Embodied transformations:
The life-world of home haemodialysis

by

Stephen Giles

A thesis submitted in conformity with the requirements for the degree of
Master of Social Work

University of Toronto
Faculty of Social Work

Copyright © 2001 by Stephen Giles
The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author’s permission.

L’auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L’auteur conserve la propriété du droit d’auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-63228-8
Acknowledgements

I would like to thank all those who supported me during this study. Primarily, Dr Adrienne Chambon, my advisor who was a constant support; her expertise and sensitivities allowed me to travel deeper. Adrienne, merci!

I would like also to thank the contributions of the committee members, Dr A. Ka Tat Tsang and Margarita Ilumin (Toronto General Hospital) for their suggestions and comments.

Marlene, my wife, editor, and proofreader extraordinaire went beyond the call. Her companionship, support, love, and incredible sense of humor saw me through this powerful journey. Marlene, eu te amo!

The support of my family and friends cannot go undetected. The calls, the conversations, the encouragement are deeply felt.

"Excuse me while I kiss the sky"

James Marshall Hendrix
Title

*Embodied transformations:*

*The life-world of home haemodialysis*

By Stephen Giles
A thesis submitted in conformity with the requirements for the degree of
Master of Social Work

Faculty of Social Work
University of Toronto
2001

Abstract

With a growth in home-care, and increased funding for dialysis, there is a need for
the field of Social Work to understand the life world of the people who experience home
haemodialysis technology. Given that little research has focussed on the lived-
experiences of this population (Nagle, 1995), an exploratory qualitative study was
employed (Strauss & Corbin, 1998). The study investigated the embodied life-world
experiences of this population using phenomenological methods (Kvale, 1996; van
Manen, 1997). A purposive sample of four was selected, with each participant
experiencing various lengths of home haemodialysis technology. The data was collected
and analyzed in terms of the four phenomenological categories of lived-time, lived-body,
lived-spatiality, and lived-relations with others and self (van Manen, 1997). The findings
revealed the embodied transformations of the participant's life-world. Implications for
social work policy, practice, and research were discussed.
# Table of Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Introduction</strong></td>
<td></td>
</tr>
<tr>
<td>Background, Rationale &amp; Significance</td>
<td>1</td>
</tr>
<tr>
<td>Literature Review</td>
<td></td>
</tr>
<tr>
<td>Humanism and Technology</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td><strong>Theoretical Framework</strong></td>
<td></td>
</tr>
<tr>
<td>The Body</td>
<td>7</td>
</tr>
<tr>
<td>Embodiment</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>Research Focus</strong></td>
<td></td>
</tr>
<tr>
<td>Embodiment:Preserved, Disembodied or Transformed?</td>
<td>11</td>
</tr>
<tr>
<td>Research Questions</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>Method and Procedures</strong></td>
<td></td>
</tr>
<tr>
<td>Methodology</td>
<td>13</td>
</tr>
<tr>
<td>Contextual Understanding of Interviews</td>
<td></td>
</tr>
<tr>
<td>Data Collection</td>
<td></td>
</tr>
<tr>
<td>Sample</td>
<td></td>
</tr>
<tr>
<td>Participant selection</td>
<td>14</td>
</tr>
<tr>
<td>Participant Demographics and Interview Context</td>
<td></td>
</tr>
<tr>
<td>Interview Questions</td>
<td></td>
</tr>
<tr>
<td>Recruitment</td>
<td></td>
</tr>
<tr>
<td>Ethical Considerations</td>
<td></td>
</tr>
<tr>
<td>Privacy and Confidentiality</td>
<td>17</td>
</tr>
<tr>
<td>Risks and Benefits</td>
<td></td>
</tr>
<tr>
<td>Informed consent</td>
<td></td>
</tr>
<tr>
<td>Data Analysis</td>
<td></td>
</tr>
<tr>
<td>Validity</td>
<td>19</td>
</tr>
<tr>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>Findings and Discussion of Highlighted Findings of Themes by Case</strong></td>
<td></td>
</tr>
<tr>
<td>List of Highlighted Themes</td>
<td>24</td>
</tr>
<tr>
<td>Case 1: Findings and Discussion of Highlighted Themes</td>
<td>30</td>
</tr>
<tr>
<td>Case 2: Findings and Discussion of Highlighted Themes</td>
<td>40</td>
</tr>
<tr>
<td>Case 3: Findings and Discussion of Highlighted Themes</td>
<td>50</td>
</tr>
<tr>
<td>Case 4: Findings and Discussion of Highlighted Themes</td>
<td>60</td>
</tr>
<tr>
<td>6</td>
<td></td>
</tr>
<tr>
<td><strong>Emergent Themes: Inter-case Discussion</strong></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td></td>
</tr>
<tr>
<td><strong>Conclusion</strong></td>
<td></td>
</tr>
<tr>
<td>Summary Discussion</td>
<td>86</td>
</tr>
<tr>
<td>Methodological significance</td>
<td>88</td>
</tr>
<tr>
<td>Recommendations for future research</td>
<td>88</td>
</tr>
<tr>
<td>Implications for social work</td>
<td>90</td>
</tr>
<tr>
<td>Limitations of the study</td>
<td>91</td>
</tr>
<tr>
<td>References</td>
<td>92</td>
</tr>
</tbody>
</table>

**Appendices**

A. Background info for participants
B. Consent forms
C. Interview guide
CHAPTER 1

Introduction

Background

The history of the relationship between humans and technology is as long as it is complicated. Our mutual histories - so intertwined, stitched and tied - that now in the second millennium it has become difficult, if not almost impossible, to identify the seams. A symbiosis so strong and vital, our survival as a species clearly hinges on it. From the first prehistoric flints, to today's advanced microchip technology, the progress has been extraordinary. The twin forces of humans and technology, together conquering nature, and reshaping the environment to better meet our needs and wants. For the most part, it has been an enduring and beneficial relationship.

In recent times, however, the relation has stumbled. What was once seen as technological progress, is now seen by many instead as the rampant destruction of the environment and the dehumanization of basic human activities (Heidegger, 1953/1977). Despite the debate surrounding the problems associated with technological "advancement", undeniably, technology has been of benefit to humankind, especially within the field of medicine.

Rationale

At a recent First Ministers meeting, held in the summer of 2000, pledges were made to increase funding for home-care and new health care technologies, such as dialysis machines.¹ These factors when considered along with Nose's (2000) suggestion that home haemodialysis is

both low cost and safe, add up to a trend towards an increase in the use of home haemodialysis treatment for people with end stage renal disease (Blagg, 1996, Boyle, 2000). Thus, increasing levels of technological advancement in health-care, combined with a shift to shorter hospital stays and increased reliance on home-care (Egan & Kadushin, 1999), means patients will have less face-to-face interaction with health care providers than in the traditional hospital settings over the course of their treatment. One can therefore predict that the trajectory of this change in health care policy will mean for patients both an increased involvement with, and reliance on, medical technology in the their home setting.

Moreover, given the recent developments in technology, home-care, and health care policy, the time has come for social work to examine the implications of technology in the home-care setting of patients. As a result, social work will need to better understand the relation between the patient and medical technology, such as home haemodialysis technology in order to develop interventions and policies that are based on a contextual understanding of the issues arising from new developments in health care policy. For without an understanding of how these developments will impact patients, social work will have abdicated its role, thereby placing patients at risk.

Significance

The role of social work in medicine has been long established (Erickson & Erickson, 1989, Roberts, 1998). It therefore follows that medical social work in general, and nephrological social work in particular, will be impacted by the changes in the advancement of medical technology and health care policy. Medical technology in the context of a hospital setting is familiar and expected by patients and social workers alike. Modern medical machinery in the
home, however, is a new development whereby the role of home haemodialysis technology and the lived-experiences of patients receiving this technology are less understood. Social work has fallen short of developing an analysis of the life-world within the context medical technology

Literature Review

A review of the home haemodialysis literature suggests that research has focussed on the patient within the context of the medical model of illness. Working within this context, research has expanded the notion of the patient from that of an individual, to that of a family (Streltzer, 1976, Stewart & Johansen, 1977, McCabe, 1977, Tsaltas, 1978, Levenberg, Jenkins & Wendorf, 1979, Brackney 1979, Goldman, Cohn & Longnecker, 1980, Palmer, Canzona & Wai, 1982) These studies focussed on the impact of the home haemodialysis treatment process on the family In doing so they suggested that the family also must be considered in the treatment plan, acknowledging that the 'treatment' has moved from the hospital to the home, thus implicating the family to a greater extent in social work interventions. This seemed to show that home haemodialysis was creating a new context for care, calling for social workers to consider the family systems approach. Similarly, other researchers have expanded what was once the traditional focus of medical treatment, the patient's physiologic response, to include what has now become the new and complimentary variable that of the patient's psychosocial response to illness (Sheriden, 1977, Mathews, 1978, Alleyne, Vassel & Morgan, 1982, Petersen, 1982, 1984, 1985, Littlewood, Hardiker, Pedley, & Oley, 1990, Courts, 2000)

The psychosocial variable considers the psychological and social aspects of illness in addition to the medically focussed biological understanding of illness. This view sees the 'illness' as a constant which social workers and patients have no control over. Thus this model
views patients as having to 'adjust' or 'respond' in a way which does not question the biological foundations of the illness in a fundamental way. The assumption is that a 'poor' psychosocial response or adjustment to the biological illness could undermine the medical treatment. Therefore, it is argued from this perspective, the psychosocial response/adjustment needs to be studied in order to develop interventions which will facilitate a medical recovery. As a result, the psychosocial construct does not critique the medical model of illness. Instead it merely perpetuates it.

Moreover, supporting the medical model of illness, and resultant treatment regime, other research has focussed on the legitimacy and importance of the health care team in the provision of home haemodialysis treatment (Palmer, 1978, Athcherson, 1978, Stevens, 1996), and on measures to improve patients' compliance and adherence to treatment (Witenberg, Blanchard, McCoy, Suls et al., 1983, Courts & Boyette, 1998, Christensen, 2000.) Thus it can be seen that the home haemodialysis literature has a medical and biological focus. It is therefore easy to understand why research has focused on issues such as the health care team, the family's response to the illness, and the psychosocial adjustment to treatment of the patient, and the various patient configurations of 'patient', such as spouse or family. The result is that there is little available research on the patient's lived-experience and understanding of illness (Wright & Kirby, 1999)

This review of the literature supports Nagle's (1995) claim that to date the research on haemodialysis has focussed on physiologic and psychosocial responses to illness. To date, other than by Nagle (1995), there has been no reported research on the life-world of people who receive home haemodialysis.
Nagle's research, noting this gap, focussed on the meaning of technology experienced by those who received haemodialysis treatment for end stage renal disease, and to what extent their experience revealed technological embodiment, which is the embodying of medical technologies. Utilizing semi-structured interviews, she concluded that the meaning of technology for the participants in her study depicted a continuing struggle against objectification and disembodiment in the context of illness care. Interestingly, though, despite the pervasive and relentless threat to embodiment posed by the technology of illness care, "the participants remained embodied" (p. 130).

This objectification or threat of disembodiment, she argues, is supported by the mind-body dualism which medical science is predicated on, where the focus on the treatment of the physiological body overlooks the totality of the human experience. It is no surprise then the social work practice tradition has also failed to acknowledge the importance of bodily knowledge (Peile, 1998). The requirement for the inclusion of the totality and unity of human experience, and a fundamental rejection of the 'objective' scientific methods is supported by existential and phenomenological philosophers such as Heidegger (1962/1990), Merleau-Ponty (1962/1999), and Sartre (1956/1973).

The limitations of her methodology from an qualitative perspective are that in using the hermeneutic circle of reflection, there is a tendency to essentialize or condense the experiences of all the participants until a final constitutive pattern is arrived which gives voice to the central experience of the participants. In this way individual differences are left out of study.
Humanism and Technology

In the context of recent writing on medicine and philosophy, the view that a humanistic perspective is required in medicine is supported by Zaner (1990) and Bevan (2000). Zaner suggests that medicine needs to be reconceived so as to provide an appropriate emphasis on the patient's experience and understanding of illness. Showing what can go wrong when this emphasis is lacking, Bevan analyzes haemodialysis from a philosophical and critical standpoint, where he questions haemodialysis as an all-saving medical wonder. Bevan exposes the element of social control embedded within the context of the "soft technologies" of dialysis by comparing the context of the treatment procedures to that of an experiment where the human patient is, in the end, seen as just another "variable" to be controlled. This controlling practice has a tendency to objectify the patient. Consequently, when there are no humanizing elements embedded in medical treatment, it is possible for the micro-practices and the contextual environment of medicine to be seen as objectifying and thus oppressive (Foucault, 1976/1990, Bevan, 2000).

Nagle, however, does not take this vantage-point in her study. She does not reject dialysis as fundamentally oppressive. Instead, she adopts a moderate approach, accepting the hard and soft technologies of dialysis treatment generally, and calling for further research to explore the notion of the meaning of technology and technological embodiment for both patients and service providers in other contexts of illness care. In doing so, she picks up a thread from Abraham (1976) who calls for a combining of humanism with the technology of medical progress, and warns that without it the "patient loses his dignity and is engulfed by a mechanical and frighteningly alien world" (p 210).
CHAPTER 2

Theoretical Framework

The Body

If we are to understand Nagle's suggestion that embodied self can be preserved in the face of dialysis technology, the substantive research area of the body must be explored. There is extensive literature on body image (Tantleff & Thompson, 1998, Furnham, Dias & McLelland, 1998, Trapnel, Meston & Gorzalka, 1997, Van Deusen, 1997, Grant & Fodor, 1986, Leventhal, 1983). Body image in these studies is analyzed in the context of social and perception based issues such as 'attractiveness' and anorexia. Some researchers have explored the body in relation to mind, calling for an end to the split imposed by Cartesian dualism (Luborsky & McLellan, 1981, Kornfeld, 1997). Others, such as Springer (1997) have discussed the meaning of body in adolescent girls who experienced violence. Haynie (1980) reviewed the literature on deprivation of body pleasure, while Martin (1998) discussed the process of the gendered body and how young girls bodies become gendered by preschool curriculum. While the construct of body image is the central conceptualization for some researchers, others have taken different paths.

Deegan (1978) provides an interesting alternative by analyzing the post-operation depression that people who have experienced amputations are perceived as having. Patient's depression is seen in terms of failure of adjustment to the operation. Deegan suggests that the problems in daily living and the phenomenon of the phantom limb are not mental aberrations but instead are the reflections of a radically altered living experience. Deegan's ideas are informative on two accounts for our purposes. First, he shows how a narrow view of 'adjustment' can cover over experiences which are real for patients. Second, and more importantly, he also hints at
the idea of embodiment through what is known as the process of bodily integrity (Gattuso, 1996). That is, despite the body actually losing part of itself, it tries to keep the experience of a whole body through the phenomena of phantom limb.

This phenomenon of bodily integrity is illustrated in another case where the recipient of the world’s first transplanted hand, begged surgeons to cut it off because he had become "mentally detached from it". He said, "as it began to be rejected, I realized that it was not my hand after all. If this is what I am going to have for the rest of my life, I'd rather not have it" ("Doctors refuse", 2000). So it appears that not only does the body try to keep its integrity intact by suggesting that parts which are not there, are, it also appears to reject things which do not belong. This extends the idea of rejection beyond the already understood process of physical rejection as witnessed in the transplant literature (Chesler & Hsu, 1995, Allilaire, 1990). The notion of bodily integrity, and the length to which a body will go to keep itself whole, as in the aforementioned cases, when considered with Martin's (1998) explanation of how bodies become gendered, leads us into the area of embodiment.

**Embodiment**

Embodiment theory represents the phenomenological focus on the body as a unified potential for action. The distinction between objective physiological bodies and phenomenal bodies are central for existential analysis of any human phenomenon (Leyland, 1995). For when Merleau-Ponty (1962/1999) writes the "world is not what I think, but what I live through", he means that body as lived-experience is where the analysis of phenomena must begin. And this paradigm of understanding, that the body is central, has been adopted by many researchers, thus contributing to the subsequent growth in the area of embodiment research.
Moving beyond the idea of body image, others are pointing to the idea that bodies are ways of knowing and that they are social products which may lead to personal and social change (Jones, 1993, Hall, 1998, Weiss, 1999) Also acknowledged are the threats to bodily integrity coming from social process, that in turn may lead to a process of bodily reconstruction (Gattuso, 1996) The argument that bodies are susceptible to social forces (Synott, 1992), is helpful to our understanding of body and embodied self because it challenges the idea that bodies are merely biological

How far can bodies be stretched by social forces? Burkit (1999) imposes limits to the idea of embodiment by suggesting that the body is not infinitely malleable within the context of social construction Despite these broad limits, however, he asserts that the body is open to a re-formation, where it acquires specific capability, enabling it to grow, work, and learn In particular, Burkit argues that this re-formation is made possible through artifacts, which are "prosthetic devices that augment bodily powers and make possible new activities and new ways of life" (p 147) Thus these artifacts reform the body and experience, "allowing a body to reconstitute the embodied experience " (p 147) For example, the subjective notion of time can be compressed with the plethora of new communication technologies, thereby prompting the body to re-experience time in a new way, effectively reconstituting the embodied experience With this move it is possible to extend this concept of artifacts or prosthetics, to include for our purposes, home haemodialysis machines In so doing, this provides a theoretical framework to help us understand how a body might assimilate a material object, such as a home haemodialysis, into the phenomenological experience of the body This lends weight to the argument that bodies can be restructured or transformed, not just from obvious medical/material processes, but also by social processes and material objects which are located in the environment
Frank (1993) furthers this position by suggesting that ill bodies have the potential to communicate in new ways. It is from this understanding, that within broad parameters bodies are malleable entities on many levels, that the question of preserving embodiment in the face of medical technology arises. Which is to say, if we acknowledge that the home haemodialysis is a technology located within the context or environment of illness care, and that these forces come to bear on the phenomenological field of the body, then we must admit to the possibility of embodying the experience of technology.
CHAPTER 3

Research Focus

Embodiment: preserved, disembodied, or transformed?

