unit expertise and develop autonomy
- Develop clinical skills such as prescribing medicines, ordering investigations and clinical assessment

## **10.4 Implications for Policy**

### **10.4.1 Conditions for Development**

Satellite unit provision expansion has developed piecemeal over the years. The means units are established is at a regional or strategic health level. The main driver for this development is to meet and increasing demand for renal services. However, what has been demonstrated in this study is that these units are very appealing to patients and staff when certain conditions apply such as proficient staff, time efficiency and availability. The likelihood of further increase in the numbers of satellite units is high. Therefore, main units should proactively consider establishing these conditions in their planning. Thoughtful planning including skills development would make a unit work effectively from the outset.

Location of the unit is essential and patients should not have to travel further or longer than they would if attending the main unit. Transport has been identified as an important issue in the National Service Framework (NSF) for Renal Services (2004). The NSF recommends that patients should not have to travel for longer than 30 minutes to and from the unit. Satellite unit patients, in this study, felt their experience was considerably better than this. Transport should be geared towards efficient and quick patient attendance and departure from the main unit and avoid multiple patient journeys. Improving time delay would reduce the lack of control patients perceived as normal at main units. Staff can improve this aspect by being ready for patients.

Staff should be trained to manage a unit and supported appropriately. Multidisciplinary teams are essential for successful healthcare management. In a systematic review of the cost

effectiveness of home versus hospital or satellite dialysis Mowatt, Vale, Perez et al (2003) conclude that under-supported programmes (home dialysis or satellite units) may not realise the same level of benefits as those where support is good. This warns that poorly supported units may not be as effective as could be which may affect healthy functioning of a unit. Healthy unit function would see it performing in a manner described in this study and not fraught with problems. Support must be organised so that immediate access to members of the multidisciplinary team occurs without delay for staff and patients

<b>Key Practice Implication Points</b>
<ul style="list-style-type: none"><li>• Locate units in appropriate geographical areas</li><li>• Establish measures that minimize a feeling of unit isolation</li><li>• Provide training for unit management</li><li>• Establish conditions that allow nurses to practice</li><li>• Organise transport to minimise patient delay</li><li>• Ensure adequate support for staff and unit management</li></ul>

## **10.5 Issues Regarding Phenomenological Research**

The method used in this research is based upon Husserl's ideas pertaining to phenomenology. What it has aimed to do is apply Husserl's phenomenological principles such as 'epoché' and imaginative variation in a pragmatic manner. Particular criticism aimed at the vagueness of nursing phenomenology was a driver for demonstrating a systematic phenomenologically consistent method that is robust was essential.

### **10.5.1 Explicit Application of Phenomenological Method**

The research report has made explicit the philosophical underpinning of phenomenology and its application to research method. The importance for this is so that readers can follow the process from start to finish and see the method in use. By adopting this approach there is a clear attempt to demonstrate consistency of method (Miles & Huberman, 1994). There is evidence of explicit use of phenomenological method at all stages of the process to demonstrate phenomenological attitude: a necessity for this kind of research. Methodological

clarity is essential and achievable by explicit understanding and application. Phenomenological attitude has been evident throughout the research including ethics, data collection and analysis.

This study has shown that a structure can be applied to phenomenological method that retains the necessary flexibility to examine subjectivity but is explicitly systematic. The systematic approach enhanced research credibility by rejecting typical opaque phenomenological research methods frequently exploited to criticise this type of research. The method has also remained consistently within the descriptive orientation. Interpretation has been identified as important and complimentary to the descriptive approach. Interpretation was recognised as being a fundamental activity of making sense but it was shown its contents can be described systematically.

### **10.5.2 Novel and Effective use of the Imaginative Variation**

One of the key methodological issues highlighted in this research has been the use of imaginative variation an essential element of phenomenological method. As discussed previously, imaginative variation is mentioned by researchers like Giorgi almost as an after thought. If imaginative variation is used as a post analysis structural refinement method then structure comes at a multiple level of abstraction. However, this study has adopted Husserl's original idea of applying the method to directly encountered phenomenon. Application of imaginative variation at this point of the method acknowledges that each participants experience is a phenomenon in its own right with multiple aspects. This means that multiple aspects must be examined, something the imaginative variation can help to achieve. The implication for this method is that participants generate the structures rather than the researcher. Participant generation of structures is important because it retains nearness to the point of origin and as such retains validity or in qualitative terms credibility and authenticity (Miles & Huberman, 1994, Whitemore, Chase & Mandle, 2001). It also remains congruent

with the distinction between phenomenology and phenomenological psychology whereby the aim is to explore phenomenon in natural attitude. Credibility is demonstrated through convergence of data and a sense of coherence gained from data nearness and relatedness (Whittemore, Chase & Mandle, 2001). The use of imaginative variation in during the interview process makes it more of an active method rather than a bland elicitation of experience. Both the participant and researcher have to work at clarifying phenomena. To add to this the imaginative variation provides a sense of structure to the interview process which may be particularly helpful to the novice researcher.

### **10.5.3 Observation as Phenomenological Methodological Necessity**

Another issue that stands out as important for this phenomenological research is the use of observation. Whilst it is not new to use multiple methods for qualitative research; this study used observation as a natural phenomenological data collection method. Observing phenomena is important to Husserl with visual presentation of phenomena as having a kind of primordial importance. This importance is related to having the phenomenon, or at least part of the phenomenon as far as the experience of others is concerned, in front of the observer. Observation must be undertaken in the same phenomenological attitude used during interviewing. Using observation in this study has given direct access to aspects of experienced not identified through interviewing. For example, reduction in delay required preparation by the nurse such as early machine preparation, and preparation by the patient such as establishing the means for distraction during dialysis. Therefore observation offers the prospect of increased adequacy, consistency and trustworthiness by providing additional aspects of experience. Observation should become an essential mode of data collection, where appropriate, for a phenomenological researcher to emphasise adequacy. For example, to examine the experience of undergoing mastectomy a researcher could easily involve observation of patients in outpatient clinics, receiving radiotherapy or in the operating theatre. By doing observation, the unseen or hazy aspects of experience become clearer and as such

more adequate. Whilst observation may increase complexity it adds authenticity to the description of experience.

#### **10.5.4 Phenomenological Interview Structure**

As part of the research process this study examined how the interview could be structured in a manner that remains flexible but focused. The research demonstrated that phenomenological investigation requires a systematic approach even at the level of the interview. Accepting the phenomenological maxim of the epoche structure can still be applied in the form of contextualization, apprehending the phenomenon and clarifying the phenomenon. For example, context for an experience must be made explicit and must include temporal aspects of that experience. The context sets the 'horizon' to which the experience is set against and provides meaning.

Understanding the essential structure of phenomenological interview will help novice researchers be more thoughtful about their approaches especially when considering attending to the phenomenological attitude. Demonstrating structure is also helpful in demonstrating methodical dependability by explicit application of phenomenological method, clarity of questions and methodological rigour.

This study adopted the descriptive approach championed by Husserl, Mohanty and Giorgi. Description can provide a meaningful picture of experience without making tenuous interpretive leaps to fill in gaps. Any gaps that emerge are there to be filled by further study and not by theorizing. The world of academia praises analytical skills that show interpretive skills and appears to cast description as a lowly skill. However, what was gleaned from this study is how difficult to maintain a descriptive approach. Descriptive methodology requires a disciplined approach that enhances a self critical approach. This method is perhaps something that researchers should learn to undertake in order to develop skills of precision and focus.

### 10.5.5 Signitive Acts

I identified signitive acts as an objective standard within the observation method. What I found was this really was an area I underestimated the importance of. This is not because of any particular orientation but rather its significance was not obvious until data analysis. The phenomenological method of horizontalisation meant that I treated objective standards equally. However, what I noticed was the importance of signitive acts. Signitive acts demonstrated a synthesis of understanding between individuals with meaning. The one signitive act that stood out for me was the 'ready' position. This act was loaded with meaning that was instantly understood by nurses and patients alike. It heralded a change not attitude and activity. However, change would not occur until the sign was present. What was exciting about this was that it was an inroad into nurse-patient relationship beyond the usual verbal expressions. Observation enabled light to be shone upon these mundane acts as aspects of experience. These would not have been available through interview alone. Unfortunately, I do believe I failed to capitalise upon them at the time of observation: something I regret. However, I am not down hearted by this because it opens up a whole new field of possibilities for further research. Nursing has found difficulty in expressing some of the practical aspects of its role because of the complexity of human interaction. Investigating signitive acts may provide a means to exploring an element of this complex relationship. For example, nurses may speak of having an intuitive knowledge of a patient or situation but not able to express it fully. Indeed, Benner explains that expert nurses have an "intuitive grasp of each situation" (Benner, 1984, p32). But a problem arises in the ability to articulate intuition because of its elusiveness. Exploration into signitive acts potentially offers a way at looking at vague concepts of practice. Examining the nurse in action with patients but from this phenomenological signitive acts perspective allows phenomena to be described as they appear. This can be nothing but helpful to nursing and has potential for student education. This kind of research requires a multi-method approach and not be dependent upon interviews

alone. Whilst the area of study may not be new the method for examining the problem is potentially innovative and exciting.

#### **Key Implications for Phenomenological Research**

- Explicit application of phenomenological method reduces external criticism and increases research credibility.
- Application of imaginative variation during the interview provides participant generated invariant structures
- Imaginative variation applied during the interview adds research credibility by maintaining phenomenal nearness.
- Imaginative variation provides an active interview process
- Observation increases phenomenological adequacy by making explicit unseen or hazy aspects of experience
- Development of phenomenological interview structure provides a systematic approach and methodological rigour.
- Phenomenological interview structure will help researchers construct appropriate questions
- Descriptive methodology is useful for developing academic precision and a critical self awareness.

