THE EXPERIENCE OF HEALTH IN CHRONIC ILLNESS:
THE PERSPECTIVES OF ADULTS DIAGNOSED
WITH END-STAGE RENAL DISEASE DURING ADOLESCENCE

by

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Abstract

The purpose of this study was to investigate the experience of health in chronic illness from the perspectives of adults diagnosed with end-stage renal disease (ESRD) during adolescence. Grounded theory methodology was used to guide this qualitative study. Data was collected in two interviews from eight young adults who were diagnosed with ESRD during adolescence. Interviews were audiotaped and transcribed for analysis using the constant comparative method. Five themes emerged from the data and included: the diagnosis in adolescence, having a sense of control over ESRD, facilitators of control, threats to control, and descriptions of the concept "health". The findings were developed into a grounded theory. The experience of health involves the fluctuating state of perceived control and perceived loss of control over the disease as individuals are faced with both facilitators and threats to control.

When individuals are diagnosed with ESRD during adolescence, they initially perceive having no control over the disease because others assume control, they are unable to do things that are important, and they feel the disease sets them apart from their peers. This lack of control and their desire for independence and to be like their normal peers, results in the adolescent with ESRD attempting to take control. Having a sense of control over ESRD becomes the preferred way of being throughout adolescence and into adulthood. When individuals are able to have a sense of control over the disease they are able to experience a sense of health which allows them to do what they want, have the abilities of a normal person, and not focus on the disease. The theory raises issues regarding the fluctuating nature of the experience of health, the implications of the diagnosis of a chronic illness in adolescence, and the concept of perceived control as a balance between being controlled by the disease and controlling the disease by not attending to its physiological needs. These issues were discussed in relation to current literature regarding the diagnosis of chronic illness in adolescence, issues of compliance, and models of chronic illness.
# TABLE OF CONTENTS

## ABSTRACT

## TABLE OF CONTENTS

## LIST OF TABLES

## LIST OF FIGURES

## ACKNOWLEDGMENTS

## CHAPTER ONE: INTRODUCTION

**Introduction** 01

**End-Stage Renal Disease** 02

- **Hemodialysis** 02
- **Peritoneal Dialysis** 03
- **Renal Transplantation** 04

**Personal Background** 04

**Purpose of the Study** 07

**Research Questions** 07

**Definition of Terms** 08

**Assumptions** 08

**Theoretical Framework** 09

**Significance of the Study** 12

**Summary and Outline of Subsequent Chapters** 13
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>15</td>
</tr>
<tr>
<td>Defining Health</td>
<td>16</td>
</tr>
<tr>
<td>Factors that Can Influence the Experience of Health in Chronic Illness</td>
<td>19</td>
</tr>
<tr>
<td>Health and Illness in Adolescence</td>
<td>20</td>
</tr>
<tr>
<td>Diagnosis of a Chronic Illness</td>
<td>22</td>
</tr>
<tr>
<td>Implications of Chronic Illness</td>
<td>26</td>
</tr>
<tr>
<td>Physical Implications of Chronic Illness</td>
<td>27</td>
</tr>
<tr>
<td>Physical Implications of End-Stage Renal Disease</td>
<td>27</td>
</tr>
<tr>
<td>Physical Implications of Renal Transplantation</td>
<td>30</td>
</tr>
<tr>
<td>Psychosocial Implications of Chronic Illness</td>
<td>31</td>
</tr>
<tr>
<td>Psychosocial Implications of End-Stage Renal Disease</td>
<td>34</td>
</tr>
<tr>
<td>Psychosocial Implications of Renal Transplantation</td>
<td>36</td>
</tr>
<tr>
<td>Functional Implications of Chronic Illness</td>
<td>39</td>
</tr>
<tr>
<td>Functional Implications of End-Stage Renal Disease</td>
<td>40</td>
</tr>
<tr>
<td>Functional Implications of Renal Transplantation</td>
<td>41</td>
</tr>
<tr>
<td>Long-term Implications of Chronic Illness</td>
<td>42</td>
</tr>
<tr>
<td>Long-term Implications of End-Stage Renal Disease</td>
<td>42</td>
</tr>
<tr>
<td>Long-term Implications of Renal Transplantation</td>
<td>43</td>
</tr>
<tr>
<td>Comparison of Long-term Adolescent and Adult Transplant Recipients</td>
<td>45</td>
</tr>
<tr>
<td>Future Long-term Impact of End-Stage Renal Disease and Renal Transplantation</td>
<td>48</td>
</tr>
<tr>
<td>Personal Meaning of Health and Illness in Chronic Illness</td>
<td>49</td>
</tr>
<tr>
<td>Negative Meaning</td>
<td>50</td>
</tr>
<tr>
<td>Positive Meaning</td>
<td>50</td>
</tr>
</tbody>
</table>
CHAPTER FOUR: PRESENTATION OF THE FINDINGS

Introduction 89
Description of the Sample 89
Introduction to the Participants 92
    “Alex” 92
    “Ben” 93
    “Jeff” 94
    “John” 95
    “Josiah” 96
    “Mary” 97
    “Maureen” 98
    “Natalie” 99
Major Themes 100
    Diagnosis in Adolescence 100
        Others Take Control 100
        Desire to be as Normal as Peers 102
        Inability to Do or Achieve What One Wants 103
        Incorporating ESRD in Life and Self Concept 105
    Having a Sense of Control over ESRD 106
        Controlling the Disease Rather Than Being Controlled by It 107
APPENDICES

Appendix A - Participant Information Letter 194
Appendix B - Recruitment Poster 196
Appendix C - Participant Consent Form 197
Appendix D - Demographic Form 199
Appendix E - Interview Guide 201
List of Tables

Table 1. Renal History of Participants 90

Table 2. Demographic Information of Participants 91
List of Figures

Figure 1. The Experience of Health: Perceived Control over ESRD 150
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CHAPTER ONE: INTRODUCTION

The Canadian Organ Replacement Registry (CORR) (1999) indicates that in Canada the number of infant, children and young adolescents, aged 0 to 14, beginning treatment for end-stage renal disease (ESRD) in 1997 was 33, and the number of older adolescent, young and middle aged adults was 634. Between the years 1981 and 1997, 741 infant, children and young adolescents, and 9513 older adolescent, young and middle aged adults started treatment for their ESRD throughout the country. Possibly because of the age-related causes of ESRD, prevalence, and the size of an individual, CORR reports on data for the following age groups: 0 to 14, 15 to 44, 45 to 64, 65 to 74, and 75+. Much of the research that has focused on the effects of ESRD pertains to adults. Although the absolute number of adolescents being diagnosed with ESRD is far less than the number of adults, the long reaching impact of the diagnosis makes it an important issue to examine.

Because of medical, technological, and pharmacological advances in renal replacement therapy over the past two decades, adolescents diagnosed with ESRD are surviving to adulthood. Adolescence is an important stage of development in an individual. Physical maturation and concepts of self, appropriate socialization, sexuality, and independence begin to develop in adolescence (Edelman & Mandel, 1994). The presence of ESRD in adolescence can have an enormous effect on these developmental tasks which in turn can have far reaching affects into adulthood. Experiences with health and illness can impact a person’s decisions and sense of self, and may permeate through all aspects of his or her life. Little is known about how being diagnosed with ESRD, or any chronic illness, during adolescence affects how adults experience health in later life. It is important for health care professionals to be aware of how individuals’ experience health so that they may be more effective in their interactions with those who have a chronic illness.
The literature available on adolescents with a chronic illness has focused primarily on the following: how adolescents' cognitive development effects their understanding of illness and why they do not always comply with their treatment (Gallo, Schultz & Breitmayer, 1992), their psychosocial and functional adjustment to the illness (Bywater, 1981; Lawry, Brouhard & Cunningham, 1994; Shaben, 1993), and morbidity and mortality indicators (Chantler, Carter, Bewick et al., 1980; Offner, Aschendorff, Hoyer et al., 1988). According to researchers, developing a chronic illness during adolescence is often viewed by the adolescent as complex and overwhelming (Allen, 1984), requiring emotional and psychological adjustments to the physical aspects of the illness. A number of factors may influence individuals' experiences with health and how they react to a chronic illness. Factors can include their developmental stage, experiences with health care professionals, personality, life situation, hardiness, and the attitude of family and friends (Davidhizar, 1997).

**End-Stage Renal Disease**

End stage renal disease is "irreversible kidney disease causing chronic abnormalities in the internal environment and necessitating treatment with dialysis or renal transplantation for survival" (Lancaster, 1995, p.76). End-stage renal disease occurs when the kidneys function at a level less than 10% of their normal rate (Kidney Foundation of Canada, 1990) and results in an accumulation of wastes, fluids, electrolytes, and aberrant levels of certain biochemicals such as erythropoietin, parathyroid hormone, and growth hormones (Lancaster, 1995). There is no cure for ESRD, but it is possible for some individuals to live with ESRD for a number of years through hemodialysis, peritoneal dialysis, and renal transplantation.

**Hemodialysis**

Hemodialysis is a process where blood and dialysate fluid flow by each other separated by a semipermeable membrane (Daugirdas & Ing, 1994). An access to
adequate blood flow is needed to allow the most efficient exchange. This usually involves the surgical creation of a fistula or placement of a graft which diverts blood from an artery to a vein, thereby increasing the blood flow in the vessel. Another common access is a catheter placed in one of the large vessels. During the dialysis treatment, small solutes molecules such as wastes and electrolytes are removed by diffusion moving from high concentration (blood) to low concentration (dialysate). The transmembrane hydrostatic pressure that is created between the blood and the dialysate compartment removes fluid from the blood. Because of advance technology and the medical care associated with hemodialysis, people usually have their treatments in a medical facility, most often a hospital. Treatments usually take place three times a week for four hours, at which time the person is confined to a chair or bed limiting freedom of movement.

**Peritoneal Dialysis**

Peritoneal dialysis involves the instillation of an aqueous dextrose containing salt solution into the peritoneal cavity through a catheter in the abdomen. Wastes, excess fluid, and solutes in the blood pass through the membranes of the visceral organs into the solution in the peritoneal cavity and are then removed when the solution is drained from the cavity (Daugirdas & Ing, 1994). Conversely, electrolytes that are deficient in the blood stream pass from the dialysis solution into the capillaries. Exchange of waste, solutes and electrolytes is driven by diffusion, moving from high to low concentration. The osmotic difference between the blood and the dialysis solution removes excess fluid. Peritoneal dialysis allows more freedom and most people are able to perform peritoneal dialysis in their homes, at school or work. Peritoneal dialysis can be performed continuously (CAPD) usually involving four to five exchanges a day which allows the person freedom while the solution sits in the peritoneal cavity for four to six hours at a time. Another common method is the
continuous cycler-assisted peritoneal dialysis (CCPD) which involves three to eight exchanges throughout the evening while the person sleeps and involves the use of a cycler which instills and drains the fluid automatically. One other method is intermittent peritoneal dialysis (IPD) which takes place in the hospital usually three days a week and usually involves 12 exchanges per treatment. This method is commonly used while people undergo training for home peritoneal dialysis.

Renal Transplantation

The most ideal treatment for ESRD is renal transplantation (Bereket & Fine, 1995; Evans, Greenbaum, & Ettenger, 1995). Kidney transplantation requires the surgical removal of a kidney from either a living or cadaveric donor and placing it in the lower abdomen of the recipient. Immunosuppressive therapy is then needed to prevent the body from rejecting the foreign organ. A successful transplant can allow an individual freedom from dialysis treatments and is currently the closest treatment to a cure.

Personal Background

My reasons for studying this topic were in part attributed to my personal story. As a child, I was very actively involved in swimming, gymnastics, school sports and figure skating. I did well in school and had many friends. In 1978 when I was 12 years old, I was diagnosed with Henoch-Schonlein Purpura, an auto immune disease for which the cause is unknown. I suffered from joint pain, a red burning rash on my legs, severe stomach pain, and impaired kidney function. For a number of months, I spent every third Friday in the hospital receiving chemotherapy in an attempt to halt the syndrome. However, one day while I was on the court in a volleyball game, my parents came to the school, took me into the locker room and told me I had kidney failure. I was taken to the hospital to have a tube placed in my abdomen to keep me alive on peritoneal dialysis until I could be put on a kidney machine to undergo
hemodialysis. Apparently I had been told that was a possibility if the chemotherapy did not work, but I do not remember that. For the next several months, my mom drove me to the hospital for 6:00am appointments three times a week, where I underwent peritoneal dialysis treatments lasting 12 to 18 hours. It was very late when I got home. I would go to school the next day where I continued to do well in school, spend time with my friends, and take part in noon-hour floor-hockey games. My parents always encouraged me to make the best of my life and we decided early on to treat my illness with humor and a positive outlook. When I remember those long days at the hospital having peritoneal dialysis, I have fond memories of my dad painting pictures on the hospital walls, and my stuffed Grover sitting in a child's wheelchair stuck with a peritoneal dialysis set up and an IV.

The nurses were great. I felt they treated me like a "normal kid" and gave me responsibilities on the unit. They would bring my Mother and me the fussy babies to rock in our arms. Later that year, a fistula was created so that I could go on hemodialysis. At the time, "going on a machine" conjured images of living IN a machine for the rest of my life. The nurses and my family encouraged me to take an active part in my treatments and it was not long before I was putting in my own needles and monitoring the machine. I often did my homework while connected to the machine. On my non-dialysis days, life went on as normally as possible. My family made many sacrifices in order to maintain some normalcy. We all gave up salt and planned our activities around dialysis. I do not ever remember feeling left out or different because of my illness. I was always encouraged to do what I wanted, and I still had my responsibilities around the house. I continued with my sports activities and practiced figure-skating a couple mornings a week. Everyone in my life, coaches, teachers, friends, family, and health care professionals, encouraged me to be all that I could be and to not let the illness rule me. Later that year, my Mother donated a
kidney to me.

The freedom from dialysis was wonderful. However, life was not all "roses." I took several pills a day and experienced some dreadful side effects from the immunosuppressive drugs, including a moon face, increased hair growth, increased bruising, and mood swings. When I was 14 years old, while my friends were worrying about blemishes on their faces and what they would do that weekend, I was worrying about my moon face and kidney rejection. Once I became accustomed to my new look, the pills and the occasional bout with rejection, life settled into a normal pattern. I skated, finished high school, and completed a degree in science. After several bouts with rejection the kidney eventually failed ten years later. I was in Australia where I had been working and travelling for the past year. At that time, I was 23 years old.

I received a cadaveric kidney two months after my first kidney failed. With that kidney I had problems from the beginning, but it held on for seven years. During those years I completed a degree in nursing and spent four months on my own travelling in Southeast Asia. For the past five and a half years, I have been back on hemodialysis. Besides dialyzing 15 hours per week, I am completing a Master's degree in Nursing, volunteering at an Aquarium, doing contract work in nursing and health care research, and sitting on a number of committees. I love to cook, travel, kayak, sail, SCUBA dive, swim, and spend time with my friends, family and pets. I have more good days than bad, and I always try to remain positive.

I tell this story because I hope it helps to show the reader why I wanted to do this study. My experience with kidney failure has shown me to live life to its fullest, to laugh at the little things and even the big things. I do not consider myself ill, but as having a condition that is part of me. It does not define me, but it has helped to shape the person that I am today. I do not let my disease rule my life, I see myself as healthy in spite of a chronic condition.
I see a similar outlook in some of the other renal patients who were diagnosed in adolescence, but unfortunately this does not seem to be true for all people who developed kidney disease at a young age. Many of the people I have come across over the years who were diagnosed with ESRD as children or adolescents, seem to approach life very differently than I have. Many of them do not work, do not travel, have few meaningful relationships, have not pursued an education, and express bitterness and anger about the disease. Although many factors influence someone's experience with health and illness, I believe that when a person has a chronic illness, the experiences and attitudes encountered around the illness must have an effect on how health is experienced.

**Purpose of the Study**

The purpose of this study is to answer some of the questions the investigator has had over the years and address what is lacking in the literature; that is, what is the experience of health in chronic illness from the perspectives of adults who were diagnosed with ESRD as adolescents? It is important to understand how adolescents with chronic illness experience health and how these experiences develop or change as they become adults. The studies that have been conducted on the experience of health and illness in adolescents with ESRD suggest that adolescents experience health and normalcy in spite of a chronic illness. However, how the experience of health changes over time after living with the diagnosis for many years, is not known. We do not know at present, for example, if people's experiences living with kidney disease through their formative years affects how they experience health as an adult.

**Research Questions**

This study set out to answer the following research questions:

1) What is the experience of health in chronic illness from the perspectives of young adults diagnosed with ESRD during adolescence?
2) How do these experiences develop or change over time?

**Definition of Terms Used in this Study**

END-STAGE RENAL DISEASE: A significant impairment in kidney function that results in the person's need for peritoneal dialysis, hemodialysis or a kidney transplant to sustain life.

HEALTH: This term will be defined by the participants.

ADOLESCENT: The term adolescent will be used to describe those aged 12 to 16.

YOUNG ADULTS: The term young adult will be used to describe those aged 20 to 35.

**Assumptions**

As a nurse, and especially a person diagnosed with ESRD as an adolescent, the investigator had a number of assumptions which were important to identify and consider. Personal values, beliefs, and experiences with health and illness had a great impact on how the literature was reviewed, the methodology chosen, how questions were developed and asked, and how responses were interpreted. It was important to identify these assumptions at the onset so that the investigator would be aware of the possibility of their influence and to reflect on how they impacted the study. Furthermore, the reader needs to know these assumptions so that they may have some insight into the choices and interpretations made by the investigator throughout this study. Some of the assumptions identified include:

1) It is possible to have a fulfilling and productive life with a chronic illness,

2) A person's experience with a chronic illness and health care can influence how a person experiences health,

3) It is possible to facilitate a positive attitude toward illness and health in a person with a chronic illness,

4) There are differences in the experiences of adolescents and adults who are diagnosed with a chronic illness that affect the way they experience health and
illness,

5) The messages that people receive from others impact on their social identity.

Theoretical Framework

Individuals living with a chronic illness, such as kidney disease, have much experience dealing with issues related to health and illness. It is the investigator's belief that individuals learn and make sense about their experience with chronic illness through their interactions with others and the objects in their world. The philosophical perspective of symbolic interactionism is consistent with the investigator's view about how people develop and attribute meaning to their experiences, and therefore, was chosen as the theoretical framework to guide this study.

Symbolic interactionism is a social-psychological theory that has the following three basic premises: 1) people act towards objects in their worlds on the basis of the meaning they attribute to them, 2) the meaning ascribed to an object arises from the social interaction one has with it, 3) the meaning one places on an object and the way she or he respond to the object is an interpretive process (Blumer, 1969). The major concepts of symbolic interactionism include: self, world, and interactions.

In the symbolic interactionist perspective "self" is considered an object. The self in symbolic interactionism is reflective and ever-evolving, and is socially constructed through interaction with the world. People act towards themselves and guide their actions towards others based on the type of object that they see themselves as, which is influenced by the way others define and see them (Blumer, 1969).

The world is composed of objects. Blumer (1969) suggests that an object can be anything that can be indicated or referred to and may be physical, social, or abstract. For a person who has experience with ESRD, objects may be related specifically to the disease, or to daily life experiences. The following outlines some of
the objects that may be present in the world of a person with ESRD. Physical objects may include such things as dialysis machines, a transplanted kidney, a tree, or a house. Social objects may include other people with ESRD, the hospital community, family, or a church congregation. Abstract objects may include beliefs related to health, independence, morality, or philosophical doctrines. The individual endows these objects with symbolic meaning. The actions directed at these objects is reflective of the meaning ascribed to them by the individual, which is determined by the interaction that takes place with that object at that time (Blumer, 1969). For example, a person with kidney disease may attribute the meaning of emotional support to his or her church congregation at a time of an acute exacerbation of the disease. Whereas, on another occasion, the church congregation may be ascribed with the meaning of a place to meet new people.

Interaction in the symbolic interactionist perspective involves the interpretive process that occurs when a person first conveys to himself or herself the object toward which her or he is acting or reacting (Blumer, 1969). The person must then communicate with his or her self about the object. The interaction that takes place involves interpreting the object, the circumstances in which it is encountered, and past encounters with the object. Meaning is then attributed to the object in the specific circumstance. As previously noted, people may encounter the same or similar objects on a daily basis, however, in each encounter the meaning of the object must be formed, and depending on the interaction, the meaning may be very different in different circumstances. In symbolic interactionism, an individual's subjective reality and the meaning ascribed to objects is not static, rather reality and meaning are continually being revised, evolved, or suspended, varying with time, context, and the interpretive process (Blumer, 1969). As individuals interact with objects in their world, they shape and are shaped by these objects and the interactions with them.
Symbolic interactionism is consistent with the qualitative method of grounded theory that was chosen to answer the research questions posed. The symbolic interactionist underpinnings of grounded theory (Hutchinson, 1993) are congruent with examining how adults diagnosed with ESRD as adolescents experience health after living for several years with the illness. In grounded theory, the interaction is the focus of the examination (Hutchinson, 1993). The actions of individuals diagnosed with ESRD can best be understood by examining their social interactions within the context of their experience. Therefore, how people with kidney disease perceive and interact with objects in their world to experience health is the focus of this grounded theory study.

An adult diagnosed with ESRD as an adolescent will encounter a number of physical, social, and abstract objects in their world, with which they will interact. Through the interaction, the individual will develop meaning which is attributed to that object at that time. How these adults experience health is developed through the interaction with others in the symbolic environment of being diagnosed with ESRD. Using grounded theory methods, it is possible to learn from the experience of adults diagnosed with ESRD during adolescence through the way they constructed accounts of their interactions with their social world. Through systematic examination of these constructed interactions, it is possible to develop an understanding and pose a theory of how health is experienced by these individuals.

The symbolic interactionist approach enhances interpretation of adults' experiences of health who were diagnosed with ESRD during adolescence. Improved understanding of these experiences and the theory developed from this study will assist nurses and other health care professionals to plan and deliver health care which adapts to the experiences of health in this group of people.
Significance of the Study

Chronic illness in adolescence can be both a traumatic time and a time for great growth and development of life long skills. The experiences and how others treat the individual can profoundly impact the formation of who the person becomes as an adult. Other personality factors and experiences greatly shape the adult that the adolescent will become, however, experiences with health, illness, and health care will further shape how an individual will experience health in future years. Indirectly or directly, these experiences may also help shape the adult they become, the choices they make, and the way they deal with life's unexpected mysteries.

This study intends to contribute to the knowledge of the effects of the onset of a chronic illness, ESRD, in adolescence and how experiences around the chronic illness shape future experiences of health. Adolescents faced with a diagnosis of ESRD will come in contact with health care professionals in a variety of settings over time. They will likely require numerous hospital admissions, frequent dialysis treatments, dialysis clinic appointments, and if fortunate, frequent post transplant clinic visits throughout their entire life. This study will provide nurses and other health care professionals with insight into how adults experience health after living for several years with a diagnosis of chronic kidney failure. Furthermore, it will provide health care professionals insights into some of the issues of which to be aware when an adolescent is diagnosed with ESRD.

Reflecting upon her experiences as an adolescent diagnosed with a chronic illness, the investigator can identify specific experiences that impacted on her experiences of health. It is important that health care professionals are aware of how specific situations may influence how a person experiences health during a chronic illness and how health is experienced may influence the person's present and future health and related behaviour. These insights may help enhance the sensitivity of
health care professionals in their interactions with adolescents and adults with a chronic illness. Also, it is hoped that this study will contribute to the knowledge of how experiences with health develop or change over time, specifically as the adolescent matures and is faced with adult challenges and responsibilities.

**Summary and Outline of Subsequent Chapters**

This chapter began with an introduction to the study and the Canadian statistics regarding the prevalence of children and young adolescents diagnosed with ESRD over the past 16 years. The physiological implications of ESRD along with the treatment options available to sustain life were presented. A narrative of the personal story of the investigator's experience of living with ESRD through much of adolescence and young adulthood was introduced. The investigator's experiences with kidney disease, the observations of others with kidney disease, and the limited literature available on this phenomenon provide the essence of the background to the study. The purpose of the study and the two research questions formulated to better understand the experience of health in this population were identified. The definition of terms set out helped to limit the study and set boundaries for participant selection. The predominant assumptions held by the investigator prior to conducting the study were outlined. This will help the reader understand the method used to set up, conduct and interpret the study. The assumptions also helped the investigator to be more reflective and critical in her approach to a subject in which she was personally immersed. The theoretical framework of symbolic interactionism chosen to guide the study was outlined. The chapter concluded with an outline of the significance of this study in giving health care professionals insight into the experiences of health in adults who were diagnosed with ESRD as an adolescent. It is hoped that health care professionals will use this information in their interactions with adolescents with ESRD to help them find ways to cope with the illness and to develop positive lifelong skills.
Chapter two will provide a review of the literature relevant to the study and will include sections on defining health, factors that may influence the experience of health, health and illness in adolescence, diagnosis and implications of a chronic illness, long-term effects of chronic illness, and the personal meaning of health and illness in those with a chronic illness. In chapter three, the grounded theory methods will be outlined along with supporting rationale. The chapter will include a discussion of the study design, participant selection and recruitment, data collection, data analysis, ethical considerations, strategies to maintain rigor, and proposed limitations of the study. Chapter four will present the research findings of the analysis of the participants' stories. Chapter five will provide a description of the theory, a discussion of the significant issues and their relation to current literature. The final chapter will discuss the implications of this study for health care practice, education, and research. The chapter will conclude with a summary of the study and the conclusions.
CHAPTER TWO: LITERATURE REVIEW

Adolescents diagnosed with End Stage Renal Disease (ESRD) prior to the 1970's had a very bleak future because there were neither reliable methods of dialysis for small-sized individuals nor hope for a successful transplant (Chantler et al., 1980; Shaben, 1993). With advances in medical pharmacology and technology, this has changed so that today, adolescents diagnosed with renal failure are surviving into adulthood.

Possibly as a reflection of the early emphasis on survival, the literature regarding long-term outcomes in adolescents diagnosed with ESRD includes a number of studies that have focused on mortality and morbidity (Öffner et al., 1988; Chantler et al., 1980; Henning, Tomlinson, Rigden, Haycock & Chantler, 1988). There has been very little investigation about living with renal failure over time or how being diagnosed at an early age affects individuals' experiences with health in adulthood. Researchers have tended to focus on psychosocial adjustment and adaptation to chronic illness and effective management of the disease. For this reason, literature selected for this chapter includes discussion papers and research articles that focus on: 1) definitions of health and illness, 2) the experience of chronic illness in adolescence and adulthood, 3) acceptance and adjustment to chronic illness, and 4) health in illness. It should be noted that there is a great deal of literature available about the general experience of adolescence and adulthood, and about health behaviour and illness management. However, since the focus of this study is the experience of health in chronic illness, the reviewed literature is limited specifically to the experiences of adolescents and adults with regard to health and illness. Much of the literature that is cited was published in the late 1970s or early 1980s. This dated research was considered as classic studies in the field. It should be acknowledged, however, that there have been substantial changes in the management of ESRD and
in transplantation since the 1970s and 1980s; therefore, the findings of these classic studies must be considered within the context of the stage of medical technology at the time.

This chapter begins with an exploration of the definitions of health in the literature and the limitations of these definitions for describing and measuring health. An overview of factors that may influence a person's experiences with health and illness is provided. The next section outlines the key developmental tasks of adolescence and the perspectives of adolescents with regard to health and illness. A definition of chronic illness is provided followed by a discussion of the impact of a diagnosis of chronic disease on an individual and his or her family. A number of long-term effects of chronic illness, particularly those related to ESRD and kidney transplantation are outlined. Based on the research reviewed, an overview of the physical, psychosocial and functional implication of chronic illness, ESRD, and transplantation is provided. A discussion of the research reviewed that provides insight into the personal meanings of health and illness in chronic illness is then presented. The chapter concludes with a brief overview of the findings and the arguments for conducting this study.

Defining Health

Authors have attempted to define and describe health for many years. Health has been described as "not only to be well, but to use well every power we have" (Nightingale, 1893/1954, p. 357), "a relatively passive state of freedom from illness...[and] a condition of relative homeostasis" (Dunn, 1959, p. 447), "an expression of the success or failure experienced by the organism in its efforts to respond adaptively to environmental changes" (Dubos, 1965, p. 17), and as "the actualization of inherent and acquired human potential through satisfying relationships with others while adjustments are made as needed to maintain structural integrity and harmony"
with the environment" (Pender, 1987, p. 27). Furthermore, various nurse theorists (King, 1990, 1993; Neuman, 1990; Orem, 1985; Parse, 1990; Peplau, 1952; Rogers, 1970) have proposed that nursing has a role in addressing people's needs in both health and illness.

Possibly the most quoted and enduring definition of health is that of the World Health Organization (WHO) which defines health as "a state of complete physical, mental and social wellbeing, not merely the absence of disease or infirmity" (1947, p. 1). Although widely accepted, it has received widespread criticism for being too abstract, simplistic, vague, and difficult to assess and measure (Edelman & Mandle, 1990). Furthermore, it reflects an ideal state which most people are unable to attain (Lindsey, 1993). The WHO has more recently revised its definition to reflect a more attainable and realistic goal. This new WHO definition (quoted in Lindsey, 1993, p. 19) moves away from a state to be achieved to a way of being, and states health is "the extent to which an individual or group is able, on the one hand, to realize aspirations and satisfy needs and, on the other hand, to change or cope with the environment" (WHO, 1984).