On the subject of embodiment, we have discovered, there exists differing views. Deegan suggests the extent to which bodies will try to remain phenomenally whole through the phenomenon of phantom limb. Similarly, Nagle’s findings suggest that embodiment was preserved, despite clear and sustained intrusions of both hard and soft technologies in the context of illness care for people who receive dialysis. Such findings suggest the phenomenal field of the lived-body appears to be robust. That is, despite the physical removal, or addition of its parts, on one hand, and on the other, a sustained effort from hard and soft technologies of care to disembody it it remains embodied.

In contrast to Nagle and Deegan, however, Martin (1998), Frank (1993), and Burkit (2000) all suggest that bodies can be transformed, re-structured or reformed by social processes and/or the addition of material artifacts or prosthetics. So if they are right, why are their suggestions not evidenced by Nagle’s findings?

This point raises many interesting questions about embodiment, highlighting the important work yet to be done in this area. How is that even when a body is hooked up to a machine, such as in home haemodialysis, that it does not succumb to disembodiment? Moreover, Nagle’s findings indicated that there was struggle for the participants in the study to remain embodied within the context of care. What would the experience be for those who lost the struggle? Does the losing of this struggle imply a failure for the body, or an option for transformation which will provide new opportunities? Nagle’s findings were presented in a way
which suggested that remaining embodied in the face of technology, though a struggle, was indeed an incredible achievement. What if the patients became disembodied, and then re-formed or re-structured in ways which led to an assimilation of the machine, thus providing a new way of being-in-the-world which was liberating, freeing and transformative?

Research Questions

The hermeneutic method of condensing themes, employed by Nagel failed to leave potentially rich individual experiences presented intact. While her method was experientially based, the open ended and unstructured interview format did not specifically focus on the basic existential themes of lived-space, lived-time, lived-body and lived relations with others and self. Finally, her study did not explore the experiences of people who received their treatment at home.

In an attempt to overcoming the limitations of Nagle's study, and following her suggestion that the "notion of threatened embodiment should be explored within different illness and contextual circumstances" (p. 136), this study investigated and explored the embodied life-world experience of four people with end stage renal disease. Specifically, it focussed on what it is like to be-in-the-world with home haemodialysis machine? Within this context is the embodied self preserved, transformed or something else?
CHAPTER 4

Method and Procedures

Methodology

Given that there is a dearth of research on the topic, a qualitative exploratory study is called for (Strauss & Corbin, 1998, Schriver, 1998, Singleton & Straits, 1999). Moreover, where context and value of the setting are critical, such as the home environment proposed here, in order to gain a deeper understanding of the phenomena qualitative methods are essential (Toombs, 1988, Moustakas, 1990, Marshal & Rossman, 1995, van Manen, 1997). In particular, phenomenological research is exceptionally well suited for investigating the lived-experience (van Manen, 1997). As such, phenomenology focuses on life-experience, precise descriptions, a bracketing of foreknowledge and a search for essential meanings (Kvale, 1996). If we grasp the lived-body in terms of being-in-the-world, it can help us understand the profound sense of disorder which is manifested in the experience of illness, for illness is experienced more as breakdown of the "world" than a break down of the "biological" body (Toombs, 1988).

We must acknowledge that the treatment procedure involves patients being hooked up to the home haemodialysis machine for two to five hours a day on average of 2-3 times per week for an average of 15 hours a week (Evans & Henderson, 1985, as cited in Nagle, 1995). The significance that this procedure has on one's lived-experience cannot be underestimated. The proposed research will utilize phenomenological analysis to provide a phenomenological description of the life-world or lived-experiences of individuals receiving home haemodialysis treatment for chronic renal failure.
Data Collection

Sample

Participant Selection

The sample was a purposive sample for conceptual reasons. As this was an exploratory study using face-to-face interviews, the participants needed to have good verbal skills. The verbal skills were assessed informally by the program staff. A sample of size of only four was chosen because phenomenological studies yield incredibly rich data. However, more than one case was chosen in order to cover people who had range of length and familiarity with home haemodialysis. This was important as the process of embodiment and transformation are processes which occur over time, and thus may be impacted by differing kinds of experiences. While a longitudinal study which tracked a single person over time could have been an alternative, the time requirements of this study did not permit this option.

All participants came from a large Canadian urban hospital. In consultation with the home haemodialysis training program, it was determined that due the nature of program at that and time constraints of this writer, that it would not be feasible to obtain participants as originally stated with regards to their length of time in the program. However, it was decided that it would be possible to maintain the spirit of the original proposal which was to include 4 participants with varying lengths of time in training and out of training. Thus the 4 participants included one person in the beginning of nocturnal home haemodialysis (NHHD) training, one person in the second week of NHHD training, one person with a year of NHHD, and another person with a year daytime HD. As this was an exploratory study no attempt was made to capture specific participants with regards to gender, age, ethnicity or socioeconomic status.
**Participant demographics and interview context**

**Participant # 1 (First week of NHHD training)**

I met this adult male participant for two interviews of approximately one hour each and one week apart. At the time of this interview this male adult participant had been in the home haemo-training program for several days, and before that, was receiving out-patient haemodialysis for several years on the ward where the rooms each held about four patients. The interviews took place on the home haemodialysis (HHD) training unit at large urban Canadian hospital. This room is off to the end of the large out patient haemodialysis (OPHD) ward.

**Participant # 2 (NHHD for one year)**

I met this adult male participant for two interviews that were approximately one month apart. The first interview lasted about 2 hours, while the second lasted about 1 25 hours. At the time of our first meeting he had been receiving nocturnal home haemodialysis (NHHD) for one year. Both interviews took place in the bedroom of his house. After making an appointment with him by phone, I arrived at his home where he answered the door, he invited me in, and then he led me upstairs to his bedroom where his dialysis machine was. Other family members resided there including his mother, sister, and nieces. The interview started both times with us both sitting on the edge of his bed, facing the wall of supplies.
Participant # 3 (Starting second week of training NHHD)

I met this adult male participant for two interviews approximately two weeks apart. The first interview lasted about one and a half-hours while second lasted about an hour. Both interviews took place in the home haemodialysis training room, while he was dialyzing. At the time of the first interview he was in his 5th day of training. Before that he had been dialyzing at a Self-Care Center, which is an satellite unit of the outpatient dialysis program at hospital where the study took place, for approximately 4 years.

Participant # 4 (HHD for one year)

I met this adult female participant for one face to face interview which lasted approximately an hour, and the had a follow up phone interview which lasted about 5 minutes. These interviews were approximately one week apart. The face to face interview took place on her lunch break, in meeting room at her employer office building. The office was located in downtown in a high-rise office building. At he time of the interview she had been receiving home haemodialysis, at a friends house for one year.

Interview Guide

All interviews were conducted according to the interview guide (appendix c). The interview guide was based on the theoretical basis of the life-world and so contained practical questions based on the four existential themes of lived-time, lived-space, lived-body and lived relations with others and self. Additionally, attention was given to experiences over time, and those of being on and off dialysis. Participants responses were explored if they detoured "off" the questions areas, and were clarified when necessary.
Recruitment

Participants were identified and recruited in consultation with the home haemodialysis program principals. Once identified as potential subjects, the prospective subjects were first approached by a nurse on the unit, to see if they were interested in participating. If they were, this writer approached them and further explained the nature of the study, and received their written consent before the interview took place.

Ethical Considerations

Ethics Review

This study was submitted to the Hospital's research ethics board for ethical approval. The following are the procedures undertaken to ensure that the data collection and analysis was carried out in an ethical manner.

Privacy and Confidentiality

To ensure privacy and confidentiality all material collected of a private and confidential nature was be kept in a locked cabinet (Singleton & Straits, 1999, Barrett, 2000). Material was not identified in a way which exposed the individuals involved without their explicit and written consent (Singleton & Straits, 1999, Barrett, 2000). Computer files were password protected (Singleton & Straits, 1999, Barrett, 2000).
Informed Consent

All subjects were be 18 years of age and above, and have capacity for consent. The process for informed consent consisted of three steps. At the first contact the basic outline of the investigation was explained. If they were interested in participating based on that information, the study was explained in more detail and they were given a copy of the background information to read. Any questions were answered. And while they were given one day to make their decision, all except one participant decided immediately to participate. The one who did not decide immediately requested a visit near her work at lunchtime where we discussed the study in depth. She called back the next day and confirmed that she would participate. Once they agreed to participate, they were asked to sign the consent form (see appendix B). During our first face to face meeting, the consent form was reviewed jointly. Each participant person was given a copy for their records.

Risks and Benefits

All respondents in this study were involved in well-established interview procedures (Moustakas, 1990, Marshal & Rossman, 1995, Kvale 1996, van Manen, 1997, Strauss & Corbin, 1998, Singleton & Straits, 1999). The interview procedures involved individual interviews that did not present particular risks to the participant.

This study asked participants for a description of their experience and did not probe into emotionally laden subjects, thus likely not provoking any serious emotional reactions. For example, the themes explored in the interview were the basic and every day themes of time, space, body, and relations with others. These themes are generally accepted as the essential categories of lived-experience (van Manen, 1997, Kvale 1996). Therefore the questions did not
attempt to explore overtly painful or emotionally difficult subjects. Instead what was aimed for was the description of their life-world. Thus the goal of the interview was to be descriptive, not invasive.

However, if an interviewee had become upset, it would have been acknowledged and the interviewer would not have left until they were calmed (Breakwell, 2000). Then they would have been assisted in contacting the nephrological social worker for further debriefing. Additionally, participants were free to drop out of the study at any time, further protecting them from harm (Barrett, 2000). As such no apparent emotional problems were witnessed by the interviewer and all of the interviews proceeded without any unusual occurrences.

The completion of this study provided valuable documentation about the lived-experience or life-world of people who use home haemodialysis machines which is currently lacking in the literature (Nagle, 1995). This knowledge is a benefit to science in that it provides information useful for future health care policy planning, and service provision. The benefit to the participants will be in knowing that contributed to scientific knowledge, which might be of benefit to themselves and others. Further, Schriver (1998) has noted that research participants may find it empowering to share and describe their experience in a way which allows their stories and experience to be heard and considered as valuable.

**Data Analysis**

The recorded interviews were transcribed by a professional transcriber. Each interview was read in its entity, one interview at a time. During the second reading I would make notes on the document underlining what stood out, and making notes identifying each segment as focusing on either of the main existential themes of lived-time, lived-body, lived-space, lived body and any other themes which emerged.
Each interview was analyzed in its entirety before moving on to the next one. The reason for this is grounded in the belief that each person is a whole, and thus should be analyzed as a whole (van Manen, 1997, Kvale, 1996). Starting with the beginning of the interview I would consider each meaning segment as a whole and analyze it, seeking to expand the meaning in order to develop the richness of the text, and give it a name pulled from the text which suggested the essence of that particular passage. From there I would interrogate the text further and develop a discussion with aims of highlighting important relevant questions, and observations which were supported by the analysis. During this process I would find myself remembering the interview and the room where it was held, visualizing the participants and space where we talked. This helped to ground my analysis in lived-experience of the interview.

When the analysis and discussion of a whole interview was completed, I would then print it out and re-read the whole document again, making notes on the document as I re-read it. When this was complete, I would give a copy to my thesis advisor who would read the entire document and make suggestion, highlighting areas for development, and further consideration. I would then modify the document accordingly. The result was 241 pages of analysis and discussion. The following is the lengths of each findings case #1 42 pages, case #2 76 pages, case #3 95 pages, #4 28 pages.

The difficult question was how to present such large amounts of data and analysis. To do this it was necessary to revisit the meaning of phenomenology. My purpose with this study was to describe the richness of the life-world of the participants. Merely condensing the data would not suffice. Instead I chose to focus on the parts of the interviews which pointed to something novel, which leaped out of the background into the foreground. This method of separating incidental from essential themes is perhaps the most controversial element in phenomenological
human sciences  As van Manen (1997) suggests, to do this the researches asks the question does this phenomenon lose its essential meaning without this theme? Thus in asking this question I was able to separate incidental from essential themes, giving me the ability to highlight the essential themes.

Validity

As this study was an exploratory naturalistic phenomenological study, the positivist criteria for validity are not applicable  this study does not have the goal of generalizability In deed, as is the case here, phenomenologists rarely place "substantial emphasis on verification beyond the perspective of the researcher (Cresswell, 1998) Reflecting on the research process, according to my own perspective, there are some procedures which were undertaken which will add to the trustworthiness of this study.

All interviews took place in the environment which suited the needs of the participants In this way they were not removed from their own environment  On the contrary, they interviewed in their own environment  By meeting the people in an environment in which they typically inhabited whether it be the hospital where they were being trained, at their work, or in their home, I was ensured that the interviews were contextually valid  In deed this proved invaluable because people were able to point to certain objects and in one case show me around their house  In this way their context supported them in explaining to me what their experiences were  It helped me to see them from their own position  The life-world they described was actually supported by their context and my own experiences of their explanation in their context.

The interviews were tape-recorded and transcribed  This provided for precise verbatim documents which contained the full interviews  Additionally, by relying on the tape-recorder I was able to witness and be present for the interview providing a deeper engagement with the
participants than would be possible if only notes were taken. Moreover, during the interview I was able to seek clarification and confirm whether or not I had the correct understanding of the experiences they were trying to describe. Thus the deep engagement with them, when coupled with my ability to clarify their comments helped to provide an authentic relation with them, further increasing the trustworthiness of the findings.

Prolonged engagement as explained in Lincoln & Guba, (1985) is established by extending the amount of time spent by the researcher both with the participants and in their environment, thereby increasing trust between the interviewer and interviewee. By having two interviews of about an hour long over a period of one week, my engagement with the participants was a prolonged. In addition to the interview time spent with the participants, I also completed my graduate internship on the ward where this research was carried out. These factors contribute to a prolonged engagement with the participants and their environs, which served to increase trust between myself and participants, thereby, increasing the trustworthiness of the data collected.

Finally, my interpretations of the interviews were supported by the text of the interviews. My own interpretations were debriefed with my thesis advisor who people my interpretations and added insight as I developed my analyses.

However, this is not to say that there is one reading of the data. Rather, what I have tried to show is how the data collection and analysis were carried out in an authentic and ethical way. I take issue with the belief that reality can be verified, and believe instead that the life-world resists such attempts at verification. Instead, what this study has produced is a snap shot, or description of four people at a certain time in a certain place. What is important is not what this says about all people, but rather that these moments were considered. From these exploratory
investigation, it is hoped that themes for further research will be established, and that new questions will be asked
CHAPTER 5

Findings and Discussion of Highlighted Themes by Case

The following is a list of all of the themes for each case. The themes which are highlighted are the themes which are discussed in following parts of this chapter, and finally again in chapter six.