### **10.6 Credibility, Dependability, Transferability, Limitations of the Research and Recommendations for Additional Research.**

One of the important purposes of any research is its plausibility. Plausibility relates to the feeling that what is read can be believed. In addition to this the researcher has to convince the reader that what is read is presented with truthfulness. Therefore, the researcher has to demonstrate clarity of methods, consistency and applicability. The researcher has to encounter the natural attitude of the reader and attempt to overcome them.

The language associated with truthfulness in qualitative research is contentious. There is a split between those researchers who use quantitative terminology and those who reject it. Those researchers who freely talk about 'validity' and 'reliability' appear content with the underlying message these concepts convey: accuracy and consistency of methods (Silverman, 1993; Kvale, 1996; Mason, 2002). These authors take the initial concept and apply it in a qualitative manner. For example, Kvale (1996), a phenomenologist, has no problem

discussing terms like reliability and validity. Indeed, the phenomenological method of Husserl was developed in an attempt to provide a reliable means for examining phenomena. Kvale (1996) uses these terms, but in doing so rejects positivistic correspondence theory of truth interpretation of reality. Kvale (1996) prefers providing argument for credibility of alternative knowledge claims. He is concerned that method is no guarantee of truth and because of this communication becomes significant. Kvale (1996) is also wary of claims of legitimation through application to external justification of grand theories, systems or meta-narratives. Kvale's justification is concerned by what he calls 'pragmatic' proof through action. What this means is that justification of knowledge is replaced by the ability to use the knowledge to perform effective actions. Validity, in this sense, is to check, ask questions, to theorize, to communicate and action.

Those qualitative researchers who reject the use of quantitative terminology have developed a parallel language to express similar concepts (Sandelowski, 1986; Holloway and Wheeler, 1996). Nurse qualitative researchers have generally adopted the criteria developed by Guba and Lincoln (1989). Guba and Lincoln (1989) retain the underlying meaning of the concepts of 'reliability' and 'validity', but felt the need for them to be expressed in a language that is congruent with qualitative research. Guba and Lincoln suggested that credibility replaced internal validity and means recognisable and faithful descriptions of human experience. They also suggested that transferability or fittingness should replace external validity (generalization) which means how the findings fit into the world and not necessarily about broad generalizations. Reliability is replaced by dependability which means method and evidence is displayed in thoroughness as well as demonstrating atypicality or multiple method approaches (Tuckett, 2005). Dependability also means that methodological approach is suitable for the research question (Maggs-Rapport, 2001). It could be argued that this is just a game of semantics whereby the language is changed to make it more palatable and setting up a smoke screen for those not in the know.

My concern is how to demonstrate attainment of these operational terms sufficiently to convince the reader, in his or her natural attitude, of plausibility. In terms of the language used, whether 'reliability' or 'credibility', I have no strong convictions. This is nothing to do with conceptual apathy on my part but rather acknowledgement of the intentions of these operational terms. I am also aware of the strength of opinion of some qualitative researchers about the use of methodological sensitive language. I appreciate the paradigmatic shift required to cleave qualitative research from the grips of positivistic ideology. The idea reflects Heidegger's concern about human experience being judged on its own merits (how it presents) rather than by comparison: apophantic judgements (Heidegger, 1962). Qualitative sensitive criteria set up a kind of apophantic orientation for making judgements.

Credibility is about whether something is worthy of belief. I believe that I have achieved credibility of this study in a number of ways. My research question is aimed at a real phenomenon. Without getting bogged down in philosophical discussions of what constitutes reality; a phenomenological perspective the world already exists so reality of phenomena is not an issue. Dialysis satellite units exist to those who use them and the NHS, but not necessarily to the wider world. From a profession perspective our knowledge of satellite units is limited and as such cannot be communicated effectively. My focus upon a real phenomenon was aimed at describing it as it is presented, rather than force concepts upon it. This does not decry methods of theoretical or conceptual application; instead it aims to describe experience from the point-of-view of the experiencer. I recognise that participants may not necessarily provide an epistemological privilege, for example, they simply may not be able to articulate their experience (Mason, 2002). A focus upon experience required a method that is sensitive and appropriate to examine it. The descriptive method adopted aimed at avoiding unnecessary or inappropriate interpretation; it was to remain faithful to the phenomenon no matter how incomplete (Giorgi, 1985). The application of an appropriate methodology to the phenomenon provides initial credibility.

Credibility is increased in two ways by the inclusion of interview and observation. The use of multiple methods is important for phenomenal adequacy. The opportunity to include as many aspects as possible of a phenomenon increases the possibility of a fulfilled description and better adequacy. Both sensuous (observation) and represented (interview) intuitions increases credibility because it allows the same phenomenon to be presented in its many way of appearing. The research is not limited to one method of data collection. Whilst I recognise there are those who have difficulty accepting the mixing of methods within a paradigm. It can be viewed as problematic due to the theoretical assumptions of each method (Barbour, 1998). However, if I look at a cup, then close my eyes and reflect about it I may be using different ways of presenting it, but it is still the same cup. My representation, in this instance, is grounded upon sensuous intuiting which is important for providing a categorial intuition: a cup as it is. So credibility is achieved from a phenomenological perspective and in doing this it allows it to be achieved through triangulation. Triangulation is helpful for credibility because it enhances “the *validity* of data findings by allowing the researcher to explore a phenomenon more fully whilst facilitating a variety of methods to encourage comprehensive understanding and explanation” (Maggs-Rapport, 2000, p222). The approach I adopted also adds to its dependability in that it is phenomenally congruent.

The sampling strategy provides a basis for credibility. Each participant has experience of the phenomenon. The purposive nature of the sample ensures that that there is consistency of experience and is not based upon ideals or imagination of non-experiencers. The inclusion of as many participants as possible increases the experiential aspects of the phenomenon. One point that limits adequacy (but not credibility) is the limited number of nursing interview participants. The fact that a limited number of nurses provided interview data does not threaten credibility because qualitative research accepts small sample numbers. However, the low numbers limits the adequacy of the nursing experience. This does not negate the findings; it accepts that this aspect is incomplete.

Having identified that a multi-method approach increases credibility (or validity) the actual methods of data collection adds to the sense of credibility. A structured but sufficiently flexible interview method that retains its affinity to phenomenology is employed. The inclusion of imaginative variation in the data collection technique, though novel, does add provide phenomenal accuracy and validity (Maggs-Rapport, 2001). Recording interviews and asking participants to check transcripts for accuracy also contributes to credibility (Tucket, 2005). All these methods ensure phenomenal proximity. The observation method is well established within ethnography and provides a set of objective standards by which social situation phenomena can be examined. The method has phenomenological congruency (see data collection chapter) and therefore maintains a cohesive strategy. These approaches demonstrate dependability as well as credibility.

The analysis of the interview data was performed through an accepted descriptive phenomenological method. The analysis of observational data was novel but utilised a thematic structure. This approach allowed triangulation to occur. The triangulation method was developed by me, which may limit its credibility. However, it was developed in order to remain phenomenological and sustain method coherence. The method was developed to provide a means of providing an adequate description of the structures of experience. It is hoped that this approach helps maintain credibility and dependability.

The findings were shared with the participants, not necessarily as a means of confirming my findings, but as an ethical principle of showing that the voices of participants are heard. This is particularly important from a phenomenological ethical perspective and demonstrates philosophical consistency. I know that some authors warn against using this method because participants may not be best suited to interpret the findings because of their point of view (Silverman, 1993; Mason, 2002). This notion does appear to have a hint of academic paternalism. Despite this favourable reports were forthcoming and an example from one nurse can be found in the appendixes.

One issue to consider is that of transferability. As previously stated transferability is about fitting into the world. The proximity to the phenomenon means that broad transferability is limited. The limited number of units and participants involved reduces broad application. Context will also limit transferability and therefore may not be applicable in units where there is constant medical cover. This aspect would need to be researched to increase adequacy. However, it may be applicable to other satellite units and understanding the experience of dialysis in a general sense. This would require a form of abstraction and theorizing which is possible but not the purpose of phenomenology. Evidence for a wider sense of transferability was found in an RCN Bulletin (December 2006) shown below. The advert for a head nurse for a satellite unit highlights many of the aspects described in this study. The advert not only shows transferability, but demonstrates phenomenal accuracy, adequacy and credibility.

Pragmatic action cannot be excluded from the credibility discussion. I have endeavoured to provide a pragmatic aspect on two levels. Firstly there has been an attempt to be explicit regarding process. I have also considered the action potential of this study. The discussion preceded this section aimed at considering the practical application of the study. It includes practice implication points as well as considerations for research. These practical points are important because they demonstrate transferability through interpreting the findings for action. This process keeps research in touch with its interest: phenomenal proximity.

**Appointments - Clinical Specialists**

**SATELLITE DIALYSIS UNIT**  
**Head Nurse**  
**Band 8A £39,178 – £46,224 inc.**

The Renal Centre at Hammersmith Hospital is one of the largest centres in Europe and, as a tertiary referral centre for West London, is the hub of several large satellite dialysis units.  
 This senior management position is based at Central Middlesex Hospital where the dialysis unit is situated in a new, purpose built facility.

**Pure  
autonomy.**

Having 26 stations, 21 staff and used by over 100 patients per week, you will manage all aspects of the units day-to-day operations. The unit is very much nurse led, so your management expertise will be coupled with your clinical knowledge and experience.  
 You will work autonomously, but in partnership with the renal consultant. You will also maintain and develop working relationships with the host hospital, as well as the centre. You will be responsible for all aspects of staff management and also the future development of the unit itself.  
 Your excellent communication and interpersonal skills will be fully utilised, as will your confidence in making decisions.  
 If you like the idea of having your own autonomy in management and enjoy using your leadership skills, give Julie Harris a call today on 020 8383 4258. For an application form, please call our Recruitment Line on 0870 7702368 quoting reference number RN/38.  
 Closing date for applications is Friday 22nd December.