Lindsey (1993) argues that early conceptualizations of health were influenced by a reductionist perspective that tended to separate health into the distinctive parts of body, mind and spirit. She suggests that a more holistic perspective of health is emerging which involves the "inter-relatedness, integration, rhythmicity of mind, body and spirit" (1993, p. 24). By viewing health holistically, it is possible for an individual to experience health when living with a chronic illness. She states "a person can move toward an expansion of consciousness, self realization and self actualization, and thus, experience feeling health while being physically ill or disabled" (1993, p. 25).

The WHO definition has been adopted by a number of health care providers and policy makers. However, the definition still does not provide health care
researchers with measurable indicators. In an attempt to define and measure health, researchers and practitioners have used a number of health and illness indicators. These indicators include measurable variables, such as functional status, perceived health status, and physical/mental health states. Furthermore, researchers have used a variety of tools, such as depression tests (Rothbaum, Salas, & Heiss, 1992), the malaise inventory (Bywater, 1981), and traditional morbidity indicators (Taylor & Newacheck, 1992) that are primarily based on the assumption of absence of illness or health problems (Benedict, Lundeen, & Morr 1981; Lewis, Pantell, & Kieckhefer, 1989).

Health care professionals have tended to focus on illness and health indicators to assess a client's control of an illness, and often equate the control of illness with health. When illness or disease is present, health is often equated with control of pathology or control of the impact of illness. For example, for adolescents with ESRD, control of fluid gain, electrolyte balance, serum phosphorus and calcium levels are used as indicators of health status. Lindsey (1993) suggests that using illness indicators to assess a client's health places emphasis on illness while ignoring the client's feelings of health. Furthermore, these indicators do not address an individual's personal meaning of health and illness or how this meaning develops over time. Health and maintaining control of an illness involve the interplay of many factors. Assessing one's metabolic control in the case of diabetes, electrolyte balance in the case of kidney failure, or the severity of symptoms does not adequately capture what it means to the individual to have control over the disease or what it means to feel healthy.

Arthur Kleinman (1988) discusses the conflicting explanatory models of medical professionals and people with chronic illness. He describes an explanatory model as a notion, an informal description, and a response to an illness. Explanatory models
are not static but develop and change over time with experience. Physicians' explanatory models are largely influenced by education and training, and the methods used for reporting a patient's disease status tend to focus on diagnosing and treating a disease process (Kleinman). On the other hand, patients' explanatory models tend to focus on the illness, how it affects their day to day lives, relationships, and how they feel about themselves in relation to the illness (Kleinman). Kleinman argues that health care professionals need to understand the explanatory models of patients in order to effectively care for them. Failure to do so may signal "disrespect for clients, hubris in the face of alternative view points, and failure to regard psychosocial dimensions of care as relevant" (p. 122). Much of the literature available regarding chronic illness is from health care professionals' point of view, which is influenced by explanatory models. Little literature is available from the patients' point of view, a view influenced by a very different explanatory model.

People view health based on their explanatory models, which are influenced by their experiences. As no two people have exactly the same experiences, it is unlikely that all people will view or experience health the same. A comprehensive definition and description of health may remain elusive for many years and a definition and description of health that everyone can agree upon may never be achieved. The subjectivity of health is succinctly described by Freeman who suggests that "it [health] may mean different things to different people...and it can mean different things at different points in time" (1970, p. 4). To understand how health is experienced in the context of chronic illness and developmental transitions it is necessary to hear from individuals regarding what it means to them to experience health.

**Factors that Can Influence the Experience of Health in Chronic Illness**

There are a number of factors that may influence individuals' experiences with health when faced with a chronic illness. Factors related to the illness, such as age of
onset, severity, length and type of illness can influence its impact (Silver et al., 1990). The person's cultural beliefs regarding causes of illness can have a great influence on how health and illness is viewed (Leichtman & Friedman, 1975). Knowledge and acceptance of an illness can give individuals the information and motivation needed to make positive changes to better control its effects (Kintner, 1997, Paterson & Thorne, in press). Personality, coping skills, educational level, social class, and social support can influence the personal resources and skills available to deal with an illness (Brock, 1990; Gorynski & Knight, 1992; Leichtman & Friedman, 1975; Melzer et al., 1989; Pless et al., 1989; Walker, 1985; Wolman, Resnick, Harris, & Blum, 1994). Age and gender can have an influence on how individuals understand their illness (Jenny, 1984), while expectations regarding levels of participation in care (Wysocki et al., 1996) and perceived threats imposed by the illness affect the ability to carry out developmental tasks (Kyngas & Barlow, 1995; Silver et al., 1990). Furthermore, how others perceive and treat an individual with a chronic illness may affect constructions of illness and health in that individual (Anderson & Chung, 1982).

**Health and Illness in Adolescence**

Adolescence begins with the onset of puberty and is an important time of rapid physical and psychosocial development. The key developmental tasks at this time include physical and sexual maturation, the development of self-concept and self-esteem, increased independence, and social maturation (Berger, 1988; Edelman & Mandle, 1990; McAnarney, 1985). It is at this time that peer relationships become increasingly important and adolescents begin to explore romantic relationships. Thinking and planning for the future becomes important as adolescents approach decisions regarding continued education, career and family (McAnarney, 1985). These tasks may result in a number of stresses related to a struggle for independence from parents, concepts of self and preoccupation with body image, relationships and
acceptance by peers, school, and decisions about the future.

An examination of the literature regarding experiences of health and illness in adolescence suggests that these concepts are not well addressed. What is available in the literature regarding individuals' perspectives of their health and illness focuses on individuals' expressed health concerns and reveals little with regard to how adolescents in particular experience health and illness. Investigators have focused primarily on adolescents' health status (McCreary, 1993; Millstein & Irwin, 1987) and health concerns (Benedict et al., 1981; Feldman, Hodgson, Corber, & Quinn, 1986) as they relate to specific illnesses. In this body of research, students were asked a number of questions regarding their perceptions and experience of specific health concerns. Researchers found that adolescents experience a number of health-related problems involving somatic states, emotional states, and psychosocial difficulties (Benedict et al., 1981; Feldman et al., 1986). The results of a large survey of 15,549 adolescents in British Columbia found that, for the most part, adolescents believe they experience a high level of heath and most report positive feelings of well-being, self-esteem, and self-image (McCreary, 1993). Despite experiencing a number of health concerns, such as acne, weight problems and emotional problems, the majority of adolescents believed themselves to be healthy.

In one study (Millstein & Irwin, 1987), the researchers went beyond the normal listing of health concerns and simultaneously investigated how children and adolescents view the concepts of health and illness. Individual interviews were conducted with 218 individuals between the ages of 11 and 18 years. To elicit perceptions of health and illness researchers asked what it meant to be healthy, how the individuals knew when they were sick, and what was the difference between the two. The researchers found that the respondents viewed health as more than just the absence of illness and illness as more than just the somatic symptoms. They identified
health as including somatic states, preventative-maintenance behaviours, and functional states. The adolescents described diverse aspects of their illness including somatic states, indicators of illness, affective states, and functional status. Adolescents over the age of 15 years reported a greater diversity in themes when describing illness and placed less emphasis on the absence of illness and on signs and symptoms than did younger participants aged 11 to 14 years. This supports the belief of others who suggest that perceptions of health originate from the experience of illness – those who have not been exposed to illness have a harder time defining health, and health becomes meaningful when illness occurs (Natapoff, 1978; Tillich, 1961). Millstein and Irwin's (1987) study provides some insight about how healthy adolescents describe the concepts of health and illness and suggests that the notion of health evolves from experiences with illness. However, it reveals little about the personal meaning of health and illness or how health is experienced, particularly in an adolescent with a chronic illness.

**Diagnosis of a Chronic Illness**

A chronic illness has been widely accepted as an illness that lasts at least three months in duration (Carroll et al., 1983; McWilliam, Stewart, Brown, Desai, & Coderre, 1996; Pless, Cripps, Davies, & Wadsworth, 1989; Silver, Bauman, Coupey, Doctors, & Boeck, 1990). Curtin and Lubkin (1990, cited in Thorne & Paterson, 1998) define a chronic illness as "a state of un-wellness produced by disability or disease requiring medico-social intervention over an extended interval and affecting many aspects of an individual’s life" (p. 74).

To gain an understanding of the impact of the diagnosis of a chronic illness on individuals and their families, two research articles and one discussion paper are reviewed. In a study by Koopman and Schweitzer (1999), the researchers investigated five selected adult participant’s experiences of having symptoms prior to a
diagnosis of multiple sclerosis (MS). As part of the study, the researchers reported the experience surrounding the disclosure of the MS diagnosis, and the telling of others about the illness. The researchers found that the diagnosis of MS created more questions than answers for participants, and was met with both relief and surprise. Most of the participants had experienced some symptoms prior to the diagnosis; however, the eventual diagnosis was traumatic and often very painful. For some, relief was experienced as there was now a name associated with what they were experiencing.

Koopman and Schweitzer (1999) found that the full understanding of a diagnosis of MS does not take place at one point in time because most people are unable to comprehend all the information that is given, or even hear all that has been said. The researchers concluded that it takes time to process information, and most people need to receive the information repeatedly to make sense of it. Eventually people begin to make sense of the diagnosis, and how it affects who they are. The researchers (Koopman & Schweitzer) found that sharing the diagnosis of MS with others was difficult for the participants in their study because they were scared that they would be ostracized, criticized, or left unsupported. However, by sharing their diagnosis with others, the participants took ownership of their diagnosis, and the sharing helped them to refocus their lives and to problem solve. Feelings of loss and hopefulness motivated them to refocus their lives, causing a need to reexamine existing values and explore new opportunities.

In another study, Kutner (1987) examined the impact of the diagnosis of ESRD by interviewing 150 people ranging in age from 18 to 79 years. Participants were recruited from dialysis facilities, home dialysis programs, and transplant clinics. The majority (n=115) were receiving in-hospital hemodialysis. Kutner described the impact of the diagnosis ESRD on individuals as an initial shock. When one participant
learned that her kidneys no longer functioned, she stated it was like "a rug being pulled out from under you" (p. 39). Another participant stated that the physician "had just handed me a death sentence" (p. 39). Kutner points out that the terminology used to describe this chronic illness, "end-stage" renal disease, implies terminality and generated fear. She found that most people diagnosed with ESRD had either no knowledge about what dialysis is or envisioned a frightening procedure. Some of the participants had more warning about the ensuing diagnosis of ESRD because they had been told their kidneys were failing, or they knew that the possibility could occur because of an underlying illness such as diabetes. Kutner concluded that those who had time to get used to the idea of ESRD had an easier time coping and adjusting to the eventual failure of their kidneys. Furthermore, she suggested that those who had an underlying disease adjusted easier to the diagnosis of ESRD because they were able to apply previously learned coping strategies from their experience with the other disease.

Kutner (1987) found that after the participants had begun to comprehend the implications of having ESRD, some expressed ambivalence towards the thought of living and going on dialysis. The thought of having to undergo dialysis treatments for survival was overwhelming for many. Kutner likened the reaction of an individual with ESRD to the grieving stages identified by Kubler-Ross (cited in Kutner, 1987): denial, anger, bargaining, depression, and acceptance. These stages are not linear and an individual can go back and forth between stages, skip stages, or experience more than one stage at a time. One of the participants in the study, a social worker, suggested that people need at least six months to three years to work through the stages of grief before accepting the chronic illness. This participant also suggested that a dramatic medical or stressful event can cause a person to go back to previous stages. Kutner found that some of the participants had never really adjusted to the dialysis treatment.
Uncertainty was a common feeling shared by participants in Kutner's (1987) study. Many reported feeling uncertain about the time left to live and felt that the treatments for ESRD gave them "borrowed time" (p. 41). The participants often had a heightened appreciation for life. One woman said, "I'm very grateful for the little things that make me feel good. Sunsets. The laughter of kids. I know how unimportant the little problems are" (p. 42). Kutner also found a level of uncertainty about the reliability of the treatment options. The reliance on dialysis also created uncertainties related to threats of infection, pain and discomforts of the dialysis procedure even for the well informed. One of the participants, a physician, stated, "all sorts of disasters may occur, blood leaks or air emboli, and all the while I'm anti-coagulated" (p. 43). The participants viewed transplantation as promising the most normal existence. However, uncertainties also arose about the success of a future transplant, the possible complications and long-term problems associated with transplantation, as well as possible degenerative changes associated with ESRD. Kutner concluded that the diagnosis of ESRD had an enormous impact on individuals. Shock, fear, ambivalence, grief, denial, anger, depression, and uncertainty were commonly reported experiences in her sample.

Experts suggest that the diagnosis of a chronic illness not only affects the individual, but has an enormous impact on the entire family. Sokol (1995) describes how the family structure is shaken and the kinds of issues that surface when a child is diagnosed with a chronic illness or disability. Initially in shock and/or denial, parents often do not hear or comprehend the information given by health care providers the first time it is presented. They often project anger inward as feelings of guilt or outwards toward physicians, nurses or even God. They may experience depression, fear of the unknown, and lack of power. Furthermore, Sokol suggests that siblings are often affected. They frequently cannot understand the seriousness of the illness of
their sibling or why their parents are absent much of the time.

The literature reviewed regarding the diagnosis experience provides insight into some of the feelings that an individual and his or her family experience when an adolescent is diagnosed with ESRD. The diagnosis of ESRD may be met with relief, surprise, fear, grief, anger, and uncertainty. Surprise may be experienced because the diagnosis was not expected; relief because the illness does not have to be life threatening; fear because of the meaning of the diagnosis, potential complications, and the possibility of death; anger because of the imposition of the illness and the treatment needed to sustain life; grief because of the loss of health and a normal life; and uncertainty because of not knowing the time left to live, available treatment options, and potential complications. Parents may feel anger, guilt, fear, and/or lack of power to help their child. Family structure may be shaken as all family members make changes in their roles and responsibilities. For the adolescent and his or her family to come to terms with the diagnosis of ESRD takes time; time to understand the diagnosis and what it means, time to grieve, time to make decisions regarding treatment, and time to refocus their lives and plan for the future.

There was very little in the literature that provides insight into how being diagnosed with ESRD in adolescence affects one's experiences with health. For example, it is not known how adolescents with ESRD meet the developmental tasks of that period, such as peer relationships, normalcy, and independence. It is not known how they experience health at the time of diagnosis or how being diagnosed as an adolescent affects future experiences with health.

**Implications of Chronic Illness**

Adolescents diagnosed with a chronic illness face a number of threats which affect the developmental tasks of this age group (Kyngas & Barlow, 1995). The diagnosis of a chronic illness adds additional stress to an already difficult period
(Silver et al., 1990). Not only do adolescents with a chronic illness suffer from the same general health concerns and psychosocial challenges as healthy adolescents, they encounter a number of concerns and challenges related to their chronic illness (Silver et al., 1990). These difficulties may be physical, psychological, social, and/or functional, as kidney failure has an effect on all aspects of an individual’s life.

**Physical Implications of Chronic Illness**

Adolescence is a time of rapid physical growth and sexual maturation. It is during this time that the individual experiences a growth spurt in which females may grow as much as nine cm and males as much as 12 cm in a given year (Berger, 1988). Sexual maturation takes place as the primary sex organs become larger and eventually the individual reaches full reproductive maturity. The female breasts and male testes enlarge and the once child-like body shape gives way to a more adult gender formation. However, an adolescent with chronic illness may not experience the normal growth and sexual maturation that a healthy adolescent experiences.

Physical threat is one of the most frequently mentioned impacts on the lives of adolescents with a chronic disease and involves many negative consequences (Kyngas & Barlow, 1995). Chronic illness may hinder the normal growth and development in adolescents (Bywater, 1981; Gavaghan & Roach, 1987; Goldberg, Isralsky & Shwachman, 1979; Greydanus, Demarest, & Sears, 1985; Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980) and result in a number of threats to their physical wellbeing. There are numerous physical difficulties associated with living with chronic illness. Some are generic to all or some chronic illnesses; whereas other physical difficulties are unique to specific illnesses.

**Physical Implications of End-Stage Renal Disease**

Physical difficulties are numerous and far reaching in ESRD because of the complex regulatory function of the kidneys. The kidneys are responsible for removing
metabolic wastes, regulating fluid balance, regulating and producing hormones, and regulating important electrolytes, such as sodium, potassium, phosphorous and calcium (Lancaster, 1995). Chronic renal failure occurs when the kidneys fail to carry out important functions and symptoms become so severe that dialysis or a transplant is needed to sustain life. A number of physical problems and challenges ensue. The most common include accumulation of metabolic wastes and other chemicals (e.g., potassium) in the body which have a detrimental effect on the body when in high concentrations. High levels of potassium lead to muscle weakness, cardiac problems and may result in cardiac arrest (Lancaster, 1995). Over time, high levels of phosphorus may lead to the depletion of calcium from bones and high levels of calcium may lead to the deposit of calcium in vital areas of the body, such as the brain, eyes, gums, heart, lungs, joints, blood vessels, soft tissue, and skin (Lancaster, 1995). The parathyroid gland may become overactive during kidney failure which further complicates the balance of calcium and phosphorus and can lead to osteopenia and/or osteoporosis (Lancaster, 1995). The kidneys are also responsible for regulating growth hormones (Lancaster, 1995). When this hormonal balance is disrupted in adolescence, growth and sexual maturation may be delayed or impaired. Furthermore, cognitive ability is impaired in people with renal failure due to the accumulation of toxins in the blood which often results in decreased attention span, speed of decision making, and memory (English, Savage, & Britton, 1978; Fraser & Arieff, 1985; Kenny, 1983; Osberg, Meares, & McKee, 1982). Once an individual has started dialysis treatment, it appears that cognitive function does improve (Fraser & Arieff, 1985).

Another important function of the kidneys is the production of chemicals which are needed in the formation of hemoglobin and the control of blood pressure. Erythropoietin is needed to form hemoglobin and is produced largely by cells in the
kidneys (Lancaster, 1995). When ESRD occurs, the kidneys cease to produce erythropoietin and anemia occurs. With the recent introduction of recombinant human erythropoietin (r-HuEPO), anemia and fatigue is becoming less of a problem in ESRD (Wolcott, Marsh, La Rue, Carr, & Nissenson, 1989). The failure of the kidneys to produce blood pressure controlling chemicals along with the decreased ability of the kidneys to remove fluid often results in hypertension. Anemia, hypertension and increased fluid places considerable stress on the heart and vessels and can cause cardiopulmonary complication, such as left ventricular hypertrophy, arrhythmias, pulmonary edema, and congestive heart failure (Evans et al., 1995).

A number of symptoms are common in kidney failure due to the accumulation of wastes, fluids and electrolytes and may include decreased appetite, nausea, pain, itching, fatigue, burning sensations, tingling, weakness, headaches, restless legs, and loss of overall feeling of physical well-being (Burton, Lindsay, Kline, & Heidenheim, 1989; Evans et al., 1995; Lancaster, 1995). Many symptoms are part of everyday life, whereas others are experienced in relation to dialysis treatments and diet and are therefore intermittent.

The treatment of renal failure results in a number of additional physical concerns which create challenges. The individual with kidney failure likely has had several surgeries for various reasons (e.g., kidney biopsy, removal of native kidneys, peritoneal dialysis (PD) tubes, fistulas/grafts, parathyroidectomy). Fistulas and grafts used for hemodialysis can cause ischemia of the extremity and can become clotted or develop aneurysms or stenosis, requiring pharmacological and/or surgical intervention (Daugirdas & Ing, 1988; Evans et al., 1995). Those with a central line/permacath used for hemodialysis may experience clotting or dislodgement of the access and/or infection and septicemia. Similarly, individuals on peritoneal dialysis may experience a feeling of bloating and possible infection of the peritoneal catheter.
tube or peritoneal cavity (Daugirdas & Ing, 1988). They are also at risk for appendicitis, pancreatitis, cholecystitis, abdominal hernias, and leakage of the peritoneal fluid into the pleural space through the diaphragm (Evans et al., 1995).

The hemodialysis treatment often results in a number of physical challenges. Removal of fluid often results in hypotension, fatigue, tachycardia, or cramping (Evans et al., 1995). Needling of the access (fistula, graft) may be painful. The changes in fluid and solute composition of the blood can result in disequilibrium syndrome, characterized by restlessness, headache, nausea, vomiting, blurred vision, and muscle twitching (Evans et al., 1995). Peritoneal dialysis involves a continuous removal of wastes and fluid and therefore metabolic control is more stable (Evans et al., 1995) and fewer symptoms are experienced that are related directly to the dialysis treatment.

**Physical Implications of Renal Transplantation**

Kidney transplantation is considered the best possible renal replacement therapy. Transplantation permits a more stable physiological state and many physical problems that occur with ESRD resolve after a transplant (Bereket & Fine, 1995), including resumption of growth and reduced stress placed on the heart. Although transplantation resolves many of the physical problems, there are considerable physical challenges that arise from the drugs used to prevent rejection. The individual having undergone a kidney transplant is often faced with increased risk of infection and cancers due to the suppression of the immune system (Shapiro, Simmons, & Starzl, 1997). Potent anti-rejection drugs have a number of side effects, the most common being increased hair growth, excessive appetite, increased weight, moon-face, cushingoid syndrome, tremors, thinning of epithelial cells, gum hypertrophy, cataracts, hypertension, impairment of growth, necrosis of bone, glucose intolerance, and liver dysfunction (Bereket & Fine, 1995; Shapiro et al., 1997).
When an adolescent is diagnosed with a chronic illness, health care tends to focus solely on the chronic illness. However, it is important to remember that adolescents with a chronic illness experience not only the physical difficulties related to their chronic illness, but also more general health complaints of acne, weight, anxiety, headaches, and menstrual problems than their healthy counterparts (Benedict et al., 1981; Feldman et al., 1986; Pless & Roghmann, 1971; Sternlieb & Munan, 1972).

**Psychosocial Implications of Chronic Illness**

The psychosocial tasks during adolescence include the development of self-concept, self-esteem, increased independence, and social maturation. It is at this time that peer relationships become increasingly important and adolescents begin to explore romantic relationships. The presence of a chronic illness can affect the adolescent's development in these crucial areas (Kyngas & Barlow, 1995) and the effects may have far reaching influence into adulthood. A child's chronic illness affects all family members (Brock, 1990; Obrecht, Gallo, & Knafi, 1992). Many changes may take place which the entire family has to accommodate, such as dialysis schedules, changing roles and responsibilities, and diet. The loss of the child's health is a loss experienced by the whole family.

There has been a vast amount of research in the area of psychosocial adjustment to chronic illness in adolescence, most of which occurred in the late 1970s and 1980s. Researchers have used a number of tools to assess various aspects of adjustment, such as ego development, peer relations, and self-concept. A number of investigators have found that adolescents with chronic illness suffer from a range of psychosocial problems, such as anxiety (Boyle di Sant'Agnese, Sack, Millican, & Kulczycki, 1976), difficulties with ego development (Hauser, Jacobson, Noam, & Powers, 1983), poor self-image (Boyle et al., 1976; Cromer et al., 1990; Hauser et al.,
1983; Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980), poor self-esteem (Devins, Mann, Mandin, & Leonard, 1990; Hayden, Davenport, & Campbell, 1979; Melzer, Leadbeater, Reisman, Jaffe, & Liberman, 1989; Wolman et al., 1994), poor body image (Boyle et al., 1976; Cromer et al., 1990; Wolman et al., 1994), inappropriate expression of feelings (Boyle et al., 1976; Pless et al., 1989), difficulties with family (Cromer et al., 1990; Zeltzer et al., 1980), problems with emotional well-being (Wolman et al., 1994), problems with social adjustment (Brem, Brem, McGrath, & Spirito, 1988; Melzer et al., 1989; King, Schultz, Steel, Gilpin, & Cathers, 1993), difficulties establishing and maintaining peer and opposite sex relationships (Boyle et al., 1976; Carroll et al., 1983; King et al., 1993; Melzer et al., 1989), feelings of isolation (Boyle et al., 1976; Cadman, Boyle, Szatmari, & Offord, 1987), depression (Bywater, 1981; Melzer et al., 1989), increased incidence of psychiatric disorders (Cadman et al., 1987; O'Malley, Koocher, Foster, & Slavin, 1979; Orr Weller, Satterwhite, & Pless, 1984; Steinhausen, Schindler, & Stephan, 1983), and concerns about the future (Gavaghan & Roach, 1987; Orr et al., 1984; Wolman et al., 1994).

Symptoms of the illness and treatment regimens often cause disturbance in social activities, including those related to establishing friendships, recreational activities, school, and work (Carroll et al., 1983). These in turn may affect the way peers, teachers, and family behave toward adolescents (Pless et al., 1989) and may lead to a decreased emotional well-being (Wolman et al., 1994), feelings of isolation, and interpersonal problems (Cadman et al., 1987). Furthermore, researchers have found that adolescents with chronic illness worry considerably more about death, school, future work, self-esteem, body image, and peer relationships than their healthy counterparts (Hayden et al., 1979; Wolman et al., 1994). In a study by Wolman et al. (1994), researchers used an Adolescent Health Survey to examine the emotional well-being, worries and concerns, and body image of adolescents in grades 7 to 12. The
results of 1,683 adolescents with chronic illness were compared with the results of 1,650 healthy adolescents. The researchers found that adolescents with a chronic illness have lower emotional well-being, worry more about school and future work, and have a poorer body image than do healthy adolescents. Other researchers found a higher incidence of psychiatric problems among individuals with a chronic illness than among healthy individuals (Cadman et al., 1987; Steinhausen & Kies, 1982; Steinhausen, et al., 1983).

Although it may appear from previous research findings that adolescents with a chronic illness have poor psychosocial outcomes, a number of other investigators have found more promising results in the areas of family relationships (Bywater, 1981; Hayden et al., 1979), ego identity (Gavaghan & Roach, 1987; Silver et al., 1990), anxiety (Kellerman et al., 1980), self-esteem (Kellerman et al., 1980), psychological status (Kellerman et al., 1980; Zeltzer et al., 1980), social adjustment (Cadman et al., 1987), peer relations (Bywater, 1981; Klein, Simmons, & Anderson, 1984), and expression of feelings (Hayden et al., 1979).

Spirito, DeLawyer and Stark (1991) reported on the findings of a number of studies in their review of the literature on peer relations and social adjustment of chronically ill children and adolescents, and suggest that the conflicting findings of researchers is due to the limited number of studies, limited use of control groups, various patient characteristics, such as disease specific differences and disease severity, and the various assessment measures used. The literature reviewed for this chapter with regard to psychosocial implications of chronic illness revealed similar limitations. For example, Zeltzer et al. (1980) studied adolescents with cancer, diabetes, cystic fibrosis, cardiac problems, renal problems, and rheumatoid problems. These investigators used a self-report method and interviews to ascertain the psychological effects of chronic illness. Cadman et al. (1987) used a survey
diagnostic instrument to assess mental and social well-being in adolescents with cystic fibrosis, asthma, cardiac problems, epilepsy, and diabetes. Although a number of the reviewed studies used a control group (Cadman et al., 1987; Cromer et al., 1990; Silver et al., 1990), others did not (Boyle et al., 1976; Brem et al., 1988; King et al., 1993). Furthermore, research regarding psychosocial implications in adolescence was primarily conducted in the late 1970s and 1980s, with few recent studies found examining this subject (Cromer et al., 1990; Devins et al., 1990; King et al., 1993; Silver et al., 1990; Wolman et al., 1994). Therefore, it is difficult to draw any conclusions about the psychosocial adjustment of adolescents diagnosed with chronic illness at the present time. Furthermore, it is difficult to determine the adjustment of adolescents with kidney disease at the present time, given that the longevity and morbidity associated with kidney failure and transplantation have improved dramatically.

**Psychosocial Implications of End-Stage Renal Disease**

A number of threats to psychosocial well-being are known to occur when living with renal failure. Threats to independence, self-concept, self-image, and social relationships are common. The reliance on time-consuming dialysis treatments and diet restrictions impacts on adolescents' ability to take part in activities with their peers or family members, leading to feelings of isolation, loneliness, depression, passivity, withdrawal, and increased dependency (Burton, Kline, Lindsay, & Heidenheim, 1986; Gorynski & Knight, 1992). Adolescent dialysis patients indicate that the predominate issues they face include those related to school, jobs, making friends, communicating with parents, relationships with the opposite sex, and issues related to body image (Gorynski & Knight, 1992; Walker, 1985). Frequent examinations and medical procedures are particularly intrusive to adolescents who, by nature of their psychosexual development, are particularly sensitive to their bodies (Zarisky, 1975).
Symptoms associated with the disease, scars from surgery and dialysis access contribute to a decreased self-image and body image (Walker, 1985). Furthermore, the need for life sustaining treatment can cause considerable worry for adolescents. Walker (1985) explains:

At a time of life when appearance and body function are of such great importance, an illness treatable only by some extraordinary measures diverts the precious psychic energy of youth toward fighting against anxieties related to altered appearance, reduced body function and threat of death (p. 28).