Case 1

Themes of the lived-experiences of time

- Getting used to the routine
- You basically have to wait your time

Themes of the lived-experiences of spatiality

- Moving between home and hospital and within the hospital
- You go home and then the next day you come back
- You come in you sit down they hook you up
- I would find that extremely horrible
- Can't walk in the park or go for a run
- I prefer the bed over the chair
- The operating room
- You're always aware

Themes of the lived-experiences of the body

- My initial concern was about the discomfort level
- A lot of maintenance involved
- You can't go out shopping
- And they said well you're sick basically and you need treatment
Themes of the lived-experiences of relations with others and self

- They & them
- If you follow the rules
- My life right now consist of two things work and dialysis
- I would find that extremely horrible
- I overheard a conversation
- When I saw the nurses
- There's a lot of sick people around
- The smaller the group the more personal the treatment appears to be
- Its just sort of understood
- Not conforming to the rules

Themes of the lived-experience of the kidney dialysis machine

- It's a machine; I don't worship it
- It's like a pretty interesting machine

Case 2

Themes of the lived-experiences of time

- If I came in late they would deduct time
- Missing a day
- I just take it one day at a time
- Waiting for a kidney
- The worst mistake I made

Themes of the lived-experiences of spatiality

- What I need is space, and space I do not have
- I know exactly where every thing is
- It's not so much the machine, its more the storage of the materials
- In case anything goes wrong
- You're in a home environment instead of a hospital environment
Themes of the lived-experiences of the body

- Almost the affect as having a hangover for three days
- Freedom from many things
- I just feel a lot more healthy than I used to be when I started this type of dialysis
- I didn't believe it at first but its amazing
- If the tube happens to slip out
- The line had ripped right out my chest
- Is this what death's all about?
- So, one fistula, two fistulas, then I had a graft here and a graft up here
- I wanted to get it out
- It's the bath I have to watch out for

Themes of the lived-experiences of relations with self and others

- No regrets
- Every body knows what's wrong with me
- My friendships at work have gotten stronger
- She's at an age where she gets curious
- The support's there
- As far as social life there's not much time for it

Themes of the lived-experiences of the dialysis machine

- And then we're done
- Hooked up
- Get on it
- You get to know the machine

Case 3

Themes of the lived-experiences of time

- It was taking a lot, a big chunk out of my life
- Being able to dialyze when I want
- It's the slowest at the end of dialysis
- Other than that though the passage of time is not unpleasant
- It's sort of more rapid because I'm at work
- Trying to get ready for dialysis
• The waiting time is lengthening

**Themes of the lived-experiences of spatiality**

• The space was very constrained
• I would actually steal a bedside table from another patient
• You would have to arrange that before you sat down
• Here its much less an issue

• There's a noise thing
• Making the environment humane

• They are people who have been trained in hospitals so they run it like a hospital
• When I'm at work
• You're also constrained by the necessity to respect, to the atmosphere of the place
• Embarking on my new life

• I do believe they actually save money
• It's an institutionalization of my private life

**Themes of the lived-experiences of the body**

• A sudden leap into dietary freedom
• There were very few things I could eat and there was no relief
• On dialysis I tend to break the diet sometimes
• I had to pass up eating
• There are sort of postural things
• Asking your blood to do two things
• This horrible sucked out feeling
• So you get tugging first, and penetration and then tugging
• I would employ sort of mental strategies
• It had evolved from a gesture
• I have to cumulate my self
• You've got to go to the bathroom
• My body has betrayed me
• Holding a threat a bay
• After dialysis
• Not being at ease in my body
• I may have to go to a fitness center
• My actual libido is much reduced
● I would be dead by now
● I'm not keen on being a sexually active gay man and not having much of an immune system

Themes of the lived-experiences of relations with others and self

● I would actually take refuge in faking a nap, sort of like faking an orgasm
● And they'll even try to rotate you
● Now the administratives don't pay the price for that but the patients do
● Why bother them?
● I was exposed to something that really disturbed me
● I'm a gay man. I lost it. I just lost it.
● There were two triggers, one psychological and one physiological
● We both have to make the relationship work
● Being there is ugly
● So they're really separate worlds, separate worlds
● You're penned up together
● I have the family obligations of two dogs
● Other people are not allowed to complain
● That friendship has not survived
● That was an outrageous intrusion into my privacy
● I anticipate you know enormous benefits from home haemo
● I don't want people to worry about me
● It's a good thing, it will make my life better

Themes of the lived-experiences of the machine

● It's a piece of alienating technology
● The training here takes it to a deeper level
● My area of responsibility has expanded

Case 4

Themes of the lived-experiences of time

● I have a lot of down time those four hours
● I don't really have a lot of time to myself because of dialysis, unfortunately
● They're wasting a lot of my time
● Time is not on my side
Themes of the lived-experiences of spatiality

- There's a lot of equipment in there taking up a lot of space
- There's a machine at the hospital waiting for me, I just need the apartment
- It's not taking up my space
- It's not my home

Themes of the lived-experiences of the body

- I am able to do almost anything on the machine since I don't have a line in my arm
- So I have to really watch a lot of things that I intake
- I felt fatigue in the beginning
- Are you aware of any sensations? No

Themes of the lived-experiences of relations with others and self

- It's an up and down roller coaster for the both of us
- After dialysis you just feel like a fresh of breath air
- You just have more freedom with having home dialysis than have to go to the hospital
- Relations with Nurses and Doctors

Themes of the lived-experiences of the machine

No
Case 1. Findings and Discussion of Highlighted Themes

Lived-experiences of time

"And then they gradually increased me"

"Well I was here on the floor and came in and they hooked me up and put me on it for two hours. And at that time the two hours wasn't too much of a problem. And then they gradually increased me to four hours and that wasn't such a [ ] and then five hours. And that was three times a week and then to every day for 3 ½ hours. And the more time as they started to you know increase the time, it started to get a little bit bothersome because I, it was quite boring to just sit and wait for a treatment. But at this point it's, I'm pretty used to the routine and it's not a bother any more but at first getting used to the routine was a bit of a drag."

From this description a sense of a gradual and yet persistent extension of time is hinted, like slowly being stretched on a rack torture? It is not each increment in itself which is the problem, rather it is the final sum: death by a thousand cuts. The result, is that has been increased. "they increased me" But at what point does the over stretched rubber band break? The gradual extension of time he experiences implies a methodical and calculated plan by those who are "increasing" him. The plan of gradual extensions, inch by inch, and second by second, is designed with the knowledge that too much and too fast, if the patient cannot bear it, will not achieve the goal of increased time.

However time, when seen as an objective measure, has no end, no breaking point. This is in stark contrast to experiential time, where seconds can seem like forever, and lifetimes pass by in a glimpse. Therefore a regimen of increasing time at some level incorporates awareness of experiential time, otherwise time would be increased to meet its objective instantly.

"Block of time"

It also became evident that this participant experienced his time as, and therefore broke it down into units of "blocks." For example, he referred to his treatment time as a block of time, "exposed to them [nurses] for a certain block of time." Time was usually quantified in multi-
hour blocks such as, "three to five hours worth of time" or "three and one half hours per
day" Moreover, these blocks of time were further seen as slots, which he could fit into, and
have "allotted" to him, thus, they were his But there was a struggle over who actually owned
these slots

"Okay I want my independence when I'm on my treatment and I've taken my treatment to a level
where I'm independent I don't necessarily follow the time constraints by coming in at 7 30 a m
in the morning I don't do that okay because, I could but I won't because that's, I don't like that
So I've come in I only have 3 ½ hours I have basically from 7 30 a m till 12 00 to come in I
come in at 8 30 a m, 9 00 a m I still get my proper treatments in and nothing is compromised
The nurses can't understand sometimes why I come in at 8 30 a m because the rest of the
population that's in the ward is coming in for their 7 30 a m treatment, okay So they're not
very flexible in their mentalities right, but I'm not compromising anything"

The nurses wanted him to use the whole block or "slot" of time, while his approach
appeared to be, that the slot was his to do with it what he chose In this way, these slots of time
appeared to become a site of resistance for him and the nurses He experienced the treatment
times as constraints, which he feels the nurses do not "understand" So the meaning of this block
of time differ for him and the nurses He feels that they cannot understand his experience, and
are thus inflexible in their "mentalities" The ownership of this time block is thus a site of
resistance for his independence Conversely, the need to assert his independence does not appear
to be an issue in his life out-side of the time blocks treatment

"My initial prescription"

Moreover, the hours per day, or blocks of time were usually connected to "time per
week" For example, "my prescription got changed from five hours, three times per week to
five days per week, for three and one half per day "

"moreover, these blocks of time were further seen as slots, which he could fit into, and
have "allotted" to him, thus, they were his but there was a struggle over who actually owned
these slots"
"Okay but the, as an outpatient patient my prescription then was, my initial prescription was three times per week, four hours per treatment. And then you know with further investigation with my blood work they figured out that my, a more appropriate prescription for me would have been five hours, three times per week, okay." (My emphasis)

His dialysis, and the complex medical prescription for it, seems to have been reduced to the conception of a time block in terms of hours and days per week duration and frequency

**Lived-experiences of spatiality**

"You're just a common pool of people and other patients"

"And then when I switched over to the Eaton side, the other side of the hospital here they put you in a room with 5 or 6 people, 5 people or so. And I found that a little more private and a little more intimate in terms of receiving the treatment. So it was a little, it was a little bit more acceptable for me to do it in that type of an environment as opposed to doing it in this type of environment where you're you know just a common pool of people and other patients. I found that also when I was doing it in the more secluded rooms with about 5 or so patients in a room, it was easier to tolerate being sick. I never really had you know a problem with knowing that I was sick but when you were in a smaller group it made me feel like I wasn't really sick because you know over here you're in a room with 30 or 40 people and there's a lot of sick people around you so that kind of brings you down mentally as well.

"But it appears to be a little more, the treatment appears to be a little more personal over there. The smaller the groups the more personal the treatment appears to be.

This reveals his desire to not see himself as being reminded of the fact that he is ill, and demonstrates how illness is linked to the size of the room and the amount of "sick people" in it

"I was in isolation"

"When I was in the other room on the other side and when I was in isolation where you're just put into one room by yourself and you had your treatment going on that was horrible. Because you're sitting in a chair or lying on a bed for 4 hours, you just basically have to wait your time and you're more. And that's when the time really slows down.

When he is in the isolation room, he is essence "in isolation" For him this was a horrible experience. Isolation itself is known to be a horrible experience, so "horrible" that in another environment such as jail, isolation is used as a punishment. There it is called solitary
What is interesting to note, is how the occasionally understated nature of his narrative, is no longer present in his description of the isolation room. Here he does not pull back and qualify the nature of his horrible experience.

"I don't want to live around an institution"

It also appeared as though space can be linked to institutions through the attaching of procedures to a simple activity such as bathing.

"See I wouldn't want, I wouldn't want a recommended procedure for taking a bath and a recommended procedure for doing this. See that starts to compromise my day-to-day function. That's reminding me that I'm sick. I don't want to be reminded that I'm sick. I don't want to live around an institution."

These procedures are experienced by him as institutional. His experience around basic daily human activities such as bathing can have an institutional quality, which he finds he does not like and therefore does not want to "live around." He appears to need to protect this part of his life-world, to keep out the institution. But is bathing just a "day-to-day function" or is it about experiencing pleasure? Certainly, bathing in Canada is usually a private matter and so it would make sense that he would want to keep this part of his life-world private. It follows also then, that if bathing has is pleasurable experience, he may therefore also want to keep this part private and inaccessible to "them" the institution.

**Lived-experiences of the body**

"I'm trying to see if I can function as normal"

Another way he talked about his bodily-experience was in terms of "disability." His disability was his "renal failure," and he experienced this as something which was part of his identity, yet at some level it was also external to him, for it was something that he felt must be worked/ incorporated into his life.
"Okay so you have to take your disability and turn it into something that you can, work it in, take your disability and work it into, incorporate it into your life where you can still function, you know at a comfortable level to yourself. And have it not compromise your health care you know, your health and mental care."

This "working it in", or "incorporating it into" his life was a way of making it "not as much of a nuisance" as it could be. It was about not compromising his "day-to-day" life and "functioning".

"I'm trying to see if I can function as normal and I've been doing very good at it at being able to function as if I had no, no illness because it can be done. It's just that I'm just tailoring my dialysis prescription to incorporate that into my lifestyle."

The "function" seems to be an as if. He is "trying to see" if he can function as normal as "if" he has no illness is not sick. He acknowledges that functioning "as if" he is normal is something which he doing "a very good job at" because "it can be done." "Trying to see" and as if are related to the "incorporating" and working in of the disability to his lifestyle. It appears that although he recognizes it is a hard job, he nonetheless is doing it. His body is functioning 'normally' as opposed to functioning as "sick". Implicitly he acknowledges that without the effort he has marshaled, this could not be accomplished, thereby indicating that he would not function "as if" he was not sick, he would function as sick.

Moreover, he experiences of health in terms of functioning. Health in this way remains embedded in the discourse of function, thereby indicating that good health or wellness for him equals normal functioning.

"So now I've basically become a medical junkyard."

The most significant aspect of his lived bodily experience was shared when his usually understated voice gave way to expressions of intense feelings regarding the altered shape and feeling of his arm due to a graft which was not removed.
I: Okay, so it's still in there.

R: So they did something for me, it didn't work but now they don't want to take it out for whatever reason. Maybe there's a health complication that maybe it's more dangerous to take out or what have you. And I wasn't even informed of that.

I: Okay, so medical junkyard just like stuff left inside you?

R: That's right.

I: Okay, it's not working any more?

R: It's not working any more but it looks like shit.

I: There's a scar.

R: I don't care about the scar so much but it looks like I've got a tumor inside my arm.

I: Okay, so if you had more choice, more information?

R: And it feels horrible, I've got bumps coming up and down my arm.

I: Right.

R: Feel that right there, see that?

I: Yeah, I can feel that. That's it in there, I can feel it eh?

R: Yeah.

I: Yeah, it must feel weird even having that in there?

R: Well, for myself knowing that I have it there, yeah it's.

I: Does it restrict your ability to do anything?

R: No nothing.

I: Okay.

R: It doesn't, it's just mental because I don't like having it in there.
I: Right how it looks, how you feel about it?

R: That's right.

I: The fact that your body is like a junkyard as opposed to?

R: Well that's, when they said well they'd rather not take it out, I'm thinking well they don't want to take it out because I can function with it in my arm and not have it compromise my you know my health or my function ability or my motor skills. Or it basically costs you know to have the surgeon go in there, staff the operating room, book an operating room, all the costs associated with that. I'm sure they didn't want to put that money into it because you know I can function fine with it in there. I don't think, maybe that's what's my thing. There could be another reason where it might be, it might be a problem to take it out and there may be more health risks involved with taking it out than just leaving it there.

I: You don't have that information?

R: That was the excuse they've given me but I, you know what I, I'm not a big fan of that explanation. I don't necessarily believe that, no.

I: You're not satisfied?

R: No.

The true nature of his strong feelings is hard to convey through this text. During much of this interview it was not uncommon for him to understate things, however during this part of the interview his emotions were not restrained. He was clearly very upset with both the condition his body was left in, and with what he believes about the rationale offered to him. His body has been compared to a medical junkyard - a space where discarded, non-working medical equipment has been thrown away. He has become a garbage dump. The graft does not work, his arm looks like shit, it looks like he has a tumor inside his arm, and it has a tactile unfamiliarity: it feels "horrible." It felt so horrible, I believe, that he asked me to feel it, I did. The inside of the forearm is usually such soft place, so it was strange to feel a hard object underneath his skin. I felt as though he needed me to verify or validate the horrible nature of this junkyard, of which he no one other than himself seemed to have noticed or cared about.
But while he uses the term of cosmetics to initially describe the issue of his arm, how he talks about it moves far beyond the issue of cosmetics. Cosmetics are understood as a surface way of looking at things; cosmetics are about appearances. However, he did not "care about the scar", he cared about it looking like he had a tumor inside his arm. A tumor has more than surface significance. As it stands, some if not most tumors are below the skin and are associated with disease and illness, especially cancer. The shape and feel of his body has been altered and it now seems as though it has a tumorous quality. The treatment for most tumors are to have them removed. His cannot be removed and what is worse is that it was put there by the doctors, whose usual job is to remove them. Ironically, for "medical" reasons a tumor was put into his arm, and now that it is there it will not be removed. Clearly this is a issue which is more than a cosmetic. This issue is about the fundamental experience of a lived-whole-body versus a sick and altered-body.

Yet one wonders how the terminology of cosmetics entered his narrative. Within medical discourse, cosmetics are related to cosmetic surgery. In this context, cosmetic surgery stands as the opposite of medically necessary surgery. If surgery is deemed medically necessary it considered as valid. Cosmetics surgery on the other hand is not seen as medically necessary not valid for funding. Clearly, this person has been told that his concerns are merely cosmetic. Clearly, his concerns are about his body and what lies below his skin. These concerns are therefore deeply meaningful, not merely superficial, or cosmetic.