**CENTRAL MIDDLESEX HOSPITAL • LONDON**  
 HAMMERSMITH HOSPITALS NHS TRUST 

RCN BULLETIN 6/12/06 - 02/01/07



**Figure 22: Recruitment advert showing required characteristics similar to those described in this research: autonomy, management skills & working relationships. RCN Bulletin December 2006.**

A further limitation is the number of participants interviewed particularly nurses. Whilst the generally accepted view that qualitative research does not require large numbers of participants, more participants would have increased adequacy. More nurse interviews would have been beneficial at least to provide a balance between units. There was an explicit attempt to recruit a wide variety of people including those from ethnic minorities; though granted in limited numbers. Interviews of medical staff could be included, particularly those involved in satellite unit patient management, as an additional phenomenal aspect for increased adequacy.

This research did not include satellite units that accepted patients who have not been stabilized at a main unit. There was one patient who came directly to unit two from without stabilization and subsequently had many physiological problems. This case was atypical but interesting nonetheless by demonstrating acute illness frequently. These units should be studied in order to see if these non-stabilized patients alter the structures described in this research. They may not negate what has been described in this research, but rather add further aspects and increase adequacy. Such research would increase adequacy and provide a fuller description.

One particular threat to credibility is that a sole researcher undertook the interviewing and data analysis. The research relies upon a single subjective impression, whereas an additional researcher would have helped provide internal quality checking. This would demonstrate investigator triangulation an increase credibility by counteracting single perspective bias (Maggs-Rapport, 2000). Two issues arise here in relation to this potential problem; firstly Giorgi (1989) insists that the role of a co-researcher or external examiner is not to examine interpretations but rather to ensure methodological rigour. Secondly, Heidegger (1988) insists that the givens of a phenomenon should be judged on how it presents itself to the examiner rather than by comparison (apophantic judgement). What Giorgi and Heidegger mean is that the findings should be judged by the reader on their plausibility and not on what is felt should be there.

The research was an adaptation of Giorgi's method and Husserl's phenomenology with novel applied methods. This means that its method cannot be perceived to be as rigorous as those already accepted. However, the attempt to avoid the limitations of other methods such as those of Giorgi and Colaizzi may be seen as increasing its credibility. Further studies using the method would enhance credibility and acceptability of the approach.

### Key Points of Research Limitation

- Transferability may be limited due to limited number of units sampled
- Units with medical cover and unstable patients not sampled
- Sample size, especially nurse participants was too small
- Reliance upon sole researcher may limit credibility of findings
- Novel method used for the first time

### Recommendations for Further Research

- Sample additional units including those with medical cover and unstable patients
- Interview more patients and staff
- Include medical staff in the sample
- Additional research using the method to establish methodological reliability
- Include observational methods
- Examination of signitive acts in nursing

## 10.7 Some Personal Reflections on Being a Researcher

Undertaking this research initially started as an exciting exploration into a speciality of healthcare that I feel passionate about. Little did I realise how much of an effort it would become to sustain the enthusiasm particularly when life gets in the way. One of the important reasons for choosing this approach was to explore phenomenology in a systematic way rather than in the fragmented fashion that occurs from reading academic papers. Phenomenology is difficult to master and I found I needed to switch between ‘beginner’s guides’ and original texts. Husserl was particularly difficult to read not only because the language was occasionally impenetrable, but because he frequently altered his explanations of important concepts. I was left with a struggle to decide which version of his method I should use. Even though his book ‘The Crisis of European Science’ was supposed to be his final version, I still had to refer back to earlier texts for clarification or meaning. I certainly recommend to those phenomenologists who adhere to Heidegger that they should read Husserl for a better appreciation of Heidegger’s work. One thing that struck me powerfully was, in spite of the differences, Heidegger uses phenomenology almost to the letter. Merleau-Ponty was aware of this which is why he remained methodologically bound to Husserl. Heidegger’s phenomenology was an adaptation of Husserl’s. He used phenomenological method with all its functional parts. Heidegger used the reduction though he couched in different ways. More

than anything I found that there was more similarity than difference. This appreciation can only be felt after reading both authors' works. The other benefit I have found is that structure can be found in phenomenological method suitable for research that does not rely upon vague statements of 'interpretive leaps.' At the time I did feel there was a certain phenomenological snobbery about Heidegger. I found that nurse researchers did not appreciate what Husserl's method had to offer. I also felt that this antipathy towards Husserl was generated out of a belief that Heidegger was right and Husserl was wrong. This was founded on Husserl's transcendentalism and was not fully justified. When I asked Heideggerian phenomenologists to describe his method it became apparent that it was particularly hazy. I can, and do appreciate Heidegger's interpretive orientation particularly as has given a voice to nursing and the patient. I also get a little annoyed when interpretivists appear to denigrate the descriptive approach. Husserl was not against interpretation, he acknowledged that we interpreted phenomena, but he did feel that they could be described with clarity and precision: I find nothing wrong with that.

I examined possible methods of phenomenological research and felt they lacked something I could not identify. I did feel that these methods were static and complex; which could be discouraging. I also felt they could be open to abuse due to some vague areas such as analysis. For me, the phenomenology was not explicit enough and was often incomplete in those methods. I wanted phenomenology to be as exciting as the day I first started reading Don Ihde's book entitled 'Experimental Phenomenology'. With this in mind I endeavoured to develop a method that had some of that dynamism and experimentalism. Developing the data collection strategy was an exciting phase. It required thought upon how to apply concepts of phenomenology in a manner that avoided a vague pondering approach. I felt this was important because Husserlian phenomenology is about being systematic but flexible at the same time. In the structure I devised (with the assistance of Seidman's work); I felt I was able to articulate phenomenological interview method in a cohesive manner. I found the structure a useful guide to obtaining descriptions of experience.

The observation method was interesting. I had limited experience with this approach but that didn't stop me. I was committed to observation because of the need for adequacy. Building up a picture of as many aspects as possible was important to attempt to provide a fuller account. Spradley's work was useful though I had to temper the ethnographic aspect with Bruyn's phenomenological approach. Bruyn's work provided me with a phenomenological method for using Spradley's observational matrix. I carried a copy of the matrix around with me as a reminder. Inclusion of signs and signitive acts was my application of phenomenological underpinning philosophy. I could see the potential at this point but I don't think I fully appreciated its possibility. If there is an area I am not happy with it is that aspect but it does leave open the possibility of more research

Data analysis was a challenge. I had two data sets to make sense of. I had to be creative to construct a method that remained phenomenological. I found the dearth of information for doing this aspect of analysis very frustrating. Spradley was no help. I took me a long time but I believe I got there in the end. It was an interesting exercise in thinking.

I found phenomenology an exciting venture. It required a disciplined approach which took some time to master. I also found I had to counter the prejudices of many people. There were those who look at qualitative research as a second rate type of study. I encountered one colleague who claimed her PhD would be of more value than mine because her PhD was quantitative. I took this rather personally and for a while I wouldn't tell anyone what I was doing. I also encountered colleagues who had a qualitative orientation but also looked down upon phenomenology as second rate to something like grounded theory. I was surprised by some people's attitude because I naively thought that these people would show some empathy. There were many people who were supportive and they made up for the others.

I found being a researcher quite a lonely venture. Whilst there were colleagues who had empathy but it was down to me in the end. This loneliness meant having to keep myself

motivated, looking forward to an end point, and having commitment to my cause. Clinical staff were very supportive and always interested in what I was doing. Attending the satellite units was always a pleasure. I expected to encounter difficulty gaining access, particularly because of constant research being undertaken in these places. I thought unit three would be particularly difficult but I was welcomed and supported by the nurse consultant. These nurses were only too happy to help.

Two aspects I was unprepared for were, how difficult I would find doing description, and the epoche. Remaining purely descriptive was hard work. The desire to reach into my experience and knowledge to explain what was in front of me was extraordinarily easy. I can see why the epoche becomes such a useful tool because it requires you to focus upon what is presented and not how I construct it with all my knowledge and experience. The epoche became a state of mind where I literally questioned every thought and decision; that certainly made my brain ache. It has become an invaluable tool for me I just have to learn to stop now.

I felt honoured by the way I was treated by patients and staff alike where ever I went. No one was difficult even when they refused to take part. I was made very welcome by everyone that made my transition less arduous. People could not have been any more helpful (well perhaps a few more interviews). I received Christmas cards and from one unit a present of some aftershave (Blue Stratos that I believe was some kind of 'in' joke I didn't get) which made for feelings of guilt while I made observations. This guilt is my nursing indoctrination of 'the only good nurse is a busy at the bedside' nurse. I did at times just join in to help when they were short of staff because I felt this was a mutual relationship and I should give something in return. I think this was a beneficial move because it appeared to establish some degree of respect from nurses and patients alike.

I have also become convinced that phenomenological research has to branch out of the interview method. Phenomenology has to become more adventurous and experiment with

phenomena something the method is most suited for. Phenomenological research needs to show it can be dynamic and exciting for it to continue to survive in a competitive research environment.

The research findings are done in a descriptive way. They describe what happened and what it meant and in that way I feel strongly that it reflects the phenomenon of satellite unit experience accurately. I feel they describe the nursing and patient co-experience of managing dialysis. Regardless of what happens to the outcome of this study it was worth completing as a testament to patients and nurses of satellite units to make known what they experience and as gratitude for their help

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## Glossary of Terms

**Adequacy:** A point where an object is known with a sense of fullness and that each presentation of the same object corresponds with the object.

**Apodictic:** Possessing certainty beyond any doubt

**Apophantic:** A judgement of truth of a thing or statement by examining the thing or statement itself and not by comparison

**Bracketing:** the term used to describe the putting out of use any knowledge or beliefs prior to phenomenological examination of phenomena. Derived from the mathematical method of putting things in to brackets so they may be dealt with separately. Often used as shorthand for the phenomenological reduction

**Chronic Kidney Disease:** pathological changes to the kidney that alters function such that it is below normal. Chronic kidney disease may lead on to end-stage renal failure.