Klein et al. (1984) reports on the results of a multifaceted longitudinal research project conducted at the University of Minnesota that investigated the impact of chronic kidney disease and transplantation on the development of the adolescent and young adults. The authors report on the data from several interrelated studies, involving 72 children and adolescents with kidney disease, 52 children and adolescents one year post kidney transplant, and 36 adolescent and young adults five to nine years post transplant. In one stage of the research project, the researchers examined the psychosocial adjustment of 72 children and adolescents between the ages of 8 and 20 with chronic kidney disease. Of those with kidney disease, 39% were not satisfied with their looks compared with 28% of their healthy siblings. In addition, 39% perceived themselves to be too short compared with 23% of their healthy siblings. However, the researchers report that the children and adolescents with kidney disease were within normal ranges with regard to self-esteem, self-consciousness, stability of self-image, a sense of distinctiveness, felt ability to reveal true feelings, self-estimates of popularity, and reported anxiety.

The researchers (Klein et al., 1984) found that a “few” of the adolescents showed severe evidence of depression and four had made suicide threats and/or
attempts. A number of factors appeared to have affected the adjustment of these children and adolescents, including severity of illness, age, gender, satisfaction with appearance, and family adjustment to illness. The more serious the illness, as perceived by the child or adolescent, the more unfavorable the adjustment, particularly in regard to happiness and self-image. The researchers found that female adolescents had a decreased self-image, more depression, less stability of self-concept, and less satisfaction with appearance. It was also found that the participants with kidney disease who were less satisfied with their looks showed more negative adjustment. However, the researchers suggest that these findings reflect normal developmental differences rather than the effects of kidney disease. The researchers also found a relationship between the level of self-care and adjustment, with those participants with kidney disease who took responsibility for their care being more positively adjusted. Those who felt their mothers held them in high regard, scored positively on self-esteem, self-consciousness, self-stability, satisfaction with looks, and ability to reveal feelings. However, if the mother indicated confusion or difficulty in managing the child’s treatment, the child was more likely to be less adjusted. It is not clear which findings are specific to kidney disease and which occur because of unhealthy family dynamics.

**Psychosocial Implications of Renal Transplantation**

Transplantation can have positive effects on the psychosocial status of an adolescent by lessening the impact of the illness. Based on the findings of one study (Melzer, Leadbeater, Reisman, Jaffe, & Liberman, 1989), it appears that adolescents who have undergone a kidney transplant assume a better body image than they did previously and have similar levels of self-esteem when compared with healthy adolescents. The volunteer participants included all 16 adolescents between the age of 13 to 20 in follow-up at post transplant clinics at two hospitals in a large US city.
The investigators compared the 16 adolescents with ESRD treated with kidney transplantation with a matched group of healthy adolescents and found that although the adolescents with a kidney transplant had fewer unrelated and opposite sex peers in their social network, they had similar levels of self-esteem as the healthy adolescents. Moreover, the adolescents with a kidney transplant perceived a higher level of acceptance by their parents. The researchers suggest that families may provide the needed social support that these adolescents require to preserve their self-esteem. The researchers also found that the improved body image of the adolescents with kidney transplants in their study compared with earlier studies may be a reflection of the improved medical management prior to the transplant, less time with ESRD because of early transplantation, and the advances in immunosuppression drugs that result in lower doses of steroid used to prevent rejection.

According to the findings of one researcher, adolescents often view a transplant as a "gift" and the opportunity for "a new life" (Muslin, 1971). However, transplantation invokes a new set of problems. The mother of an adolescent in a case study of family management style in ESRD (Obrecht et al., 1992) felt transplantation was "exchanging one set of worries for another" (p. 258). Although the transplant had eased her responsibilities of attending to and managing her son's illness, and protecting him from complications of the dialysis, she now felt she had to protect him from kidney rejection and future complications.

An adolescent who has had a kidney transplant experiences a number of issues. Some of the psychosocial challenges that adolescents face after a transplant include sexual maturity, independence, acceptable socialization, acceptance of self-concept and identity (Zarinsky, 1975), return to school, and relationships with siblings and peers (Shaben, 1993). The need to take medications for the remainder of one's life, the body changes that take place because of the immunosuppressive drugs (e.g.,
moon face, weight gain), and the impaired growth from long-term steroid use (Bereket & Fine, 1995) are particularly stressful during adolescence and can interfere with an individual's need for independence and ability to fit in with peers. Common emotional reactions to having a kidney transplant include feelings of guilt, depression, suicide, being altered ( Bernstein, 1971; Muslin, 1971; Zarinsky, 1975 ), uncertainty about kidney rejection, and worry of death ( Norris, 1991; Poznanski, Miller, Salguero, & Kelsh, 1978 ). In some cases, the side effects of the post-transplant medication are more traumatic than the rejection of the kidney or death ( Norris, 1991 ). When compared with healthy adolescents, researchers in one study found that adolescents with a transplant had fewer close relationships, especially unrelated and opposite sex peers in their social network, and experienced more feelings of social isolation than did healthy adolescents ( Melzer et al., 1989 ).

In the second part of the multifaceted longitudinal project described by Klein et al. (1984), researchers examined the psychosocial adjustment of 52 children and adolescents between the ages 8 and 19 years who had undergone a kidney transplant between the years 1970 and 1974. To be eligible for the study, they had to have had their transplant at least one year prior to being enrolled in the study. All participants were given a questionnaire that contained both open and closed questions. Data from psychiatric evaluations of all children and adolescents who had received a transplant between the years 1970 and 1974 ( n=100 ) were also included. The findings revealed that children and adolescents with a kidney transplant were concerned about their height, delayed sexual maturation, deformity from bone disease, and the effects of immunosuppressive medications, such as cushingoid appearance. Psychiatric evaluations revealed that child and adolescent kidney transplant recipients reported an increase in energy which had a positive effect on their physical ability, personality traits, cognitive skills, and educational achievement.
Although school age children reported few problems with peers, adolescents were frequently teased by their peers because of their appearance.

Similar to the findings of the study conducted by the same researchers (Klein, et al., 1984) in children and adolescents with kidney disease, reported earlier in the chapter, the researchers found a number of factors which influence the psychosocial adjustment to transplantation in children and adolescents in the current study (Klein et al, 1984). The severity of the medical problems following the transplant impacted negatively on the adjustment of these children and adolescents. Psychological problems often resulted when kidney function was threatened. Age also affected adjustment. Emotional problems were reported to occur less among young patients than among adolescents. Suicidal thinking was found in 7 of the 68 adolescent transplant recipients who had a psychiatric evaluation. A positive perceived appearance among children and adolescents with a transplant resulted in a better adjustment than those who were dissatisfied with their appearance. Those who indicated that they were dissatisfied with their appearance appeared to have lower self-esteem, be more self-conscious, have a greater sense of distinctness, experience more anxiety and unhappiness, report less popularity, and have less stability of self-image. Furthermore, those dissatisfied with their appearance were less likely to have same or opposite sex peers and less likely to take part in activities with peers outside school.

**Functional Implications of Chronic Illness**

There is conflicting evidence in the literature regarding the functional status of adolescents with chronic illness. The methodological limitations discussed previously regarding studies of psychosocial implications of chronic illness in adolescents are also true for studies that examined functional implications. Specifically, the limitations include: limited number of studies and use of control groups, and non-delineation of
the effects of various patient characteristics, such as disease specific differences and
disease severity, and the various assessment measures used. Furthermore,
researchers often studied consequences of chronic illness with regard to functional
implications simultaneously with psychosocial implications (Boyle et al., 1976;
Cadman et al., 1987; Cromer et al., 1990; Gavaghan & Roach, 1987; King et al., 1993;
Orr et al., 1984; Pless et al., 1989; Zeltzer et al., 1980).

A number of investigators have reported that adolescents with chronic illness
have increased difficulties in functional status in the areas of knowledge of sex
(Cromer et al., 1990; Hayden et al., 1979), dependence on parents (Khan, Herndon, &
Ahmadian, 1971), daily living (Hayden et al., 1979; Orr et al., 1984), athletic and
scholastic achievement (Carroll et al., 1983; Gavaghan & Roach, 1987; King et al.,
1993; Pless et al., 1989), freedom (Zeltzer et al., 1980), and recreational activities
(Carroll et al., 1983). Other researchers, however, indicate that adolescents with
chronic illness are similar to healthy adolescents in the areas of daily living (Boyle et
al., 1976), sexual function (Cromer et al., 1990), school delinquency (Pless et al.,
1989), and participation in activities (Cadman et al., 1987).

**Functional Implications of End-Stage Renal Disease**

The adolescent with ESRD often misses school or is unable to take part in
activities with peers or family members because of decreased energy levels, cognitive
impairment, and inconvenient and/or time-consuming dialysis treatments (Obrecht et
al., 1992; Walker, 1985). In the study by Klein et al. (1984), the mothers of children
and adolescents with ESRD indicated that their ill children were less active and less
able to compete physically than their healthy children. Absenteeism was common for
these children with one third of the mothers indicated that missing school was a
problem for their child with ESRD with 25% missing more than five days of school a
month. Furthermore, 25% were at least one grade year behind in school.
Functional Implications of Renal Transplantation

Transplantation may lead to an improvement in an adolescent's functional status, particularly if there have been few complicating factors following the transplant (Poznanski et al., 1978). Cognitive function often improves with the resolution of uremia and anemia following a transplant (Shapiro et al., 1997). In a study examining the effects of renal transplantation on the neurocognitive function in nine children and adolescents with ESRD, researchers reported that renal transplantation resulted in a significant improvement in the areas of mental processing speed, attention span, reaction time, and memory (Mendley & Zelko, 1999). Other researchers who examined the cognitive function and school performance in school aged children, 11 of whom were on dialysis and 13 who had a kidney transplant, found that those with kidney transplants scored higher in the areas of achievement in written language and school performance than did those on dialysis (Lawry, Brouhard, & Cunningham, 1994). However, there were no differences with regard to overall IQ, grade point average, or mathematical ability. These studies (Lawry et al.; Mendley & Zelko) suggest that kidney transplantation has a positive affect on the cognitive ability and school performance of adolescents with ESRD.

Research evidence suggests that freedom from dialysis and a less restricted diet allow adolescents to lead a more normal life (Chantler et al., 1980), enjoy better social relationships (Poznanski et al., 1978), attend school more regularly (Offner et al., 1988), and participate in more activities post-transplantation (Klein et al., 1984). However, the many psychological and self-image problems that can result following a transplant may, as previously discussed, cause stress when the adolescent returns to school, and may affect performance in school or activities with peers (Bernstein, 1971; Zarinsky, 1975). Furthermore, many adolescents with a renal transplant feel the need to protect the newly transplanted kidney and consequently do not take part in activities...
that may result in damage to the organ (Muslin, 1971).

**Long-term Impact of Chronic Illness**

Since chronic illness may have long-term impacts, it is necessary to examine how the length of an illness affects a person's adjustment to living with chronic illness. In a longitudinal study conducted by Pless et al. (1989), data was collected on all individuals born in the United Kingdom over a one-week period in 1946 (N=5362). Medical, social, psychological, and educational data was collected at two year intervals until age 15 and then in five year intervals thereafter until the study was published in 1989. The researchers found that those who had a chronic illness in childhood, but no serious illness as an adult, were not at an increased risk of lower educational achievement, unemployment, or psychiatric problems. They had similar chances of marriage, jobs, becoming a parent, and having a social life as those who never had a chronic illness. However, those who had a chronic illness that started in childhood and lasted into adult life showed more emotional disorders, unemployment, and were less likely to purchase a home or be married. Unfortunately, differences in impact according to diagnosis were not explored.

**Long-term Impact of End-Stage Renal Disease**

There is very little in the literature regarding the implications of living with ESRD from adolescence into adulthood, particularly with respect to how individuals with ESRD experience health. In 1988, Henning et al. examined the long-term effects of chronic illness in 27 adolescents diagnosed with ESRD and 17 adolescents with diabetes diagnosed before the age of 15 and between the years 1972 and 1977. At the time of the study, those with ESRD were between the ages of 14 and 27; those with diabetes were between the ages of 16 and 29. It is not clear what the distribution is with regard to age because the researchers indicate that 87% of the original 31 who received the questionnaire were over the age of 18 years but they do not indicate how
many were over 18 years of age in the 27 that responded to the questionnaire, nor do they report on the number of participants over 18 years of age with diabetes.

The researchers found that all individuals with ESRD were disappointed with their final heights, 17% had some form of bone disease and another 23% had other disabilities or disease, half of which could be attributed to their kidney disease. Of those with ESRD who responded to questions about education (n=26), 70% had obtained at least a general certificate of education; another three individuals were still attending school. The results indicate that 67% in the group with ESRD worked either full or part time. The respondents' gender, and their need and/or desire to work may have influenced employment status, however, these factors are not reported specifically by the researchers. The researchers do indicate that 55% of the individuals with ESRD were female, 22 of the 27 individuals with ESRD were permanent job seekers, and 61% of the individuals over 18 years with kidney failure were still living with their parents or a relative. Furthermore, those with ESRD showed a general dissatisfaction with their social relationships, with 46% of those with kidney failure believing their social life had been adversely affected by the illness. When compared to adolescents with diabetes, the researchers found that adolescents with ESRD had more difficulty with school or work and more lived with their parents. However, fewer adolescents with ESRD were dissatisfied with their social life than were the adolescents with diabetes.

**Long-term Impact of Renal Transplantation**

Three studies were conducted in the late 1970s and 1980s that focused on the long-term impact of ESRD treated with transplantation (Klein et al., 1984; Offner et al., 1988; Poznanski et al., 1978). The long-term effects of ESRD as measured in adults who were diagnosed with ESRD as a child or adolescent appears to vary considerably between those who have a functioning transplant and those who do not.
To assess the psychosocial adaptation of children and adolescents who have undergone kidney transplantation as a means of managing their renal failure, researchers interviewed 18 children and adolescents who had received a transplant prior to age 17 (Poznanski et al., 1978). At the time of the study, the participants were between 11 and 26 years of age. Semi-structured interviews occurred two or more years after the transplant. The participants were split into two groups, group A (n=9) participants had a successful transplant; group B (n=9) included those who were experiencing rejection and had reduced renal function, and those who had rejected a previous transplant and were experiencing rejection of the present transplant.

In group A, 89% of those who had functioning kidneys were either in school or working full-time. In group B, the findings are not as positive, with 66% experiencing problems with school, specifically irregular and/or part-time attendance, homebound schooling, dropped out, or no schooling at all. With regard to social relationships, those in group A fared considerably better than those in group B. Those with a successful transplant perceived that they had good friendships and romantic relationships more often, and were more satisfied with their physical health than those who did not have a successfully functioning transplant. However, individuals in both groups had issues with their height, facial appearance, and self-image. Depression was common in both groups; 88% in group B and 44% in group A, experienced some kind of depression. The results of this study indicate that a positive psychosocial adaptation to kidney failure during childhood and adolescence is associated with a successful kidney transplant. Younger participants in both groups used denial as a response to questions regarding kidney rejection.

In another study researchers followed 113 adolescents between the ages of 12 and 16 years who were diagnosed with kidney failure between the years 1972 and 1983 with regard to mortality, morbidity, and rehabilitation (Offner et al., 1988). At the
end of the study in 1985, 94 were still alive with 81 having functioning grafts, 11 on hemodialysis, 2 on peritoneal dialysis, and 3 were lost to follow-up. The main complications in all participants included retarded growth (43%), hypertension (66%), and osteopathy (32%). In spite of the complications, 95% of those that received a transplant and 29% of those on dialysis reported their health as good or excellent. The results of this study indicate that individuals with functioning transplants had better rehabilitation outcomes with regard to educational achievement and ability to work than did those treated with dialysis.

In one stage of the multifaceted research program by Klein and colleagues (1984), individuals who had received a transplant (N=36) were included in the study and followed five to nine years post-transplant. Data was collected from the subjects using an open and closed answer questionnaire. At the time of the study, 11 participants were between the ages of 8 and 15. Most had received the transplanted kidney at the age of five years. There were 25 participants between the ages of 16 and 27 years. The results showed that the participants had high levels of adjustment with regard to attending and functioning at school, and taking part in physical education. Three were unable to participate fully in school and one could not participate in all gym activities. Several of the young adolescents reported being teased about their appearance.

Comparison of Long-term Adolescent and Adult Transplant Recipients

In another phase of the research project involving the late adolescent - young adult group (ages 16 to 27 years), Klein et al. (1984) report that all the participants in the late adolescent/ young adult group had spent some or all of their adolescent years as a kidney transplant recipient. Seventy-six of the participants perceived themselves to be as healthy as their peers, 40% reported having some medical difficulty in the preceding year, 29% had been hospitalized in the preceding year, and 20% had
chronic rejection. When compared with adult transplant recipients from another study (Simmons, Klein, & Simmons, 1977), the researchers found that the participants in their study (Klein et al., 1984) reported feeling better and experiencing fewer symptoms of uremia than did the adults who received a transplant. The researchers report that the late adolescent - young adult transplant recipients were more likely to be vocationally rehabilitated and were “reasonably happy” (Klein et al., p. 444) with their lives when compared with adult transplant recipients (Simmons et al.) and with a nationwide survey of the general population (Aldine, 1969).

A number of factors influenced the psychosocial adjustment of the late adolescent and young adult transplant recipients. One group of researchers found that those recipients who had few medical difficulties in the preceding year demonstrated a higher level of independence, self-esteem, and perceived control over their destiny, as well as lower levels of depression and self-preoccupation, than those who experienced medical difficulties (Klein et al., 1984). They also found that dissatisfaction with appearance negatively influenced overall adjustment. Those participants dissatisfied with their appearance had more depression, lower self-esteem, lower perceived control over their destiny, higher anxiety, higher self-preoccupation, and lower independence. Those satisfied with their appearance were more likely to be employed or going to school full-time.

Gender appeared to negatively influence the adjustment of late adolescent and young adult transplant recipients. Young females indicated a greater dissatisfaction with their bodies, felt less healthy, and expressed more negative feelings about the transplant than did young male or adult male and female transplant recipients. Klein et al. (1984) suggest the young female transplant recipients suffer more than any other group because of their age and developmental status. They state that a young female is often preoccupied with her appearance and self-image and the effects of a
transplant may exacerbate this preoccupation; however, this gender differentiation may not be relevant today.

Klein et al. (1984) found that there were no differences between the late adolescent - young adult group in their study, and the older adult group in the study conducted by Simmons et al. (1977) with regard to satisfaction of social relationships; both groups were satisfied with recreational activities, social life, and relationships with friends, spouses, and children. However, Klein et al. (1984) found that few of the late adolescent - young adult group had significant romantic relationships. Whereas 86% of the adult transplant recipients (Simmons et al., 1977) had spouses, only 20% of the young adult group were married (Klein et al., 1984). It was found that 9 of the 20 unmarried late adolescents and young adults had not dated in the past three months, and only 3 had a regular girlfriend or boyfriend. The results showed that half of the young females were neither married nor dating. These findings could be a reflection of the age of participants, their desire to marry, or the focus of the researchers on only heterosexual relationships. The researchers do suggest that the differences between the findings for the late adolescent - young adult group and the findings for the adult recipient group indicate that younger transplant recipients have difficulty establishing romantic relationships, whereas adult transplant recipients have already done so. The researchers do not suggest possible reasons for the observed difficulty adolescents had in establishing relationships. However, these findings could be the reflection of several factors. People may be reluctant to become involved with someone with ESRD or a renal transplant due to fears of premature death, possible complications of the illness, unknown implications of the illness, or discomfort with illness or transplantation. It may also be reflective of the psychosocial problems, such as, decreased self-esteem, experienced by some adolescent transplant recipients.

The final influence on psychosocial adjustment that Klein et al. (1984) report on
are the effects of the family. In another related study of the psychosocial adjustment of children and adolescents to kidney disease, the researchers found that family support had a positive influence on psychosocial adjustment. Klein et al. (1984) suggest the transition to adulthood and independent life that occurs in older adolescence may result in the transplant recipient not having this family support readily available. They found that 32% of the participants with renal transplants did not live with their families. Furthermore, the late adolescent and young adult participants were less likely to report close family connections.

For the most part, the studies reported by Klein et al. (1984), Offner et al. (1988), and Poznanski et al. (1978) suggest that adolescents who have undergone transplantation and have functioning grafts have better outcomes with respect to employment, social relationships, emotional well-being, and education than those who do not have a successful transplant or are on dialysis. However, the findings from these studies suggest that there are still a number of issues that with which adolescents struggle. Satisfaction with appearance and establishing romantic relationships are particularly difficult for adolescents with a kidney transplant, possibly because of altered appearance due to immunosuppressive medications, and the threat of kidney rejection or death.

**Future Long-term Impact of ESRD and Renal Transplantation**

Recent advances in the management of ESRD and kidney transplantation through the use of growth hormones (Lancaster, 1995), r-HuEPO (Wolcott et al., 1989), better dialysis procedures, more specific immunosuppression (Melzer et al., 1989), and aggressive therapies to balance calcium and phosphate levels, such as parathyroidectomy, low calcium dialysate baths, and phosphate binders (Daugirdas & Ing, 1994), may positively influence the long-term outcomes of people with ESRD and transplantation. These advances may result in individuals with ESRD and kidney
transplants having healthier bones, increased growth, higher energy levels, greater satisfaction with appearance, and a reduced threat of kidney rejection or death. The improvements in physical and psychosocial status may help adolescents with ESRD or a kidney transplant feel that they may lead a more normal life and improve their ability to establish relationships than was found in earlier research.

**Personal Meaning of Health and Illness in Chronic Illness**

There was very little located research that examined the personal meaning of health and illness in adolescents with a chronic illness. The following discussion is primarily related to diabetes. While some similarities can be found with regard to the personal meaning of health and illness in diabetes and ESRD, there are other attributes that are not the same. For example, adolescents with diabetes can monitor their physiological status at home with a glucometer but one with ESRD must rely on in-hospital or clinic blood tests to determine his or her status.

Studies conducted by Standiford, Turner, Allen, Drozda and McCain (1997), Kyngas and Barlow (1995) and Gallo, Schultz and Breitmayer (1992) reveal some insights about the personal meaning of health and illness for adolescents with chronic illness. Researchers have identified two distinct perspectives that an adolescent with diabetes or kidney disease can hold regarding their illness; one perspective focuses on the negative aspects of the disease, such as threat to physical and psychological well-being (Gallo et al., 1992; Kyngas & Barlow, 1995), pathology and associated restrictions and fears (Gallo et al., 1992; Standiford et al., 1997), and the other focuses on positive aspects of a chronic illness (Standiford et al., 1997) and the opportunity for a healthy lifestyle (Kyngas & Barlow, 1995). The findings from these studies suggest that the adolescents with diabetes were able to see positive outcomes of having diabetes, whereas, those with kidney disease did not.
**Negative Meaning**

In one study of adolescents with diabetes between the ages of 12 and 16, 51 described their illness using terms such as a “never ending nightmare,” “stress,” “prison,” “lives finished,” and “hell” (Kyngas & Barlow, 1995, p. 943). Two studies that included adolescents with diabetes found that they feared the long-term complications of their illness, such as amputations, blindness, digestive problems, liver damage, neuropathy, a shortened life span, and renal failure (Kyngas & Barlow, 1995; Standiford et al., 1997). Adolescents with kidney disease or diabetes discussed the long-term duration of their illness. Adolescents with diabetes described it as something that would “last a very long time or for the rest of their lives” (Standiford, 1997, p. 148). In another study of five adolescents with chronic renal disease, including adolescents who still had functioning kidneys, were on dialysis, and/or having experienced the failure of a transplant, the participants believed they would always have kidney disease (Gallo et al., 1992) but they did not see themselves as different from other adolescents their age and believed they were as healthy as their peers. They all had responsibilities at home in spite of their illness and took part in normal activities, such as gym, swimming, watching TV, going on sleep overs, and having fun with friends (Gallo et al., 1992). The same was not true for adolescents with diabetes, who felt the disease prevented them from being independent, healthy, leading a normal future life, and unfavourably influenced their occupational choices and ability to have a family (Kyngas & Barlow, 1995). However, despite the negative feelings towards having diabetes and its restrictions, inconveniences and complications, these adolescents did not see their illness as severe (Standiford et al., 1997).

**Positive Meaning**

For some adolescents, diabetes was viewed as a “habit” (taking care of
diabetes was an integral part of their life) and "a little devil" (in the Finnish culture meaning something that needs to be taken care of and not necessarily a major disturbance) (Kyngas & Barlow, 1995). A number of adolescents felt the close monitoring and healthy lifestyle offered an opportunity to live a healthy life. These adolescents did not feel controlled by their disease but felt diabetes was part of their lives. They appreciated help from health care professionals and families and were grateful for having resources to help them have a healthy lifestyle.

Meaning of Health and Illness

In studies by Gallo et al. (1992), Kyngas and Barlow (1995), and Standiford et al. (1997), adolescents considered themselves at a higher level of health if they were able to carry out their roles, and do the things they wanted. They had an overall feeling of positive self-concept and self-image. It appears that health was equated with independence, normalcy, and keeping up with others, whereas illness was viewed as a physical and psychological threat to health often preventing the individual in achieving normalcy, independence, and positive feelings of self.

Strengths and Limitations of Current Research

Strengths

The reviewed literature for this study identified a number of findings which contribute to the knowledge of the effects of a chronic illness on an adolescent. Adolescents diagnosed with a chronic illness face a number of physical, psychosocial, and functional challenges during adolescents and adulthood. Much is known about the physical impact of the failure of the kidneys and associated symptoms. It appears from the studies reviewed that physical challenges faced by adolescents with ESRD include threats of bone disease, heart disease, and impaired growth. There is some evidence that adolescents who have undergone transplantation have fewer symptoms, less incidence of heart disease and bone disease, and a resumption of
growth. However there are a number of physical challenges that can result from the immunosuppressive drugs used in transplantation including risk of infection, cancers, and pathological effects on various organ systems.

The reviewed literature revealed a number of psychosocial challenges faced by adolescents with any chronic illness. These included challenges related to anxiety, ego development, self-esteem, body image, expression of feelings, family relationships, emotional well-being, social adaptation, peer and opposite sex relationships, depression, psychiatric disorders, and concerns about the future. The available literature on the psychosocial adjustment of adolescents with ESRD suggests that they face similar challenges. There is some evidence that those adolescents who have a functioning transplant appear to fare better with regard to psychosocial adjustment than those who did not have a transplant or who had problems with their transplant.

The literature revealed a number of functional challenges faced by adolescents with chronic illness. These include challenges related to independence, daily living, athletic and scholastic achievement, recreational activities, school delinquency, and sexual function. It appears from the available literature on adolescents with ESRD that they face similar challenges. There is again some evidence that adolescents who have functioning transplants fare better in terms of functional abilities than those who did not have transplants or who had problems with them.

The limited research located pertaining to the long-term effects of the diagnosis of a chronic illness in childhood and adolescence (Pless et al., 1989) found that individuals with long-term illness were negatively affected in the areas of emotional well-being and employment. Furthermore these individuals were less likely to purchase a home or be married. The limited literature located regarding the long-term effects of the diagnosis of ESRD and transplantation in adolescence (Henning et al.,
1988; Klein et al., 1984; Offner et al., 1988; Pozanski et al., 1978) revealed some evidence that those individuals who had a functioning transplant with few complications had fewer physical, psychological, and/or functional problems that those who did not have a successful transplant. Furthermore, the reviewed research suggests that pharmacological and technological advances, specifically in the areas of immunosuppression, r-HuEPO, and early transplantation has led to better outcomes for adolescents with renal transplants today than ten years ago.

There is some evidence that adolescents with a chronic illness can cope and adjust positively to the effects of a chronic illness. Three articles (Standiford et al., 1997; Kyngas & Barlow, 1995; Gallo et al., 1992) were located pertaining to the personal meaning of health and illness in adolescence with a chronic illness. This body of literature suggests that adolescents with a chronic illness view themselves as healthy when they are able to lead a normal life. Some are even able to see positive aspects of having a chronic illness.

In addition to revealing a number of physical, psychosocial, and functional challenges faced by adolescents with a chronic illness, the literature illuminates the complex process of the diagnosis of chronic illness in adolescents and some of the long-term challenges faced by adolescents as they mature into adults.

**Limitations**

The reviewed literature revealed that the definitions, descriptions, and meaning of health is not well understood and that the concept of health needs further investigation, particularly from the perspectives of individuals with chronic illness. The review of the research revealed a number of issues raised by researchers regarding the effects of chronic illness in adolescence. However, much of the research that was located occurred in the 1970s and 1980s. This dated research does not reflect the advances made in the treatment of chronic illness. Furthermore, the research
revealed a number of conflicting findings regarding the psychosocial and functional implications of chronic illness on adolescence. The conflicting findings may be due to the limited use of control groups, failure to differentiate disease specific differences, disease severity, as well as the limitations of various tools and methods used to assess the impact of chronic illness. Furthermore, few studies have been conducted to examine the effects of ESRD and transplantation on the psychosocial and functional ability of adolescents.

A further limitation of the current research is the small number of long-term studies in chronic illness. The studies that were located provided quantitative data that provides little insight into how individuals actually experience health as they mature from adolescence into adulthood. Furthermore, there has been very little research that examines the long-term effects of ESRD and transplantation in adolescents or in adults who were diagnosed with ESRD during adolescence. The examined literature tended towards grouping individuals with a variety of chronic illnesses together as one group and comparing them with healthy control groups or comparing those with one chronic illness to another. These forms of comparison suggests that individuals' experiences with health can be compared. It does not address the personal experience unique to each chronic illness or to each individual.