What seems worse is his understanding of why the graft was left in there. The rationale offered. While he was given a functional and risk aversion argument, that his arm still functions and that taking it out may be a further health risk, he also understands that there are financial costs associated with its removal. He remains skeptical of the reasons offered and instead sees
them as an excuse of which he is "not a big fan of" Hence, he is left to ponder if the real reason for not taking the graft out centers on the financial aspects of the procedures that it costs [the hospital] too much money

**Lived-experiences of relations with others and self**

"A little bit of a bond"

Another aspect of other patients was discussed in relation to the person who is sitting beside him receiving treatment In the smaller rooms, he found he could develop a "little bit of a bond" with the people that were in his group because it was a smaller group In the smaller room he would know who he would be sitting with, whereas in the larger room, he did not know who he would be sitting with each day Knowing the people he was sitting beside allowed him to build a bond, which had some profound consequences

"So you build a bond, there's a bit of camaraderie there that occurs and you, it just puts your whole, you know sense of being at peace"

**The lived-experiences of the kidney dialysis machine**

"It's a machine. I don't worship it"

"Well it's a machine I don't worship it I come in and I just, it appeared to be a little intimidating at first It appeared to be a little intimidating at first but once you get to find out more about the machine, it's not as intimidating as I anticipated it to be, was"

The dialysis machine was something that he talked about being "hooked up to" You "go to your machine" where the nurse puts him "on it for two hours" and when treatment is over they "got me off and what have you" This machine was part of a routine, which involved building a familiarity with "a routine" Initially, he reported not liking or disliking the machine For it was a machine, just like a "car is a car" It did not "intimidate" him, for it was "just a machine"
Yet it was something he was "hooked up to" People it seems, are not 'hooked-up to other people" This activity or process appears more like a 'machine to machine' activity in the same way a TV may be hooked to cablevision, or as a car is hooked to its trailer So in this way it appears as though his relation to the machine is described in more mechanistic terms than personal

While we were talking an alarm on the machine went off He called the nurse in, and I turned off the tape recorder They talked about how to fix the situation The nurse talked about the machine in terms of it being a person She said, "oh, he just needs to have this done" and went to fix the problem When the nurse left the room, I said to the participant that I noticed that the nurse talked about the machine in the terms of a person, and did he think about the machine in terms of a person? He replied "no"

He is working hard to keep it in its place as a machine by saying "it's just a machine", but then he replies "no" it's not a "person" He seems to be trying to ensure that it does obtain a position of importance or stature, a place that the nurse may have already acknowledged by personifying it But this machine, as the nurse knows, is something more than the kind of a machine than a car represents It is a life saving machine, which replicates the function of a living-human organ If it can do that, maybe it is more than just a machine Thus, he seems to be acknowledging that if he stops putting it in its place, then it may become more than just a machine But what would it be if it was more than just a machine? Perhaps it may become a human And this is exactly what we know about machines, they are becoming more advanced every day, and so this speaks directly to that issue What will happen if machine become human like? This discourse, once the sole domain of science fiction writers is now a reality that raises many ethical question about the goals of science
Case 2. Findings and Discussion of Highlighted Themes

The lived-experiences of spatiality

The dresser

We got up from sitting down and stood near the dresser. The dresser had a TV on top and a centrifuge beside it. In explaining the protocols for his blood work, which included putting his blood into a vial and then placing into the centrifuge, he opened his dresser drawer to show me where all the vials were kept. His drawer was full of brightly colored glass vials in neat rows. Then he went down each drawer and showed me what was in each one. Each one contained differing medical supplies including swabs and tubes, all of which he uses in his dialysis procedures. The swabs, cleaned the tube which came from his chest, the two types of tape, one for taping the tube to his skin and one for taping the tube to the bed.

"I gave her my double and she gave me her single"

Other objects talked about were a kitchen knife and a tape measure visible on the dresser. As these objects did not seem like medical objects, or even bedroom objects, I inquired about them.

I  "And what about the tape measure?

R  This was already here actually. I was doing some measurements to [ ] I would sort out the room. It ended up staying here.

I  So you had to sort out your room with it before this really came?

R  Yeah, yeah because what I used to have here was a double bed"

"This was my sister’s bed and my double bed was in here. So we just exchanged beds?"

"I gave her my double and she gave me her single"
"So all I did was move the nightstands, which went to my sister's room and the bed. So I basically got her furniture and she got my furniture."

"Into the fridge the next morning"

Additionally, he would store vials of blood for the lab in the family refrigerator, inside a cup. "My mother will come up, take the blood tubing [vial], put into a cup and put into the fridge until the next morning." He then takes it to the lab at the hospital the next morning. The fridge has now become a storage place for blood. The dual purpose of the refrigerator is revealed. In hospitals refrigerators are used not for food storage but for storage of organic samples and chemical supplies. From this overlapping purpose, the two uses of fridge, clinical and food storage, are becoming confused. This raises questions at the very least about safety. I want to say safety in the work-place, but it is really about safety in their home or living-space. Is the home now a work place or a home space? If it were a hospital work place there would be a policy about storing food in clinical fridges and this policy would no doubt prohibit such a procedure. Placing blood samples in the family fridge also raises the safety issues of a having a living-space being transformed into a work-space.

**The lived-experiences of the body**

"Overloaded"

He goes on to explain the experience of OPHD on the unit and compares it again to NHHD. Here he explains how his body feels while he is dialyzing on the unit, and in doing so he introduces and describes the sensation of being "overloaded."

"I think the only difference you know which happens here and also happens in the unit is if you’re overloaded and you find it hard to breath. Once you’re on the machine for a while."

"then you notice that there, a difference starts coming along, you start breathing much easier because there’s not so much fluid in your lungs. I think that’s the only difference but that..."
happens here and it happens in the unit dialysis which is more I think because of the machine
Now it's removing that fluid off you so your breathing becomes much better

Overloaded seems to mean that he has too much fluid in his lungs When he was on the
OPHD unit he would start to feel and breathe better once the fluid was removed The relieving
of overloaded may be about the correct "load", or amount of fluid, which is the 'right' or normal
load of fluid, which should be in his lungs It is understandable that one would not want too
much fluid in one's lungs Too much fluid in the lungs can cause death drowning It is
remarkable that when he talks about being overloaded, that drowning or a reference to it does not
come up But if he uses the term "hard to breathe" one would also think that the notion of
suffocating maybe mentioned It is interesting that the term overloaded is used and not these
terms mentioned above Maybe, this is because that being overloaded is connected to the idea of
weight thus the suffix -- load This makes sense because he talks about gaining weight and
taking it off However, this weight is really about the weight of the liquid Here instead of
weight he uses volume "But if I'm over by half a litre sometimes ah what the hell you know
what I'm going to take it easy tonight" and not do the dialysis So overloaded is really about
being overloaded by fluid To appreciate his experience of fluid coming off, or building up in
his body, we must understand his experience of urination

"So it's basically if my sister's got to go like during the night or I've got to go well I
can't go Well I really don't have any sense of going because I don't urinate any more so"

Because he cannot urinate any more, the process of dialysis takes off the excess fluid
from his body It removes the build up But perhaps because urinating was such a frequent
daily-experience in his past, he seems to have forgotten momentarily that he no longer urinates
This momentarily forgetting highlights the important role which urinating played, and still plays
in the experience of his life-world
His failed transplant led him back to CAPD, due to an infection which almost led to his death and the reading of his last rites. In his recounting of this experience this serious moment of his potential death is quickly stepped over. It's like he is rushing to get to the end of his kidney disease history, which at this point is really the history of his arms. So no surprise he ends up by showing the next fistula they "did". This leads him to counting all the operations on his arm.

"I had a fistula here and then I had one, yeah I had one here. So one fistula, two fistulas, then I had a graft here and a graft up here."

"I wanted to get it out."

With this deepened understanding of what is actually done, the idea of tubing in the arm strikes me. I asked him if he still has any of this tubing left in his arm since he no longer uses the fistula or grafts. He reported that they were still in his arm, and that "they don't take them out because they do more damage pulling them out than actually leaving them in." When asked how he felt about that, at first he reported that it did "not bother him at all." Then he explained it a bit further:

I: "How do you feel about that?"
R: Oh it doesn't bother me at all.
I: Okay.
R: No it's that you just feel a, you know it's hard and you can feel it. You can actually feel the tubing.
I: You can feel it?
R: Yeah, oh yeah.
I: The tubing?
R: Well you can feel the tubing here, you know it's hard, it's the tubing.
Okay I feel the tubing right here. So how long, does it go back to there, how far does it go back?

It's here and then you can feel it up here, the tube.

So it's about 6 inches?

Six inches yeah [ ]

So that's left in there?

Yeah

Okay

When it's hooked in, so I wanted to get it out and he says no they do more damage to you than leaving it in there.

How come you wanted it out?

Well I just didn't like the [ ] of having it because that's what I thought they'd do for a graft is actually remove it. Because before a graft used to be, when I was at Sick Kids a graft was the same concept as this but it was on the outside.

Okay

It wasn't on the inside

Wow

That was the difference.

He explains that he does not like it because of how it feels hard. As if to get his point across and help me understand what his experience is, he asks me to feel it. I agree it is hard. I also wonder how long it is, how far it actually goes up or into his body. This for me is assessing the extent of this foreign element that is located in his body. It feels hard, which is not like how the body usually feels on the inside of the forearm. This part of the body usually feels soft. He is thus able to explain that he wanted to get it out, but they said it would do more damage taking
it out than leaving it in. This was surprising to him because he thought they would "remove it", because that was his experience as a child when at Sick Kids Hospital.

"It's the bath I have to watch out for"

He reports that with having the UC line, it is the "bath I have to watch out for", so he uses a "hand-held shower".

"Aim, good aim exactly and then when it's to wash my hair there's also, in the hand-held shower there's also the spout that comes out, then I get on my knees and wash my hair"

Moreover he reports that he usually took showers, so the adjusting to taking hand-held showers so was difficult.

"I never, I didn't like taking baths very much. I'm more of a shower person. Well yeah it's kind of hard to adjust because it's longer doing it with the hand-held shower because you have to be careful"

"When I'm done the shower then I take my dressing off in the shower, wipe it down with a clean towel.

"I get on with the dressing that I have now so say come tomorrow after work, this dressing will go underneath the shower. I'll wash all myself and when I'm done with the shower the first thing I do I rip out my dressing, wipe it down with a clean towel, dry all myself off, then I come right away upstairs and disinfect it with the swabs and stuff"

His procedure is usually that he has a hand-held shower except the day he works at his brother's fish store on Saturdays. On that day he just takes an "ordinary" style full body shower, and takes off his dressing after the shower. He then has to disinfect the areas and then re-tape it with a two-inch by two-inch piece of gauze. This is the process of doing his "dressings".

"I found it's a lot easier on your skin if you wet it. So that's why on Saturdays I just take a complete shower so it's soaked really nicely and then I just rip off the dressing"

He found this out himself. It is contrary to what he was told, that he could leave the dressing off for showering, but "they said the same thing with CAPD where you could take a
shower, it'd be no problem, you don't need the dressing, just take a shower and then just

scrub"

When he started to explain about his dressings, he lifted up his shirt and showed me the
dressing on his upper chest I was surprised at the ease with which he lifted up his shirt and
showed me his "dressing" I wondered that if this was part of his body becoming public That if
he was so used to nurses and doctors looking, at his body, that it was no problem for him to lift it
up and just show it to me Perhaps this also says something about how he felt about me
Perhaps, as a social work student, I am perceived as a part of the "healthcare-team" Maybe I
am just one of them This might explain why he so easily showed me his bandage

But what he said was that he put the tape over the "exit site" What does this term "exit
site" mean? It sounds like an technical term for the part of his body where the tube is attached
Is the tube part of his body? I guess he does not know what to call it Perhaps this is a medical
term, used by doctors as a way of identifying this part of his body It seems strange to call a part
of the body an exit site It sounds like an excavation site, where something is dug out of the
ground It also reminds me of a forensic description of a bullet wound Bullet wounds,
according to this way of thinking have entry and exist sites So a site is a place, a location,
where you go in and get something which is under the ground/body If you enter you can exit
For him, the site, or space on his body, is the site of an exit The tube therefore exits his body
from this place But does it not also go in insertion Or perhaps the exit is his blood, which
travels out of his body through this tube, but it also travels in so why is it not an entry site? This
terminology has introduced a significant notion of confusion and ambiguity to his body
Certainly the term is a functionalist-based term Yet the function is misleading and unclear The
body has been renamed in terms of an ambiguous function. This raises important questions about the body.

The lived-experiences of relations with self and others

"My friendships at work have gotten stronger"

"Many a time my friendships have gotten stronger at work. I'm very family oriented. I like the concept of family so I try to share everything that happens to me. I share with my family. I'm very close with my mother. The main thing is not to be it's again it's opened my eyes more. It's, you realize that we're only on borrowed time type thing so you might as well enjoy it while you can."

That his friendships at work have "gotten stronger", seems related to the fact that he is family oriented. He likes to share personal information with his family and friends. Indeed this is what seems important to him. His illness has helped to underline that his life may end. The resulting realization from this helps him to focus on enjoying his life, because you're only on borrowed time you might as well enjoy it while you can.

The lived-experiences of the dialysis machine

"Taking care of it, because more or less it's a family member"

He sees the machine in a way that resembles a family member. "It becomes like a, I would say more or less like a family member." He goes on to describe what sort things are required to take care of this family member.

"Keep it clean, make sure it's running properly. Every little thing that goes wrong that I can't figure out I'll call a technician because you're sort of, you get that mentality where this is my lifeline."

"So I've got to look after it."

"So I think it's just more it's like if you have children, it's your kids you have to, you'd do anything for it type of thing."
"Not so much where you sort of cancel your plans type thing but in my life now, besides my family, this is next

"So I make sure it’s running right so that when it’s time to do my dialysis everything’s all operating fine. So it becomes, you learn to for one to cope and another is to look after it because if it’s not this then it’s back to the hospital type of thing. And I don’t want that, like I really don’t want to go back to the hospital. I’m much happier this way"

Thus in taking care of it, he realizes that he may have to call the technician because this is his "life line." In this way, it is like having kids in that "it’s like if you have children you would do anything for them." He acknowledges there are some limits to the relationship, but next to his family, the machine is the most important. So although it is not his family, he can acknowledge that in some ways it is like his family. You would do anything for it, like you would for your children. And finally, like a child, you keep it "clean", call for help if you need it, and "learn to look after it." But here though, the reasons for caring for it seem different than if it were an actual family member. He takes care of the machine, not for its own sake, as we might see in the family or parental relationships, but instead for his sake. If he does not take care of it, the consequences are for him, not the machine. And the consequences are severe, because if he does not care for it then it is the "back to the hospital type of thing", which for him seems to be a terrible thing.

Thus caring for the machine like a family member helps to ensure that he does not return to the hospital. So it can be seen that the machine needs care, like children or family, albeit for very different reasons than might be observed in a family where care for the children or other family members to some extent is altruistic. Here caring for the machine is about him and his fear of returning to the hospital. These reasons when contrasted against altruism appear to be more self-orientated.
While he acknowledged the similarities the machine shares with potential family members, his family acknowledges its importance also, for they know what the "machine means" to him because "they know what's involved" with it. For example, not only does he care for the machine, so does his sister.

R: "They know the importance of it. Um, most of the times usually my sister will come to clean my room. She'll wipe down the machine for me. And you always get these little odd drops and stuff, this acid stuff and then there's the bicarb. The bicarb is the worst actually and if I see it, I'll wipe it up and if I don't then my sister usually when she cleans on Saturdays. She always passes a mop anywhere in this room here, well actually the whole house. She doesn't, it's not the thing where it's his problem, he does it.

I: Right she's assisting you doing it?

R: Yeah, yeah that's true.

I: She cares I guess right?

R: Yeah.

Consequently, his sister has incorporated the cleaning of the machine into her cleaning of the whole house. In this way, it is wiped down, and mopped, just like the rest of the room and house are cleaned. It seems that in some ways it may just be another thing to be cleaned. So possibly for his sister it is not that it's a family member so much as it is just another thing to clean. Thus she may be responding in a gendered way to its presence, cleaning it, while his gendered response is more along the lines of seeing it as a wife that you get used to or as child that you take care of. Cleaning and caring are activities that are related. Caring for a child also includes cleaning him or her. So it is hard to say that in just cleaning, she is not caring for him. In fact because she is helping him, which is a form of caring, it is possible to say, by cleaning the machine and his room, she is caring for him. As a result, the machine is an extension of him, and
by caring for it, she in turn is caring for him. Hence, the machine becomes a family member through which elements of care are passed through.

This machine has become a family member. It seems that while its initial purpose was clearly instrumental, it has however been transformed through its involvement with the family into a new family member who receives care. As such, it has created a new class of family member. This of course raises interesting questions about the extension of family to include the new and additional category of machines as members of the family.

Case 3. Findings and Discussion of Highlighted Themes

The lived-experiences of time

"Making up time"

If he had missed time on dialysis he reported that he would have to make it up.

"So I would have, sometimes have time to make up, that would drag terribly because I guess you're habituated to a standard passage of time like 4 hours. And you'd throw in another 15 minutes and it's agony you know it's just excruciating. A half an hour is like the end of the world you know."

"Yeah they're not rigid about it but I felt I should and I'm kind of a rigid guy. So I felt if I had been you know carrying my time for several days then I would try to make it up."