**Constitution:** an operational term used to describe how a thing is constituted (crystallized) in consciousness to provide meaning.

**Diabetes Mellitus:** An endocrine disorder where the pancreas produces insufficient insulin for the metabolism of glucose by the body. Subsequently there are uncontrolled and high levels of blood glucose that damages small blood vessels including those in the kidney. Diabetes may cause chronic kidney disease and failure.

**Dialysis:** The process of random movement (diffusion) of solutes across a semipermeable membrane

**Dialysis Satellite Unit:** A small nurse-led dialysis unit that is geographically distant but linked to a main unit.

**End-Stage Renal Failure:** The point where kidney function can no longer sustain life and death would ensue without dialysis.

**Epoché:** The epoché is to be seen as a critical-position taking attitude that requires the phenomenologist to adopt and accept a resolve to take nothing for granted.

**Fistula:** The surgical procedure that joins a vein to an artery in the arm that causes the vein to become distended. The distended vein enables hollow needles to be inserted for connection to a dialysis machine.

**Glomerulonephritis:** An inflammatory condition that causes damage to the microscopic filtration blood vessels in the kidney. The condition can be acute or can lead to chronic kidney disease and kidney failure.

**‘Going off’:** dialysis jargon for a hypotensive episode experienced by a patient during dialysis

**Haemodialysis:** The diffusive removal of toxic and excessive substances across a semipermeable membrane (artificial kidney) from the blood of someone with kidney failure.

**Horizon:** is a correlate of the consciousness of the world and the objects or experiences within it. It is the context or background for individuals to make sense of phenomena.

**Horizontilize:** The method of treating all data as equal and avoiding any hierarchical assumptions

**Identity as Manifold:** Objects of consciousness or experience are not experienced in a single unchangeable way rather these objects of consciousness can be experienced in many ways and are not limited to an individual alone.

**Imaginative Variation:** the process of attempting to imagine changes in a thing by adding or removing elements to see what is preserved (invariant structures) and what can be discarded (variant structures)

**Intentionality:** Every act of consciousness is a consciousness of something

**Intuition:** Having a thing presented to consciousness in its fullness and certainty through perception, reflection, memory or imagination.

**Lifeworld:** is the pre-given world experienced which is always present and provides meaning through context. The context is known as the horizon.

**Main Unit:** A central treatment unit responsible for the overall management of dialysis patients including those at dialysis satellite units.

**Natural Attitude:** is the pre-reflective way in which a person focuses upon things and projects in the world and experiences them as such.

**Noema:** The thing experienced as experienced

**Noesis:** The way in which a thing is experienced

**Participants:** patients and nurses who consented to take part in the research.

**Phenomenology:** The study of phenomenon as they present themselves as themselves.

**Phenomenological Reduction:** is the means for examining intentionality of consciousness which is related to things (like cars or people) and psychological phenomena (like memory) which requires the suspension of natural attitude.

**‘Putting on’:** dialysis jargon for the connection of patients to dialysis machines and commencing dialysis

**Taking off’:** dialysis jargon for the discontinuation of dialysis treatment

# Appendices

# Appendix 1

## Outline of Ethical Approval

It was deemed important to discuss the potential study with the managers of the units involved. The medical and nursing managers of units involved were consulted to clarify the purpose of the research. The reason for this was to develop a relationship of trust and openness so that transparency can be achieved. Additionally I felt that as third parties the managers were potentially at threat in relation to the manner of information that may be elicited, thus exposing their vulnerability through a lack of information and autonomy. There may potentially have been, for example, unfavourable accounts from patients or staff as to how they were treated which may reflect unfairly upon the renal services and personnel, or observations that may demonstrate poor clinical standards. Furthermore there was a need to reassure the unit managers of confidentiality and that anonymity of not only patients and staff but also the main units would be maintained. It was highlighted that the nature of the research approach would require descriptive accounts but there would be every attempt to omit identifying characteristics. This approach is congruent with the NMC code of conduct which requires the nurse to be trustworthy, cooperate with others in the healthcare team, and treat colleagues fairly (NMC, 2004). Although this approach preceded the Guidelines for Research Governance it was in line with what is a responsibility of the principal researcher to inform the participants under the care of a doctor or nurse (DOH, 2001, p25).

A copy of the written proposal was provided to the managers to allow them to distribute it amongst their colleagues for discussion. To add to this a presentation of the proposal was made to the senior nursing staff at one of their monthly meetings which provided an opportunity for questions and discussion. There was support for the study and no issues were raised by the nursing staff. The medical staff discussed the proposal at their monthly meeting no objections being raised. A letter of approval and support from the unit medical director was received in December 1999 (See appendix 1). Gaining this support from the clinical

managers was important because not only was it a requirement from the ethics approval committee, it also demonstrated effective communication and clinical cooperation at the unit level.

In order to proceed with acquiring ethical approval, guidance was sought from the local NHS trust research and development department. The department which is linked to the local research ethics committee (LREC) advised that an application should be completed and forwarded as soon as possible due to a long turnaround time for gaining approval. Their belief was that the non-therapeutic or non-interventional manner of the research would enable the proposal to gain approval via chair's action. The initial proposal was sent to the chairperson of the LREC in February 2000. The chairperson responded to the application but was reluctant to take chair's action and so referred it to the committee. The LREC replied to the proposal application in March 2000 and gave approval in principle but they required some amendments to the patient information sheet. The research could only proceed once they were satisfied with the patient information sheet. The amendments that were required centred on providing more detail and an outline of the areas of questioning. Modifications were made to the information sheet and forwarded to the LREC in May 2000. A reply was received in June 2000 which stated that although there were improvements it was felt that the language was 'too high a level' for the average reader. Further amendments were made to the information sheet and resubmitted in August 2000. Final approval was received in September 2000 which meant the research could proceed (See appendix 1). There was no need to seek an honorary contract to practice in this hospital because one already existed as an agreement between the university and the NHS trust. The honorary contract is an important element as it will provide legal cover for practice in an NHS trust.

The delay that occurred due to repeated resubmission of the information sheet to the LREC caused me much frustration. However I acknowledged the importance of this delay as the

necessary role of the LREC to ensure that potential research participants are protected and that they have accurate information in order to make decisions (DoH 2001).

The approval by the NHS trust only covered units one and two. Unit three was within a different NHS trust. In order to gain approval from this NHS trust a meeting was planned with the senior nurse manager from the unit in July 2002. The meeting outlined the research and provided an opportunity for questions. The manager was pleased to be able to support the research and offered to take the research to the medical director and head of research and development. Approval was granted by the NHS trust with full support in August 2002. The head of the research and development department was satisfied with the study proposal on the basis that ethical approval had been granted and study already undertaken in another NHS trust. An honorary contract was obtained in January 2003 for legal cover for practice and was necessary before any research could be undertaken.

# Letters of Ethical Approval

Chairman  
Chief Executive

THE HOSPITALS

ST JAMES'S UNIVERSITY HOSPITAL

Mr. Mark Bevan,  
School of Healthcare Studies  
University of Leeds  
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Miss R. Newson, BSc, PhD

AMDRN

Direct Line: 0113 275 3333

Fax: 0113 275 3333

16 December 1999

Dear Mark,

Thank you for submitting your plan relating to your PhD Thesis. I have distributed this amongst the staff in the unit and no objections have been forthcoming. I would be grateful therefore if you would proceed with your application and I would wish you well with your activities.

Kindest regards,

Yours sincerely,

DAVIDSON BSc, MD, FRCR  
PROFESSOR OF RENAL MEDICINE



Chairman  
Chief Executive

THE HOSPITALS

ST JAMES'S UNIVERSITY HOSPITAL

Mr. Mark Bevan,  
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Kindest regards,

Yours sincerely,

PROFESSOR OF RENAL MEDICINE



## Appendix 2

### Letter to Participants

My address & contact numbers

Date

Dear

I am a nursing lecturer at the University of Leeds. I have been involved in renal nursing for 15 years. I am currently studying for a PhD in psychology and the areas I am studying are dialysis satellite units. I have recognised that there has been very little research into dialysis satellite units and what satellite units mean for those involved. Therefore I seek to start to address this problem by becoming involved in satellite unit life.

I am undertaking research in to the experience of those who use dialysis satellite units. The aim is to uncover how both nurses and patients view their experience, what their behaviour is, what their feelings are, situations and events that occur, people who are involved, places in the unit, and what are the meaningful areas for those involved. The research is a psychological study but does not involve any form of testing.

The study is concerned about the quality of your experience. This means that I am interested in what you have to say, what you mean, and how you feel. There are no experiments or tests of any kind involved. The approach is one geared to help me gain clear, accurate and thorough descriptions or depictions of dialysis satellite unit life.

The study will involve my being on the unit on a weekly basis for \_\_\_\_\_ weeks. I will be making notes and talking to people. During my stay on the unit I will invite members of staff and patients to be interviewed. The interview will last approximately 30 to 60 minutes. The interviews will focus upon your experience of being in a satellite unit and will include topics such as the first visit, aspects and issues of importance to you.

I will, with your consent, be recording the interviews on tape and making notes so that I may keep accurate records of what is said. Anything that is said will be confidential between you and my self. Names of individuals and unit names will be omitted from the data in order to maintain confidentiality including the final document.

Should you be approached to be involved in the study do not feel that you have to be involved. You can refuse to participate and you will continue to be treated as before with no comeback at all.

I value the participation of those involved and in anticipation I thank those who agree to be involved. Should you have any questions please do not hesitate to contact me on the numbers stated above.

Warm Regards  
Mark Bevan

**CONSENT FORM**

**A Phenomenological Psychological Study of Patients and Nurses in Dialysis Satellite Units.**

Please circle as necessary

Have you read the information sheet? YES/NO

Have you had the opportunity to ask questions and discuss this study? YES/NO

Have you received satisfactory answers to your questions? YES/NO

Have you received enough information about this study? YES/NO

Who have you spoken to? Mr/Ms/ Dr.....