The limited use of qualitative methods in this review to study the effects of chronic illness in adolescence is a further limitation. Much of the previous research regarding chronic illness in adolescents utilizes quantitative methodology using predetermined assessment tools. The use of such tools requires the participants to fit their experiences into existing categories. This method of research does not allow for the investigation of the details and specifics of the experience as perceived by the individual.

Another limitation of the current research in illuminating the experience of
health in chronic illness is the perspective from which the research was conducted. The reviewed literature about chronic illness in adolescence is predominantly from the health care providers' point of view and what they believe are pertinent areas of exploration, as influenced by their explanatory models. The majority of the literature located focused on professional definitions and explanations of health using health and illness indicators. Little research was located that examined individuals' experience of health when living with a chronic illness from their point of view, as influenced by their explanatory models. Moreover, no studies were found examining the experience of health from the perspectives of adolescents with ESRD or adults diagnosed with ESRD during adolescence.

The literature reviewed indicates that the experience of health in adults diagnosed with ESRD during adolescence is an unexplored area. This is a timely study, given that individuals who were diagnosed during adolescence prior to the 1970s did not have available treatment options, and therefore did not survive into adulthood. Those diagnosed in the 1970s and 1980s did have treatment options and are now adults. Clearly there is a need for qualitative research examining the experience of health from the perspectives of adults diagnosed with ESRD during adolescence. Qualitative research has the potential to illuminate and provide insight into the experience of health in adults diagnosed with ESRD during adolescence by enabling them to share their experiences in detail.

**Summary**

In this chapter, literature was reviewed pertinent to the exploration of the experience of health in adults diagnosed with ESRD during adolescence. The review revealed a number of challenges faced by adolescents with ESRD during adolescence and adulthood. However, the review suggests that few general conclusions can be made due to the conflicting findings. Furthermore, little evidence
was found in the literature pertaining to the experience of health. The review has helped to illuminate the complex processes involved in the diagnosis of a chronic illness in adolescence. The discussion regarding the strengths and limitations of the current research identified the need for qualitative research in this area. This research would be valuable at providing insights into how health is defined and experienced by this group of people so that health care professionals may better serve them during adolescence and adulthood.
CHAPTER THREE: METHODOLOGY

It is evident from the preliminary literature review that there is little information about how individuals' experience health, specifically in relation to how experiences with health develop or change in individuals who have lived with a chronic illness for several years. In this chapter, the research design, sampling techniques, procedure for approaching and informing participants, data collection setting and procedures, data analysis, ethical considerations, methodological rigor and potential limitations of the study are presented. Using these methods, a substantive theory is developed to describe and explain how adults who were diagnosed with ESRD during adolescence experience health.

Research Design

The qualitative research method of grounded theory, as described by Strauss and Corbin (1998), was used to guide this study. This method was chosen for the following four reasons. First, grounded theory provides a means of understanding and explaining human behaviour when very little is known about the phenomena of study and when there are few adequate theories to explain the behaviour (Hutchinson, 1993). Grounded theory is appropriate for this study as there is little theoretical information available about how health is experienced in adults who were diagnosed with ESRD during adolescence. Second, the symbolic interactionist perspective chosen as the philosophical framework for this study is based on the premise that people give meaning to their lives through interactions with objects in their social world (Blumer, 1969), and is consistent with grounded theory methods. The meaning people gives to objects in their world and the way they experience health is ever changing and evolving. Grounded theory is process-oriented and therefore is particularly suited to uncover the changes that take place in the development of how health is experienced. Grounded theory was a particularly useful method for this study
because it attempts to understand and explain the nature of human behaviour as understood by people that share similar life patterns, through the systematic gathering and analysis of data (Hutchinson, 1993). Grounded theory was used to discover how adults who were diagnosed with ESRD as an adolescent experience health after living with renal disease for several years and interacting with others and objects in their environment. Third, Kirby and Slevin (1992) state that grounded theory is particularly suited for nursing research as it "embraces the multiple realities and provides an eclectic view of the 'truth,' something that is needed for a discipline such as nursing where its reality is at the interface between humanity and technology" (cited in Sheldon, 1998, p. 49). It was possible, using grounded theory methods, to capture the multiple experiences and perspectives of this group of individuals as they experience health in their day to day living with kidney disease, which often include advanced technology associated with dialysis and renal transplantation. Finally, grounded theory methods have established credibility and have been used by researchers in a variety of disciplines for many years (Strauss & Corbin, 1994,1998).

Data collected from interviews with adults who were diagnosed with ESRD during adolescence was used to generate a substantive grounded theory to explain their experiences with health. During interviews, participants recounted their experiences and interactions associated with having ESRD and the meanings they develop related to their experience of health in spite of having a chronic illness. Data from interviews was analyzed through an inductive and deductive process in the discovery of themes, similarities and differences. Relationships between themes were tested and constantly compared and contrasted with the data until a theory evolved which explained the phenomenon under investigation. Through the examination and conceptualization of the processes that these individuals use to make sense of and give meaning to their experience of health, it was possible to explain how health is
experienced. Grounded theory provides a means for exploring the process of developing meanings and experiences of health and conceptualizing the differences and similarities of these experiences within this particular group. A grounded theory was derived scientifically, creatively, and methodically from the data which represented the phenomenon being studied as experienced and articulated by the participants.

**Sample**

The final sample size was determined by the data collected, the on-going analysis of that data, and the individuals that agreed to participate in this study. The sample was determined by the quality, appropriateness and adequacy of the participants experiences rather than on the quantity of subjects (Strauss & Corbin, 1998). In grounded theory, sampling continues until no new information occurs to suggest new themes or patterns in the data; that is, until the data is saturated. The sample included eight participants selected through purposeful and theoretical sampling techniques. The population of eligible participants from which the sample was obtained was approximately 300. This value was estimated from data obtained from the Canadian Organ Replacement Registry, and the catchment area of the two hospitals involved in this study. However the actual number of potential participants appeared to be considerably smaller because a number of these individuals had transferred their care to agencies outside of the two hospitals. Although still part of the renal program they were not currently followed at the two hospitals. Furthermore, the original estimation did not take into account those individuals who were diagnosed as adolescents but were not longer alive at the time of the study.

**Purposeful Sampling**

Participants were selected based on the nature of their experiences, ability to recall and communicate their experiences, and their receptiveness to share their
experiences with the researcher (Morse, 1986). The target group for this study was adults between the ages of 20 to 35 who were diagnosed with ESRD during adolescence between the ages of 12 to 16. These individuals were currently followed by medical practitioners at post-transplant clinics or at dialysis units and clinics. It is appreciated that including other ages within the adult and adolescent age groups would have allowed for a more detailed description of how health is experienced from the perspectives of adults diagnosed during adolescence; however, the sample was limited to these ages to restrict the sample to a feasible size and to describe the experience of a particular sub-group within all those who were diagnosed as adolescents. In addition, such a restriction limits the variation of treatment that has occurred for ESRD within the past decades. The participants included only those individuals whose kidney failure was the result of primary kidney disease, such as focal segmental glomerular sclerosis, glomerulonephritis, and Henoch-Schonlein purpura, and not the complication of another disease, such as diabetes, lupus, or cystic fibrosis. The investigator believes that individuals who have been exposed to a chronic illness other than kidney disease will have a range of experiences and will have developed ideas of what health and illness means with that disease. This is consistent with the views of Tillich (1961) and Natapoff (1978) who suggest that other experiences with illness affect the way an individual defines and experiences health when a new illness occurs. An individual's experiences with a previous chronic illness has the potential to influence the experience of living with ESRD.

**Theoretical Sampling**

Theoretical sampling principles guided subsequent recruitment following the analysis of the first few participants' interviews. The selection of participants was initially directed with the goal of gaining a beginning understanding of the how health is experienced in adults diagnosed with ESRD during adolescence. Subsequent
participants were sought based on the emerging theoretical themes and concepts developed from the analyzed data. Participants were selected based on their ability to contribute to the needs of the study at that time, to expand on, refute, or test the emerging themes and/or relationships emerging from the data. For example, in initial interviews, participants indicated that their relationship with others who had ESRD was influential in their experiences, therefore an attempt was made to locate people who knew others with ESRD at the time of their kidney failure and those who did not. Furthermore, theoretical sampling allowed for previously unforeseen lines of questioning to be pursued, which enabled a closer inspection of the phenomenon being studied. Theoretical sampling was also directed by the reviewed literature. For example, the literature suggested that gender influenced the self-image of individuals with kidney transplants, with young females experiencing greater difficulties with self-image than do males. Therefore, the investigator aimed to have equal numbers of male and female participants. Through simultaneous theoretical sampling and the making of comparisons, emerging themes and relationships were tested and compared with subsequent data regarding similarities and differences of the themes and relationships.

Theoretical sampling was done with the aim of making comparisons between people with diverse educational, occupational, cultural, and socioeconomic backgrounds. Furthermore, an effort was made to select participants having various marital statuses, first languages, and who came from various residential locations. The sample was not restricted in any way to the level of present kidney function, and was selected from those eligible participants on hemodialysis, peritoneal dialysis, and those with functioning kidney transplants. Including participants who received different treatment modalities, as well as those with diverse socioeconomic and cultural backgrounds, allowed for maximum variation in experiences from which to derive the
theory (Strauss & Corbin, 1998). Given the constraints of time and access to specific participant variables, it was not possible to have all these variables represented in the eight participants in this study. However, the aim of theoretical sampling was to include as many participant variables as possible. The description of the sample in the results section includes the participant variables that were represented in the study. In addition to a description of the sample, an introduction to each of the eight participants is provided in the presentation of the findings chapter.

**Procedure for Approaching and Informing Participants**

Following ethics approval from the behavioural Research Ethics Board of the University of British Columbia and the In-hospital Research Review Boards for the two hospitals from where participants were recruited, meetings were arranged with a contact person, either a nurse or a physician, in the renal programs to explain the study, the selection criteria, and recruitment strategies. The contact person was asked to approach potential participants who met the selection criteria and provide them with an introduction letter (Appendix A) that was prepared by the investigator. The introduction letter provided an outline of the study and explained that individuals interested in participating or requiring further information should contact the investigator by telephone. Additionally, a poster describing the study and inviting participation (Appendix B) was displayed at out-patient waiting areas of transplant follow-up clinics and dialysis units at the two hospitals.

Further explanation of the study and a chance to answer questions regarding the study was provided by the investigator by telephone with potential participants who express an interest in being involved. When a potential participant agreed to be involved, an informed consent form (Appendix C) was signed. Theoretical sampling of participants that were not previously identified was done by presenting the contact person with a description of the desired participant characteristics. The contact person...
was asked to approach persons meeting those criteria for possible inclusion in the study.

**Data Collection Setting and Procedures**

Data was collected through two interviews with each of the eight participants. Data collection took place at a mutually agreed upon time and location. Every effort was made to make the interview experience as convenient as possible and privacy was considered of utmost importance. To establish rapport and trust, participants were assured that confidentiality would be maintained and no original names, obvious demographics or identifiers would be used in any presentation of the study findings. The participants were informed that they could rescind any information that was disclosed at anytime during the study. It was stressed that there were no correct answers, that people respond to a chronic illness in a variety of ways, and that the participants were the experts about their experiences. A brief introduction to the study, the reasons the study was undertaken, and how the results would be used was provided. Once the investigator felt that the participant's questions had been answered and that he or she fully understood the study, the data collection began. Participants were asked if they would agree to have the session tape recorded.

Initially, participants were asked a series of questions to obtain demographic information (Appendix D). This data was used to describe the sample. Data was collected using open ended questions following the semi-structured interview guide developed for this study (Appendix E). Initially, open-ended questions were used that focus on the participants’ experiences with health and their perspectives of how their experiences with health have developed or changed over time. Using interviews to collect data helped the investigator to understand the phenomenon in question from the perspectives of the participants (Hutchinson, 1993). Additional questioning was kept to a minimum and was directed at encouraging the participants to elaborate upon
information and to ensure comprehensiveness of the phenomenon being studied. The interviews were flexible in scope and depth. Probing, paraphrasing, hypothetical questioning and silence were used to encourage an in-depth expression of the participants' experiences. Flexibility was appropriate for these interviews for which the investigator did not already know the most significant feature of the phenomenon under study (Polit & Hungler, 1993). Furthermore, flexibility with the interview structure allowed for a more natural description of participants' experiences. Interview questions were evaluated and revised after the first couple of interviews in order to more appropriately elicit information. Furthermore, adjustments were made to the interview questions based on the analysis of data previously collected so that specific phenomenon identified in earlier interviews could be developed with subsequent participants. At the conclusion of the interviews, participants were thanked and reminded that they could contact the investigator at any time if they had any concerns with any aspects of the study. The transcripts were transcribed verbatim. To ensure accuracy of the transcription, the investigator listened to the tape while reading the transcript, making notations of any inconsistencies and indicating any "meaning-filled pauses or displays of emotion" (Swanson-Kauffman, 1986, p. 62).

Once the transcripts had been reviewed and analyzed, a second interview was arranged with the participants. During these second interviews, the investigator followed-up on significant themes that were identified in the first interview, verified the interpretations of the first interview, and asked for commentary on the findings developed from the analysis of interviews with other participants. Second interviews allowed the investigator to determine if she interpreted their responses accurately, to clarify areas that were uncertain, and/or to expand on any of the information participants had previously given. Asking participants to reflect on concepts derived from others' interviews allowed the investigator to ascertain if they had similar
experiences and perspectives.

**Data Analysis**

The transcribed interviews were entered into the computer assisted qualitative data analysis program, NUD*IST (Non-numerical Unstructured Data. Indexing, Searching and Theorizing). The computer program is capable of processing, storing, cataloguing and sorting data (Richards, 1998). Through the program, data could be coded, recoded and/or grouped according to themes based on the analytical work of the investigator. The program facilitated and expedited the tasks associated with data handing, allowing the investigator more time to spend analyzing, conceptualizing, and theorizing (Morrison & Moir, 1998).

Strauss and Corbin (1998) identify three levels of analysis in grounded theory methodology: open coding, axial coding, and selective coding. Analysis takes place simultaneously with data collection. The first level, open coding, involved the identification of codes, categories and the properties and dimensions of the categories. The second level, axial coding, involved developing the categories beyond their properties and dimensions to include the conditions, contexts, actions/interactions, and consequences associated with them. Hypothetically proposed relationships were developed among and between categories. These relationships were tested by using theoretical sampling and the making of comparisons. The third level, selective coding, involved the identification of a core variable which represented the main theme occurring in the data. Once a core variable had been identified, subsequent data collection and analysis was conducted with the aim of relating the data to the core variable. Through theoretical sampling and the making of constant comparisons, all data was related to the emerging themes and the core concept.
Open Coding

The first level of coding, open coding, involved the conceptualizing, and categorizing of the data (Strauss & Corbin, 1998). Codes were identified along with their properties and dimensions. By examining these properties and dimensions, codes were grouped into categories. Refining the categories in terms of their properties and dimensions allowed for the determination of initial subcategories which helped to clarify the meaning and give depth to the categories.

Open coding began after the first interview. The first step was to read the interview in its entirety to determine its overall theme. The interview was then examined line by line to identify codes that related to the overall theme. Each segment of dialogue was broken into as many possible meaningful codes so that each incidence and fact was coded to ensure theoretical coverage. Every piece of information was given meaning, examined and compared with other codes to discern similarities and differences (Strauss & Corbin, 1998). These codes were as simple as possible and were labeled using key words that represent, summarize, and directly relate to what the participant had said. Participants' own words were used as labels, when possible, to minimize the possibility that what the participant said was not inadvertently superimposed with the investigator's interpretations (Donovan, 1995). For example, a participant indicated it was important to appear normal like his peers. The term "normal like peers" was used as the label for this concept. Every labeled code identified was compared and contrasted with other codes to expose the meaning and to allow for categorization. Those that had similar properties were given the same name and placed into the same code. For example, a participant stated that he wanted to keep up with his peers that were normal. This concept was placed in the code labeled "normal like peers" as they shared the property of being like peers that did not have an illness. Initial codes were treated as provisional and were essentially
descriptive summaries of the respondents own accounts and remain provisional until they were supported by all the data (Strauss & Corbin, 1998).

The second step of open coding involved discerning the properties and dimensions of the codes. This began when a number of codes had been identified. The data was further examined to gain a greater understanding of the code and to determine its properties and dimensions. This involved asking analytical questions to break apart the code to discern the range of potential meanings associated with the words used by the participants (Strauss & Corbin, 1998). The investigator asked questions of the data, such as, "what is going on here?, what does this represent?, what else could it mean?" For example, "normal like peers" could have meant a number of things, such as being free from symptoms, being treated like someone without kidney disease, or being able to lead an independent life free from dialysis or medication. Once these questions had been thought through and a number of various meanings associated with the code had been identified, the investigator then reflected on whether the label chosen was relevant and described what it intended to describe. If it did not, existing and new data, and the properties and dimensions were searched until an appropriate label was identified that adequately depicted the concept.

The third step, developing categories, involved grouping the codes that related to the same concept into categories based on what they shared in common and their ability to explain what was going on (Strauss & Corbin, 1998). Codes were sorted into more abstract higher ordered concepts that suggested an underlying theme, and shared similar properties and dimensions (Strauss & Corbin, 1998). Categories were developed by asking what each code might indicate and then comparing it with all other codes to determine how they were similar or dissimilar, and what similar properties and dimensions the codes shared. Through a constant comparison, every
code was compared with every other code and categorized accordingly so that each category explained the data, described a unique thought, and denoted underlying patterns. "Categories are concepts, derived from data, that stand for phenomena...phenomena are important analytic ideas that emerge from [the] data." (Strauss & Corbin, 1998). The categories were labeled to reflect the data allocated to it. By examining the similarities and differences between the labeled codes, it was possible to determine similar attributes of the codes and then to group them together in a category. For example, the codes "fluid overload," "restlessness," and "hypotension" were grouped into the category of "symptoms of kidney failure."

Another source of concepts for the development of the theory was from the literature. Concepts in the literature were identified that helped to extend the identification of concepts in the data. Concepts in the literature were determined to be relevant to the data by examining their similarities, differences, and ability to extend the data (Strauss & Corbin, 1998). For example, much has been written about normalcy. The literature pertaining to the concept of normalcy was compared with the concept of "normal like peers" and "normalizing" in the data to determine the similarities and differences of the concepts.

The fourth step involved refining the categories in terms of their properties and dimensions. To develop the properties and dimensions of the categories, the investigator defined what was meant by the category by asking questions related to the how, why, and when this phenomenon occurred. By analytically examining the categories, their properties and dimensions became evident. The concepts in the category "symptoms of kidney failure" shared the general property of physical manifestations of kidney disease. The concepts within this category were then examined in terms of their dimensions. For example, how long did the symptom last, when did it occur, and how intense was it? All the concepts in the category varied
along these dimensions. Fluid overload could be mild to severe, or occur at anytime, whereas hypotension most often occurred during or immediately following dialysis. Through this clustering of codes and determination of their properties and dimensions, it became clearer how codes integrated with one another and described the phenomenon evolving from the data. The categories were then compared at the level of their properties and dimensions to ascertain similarities and differences to ensure that the categories were mutually exclusive. "Through the delineation of properties and dimensions, we differentiate a category from other categories and give it precision" (Strauss & Corbin, 1998, p. 117).

The final step of open coding involved identifying subcategories. Subcategories are sub-groups of categories that denote information about a category such as the why, where and how a phenomenon is likely to occur (Strauss & Corbin, 1998). For example, subcategories of "normal like peers" included "physical," "psychosocial," or "functional" based on the specific properties the subcategories demonstrated. The subcategory "functional" indicated that people felt normal when they could take part in desired social events. The subcategory "physical" indicated that people felt normal when they did not experience physical symptoms of illness or could hide their symptoms.

Theoretical sampling throughout the procedures of open coding was aimed at exposing as many codes and categories as possible. Categories that emerged from interviews were tested in subsequent interviews with additional participants to evolve their meaning. Additional categories were searched for in the present data and in additional data obtained from participants that were theoretically chosen. For example, to further develop the meaning of the category "symptoms of kidney disease" sampling included individuals undergoing various treatment modalities to see if they experienced similar symptoms and whether the properties and dimensions of the
symptoms were the same or different. When new information was uncovered in the
data that was not explained by previous categories or subcategories, then the
category or subcategory was modified or a new category or subcategory was
formulated.

**Axial Coding**

The second level of coding, axial coding, involved the reconstruction of the
data, whereby conceptual links were made between categories (Strauss & Corbin,
1998). Coding occurred around the axis of the category linking categories at the level
of their properties and dimensions. Through this process, subcategories were clarified
and further developed to give greater depth and meaning to the category.
Relationships between different categories and between categories and their
subcategories were posed, tested and verified.

The first step of axial coding involved laying out the properties and dimensions
of a category. During open coding, a number of categories emerged through the
process of delineating properties and dimensions of the categories. The conditions
that gave rise to the category, the context in which it occurred, the actions/interactional
strategies by which it was managed, and the consequences of those strategies were
examined. By coding around a category, the relationships inherent in the
phenomenon began to emerge.

The second step of axial coding involved identifying the various conditions,
contexts, actions/interactions and consequences associated with a phenomenon.
Through the process of examining the conditions, contexts, actions/interactions, and
consequences associated with a category, subcategories became more apparent and
developed. Categories represented the phenomenon, whereas subcategories
explained the when, where, why, who and with what consequences the phenomenon
occurred. The conditions, contexts, actions/interactions and consequences associated
with a phenomenon delineate the subcategories. Subcategories were related to the
categories in terms of their properties and dimensions to give a greater depth of
meaning to the phenomenon examined. Through intense focusing on each category,
relationships within data emerged explaining under what conditions the phenomenon
occurred and in what contexts. The actions and interactive strategies used to handle
the phenomenon and the consequences of those actions/interactions became
apparent.

Similar to the process used during open coding for codes and categories,
subcategories were developed in terms of their properties and dimensions. For
example, the subcategory “functional” of the category “normal like peers” had the
property of perceived functional ability. By examining the dimensions of that
subcategory, it became apparent that there was a range of possible meanings
associated with being normal from taking part in desired activities all the time to none
of the time. Through this process, subcategories began to look different and explained
different aspects of the phenomenon when they were compared at the dimensional
level. For example, the subcategory “physical” had the property of physical
manifestations. When the dimensions of this subcategory were examined, it became
apparent that possible meanings ranged from lots of physical symptoms to no
symptoms. Because this subcategory could have been related to the category
“symptoms of kidney disease,” these concepts were compared and contrasted. The
end result was to incorporate the category of “symptoms of kidney disease” together
with the subcategory “physical” because they both related to physical manifestations.

By looking for themes and patterns and using the coding paradigm of
examining the conditions, contexts, actions/interactions and consequences, the
structure and process occurring around the phenomenon became apparent. The
conditions and context around which a phenomenon was observed provided the
structure, whereas the actions/interactions used to deal with the phenomenon and the consequences associated with the actions/interactions in that condition formed the process taking place around the phenomenon. For example, to feel healthy, one of the participants used the strategy of limiting fluid intake and the consequences of this action resulted in a lower fluid gain and less symptoms, thereby allowing her to take part in desired activities. It was then necessary to examine other actions/interactions and consequences associated with various conditions. Examining how participants dealt with fluid and diet during a social event and the consequence of their choices were examined to ascertain if the actions/interactions and consequences of those actions were similar or different depending on the condition and context around the phenomenon. By examining various conditions, contexts, action/interactions and consequences, relationships in the data began to emerge and became clearer.

The third step of axial coding involved relating categories to their subcategories by developing hypotheses about the relationships between categories and subcategories. Relationships in the data began to emerge during the process of open coding and through the process of relating categories to subcategories. The linking of a category with its subcategories was done at the level of their properties and dimensions to generate dense, well developed and related categories. Hypotheses regarding the causal conditions were developed that conceptualize the meaning and relationships between the categories, their conditions, contexts, actions/interactions and consequences. Proposed relationships were based on the analyzed data and relevant literature pertaining to the emerging concepts. By asking questions central to the coding paradigm, questions or statements were proposed relating subcategories to a given category or categories with other categories. Hypotheses were posed to explain the what, why, where and how of a phenomenon. For example, a hypothesis was generated suggesting that adolescents did not comply with their diet at social
gatherings in an attempt to appear like their peers and to feel more normal, and it was hypothesized that for a person to feel normal at a functional level, they needed to be able to take part in desired social activities. These hypotheses were treated as provisional until supported by the data.

The final step involved the testing of the proposed hypotheses. Hypotheses regarding the relationships between the categories, and between subcategories and categories were proposed and tested through theoretical sampling and constant comparison analysis of existing and incoming data. This involved examining the emerging relationships by examining existing data and asking participants to clarify and validate these proposed relationships. Sampling was done to maximize differences, to enhance understanding, and to verify the emerging relationships (Strauss & Corbin, 1998). Literature was reviewed pertaining to these relationships and was used to support, expand on, or used to generate additional questions to test the hypotheses. Hypotheses generated were considered with due skepticism, and were tested and verified by performing comparisons with previous data and new data.

**Selective Coding**

The third level of coding involved selective coding. Throughout the process of selective coding, themes were identified through the close and detailed examination of categories and their relationships. A core variable emerged which was then theoretically related to other categories. Data collection and analysis continued with the goal of saturating the data. A grounded theory was developed that explained the phenomenon being studied.

The first step of selective coding involved the identification of a central theme or core variable. A core variable eventually emerged through the process of identifying and developing categories and posing and testing relationships. The core variable became apparent as it occurred repeatedly in the data, explained most of the variation
in the data, and inextricably linked the categories, their properties and dimensions, and the relationships between the concepts (Hutchinson, 1993).

The second step of selective coding involved theoretically relating the core variable to other categories through their properties, dimension, conditions, contexts, actions/interactions and consequences. By critically examining the emerging theory, identifying gaps, examining the proposed relationships, and questioning hypothesis, existing and new data was searched to find instances that helped to explain any inconsistencies or gaps in the theory. The theory had precision and density when all aspects of the categories and their relationships were considered and compared with the data (Strauss & Corbin, 1998).

The third step of selective coding involved saturation of the data. This involved examining all categories and relationships to ensure that no additional information was identified to indicate new categories or relationships or the expansion of existing ones. Sampling during selective coding focused on clarifying and verifying concepts of the theory until the data was saturated. The data was saturated within the eight participants, however, it is anticipated that additional codes, categories, and relationships may have emerged with additional subjects. Specifically subjects of different cultures and ethnic backgrounds may have expanded on the concepts of the theory. However due to time constraints and the limited number of participants that contacted the investigator for involvement in the study, the data did not reach saturation beyond the eight participants.

The final step of axial coding involved presenting the grounded theory as both a descriptive narrative and a graphic representation describing the central phenomenon, categories, and relationships between the components. A grounded theory was developed that describes how health is experienced from the perspectives of adults who were diagnosed with ESRD during adolescence.
Detailed memos and diagramming of the concepts and relationships emerging during the three levels of coding was used to record the progress of the analysis, thoughts and feelings, and direction taken during the research process, and provides a trail of the logic used to develop the theory (Strauss & Corbin, 1998).

**Memos**

Memoing was used to maintain ideas pertinent to the emerging concepts, hypotheses, analytical scheme, hunches, and abstractions (Strauss & Corbin, 1998). Throughout the entire data collection and data analysis process, memos were kept regarding ideas about the coding, theorizing and operations carried out throughout the study so that it is possible to track and recall the analytical process that took place in the development of the theory (Strauss & Corbin, 1998). Detailed memoing provided a means of retaining ideas about sampling, what questions to ask, which literature to consult, and the analytical processes used to analyze, interpret, and theorize about the data. During open coding, memos focused on initial impressions, thoughts, ideas, and direction for further sampling and analysis. During axial coding, memos focused on the development of subcategories by answering the questions of what, when, where, with whom, how, and with what consequences. During selective coding, memos focused on saturating categories, identifying the core variable, relating the core variable to other categories, and refining the theory.

**Diagrams**

Throughout the process of open, axial, and selective coding, thoughts about the emerging concepts and relationships were graphically represented. Initially, a list of codes and categories were generated from the open coding process. As the analysis progressed during axial coding, diagrams were simple and denoted emerging relationships between categories. The diagrams became more complex
and sophisticated as relationships were further developed and tested. During selective coding, diagramming depicted the density and complexity of the theory. Diagramming allowed for identification of gaps in the theory and breaks in logic. The core variable, major concepts, and relationships pertinent to the phenomenon were depicted. The final diagram provides a graphic representation of the phenomenon and includes the core variable, major concepts, and the relationships between the components of the theory.

**Theoretical Sensitivity**

Theoretical sensitivity refers to the attribute of having insight, the ability to give meaning to data, the capacity to understand, and the capacity to separate the pertinent from that which isn't...it is theoretical sensitivity that allows one to develop a theory that is grounded, conceptually dense, and well integrated (Strauss & Corbin, 1990, p. 42).