He experienced a "carrying my time for several days", which caused him to try and make it up. Carrying the time is therefore experienced as a problem for it is the antecedent to having to making up time. While making up time is what he has to do to relieve the carrying of time, the actual time spent was described as "doing" of time. "Doing time" resembles what an individual does in jail doing time. To be in jail is doing time, it is a punishment for a crime committed. Therefore this participant's crime may be that he went home early from dialysis.
While it sounds nice to get off early, this was not a pleasure that he was afforded. On the contrary, getting off of dialysis early was a problem. He usually had his time on dialysis shortened because he either got off early, or he had arrived late. Whatever the reason, he knew that he would eventually have to make the time up.

"Usually it was shortened because either I had arrived late or I had some reason to you know I had to get on and do something myself. I mean I had an appointment downtown or I was trying to make a class or something like that. And that didn’t really I mean it didn’t sort of make things better because it was shorter. Like you don't win by doing that."

"There's a strain yeah. There were other people at the clinic who would say oh I’m only going to do 3 1/2 hours. They wouldn’t necessarily you know if their regular time was 4, that wasn’t necessarily because they had anything to do. They just didn’t feel like doing the 4 hours."

R: But I’m kind of I think I have an excessive respect for authority and routine so I would not, I wouldn’t do that. I mean if I had shortened my time there was usually a good reason for it.

So while it was a solution for being late, or leaving early, having a shorter dialysis time was a long-term problem, because he carried it until he had to make it up. In this way, time has become a commodity that can be exchanged. It has become a experience, which has weight.

Outside forces would thus cause him to arrive late or leave early for dialysis. The impact of these forces turned his time into a heavy object, perhaps a burden, which he would have to carry and eventually do. The experience of doing this heavy time was excruciating. Perhaps indicating that the weight of time, 4 hours of treatment, was already a load he could barely carry, but had learned to do it through repetition. The sporadic nature of the external forces thus fell out side of his routine, causing him to experience the weight of time in a way that allowed it to drag on and be carried, thereby causing him extreme discomfort.
The lived-experiences of spatiality

"You sort of feel like you're a voyeur"

What he liked about the space at the Self-care center was that he faced the nursing station and not "into other patients" faces as is the case on the OPHD ward.

R: Into the unit but not looking into other patients' faces, which is good. Unlike what goes on here, you can inadvertently make eye contact with other patients and that's kind of distressing.

"And I wouldn't like that you know that would be, you're also because patients here are sicker, it's that kind of thing, it's more distressing. There are people in beds, people having a lot of difficulty and so it's..."

I: Why is that more distressing?

R: Um well because people are sick and you sort of feel like a voyeur if you're looking at them.

He asserts he does not like looking at the other patients who are sick because he feels like a voyeur. Thus the important thing is not to have eye contact with other sick people.

"You could blow a vein, and you don't want to do that"

The Self-care center was associated with the pain of "blowing a vein" due to the steel needles used there, "If they move around in your arm when they're steel, you could blow a vein and you don't want to do that." The problem with blowing a vein does not lie in pain, as "it would be a little bit painful, not terribly". The essential problem seems to be that blowing a vein involves a lot of "running around and getting a nurse".

"Blowing a vein means that the needle inserted into the vein has gone right through it. This idea was discussed above, when he referred to "ripping the shit" out of his vein. But here blowing a vein is first related to the Self-care center.

R: That site, that site's just not going to work correct. So that involves a lot of running around and getting the nurse and stuff like that, oh I think I've blown a vein and stuff like that. And it's, part of the procedure when you get on is watching these I'm pointing to some bars that indicate the pressure in the arterial and venus line.
In this way it seems like more of an inconvenience, like blowing a tire, for example. Both have a bursting quality cause due to the puncture of a foreign object. However, for his body this puncture causes a flow of blood into his surrounding tissue. This escape of blood into the body means that he has to start over again. Knowing that this may happen leads to the development of procedures. One procedure is to watch the machine to ensure that the pressure in the arterial and venous lines are normal. The other is to watch his arm where the needles go in. If the skin is swollen this indicates that there may be a blow. Also, he has to watch that he "cranks up" the pump speed to see if the pressure goes up too fast. He watches to see if he "might have blow".

"So those are reasonable pressures but when you're starting dialysis and cranking up your pump speed you're watching these to see if you might have a blow. You're also watching the sites themselves because what happens is the flesh around the needle site swells and you have to be quite attentive to that. Because you want to stop it, if it's happening you want to stop it as quickly as possible, get that pump off, and so that you're not you know putting more pressure onto the machine."

"*It de-institutionalizes it*"

In talking about the atmosphere of the Self-care center, he speaks to elements which make it more humane and less institutional.

"And it's also a distraction for the patient and if she's laughing heartily with a patient that means she's the patient's enjoying himself. And you know I didn't want to be grouchy and intrude on that. And I think also when people are laughing or having a good time it just makes the environment healthier. It de-institutionalizes it, it makes it less, well, less like an institution."

"And by making the environment humane like that, by saying hello to the patients and talking about their dogs or their children or laughing and stuff like that, it went a long way to making it much less institutional."

The benefit of laughter is that it is a non-institutional action, and it is therefore healthier. It is undeniably human. Thus having a good time is humane and hence non-institutional.
"Modifications need to be made"

For him to be able to dialysis at home, his bedroom will have to be modified

"Uh well it is the bedroom so it's not really separate but it has to be of sufficient size. And on top of that the people from the hospital went out and surveyed to find out what modifications need to be made in terms of plumbing connections and things like that. And then they hired contractors to go in and make electrical modifications, I guess more outlets and stuff like that and plumbing modifications. And what they're doing is my bedroom is the other side of the wall from there is the bathroom so they don't have to go very far. They've got to go through the wall to get to the cold water and to get to the drain. And it seems like a, a good setup. The other things is there will be a constraint is once I'm kind of set up that way that's sort of how my bedroom furniture will be. You know I won't be able to rearrange the furniture so it's going to be kind of [ ] to sort of cover space."

"Like I might decide you know probably once I've settled in and I finally put everything you know it terms of light in the morning and stuff like that I probably would stick with it. But I still don't know what's really going to work and so I'm guessing okay well I'm going to want to sleep this way, I'm going to have the machine on this side of my body and all this crap. But I may decide no I don't want it that way at all and then you know I'm kind of stuck so but I think actually they might make modifications. They might not be expensive and I can pay for them myself but there's still a barrier there, there's a hindrance."

His bedroom was assessed by the hospital in terms of it electrical and plumbing capabilities. Then contractors went in and did the renovations. The modifications are not so much as addressing his space concerns, as they are addressing the infrastructure of his house. In this way the hospital is modifying the substructure of his living environment.

The lived-experiences of the body

"Handling my sites"

He uses the term "sites" to refer to parts of his body and he uses "handling" as a description of how he engages with the "sites."

"They would, there would be a little alarm that would happen because they hadn't connected this back to the machine as they were putting it through its rinse cycle and that would always happen when I was at the point of handling my sites. I would have gotten my needles out and I'd be holding dressings against the sites and I couldn't really do anything."
The "sites" refers to the locations on his body where the needles go in to and come out of his arm. But he does not use the term "arm". He uses the term "sites" in the plural sense because there are two needles that go into his arm, in two differing locations. When he refers to the needles he uses the possessive term "my", yet when he refers to the sites he uses the article "the". What seems odd here is that people would usually use possessive terms to refer to their body. For example, it would be said, I hurt my leg, or my eyes are brown. Moreover, the needles are referred to in the possessive term "my". While it is not strange to possess objects such as needles, what stands out here is how his possession of the needles is apparent, but not the possession of the arm. Perhaps because the term "site" is employed rather than arm, because it is easier to distance himself from a site than an arm. Surely it would have been hard for him to say holding the dressing against the arm, as opposed to my arm. While he can possess his arm, the site is not his. So in using the term site, the arm or body are also attributed to a non-bodily term. One might even be tempted to say it has been given neutral terms but this is not so. Site is a medical term, employed to locate the target area for needle insertion.

"There are two, there is an arterial site and a venous site"

In talking about the changes that he will realize when he moves to NHHD he indicates that the changing of the canulation procedure will be easier.

"The canulation procedure has changed, although I think it's going to be actually easier than it was before. So there are you know there are a number of changes too.

Here he develops further what he means by sites.

"Canulation procedure is inserting the dialysis needles into the access sites. There are two, there is an arterial site and a venous site. At the Self-care center you have a fistula which is a long rubber tube or plastic tube with the canulation needle at the end. The canulation needle is wider. It's a thicker diameter. The ones here are narrower which means that it's easier to canulate something that's small. One of my accesses is a bit thinner than the other. Like that vein is huge, it's quite wide."
Sites are the access points to his veins and arteries, as such they are access sites. One of his accesses is a bit thinner than the other. When he explains this to me and points to his arm, I can see that one is larger than the other. Yet it looks like an arm, not a site. He even says one of his "accesses" is thinner, and then in the next sentence, switches to using the word vein. So he interchanges the word vein with accesses. His vein has become a site of accessibility, it is now labeled in terms of its function. Yet when he looks at it, and gets me to look at it, he shows me how its width, so wide that he could do it with "his eyes" closed. When he looks at it he calls it his vein, but when he talks about it without looking at it, it becomes an access site or two access sites: the venous site and the arterial site.

It seems like there is an informational medical description versus an experiential description. When he experiences his arm with his eye, he calls them veins, but when he explains them to me he calls them access sites. However, this division becomes blurred when for example, he describes the visual qualities of them and says, "one of my accesses is thinner than the other." This shows how the narrative of medical information is transforming his body from an experiential and sensation oriented experience to informational and functional orientated description. The process of description is overpowering, and thereby writing over the experience of the life-world.

The lived-experiences of relations with others and self

"I was exposed to something that really disturbed me"

The witnessing of a conflict between other patients at the center was something that he experienced as disturbing. (In the following texts only the initials of the patients have been used to hide their identity.)
"I mean I was exposed to something that really disturbed me. There was this guy at the clinic whose name is D and D is I think at least half First Nations and there was this Russian immigrant by the name of M. And M was Russian and Jewish and he went after D one day and he said something about you [ ] people you get welfare and you get free dialysis and stuff like this. On and on like that and I was sitting beside D and I became angry and very disturbed by that because you know it was very racist. I mean this guy M was a pig and he'd done stuff like that before. Now I didn't say anything and that caused me to feel a very intense sense of shame because D was not a very articulate guy. You know I mean he, and he just kind of sat there stunned by the onslaught. I was kind of stunned by it too so I didn't do anything at the time but I did complain quite vigorously to the administration. I said this is you know, I really wanted to say something and I thought of something sarcastic to say that I didn't say. And that was M isn't there a [ ] somewhere you should be going to. You know it [ ] very emotionally satisfying but it wouldn't have felt. So that is another thing about constraint and the impact of people around you and stuff like that.

The witnessing of this racist act had a strong impact on the participant, and because he did not do anything at the time he felt an intense feeling of shame for not doing so. Later he complained to the administration. But in not approaching the person who made the racist comment he felt he had constrained himself.

The lived-experiences of the dialysis machine

"Cozy with the machine"

When asked about whether he felt he had a relation with the dialysis machine, he shared that while the staff has suggested to him, this idea of having a relation with it, it was in his estimation, "whimsical"

"It's kind of funny because the, one of the dialysis technicians at the self-care clinic where I was before I trained here, explained to me that the machine was my girlfriend and I should feel very cozy with the machine. He was being whimsical. No I mean it's a piece of technology and you know it sort of has its own demands. I mean you have to put the machine together carefully and stuff like that so I don't feel one with the machine at all no".

Here he re-tells the story of the technician who suggested that the machine would be his girlfriend, and he should feel very cozy with it. His version of this telling shows that he does not take it seriously and suggests that the technician does not either. Yet it is important that it was
mentioned  This sort of off hand comment, if that's what it was, and it may not be, reveals several interesting ideas. First, it shows that it was the technician who first suggests that the machine and the patient would have a relationship. Secondly, what is interesting is the kind of relation the technician suggests that the patient would have with the machine. Because the patient is male and the technician suggests a female-orientated relationship, the bias of heterosexuality is revealed. Further, it is not a marriage relationship where the machine would be his wife. Rather it is instead suggested that it be his girlfriend. Moreover, the fact that is a "cozy" girlfriend relation and not a paternal relation further suggests that it is a sexual relationship. Thus the technician is sending the message that the relation that the patient has with the machine will be an intimate heterosexual relationship.

"The machine has its own priorities"

What made this machine alienating is it has a universe which is "constructed from its own point-view"

"You're sort of dealing with a machine which has its own priorities and they're not necessarily what you do"

As a result, it would get in the way of what he was doing for example, if his hands were busy, the alarm would sound, which required his attention, however he was not able to attend to it.

"They would, there would be a little alarm that would happen because they hadn't connected this back to the machine as they were putting it through its rinse cycle and that would always happen when I was at the point of handling my sites I would have gotten my needles out and I'd be holding dressings against the sites and I couldn't really do anything"

The machine's alarm going off means that it is demanding someone's attention. He would like to be able to respond to it but is unable. While the nurses did not expect him to respond, he felt a need so that they could respond to the more "difficult things". As the required response
was difficult, he seemed to be caught, unable to respond to something that would be easy to solve. Further, he feels the need to do the task that the nurses do, even though this is not expected of him.

"And I can't do anything. The thing is the nurses didn't expect me to do it but it still bothered me because I felt I should do it so they could do the more difficult things. And it's not rocket science to disconnect this from the wand and put it in the tank."

"I can change my blood temperature"

Speaking about his respect for authority led him to talk about how some nurses were intrusive in asking him to do or not do certain things. As an example of nurses that were not intrusive, he spoke about how they would let him change his body's blood temperature by adjusting the machine.

"Um some of the nurses were kind of intrusive in asking you to do things or not do things. Other nurses basically saw that you were not endangering yourself or they could see that you could, had a certain amount of awareness you could handle various things. And they'd kind of let things go. I would get cold on the machine and I raised my blood temperature here. Like it's, the default temperature for me is 36.5."

"I can change my blood temperature so the machine returns my blood at a warmer temperature, whatever temperature I set. And I would usually raise it to 37 because they had a climate control problem with this place and I was always cold. I get kind of cold easily. And one of the nurses would get really fussed about my doing this without asking."

Hence his experience of authority had a direct impact on his body. The authority came from the nurses but was also linked to the building's climate control system. But authority was not persistent, instead it varied, depending on which nurse he was dealing with.

And the other nurses would be you know they could see that I handled the machine easily well, if slowly. I wasn't, I was a very kind of very cautious person because they would see the way I canulated or put my lines together knew I wouldn't be doing anything rash. And they just sort of let me go. And they weren't being irresponsible but they were also not intruding."
What is interesting here is not so much that some nurses exercised their authority more than others. What is interesting is that he experienced personal authority over his body in making a decision to meet his needs. He needed to be warm, and the building was not warm, therefore he warmed himself by turning up the thermostat on his machine, thus leading this blood to heat up, and by extension his body, thereby making himself feel more comfortable.

Case 4. Findings and Discussion of Highlighted Themes

The lived-experiences of time

"They're wasting a lot of my time"

This part talks about how others have contributed to sense of wasted time

"I do have a problem with the team that is taking care of the living related donor team. They just are not on the ball. They're wasting a lot of my time. They estimated that it would take 3 months, 3 to 6 months to have my transplant completed and they've wasted already a month and a half by not even faxing the information to the doctor's office for my mother so she can go through her procedures to get tested. So now I'm just really annoyed with that team in itself which I'm going to take measures. I'm calling their management to let them know how unhappy I am and have him put the fire under their tail. Because I don't think it's very fair as me as a patient to have to have the whip out on my end to get my people in order. Meaning my mom's doctor which was my old doctor and my mother, getting them situated as well as whipping in the other direction to make sure that they do their job. It's not my duty, I shouldn't have to take on so much responsibility. So I'm going to go over their head and speak to their manager and have him take care of the situation because I'm not happy."

The time being wasted here is related to the time frame given to her for the transplant completion. The responsibility for the wasted time is placed on the living related donor team. To date they have not faxed the information yet, she is therefore upset and is intending on complaining to management. What is revealed here is a sense of urgency, and anger. Her lived-experience of time is that others are wasting it. What this means is that her transplant may be
delayed  This in turn suggests more time spent on dialysis  Clearly, and understandably, she
does not want to spend any more time on dialysis  It is something she urgently wants to get off
No doubt the transplant will improve her quality of life  What is being wasted then, is her
quality of life her life  This perhaps explains why she is so distraught, for her life is being
postponed due to the failure to send a fax  Moreover, she feels that in taking on the
responsibility by "putting the fire under their tail" it is not her "duty", which only serves to
amplify her anger  It is difficult enough that this has happened  What makes matters worse, is
that she has to act to correct it  Thus time may be further wasted unless she acts  This corrective
action is a burden that she should not have to carry and she is angry about it  Hence she is
attempting to regain control of her life (time) by complaining to the administration

"Time is not on my side"

Being busy and experiencing others wasting time is linked to her experience that "time is
not on my side"  I was able to identify my feeling of being rushed during the interview  In this
way, I sense that I too was viewed as wasting her time

"As I've already explained time's not been on my side since I'm a very busy person"

R  " No I didn't say I was on the list for a transplant  I'm getting, I'm not waiting for [ ] a
kidney, I am actually having a live donor, which is my mother, which I mentioned earlier

I  Okay, sorry about that wrong, does that impact for instance the time at all like waiting for that
or?