Do you understand that you are free to withdraw from the study:

\*at any time

\*without having to give a reason for withdrawing

\*and without affecting your medical care? YES/NO

Do you agree to take part in this study? YES/NO

**Signed**.....

**Date** .....

**(NAME IN BLOCK LETTERS)** .....

## Appendix 3

### Sample Phenomenological Semi-structured Interview Question Schedule

#### **Gaining Context**

Please describe becoming ill with kidney failure

Please describe your experience of hearing you will require dialysis

Tell me about starting dialysis

Describe your experience on the main unit

Please describe who does what

Please describe how you prepare for dialysis at the main unit

#### **Apprehending the phenomenon**

Describe how you found out about the satellite unit

Describe how you came to be at the satellite unit

Please tell me about your first day at the satellite unit

Please describe the unit for me: What happens in each room (Grand Tour question)

Describe how you prepare for your dialysis at the DSU

Describe your dialysis station

Please describe who does what at the satellite unit

Please describe your typical day

Please describe what you do on your none dialysis days

Describe what the staff do

Describe what other patients do

Describe your contact with the main unit

#### **Clarifying the Phenomenon**

Questions are generated by the previous two sections and vary depending upon the individual

## Appendix 4

### CODE LIST

- 1 A community Description: The DSU is seen as a separate community
- 2 A dialysis machine Description: description of a dialysis machine
- 3 A family' Description: the description that the unit is like a family helping each other
- 4 A patient's day Description: description of a patient's day
- 5 A typical patient's day Description: description of a patient's day
- 6 Absence of doctors Description: where the absence of doctors is noted as an aspect of experience on the DSU
- 7 Act- access assessment Description: assessment of vascular access
- 8 Act- attaching artificial kidney
- 9 Act- dialysis prescription
- 10 Act-chair preparation
- 11 Activity- cannulation
- 12 Activity- cannulation communication
- 13 Activity communication Description: an activity that involves some form of communication
- 14 Activity- dialysis preparation Description: activities undertaken in the preparation for dialysis
- 15 Activity- dialysis preparation by pa
- 16 Activity helping
- 17 Activity housekeeping
- 18 Activity- identifying ~going off~
- 19 Activity- intradialysis
- 20 Activity- intradialysis HCA
- 21 Activity- intradyalysis
- 22 Activity- local anaesthetic Description: application of local anaesthetic for cannulation
- 23 Activity- machine treatment initiation Description activity undertaken in the initiation of dialysis
  
- 24 Activity- nurses at nurse's station Description: activities of nurses together at the nurse's station
- 25 Activity- nurses station communication
- 26 Activity- nurses station information
- 27 Activity- nurses station staff refreshments
- 28 Activity- nurses station staff work
- 29 Activity- patient cleans chair Description: patient cleans chair after dialysis
- 30 activity- patient role during ~going
- 31 activity- patient's preparation Description: what the patient does to prepare for dialysis
- 32 activity preparation
- 33 activity- putting on Description: activities that occur when it is putting on time
- 34 activity putting on time orientated
- 35 activity sharing
- 36 Activity-cannulation Description: cannulation activity
- 37 Activity-cannulation-patient Description: activity the patient undertakes during cannulation
- 38 activity-Christmas Description: Christmas activities
- 39 activity-dialysis discontinuation
- 40 activity-dialysis initiation

- 41 Activity-dialysis monitoring
- 42 Activity-food & drink Description: activities involving food and drink
- 43 Activity-going off nurse Description: activities of the nurse when the patient is hypotensive
- 44 Activity-going off patient Description: what the patient does during a hypotensive episode
- 45 Activity-humour Description: humour activities
- 46 Activity-managing time effectively Description: activities employed to use time efficiently
- 47 Activity-nurse and patient Description: activities during nurse-patient interaction
- 48 Activity-nurse and patient sharing Description: nurse and patient sharing experiences
- 49 Activity-nurse attending to a patient
- 50 Activity-nurse attending to distress
- 51 Activity-nurse intradialysis Description: activity of nurses in the intradialysis period
- 52 Activity-nurse's station Description: activities undertaken at the nurse's station
- 53 activity-patient intradialysis Description: activities of patients in the intradialysis period
- 54 Activity-putting on nurse Description: activities of nurses when putting patients on dialysis
- 55 Activity-staff refreshments
- 56 Activity-taking off Description: activities that occur when taking the patient off dialysis
- 57 Activity-technicians Description: activity of technical staff
- 58 Activity-what patients do when illness
- 59 Activity- patient comfort
- 60 Act-putting on Description: a single act when putting the patient on dialysis
- 61 Activity- cannulation preparation
- 62 Activity- dialysis preparation
- 63 Activity- lining the machine
- 64 Activity- machine preparation
- 65 Activity- TV watching
- 66 Age Description: the age of a person
- 67 An incident Description: A description of an incident on the DSU
- 68 And routine work
- 69 Anxious Description: an example of anxiousness
- 70 Appreciating patient experience Description: staff appreciation of the patient experience
- 71 Autonomy Description: staff experience of autonomy of practice in patient management
- 72 Barriers to care Description: perceived barriers to providing the best care
- 73 Becoming ill Description: description of becoming ill with renal failure
- 74 Being a team Description: descriptions of being in a team
- 75 Being able to talk Description: evidence of being able to talk to people
- 76 Being cared for Description: a description/explanation of being cared for by staff
- 77 Being comfortable Description: an example of an experience of being comfortable
- 78 Being for the patients Description: nurse's perception of role
- 79 Being friendly Description: examples of being friendly to others
- 80 Being ill Description: the experience of being ill
- 81 Being known Description: describes the importance of being known as opposed to not being known and that it affects the level of care.
- 82 Being listened to Description: the importance of staff listening to the patient
- 83 Being on top of things Description: nurse view of having the unit under control
- 84 Being put on Description: MU taking advantage of DSU staff
- 85 Being respected Description: example of being respected by others or showing respect

- 86 Being successful Description: achieving expected patient care outcome
- 87 Belief about patients Description:
- 88 Belonging to the DSU Description: a sense of belonging to somewhere where people care about you
- 89 Better communication between staff Description:
- 90 Blurring of role Description: no fixed role when doing activities or tasks by nurses
- 91 Cared for Description: what being cared for is described as
- 92 Caring activity Description: an activity demonstrating caring
- 93 Caring for patients Description: example of caring behaviour or attitude
- 94 Certainty Description: about knowing what to expect on the unit and staff behaviour/attitude
- 95 Clinical support Description: support by other staff on the DSU
- 96 Closeness Description: Physical closeness to each other and closeness in relationship
- 97 Closeness to home Description: the importance of the close proximity of the unit to the patient's home
- 98 Comfortable Description: patient expression of comfort at the DSU
- 99 Committed to patient care Description:
- 100 Communication with MU activity Description: an activity where there is communication with the MU
- 101 Comparing DSU & MU Description: patient and/or nurse comparison between the units
- 102 Comparing events dialysis preparation Description:
- 103 Concern Description: Staff expression or acts of concern for the patient
- 104 Confidence to make decisions Description:
- 105 Conflict Description: conflict of opinion between staff/ MU
- 106 Conscious of being judged Description:
- 107 Constant anxiety of failure Description: feeling anxious about failing to do the right thing
- 108 Content of talk Description: the content of discussions between people
- 109 Control Description: expression/acts of control over life events
- 110 Creativity Description: being creative about patient care
- 111 Dialysis activity taking off Description:
- 112 Decision making better for patients Description: the decisions made by staff are better for patients and relates to autonomy and confidence
- 113 Decision-making Description: the importance of improved decision making ability
- 114 Denial Description: expression of denial
- 115 Description of a DSU patient Description: nurses description of a DSU patients
- 116 Developing renal nursing skills Description: How skills in renal nursing developed
- 117 Dialysis activity 'going off' nurse Description: the activity nurses undertake when a patient becomes hypotensive
- 118 Dialysis activity patient nesting Description: what patients do to prepare themselves for dialysis
- 119 Dialysis activity taking off Description: the activity by nurses when terminating dialysis
- 120 Dialysis event 'going off' Description: The event of a patient hypotensive episode
- 121 Dialysis event putting on Description: The event of 'putting on' dialysis as a major event
- 122 Dialysis event taking off Description: major event 'taking off' dialysis
- 123 Dialysis object Description: a dialysis related object
- 124 Dialysis preparation Description: what is done to prepare for dialysis
- 125 Dialysis putting on activity Description: the activity of putting the patient on dialysis
- 126 Dialysis space is used by MU Description: The MU uses space available at the DSU for overflow
- 127 Dialysis station activity Description: What activities happen at the dialysis space
- 128 Dialysis station space Description: The space in the DSU where dialysis occurs