A researcher who has developed theoretical sensitivity to the phenomenon being studied can creatively examine new ways to look at the data. Researchers often have a degree of sensitivity to the area being studied by reading previous literature on the phenomenon being studied and/or by personal and professional experience with the subject area (Strauss & Corbin, 1990). The investigator approached this study with sensitivity to the phenomenon through her personal experience with kidney failure, her work in a nephrology research department, and the reading she had done during the review of the literature in chapter two. Further theoretical sensitivity was developed through close and prolonged engagement with the data during data collection, theoretical sampling, constant comparison analysis, and review of existing literature relevant to the concepts that emerged in the analysis.

In order to arrive at impartial and accurate interpretations of the data, it is necessary for a researcher to maintain a balance between objectivity and sensitivity...
(Strauss & Corbin, 1990). The investigator attempted to achieve this balance by following the suggestions outlined by Strauss and Corbin (1990) and periodically stepping back, maintaining an attitude of skepticism, and following the research procedures. The investigator frequently stepped back from her interpretations to examine whether or not her interpretation of what was going on was in fact the reality of the situation. This was done by comparing her interpretations of the data with existing interviews and interviews with participants that were identified through theoretical sampling. Theoretical sensitivity was ensured through questioning of the proposed relationships in the data and by identifying assumptions made during the interpretation of the data and the analysis. All concepts and relationships identified from the data were treated with skepticism and remained provisional until they were supported and tested through existing and new data. The third suggestion provided by Strauss and Corbin (1990), which was followed, was the strict adherence to the grounded theory methods described in this chapter.

**Ethical Considerations**

Attempts to ensure the participants' rights were made through the submission of the study proposal to the behavioural Research Ethics Board of the University of British Columbia and the In-Hospital Research Review Committee of the two hospitals involved. Potential participants were not approached nor was any aspect of the actual study begun until approval had been obtained. Contact with potential participants who met the study criteria was formally made through the introductory letter (Appendix A) provided to them by nurses or physicians at the hospitals who were identified as contact persons. Direct contact with the participants for the purpose of enrolling in the study was made once an individual had indicated a desire to learn more about the study and possibly become involved. Furthermore, all subjects were informed of their rights to refuse to participate or withdraw from the study at any time without any
consequences. Once the study had been explained to the participants and the investigator believed they have all the pertinent information, the consent form (Appendix C) was signed and a copy given to the participants.

Confidentiality was maintained through the careful handling of tapes, transcripts, and any documents that contained the name of the participants. All study data was locked in a filing cabinet in the investigator’s home. Data contained in the computer did not indicate the true identity of the participants, and was protected by a password known only to the investigator. An alias was assigned to each participant. These aliases were used in the labelling of tapes, in the transcripts, and on the demographic forms and only the investigator knew the true identity of each participant. These aliases are used in the thesis report, and will be used in future publications and presentations to ensure ongoing participant confidentiality. Furthermore, any obvious demographic data was not used that could identify the participants. The participants were provided with a written summary of the findings.

**Methodological Rigor**

"Rigor in qualitative research is associated with openness, scrupulous adherence to a philosophical perspective, thoroughness in collecting data, and consideration of all the data in the subjective theory development phase" (Burns & Grove, 1993, p. 64). Guba and Lincoln (1981) argue that rigor in qualitative studies is measured by truth value, applicability, consistency, and neutrality. These aspects of rigor are discussed based on the work of Sandelowski (1986).

**Truth Value/Credibility**

In grounded theory, truth value or credibility refers to the ability of the theory to describe the experiences of a group of people so that individuals of that group immediately recognize the experience as their own (Sandelowski, 1986). Stern (1985) suggests that a quality grounded theory must be credible because it is derived
directly from the data. When conducting grounded theory, investigators may become so engrossed in the data and the interaction that they may be unable to distinguish between their experiences and that of the participants, and consequently misinterpret the participants' experiences. Attempts to ensure credibility were made by presenting the findings to participants on an ongoing basis during data collection and analysis and asking participants if the findings are representative of their experiences. Furthermore, the presence of the investigator and the nature of the interaction may affect the way the participants respond to the researcher and vice versa. Paterson (1994) refers to this as reactivity.

**Reactivity**

Reactivity may affect the process, the responses of either the investigator or participant and consequently the content and nature of the interview. Paterson (1994) identifies five common areas of reactivity which were considered with regard to this study. These include: emotional valence, distribution of power, the goal of the interaction, perceived importance of the interview by both the investigator and the participant, and normative or cultural criteria.

Emotional valence represents the feelings of the investigator and the participant towards each other. Feelings such as trust, comfort with certain topics, empathy, friendship, or other feelings towards each other may affect the way the investigator and participant respond to each other. Considering the feelings that might have occurred during the data collection or data analysis, an attempt was made to establish trust in the interviews by ensuring participants of the study's confidential nature. They were assured that there were no correct answers, but that they were the experts of their experiences, and that the investigator was seeking a variety of experiences from a number of people. The investigator used a daily journal to document her own feelings and those she believed the participants experienced during the study, along with how
these feelings may have affected the interaction, and/or the analysis. The investigator believes that the participants were comfortable with the interactions and felt safe in revealing their feelings and thoughts. Participants appeared to be open with their comments. If anything, the interaction was strengthened by the shared experience with ESRD of the investigator and participants who were aware of the investigator's kidney disease.

The second area of reactivity involves the distribution of power that either the investigator or the participant perceives to exist (Paterson, 1994). Participants may perceive the investigator to have more power over them because of the role as researcher, or because the participant has provided the investigator with information regarding their illness and their experiences. A participant may feel vulnerable and consequently not share certain information or they may alter their responses to please the investigator. In this study, some of the participants knew that the investigator was a fellow kidney patient and this affected the way in which they responded to her. Participants may share information with the investigator because they are trying to be liked, or the investigator may share personal information with participants in an attempt to get them to open up. Attempts to even the power distribution were made by reassuring the participants that they possessed information that the investigator did not have, that people experience things differently, and that any information the participants wished to relay was valuable in understanding their perspectives. Furthermore, the investigator avoided using "professional jargon" that might have intimidated the participants or that they might not have understood. The investigator's perceptions regarding the distribution of power and its effects on the questions and responses were documented and reflected upon in her daily journal. Some participants appeared to be affected by a perceived power distribution, often agreeing to the investigator's interpretations of the data without questioning, whereas others
seemed to openly question her interpretations. When interpreting the responses, consideration was given to the responses and the affects of the perceived power distribution.

The third area of reactivity, discussed by Paterson (1994), involves the goal of the interaction. The goal of the interaction for the investigator and for the participant may be very different. Furthermore, the investigator may not be clear in describing the goal of the study, or the participant may misinterpret the goal. The participant may have ulterior motives for participating in the study which may be expressed or of which the investigator is not aware. For example, in this study a participant on the waiting list for a kidney may have seen the investigator as an opportunity to gain knowledge about how recipients were selected or how long the wait would be, believing that she had this information. To ensure that the participants understood the goal of the interaction, time was taken to describe the study and what the investigator hoped to gain from it. Thoughts and perceptions regarding participants’ possible motives and thoughts, along with the stated and unstated goals of the interaction were documented and reflected upon in her daily journal. It did not become apparent to the investigator that any of the participants had ulterior motives beyond wanting to advance research in this area.

The fourth area of reactivity is the importance of the interaction. The perceived importance of the study or the interaction may affect the responses of either the investigator or the participant (Paterson, 1994). A participant may neglect to mention experiences that he or she believed to be unimportant to the investigator or the phenomenon under study. Furthermore, a participant may believe that the investigator already has the knowledge and understanding of the topic and therefore believe it is unnecessary to mention. This may also be true for the investigator who may believe that she has sufficient knowledge and understanding of the experience and therefore
may neglect to ask the participant about experiences in that area. For example, upon sharing the interviews with her advisor, it became apparent that there were certain times that the investigator did not further explore certain areas because she believed she understood, from her own experiences with kidney disease, what the participants meant. Furthermore, Paterson (1994) suggests that the researcher who is tired or bored may unintentionally portray a disinterest in the participant, his or her responses, or the phenomenon under study. The same is true for the participant who is bored, tired, or unable to stay focused during the interview. For example, one of the participants was very tired as she had been studying late the night before and appeared preoccupied with the time as she had to be somewhere that afternoon. She was unable to concentrate on the subject being discussed because of the tiredness and preoccupation. In an attempt to consider the effects of the perceived importance of the interaction by the participant, the investigator tried to stay focused and to appear interested in all aspects of the interaction. Furthermore, the investigator was aware of the level of concentration and interest on the part of the participant in the dialogue taking place. The level and type of responses, and the body language displayed by the participant was noted. Based upon an evaluation of the interaction at the time, it was necessary in some instances to prematurely end the interview and postpone it to another time. In accordance with the constant comparative method of data collection and analysis, this time was used to analyze data already collected which led to a rejuvenated motivation to collect more data to answer some of the issues that came up in the analysis. Thoughts the investigator had about the perceived importance of the interaction by the participant or herself, possible reasons for this perception, and any effects it might have had on the interaction were documented and reflected upon in her daily journal. It appeared to the investigator that all the participants believed the experience of health in adults diagnosed with ESRD during adolescence was an
important topic to study. However, there were instances where the investigator's and
the participants' responses may have conveyed a disinterest in the topic of
conversation because of the timing of the interview. There were times when the
participants were tired and/or focused on the time because they had another
appointment. In one instance the investigator was preoccupied with the tape recorder
because it had been malfunctioning.

The final area of reactivity discussed by Paterson (1994) involves normative or
cultural criteria. When considering this area of reactivity one must take into account
what is considered the standard or normal behaviour when interacting with another
person. The beliefs and values of the other person must be respected to ensure that
trust and sensitivity are observed. Additionally, the investigator as a nurse may feel
obligated to interact in a way that is the standard or "norm" for a nurse. Therefore,
when interacting with all participants, the investigator was sensitive to the effects of the
questions she asked and the responses given by the participants. In considering the
effects of the normative and cultural criteria of both the investigator and the participant,
a respectful and sensitive approach when interacting with participants was
maintained. Questions were asked and responses given were conveyed in a sensitive
and respectful manner in an attempt to create a safe environment for the participant.
Furthermore, when participants had questions or issues that came up that needed to
be addressed which the investigator did not have information about or that she
believed required professional intervention, the investigator directed the participant to
the appropriate health care professional in the renal program. The investigator
documented in her journal any perceptions she had regarding the effects of the
person's culture or behaviour, or her culture, behaviour, or role as a nurse on the
interaction.
Applicability/Fittingness

Another criteria of rigor in qualitative studies, as described by Sandelowski (1986) and based on the work of Guba and Lincoln (1981), is the applicability or fittingness of the study. The fittingness of a study refers to its generalizability.

Hutchinson (1993) suggests that a “quality theory” can predict a basic process that may be applicable to others. A study meets the criteria of fittingness “when it’s findings can fit into context outside the study situation and when its audience views the findings as meaningful and applicable in terms of their own experience” (Sandelowski, 1986, p. 32). To ensure the fittingness of this study, data was searched for typical and atypical occurrences and for occurrences that confirmed or disproved the investigator’s findings, to ascertain whether the investigator’s interpretations of the data were accurate, whether aberrant events were interpreted as typical, and whether the investigator made accurate assumptions regarding the equivalence of experiences.

The investigator coded, categorized, and developed relationships from the data and present them to her thesis advisor for feedback regarding her interpretation of the data. Moreover, throughout data collection and analysis, the findings were presented to the participants to determine whether the investigator’s findings were a true representation of their perspectives and experiences. Participants are the best judges to determine if the emerging codes, categories and relationships are reliable because they “serve as the most reliable judges of their reality of the situation under study” (Stern, 1985, p.150). However, Sandelowski (1993) argues that there are a number of complexities with this form of member checking that ought to be addressed. When member checking, the investigator must be aware that the stories articulated by the participants are based on their recollections of past events, which are conveyed in a short time with little time given to think about their importance. When given time, new
experiences and the act of reflecting upon the story told in a previous interview, the participant may see the experience in a different way (Sandelowski, 1993). Feelings previously experienced within the context of the interview and the interaction taking place at the time may no longer be valid, may be regretted, and/or forgotten during the member checking process (Sandelowski, 1993). Furthermore, Sandelowski argues that the investigator's abstract synthesis of the interpretations of the participants' experiences may not be viewed by the participants as representing their concrete experiences.

Strategies suggested by Sandelowski (1993) were used by the investigator to combat the problems associated with member checking. The investigator was aware of the language used and the abstract level of the information being checked with participants. The investigator was also aware of the context in which the original data was elicited in an attempt to frame the questions appropriately and consistently with the original context. Information was presented in a simple form using lay language to make the information understandable and relevant to the particular participant's experiences with whom the investigator was conducting the member checking process. When discrepancies arose, the investigator critically examined the discrepancies and the context and interaction that had taken place at the time the information was first given and at the time of member checking. Decisions were made based on this critical examination as to whether true discrepancies existed, whether the discrepancies represented the same story, or whether they were variations on the same phenomenon. Decisions were made regarding the analytical importance of each discrepancy; that is, was it important to resolve the issue of a particular discrepancy to maintain theoretical soundness of the phenomenon in question?

**Consistency/Auditability**

Auditability is another area of methodological rigor that must be addressed and
pertains to the consistency of the study (Guba & Lincoln, 1981). Consistency is achieved through auditability and the use of an audit trail. The uniqueness and variation of human experiences which is critical to grounded theory necessitates that the consistency of a study depend largely upon the investigator's ability to accurately interpret the phenomenon under study and to then describe how the theory was derived so others can follow the logic involved (Sandelowski, 1986). To achieve auditability, the investigator must detail all of the decisions involved in the rationale, the data the decision was made on, the investigator's perspective of the data, and the evolution of the findings, with regard to the coding, categorizing and construction of relationships between data during analysis. "This reporting should be in sufficient detail to allow a second researcher, using the original data and the [audit] trail, to arrive at conclusions similar to those of the original researcher" (Burns & Grove, 1993, p. 661). To maintain auditability, an audit trail was developed for this study. This included the decisions made, the rationale for those decisions, the data involved in the decisions when making interpretations of the data, and classifying it into codes, categories, and relationships. The decisions were shared with the investigator's thesis advisor for her interpretations of the data using the audit trail, and depending on the feedback, the interpretations and/or the audit trail were modified to allow for a more accurate and consistent audit trail.

**Neutrality/Confirmability**

The final area of rigor discussed by Sandelowski (1986) involves the neutrality or confirmability of a study (Guba & Lincoln, 1981). Confirmability in grounded theory refers to an unbiased theory that is derived from the interaction between the investigator and the participant. According to Sandelowski (1986), confirmability is achieved "when auditability, credibility, and applicability are achieved" (p. 33) Although the investigator or the participant may have biases or preconceived ideas of
how the theory will evolve, a rigorous adherence to the analysis of all data, and the
process of looking for occurrences that support or negate the emerging theory should
result in a theory that describes human experience in the phenomenon under study.
To ensure confirmability, the previously discussed strategies to ensure credibility,
fittingness, and auditability of the study were utilized. Furthermore, the investigator
tried to be aware of instances in which she might have given more credibility to one
informant over the other, and times when she believed biases, values, or beliefs
influenced the collection or analysis of the data. These issues were discussed with
her thesis advisor as to their effect on the development of the theory.

Limitations

One limitation of this study that could be foreseen prior to its actual conduct is
that of generalizability. Findings from grounded theory methodology cannot be
generalizable to other sample populations due to the purposeful and theoretical
sampling methods. Furthermore, the participants who volunteered to participate in this
study might have had specific characteristics which non-volunteers did not have.
Those who chose to participate may have had a desire to help advance knowledge in
this area and/or they may have come to terms with their disease. Also, volunteers may
have had a variety of motives to becoming involved which did or did not become
apparent. Those who declined to participate may have had issues with being a
research subject, had aspects of their medical condition that prevent them from being
able to participate, or had not come to terms with their disease and wished to avoid
focusing on the disease in such a study. Furthermore, non-volunteers may have
chosen not to participate in this study because they may have had knowledge that the
investigator was a fellow kidney patient and/or because she worked with their health
care providers. For these reasons, they may have been reluctant to give her personal
knowledge of their kidney disease or aspects of the care they receive.
An additional limitation of this study that may be present is the inability to attain saturation of the data. Constraints related to time, finances, and subject recruitment resulted in the investigator having to halt data collection and analysis before all participant variables could be sampled. The investigator did obtain saturation of the categories within the eight participants. By the last few interviews, no additional data had emerged to indicate additional codes, categories, themes, or relationships. However, additional information may have emerged with additional participants, particularly those from other countries of origin and languages.

**Summary**

In this chapter, the research method of grounded theory which was used for this study, along with the rationale for choosing it, has been presented. A description of sampling techniques using purposeful and theoretical sampling, as well as the method for approaching and informing participants has been outlined. The process of data collection and analysis was done through theoretical sampling and constant comparisons, which was in accordance with grounded theory principles. The strategies used to develop theoretical sensitivity were outlined, as was the process and use of memoing and diagramming. Furthermore, issues regarding ethical consideration, methodological rigor, and limitations of the study have been presented.
CHAPTER FOUR: PRESENTATION OF THE FINDINGS

The findings of the study are presented in this chapter. It begins with a description of the sample and includes demographic information and renal history for the eight participants. An introduction to each of the participants, "Alex," "Ben," "Jeff," "John," "Josiah," "Mary," "Maureen," and "Natalie," who shared their experience with kidney failure is presented. This introduction includes a brief description of who they are and an outline of their personal experience with kidney failure.

Following this, the major themes developed from the participants’ stories, as shared with the investigator, are presented. The data was analyzed, coded, and grouped into categories that emerged throughout data collection. These categories and the relationships between them were presented to the participants in second interviews to modify, further develop, and/or refine the themes. The themes that were validated by participants are 1) Diagnosis in Adolescence, 2) Having a Sense of Control over ESRD, 3) facilitators of Having a Sense of Control, 4) Threats to Having a Sense of Control, and 5) Descriptions of the Concept “Health.” The discussion of the findings begins with the participants’ descriptions of diagnosis of ESRD in adolescence and then progresses to the participants’ descriptions of health.

Description of the Sample

Eight young adults between the ages of 20 and 33 years participated in this study. Three of the participants were male and five were female. A summary of the renal history of the participants is presented in Table 1. A summary of the demographic information is presented in Table 2. The age at time of diagnosis of ESRD ranged between 13 and 16 years. The cause of kidney failure in all participants was primary renal disease and included: glomerulonephritis (three), Henoch-Schonlein purpura (one), focal sclerosis (one), congenital dysplastic kidneys (one), and primary kidney disease origin unknown (two). Time since diagnosis of ESRD to
Table 1: Renal History of Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Current Age</th>
<th>Age at Diagnosis</th>
<th>Diagnosis</th>
<th>Current Treatments</th>
<th>Previous Dialysis Types</th>
<th>Number of Transplant</th>
<th>Type of Transplant</th>
<th>Total Years on Dialysis</th>
<th>Total Years with Transplant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alex</td>
<td>21</td>
<td>14</td>
<td>unknown, possibly genetic</td>
<td>transplant</td>
<td>CCPD</td>
<td>1</td>
<td>CD</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Ben</td>
<td>32</td>
<td>16</td>
<td>membranoproliferate glomerulonephritis</td>
<td>hemodialysis (HD)</td>
<td>CAPD, HD</td>
<td>2</td>
<td>1 LD, 1 CD</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Jeff</td>
<td>28</td>
<td>15</td>
<td>glomerulonephritis</td>
<td>transplant</td>
<td>CAPD, HD</td>
<td>3</td>
<td>2 CD, 1 LD</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>John</td>
<td>30</td>
<td>14</td>
<td>unknown</td>
<td>transplant</td>
<td>HD</td>
<td>2</td>
<td>1 CD, 1 LD</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Josiah</td>
<td>33</td>
<td>14</td>
<td>Henoch-Schönlein purpura</td>
<td>transplant (chronic rejection)</td>
<td>IPD, HD</td>
<td>2</td>
<td>2 CD</td>
<td>12</td>
<td>7</td>
</tr>
<tr>
<td>Mary</td>
<td>30</td>
<td>16</td>
<td>congenital dysplastic kidneys</td>
<td>continuous ambulatory peritoneal dialysis (CAPD)</td>
<td>CAPD</td>
<td>1</td>
<td>CD</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Maureen</td>
<td>20</td>
<td>13</td>
<td>focal sclerosis</td>
<td>failed transplant and not on dialysis</td>
<td>HD</td>
<td>1</td>
<td>CD</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Natalie</td>
<td>29</td>
<td>15</td>
<td>glomerulonephritis</td>
<td>cycler-assisted peritoneal dialysis (CCPD)</td>
<td>CAPD</td>
<td>2</td>
<td>2 CD</td>
<td>7</td>
<td>7</td>
</tr>
</tbody>
</table>

Key: IPD - intermittent peritoneal dialysis, CD - cadaveric kidney donor, LD - living kidney donor
Table 2: Demographic Information of Participants

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Education Completed</th>
<th>Current Employment Status</th>
<th>Country</th>
<th>Geographic Location at Diagnosis</th>
<th>Geographic Location</th>
<th>Residence</th>
<th>Living Arrangements</th>
<th>Significant Other</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alex</td>
<td>21</td>
<td>female</td>
<td>grade 12</td>
<td>full time</td>
<td>Canada</td>
<td>Misson</td>
<td>Burnaby</td>
<td>apartment</td>
<td>lives with fiancé in rented apartment</td>
<td>fiancé</td>
<td>step son</td>
</tr>
<tr>
<td>Ben</td>
<td>32</td>
<td>male</td>
<td>university degree</td>
<td>full time</td>
<td>Canada</td>
<td>Brandford</td>
<td>Yaletown</td>
<td>apartment</td>
<td>lives with wife in rented apartment</td>
<td>wife</td>
<td>none</td>
</tr>
<tr>
<td>Jeff</td>
<td>28</td>
<td>male</td>
<td>university degree</td>
<td>student/disability</td>
<td>Canada</td>
<td>Squamish</td>
<td>Squamish</td>
<td>house</td>
<td>lives with parents in their home</td>
<td>none</td>
<td>none</td>
</tr>
<tr>
<td>John</td>
<td>30</td>
<td>male</td>
<td>grade 8</td>
<td>full time</td>
<td>Canada</td>
<td>Coquitlam</td>
<td>Aldergrove</td>
<td>apartment</td>
<td>lives alone in a rented suite in his sister's house</td>
<td>none</td>
<td>none</td>
</tr>
<tr>
<td>Josiah</td>
<td>33</td>
<td>female</td>
<td>grade 12</td>
<td>full time</td>
<td>Canada</td>
<td>Tsawassen</td>
<td>Tsawassen</td>
<td>house</td>
<td>lives with husband and son in own home</td>
<td>husband</td>
<td>son</td>
</tr>
<tr>
<td>Mary</td>
<td>30</td>
<td>female</td>
<td>grade 12</td>
<td>volunteer/disability</td>
<td>Canada</td>
<td>Pt Alberni</td>
<td>Ladner</td>
<td>house</td>
<td>lives with parents in their home</td>
<td>none</td>
<td>none</td>
</tr>
<tr>
<td>Maureen</td>
<td>20</td>
<td>female</td>
<td>2nd year of university</td>
<td>student</td>
<td>Canada</td>
<td>Richmond</td>
<td>Victoria</td>
<td>house</td>
<td>lives with parents in their home</td>
<td>none</td>
<td>none</td>
</tr>
<tr>
<td>Natalie</td>
<td>29</td>
<td>female</td>
<td>2 years of college</td>
<td>unemployed/disability</td>
<td>Canada</td>
<td>North Vancouver</td>
<td>Burnaby</td>
<td>apartment</td>
<td>lives with Aunt in rented apartment</td>
<td>none</td>
<td>none</td>
</tr>
</tbody>
</table>
the time of the study ranged from 7 to 19 years. All of the participants had been on some form of dialysis and had a transplant at some time throughout their lives. At the time of the study, the participants were receiving the range of available renal replacement therapies, including functioning transplant (three), failed transplant (one), chronically rejecting transplant (one), hemodialysis (one), and peritoneal dialysis (two).

Four of the participants were living in towns and four were living in urban centres at the time of the diagnosis of ESRD. At the time of the study, three were living in towns and the remaining five were living in urban centres. All participants were born in Canada. Their highest level of education ranged from the completion of grade eight to the completion of a university degree. At the time of the study, four were working full time, two were students at university, one was unemployed but did volunteer work, and one was not working at the time but intended to go to school in the near future. Of the eight participants, three were on disability, including a student, a volunteer, and one who was currently unemployed. Two of the participants were married, one was engaged, and the remaining five were single and not currently in a relationship. Three of the participants were living with their parents, three with their spouse or fiancé, one with a roommate, and one lived on his own.

Introduction to the Participants

"Alex"

The investigator first met Alex in the apartment that she shares with her fiancé Noah and their cat, Mickey. Noah’s five year old son spends every other weekend with them. Alex is a young 21 year old female who describes herself as shy yet outspoken. She was diagnosed with ESRD at the age of 14 and was started on peritoneal dialysis at that time. Before she was diagnosed she described herself as “small for [her] height,” her “eyes used to wander or they would be crossed,” and “it
took [her] longer to get over colds and stuff” which she attributed to early kidney disease. Alex stated that she did not know why her kidneys failed but believed it to be maternally inherited because one of her mother’s kidneys “disappeared when she was 18,” her “aunt [had] three kidneys”, and her grandmother has “trouble with her kidneys.” She is the only one in her family that developed ESRD but she worries about passing kidney disease on to a daughter that she may have in the future.

After dialyzing for two years she received a kidney from a young cadaveric donor. She had met the donor’s mother and is very grateful for her gift. Alex had a difficult time while on dialysis and views a transplant as the only way for her to enjoy an independent and productive life. The transplant has allowed her to be independent of her family as she previously relied on her family to do her dialysis and take her to medical appointments. Alex believes the transplant has allowed her to be independent, to move out of her parents’ home, to get a job, and to make her own money. At the time of the study, Alex had gone back to school to obtain her high school diploma and was working full time.

“Ben”

Ben is a 32 year old computer software designer. The investigator first met Ben and his wife Barb when they were having dinner at the hospital dialysis unit where he dialyzes for four hours three times a week. He is a very articulate young man who appears to have given much thought to his kidney disease. He was diagnosed at the age of 16 with ESRD due to membranoproliferic glomerulonephritis. He was on peritoneal dialysis for two years and then spent one and a half years on hemodialysis. He received his first kidney transplant from his mother. Even though that kidney lasted only one year, he believes it was at an important time for him. He was able to spend his first year at university and “blend into the normal group of people.” He also felt the kidney allowed him to grow in height and believed he would “be much shorter” than he
was now if not for the transplant. Ben was then on hemodialysis for three years until he received a second transplant. That kidney lasted for seven years. During those seven years, he joined a rowing team at the university and became “extremely fit.” He believes if it had not been for his experience with kidney disease he would have “never been physically fit.” He realized that by pushing himself he could achieve a level of fitness beyond that of most people. Without the experience with kidney disease, he believes that academia would have been his focus and that he would probably have become a doctor. He is grateful that he did not stay on that road and attributes that to the kidney disease. When Ben found out he was going to lose the second transplant, he moved to California to work for a major software company. He is now back in Canada and has been dialyzing for the last three years at an in-hospital hemodialysis unit. Ben strongly believes that individuals should take responsibility for their dialysis and be involved in their health care. He has chosen not to dialyze in a self care unit at this time. He prefers to have the machine set up for him because he goes to dialysis straight from work and prefers to go straight on dialysis. Ben takes responsibility in other ways which he described as wanting to know exactly what the treatment entails, and he puts in his own needles. He currently lives in a trendy neighbourhood with his wife Barb and their dog Brandy. At the time of the study, Ben was presently on the waiting list for a third transplant.

“Jeff”

Jeff is a 28 year old university student. He currently lives with his parents and sister in a warm and inviting home surrounded by picturesque mountains. The first interview took place on the balcony behind his parent’s home shortly after he finished a game of golf. Jeff developed ESRD due to glomerulonephritis at the age of 15. Following the failure of his native kidneys, he was on peritoneal dialysis for one year. He received a transplant at the age of 16 which was unsuccessful and returned to
dialysis two weeks after the transplant. He received a subsequent transplant later that year which he kept for ten years. During that time he completed a degree in Arts and worked in the bush for a forestry company. When the kidney failed, he went on hemodialysis for the following two years. While on dialysis he went back to university. In spite of taking courses and participating in sports, Jeff considered his life on dialysis as "stagnant." Jeff used his time on dialysis to "sit back and reflect" and feels he now has "a very good idea of what it takes to succeed in life." It has always been important to Jeff to compete physically, to accomplish goals, and to succeed in life. He believes he excels at any activity he takes part in. On dialysis he shifts his focus from physically demanding sports (hockey, football) to "less strenuous" sports (bowling, curling) so that he may be competitive. He appreciates the more active sports "for just being able to do it" rather than having to dominate. Jeff received a living donor transplant from his sister five months prior to the study. He was currently going through an acute rejection period but was confident that it was under control. He believed he was getting stronger every week and his golf game was improving significantly.