R  Well just the frustration that I explained earlier

I  With the team?

R  Yes that's time wasted

"In regards to them wasting the time, not my mother or the doctor or me  It's them as a team"
"my mother's ready and she's calling me asking me what's going on, how come you haven't called and how come they haven't faxed me the stuff? How come the doctor doesn't have it yet and she shouldn't have to go through all that either"

Statements such as "as I've already explained," and "which I mentioned earlier", indicated to me that we had already covered this material perhaps implying she was growing impatient and perceiving the interview as "wasting her time" Like the other team members, I too was wasting her time. This sheds new light on her phrase, "time is not on my side" This phrase may indicate that the amount of time in her life is running out. She cannot wait forever because kidney disease can be fatal. From this emerges an intense sense of urgency. In this way, the team and by extension myself, are both wasting her time her life. And since from her experience, her time left to live may be limited, she is frustrated when she experiences what little time left she does have, is being wasted. The issue then is a sense of impending death. Thus the statement, "time is not on my side" Wasting her time is thus equated to wasting her life. "Time is not on my side" in this context refers to his approaching death. Yet there is also a sense that something could be done to thwart the arrival of death. The key to this would be to increase the time, or to be quicker and more efficient with the time that is left. Since she cannot increase her time, the only thing she can do is be more efficient with it. But as the situation is out of her hands it is up to others. And this is where her frustration comes from. She cannot control how they spend their time. Therefore her destiny is in the hands of others. She is not in control.

The lived-experiences of relations with others and self

"It gets kind of sticky when it comes to sharing the machine"

This participant dialyzes at a friend's house who also dialyzes, they share the machine. Sharing the machine can be problematic.
"Well it's kind of difficult at times. We've been friends for quite a long time now for about 7 years and it gets, it gets kind of sticky when it comes to sharing the machine and her social life. She does her dialysis in the morning, I do mine in the evenings. In the evenings you tend to have your friends over, they finish work and it's kind of some people know, some people don't know I'm a pretty private person, I don't want everybody knowing my business and what I'm doing there. So she tries to be flexible and she misses out on certain things or she's restricted to having certain people over because of the situation, trying to make me as comfortable as possible. And sometimes there's we crisscross and sometimes I'm on and somebody is there and I'm uncomfortable. And she has to deal with her life as well as my life too so that's intertwined. So hopefully when I get my own machine and my own apartment to be able to do it at any time, that'll be great because sometimes I'd love to do it on a Sunday instead of a Monday. That'll free up more time for me since I'm not doing anything on Sunday evenings. I can actually take the time to do 4 hours, get it out of the way and have Monday to myself to do whatever I want to do. But I don't really have that flexibility sharing with somebody else because I'm inconveniencing her. Her Sunday nights if she wants to have friends over or to do stuff, I have to call ahead, in advance, and book in advance, different time schedule changes with her. So me having my own would be a lot more, a lot better for me because there's more flexibility, more time to myself as far as I'm concerned and less time travelling back-and-forth.

They have been friends for a longtime, however, sharing the machine causes some problems. The participants sense of privacy is challenged when her friend has people over while she is dialyzing, which can make her uncomfortable. While they try to negotiate the sharing of the machine, nonetheless it does not always work for either of them. Additionally, their lives have become more intertwined or intimate than when they did not share the machine. This is experienced as inconveniencing her friend. If she changes her schedule she has to call in and book in advance. By suggesting that she has to "book in advance", she indicates the additional aspects of the relations beyond that of friendship. Their friendship is becoming slightly bureaucratic. While friends do book appointments with each other they do not book with each other for medical appointments. Thus the reason for the 'bookings in advance' is the difference. These aspects are the ones that cause her to suggest that having her own machine would be a lot better. She will have an increased sense of privacy, more flexibility and less time spent traveling.
The lived-experiences of spatiality

"People were coming in and out all the time"

The home haemo training room at the hospital was not what she expected. It was not as private as she expected, and being a private person, this made the experience of the room uncomfortable for her.

"It was kind of open, it wasn't as quiet as I had expected it. People were coming in and out all the time. Sometimes people were waiting on the nurses that were dealing with calls or dealing with doctors or dealing other nurses, colleagues. And they were patients, home dialysis patients waiting to be taken care of which took up some of my personal space in the room that I was training in. Them watching me, making me feel a little uncomfortable but that's just the way it was set up. And it's unfortunate that the office isn't more, having people direct the other way around instead of coming through the unit where the patient is and then going to see a nurse, but going the other way around. The other entrance would have been the more personable, leaving the other person to do what they have to do.

The problem she had was the room was also used as a hallway or a shortcut to get through to the nurse station when another path was unavailable. Additionally, she found that there was a lot of interaction in the area between nurses, doctors, and patients. What this meant for her was that she felt like she was being watched.

Moreover, while she was simultaneously receiving her treatment and training, she would be in the chair connected to the machine. This meant that she was unable to move far from the chair. This passive body position further helps to clarify why she felt no privacy. Being immobilized probably increases feelings of helplessness and vulnerability. To be watched by others, whilst being vulnerable, would only increase the desire for privacy. In this way privacy implies a shielding of the body from the gaze of others.

"My home is still the same"

Because she does not dialyze at her home, nothing has changed there.

"I don't, I do it at somebody else's home so my home is still the same"
"It's the same space that I've always lived in for the last 5 years so that question's more relevant to someone who has a home dialysis machine which I don't. So it's not taking up any of my space, it's taking up her space.

What is evident is that she is concerned about space. If it was at her home it would be taking up her space. And since it is not taking up her space it is taking up her friend's space. Dialysis takes up space, but it also causes her to shift living spaces. She will be moving from the place she has lived in for five years, so that she will be able to afford her rent while she recovers from her transplant. In this way, it not only takes up space it also takes it away. The issues of space being taken away, and being forced to move for financial reasons, is also about the loss of space. Illness affects space. In this case it is causing her to move, due to the financial implication brought about by not being able to work during her recovery from the transplant. Home dialysis, consequently, may not be about the home, as it is generally understood. Her home is actually being threatened or even destroyed by the dialysis.

"It's not my home"

While her place is not big enough to have the machine at her home, there are other reasons for not having the machine.

"I'd have to have a bigger place. I only have a basement apartment where there's only one bedroom. There's no, there's no room for a machine and all its equipment."

"Yeah and there's other units that when it's at home because the system, the hospital it's plugged into the walls. You can't see the big systems that are behind the scene. But there's other parts, there's other, other parts of the machine that need to add onto it so it does take up even more space, like a television. Or like 2 VCRs piled on top of each other, no 3 VCRs piled on top of each other, there's that unit to do with the water system, the rinsing and running. So that unit as well so you have to have a [ ] for that unit and then you have to have all your stock, all the lines, all the needles, all - everything which takes up more space. So you combine everything, there's a lot of room that is needed, more room than I have and the water system, the water purification system wouldn't be good in my apartment because it's an old house and I don't even drink the water. The water's not clear and clean like the water you're drinking there. It's kind of like old
pipes It looks kind of rusty It's good enough to bath in and wash your dishes and stuff but I wouldn't advise anyone to drink from it I always buy bottled water So knowing that I can't really see them if they did a water testing and a water pressure testing it just wouldn't be feasible in my apartment [ ] home and it's not my home"

While the amount space is an obvious issue, ownership is also at issue, because it is not her home This scenario implies that the upgrading required for home haemodialysis may not be feasible for those who do not own the place in which they live In this way, income or personal wealth may be a factor in obtaining home dialysis

_The lived-experiences of the body_

"I had no clothes that could fit me"

Initially she had experienced a dramatic weight loss

"The other change in the beginning was the weight, the drastic weight loss I was size 9-10 and I went down to a 5-6 That was very drastic so I had no clothes that could fit me I'm building back up, getting my size back and getting my muscles back from the gym and I'm up to a size 7 which I'm comfortable with"

"It was just because there was no muscle, muscle and my body was just accustomed to just lying around for a month in the bed in the hospital You know I tried to get up and walk around as much as possible but when I got out that's when I spent most of the time exercising, trying to get myself back I didn't want to really go too hard because I didn't want to lose more weight because you know I looked sick at 5 - 6, size 5 - 6, I was very skinny So people knew something was wrong looking at me, wow she looked healthy before, now she's so skinny"

Because of this difficulty with having people talk behind her back, about what had happened to her she was determined to gain back the weight as soon as possible "Looking unhealthy" was the problem, and the goal was to gain the weight back in order to look 'healthy'

This way of approaching the illness describes the nature of kidney disease and how it impacts relation with others and the self With individuals she does not know, there still exists the problem of looking unhealthy before them
"No some people came and asked me what’s wrong or what happened, why you know or some people reacted thinking I did something. Well a lot of people reacted saying wow you’ve lost a lot of weight. But I know deep in their mind that they were thinking how come she lost so much weight so soon? What’s wrong with her you know? Of course people are going to think Aids or cancer, all the big ones.

"They would tell other people but they wouldn’t embarrass themselves by coming and telling me that so that was difficult. That’s why I wanted to gain the weight back, at least some of the weight back as much, as soon as possible so I didn’t look so unhealthy at that weight. Didn’t have the clothes falling off my body at that weight you know?"

The body is therefore a way of relating to others, and how the body looks impacts relations. A healthy body in this case is the best way to present to others. Moreover, if others are unaware of her situation they may speculate about why she has an unhealthy look. The realm of cause may lead to responsibility, others may think that she caused this unhealthy look. "some people reacted thinking I did something." Who is to blame for an unhealthy body becomes an issue. But as long as the matter remains unknown, her concern is that people think that she has AIDS or cancer. While both of these diseases have stigmas, AIDS clearly has the most. Without acknowledging her situation to others she is concerned that her body resembles illness. In this way what the body communicates is at times ambiguous. While, unhealthy bodies may be visible, the cause of them may not be. And the worst case for her is to be judged as the person responsible for this unhealthy looking body, which has clothes fallings off of it. Moreover, clothes are about identity, as such they are one medium through which messages are sent to others about the identity of the body they cover. Thus clothes "falling off" send a message about the body below.

This seems to explain her desire to put back on weight in terms of reestablishing what message her body sends to others, as healthy bodies it seems are not questioned by the public. In
this way she could send the false message that nothing is wrong with her body thereby ending public speculation, and leaving the health of her body unquestioned
CHAPTER 6
Emergent Themes  Inter-Case Discussion

Time is the prescription  the embodiment of time

In case 1 the framework for his treatment regime was time. In this way, his "initial prescription" time was broken down not only into hours and days, but also weeks. These prescriptions gradually increased. In the theme "and they gradually increased me", again from case 1, the pacing of time is a regime of progress and extension for those set the plan, but for him the gradual progress is experienced as a delay of experiential time flow. Thus the time pacing regime is artificial. But, from the perspective of those who set the regime of time and the artificial pacing of it, this delay in reaching the object of a certain amount of time may also be related to "organic" limitations of the body which requires medical treatment. Whatever the situation, the lived-experience of time as increasing, or artificially paced instead of flowing according to the life-world, is experienced as a stretching or extension of the self; thus he was "increased".

A concrete example of artificial time was seen in his experience of time as blocks. The meaning of this "block of time", from case 1, is experienced as differently for him and the nurses. He feels that they cannot understand his experience, and are thus inflexible in their "mentalities". The ownership of this time block is thus a site of resistance for his independence. Conversely and understandably, the need to assert his independence does not appear to be an issue in his life out-side of the time blocks treatment. Thus with the ever increasing and stretching of time as an prescription, the result is that the experiential increasing of time on dialysis is embodied as an "increasment".
In case 3, the theme of "making up time" revealed how the commodification of time, in relation to dialysis, led him to experience the heaviness of missed time as something he had to carry between treatments. This lived-time was a weight which his body had to carry between treatments. These cases reveal the varied ways in which lived-time becomes embodied.

Isolation, intrusions, sickness, voyeurism, and bonding

Living the spatiality of the hospital

The participant from case 1 explains that when he was in the large in-center ward, he experienced it as "just a pool of common people", thereby reflecting to him sickness and reinforcing that which he is trying to overcome illness. In the theme of "I was in isolation" when he was in the isolation room, he experienced it as social isolation, and thus a dragging on of time, which was extremely "horrible". This is contrasted against the medium sized rooms where he found that he could develop a "bit of a bond" with the other patients, thereby assisting him in becoming comfortable and gaining a sense of being at peace.

Case 3 provides support for the problem with the large in-center ward, albeit for different reasons. In the theme of "you sort of feel like a voyeur", he explained that he did not like that the patients were facing each other. By looking at them, he felt like a voyeur. In contrast to this, the self-care center provided more privacy than out on the large in-center ward. Privacy however was not an issue for him in the home haemo training room, presumably because he did not have to look at, or make eye contact with, the other patients who were sick. This is in contrast however to case 4, where the theme of "people were coming in and out all the time" revealed that her experiences in the training room of being vulnerable in clear view of others was an intrusion into her privacy.
Pleasure and pain  The last frontier of embodied resistance

In case 3, the theme "it de-institutionalizes it" aids us to understand that the opposite of institutions must then be the human life-world. So in this way even though the nurse's laughter was quite annoying for him, he found laughter to be an anti-dote to the institutional qualities of the Self-care center which therefore was experienced as institutional.

In the theme, "there are two, there is an arterial site and a venus site", from case 2, we discover the problem with medical description is that content and meaning are left out. Thus with the word access, we wonder — access to what and why? It is an access to his body, a site where entry is gained to the body. Where non-body things, or forced objects find, or push their way in. This reveals the goal of medical science in a nutshell to gain access to the body. But it is not access in the literal sense. It is a gaining access to the mystery of life, the holy grail of humanity. Thus to get in is the goal, and the legacy of this quest is revealed in the every day and ordinary terminology employed by medical science. The difficulty is that in describing the body in terms of function, the mystery dissolves. And in this way medical science obscures its own goals. The mystery of life will never be described, only experienced.

Canulation is the insertion of the needle into his arm. It is a one-word description which glosses over what the experience can be like. The needle at the Self-care center is wider than what he will be using at home. The quality of the wide needle caused him concern. The larger needle meant that he was afraid that he would use too much force and stick the needle right through the other side of his vein, or in his words "just rip the shit out of it". Notice here, in describing the pain, fear, and damage he might do to his arm, he does not talk about "ripping the shit" out his access site. Rather, when talks about his body being damaged, by using words like rip, he uses vein instead of access site. The word "rip" seems to better imply the experiential
nature of the flesh of the body. Flesh rips, while access sites probably fail and become inaccessible. Thus when he gets closer to his experience of his body he drops the medical narrative and instead describes his experience in his own words. What does this mean?

It means that experience of pain and ripping of the flesh have not been overtaken by a medical and functional narrative. This makes sense, because the experience of pain is acknowledged by Western medicine to be of a "subjective" nature. This is the area where medical narration, according to its own logic fails. Pain may be the last frontier of experience. As a result, the benefit of using medical vernacular such as "canulation procedures" is that one can avoid the rich experience of the body and therefore pain. It may be more comfortable to talk about procedures than experiences. Thus the pain associated with flesh is a point of resistance against the vernacular of the descriptive procedural medical narrative. In this way pain is resistance.

Case 1 confirms that pleasure, is also a resistance to institutionality, for when he says "I don't want to live around an institution", he reveals how the institutional procedures of taking a bath could erase the pleasurable aspects of bathing.

In case 4, the theme "so I really have to watch a lot of things I intake", the medical functionalist term 'intake' displaced the life-world term of eating. When she explains her experiences she uses eating and drinking but when she talks about diet restrictions she employs the terminology of intake/output. Consequently, hospital-functional words are being used to describe aspects of daily living. The life-world is thereby being assailed by terminology. It would seem that the senses in and of themselves are resistant to this terminology. Pleasure, it appears, is a site for resistance against medical institutional discourse. Thus it is confirmed that
everyday pleasures such as laughing, bathing, eating and even pain, are aspects of the life-world of these three participants which resisted the institutional tendencies of the hospital spatiality.

**Carbon and silicon. Struggles between the body and machine**

In the theme "hooked up", from case 1, the control over the relational aspects between the machine and him were heightened by the fact that the machine is maintained in the role of machine. This can be so because machines, apparently, are easier to control than humans. But is this really the case? In some aspects humans are controlled by machines, which is why the relations between humans and machine are so complex. While most would admit that society today is to a large extent mediated by technology, not all are comfortable with this. Thus his attempt to maintain power over the machine, and by extension, control over his life may in fact help to explain why he may benefit from saying, "I am hooked-up to it". As a result, this machine centered language of hooking and un-hooking serves both the purpose to refer to an actual event.