- 129 Difference of dialysis shifts Description: a patient's preference for a specific dialysis shift
- 130 Disease Description: Description of illness
- 131 Dislike of MU Description: expression of dislike of the main unit
- 132 Doing care for patients Description:
- 133 Drink Description:
- 134 DSU as community Description: views by staff and patients who feel that the unit is like a community
- 135 DSU attraction Description: Why the DSU is attractive for staff
- 136 DSU being listened to Description: the view that DSU staff listen more than MU staff
- 137 DSU competent staff Description: importance of staff being competent
- 138 DSU event Description: different events, variety
- 139 DSU experience Description: description of general experience in the DSU
- 140 DSU imaginative variation Description: Where imaginative variation is used to elicit essential elements from patients/staff.
- 141 DSU low patient numbers Description: why low numbers of patients is important for the DSU
- 142 DSU maintenance activity Description: general unit maintenance activity
- 143 DSU management issues Description: Management of the unit
- 144 DSU nursing limitations Description: Staff personal limitations
- 145 DSU patient behaviour Description: staff perception of patient behaviour
- 146 DSU patients Description: Other's views of DSU patients
- 147 DSU Personal care Description: Where patients feel they get more personalised care than at the MU
- 148 DSU routine day Description: A DSU routine day description
- 149 DSU staff influence on patients Description: the closeness of staff can influence patient behaviour
- 150 DSU structure Description: Patient identified important structures for a DSU
- 151 Encouraging patients Description:
- 152 Entertaining Description: a nurse's perception of why they organise activities
- 153 Essential structure Description: identification of a potential essential structure of the DSU
- 154 Event food Description: what happens when food arrives
- 155 Event- patient transport Description: The event of patient transport to and from the unit
- 156 Event staff shortage Description: How shortages of staff affect the DSU
- 157 Event- taking off Description: the event of taking patients off dialysis
- 158 Event-Christmas Description: the occasion of Christmas on the unit
- 159 Event-going off Description: when a patient's blood pressure drops
- 160 Event-nurse consultant attendance Description: When the nurse consultant attends the unit
- 161 Event-patient admission Description: when a patient is admitted to hospital
- 162 Event-patient withdrawal from dialysis Description: when a patient withdraws from treatment
- 163 Event-pre dialysis preparation Description: the period prior to patients entering the unit for treatment
- 164 Event-putting on Description: the putting on time
- 165 Events-off duty reorganisation staff Description:
- 166 Event-unacceptable patient behaviour Description: when a patient behaves inappropriately
- 167 Event-Xmas party for patients Description: Christmas party on the unit
- 168 Everyone contributes to the unit Description:
- 169 Experiencing dialysis Description: personal experience of a dialysis treatment
- 170 Explaining MU experience Description: An explanation of MU experience in relation to DSU

- 171 Explanation to another patient Description: explaining a DSU to another patient
- 172 Family Description: the DSU as a family
- 173 Fear Description: description/explanations of fear by patients
- 174 Feeling better Description: being at a DSU makes you feel better
- 175 Feeling down Description: Patient view of experience of being on dialysis, feeling low
- 176 Feeling safe Description: descriptions of feeling safe
- 177 Feeling secure Description: descriptions of feeling secure
- 178 Feeling undervalued Description: Not feeling valued by the MU
- 179 Feeling vulnerable Description: Staff feeling vulnerable in the DSU
- 180 Fewer patients Description: importance of fewer patients
- 181 Finding out about DSU Description: how patients found out about the DSU
- 182 First experience of dialysis Description: staff first experience of dialysis
- 183 First exposure to dialysis Description: staff first exposure to dialysis
- 184 First HD Description: Description of first HD experience
- 185 First HD at the MU Description: patient's first dialysis at the MU
- 186 First visit to DSU Description: description of first visit to a DSU
- 187 Flexibility Description: patient statement of the flexible approach the DSU has to treatment
- 188 Freedom to make decisions Description: staff freedom to have autonomy for making decisions
- 189 Friendly Description: the unit as friendly
- 190 Friendship Description: staff and patients become 'friends'
- 191 Friendship beyond dialysis Description: friendship the extends beyond dialysis treatment
- 192 Frustration Description: feelings of frustration that occurs at the DSU
- 193 Gaining control over technology Description:
- 194 Getting involved Description: getting involved with patients
- 195 Getting on with people Description: the importance of getting on with other people
- 196 Getting to know about your treatment Description: importance of being able to talk to staff
- 197 Goal- local anaesthesia
- 198 Goal- patient involvement
- 199 Goal-taking off
- 200 Going to DSU Description: How patients found out they were going to a DSU
- 201 Having your own TV Description: importance of having your own TV, freedom
- 202 HCA activity Description: what the HCA does
- 203 Helping another DSU Description: helping another unit
- 204 Helping the patient Description: importance of helping the patient, nurse view
- 205 Hope for the future Description: expressions of hope of escaping from dialysis
- 206 How you were treated at main unit Description: How the patient was treated at the MU
- 207 Humour Description: the use of humour and its importance.
- 208 Impact of staff shortages Description: staff shortages
- 209 Impact on patients of ill patients Description: how an ill patient influences atmosphere
- 210 Impersonal care Description: perceptions of impersonal care at the MU
- 211 Importance of small size Description: unit size is important
- 212 Improving patient care Description: nurse philosophy
- 213 Increased confidence Description: working in the DSU increases personal confidence
- 214 Increased patient contact Description:
- 215 Informal atmosphere Description: informality in the unit to help the patient
- 216 Initial problems Description: problems of setting up the dialysis unit
- 217 Initial vascular access Description: vascular access implantation
- 218 Interaction activity Description: description of interaction between staff and patients

- 219 Intradialysis activity Description: activities of staff during the dialysis period
- 220 Involvement Description: being involved with staff/patients
- 221 Isolated Description: a sense of isolation from the main unit
- 222 Job satisfaction Description: attaining job satisfaction
- 223 Justifying your work Description:
- 224 Keeping in contact with the patient Description: when the patient is transferred to the MU, keep in-touch
- 225 Keeping in touch with patients Description:
- 226 Knowing other dialysis patients Description: The importance of knowing other patients
- 227 Knowing the staff Description: knowing the staff makes a difference
- 228 Knowing your patient Description: knowing your patient through frequent contact
- 229 Lack of control Description: situations when there is a lack or personal control
- 230 Lack of information Description: importance of information to patients
- 231 Lack of medical cover causes some anxiety Description:
- 232 Learning Description: helping patients learn
- 233 Less stressful Description: transport as less stressful
- 234 Life made easier Description: DSU makes life easier
- 235 Life restrictions Description: restrictions upon managing your life
- 236 Local anaesthetic is applied to the fistula
- 237 Loss of livelihood Description: loss of job and income
- 238 Main unit as a veiled threat Description: the unspoken/spoken threat of returning to the main unit
- 239 Maintaining contact with MU Description: staff contact with the main unit
- 240 Make a difference to the patient Description: nurse's belief they make a difference to the patient
- 241 Making a difference Description: to the patient
- 242 Making a fuss over patients Description: activities to make the patient feel important
- 243 Making patients comfortable Description: staff making the patient comfortable
- 244 Manageing patient treatment Description:
- 245 More patient contact Description: nurses have more patient contact at the DSU
- 246 Moving to the DSU Description: finding out about going to a DSU
- 247 MU communication activity Description: what is done to keep in contact with the main unit
- 248 MU experience Description: describing personal MU experience
- 249 MU lack of personal input Description: lack of personal care experienced in the MU
- 250 MU nurses perception of DSU Description: how non-DSU staff perceived the unit or are perceived by DSU staff
- 251 MU nursing experience Description: staff experiencing dialysis on the MU
- 252 MU Patients Description: what MU patients are like to DSU patients
- 253 MU too big Description: views that the MU is too big
- 254 MU too busy Description: too busy compared to the DSU
- 255 MU transport issue Description: problems of transport to the MU
- 256 My life Description: a description of a patient's experience
- 257 Nearer Description: the unit is nearer to home
- 258 Need more space Description: a problem with lack of space
- 259 Needing to attend the MU Description: reason for attending the MU
- 260 New patients nursing action Description: what new patients do
- 261 No doctors allows decision making Description: freedom to make decisions based on own experience due to absence of medical staff
- 262 No sick patients Description: importance of not having sick patients on the DSU
- 263 Non-dialysis activity Description: staff non-dialysis related activities
- 264 Non-dialysis activity Description: staff non-dialysis related activities
- 265 Normalising patient experience Description: a nursing goal
- 266 Not a DSU type of patient Description: description of a patient not suited to the DSU

- 267 Not able to provide the care you would to Description: occasions when ideal care cannot be provided
- 268 Not being cared for Description: description of experience of not being cared for
- 269 Not being ill Description: How patients deal with needing dialysis
- 270 Not belonging to the MU Description: Explaining why DSU patients do not belong to the MU
- 271 Not busy Description: DSU not as busy as MU
- 272 Not feeling safe Description: a feeling that the patient does not feel safe during the treatment
- 273 Not wanting to see ill patients Description: ill patients not for the DSU
- 274 Nurse activity Description: activities that nurses do
- 275 Nurse dialysis machine activity Description: a dialysis related activity
- 276 Nurse perception of a type of DSU patient Description: a patient type for a DSU
- 277 Nurse view of patients doing preparation Description:
- 278 Nurse-patient interaction Description: description of interaction
- 279 Nurse's station activity Description: activities at the nurses station
- 280 Nurses station not for patients Description: the station is for patients to attend for long periods
- 281 Nurse's station space Description: description of the nurse's station space
- 282 Nursing background Description: descriptions of nursing experience
- 283 Nursing difference between MU & DSU Description: views of comparison
- 284 Nursing division of labour observation Description: observations about who does which job/work
- 285 Nursing imaginative variation Description: IV responses
- 286 Nursing perception of patient experience Description: understanding the patient situation
- 287 Object- dialysis pack Description: the pack used by staff for the cannulation activity
- 288 Object dialysis station-chair Description: the dialysis station chair used by patients
- 289 Object- nurse's station Description: the physical object of the nurse's station
- 290 Object- pillow and sheet Description: pillows and sheets used by patients during treatment
- 291 Object- trolley moveable Description: a trolley used throughout the unit to carry equipment for treatment or refreshments
- 292 Object- weighing scales Description: scales used by patients to measure their weight
- 293 Object-chairs Description: chairs around the unit not for treatment sessions
- 294 Object-computer Description: the staff computer
- 295 Object-dialysis machine Description: a dialysis machine
- 296 Object-medication Description: medications administered by nurses to patients
- 297 Object-moveable Description: objects that are moveable throughout the unit such as trolleys, patient records
- 298 Object-notice board Description: information notice boards for patients and staff
- 299 Object-nurse's station Description: Objects found at the nurse's station
- 300 Object-patient's lockers Description: patient's lockers for clothes and valuables
- 301 Objects-food & drink Description: food and drink for patients
- 302 Object-trolley moveable Description: a moveable trolley
- 303 One to one care Description: patient one-to-one care
- 304 Organisation activity Description: activity for dealing with an issue
- 305 Organising care Description: how care is organised
- 306 Other DSU experience Description: experience of other DSU
- 307 Other illness Description: non-renal illness
- 308 Other patients Description: patient perception of other patients
- 309 Ownership Description: a sense of ownership of unit & staff
- 310 Patient activity Description: patient activity during dialysis
- 311 Patient activity putting on Description: putting on activity of patients
- 312 Patient benefit Description: helping the patient