"John"

John is a 30 year old male who lost his kidney function 16 years prior to agreeing to participate in this study. Diagnosed at the age of 14, he lost his kidney function to an unknown cause. John stopped going to school in grade eight because of his kidney failure. He was on hemodialysis for two years before he received his first kidney transplant. He gained considerable weight due to the immunosuppressive drugs. When he returned to school his classmates did not recognize him. He dropped out of school at that time because he was "fed up" and "hated the way" he looked. His first transplant lasted eight years and then he was back on hemodialysis. He dealt with the additional two years on hemodialysis by not following the nurses' "rules." He felt that if he was "going to be on this machine," he was "not going to live like that."
Therefore, he ate and drank whatever he wanted and did what his friends did. He was willing to suffer the consequences which involved having to remove large quantities of fluid at dialysis. At one time, he ate so much fruit that his potassium level was so high that he was in danger of having a "heart attack." John received a second transplant from the donation of a kidney from his mother. At the time of the study, John had his current transplant for four years and believed he was doing very well. He was working full-time as a graphic artist, had a place to live, money, a vehicle, and a lot of friends that he liked to "hang out and do things" with. John believes he is at his very best right now because he has "everything [he] really wanted in life."

Josiah

Josiah is a very positive 33 year old woman. She married her high school boyfriend, Tom, and they live in their own house with their son, Jordan. Josiah developed ESRD due to Henoch-Schonlein purpura when she was 14 years old. At that time she went on in-hospital intermittent peritoneal dialysis. She would spend Wednesdays and every weekend at the hospital undergoing dialysis. She had a very supportive group of friends and often "30 kids would come [to the hospital] Saturday nights" to watch movies with her. Once her fistula had matured, she switched to hemodialysis. Four and a half years after she was diagnosed with ESRD, she had a kidney transplant which was unsuccessful. She then remained on hemodialysis for another eight years. When she was 24 years old, she gave her boyfriend the ultimatum, "this is the way it's going to be, you either deal with it or get out of my life." Two years later they were married, a year after she received her second transplant. Initially she had severe rejection with that transplant but it continued to function without any further rejection for seven years. In that time, she worked full-time, gave birth to their son Jordan, and she and her husband bought their own home. She is very proud of her accomplishments and attributes her success with kidney disease to "positive
thinking" and doing the things she did, "I finished school, I started work, I travelled, I had family support." When she was approached for this study, she had just learned that she was undergoing chronic rejection of her kidney and would be going back on dialysis likely within the next year.

**"Mary"**

Mary is a very courageous 30 year old female. It was known since her birth that she would develop kidney failure due to congenital dysplastic kidneys. Mary was eventually diagnosed with ESRD at the age of 16. She was on peritoneal dialysis for a year before she received a transplant. Unfortunately she developed a serious complication of the immunosuppression, a brain lymphoma, ten months after receiving the transplant. She was taken off much of the immunosuppressive drugs but maintained kidney function for five years. The brain tumor and the chemotherapy has left her with a number of additional challenges, such as alopecia, a cerebral shunt, no spleen, partial paralysis to her right side, limited vision, and some cognitive impairment. In spite of her problems she finished high school. Mary has been back on peritoneal dialysis for the last eight years. She takes pride in the fact that she can manage dialysis on her own. She had wanted to be a teacher but because of her disabilities she was not able to realize that goal. She does enjoy volunteering with children and finds it makes her "feel good." She is saving the small amount of money she receives for volunteering and her disability money for a trip to Europe with her father. Mary describes herself as a "positive person" and believes "you have to put your medical needs and everything in a separate barrel" and that you need to "keep everything up but don't dwell on it." Without her positive attitude and the support of her family she believes she would "be gone." At the time of the study, Mary was not eligible for a second transplant because of the high risk for cancer. She was hopeful that one day medical advances in immunosuppression would allow her another
transplant in the future.

"Maureen"

Maureen, the youngest participant in this study, is a 20 year old third-year biology student at university. She describes herself as strong-willed. She is currently living at home with her father. Her mother is deceased. Maureen was diagnosed at the age of 13 with ESRD due to focal sclerosis of her kidneys. She had developed kidney disease when she was ten years old and was on prednisone for a year to try and stop the progression of renal disease. She was placed on the transplant list at the age of 11 prior to developing ESRD. Maureen was started on hemodialysis when her creatinine reached 1500 even though she claims she “felt great” at the time. When she was 15, she received a transplant. She developed precancerous cells in her ovaries so they were removed when she was 16 years old. During the surgery she claims they “cut into the renal pelvis” of the transplanted kidney. She believes she developed hypertension and chronic rejection because of it. Maureen was placed back on the transplant list when she was 18 years old. Recently it was decided that she would receive a living donor transplant from her sister at the end of this year. Her transplanted kidney had essentially failed and her creatinine had risen to over 1000 at the time of the study. She was adamant about not going on dialysis until just prior to the transplant. In spite of the high creatinine, not being able to work as a lifeguard which is important to her, or being “able to find the energy in the morning to get up out of bed,” she insists she feels “fine” and does not have any symptoms except that she is “tired a lot of the time.” Maureen feels that with all she has “been through for so long,” she does not “get emotional about [kidney disease] much anymore.” Maureen believes that everyone has some kind of physical complaint and that to be completely healthy is abnormal.
"Natalie"

Natalie is a very insightful and talkative 29 year old female. The interviews with Natalie lasted two to three hours. Her insight and reflective nature helped immensely in the development of concepts and relationships in the model. Natalie was diagnosed with ESRD due to glomerulonephritis at the age of 15. She believes being diagnosed during adolescence has helped her to realize what is important in life, and feels that kidney disease has been incorporated into her self concept. It does not define her, but it is a small part of who she is. Natalie was initially on peritoneal dialysis for two years. She felt she initially had no control over kidney failure because her mother "took it on," restricting her activities and foods and doing her dialysis. Natalie felt like "she [her mother] was taking some control away from" her. Her mother died when Natalie was 17 and consequently Natalie believed she would die soon as well. Therefore she lived life with no long-term goals, and wanted to "experience everything." She had her first transplant for two years and believed it failed partially because she did not take the immunosuppressive drugs regularly because of the side effects she experienced including a "hairy back," "extra hair" on her face, and "extra fat." She felt that the side effects were unbearable for an adolescent female to endure. Natalie received a second transplant right away and did not have to return to dialysis in between the two transplants. With that transplant she felt she was out of control, "getting drunk all the time," had no focus in her life, and "was just being a complete ass." Natalie was grateful that the transplant failed five years later and saw the failure as "a total wakeup call" that "the party can't last forever." Recently Natalie has taken ownership of the kidney failure and has found she has more control of the disease and her life. She is making long-term future plans and now believes that she can live for many years with kidney failure. She attributes her change of attitude to the support of her social workers, a naturopath, a supportive network of friends, and to doing self
affirmations. She believes that kidney failure has made her “self analytical,” a stronger person, and she has gained an appreciation of “earth bound” goals. At the time of the study, Natalie was unsure of whether or not she was on the transplant list, and expressed ambivalence to receiving another transplant at this time.

Major Themes

Diagnosis in Adolescence

The first major theme to emerge from the participants' stories of their experience with health was the diagnosis in adolescence. All of the participants in this study were diagnosed with ESRD during adolescence between the ages of 13 and 16 years. The categories that emerged during the research about the diagnosis included, others take control, desire to be as normal as peers, inability to do or achieve what one wants, and incorporating ESRD into life and self concept.

Others Take Control

During adolescence, the participants felt they had no control over their disease because others took control of the kidney disease by making decisions regarding their treatment, restricting their food and fluid intake, and restricting their activities. The diagnosis came at a time when even "normal" adolescents and parents are often challenged to deal with tensions related to adolescents' desire for increased independence. Parents' taking control of the adolescents' disease may be a reflection of the developmental stage of the adolescent and the parents' desire to minimize further assault to their child's health. Furthermore, when first diagnosed with ESRD, some participants felt it was easier to let others take control because they often did not know what to expect or how to deal with having the disease. Ben felt that when he was first diagnosed, it was easier for him to let others make decisions for him and that it eventually became routine.

I think at first, it's you know, everything is kind of done for you and everybody tells you what to do and it's just easy. You know it's like being
in prison you know, you don't have a choice, or at least you don't feel like you have a choice, so you just do it. And then it becomes routine and then after that you know, it's kind of game over (Ben).

Control over the participants' illness was assumed by parents and by health care providers. Parents often took control over the treatment decisions and food and fluid choices. Natalie had little to no control over her disease or what she ate when she was first diagnosed because her mother took control over her disease.

I was always on a diet. She [mother] was so paranoid about food. I was on like the diet where I couldn't eat white flour, white sugar, and everything had to be buckwheat...I was like, you know whatever and I just kind of did it, and resented it, but did it anyway.... I'd come downstairs and my pills would be on the counter and I'm like, "Hey, do you mind if I do it myself?" So I also felt like she imposed control on me too like I never had control over it at all. Because she was worried that I would fuck up essentially and I'm like, "Okay you know what? I think I can do this." But at 15, she did everything for me, she had the pills out all the time and she was like, "Oh, blah blah blah Dialysis this and dialysis that" and I'd come home from school and she'd have the bag heating in the microwave and I was like, "Can you just not do that?" And for us, we'd constantly butt heads cause I'm like, "Look, I can do this, I'm perfectly capable," but she was so worried that I wasn't capable...and I was like, you know, "If you just backed off and let me do it myself, let me have control over it I would be dealing with it a lot better" (Natalie).

In addition to imposing restrictions on diet and taking control of the treatment, many parents restricted the participants from taking part in certain activities when they were adolescents. While the participant often knew that the activity was forbidden, some spoke of times when their parents went "behind their back" to restrict activities.

My mom is, she's way overprotective on a lot of things. Like, ah, some of the stuff that I find out years later, like ah, baseball, wouldn't let me pitch. Like you know, told the coach, "My kid's too sick, he can't pitch." Like and I was the best pitcher in the league (Jeff).

Health care providers also placed restrictions on the participants. Most of the participants when first diagnosed had received treatment at some point from the staff at children's hospital and felt that they were very restrictive.
They restricted me big time, like really bad. Like my first biopsy I was allowed to do nothing for six months. Yeah like they were totally, now I think they are totally in the dark ages, like no sports, like I wasn't allowed to play hockey, I wasn't allowed basketball, like I sit there in gym class and just go like this [hands on face] for six months (Jeff).

I understand what is going on and they [nurses at children's hospital] would treat me like a 10 year old, you know, um, I know when things aren't right and, um, they would come back and say, "Oh everything is fine, everything is fine." When I knew that things were going wrong, things, and um, it got to the point when they wouldn't let me watch my machine. They would turn it away from me, um, so that to me used to drive me nuts, cause again they were taking the control away.... I think that in too many situations, kids are brushed aside when they ask questions in kids hospitals. And especially teenagers are brushed aside (Maureen).

Desire to be as Normal as Peers

When diagnosed with ESRD during adolescence, participants had a desire to "be as normal as possible" like their peers. They did not want to be different or appear different, "I had a lot of friends and ah, they were all normal and I tried to like them" (John). When first diagnosed, participants did not know what it meant to have kidney failure, or how to live with it, and grieved the loss of a normal life.

I can remember sitting in the hospital, like 16 years old thinking I will never be a normal person...I mean, definitely when I was, and I can very well remember, I can remember looking out my window seeing normal people, a normal person with a dog actually, strange how I remember this but, thinking that I will never be able to do that. So that was kind of, that's a bummer at 16 (Ben).

Participants desired to be accepted by their peers. To be accepted participants felt it was necessary to appear normal, "I just carried on like my friends, cause you want to fit in" (Mary). Ben talked about how he felt when he missed school because of his disease and how he wanted to go to school in spite of how he might have felt physically at the time.

And I can remember being, you know in high school and things, not wanting to, even take time off of school and, whereas it's not really all that
important, high school is not really all that important, um, I didn't want to do anything that was beyond the norm. And maybe at 16 or 17, 18, it's less to do with inner strength and more to do with just being accepted that's important. You know, it's tough for kids, for sure, to be on dialysis, you know (Ben).

The desire to be normal like their peers sometimes meant the participants hid their symptoms or not follow the diet, fluid, and activity restrictions.

I never followed my diet, you know I ate what the other kids did, you know and ah, that hurt too cause I had a lot of sodium, I ate pizza and burgers anytime I wanted. I used to eat, um, I used to go to Denny's with my friends and have like 3 spaghetti dinners like all day because it was so good (John).

I did whatever the hell I wanted to, and I went out like hiking all over the place, and in [small town] I could do that. Me and my friends used to take off and go hiking and do whatever. And then I'd lie about it, like about where I was or whatever (Natalie).

I can remember actually very very well, walking from class to class or walking places and, um, getting good at pretending I was waiting for someone because I was catching my breath...so, just kind of stop and look around a little bit (Ben).

**Inability to Do or Achieve What One Wants**

During adolescence many of the participants identified activities in which they could no longer participate when they developed ESRD. In addition to having activities restricted by others, the disease process and treatment often restricted participants' abilities to do things that they wanted. The time-consuming and inconvenient dialysis treatments prevented many of the participants from taking part in activities that were important to them, such as playing sports, spending time with their friends, and/or attending school.

Dialysis, you know, it's just, it wears you down. And you get tired of it. Um, just being hooked up to that machine all the time, can't do anything, can't go anywhere, you can't go on a family vacation...[you can't go out with your friends at night] and at my age it was like the prime [time], when you were supposed to be going out with boys and stuff, and you can't (Alex).
When Josiah was first diagnosed, she felt the time-consuming in-hospital dialysis schedule prevented her from spending time with her friends on the weekends.

I was quite a good student, until, 'til my dialysis days, and then I missed things like French...I did peritoneal the first year...I would go all weekend, and then Wednesday...[I missed school] only for the Wednesday. But then as a teenager, my whole weekend was gone (Josiah).

When she switched to hemodialysis, she found that it was not as time-consuming but that the hospital schedule was not conducive to her attending school regularly.

When I went on [hemo] dialysis in grade 9, I missed, I missed more school [than when I was on peritoneal dialysis]...because children's hospital didn't open Saturdays, Sundays, Evenings, so you dialyzed Tuesday, Thursdays, and Saturdays. Well they did open Saturdays, excuse me (Josiah).

In addition to the time-consuming and inconvenient dialysis treatments, the symptoms associated with the disease prevented the participants from being able to do things. The biggest complaint associated with the symptoms of the disease was feeling tired. Participants often felt they did not have the energy to take part in activities because of a low hemoglobin or the effects of the dialysis procedure.

Sometimes my friends would phone me to you know play hockey or do this afterwards, and I couldn't [because he was tired]. And I don't think it's, um, I don't blame dialysis for all that, I blame myself...cause, I didn't take care of myself [by drinking too much between treatments]. That was the price I was going to pay, and I knew about it (John).

A lot of my friends danced all the time and I just didn't have the energy to do anything anymore. Like it was a struggle for me when I used to get out of school, I'd walk home, which was quite far...quite far, it was at least a mile. So, I used to get home and I'd just have a nap...so you could just see how tired I was (Mary).

In addition to the disease restricting the participants' ability to do things during adolescence, they felt that the disease prevented them from achieving what they believed their life goals were at the time. John wanted to be a hockey player for the
NHL but realized this was not possible when he found out he had kidney disease.

I wanted to be a hockey player for the NHL kind of thing when I was younger. So I started and had to stop when I found out about this... I stopped because, um, 3 times a week dialysis, you can't play hockey, I mean, you know I mean especially after you get off the machine kind of thing (John).

Jeff thought that if he had not developed kidney failure, he would be working at a mill but felt that "since I have kidney disease, I can't go near the bush [which is required for this work]...I can't do the physical [work] – just go sling work at the saw mill and flip boards all day" (Jeff).

**Incorporating ESRD into Life and Self Concept**

At the time of the study, the participants had all been living with kidney disease for seven to 19 years. They had the disease for so long that they did not really remember a life without it; having kidney disease was normal for them.

I dialyzed for 13 years. I didn't know anything different. That was my life.... Normal to me is kidney disease because I've had it for so long... but I think having been sick, if that's what you want to call it, is normal for me. So that's the way I've always dealt with life (Josiah).

Living life with kidney disease is something that hit me young and I've had to live with it ever since so I've never had a second thought (Jeff).

I don't know what it would be like to not have it [kidney disease]. So I'm like I don't know what I'd be thinking about if I didn't have kidney disease, cause I don't think about it that much. But because I do have it, I know that with every decision I make and everything I think about, in the back of my mind, it's based on the fact that I have kidney disease (Natalie).

The participants felt that being diagnosed during adolescence had resulted in them incorporating kidney disease into their lives and into their self concept. Kidney disease did not define them, but it was a part of their lives and part of their self concept, "It's [kidney disease] part of my life, but it's not who I am, but it's part of who I am, but it isn't entirely who I am" (Natalie), "It does become completely a part of you.... It's [kidney disease] part of you already, to deal with, and blend into your lifestyle" (Alex).
Participants felt that this was unique to being diagnosed as an adolescent because their self concepts had not yet been defined when they were diagnosed.

They just mixed [kidney disease and self concept], you know. Like this is, that's they way it goes...you're so busy in adolescence and stuff you don't really, you know, like you're just doing whatever...you don't have a choice...that's the deal, like you never had a choice, you never had the pure health...we never had a choice and we grew up with it (Jeff).

All participants felt that being diagnosed during adolescence was less traumatic to them than if they had been diagnosed later in life. Participants believed that as adolescents, they were able to adapt easier to the restrictions imposed on them by the disease. While still very traumatic at the time, they felt it was easier on them than if they had been adults when they were diagnosed. Participants spoke of how they believed the diagnosis of ESRD would affect adults and their families.

It all depends like how old you were when you were diagnosed. Because you just think some of the adults now, it seems like, I don't know how some of them can handle it, especially with kids and stuff. Because I read some stories, and it's just like, actually there is a person in [name of city] my Grandma told me, and the father was diagnosed with kidney failure, and he's got a teenage daughter and a wife, and it really hit the teenage daughter hard, really hard (Alex).

Whereas if I was fresh and diagnosed like last month or something, wow! You know if I had 28 years or, yeah 28 years of like the good program [health] or you know and they just say suddenly you're going to be faced with, you may have to go on to a machine, you're going to do this, you're going to do that and bam, there would be significant things [to deal with] (Jeff).

**Having a Sense of Control over ESRD**

The second major theme to emerge from the participants' stories of their experiences with health was having a sense of control over ESRD. Complete control over the disease was not possible because even with the best efforts to control the disease there were times when the disease progressed or problems occurred. Participants felt they had a sense of control over ESRD when some of their actions
could directly influence the course of the disease, minimize symptoms, and lessen the impact of the disease on their lives. Participants attempted to take control of their disease by controlling the disease rather than being controlled by it, thinking and doing differently, reasoned non-compliance, and making conscious choices which resulted in the participants having a sense of control over the disease.

**Controlling the Disease Rather Than Being Controlled by It**

Participants concurred that having a sense of control over the disease, rather than being controlled by it, was important and necessary to the experience of health. "There is a fine line between being in control of [kidney failure] and sort of being in denial or being a slave to it" (Natalie). Participants stated that focusing on diet, restrictions, tests, and dialysis could be overwhelming and lead to a sense that the disease was controlling them.

I was not dealing with it at all. You know I was taking pills. I was following the diet really strictly and you know doing dialysis like a Nazi and I was just like, you know, this isn't working for me at all. Like and I didn't realize until after I stopped doing it how much it didn't work. And how much of my life, I really did miss out on for that two-year period (Natalie).

Having a sense of control over the disease helped participants to live their lives without being too focused on kidney disease and to do things that were important to them.

You have to have control over it to be able to have a life outside of kidney disease...if you have control over it, you can do whatever you want. And if you're living life outside of it, they you obviously do have control over it.... For me personally if I'm climbing with somebody who doesn't have kidney disease and I'm doing exactly what they're doing then I feel like I have way more control over my disease than maybe somebody else who is sitting at home or who doesn't go out at all...So obviously I have some kind of control over it (Natalie).

I don't, to be honest I don't think about, um, the kidney that much. You know, especially when you're living life and having fun, you just don't think about it, you know? (John).
At the time of the study, all the participants believed they had a sense of control over the disease. How they believed they had control differed. The majority (six) of the participants believed control over the disease was enhanced with dialysis or a transplant, while the remaining (two) participants believed that the disease controlled them without a transplant. Those that believed their control over kidney failure was enhanced with dialysis described the benefits of dialysis in controlling symptoms associated with kidney failure. Following dialysis, participants felt physically better and mentally clearer to do things they needed to do or enjoyed doing, giving them a feeling of having some control over the disease. However, participants who felt they could have a sense of control over kidney failure with dialysis stated that a transplant gave them more control over kidney failure than did dialysis. With a transplant, there was more freedom to travel, less time spent doing dialysis allowed them more time to do other things, and the symptoms associated with kidney failure were not experienced with a transplant.

I think [it is] easier to reach your goals by getting a transplant, you know? Um, you know you can travel, you can do what you want. You can at least get a job where you can go in every day like a normal person kind of thing...Like say I was on dialysis. I felt like crap afterwards. I couldn’t do anything but lay down. So that’s why I’m telling you it’s better with a transplant. In my opinion I can do what I want afterward (John).

Jeff believed he could accomplish more with a transplant: "[A transplant] gives you more possibilities to attain greater things than what you could on dialysis.... Transplant is the answer in my books. It is totally" (Jeff). Two of the participants, Alex and Maureen, felt that a transplant was necessary in order to not be controlled by the disease. Alex explained why she believed that kidney failure controlled her when she was on dialysis.

Cause before [the transplant] you were relying on people, like I was relying on my mom to take me to the hospital, help with my dialysis. Now
it's just I do it all myself. You know take the pills myself, see the doctors myself and all that stuff...[I did not feel in control before on dialysis] cause there were sometimes where you're at real weak points and it's just like you had no control over it at all...I was always tired. Like I'd come home from school and go to sleep (Alex).

Alex also explained how she was able to have a sense of control over the disease after she had a transplant.

You know, you don't have to be in [hospital] all the time I guess. Like not, like not going for blood tests all the time, yuk. Um, I don't know, you just take your medication in the morning, you can just go about your day and have your freedom. You don't have to be at this appointment, that appointment (Alex).

**Thinking and Doing Differently**

Over time after diagnosis, some of the participants began to think differently about the kidney disease and to do things differently regarding their disease. At some point, all participants saw having kidney disease as inconvenient and time-consuming, resenting the fact that they had the disease and had to do dialysis. Those that spent a long time on dialysis began to see it as a part of their lives and necessary to gaining control over the disease. Furthermore, with time and experience with kidney disease, the participants believed that having a sense of control over the disease rather than being controlled by it became second nature.

I never really feel like I lose control over kidney disease that often, because I've been doing it for so long. It's like I said, it's second nature now. And I know that I'm, I am in control of it...Like if I get all stupid and not do dialysis, because I don't feel like doing it, I'm only going to pay the next day (Natalie).

Josiah found that looking at dialysis differently helped her to have a sense of control over the disease. She explained that accepting the need for dialysis involved a mindset of just incorporating it into her life and not letting the fact that she had to do dialysis bother her.

I mean I've never been one to feel sorry for me...I've been sick for, well
more of my life than not of my life. It's just dialysis was a slot in my life and it had to be done. It was not, "Oh my God, I have to do this." I never knew any different really (Josiah).

One participant, after realizing her identity was not kidney disease but that it was a part of her, began doing more things and taking more responsibility for herself and her health. Natalie found that by thinking differently about kidney disease she was able to have a sense of control over the disease.

And everything's sort of different since then...I think before that point I was sort of like, I can't do this because I have kidney disease, and kidney disease this and kidney disease that...is how I thought about it. And then once she [the social worker] made that point to me, you know, "You aren't kidney disease, but you employ it, look at it as an employer or as an employee." And as soon as she said that to me I was like 'you're right' and I started doing a lot more things like going out more and being more social, and you know, just doing more active things (Natalie).

When participants had a sense of control over their kidney disease by thinking differently about it, food and fluid restrictions often became "second nature." By no longer constantly thinking about the restrictions or having to make conscious decisions about what foods to avoid and how much fluid they could drink, the participants felt more in control of the kidney disease. With time and experience with kidney disease, the participants found they just naturally avoided such things.

I mean I'm not a fruit person at all, not a vegetable person and probably some of that comes from, you know...I've been told it's bad for so long, especially things like bananas, which I like. But I have a problem. I don't buy them, I'll eat them when they're around, but I don't buy them. So that's maybe some kind of background psychological thing happening (Ben).

I don't even think about my choices at the grocery store. I don't even really think about why I'm making those choices. I just am...It's just like I inherently know tomatoes are high in potassium, don't buy tomatoes. I inherently know cantaloupe is like potassium death, so I don't buy it. I don't know why I don't buy it, I just don't. I'm there and I see it and I'm like I really don't feel like cantaloupe and go on to something else, you know watermelon. I don't really know, I'm not physically or mentally going, "Oh too much potassium in that" (Natalie).
Reasoned Non-Compliance

All participants in this study experienced a time when they did not follow diet, fluid, or activity restrictions. Doing so gave them some sense of having control over the disease. For most participants, there were times in their lives when following the treatment regimen and restrictions interfered with other goals in their life, the need to take part in certain activities, or the need to promote normalcy. Other times participants chose not to follow restrictions or treatment regimens because they had no faith in the advice. This behaviour, typically termed non-compliance by health care professionals, was how participants enhanced their control over the disease.

Non-compliant behaviours were often the conscious choice of the participants to not follow restrictions because they believed that the ingestion of fluids or certain foods was appropriate prior to dialysis because the fluid and sodium would be removed during the dialysis treatment. Participants all talked about consuming “forbidden” foods while on dialysis.

I felt great eating McDonald's everyday when I got there. I just like eat pizza down there [at the McDonald's next to the dialysis unit] and I would bring it back [to the dialysis unit] with me, and the nurses would bitch about it, but so what (John).

I ate pizza there...I used to order food. You know, Mom and I, or Tom and I, whoever. We used to always have food.... But why not? People couldn't understand. Like on the Monday mornings [before dialysis] once and a while I'd get the McDonald's Breakfast (Josiah).

They reasoned that the sodium and fluid ingested would be dialyzed out of their bodies, “I would always calculate whatever I'm going to eat and drink on there [the sodium and fluid dialysis profile]” (Josiah). Some participants talked about how alcohol could be consumed prior to dialysis because the fluid and alcohol would be dialyzed out at their next treatment.

If I had alcohol, the alcohol always had to be consumed on a Saturday night because if I had it Friday night, I didn't dialyze till Monday. I would
feel the effects in my legs and whatever. So we always knew that if I drank I had to have a triple Long Island ice tea and that would do the trick, because triple Long Island was only like that much fluid but it was all alcohol (Josiah).

I drank too much at the bar before dialysis and I came in all drunk...four hours later I was all sober and I drove home [laugh]. So I took some advantages of it, they’d say it was not good for you, your blood pressure and this, but I just did it...It felt great. I ah, to be honest I could have drank alcohol everyday I went down there, took advantage of it you know. All my friends would be throwing up and I’ll just on the machine and be sober again (John).

Other times the participants ignored the warnings of their health care providers to not take part in certain activities when they believed the activity restrictions were not warranted. After Ben’s first transplant he was told that he should avoid public places because he was more susceptible to infections because of the immunosuppression. However, he did not heed that warning and found that he did not get sick; therefore, he did not listen to the same warning with his second transplant.

I mean I probably didn’t obey anyway as far as staying away from places...I didn’t notice I got sick, at all, so...didn’t find it at all. And the second time I had a transplant I was very much into you know, sports and those kinds of things where I met a lot of people and never had a problem with catching, catching you know viruses and things like that (Ben).

While most of the participants, on occasion, did not follow their diet or other restrictions, their behaviours were not particularly dangerous. John, on the other hand, chose to ignore the diet and fluid restrictions and at times skipped dialysis. John had a sense of control by doing things that were obviously dangerous. However, he believed he had valid reasons for this behaviour. He felt it was necessary not to follow the advice of health care professionals to have a meaningful and normal life.

I just didn’t listen to rules. I didn’t want to listen to rules because... if I’m going to be on this machine, I’m not going to live like that. I don’t think anybody should live like that. If you want to live like that fine, but I don’t want to live like that, so I’m not...[I did] whatever I wanted, [or did] what
other people did (John).

He felt that by not following the restrictions, he could have some control over the disease.

I could control it because basically I did what I wanted. But the only thing you couldn't control was you have to go on dialysis right.... I broke all the rules so it didn't really, you know, the only part that controlled me was going on dialysis. The rest, I just did what I wanted, you know? (John).

He also stated that he would "skip" dialysis: " I felt so good, I'd say, "Why should I go now?" So I skipped it." He reasoned that he would not need dialysis on occasions when he felt good.

**Making Conscious Choices**

Participants felt they had more control over their kidney disease when they made a conscious choice to increase their level of involvement in their care and make decisions about their treatment. Making the conscious choice to be actively involved in their health care helped participants to gain a sense of control over their kidney disease because through this process they acquired a better understanding of their disease, made decisions regarding their care, and exercised their independence.

I think if I'm involved in my health care I have a better understanding of exactly what the problem is and if people ask me about it, I know, I can tell them what's going on. Where I think part of the reason I didn't tell anybody what was going on when I was 15 was because I really didn't know. I knew I was on dialysis, that's pretty much it. I didn't really know (Natalie).