From the theme of "it's a machine. I don't worship it", from case 1, when he says that he "does not worship it" we understand that despite the fact that it is not worshipped, still it has somehow found itself in the category of the divine. Hence, he appears to be acknowledging the critical importance this machine plays in his life by raising the issue of worship, yet with the same stroke he negates its divinity. Thus one senses a struggle between his experience of the machine between both its divine life saving qualities and its ordinary but intriguing routine properties. Consequently, for case 1, it is revealed an attempt to maintain a human over machine hierarchy carbon over silicon.

In case 3 the theme of "the machine has its own priorities", further develops the struggle. Thus the machine's own priorities are setting up a relational triangle between the
nurses, the patient, and the machine. The machine demands attention, but because he cannot respond, the nurses come and do it. The result is he seems to feel guilty that he cannot do it himself; he is unable to do something that he feels he should do, thereby reminding him that he is dependent on the nurses and the machine.

In the theme from case 2, *cozy with the machine*, the machine becomes messenger of values. In disagreeing with the staff, he suggests that the machine was "a piece of technology." It may be possible that he rejected the heterosexual assumption of the technician and was thus not able to identify with the statement. This heterosexual assumption of the technician could be deemed as homophobic. While the participant did not refer to being offended, it is entirely possible that he was but chose not to mention it. The comment of the technician reveals how the machine can be personalized, and attributed human-like qualities. It also displays the complex way in which the machine can have biases or belief projected on it from staff, which are then transmitted to patients. This heterosexual bias demonstrates the personal and sexual qualities which staff such as technicians may attribute to the machine, even if it is denied by the patient.

The theme of "taking care of it, because more or less it's a family member", in case 3 demonstrates the adoption of the machine as a family member. While his sister cares for him by caring for the machine, he on the other hand cares for himself by caring for it. Both he and his sister care for the machine, not for its sake, but for his. It is like a family member in the way that it is cared for, but it is not like a family member, in the way that its care serves a purely instrumental purpose. While we know that care in the context of families may be altruistic, we also know, that it may not be. Care may also be about oppression, domination, or even self-interest. Thus this machine as a family member whose care may not be based on altruism may in fact reflect a reality which exists in many families where some members are used for the
personal gain or instrumental needs of other members. While I am not saying that this machine is abused, what I am saying is that because it serves a merely instrumental need, it therefore cannot be excluded from the position of a family member. This machine has become a family member.

Within the theme, "it gets kind of sticky when it comes to sharing the machine", from case 4 we find that this participant is sharing the machine with her friend. This situation of sharing raises questions beyond the issues of privacy, convenience, and flexibility. The main issue really is the nature of the relation between these two people who share the machine. What are the obligations and responsibilities between them? What if the relation breaks down to the point where sharing cannot continue? It is not uncommon for friends to have breakdowns in their relation. While the issue of sharing a machine is not discussed by her, it remains substantially important. Why are these two people sharing a machine and what procedures, precedents and protocols are in place to protect them?

While one can imagine that it may be more convenient, it can also be seen that it is considerably cheaper for the hospital. What social costs may this have on their relationship? While it may improve the bond between the two friends, it could also lead to a tenuous relation. If it does cause a relationship breakdown, it will have a significant and complicated impact on them both.

In case 3 the theme of "I can change my blood temperature" indicates that the machine can be used as a way to compensate for deficiencies in the building environment. He was able to use the machine as a thermostat for his body. But why does this seem strange? Reflecting on the dual purpose of the machine, the machine is being used as a kidney, why not use it as a thermostat? This is because the machine replaces the kidney, and one can understand what it is
that is being replaced. But was does a thermostat replace? It does not seem to replace anything in particular biologically speaking, although admittedly, my knowledge in this area is lacking. Is it possible to have a single organ that regulates body temperature? Thermostats are usually part of buildings, and as such they are located on walls. To adjust the temperature one just reaches out and adjusts it. Such a simple act. Perhaps that is what he is doing here, just a simple act. To regulate the body temperature, no doubt a complicated organic process, in such a simple way is odd. His machine and its temperature control system is a site for resistance against the system.

This reveals subversive possibilities for the meaning and operation of the machine. No doubt the machine’s thermostat was not designed to compensate for a low room temperature, or as a way to resist the exercise of authority of the nurses. The machine seen this way is thus an instrument of rebellion for his body. His body is localized as a material force from where the seeds of rebellion are planted and harvested. When his body is cold he uses the machine to overcome the forces which work to keep him cold. The machine is simply the instrument that enables him to overcome the social situation and restore his bodies comfort. It is an instrument of personal autonomy and control. In this way the machine can be subverted from original and primary purpose and become an extension of bodily resistance.

**Function & privacy Embodied wellness and the struggles of gendered health**

In the theme “*I’m trying to see if I can function as* ”, from case 1, the outcome of the functioning as if he “wasn’t really sick” appears as a result of his process of tailoring his disability and dialysis prescription into his lifestyle in a way that does not “compromise” his health. Thus the compromise appears to be a balancing act between functioning as a normal body and functioning as a sick body.
In case 4, a similarity was found in the theme of "I had no clothes that could fit me". Here, we find unhealthy bodies, more so than healthy bodies may be the objects of negative speculation in the realm of public discourse. The transformation of the body may in this way indicate an underlying illness. Her desire to regain lost weight and to return to looking healthy means that a healthy body will lead to less speculation by others. In this way she can limit the possibility that her body will be the object of public discourse. Consequently the life-world of her illness may be about the publicity of her body. Unhealthy looking bodies are public, while healthy looking bodies are private.

Thus while we see that in both cases there is a struggle to maintain a healthy body they have differing reason which may be gendered. The female wanted her body to look healthy so that her body will not be the subject of other peoples speculation, while the male's struggle centers around function. In this way functional discourse may be a masculine discourse, while publicity, speculation and relational concerns may indicate a feminine discourse.

**Hospital or Home? Transformation and negotiation of lived-space**

With this grouping of themes we see how the transformation of living space to hospital-work-space. In the theme of the dresser from case 2 we saw that each drawer contained a medical supply seemingly related to some part of his care, which in turn referred to some part of his body, and in one case even to his underwear. This organization of drawers by differing thematic items, implying different uses seems normal enough. For example, sock drawer for feet, pants drawer for legs and shirts drawer for torso. But what is interesting is that the drawers did not contain clothes for different parts of his body, but instead were filled by medical supplies.
which in turn refer to different parts of his body. His new set of clothes have become medical supplies.

In talking about the tape measure, in the theme of "I gave her my double and she gave me her single", from case 2, it was revealed that this room had a history. At one time it was a kitchen, but was later renovated to be a bedroom. This renovation took place before he started nocturnal dialysis. His room was small because it used to be a kitchen, which implies that bedrooms are larger than kitchens. Thus, whoever renovated never thought it may be a bedroom.

When he started dialysis, because there was not enough room, he had to exchange his furniture with his sister's. He thus moved down in size, and probably comfort too. They exchanged furniture, because her furniture was a lot smaller than his. The only pieces he retained were his TV and a small armoire. The TV was on the dresser because that was the only place left for it to go. Thus perhaps the tape measure was a meaningful symbol of the way things used to be, including previous renovations of the room, its original intended purpose, and the process of how it came to be what it is now. It signals a negotiation of space and objects, both within the room between the medical supplies and bedroom furniture, and moreover the space between his sister and himself. It implies a thoughtful working out and calculating of space and in this case a lack of it. But this calculating of space served another purpose. It served as an organization of space which was a response to the arrival of the machine and its related supplies.

Another transformation of lived-space was further witnessed in the theme, into the fridge the next morning, from case 2. Here we saw a transformation of a private residential non-medical space into a hospital-work-space. But more than a juxtaposition of divergent themes, there was an integration of them. The integration of a bedroom-space with an institutional space, or a food-storage-fridge with a blood-sample-storage-fridge, provokes a jarring feel. When an
overpowering institution such as a hospital is materially introduced to a private-residential-lived-space such as a bedroom and kitchen, one wonders if these home-spaces can withstand the force of the institutional-hospital-space. In this case, materially, the institutional-feel-space has at least found its way into his fridge and into his dresser.

The question remains, is the transformation of private residential-lived-home-space such as bedrooms, refrigerators and hallways into an institutional-hospital-work-space, giving a 'homey' feel to a hospital procedure such as dialysis, or is giving an institutional-hospital-work-space feel to some of the most private lived residential-spaces known the bedroom and the fridge? The answer I believe is the latter.

**Bodies without homes  Access barriers for homeless and renters**

In case four the theme "my home is still the same" reveals the binary relation between the concepts of home and hospital. Spatiality is not solely a home or hospital. By shifting the dialysis program to outside the hospital, the name "home" was incorporated. The use of home implied that it was the person's home. While it would be at their home so to speak, homes generally do not have dialysis machines in them. The use of "home" in home haemodialysis therefore is misleading. The understanding of home-space is being co-opted to describe the idea of not performing dialysis at the hospital. This is understandable because it at least sounds comforting. Home is powerful concept which includes feelings of comfort and safety, and by invoking our sense of home and attaching it to a medical treatment such as dialysis, dialysis has been given a free ride into home. But "homes" do not have dialysis machine in them.

In case 4, even more fundamental to how her home will change, the theme "it's not my home", also from case 4, reveals that the home, in home haemodialysis, is a criterion rather than
a location If you have a home you can receive the many benefits of home haemodialysis, and if you do not have a home, dialyzing in the hospital is the main option For those who are fortunate there is the option of social housing However, at this time in Ontario both the federal and provincial governments are abandoning social housing (Layton, 2000) Thus for those who rent, home-haemodialysis may be possible if there is enough space and if the landlord is willing to permit the required upgrade If not they are forced to find social housing which is in great demand with long waiting lists (Layton, 2000)

**Transformations  Embodying discourse and practice**

This cluster of themes reveals the subtle and not so subtle ways in which discourse and practice transform the body With the theme of "overloaded", from case 2, the participant indicates that while he no longer has the sense of urinating, it seems to be still fresh in his mind So much so that he had to correct himself Is experiencing the sensation of being overloaded the new sensation for having to urinate? Is a lung full of liquid the same as a bladder full of liquid? No And does having a full bladder make it hard to breath? It seems here that a sense of having to urinate has been exchanged for the new sensation of feeling "overloaded", with its attendant symptom of poor breathing This is a transformation, traveling, or relocation of the phenomenon of urination, which is having too much liquid and therefore toxins, in the body

Secondly, another difference is the attending conceptual differences Most people, it seems, do not think of urinating as the removal of toxins or toxic build up from the body It seems as though with his condition the pathologizing of urine has occurred Instead of urine he now has toxins So instead of urinating or having the sensation of urinating, he now has toxic build up and removal, or fluid taken off His urine has been medicalized and given a new schema His body now appears like a toxic dump
He uses the discourse of medicine/toxins to talk about his body. Further, he now has new bodily sensations and attendant feelings such as being overloaded. His body and the way he talks about it have been transformed by illness. His illness has been reconstituted as a bodily phenomenon.

In the theme of "I wanted to get it out", from case 2, it seems that his prior experience of a graft had a bearing on his expectation with the new graft that it would be removed. This was never mentioned to him however. In fact he was told that it was to his advantage to leave it in, because taking it out would be worse. Further he purports not noticing the graft inside his arm when he moves it. He notices it "only by feel". In this way "feel" seems to be minimized as a sense. That is, function appears to take priority. As long as his arm functions with the graft in it there is no problem, other than how it feels. So even though he wanted, and even expected that it would be removed, an institutional-risk-based-functional-argument has superseded the bodies sense of feel. As long as it only feels different, it does not matter it will stay in. This illuminates how the institutional narratives of function and risk overpower and supersede bodily tactile sensations such as touch and feel. The body has been subjugated by material function.

In case 2, the theme of "it's the bath I have to watch out for", the issue of who names parts of the body and what their perspectives are, is illuminated, suggesting how this has a significant impact of the experientially-whole phenomena of the lived-body. Perhaps this sort of terminology serves to help him not think about how his body has been transformed, in this situation a from a chest, to an "exit site". Where does the chest end and begin? A site has a fixed locality. A fixed locality and function may help him to integrate this transformation, and to normalize it. But the phrase exit site is anything but normal, and is clearly a medical term. His body has become the location of a struggle between medical terminology and the life-world.
The fact that he does not seem to acknowledge this struggle suggests that he is not aware of it. Moreover, it may indicate that the institutional and medical narrative may have already established itself on/in his body.

Let us consider in case 3 the theme of "modifications need to be made." Not only does the hospital impact the visible elements of his bedroom with additions of the machine and associated supplies, the hospital is working behind the scenes -- it is altering the way his house works/functions. One can guess that his house is being altered to provide power and plumbing that are up to hospital standards. Hospital plumbing and power requirements are substantial when compared to residential requirements. In this way his house is being transformed from residential capacity to a hospital-industrial capacity.

The parallel between his house and his body are striking. The hospital is transforming his house, and his body, in substantial material ways. It works below the surface of the skin and behind the walls of his house. It upgrades him and his house to adhere to hospital/industrial standards of operation. But while some things are being upgraded to hospital standards (hard standards such as electricity and plumbing) one wonders if all hospital standards (soft standards such as policies and procedures) are being considered. If they are not, what is the rationale for this?

In "handling my sites" from case 4, the participant is integrating a term that locates a medical procedure or function a transformation is taking place. His body is losing its status of a body, or even his body, and thus his ownership or sovereignty over it. Its ownership is now in question, thus it is no longer solely his. But who else is impacted? The medical narrative has moved in and attached itself to his body. So far it has been localized to this site. Does this mean the site is contained? Sites are often contained on the surface. Take for example a construction
site where a fence is placed around the perimeter. A deep hole is dug in the body of the earth, and a new non-earth human made structure is inserted into the earth and then buried over. Later the fence is brought down and it is no longer a construction site. It is no longer the same, it has been transformed both below and above the surface. Is a site in fact a signal of the end of, or the beginning of a bodily transformation? It seems that it is both a testament to a construction or excavation which has taken place and a signal of what the future may become. The process of construction practices, and building development are not isolated phenomena. Thus an individual site is usually related to other sites which are in term part of a planning process for a city or a body. Does this mean then that there is a plan for his body? If so where will the next site appear? Will it be planned well? Will the planning process be inclusive or exclusive? Does construction have its own logic? Are medical operations nothing more than construction sites on the body? If this analogy holds, then the body will be in line for the same fate as the earth overdevelopment. What are the social implications of an overdeveloped body? Are medical bodies therefore industrialized bodies or first world bodies? Is the march of science the end of organic bodies? Will bodies lose their carbon and eventually be replaced by silicon, is our future a cyborg future? Seeing a body as a site may then provide a sense of where the body is heading in the future. The question is therefore this: can the human body sustain development, is there such a thing as sustainable development of the body, or will the logic of "progress" deplete the resources of the body thus bringing about its end?

In the theme, "you could blow a vein, and you don't want to do that", from case 3, we find that there are two ways to watch for a blow, by looking at the shape of his body and by watching the pressure levels indicators on the machine. These incidents are not dissimilar from how one fills up a car or bicycle tire. One has the sense that it is a mechanical situation,
especially when he talks about "cranking up pump speed" This language certainly gives him control over the machine It reminds me of the television show Star Trek, where the Captain says to the engineer, "to warp speed" and Scotty the engineer replies, "I am giving it all I've got Captain" The background fear is that what is required, is more than the ship can withstand In this way his body is the ship, the machine is the engineer, and the participant is the Captain In telling the machine to move full steam ahead, which is like "cranking up the pump speed", the question which begs answering is whether the ship can withstand it? If it does not, the result is a blown vein, and redoing the procedure The blowing of a vein is thus seen, from a procedural perspective as a minor inconvenience As such it is a procedure that covers over the earlier description of his flesh having the "shit ripped out of it" It is easy to grasp the distance between a minor procedure, and the 'blowing' of a vein By weaving the "blow" into the discourse of mechanics, it seems to have the ability to "lessen the blow" that the reality of a blown vein must have

In the theme "so now I've basically become a medical junkyard", from case 1, he worries about the cost of the medical procedures In doing so it appears as though the institutional discourse of health care finances is having a direct impact on the patient's lived-bodily-experience, which in turn leads to a skepticism surrounding the reasons offered for a "medical" decision It seems as if the institutional discourses of function, and finance, have overridden his personal sense of his bodily integrity The result is a cost-effective-functional-altered-body, which he experiences as a medical junkyard In essence, the institutional-hospital discourse has left its signature on/in his body The result is having the status of his body downgraded from the status of a living-whole-body to a cost-effective-functional-altered-body, which in his experience, is a medical-junkyard-body And it does not get much worse than that
Thus we see the cross case support for the way the lived-body is transformed by discourse and practice. In case one 1 and 2, it was found that material bodily-integrity can be challenged by having junk left in it, due to function taking precedence over sensation and experiences. Additionally, in case 2, sensations can travel from one part of the body to another. In case 2 again, certain technical terms such as "site" were found to attach to his body, thereby destabilizing its sovereignty by exposing to the forces of medical development and thus revealing a struggle for sovereignty at a corporeal level. Finally, in case 3 we see how both home and body are linked by the twin and simultaneous transformation of the sub structures of body and home.
CHAPTER 7

Conclusion

Summary Discussion

The findings suggest clearly that the life-world of participants were transformed by home haemodialysis and that the transformative nature of home haemodialysis is far-reaching. The embodiment of these transformations was experienced in all the basic phenomenological themes - transforming the body, the home, relationships with self and others. It was evident from the findings that the discourse and practices of the hospital-medical-functional-world impacted all aspects of the participants' life-world. These transformations have raised questions surrounding sovereignty of the body and bodily integrity. Who owns the body after it has been transformed medically? Is bodily integrity preserved experientially?