- 313 Patient care concern Description: concern for patient's care
- 314 Patient experience of illness Description: description of patient's experience of illness at the DSU
- 315 Patient interpretation of experience Description: how patients interpret their experience
- 316 Patient outcome reflects care Description: nurse's views that patient's outcome related to the quality of nursing care
- 317 Patient perception of MU Description: what patients think of the MU
- 318 Patient problem solved Description: patient's have their problems sorted by staff
- 319 Patient problems Description: managing patient problems
- 320 Patient trust Description: gaining patient trust
- 321 Patient view of situation Description: how patients view being ill and on dialysis
- 322 Patient waiting area Description: description of the patient waiting area
- 323 Patient-machine tension Description: patient's anxiety over machines and possible failure
- 324 Patients and staff are visible Description: where people are visible around the unit
- 325 Patients are settled: Description: patients are more relaxed in their approach
- 326 Patients as a family Description: see 'family'
- 327 Patients as friends Description: patients are viewed as a friend by nurses
- 328 Patients chat to each other Description: patient interaction
- 329 Patients open up more Description: increased personal interaction
- 330 Patients prepare their dialysis area Description: patient preparation activity
- 331 Patients tell you more Description: nurses feel patients tell them more about their lives and health
- 332 PD Description: PD as a form of treatment
- 333 PD Failure Description: Reason why started haemodialysis
- 334 Perception of closeness of relations Description: closeness of relationship with staff and other patients
- 335 Perception of DSU staff Description: patient description of DSU staff behaviour
- 336 Perception of patient Description: staff description of the patient
- 337 Perception of staff Description: description of DSU staff
- 338 Personal care Description: descriptions of personal care
- 339 Personal development Description: DSU has enabled personal and professional development
- 340 Personal philosophy of care Description: a nurse's view of what they should be doing
- 341 Personality clash Description: potential problem of personality clash
- 342 Physical access to the unit
- 343 Planning Description: description of planning activity
- 344 Positive outlook Description: patient outlook as positive
- 345 Power and control by others Description: here power and control lies
- 346 Predictability Description: the importance of being able to predict what the dialysis will be like such as staff cannulation, not feeling ill.
- 347 Preference of the DSU Description: Why the patient prefers being at the DSU
- 348 Problem solving Description: staff problem-solving
- 349 Problems sorted Description: description of problems sorted
- 350 Providing continuity Description: problem solving through continuity of care
- 351 Providing individualised care Description: description of staff providing individualised care
- 352 Providing intermittent care at the MU
- 353 Put out to grass Description: being sent to a DSU is being forgotten about by the MU
- 354 Quietness of DSU Description: DSU have a quiet atmosphere
- 355 Rationale to go to DSU Description: reason for going to the DSU
- 356 Redirecting your thoughts Description: taking your mind off the treatment
- 357 Relaxed Description: why and how the patient feels relaxed at the DSU
- 358 Repetition and routine Description: work: work in the routine

- 359 Response to diagnosis Description: Responding to the diagnosis of renal failure and/or the need for dialysis
- 360 Response to starting dialysis Description: the patient's emotional response to starting dialysis
- 361 Safety activity Description: activities for keeping the patient safe
- 362 Satellite nursing is better for patients Description: nurse's views that SU care is good for patients
- 363 Satisfied Description: feeling satisfied with the DSU
- 364 Self appraisal Description: nurse self description
- 365 Sign- temporal activity Description: when activity alters in a time orientated manner
- 366 Sign-dialysis preparation Description: a point when staff know when to prepare for dialysis
- 367 Sign-for interaction Description: signs that invite interaction with patients
- 368 Sign-taking off time Description: signs that indicate taking off time
- 369 Sign-temporal patient entry Description: sign that patients understand as allowing them into the unit
- 370 Sign-temporal to do the next thing Description: a perception of when it is time to do something
- 371 Sign-the ready position Description: a sign that the patient is ready for cannulation and dialysis on the unit
- 372 Situation of DSU Description: where the DSU is sited
- 373 Smallness of the unit Description: what being small means
- 374 Smallness of unit Description: what being small means
- 375 Sociable Description: a sociable atmosphere
- 376 Space-nurse's station
- 377 Space-nurse's station
- 378 Space-patient waiting area
- 379 Space-the DSU
- 380 Space-the treatment area
- 381 Space-waiting area
- 382 Space-weighing area
- 383 Staff as friends Description: patient perception of staff as friends
- 384 Staff attitude Description: the importance of staff attitude on how patients view their care
- 385 Staff comparing MU & DSU
- 386 Staff first day at DSU
- 387 Staff frustration Description: incidences of frustration in staff
- 388 Staff have time Description: description of time made available to patients by DSU staff
- 389 Staff help each other Description: helping each other, team-work
- 390 Staff imaginative variation Description: outcome of IV method
- 391 Staff- in control Description: a sense of control
- 392 Staff increased responsibility Description: assuming more responsibility
- 393 Staff lack of experience to set up the DSU Description: staff lack skills to set up a unit
- 394 Staff providing information Description: providing information
- 395 Staff quiet area Description: staff room/space away from patients
- 396 Staff rationale to go to DSU Description: why they chose to go
- 397 Staff shortages Description: the effects of staff shortages upon unit activity and patients
- 398 Staff staying at the DSU Description: why staying at the DSU
- 399 Staff time spent at DSU: the length of time staff have spent at the DSU
- 400 Staff time used for unit management Description: developing a broader perception of management

- 401 Staff unit responsibility Description: what DSU staff have to do; including non-dialysis activities
- 402 Starting dialysis Description: patient's experience of commencing dialysis
- 403 Staying at the DSU Description: why the patient would want to stay at the DSU
- 404 Strangers Description: feeling unsettled by new staff or strangers on the unit. Feeling like a stranger on the MU
- 405 Stressful Description: causes of stress
- 406 Success of nursing in the actions of others Description: nurses view their success in the action of others
- 407 Success of nursing in the comments of patients Description: success is viewed by what patients say
- 408 Success reflected in patient outcome Description: Success viewed in good patient outcome
- 409 Talking to other patients: Patients talking to other patients
- 410 Team work Description: Nurses view of working as a team
- 411 Technical problems Description: management activities
- 412 Technical support activity Description: support from technicians
- 413 The entrance lobby is a short corridor
- 414 The ideal patient Description: nurse's view of the ideal DSU patient
- 115 The unit as a community Description: see family
- 416 Time Description: A statement of the importance of time
- 417 Time at DSU
- 418 Time at MU Description: patient time spent at the MU
- 419 Time drags Description: descriptions of time passing slowly
- 420 Time is precious Description: descriptions of personal time being important and not wanting to lose it
- 421 Time lost Description: conditions when patient time is lost
- 422 Time made available Description: conditions when time is made available by staff
- 423 Time making it go fast Description: activities to make the time pass quickly
- 424 Time more of it Description: there is more time available for staff to help patients
- 425 Time not an issue Description: where transport is concerned
- 426 Time not enough Description: not enough time to do everything needed for care
- 427 Time not made available Description: conditions when time is not made available by staff (usually on the main unit)
- 428 Time on dialysis Description: time spent on dialysis
- 429 Time saved Description: conditions or experience when time is saved for the patient
- 430 Time spent at DSU Description: staff
- 431 Time spent at the main unit Description: how long spent on the MU
- 432 Time to talk Description: staff making time available to talk
- 433 Time to think Description: nurse's station activity
- 434 Time used efficiently Description: how time is used efficiently
- 435 Transplant Description: transplant experiences described
- 436 Treated as an individual Description: patient perception
- 437 Trust Description: staff developing trust
- 438 Trying to improve care: Nurse's intention to improve care
- 439 TV activity Description: How the TV affects activity
- 440 TV space Description: where the TV is situated
- 441 Typical patient Description: staff description of a typical patient
- 442 Uncertainty Description: How uncertainty affects patients
- 443 Unfairness Description: experience of unfair activity
- 444 Unit jargon Description: the language used by staff and patients
- 445 Unit jargon Description: the language used by staff and patients
- 446 Unit noise Description: sources of noise
- 447 Unit support politics Description: the politics between the DSU and the MU
- 448 Using humour Description: description of the use of humour during treatment

- 449 Utility room activity Description: activity in non-dialysis room
- 450 Utility room space Description: the space where cleaning equipment is kept
- 451 Variety in routine Description: when variety /changes occur in the routine
- 452 Vascular Access Description: type of vascular access when entering the DSU
- 453 Vascular access activity Description: activity associated with vascular activity
- 454 Vascular access tension Description: atmospheric tension associated with vascular access
- 455 Visibility of staff Description: staff can be seen at all times
- 456 Waiting Description: issues related to waiting, time saved/lost
- 457 What DSU Staff do Description: description of what DSU staff do for patients
- 458 What patients say Description: the comments patients say during discussion whilst on dialysis
- 459 Would not want to leave Description: reasons for not wanting to leave the DSU
- 460 You make them comfortable Description: Nurse's intention to make patients comfortable

# Appendix 5

## Example of Feedback (From unit two which moved after the study was undertaken)

14<sup>th</sup> Nov 2006

Hi Mark,

Many thanks for the draft copy of your findings. I really enjoyed reading it and felt it reflected the experiences of both the patients and nursing staff in the Satellite Unit. I've made a few comments which I hope you will find helpful.