You know I want to know more specifics. I want to know, and figure out why and stuff...you have to take in and make your own judgment, you can't just get swayed in...and it's just like everything in life, the more information you have the more you can make an informed decision. (Jeff).

I'm always a person to want to know the why and just the what...You know, they have some determination of my outcome but I'm the one that has the most...I'm their customer, you know. They are responsible for providing a service to me and you know, I should have the voice to be
able to guide that service a little bit (Ben).

For some making a conscious choice to take responsibility for aspects of their care was motivated by an appreciation of the benefits of having a sense of personal control over their health.

I made a conscious choice to start following the diet myself. Not because I was told I had to but because I all of a sudden realized it would be better for me to do it that way (Natalie).

Ben decided to have some control over his dialysis treatments by putting in his own needles. He felt that taking that responsibility for himself removed the possibility that some one else would make a mistake.

I put my own needles in, I, you know, I've done my own arm hundreds or thousands of times and I can't, wouldn't be able to count how many, but, um, whereas other people have not done my arm that many times. So, you know I'm the best one to know how it works (Ben).

Making conscious choices about which form of dialysis they were to undergo helped participants to have a sense of control over their disease. Interestingly, participants chose different forms of dialysis treatments, but for the same reason – to have some control over the impact of the kidney disease on their lives. To Ben it was important to be on hemodialysis so that he could minimize the amount of time he spent having to think about it. When he was not at the hospital for dialysis he rarely thought of his disease and could live his life as normally as possible.

That's why I like hemodialysis. Because it's away, you know, and when I'm not on hemodialysis, I don't think about dialysis, not much anyway. Whereas peritoneal dialysis, which I have been on, is an all day kind of thing and you do it, you change the fluid four times a day...That's something you can't really get away from and you are always with it, and I don't really like that...So, on the days that I don't come here, I rarely think about this place (Ben).

Natalie, on the other hand, made the conscious choice of doing CCPD, because she did not have to go into the hospital for treatment and could do it while she slept.
leaving her waking hours to do whatever she wanted without having to think about dialysis.

I actually made a conscious choice not...to go on hemo because I didn’t want to have to come into the hospital. I didn’t want it to restrict my life that much...I didn’t want to have it like, you know, have to actually not go to school or whatever because I had to come in and do dialysis...I think I would feel less in control if I was on hemo just because you have to go in every three days or whatever. That’s one of the reasons I didn’t want to go on hemo this time...it’s just the whole thing of being trapped to that. I just don’t want to deal with right now (Natalie).

Participants in this study made conscious choices of treatment – transplantation or dialysis. While some wanted a transplant right away to limit their time on dialysis, others did not. Maureen did not feel she had control over her kidney disease when she was on dialysis, therefore, she made the conscious choice not to go on dialysis before her next transplant. In spite of stating that doctors preferred to put people on dialysis when their creatinine reached 800 (in actual practice it is closer to 600), she made the conscious choice not to undergo dialysis treatments until just prior to her upcoming transplant in December.

He [the doctor] used to say that the place that you’re dialyzed is about 800.... I am trying to avoid dialysis before December...I’m pretty savvy. I know that if I get much closer to about 1,000 that they are going to have to put me on dialysis. I understand that and so for me it’s like dodging a bullet every month when I do my blood work, it’s that I have to get just one month closer to not having to go on dialysis (Maureen).

In spite of originally thinking she would go on dialysis when her creatinine reached 1000, she still chose not to go on dialysis when her creatinine went over 1000 at the time of the second interview. She made the conscious choice to ignore the doctors warning that this may lead to "long-term injury". Natalie, on the other hand, made the conscious choice to control her disease by undergoing dialysis rather than having a transplant at the time of the study. She felt that she would only be given one more transplant so she made the conscious choice of not having a transplant at that time.
She wanted to realize a dream of travelling to Tibet and Nepal but she was not in a financial position to do so. Natalie felt she had some control over her disease by making the conscious choice to stay on dialysis for the time being and to have a transplant later when she could use it to realize her dream. Making the conscious choice to postpone a transplant helped Natalie to have a sense of control over the impact of the disease on her future goals.

Like you're only to get one more [transplant]. They're not going to keep giving them to you. I don't want to get it anytime before I'm like totally ready. So that, cause I don't want to be like 35 and be on dialysis for the rest of my life. I just don't want, I don't want to be there. That would just make me really unhappy. Because I mean the travelling I want to do, like I want to go to places like Tibet and Nepal and places like that and I want to do things that I can't do, I just could not do, physically could not do on dialysis. The logistics just wouldn't work for me.... I'd rather have a transplant to do all that kind of stuff, and I figure I'm not going to be able to go anywhere like that before I'm...40 to 45 anyway. Just money wise. So I'm not in a big hurry to get a transplant. I'd rather wait (Natalie).

**Facilitators of Having a Sense of Control**

The third major theme to emerge from the participants' stories of their experiences with health was facilitators of having a sense of control. The categories that were included in this theme were accepting kidney disease, normalizing, reframing, following advice that works, appropriate resources, being perceived positively by others, and time.

**Accepting Kidney Disease**

Having a sense of control over kidney disease was facilitated when participants accepted that they had kidney failure and that they could live with kidney failure. For some of the participants, accepting that they had kidney disease took time. "It took a lot of time to get it sunk into my head that I actually had something wrong with me. Cause for the longest time I didn't believe that I did" (Alex). For Natalie, it took years of living with kidney disease for her to accept that she could actually live with it.
When I hit like 16, I was like I'm going to be dead before I'm 20 anyway so what the fuck do I care, this stuff just isn't important and I just want to do whatever. But looking back I'm like gee if I'd known at 17 that I was still going to be here at 30 I would have done things differently (Natalie).

Accepting that they had kidney disease and they could live with it helped participants to feel they had some control over the kidney disease and that it did not have to control them. In addition to having a mind-set of accepting kidney disease as part of their lives, the participants also accepted that they needed to take responsibility for their care. There were certain things that they had to do to maintain a sense of control over the disease. They accepted that they needed to take medications, do dialysis, and follow restrictions in order to maintain control over the disease, "I mean if I don't take my pills, I'm going to end up not having control over it" (Natalie).

Just by taking the medicine and watching, well I don't do it as much but you're supposed to watch what you eat and stuff like that. Um, you just feel that you have the control over it. It's not controlling over you, you just have that feeling (Alex).

Having a sense of control over the disease by accepting that they had kidney disease and had to take responsibility for it, helped participants to get on with living.

And I also started taking more responsibility for myself...I wasn't going to just do dialysis and have it just make me feel great. It was going to take more than that, so take diet, take exercise...like it all sort of came to head at the same time, was accepting kidney disease..... I decided at that point that I wanted to go back to school, that I wanted to do other things, I wanted to go to Ireland...it just seemed, just seemed like a total burden was lifted off me Where before [I decided this], everything was tainted by the fact that, well, I have kidney disease so I can't do that. And whether I actually voiced it or not, it was still in the back of my mind. It was like a subliminal thing, but it tainted everything I did, my job, my personal life, the people I was choosing to be with and stuff. Kidney disease tainted that too. You know, all these other things that I didn't realize were going on until I sort of took ownership of it (Natalie).

**Normalizing**

The participants concurred that having normalcy was important to promoting the
feeling of having a sense of control over kidney disease. Normalcy was fostered by feeling normal, appearing normal to their peers, and being treated as normal by others. All of the participants spoke positively of times when someone who knew they had kidney disease did not treat them any differently than if they did not have the disease. Being treated like everyone else helped the participants to have some control over the kidney disease. It helped them realize that kidney disease did not have to control all aspects of their lives.

Most of the participants indicated that their families encouraged them to lead a normal life by promoting normality in their lives and treating them in the same way as their siblings. When living at home, all of the participants had household responsibilities such as doing "housework," helping with the laundry, and "doing dishes." When John was younger and still living at home, he was responsible for cleaning the house for which he received an allowance.

Yeah, yeah, you know, do the dishes and all that stuff. I'd argue about it. Every kid does you know but I'd do it, you know and ah, my mom would pay me like 30 dollars a week to clean the house up (John).

Being disciplined when they did something wrong also helped participants feel they had a normal life. As Josiah explained, "I was still reprimanded for the wrong things that I did. Still had a curfew. I wasn't treated anything, any differently" (Josiah). It was not just parents that promoted normalization. Teachers often expected them to be like other adolescents at school and this helped them to feel healthy.

The only person in my school who was essentially get off your ass and get out and do it was my gym teacher. He was completely ruthless, I came to school one day and he's like, "Where's your bike?" I'm like, "What do you mean where's my bike?" "Where's your bike?" "I can't ride my bike." "No? Do you have legs, do they work, then you can ride. Get your bike." He made me go home and get my bike and ride back to school and I mean I didn't live close to school and it was all uphill and I'm like AH.... Most of the influences around me, other than my friends, like my mom especially and my doctors and stuff were all not especially positive and not especially, they were all kidney disease related. But
then to have school where no one was kidney disease related where I had to be like everybody else whether I liked it or not was actually good. I felt healthier then (Natalie).

As adults, normalization was promoted when friends, families, and employers treated the participants like they would treat other people and were not focused on the fact that they had kidney disease. Participants talked about the importance of feeling normal and appearing normal to other people to their experience of health.

I think that my goal, my life goal is to become, you know, is to skate right next to normality and normality meaning someone with two kidneys that work.... To appear [normal] to them and to me, you know. I don't feel like, I don't feel particularly sick or unhealthy even though 99.9 percent of people would look at me here [at dialysis] and think, wow this guy is really sick (Ben).

Just because that's the way I am. I like to do those things, I like to be like other people. I don't like to be different, I never did. I'll do what other people do and that's the way I am I guess. I feel more comfortable that way. I don't like, I just don't like being un-normal (John).

Maureen believed it was important to feel and be perceived as normal by others. It was important that she keep up with others her age who were doing the same things as they did. She defined what was important for her to feel normal,

For me normal is just, um, I guess being able to keep up with people my own age at the same level as myself. You know other university students at university who are up to 2am studying and still find the time some how to go out for three hours to a bar. Um, and then wake up at 7am to go to class and not think twice about it. Um, so for me, I think that is what normal is (Maureen).

When friends were willing to make concessions so that the participants could take part in activities, it helped them to feel normal and to feel they had some control of the impact of kidney disease over their activities.

My friends will make concessions, like if we're going out or whatever, we'll come home early so that I can get enough [sleep] and not have to be in bed until like 12 o'clock in the morning the next day or whatever...most of my friends are usually pretty good that way (Natalie).
One way participants normalized the implications of having kidney disease was by comparing themselves to others and finding that everybody has some kind of physical complaint. Natalie found that everyone in her life had some sort of physical complaint; therefore, she was no different from her friends.

You're abnormal if you're totally healthy and there is nothing wrong with you...everybody has something.... Sometimes I compare myself to people around me, and I'm like, I'm no worse off than anybody else around me. Like I have a friend with Crohns disease and I'm like, I'm healthier than you are. And, you know, my cousin who I always thought was really healthy, he was like debilitating migraines, and I'm like, okay, okay, you're not healthy either. So I don't really have like a normal scale. I don't really have anybody like I can look at and go, "Okay, you're healthy and you're normal, so you're the person, I want your level of health" (Natalie).

Regardless of how they defined normal, participants wanted to feel, appear, and be treated like people that they believed were normal. When this was possible, the participants believed they had some control over kidney disease and were able to experience some sense of health.

**Reframing**

Participants found that by reframing the experience of having kidney disease and/or disappointments associated with it into positive experiences helped them to have a sense of control over the disease. All the participants stated there were positive aspects about having kidney disease, including that it made them stronger ("I'm stronger than I think I would have been without it [kidney disease]"), helped them appreciate life more ("I think I appreciate life a lot more than other people do, I don't take things for granted"), helped them cope better ("I don't get flustered easily...for me I don't do that, it takes a lot more to get me flustered"), and it provided the motivation to take time to enjoy life ("I can actually basically take time to smell the roses or whatever you want to call it, but like take time to like look at things and I don't feel like I'm in a big hurry").
Josiah found that she could identify something positive about the long hours she spent on dialysis. "You liked it if you had [a cute male nurse] or something like that, that you really had a good chat with" (Josiah). Whereas John focused on the benefits of dialysis for weight control. "I can eat what I want and not gain weight. That was the bright side about it. What I was thinking, you know, so it was really hard to gain weight on that, going on dialysis kind of thing." Natalie believed that she had received so much that was positive from having kidney disease that she would not trade the opportunity of having gone through it for a healthy past. Natalie's words provides a powerful example of how someone living with kidney disease can reframe the experience into a positive one.

You know, if I could be anything, I'd be healthy. Like I wouldn't have kidney disease anymore but I would have had it but not have it now...I wouldn't trade the experience of having kidney disease in to not have it. I'm not glad, I don't want to sound like that either, I'm not glad that I had it. But I don't really feel like I missed that much. And the stuff that I did miss, I don't really think I needed to have in my life anyway...I think if you see it as a learning experience.... I mean having kidney disease is like a learning experience...I mean it's given me a chance to learn a lot about myself and how I deal with things...The fact that...you are a stronger person because of this. You know, regardless of kidney disease, I've done things with my life that a lot of people that don't have kidney disease haven't done (Natalie).

In addition to finding positive outcomes of having the disease, participants were also able to reframe disappointments regarding their disease into situations for which they were grateful. "The only thing you can do is look at what's good about it, or at least look at what's not bad about it" (Natalie). Ben and Natalie reframed the disappointment of losing a transplanted kidney into a positive experience. Ben was able to draw something positive from having his mother's kidney for only a year. He explained,

In order to ease the pain a little bit, we said, we always said that I had it [the transplant] during my first year of university which is fairly important, so I wasn't dialyzing during that year which is good.... I managed to live
without dialysis for a period of time, an important period of time (Ben).

Natalie believed that if she had not lost her transplant, she would have continued doing destructive behaviours and that she would probably have died.

I was really doing stupid things. I was going out and getting drunk all the time...so when I lost my transplant I was like Thank God.... I can't drink anymore, which was cool cause I was starting to turn into a real ass when it came to that kind of stuff.... I was coming home at 5 o'clock in the morning and stuff like that, like crashing at friends' houses all the time. I was just never home. I was never around.... I was so hung over I could hardly, like hardly speak, let alone actually function at work and I was just like "Oh my God I gotta stop doing this." But I did it again anyway and I kept doing it. And I was like, I lost my transplant and I'm like, okay and all of a sudden those people were gone out of my life because I had nothing in common with them anymore...I had a whole completely different healthier lifestyle.... It was weird. And I'm like, I'm glad I lost that transplant...I would be dead now, more than likely. At that point probably AIDS if I hadn't lost my transplant. It was a total wake up call to me that, you know, basically the party can't last forever and this is like, you are fallible and wake up and stop being a complete ass (Natalie).

**Following Advice that Works**

Participants talked about how following constructive advice helped them to have a sense of control over the disease. Parents, health care professionals, and other patients often gave the participants advice about how to live with kidney disease. Participants talked about when they were first diagnosed, they tended to follow the advice given to them because they did not know any better. As they gained experience with kidney disease, they tended to not follow the advice or treatment unconditionally, but rather questioned it. When the participants found that the advice in fact did help them, they continued to follow those suggestions. When first diagnosed, Jeff initially followed the advice of adults unquestionably.

That's just the way I was raised I guess, I, you know they tell you something and you do it I guess you know. And I was too young. When you're 12, 13 you know, they say do this, you do it, you know? (Jeff).

Now that he was older and had more confidence in his decisions, he tended to
question the advice more and only followed it when he believed it would help or when it in fact did help.

I want to know more specifics. I want to know, and figure out why and stuff. Now that I’m older I question a lot more...I have confidence in my ability and my own judgment...you have to take in [the information] and make your own judgment, you can’t just get swayed in on the whole you know. And it’s just like everything in life, the more information you have the more you can make an informed decision (Jeff).

Participants gained knowledge about what restrictions or treatment worked for them regarding their kidney disease over their lives with the disease. When they found something that worked in the past, they tended to use that experience in the future, “I do my five dialysis a day...I take my medicine, I do everything they tell me...I do it because I know it will make me better”(Mary).

I made mistakes by eating, I was picking apples from a tree and I ate about 10 of them and of course [they have] potassium. So my level was like eight and they said you can have a heart attack and all this stuff. So I stopped eating apples (John).

I went in one time to the hospital with high blood pressure, I told them, “For me, if you give me a fast acting Nephedipine, it works, 20 mgs underneath my tongue, it works. And I will be fine in about 10 minutes” (Maureen).

Appropriate Resources

There were a number of resources that the participants mentioned that helped them to have a sense of control over their kidney disease and helped them to experience health including, a positive attitude, positive social support, and positive health care providers.

Positive attitude.

The participants concurred that having a positive attitude was key to living with kidney disease. Having a positive attitude was a way of being for the participants when they faced life with kidney disease with optimism and a positive outlook. Alex
described having a positive outlook as “just knowing that you’re going to achieve something. Just keeping, like saying I’m going to get through it. I’ll do it. I’ll stick out until the end.” Mary believed that it was important to live day to day with a positive attitude. She felt that not being positive “just doesn’t make sense” and it was “better to be positive.” Maureen believed that her positive outlook allowed her to focus on other things rather than the negative aspects of having kidney disease.

Yeah, to not let it [kidney disease] take over your life, it’s a positive outlook. There are a lot of things to be positive about, you just need to focus on them. The way I deal with it, I have lots of ways to deal with it...it depends on what you’re willing to accept and then dealing with it positively (Maureen).

The importance of having a positive attitude was reflected in the participants’ stories. Participants spoke of where they would be without a positive attitude, other people they knew that were not positive, and times when they themselves did not have a positive attitude. Without a positive attitude about life with kidney disease, participants believed they would not be able to deal with having the disease, (“Those constantly leaning on others, how sad they are, they don’t think they can deal with things, they don’t really have a positive outlook”), would not be able to accomplish things, (“If you don’t have a good attitude, then nothing is going to work out”), would be nowhere (“Nowhere, that’s all I can say, I wouldn’t have everything I have now, I’ll tell you that”), and/or would not have survived, (“I think I’d be dead”). Natalie felt that when she did not have a positive attitude about kidney disease her ability to have a sense of control over the disease was threatened because she was focused on the disease and believed she could not do things because of the disease. She explained,

If you’re negative, you’re not going anywhere...Oh I have kidney disease and I’m so sick and blah blah blah and I can’t do this and you have to be not like that otherwise you just get, it’s really easy to get stuck doing that (Natalie).
**Positive health care providers.**

Health care professionals were mentioned frequently in the participants' stories as helping participants to live with kidney disease and to help them have some sense of control over it. The participants in this study received medical care at hemodialysis units, peritoneal dialysis clinics, and post-transplant clinics. They had regular contact with a variety of health care professionals within the renal program, such as physicians, nurses, pharmacists, dietitians, and social workers. At one time or another, they also had contact with practitioners outside of the renal program. Participants talked about how some health care professionals helped them to maintain or promote their health, regardless of whether the health care provider had specialized training in renal disease.

Health care providers that the participants believed had a positive influence on their health or health care had “a way of making” them feel important and cared for by spending time with them.

One nurse, I can remember her. I was in a lot of pain, and she was into the touch therapy, to where you actually don’t touch the person...and it actually worked. I was amazed. And she just stood there all night, until I was asleep she did it.... The way they treat you is very important I think. Um, them spending the time with you if you have a problem is important because you know that they care, they want to get you better...Having positive health care is very important. Cause you don’t feel important otherwise (Alex).

The participants concurred that when doctors did not spend enough time with them to answer their questions, it made them feel unimportant and that the doctors' time was more important than theirs.

It makes you feel like you're basically not important...that their time is more important than yours. That's the way I feel, just like, okay, you have time to sit in your office, eat your food, do whatever you want, wander around the hospital, but you don't have the time to see your patient for, what, 15 minutes that maybe they need to spend for you or whatever. Where it's just, “Okay, see ya” (Alex).
Ben provided a possible explanation for why health care professionals did not spend more time with patients or encourage them to be more involved.

...relatively young people and intelligent people that are not being encouraged to change their situation and maybe, some people have explained to me, that it's, there's just not enough time to do that and guaranteed it's easier for a doctor or a nurse to work on a person who is not asking questions. You know, sit there and do what I tell you to do, that's easy, you know. But some one who is saying why are you doing that and don't do that and you know, it's a pain in the butt for people...the patient requiring an explanation, an intelligent explanation and not just a, one liner kind of [simple one line explanations].... I think it's easy for one thing and I think that maybe sometimes, well all these things require time and that's a precious commodity and I understand that so...you know in some cases I could see less of, less interaction unless the patient really encouraged that (Ben).

A positive health care professional-patient relationship was fostered when the health care professionals showed an interest in the participants' lives, not just around kidney disease, but in aspects of their lives that had nothing to do with kidney disease. Jeff found that those health care professionals who took an interest in his life and shared aspects of their lives outside the renal program helped him to relate to those health care professionals. Jeff found he could open up and share things with health care professionals that he could relate to.

He's [one of the social workers] just someone I used to talk to. He was a guy, you can relate to him, you know it was good...It's got to be a two way street. It can't be me giving a little bit and then you know. And [the social worker] like he opened up to me as well, just like a regular conversation. It's not like I am feeling like, I'm not into this psychoanalyze BS...I came to him and I was concerned about school or whatever, and you know, at the time and he said, like he, you know flat out he goes "Yeah well I didn't choose," cause I was getting worried that I was getting like 26 or whatever and I didn't know what I was going to do with my life... And he said, "Well you're still young, I didn't decide until I was 30 almost or whatever before I figured it out. There is plenty of time left." You know, it's stuff like that (Jeff).

Participants mentioned that they found it difficult to be open and honest about their problems with health care professionals who did not take a real interest in them or
when they believed the sharing was one way.

[Some] social workers are just meat-heads, you know. Like you [social workers] can't expect people to give [personal information] when you're [social worker] just sitting there going "Um, yeah, um, that's a good thought you know." It's just like, same thing when you meet someone, you can just tell that they're kind of phony and [it's like]well I'm telling you this and you're just going to write a report (Jeff).

Familiarity with a health care provider was also viewed as an important aspect of promoting and maintaining health. The participants in this study had all been living with the diagnosis of kidney failure for seven to 19 years. Due to the chronicity and longevity of kidney failure, participants often developed relationships with their health care providers that were outside of the health care environment. Josiah felt she was very close to one of her doctors. It is evident that their relationships was more than just the typical doctor-patient relationship as Josiah had not only invited him to her wedding but "he was supposed to do my speech to the bride." Unfortunately, he was called out of town at the last minute. Maureen also had more than a professional relationships with her doctors.

My doctors used to like me enough to have lunch with me. You know, we used to go out and have lunch and we used to discuss stuff...I used to have conversations at lunch and about central lines and stuff like that, because I'm hoping to go into medicine (Maureen).

The participants felt that they were better cared for by health care professionals who knew their history, their current condition, and their wishes regarding health care and health care relationships. Familiar health care professionals were viewed as being better suited to offer decisions and provide consistent health care because they knew better what was suited to the participants. Natalie was very adamant about having one particular doctor see her when she went to clinic.

I'm like you know what, again I didn't feel like I was involved, like there was any control sort of thing so that's when I said to Dr [the doctor's name], "If I'm not seeing you I'm not coming, plain and simple." I want to talk to one person who knows what's going on who I can actually have,
you know a conversation with who knows what was happening last time I was here. Who I can talk to this time and who knows what’s been happening, not somebody different every time who doesn’t have a clue...I’m only here for a short period of time, I don’t want to come in again and have to discuss my chart again with somebody, again and again and again (Natalie).

**Positive social support.**

Participants stated that having the positive social support of others was key to helping them have a sense of control over their disease and to promoting the experience of health. All the participants in this study talked of ways that they felt supported by others. Positive social support was primarily experienced from family, friends, and other patients. Participants felt that without the social support of family and friends, they would not have survived for as long as they had.

I also know that I wouldn’t be here if it wasn’t for my mom, because I’ve often thought of people, and I’ve been with people that don’t have any support, and how sad. So I know I wouldn’t be here without certain people in my life that made it positive for me (Josiah).

Participants mentioned the support of at least one family member who helped them to experience health. Family members had a profound impact on the participants as they were growing up with kidney disease and even now that they were adults. By spending time with them at dialysis, encouraging them to lead a normal life, and listening to their concerns, participants felt supported by their family which helped them to have a sense of control over kidney disease and live a life not focused on it. Family members often spent time with the participants at dialysis which helped them to pass the time and take their minds off of having to be there.

My mom and my grandparents, they were always the ones that came to dialysis and picked me up from work and sat with me and took me home.... But that was my sanity. My grandparents used to come up...I used to order food. You know, Mom and I, Tom and I, whoever, we used to always have food (Josiah).

Jeff believed that his father was an important influence in his life. His father often set
him straight when he felt discouraged about having kidney disease.

I get along excellently with my dad, very well, very well. And that's, ah, very important, probably very.... My dad knows when, my dad's exceptional, he knows when to set me straight and when to just let it blow over, let it, like he just knows about everything.... I'm really fortunate to have my dad as a big thing in my life you know (Jeff).

John found that his sister listened and helped him to believe in himself.

Well mostly my sister was, you know, talking to her, she made me feel better...She's just great to talk to, you know.... I go to [her] for advise. She's just good to talk to. She makes you feel better, cause you tell her your problems, she'll talk about it and make you feel better...She'd tell me other stuff you know, you can do it, don't worry about it, things will get better, that kind of thing. Kind of a coaching kind of thing I guess I could say (John).

The importance of positive social support from family is reflected in Natalie's statement.

I think for me it [to have a sense of control over kidney disease] took me that long but also because I didn't have that much of a support system...at home, I didn't really talk to anybody about it. My family isn't like that. We don't really talk about that kind of stuff. So I don't really talk to my brother about it, never really talked to my dad about it, I just didn't want to talk to my mom about it because it was such a huge issue between us anyway. Um, so I think if you have that kind of support system it could take a lot less time to be in control of it or feel like you are and make the goals and have the meaningful relationships and if you're not in control, you know, and if you don't have that support system, I think the support system and time is. There is a direct correlation like if you, like for you, you said your family was very supportive and encouraged you and all that stuff, so for you to deal with it and get to the point where I'm at right now probably took you probably 10, 15 years less than it took me [she is referring to the investigator having a lot of social support and feeling in control of kidney disease when she was younger] (Natalie).

When family were not focusing on kidney disease but rather treating it as "no big deal," participants believed that it helped them to have a sense of control over their disease. Ben's family encouraged him to lead a normal life. He believed that he grew up with the idea that kidney disease was not a big deal because this is how his family dealt
with it. Having incorporated the attitude that kidney disease was “no big deal,” he carried this attitude with him always.

You know, or maybe I just got it because that’s the kind of family that I grew up in and. I mean I guess this is a pretty common thing. But it was never treated as, in my family as being a big deal. And I never let it be treated as a big deal, maybe that, that combination of things. So, when I get out to the outside world, I expect the same thing to happen (Ben).

Friends were another source of social support frequently mentioned in the participants’ stories. When friends supported the participants by not focusing on the participants’ kidney disease, they too were able to believe that kidney disease did not have to be a big deal.

It’s like, I can do this. It’s no big deal. I mean I can go back on dialysis and whatever. And I had a really good support system as well in place, just with friends. Family sort of. I mean my cousin and stuff, but I had a really good set of friends who understood what was going on and who were really interested in it, and basically took part. Like I have friends who wanted to know how my machine worked, and I have friends who know how to set it up for me and stuff, that were really curious about how it worked, and you know, who weren’t afraid to ask me questions about it (Natalie).

Participants believed that having friends who supported them promoted the experience of health. They felt supported when friends spent time with them at dialysis, understood what they were going through, and helped them to follow their treatment and restrictions.

I had a couple of really good friends who knew what was going on, who used to come in [to the nurse’s room] with me and stuff and like hang out with me at lunch [while I did my dialysis] (Natalie),

I had a great group of friends that, the term was I was going to go change the oil, change my oil, that was the [saying] for dialysis. They knew. So but, completely normal about it. Um, which was great. I mean, they were a great bunch of people and I had no problem letting them kind of understand some of this if they wanted to (Ben).

I mean my friends were like, Josiah you can’t eat that, you can’t drink that. Watched what I ate if I went out. You know, like they were very
protective of me (Josiah).

Well for me it's important just because your friends are your support system and like they're the ones that push you, like my friends are the ones that push me to, you know, look after myself better or do dialysis when I'm supposed to and stuff like that. They don't push me to do it, I mean I would probably do it anyway, but I still sort of, okay, I went to Whistler, um, a couple of weeks ago for my friend's stagette party, I didn't take any dialysis with me and she was just like, "What the hell, didn't you bring it [materials for dialysis]?" I'm like, "I didn't." And my whole thing is I didn't want to be a burden, and she's just like, "You are an ass" (Natalie).

At the time of the study, all the participants felt that their friends did support them, however, they did mention times when they believed this support was negative. Jeff found that when he was on dialysis, his friends tried to support him financially by offering to buy him drinks, however they did not understand his fluid restriction which he found difficult.