Of interest is that the findings did not support those of Nagel's study (1995) in which she found that embodiment was preserved in the face of technology. The findings of this study suggest that embodiment was transformed. Of difference, Nagel's study did not locate the embodiment within the context of lived-body, lived-time, lived-space, and lived-relations. In addition, Nagel's study focused on the experience of individuals receiving in-hospital dialysis, and not home-dialysis. This may explain the difference in findings. The findings here suggest that the embodiment of transformations is fundamentally related to the lived-experience of one's life-world.

Of particular interest is the finding that the transformative quality of the hospital medical functional discourse, and practice, simultaneously impacted the body and the home. This was revealed in the reconstitution of the hospital in both the home and the participants' bodies. Beyond embodied transformation as already discussed, this raised the question of the use of the
term *home* in home haemodialysis. Those who rent, sublet, or something else may not have a home to be transformed by the hospital, while those who are homeless do not. Thus they will not receive the benefits of home haemodialysis. Home haemodialysis effectively sets up some barriers to people who rent, and a permanent barrier to those who experience homelessness. This is disturbing because people who are homeless already face considerable barriers to healthcare (Jahiel, 1992).

Additionally, the transformation of the home into a hospital was revealed. Wellard and Street (1999) describe a similar finding in their study on home haemodialysis whereby each family they studied eventually established a clinic in their home. However, what they did not discuss was the implication of this factor on home and workplace safety.

In this study, examples of unsafe working/living conditions were found, such as storing blood in the kitchen fridge. This study highlighted the necessity for further investigation in the area of developing health and safety protocols for dialysis within the home environment.

This study also poses an interesting challenge to Toombs' (1988) suggestion that the lived-experience of illness is more about a disruption of the life-world, than it is about the disruption of the biological body. Findings in this study suggest that the lived-experience of illness is impacted by the medical-functional-discourse and practices of home haemodialysis technology. This impact thereby prompts the embodiment of the discourse framework, allowing for an experiential transformation of the body as well as the life-world with which it is intertwined. This creates conceptual space for the consideration that the life-world is not excluded from the discourse of the biological body. With this opening one can see how the life-world is transformed, and finally embodies technological discourse and practice.
Methodological Significance

By employing the phenomenological method for exploring the life-world in terms of the basic existential themes of lived-time, lived-body, lived-spatiality and lived-relations, an incredibly rich description was obtained, revealing the complex nuances of experience. The responses of the participants demonstrated time and time again that each theme was interlinked and entangled in ways that demonstrated their relation. For example, time, body and relations were often related to space. In this way, every piece of information was located along a time-space-body-relational continuum. While each response may have emphasized certain aspects of the life-world, nonetheless all responses were embedded within the web of the four basic existential themes. In fact, if only one theme was investigated, the data would have been incredibly thin. The scope of data collected was therefore impressive, and even overwhelming at times, allowing for a deep and contextual understanding of the life-world as related to home haemodialysis. Phenomenology requires the researcher to have patience both in data collection and analysis. If one has the patience, and the resources of time and energy to employ such methods, they will be rewarded with an incredibly complex and rich data set, allowing for a deeper understanding of the human experience and a furthering of scientific knowledge.

Recommendations for future research

1. Phenomenology is a growing method of research, its methodological significance in exploring the lived-experience of people who receive home haemodialysis treatment has proven valuable in enriching our understanding of the life-world of these individuals. Continued research in this area is necessary to expand our existing knowledge of the implications of this form of technological treatment on the individuals and families who experience it and those who provide it.
2 Of benefit, would be research focused on exploring the implications of other forms of technological medical treatment on the life-world of the recipients to further illuminate our understanding of the process of embodied transformations across medical treatments.

3 Future initiatives could include a longitudinal phenomenological study focused on exploring the lived-experience of people receiving home-haemodialysis over time. This research would aid in providing a deeper understanding of the process and long-term implications of embodied transformations.

4 Future research might also include a multi-method study such as an Ethnosurvey (Singleton & Straits, 1999) to allow for the generalizability of results.

5 Once a substantial inventory of research is available across dialysis treatment settings (in-hospital and in-home dialysis), comparative research could be conducted.

6 Given that in an exploratory study such as this, it is initially useful to start with a homogenous sample in social terms to explore the range and meanings with a similar population, the second phase of research however, might incorporate issues of diversity.
Implications for Social Work

This study generated a number of implications for the field of social work and renal social work practice.

Implications for renal social work practice would include ensuring that the same consideration to health and safety within the hospital be standardized within the home setting. Given that this study highlighted instances of unsafe practices, there is a need to develop a mechanism which monitors health and safety protocols within the home. In light of this finding, a review of the health and safety standards for home hemodialysis is called for.

The implications of this study go far beyond developing practices and policies specific to home-hemodialysis. In the wake of both federal and provincial government funding cutbacks to subsidized housing, the development of housing initiatives has halted. At the same time, medical treatment and care within the home is ever increasing. For home dialysis a home is integral to treatment. Therefore there is a need for renal, and all, social workers alike to advocate for increased funding to housing initiatives, and for their clients to access subsidized housing.

Phenomenological research is beneficial to the field of social work as it helps to illuminate the complexity of the human condition. In particular, in an increasingly globalized world which generates multifaceted and subtle environmental, societal and personal transformations, a sensitive methodology, like phenomenology, is well situated to detect the nuances in our ever-changing life-world. Other methodologies may be helpful once nuances have been understood phenomenologically. Phenomenology, however, will aid in the detection of changes as experienced in the life-world of people in ways other methodologies can not. In this way, phenomenology, embodiment, and by extension — the body, can be said to be the final...
resting places of all social developments. As such, a shift to seeing the body as a valid starting point for social work research has been highlighted by this study.

**Limitations of the study**

The limitations of this study must be understood from within the context of phenomenology. As such, the goals of phenomenology are to describe and interpret the phenomena of the life-world. The way to increase the understanding of the participant's life-world would have been to increase the time spent with them. While a two-hour interview is in-depth, more time could have been spent with them. Along this line, a more in-depth case study of one individual's experience, as opposed to a cursory understanding of four individuals, may have provided more richness.

Further, employing the method of ethnography could have been beneficial. This method incorporates a wider inclusion of data, such as participant observation of routine activities, and also photographs, poems, artwork, and journals from the participants. Moreover, additional people could have been interviewed such as friends, family members, and even other members of the healthcare teams.
References

Abrams, Harry, S (1975) Psychiatry and Medical Progress Therapeutic Considerations International Journal of Psychiatry in Medicine 6(1-2) 203-211


Bevan, Mark, Thomas (2000) Dialysis as 'deus ex machina' A critical analysis of haemodialysis Journal of Advanced Nursing. 31(2) 437-443, February


Boyle, Theresa (2000, October 17) $22 Million will fight kidney disease The Globe and Mail. (On line www.globemail.com)

Brackney, B, E (1979) The impact of home hemodialysis on the marital dyad Journal of Marital and Family Therapy. 5(1) 55-60


Grany, C, L, & Fodor, I, G (1986) Adolescent attitudes toward body image and anorexic behavior Adolescence. 21(82), 269-81


Heidegger, Martin (1953/1977) The question concerning technology In David J Glenn Gray & Joan Stambough (Eds), Martin Heidegger Basic Writings, San Francisco Harper


Kornfeld, M (1997) Integrating spirituality and psychotherapy What can happen when we stop our turf wars over mind, body and spirit American Journal of Pastoral Counseling, 1(1) 75-86


Luborsky, L , & McLellan, A T (1980-81) A sound mind in a sound body To what extent do they go together before and after psychotherapy International Journal of Psychiatry in Medicine, 10(2) 123-33

Mathews, D , E (1978) Beyond survival Preliminary report of rehabilitation of patients on dialysis or after transplantation Perspectives, 2(2) 67-78, 1978


_________ (1984) Integration of medical and psychosocial needs of the home hemodialysis patient. Implications for the nephrology social worker. Social Work in Health Care. (9)4 Summer 33-44

_________ (1985) Psychosocial adjustment of the family caregiver. Home hemodialysis as an example. Social Work in Health Care. (10)3 Spring 15-32


Wellard, Sally & Street, Annette (1999) Family issues in home-based care
International Journal of Nursing (5), 132-136

Evaluation of compliance in home and center hemodialysis patients Health Psychology.
Summer, Vol 2(3) 227-337

Wright, Stephen & Angela Kirby (1999) Deconstructing conceptualizations of
'adjustment' to chronic illness A proposed integrative framework Journal of Health
Psychology Apr, Vol 4(2) 259-272

Zaner, Richard, M (1990) Medicine and dialogue The Journal of Medicine and
Philosophy 15, 303-325
Appendix A

Introduction to Research Study Procedures

A study of the lived-experience of people who receive home hemodialysis is being conducted by
the following researcher

Stephen Giles, M S W (Candidate), Faculty of Social Work: University of Toronto

The major purpose of this study is to explore the lived-experience of people who use a
home haemodialysis machine. Through your participation I hope to understand what it is like for
you to live with a home-haemodialysis machine. You are being invited to participate in one
unstructured interview, and a follow-up interview at places and times which are convenient to
you. This will not take more than two hours of your time for each meeting.

The information collected will be analyzed to improve understanding of the lived-experience for
people like yourself who receive home haemodialysis. It is my hope that the information and
analysis will benefit the development of health care policy, and service provisions for people
who receive home haemodialysis.

During the interview, you will be invited to share specific episodes or events in your life in
which you experienced the phenomenon we are investigating. I am seeking vivid, accurate, and
comprehensive portrayals of what these experiences were like for you, your thoughts, feelings,
and behaviors, as well as situations, events, places, and people connected with your experience.

Your participation in this study is strictly voluntary. You can refuse to answer any question you
do not feel comfortable with. You can also choose to stop participating in the interview at any
point. Whereas the interview will be audio-taped with your permission, you can request the
recording to be stopped at any point during the interview. You also have the right to withdraw
your consent at any time, and all information related to you will be erased and removed from the
study.

All personal information collected will be kept confidential. The audio-tape and transcripts, and
other material will be kept in a safe place, and will only be accessible to the researcher. All
specific information identifying you personally will be removed from transcripts and will not
appear in the graduating M S W thesis or any other future publication. I value your participation
and thank you for the commitment of time, energy, and effort.

Sincerely,
Stephen Giles M S W (Candidate)
Faculty of Social Work
University of Toronto
Appendix B

Research Consent Form

Project Title: The Lived-Experience of People Who Receive Home Haemodialysis

Investigator:
Stephen Giles, M S W (Candidate), Faculty of Social Work, University of Toronto

It has been explained to me by _____________ that a study exploring the lived-experience of people who use home haemodialysis machines is being conducted. The aim of the study is to explore the lived-experience for people who are currently being trained for, or are using home haemodialysis machines in the treatment of end stage renal disease.

My participation in the study will involve attending a research interview. I understand that each interview will not take more than two hours of my time. I understand that these interviews are to be audio-taped and transcribed, and this information is only accessible to the investigator. I can also request that tape-recording be stopped at any time during the interview. I understand that all information that personally identifies me will be removed from the transcripts, and that all information I give will be kept completely confidential. I understand that my participation in this research is voluntary. I can refuse to answer any question that I do not feel comfortable with, and I can withdraw from the study at any time without any consequence. I understand that if, at any time, I have any questions about the research procedures, I may contact Stephen Giles at 416-964-6003.

My signature indicates my agreement and consent to be involved in this research as described above.

_________________________  __________________________
Your Signature                  Witness

Name (Please Print)_________________________  Name  Stephen Giles

Date ___________________________  Date ___________________________
Appendix C
Interview Guide

Part I  Identifying Information

Date
Participant Name
Length of time in training, or on dialysis

Part II  Experiences Across Four Themes: On and Off of Dialysis

1) Time:

A) Can you tell me about your experience of time when you are receiving dialysis?
Prompt: Does it slow down or speed up? Do you feel hurried? Does time drag or race? Are you waiting for anything to happen? What are you able to do or not do because of the time spent on dialysis? (shopping, cooking, cleaning, working, childcare, parenting etc)
Probe Can you tell me more about that?

B) Can you tell me about your experience of time when you are not receiving dialysis?
Prompt: Does it slow down or speed up? Do you feel hurried? Does time drag or race? Are you waiting for anything to happen? What are you able to do or not do because of the time spent on dialysis? (shopping, cooking, cleaning, working, childcare, parenting etc)
Probe Can you tell me more about that?

2) Space:

A) Can you tell me about your experience of space (the room you are in, or not in; The rest of the house/apt/hospital/neighborhood/shopping) when you are receiving dialysis?

Prompt: Are things easy to grasp such as a drink, phone or supplies? Do you have to arrange the room in a certain way?
Probe: What happens when you can't reach something? How far or close are you to the machine? Are you able to go out to park, walk dog, shopping?

B) Can you tell me about your experience of space (the room you are in, or not in; the rest of the house/apartment/hospital etc) when you are not receiving dialysis?

Prompt: Are things easy to grasp such as a drink, phone or supplies? Do you have to arrange the room in a certain way?
Probe: What happens when you can't reach something? How far or close are you to the machine? Are you able to go out to park, walk dog, shopping?
3) Self/Others:

A) Can you tell me about your experience of other people and your relations with them when you are receiving dialysis?

Prompt: Do you see/or talk to friends/neighbors, family members? How about pets are you able to care for them go for walks feed them etc? What about professionals such as healthcare team--do you communicate with them?
Probe: Do you want to communicate or connect with other people during this time? What makes any of this difficult or easy? Are you able to develop new relations with others? Can you tell me more about that?

B) Can you tell me about your experience of other people and your relations with them when you are not receiving dialysis?

Prompt: Do you see/or talk to friends/neighbors, family members? How about pets, are you able to care for them go for walks feed them etc? What about professionals such as healthcare team, do you communicate with them?
Probe: Do you want to communicate or connect with other people during this time? What makes any of this difficult or easy? Are you able to develop new relations with others? Can you tell me more about that?

4) Body:

A) Can you tell me about your experience of your body when you are receiving dialysis?

Prompt: What does it feel like? Are you aware of any sensations, where are they located?
Probe: Can you tell me more about that? Can you do new things with your body such as bend or feel in new ways? Is it more difficult to bend or maybe tie you shoes or cook or carry things such as groceries, clothes, pets, or children? Does your body feel transformed, or re-formed by this machine? In which ways? Are you aware of any struggles your body is having? Can you tell me more about that?

B) Can you tell me about your experience of your body when you are not receiving dialysis?

Prompt: What does it feel like, are you aware of any sensations, where are they located?
Probe: Can you tell me more about that. Can your do new things with your body such as bend or feel in new ways. Or is it more difficult to bend or maybe tie you shoes or cook or carry things such as groceries, clothes, pets, or children Does your body feel transformed, or re-formed by this machine? In which ways? Are you aware of any struggles your body is having? Can you tell me more about that?
Part III  Experiences Since You Have Been in The Program

1) Time:
Since you have been in the program, what changes in your experience of time are you aware of, if any?

Prompt  Think of time as we talked about earlier in this interview.

2) Space
Since you have been in the program, what changes in your experience of your environment, are you aware of, if any?

Prompt: Think of your environment as we talked about earlier in this interview

3) Body:
Since you have been in the program, what changes in your experience of your body, are you aware of, if any?

Prompt  Think of your body as we talked about earlier in this interview.

4) Others/Self:
Since you have been in the program, what changes in your experiences of yourself and others, are you aware of, if any?

Prompt  Think of relations as we talked about earlier in this interview.

Part IV  Closing

1) Is there any thing more about your experience, which I may have missed, that you feel is important and would like to share?

2) If there was a message you could give to people who never have experienced home haemodialysis, what would it be? What would be important for them to know?

2) TURN OFF TAPE RECORDER
3) DEBRIEFING
Thank-you for participating, how was the interview for you?
If participant would like to debrief later, the interviewer will set a time and place where this can be done