### Illness

I liked the 3 types of illness you described as I am sure how they arrive on dialysis impacts on their 'state of mind' and how they are able to adjust to it mentally.

I identified with the patients never wanting to go back to the main unit and looking out for each other during dialysis.

I feel that the absence of Drs is often perceived as a problem by some patients prior to coming to the Satellite Unit, but they seem to get used to this and it isn't an issue for them after a few weeks.

I don't know if you picked up on some patients' reluctance to visit their GP with non renal problems. The patients comment that their GP doesn't understand their illness or aren't interested and prefer to be seen by the renal Drs. They sometimes arrive on the Unit really poorly, haven't contacted a Dr and expect us to sort them out!

Yes I agree that the nursing staff don't like illness on the unit.

### Feeling safe

Nearness and closeness. Now we are in a community setting it is even better for the patients; near to home and easy to park for patients' with their own transport. Also not being in a hospital environment helps to create a feeling of not being ill.

Knowing staff – sometimes patient/staff boundaries are blurred. The staff learn how to handle this. New staff to Satellites are advised about staff / patient relationships.

Feeling safe – a true reflection.

A community and a family – a true reflection. Trips to the coast have been organised by the staff at some of the Satellite Units and are popular with the patients. It's a good opportunity for staff to meet relatives and visa versa. Some patients also want to spend time with each other outside the unit and contact each other at home. Patients also show concern for each other when one of them from their shift is in hospital.

### Time Saved

Dialysis time – a true reflection.

Time saved All patients say they spend less time 'waiting' at Beeston.

Time made available – a true reflection

Nursing time - agree with this. Also there is sometimes conflict with the patients and nursing staff about getting on dialysis. Some patients when they initially come to the satellite unit complain they are always last to get on. The nursing staff try to discourage this behaviour.

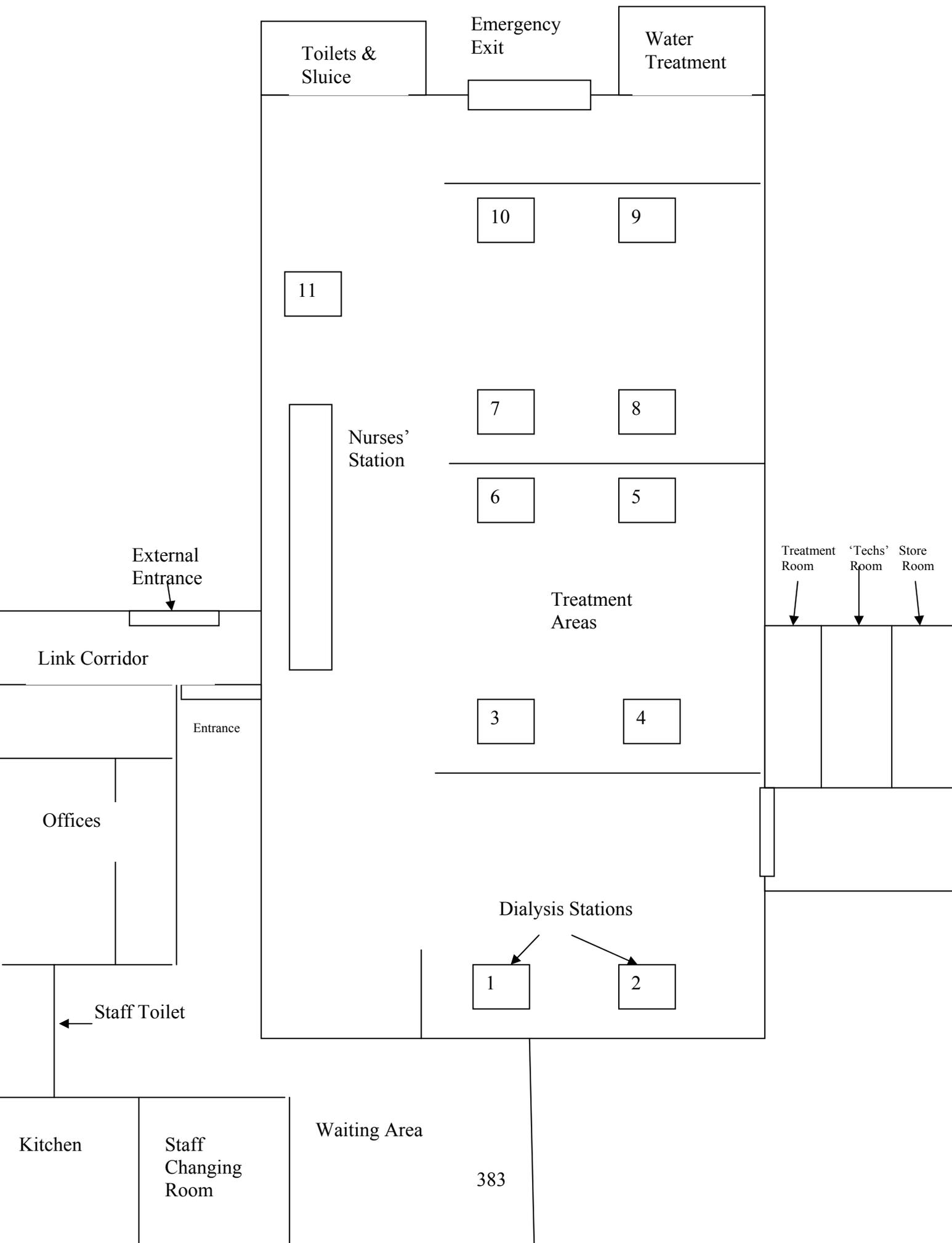
Patients sometimes don't appreciate how staff are trying to accommodate them with the big/small chair they like to sit on, to sit next to their friends, to start dialysis the same time as those that travel in the same car etc, etc.

### Freedom to Practice

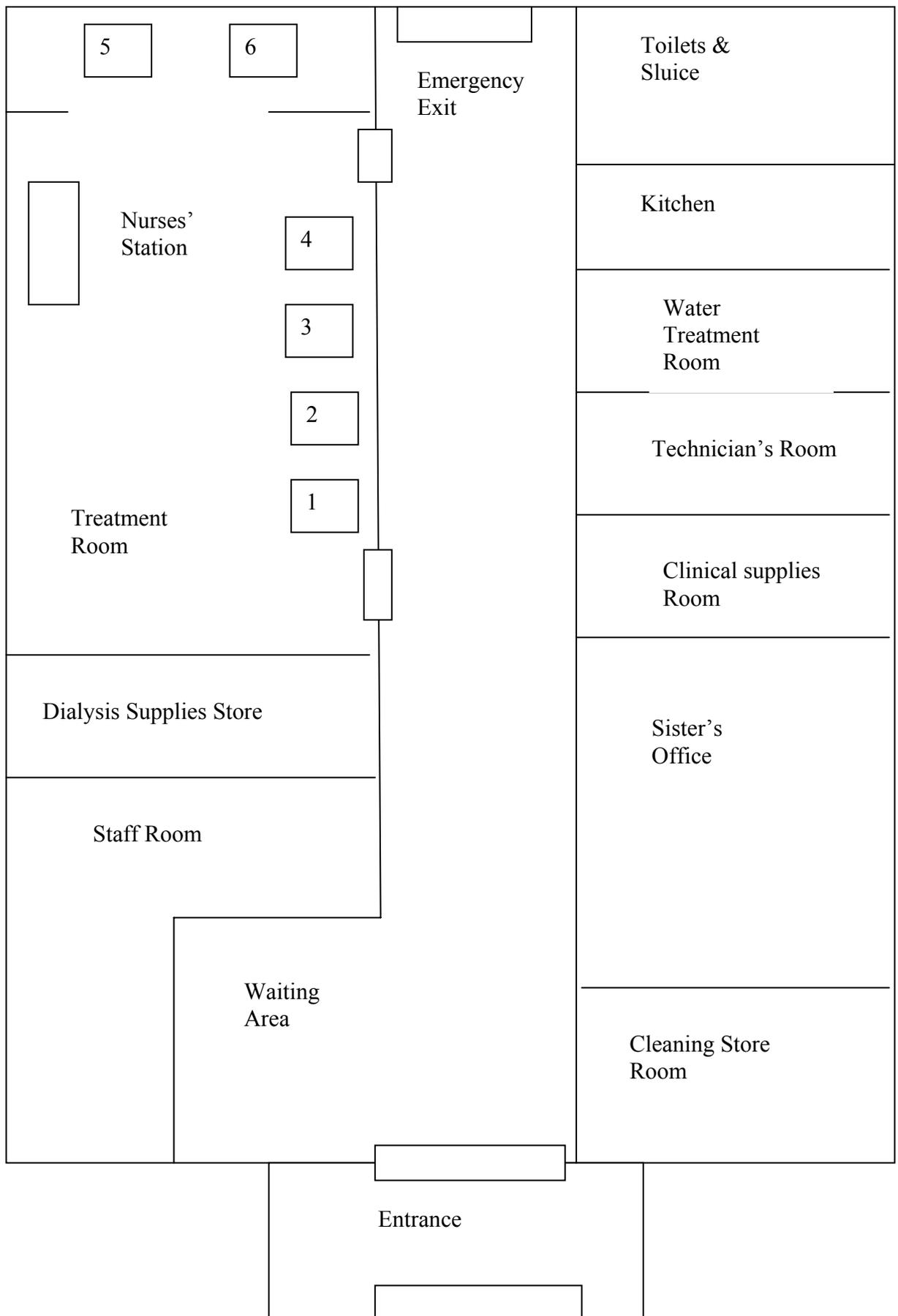
A true reflection. Since moving to B I don't feel quite as isolated. The building seems to make a difference – we have visitors from other departments within the building, daily deliveries of bread and milk etc from the COOP, and managers from the PCT (our landlords) visit us regularly.

# Appendix 6

## Layout of Satellite Unit One



# Layout to Satellite Unit Two



# Layout of Satellite Unit Three