You go to the bar even or whatever and your like, "Well I'll just have nothing" and then they look at you like you're Mr. Cheapskate or, you know, I've gotten dirty looks big time and stuff. Or you say, "I'd just like a water" or something, or even times when I said, "No I don't want nothing." They're like, "Are you sure, sure, I'll get it for you for free" and stuff and it's not a matter of that (Jeff).

The participants indicated that some other patients with kidney disease were a source of positive social support. They perceived patients as a form of support because they were going through a similar experience.

Well, they [other patients] knew what you were going through, and so it just, you felt more at ease, to where you have to explain everything to everybody else. Why you're being moody, why this and why that. They already know what you're going through (Alex).

Having this common ground helped participants to "get things off [their] chest." Although the participants did not spend a lot of time with other patients outside the dialysis unit or clinic, they found it helpful to share experiences and information and to learn from each other. In addition to finding other patients as a form of social support,
participants indicated that they were also form of support to other patients.

It did help me talking to other people in the dialysis. I find that at the [self care dialysis unit]...people come in do their thing and leave...I formed a good friendship with the guy beside me.... There are a lot of things [resources] I didn’t know that was out there. And he didn’t know [some of the resources I knew about] either..... If you could find a buddy system. If you could find someone to talk to about blah blah blah, so you’re not sharing in a big group. It does help a bit to talk about it and get it out of the way...I think a buddy thing, like say, 2 people are going to dialysis the same time...So that way they’re going through it together...I think that would help cause I helped this guy out a lot. Cause I’ve been through like a lot of stuff compared to a lot of the older people and stuff and they’re all freaking out (Jeff).

Although some participants saw other patients as a form of social support, they often restricted their contact with other patients to the dialysis unit and out-patient clinic because they found that most other patients were focused on kidney disease.

I didn’t even want nothing to do with other kidney people...like even the ladies organizing it [Nephron Mania]...[all the discussions] evolved around kidney stuff. Like the Transplant Games...And the kidney this and that...I was just, Oh my God! Have you ever lived at all [without totally focusing on kidney disease]. Like what have you done. That stuff just kills me.... That’s the reason I had to quit...cause they were getting too much, to involved with the kidney garbage and I’m not ready to talk about kidney stuff...I’m not ready to focus on it 24/7 [24 hours a day, 7 days a week]...I think they’re setting a poor example..... It’s one thing to be concerned and stuff but to be obsessed like that...I didn’t think it was a healthy...I didn’t think it was a great attitude to spread...I notice too at dialysis and the clinic as well, like it seems like that is their life, the kidney disease. They’ll talk about everything from tax breaks to everything, it’s all kidney thing, you know.... I’m adamant on that point, you can’t linger around [those] people...you know, you’re going through something you don’t need to [listening to others talk about the disease all the time] (Jeff).

**Being Perceived Positively by Others**

The perceptions of others had an influence on how participants perceived themselves and the impact of their disease on their lives. When others perceived the participants positively, it helped participants to feel better about themselves and their life with kidney disease. Josiah felt that when others perceived her favorably, it helped
Josiah believed that being positively perceived by others made her "feel better about [her] self" and gave her a sense of feeling she had some control over the disease. To be perceived positively, participants felt it was important that they be perceived as a normal person, rather than as a "patient." When they were not perceived as a sick person, they felt better about having the disease and less controlled by it.

Cause I'm definitely not one to be wanting to be labeled ill. Because it's a big, you know, there is a whole mentality to being a patient and to being ill, and if you let, like I mean I always think that if you let yourself become a patient, you know, that's it, game over (Ben).

Participants felt they were perceived negatively when others viewed them as being a sick person. Being perceived this way upset the participants because they did not see themselves as ill. Furthermore, some participants felt that when they were perceived as ill, it made them feel ill. Ben explained that when other people treat someone with kidney failure "as ill and that only reinforces your feeling ill." Frequently, other people had limited knowledge about ESRD and/or did not know how the person lived day to day with the disease and therefore perceived the participants inaccurately. By communicating their perceptions to the participants, the participants found they could start to believe them.

As long as no one's pointing out to me...I have had people that go, "Well you have kidney disease, you shouldn't be doing that." And I'm like, part of me wants to tell them to, you know, "Bite me." And the other part of me is like, "Oh yeah, you're right." I went rafting, river rafting with my dad and some other friends, and one of my friend's mother was there, and she was like, you know, "Should you be going rafting...isn't it bad for your kidneys." For an instant I went, "Oh gee, I don't know, maybe I shouldn't go." And then I went, "No, I'm going anyway. Like I don't care." But there was an instant where I kind of went, "Oh, you know, maybe you're right." I'll find the odd person, and it's usually someone who doesn't understand what's wrong... somebody like that who I'm not in direct contact with all the time and doesn't see how I live day-to-day and doesn't understand
exactly. Just knows that I have kidney disease...they tend to make assumptions on like how healthy you are or whatever.... If I'm left to my own devices, I'm fairly, fairly determined and fairly like, I'm fine, it's no big deal, I can do whatever I want. But if I have someone pointing out to me that I'm sick, it's not hard for me to go, "Oh yeah, you're right." And just sort of like...slide into a depression about it if I just kept thinking about it too much (Natalie).

**Time**

Time allowed the participants the opportunity to accept, learn about, experience, deal with losses and restrictions, and find ways to cope with kidney disease. Having been diagnosed 7 to 19 years prior to this study, all the participants had a considerable amount of time to experience living with ESRD. "Yeah, but just like everything, like anything else, over time you learn to accept it and learn to live with it and you adjust to that, you know, like people adjust to things fantastically given enough time" (Jeff). Time helped participants to have a sense of control over the disease by allowing them to accept that they had kidney disease and that they could have a life in spite of it.

I think time is a good way to deal with it as well. Like...Cause I think it takes time, it takes time to have control over it. It takes time to make goals and realize them and to, like for me it took me like, I'm not going to say 20 years, but it took me a long time to have control over the disease it's self. I mean all along I had this idea that I wanted to, you know, basically wanted to do these things, but I have kidney disease and blah blah blah and then it was like, just over time and especially within the last five or six years, I've been like, I'm just going to do whatever I want. You know I'm still going to live my life (Natalie).

Time to learn about kidney disease allowed participants to obtain information about their condition so that they could make informed decisions regarding their health and health care. "I am learning too, so that I know what works next time. So I want to be involved. If I know something, I'll share that this is a good idea or that it worked in the past" (Maureen). Time allowed participants to experience various treatments and their associated restrictions and consequence. Time and experience helped them to know
what one could expect from kidney disease and its treatments.

I think as an adolescent if you, you know, have kidney disease, you’re diagnosed as an adolescent or whatever and you do what’s happened to us where you’ve had a transplant and then you don’t, then you have a transplant and then you don’t, you’ve got that time to kind of prepare and you’re sort of used to the fact. But I think as an adult, you have kidney disease, or not even, you don’t even know, it’s acute or whatever, I think it kind of screws you cause you have no time to prepare. And as a kid like I said before you can bounce back faster as a kid (Natalie).

Time was helpful at helping people to deal with the symptoms, losses, restrictions, and complications associated with kidney disease.

I think I’m, a lot of the thing is ah, um, what’s the words, trial and error. Where someone fresh doesn’t have the trial and error you know. Like I’ve, there’s been so many scenarios, just like anything you get to perfect a technique, and people who freshly get it, they, they’re starting to perfect this technique whereas I’ve had 15, 20 years you know, so, I think that’s part of living with it as well (Jeff).

Well when I was first diagnosed it took five people to hold me down to get blood, so, and then later on two, then one, then it was somebody needs to hold my hand and now it’s nobody...so time, it took a little time (Alex).

Time also helped participants to find effective ways to cope with having kidney disease.

And that’s another time thing too is time had kind of made me see like it’s not that big of deal. And because I’ve had, I had time this time to sort of prepare for it. you know, like it could happen and you know and what am I going to do and I better deal with it and you know (Natalie).

You learn how to deal with things and there’s no more, I used to say, the curve ball, you’re sitting there and the fast ball is going straight and everything and every once in a while you get a big curve ball. And I, like I can deal pretty well with almost any curve ball now (Jeff).

**Threats to Having a Sense of Control**

The fourth major theme to emerge from the participants’ stories of their experiences with health was threats to having a sense of control over their disease. The categories that emerged during data collection and analysis regarding threats to
having a sense of control included, others taking control, exacerbation of disease, treatments interfering with living, and developmental changes. Furthermore, it was evident in the participants' stories about their experiences with health, that their ability to have a sense of control over their kidney disease was threatened when they did not have facilitators of control present in their lives.

**Others Taking Control**

As previously discussed, others took control of the participants' kidney disease when they were first diagnosed as adolescents. As adults, participants felt that there were times that their ability to have a sense of control over their disease was threatened when others took control over their activities, diet, and aspects of their health care. At times in their lives, other people asserted control over participants' activities because they had kidney disease. One of Maureen's teachers prevented her from taking part in two out-of-country school trips that were very important to her.

> It was after dialysis, I wasn't having any problems at that time. I was transplanted, and it was during the nine months of being well. I think it was more, he was a biology teacher, he knew about rejection, and I think he had in his mind a picture of us being down there and me going into rejection and having to find a hospital...it was for the first time, I really felt like someone really doesn't understand and, um, that was a really big deal because I had no control over his decision (Maureen).

For most of the participants, it seemed their parents had the hardest time giving up control over the participants' disease. Used to being in control of their child's illness management when they were younger, parents seemed particularly determined to have some control over how the person lived with the disease as an adult. Participants described how their parents would not let them have sole control of the disease, even after they became adults and were living on their own.

> My mom bugs me about what I eat and stuff. So does my dad. But they're doing it, they say they're doing it for my own health, but it bothers me. You know, it's like "Let me be me right now." They're doing it for my own good. I know they are. But it's just like, "Leave me alone!" Because
of so many years of telling me what to eat and what not to eat. Now it's like I'm free, I can eat whatever I want (Alex).

Health care providers also threatened the participants' ability to have personal control over their disease. Participants felt that health care providers threatened their control by imposing rules on them. "I felt they were treating me like an ill person, you know all these rules, you know, they talk and talk and I'm just thinking go away, because I'm not going to change...Oh, yeah, they've [nurses at dialysis] got rules" (John).

Participants spoke about how they felt they had little to no control over the clinic schedule or the long wait times and how it left them feeling they had little control over the process. Having to spend so much time waiting to see the doctor and then only being able to spend a short time with the physician, left the participants feeling it was a waste of their time and that their time was basically unimportant to the practitioners.

I was pretty choked. I was the first one there. I was there like quarter after 12, 12:30, something like that. They didn't start until like quarter after 1:00. I got my height done, I'm sorry I did my weight before I even started. They checked my blood pressure, asked about the pills I was on, and then the doctor calls me. I see him for not even two minutes and I was done. It made me really mad. Like there was really even no sense of me going. He was just going to say, "You're fine."...[Being made to wait] makes you feel like you're basically not important...that their time is more important than yours. That's the way I feel, just like, okay, you have time to sit in your office, eat your food, do whatever you want, wander around the hospital, but you don't have time to see your patient for, what, 15 minutes that maybe they need to spend with you or whatever. Where it's just, "Okay, see ya" (Alex).

Natalie described how she would have liked to be more involved in her care and how she felt threatened, treated like a child, and made to feel that her questions were unimportant when she attended the peritoneal dialysis clinic. Having to go to the clinic, spend so much time there, and then not have her concerns addressed, threatened her ability to have a sense of control over kidney disease.

I still think they're talking to me like I'm a kid, and like almost threatening me. Like, oh, "If you don't do this then this is going to happen..." I sort of
look at them and go "pfft, yeah, okay," and then walk away pissed off. And I'm like, I usually leave here feeling sick because I had to spend the entire day here most of the time, because, you know, I sit in that office and I'm just like, "God, I hate being here." And I think that's my biggest complaint, is that I'd rather just come in, deal with them and go home...I feel like I'm getting talked to like a child still. So I'd like to have more involvement...just sort of be more responsible for what's going on...I don't like being told that I have to wait to talk to the pharmacist and, I think the only time I ever get really irate, not irate but really tense about having kidney disease is when I come here and have to talk to people about it...it feels like I'm getting my hands slapped every time I come here, and I just don't want to deal with that because I'm like, "You know what? I'm like 30 years old and I really don't need that." You know, I'd rather be more involved that way, and like...I sort of feel like when I ask them questions, they're like, "Oh silly you," and walk away. And I'm like, well, okay, whatever, you know, I only spent like seven days thinking about that (Natalie).

**Exacerbation of Disease**

Many of the participants felt they were losing or had lost control over their disease when there was an unexpected change in the kidney's function or the disease progression. All the participants who had lost a transplanted kidney experienced worry and uncertainty when they learned that they were losing the transplant. Josiah experienced a loss in control when she learned that the kidney she had had for seven years was chronically rejecting. Not knowing when she would return to dialysis or how being on dialysis would affect her son, Josiah felt she was losing some control over the disease. She did not fear going back on dialysis because she knew what to expect, but she felt she had no control over the rate at which she was losing the kidney.

Constantly in the last two weeks, three weeks, I have been analyzing, like what's it [creatinine] going to do. Thinking about it all the time. And I never used to think about it. The only time I ever used to think about my health was the night before my blood work. And now I think about it all the time...I'm hoping it's still going to be a little bit longer before I go back on, [dialysis] but I'm finding myself thinking more and more just in the last couple of weeks or, since that blood work... "What kind [of dialysis] should I do? Peritoneal, should I do hemo? What should I do?" You
know, and I know all that stuff...I'm not nervous about it. I'm not looking forward to it, to be honest with you, but I'm not nervous about it.... They haven't said how long it's going to be. I don't think they know the pattern of my blood work yet. I almost wish they would, but I don't want to bring it up...I do think of myself as being sick now. But because I, the unknown. Where when I was on dialysis there was no unknown. I knew exactly what life was going to be like...that was normal for me (Josiah).

When Jeff learned he was going through a rejection episode with his new kidney, the repeated trips to the hospital and the uncertainty prevented him from focusing on his studies and getting into physical shape. He felt a loss of control because the rejection was so unexpected. Therefore, he put off doing things as he was preoccupied with worry about the possibility of losing his new transplant.

The nephrotic syndrome, glomerular nephrotic syndrome. They said that, something that I didn't know but that I've lost a kidney before to that and if this one went, then I wasn't going to be transplanted. So then like the last month had been hectic for me right. You see, but, but like, now it turns out it's just acute rejection and now, you know like I put everything, like I couldn't do my school work. I cut back everything (Jeff).

Natalie's repeated bouts with peritonitis was threatening her ability to have control over the form of dialysis she underwent, which was important to her to have a sense of control over the disease. She feared that she would have to switch to hemodialysis because she was not receiving adequate dialysis.

The only thing I worry about now is that because I've had peritonitis so many times that I'm going to hit a point where I have to be on hemo, and I do not want to be on hemo. I have been adamant about that, you know, for like 20 years. I just don't want to do it. They have been asking me for years to get a fistula and I'm like I'll make an appointment to do it and then I'll cancel...I think it's because I've had peritonitis so many times, I'm just not getting enough dialysis, it's just not working that well (Natalie).

When Maureen lost the function of her transplant, she found the overwhelming symptoms associated with the kidney failure, such as tiredness, prevented her from being able to study. When she was too tired to go to school and "come home and study for 3 hours" without the "need to go right to bed" or having to "turn off my brain for
15, 20 minutes while it kind of recharges,” she felt the symptoms of kidney failure were controlling her life.

**Treatment Interfering with Living**

When the need for dialysis or other treatments interfered with doing something perceived as important, participants felt they had little control over the kidney failure. All participants discussed times when they felt they had little control over the kidney failure because dialysis prevented them from living their life and doing things that were important to them. The weakness experienced after dialysis prevented John from doing things with his friends.

John: After dialysis I was in really bad shape a lot of the times, and sometimes when I was at home, I'd get up and I'd feel like I was going to faint and my blood pressure dropping, I needed salt, big pain kind of thing so.

Lisa: Were there times that you really wanted to do something badly, whatever, something, like go out with your friends?

John: Yeah. I missed a Judas Priest concert with my friends because of that. I felt so lousy after I couldn't go, I couldn't do it...I had to sleep it off, I couldn't go. So that I regretted, I was looking forward to that.

Having to do dialysis often interrupted an activity that the participants were involved in or prevented them from participating in an activity.

If we were in the middle of something, I had to leave and I didn't want to leave cause, that bothered me a lot. You know, you got to think, you'd make plans but then you gotta think, no I can't do it I gotta go to dialysis or you go to work and you're tired, you gotta go to dialysis, very inconvenient, very yeah (John).

Other treatments also affected the participants’ ability to take part in activities. When Jeff underwent high-dose steroid pulsing in an attempt to halt the acute rejection episode he was experiencing, he found the effects of the drug prevented him from concentrating.

This pulse [high dose IV steroid] and the high prednisone killed me. Like totally bad. It's been a horrible two weeks, a horrible week and a half whatever...But it was tough though, you loose it...like my concentration level is zip, zero, I didn't sleep...I didn't even sleep. I over worked out, l
got a sore throat now, all these minor things are coming out now. Like it's going to take me like a week to get back (Jeff).

**Developmental Changes**

The participants in this study were diagnosed in adolescence and were now adults. As participants passed through this transition, certain challenges regarding the developmental tasks of this period were experienced because of their kidney disease. At times, participants perceived a threat to having a sense of control over kidney disease because the disease was exerting some control over their ability to carry out these developmental tasks. The developmental changes these participants encountered threatened their ability to have a sense of control over kidney disease and included, finding a life partner, starting a career, and having families.

Participants spoke about how they wanted to have somebody special with whom to share their lives. Some believed that having kidney disease threatened their ability to find someone who would accept them. Not being able to meet this developmental task threatened participants' ability to live a normal life which in turn threatened their sense of having control over the disease. A common concern of the participants with regard to finding a life partner was, "I have kidney disease so no one is going to want me" (Natalie). Three of the participants were in permanent relationships, whereas the remaining five were not. The three that were in relationships talked about struggles they had finding someone who would accept them as partners in spite of having kidney disease.

When I met Noah, I told him right away. I told him just right away. I told him. Where once there was another person that I knew, he took me out for dinner. It was like I couldn't tell him. You know, just the vibe you get from somebody. It's like, okay, can I tell you? Will you run away, kind of thing (Alex).

The remaining participants spoke of their struggles to meet someone and believed that many people would not accept them as partners because of the disease.
I think in a world, girls, some of them are picky and, ah, you know they, if you're not perfect and you have a transplant, it might scare them away. That's what I think in my mind, I don't know if it's true but that's the thought I have...I don't tell them. I just want them to see me as a normal person (John).

Having or starting careers was important to all of the participants at the time of the study. Four of the participants were working in areas they enjoyed, one volunteered in an area she enjoyed, whereas the remaining three had ideas of what they wanted to do and were working towards those careers. Those participants who were in their chosen careers spoke of some of the struggles they had to get there and how they had to plan their careers around the fact that they had kidney disease.

I was going to be a hockey player...[I] couldn't do it with going to dialysis and all that right. So yeah, I had to plan around that and think of something else, and ah, you know without my parents help I don't know where I'd be right now or what I'd be doing right now, you know. Cause it also interrupts school right for me, so like, I don't know [I would] probably [be] on welfare or something like that (John).

Those who were not yet in their chosen careers talked about how they felt they were behind with respect to careers and material possessions.

I think it comes down to like looking at people your own age and stuff and just...doing the same things as them.... They're talking about, "Oh I got...a mortgage payment" or something goofy like that and I'm still on a truck payment...I'm at the 23-year old stage and they're at the 28 [year old stage] (Jeff).

If I didn't have kidney disease I'd be able to work full-time and I wouldn't be in this position. Because I would have finished school and I would have done these other things if I didn't have kidney disease.... I would have gotten down to business like everybody else I know...I just feel like I should be in a different place...I'm a lot less mature than most people my age...like I don't have a career.... If I didn't have kidney disease...I think I would be more successful like goal-wise and career-wise (Natalie).

Having kidney disease resulted in struggles to attaining a career which threatened participants' ability to meet this developmental task. Consequently, when participants had considerable difficulty or failed to meet this task, they perceived that kidney
disease was having some control over their lives. To minimize the effect of ESRD on their careers, all the participants believed it was important to choose a career that they could do on dialysis or with a transplant.

If I can get this education thing done and everything then I can teach when I'm either on dialysis or when I'm transplanted...that's the reason I'm looking for a profession in which no matter what happens to me I can still work in that profession (Jeff).

When participants were able to start and maintain careers in spite of kidney disease they felt less like the disease was controlling their lives.

Starting families was another developmental task that some of the participants spoke about. One of the participants had a son, one had a step-son, and the remaining six did not have any children. Two of the female participants spoke about their concerns regarding the impact of their kidney disease on their current or future children. None of the male participants talked about the implications of having kidney disease on having children. When kidney disease threatened the female participants' abilities to have children or care for children, they felt kidney disease exerted some control over them. The threat to this task left participants feeling that the disease had some control over their lives and consequently felt less in control of the effects of the disease. Alex worried about not being able to have children because of her transplant. If she were able to have a child, she worried that the immunosuppressive medications she was taking could be detrimental to the child, "I worry about what the medication I'm on would do to a child." Alex also worried about the possibility that she would pass kidney disease on to her offspring because of its hereditary nature: "My biggest fear is if I have a daughter, is she going to get it [kidney disease]?"

Having a child to care for threatened Josiah's ability to have a sense of control over the disease. With the upcoming return to dialysis, Josiah was unsure how she was going to work, dialyze three times a week, and care for her son. Having a sense
of control over her kidney disease was more important to her now that she had a child; however, this control was threatened because “things are different now.”

Josiah: Life is different now that I have Jordan... you know, I often think, before, you know, if something was to happen, then that would be life. But now I don’t want him to grow up without a mom. You know, you think differently than I would have before... If kidney disease or cancer or something was to take me, it wouldn’t be so bad. But now that I have Jordan, I think to leave him without a mom would be horrific, you know... a different perspective on things. But I was never frightened of, um, if something, you know if I was to pass away for something.... But now it’s different that I have him. I think, I don’t want him to grow up without a mom

Lisa: Do you think your health is more important to you then, now that you’ve got a child?

Josiah: I think about it more often. And I think just since I’ve been sick. Probably last year if we had the same conversation I would have never thought of that.

The added strain and time commitment with dialysis threatened her ability to have control over the impact of the disease on her family life and consequently threatened her ability to feel in control of her kidney disease.

I think if I went back on dialysis, financially, Tom and I have to work. There’s no question about it. But I enjoy my work, therefore I would want to work, but I’ve already come to the conclusion that if I go on hemo with a baby, I am not working full-time and dialyzing three evenings (Josiah).

Alex and Josiah spoke of the potential threat of a pregnancy to existing health and control over the disease. Alex worried about the ability to have children of her own. She feared that if she were to get pregnant, the pregnancy could be detrimental to her transplant, “I don’t know how a pregnancy would affect my transplant.” Whereas, Josiah already had a child. However, her transplant began to reject shortly after her pregnancy. While the cause of the rejection was unknown, there was some uncertainty as to how the pregnancy affected her transplant.

**Descriptions of the Concept “Health”**

The fifth theme to emerge in the participants’ stories was their descriptions of
the concept of health. The categories that emerged included, aspects of health, range of health, and what it means to be healthy with ESRD. The participants had difficulties defining what it meant to experience health. However, some common descriptions were apparent. Specifically, health was viewed as encompassing physical, mental, and social aspects and that there is a range of health that one experiences. Health was described in terms of having the abilities of other people, being able to do what is important, and not focusing on the disease.

**Aspects of Health**

All participants believed that health was more than just physical, and that there were also mental and social aspects of health, "It's not just physical right...there are tones of people that are physically healthy and they're just messed up, you know" (Jeff), "Being healthy mentally is a big thing too" (Ben). Participants spoke of physical aspects of health, mental aspects of health, and social aspects of health.

I think it has more to do with like accepting what's going on and, and like being okay with it, sort of, rather than physically feeling okay because if I, mentally I'm okay with it, physically I don't feel bad either, they seem to be hand and hand for me.... I guess I feel healthy when I'm not like focused on being sick or whatever. I mean I could feel horrible, but as long as I'm not focusing on, or moping around my house going, "I feel sick," whatever, whatever, feeling sorry for myself, then I feel pretty healthy (Natalie).

When I was on dialysis, on the hemo, and stuff like, even like minor things like confidence and stuff...the social aspect is huge, like ah, the dialysis killed ya. Cause anytime you go out, there is always, it's go for coffee, or go for beers, or whatever, that's the killer thing.... Socially, I find socially for me is, ah, it has to be a level playing field. Like I socially drop when I'm on dialysis...like I'm hindered cause I'm not feeling at my peak...like it's a disease and it affects you and there's nothing you can do about that, but I limit my social circles when I'm on dialysis (Jeff).

I think if you're just sitting at home and you're not making goals and you're just kind of sitting there and you're not doing anything, you have nothing to talk about first of all so you have nothing socially to offer anybody...I don't know, I can't say that I know for sure how it makes me
feel healthy but I know if I didn’t have them [relationships with people] I wouldn’t feel healthy (Natalie).

Range of Health

When discussing the concept of health, participants spoke of a range of health. They spoke of health as a continuum ranging from being very ill to very healthy.

I think it’s important to have a lot of health but you can survive with some sense [of health], you know what I mean? Like if your ultimate thing is you want the best health you can get right. But ultimately that doesn’t work out for every individual. You know, you have to realize that...take what you get kind of deal in the health part and that’s the way it goes...like health’s tough to define you know...It’s a personal thing cause you see like whatever, Lance Armstrong with cancer and then he won the Tour de France kind of deal (Jeff).

I’m not sure if I would consider myself unhealthy or ill, probably I wouldn’t, so maybe I’m floating somewhere in the middle of those two words [ill and healthy] (Ben).

Participants believed that to be totally healthy was abnormal because everybody has something that negatively affects their well-being. Maureen felt that having enough health was important to avoid being sick.

I’ve never met somebody who hasn’t had something wrong with them...I don’t think that healthy is normal, I think that, um, having enough health, um, to get through a couple of weeks without being sick, getting through a month or two without being sick...is average and average, you know everyone has something wrong with them (Maureen).

What it Means to be Healthy with ESRD

When participants perceived they had a sense of control over the kidney disease they believed themselves to experience positive health. Participants discussed positive health in terms of having the same abilities as people without kidney disease, ("Having the health...the abilities of a normal, of an average person" ), being able to do the things they wanted, ("Feeling well just means I get to accomplish the things that I really want to do regardless of having kidney disease"), and not being
focused on the disease, ("You need to be healthy, to be strong enough, mind and physically to live outside of it [kidney disease]."

I think it goes by accomplishments, I set certain goals and everything and then there is a lot of things that I set or whatever that I haven't accomplished or whatever but I find that when I'm healthier and stuff, they are more attainable (Jeff).

When I feel healthy, um, I have, for me that really means I have energy to do stuff, um, to do work.... When I was healthy for those nine, ten months, I got a lot done. I got my, you know, life-guarding...I worked, I volunteered, I did all sorts of stuff (Maureen).

I feel healthy when I'm not like focused on being sick or whatever. I mean I could feel horrible, but as long as I'm not focusing on, or moping around the house going I feel sick, whatever, whatever, feeling sorry for myself, then I feel pretty healthy (Natalie).

Participants also talked about how feeling healthy helped them to have a sense of control over the kidney disease. The experience of health involved the interconnectedness of health and having a sense of control over the disease. Natalie explained,

It's really circular, cause if you, if you're happy and you're healthy and you're making goals and you're reaching goals, you're that much more healthier and that much happier and that much more able to live with the disease and control the disease and you know, have a life outside of it (Natalie).

Summary

In this chapter, the findings of the study were presented regarding the experience of health in adults diagnosed with ESRD during adolescence. The study participants validated, clarified, and/or revised the data analysis to reveal five themes regarding the experience of health. The themes presented included diagnosis in adolescence, having a sense of control over ESRD, facilitators of having a sense of control, threats to having a sense of control, and descriptions of the concept "health." In summary, when first diagnosed the participants had a number of issues about being diagnosed
as adolescence including others taking control, desire to be as normal as peers, inability to do or achieve what one wants, and incorporating ESRD into life and self concept. The experience of health, for the participants, involved the fluctuating state of perceived control and perceived loss of control over the disease. Participants took control of the disease by controlling the disease rather than being controlled by it, thinking and doing differently, reasoned non-compliance, and making conscious choices which resulted in the participants having a sense of control over the disease. There were a number of ways that participants identified to facilitate having a sense of control that included accepting kidney disease, normalizing, reframing, following advice that works, appropriate resources, being perceived positively by others, and time. A number of threats to having a sense of control were presented that included the absence of facilitators of control, others taking control, exacerbation of disease, treatment interfering with living, and developmental changes. The chapter concluded with the participants descriptions of health, which included, aspects of health, range of health, and health within ESRD. These findings revealed a number of themes to be discussed in the following chapter.
CHAPTER FIVE: DISCUSSION, IMPLICATIONS, SUMMARY, CONCLUSIONS, AND FINAL THOUGHTS

The grounded theory that arose from the study findings and significant aspects of this theory as they compare to current understandings in relevant literature will be presented in this chapter. A discussion of the significance and implications of the components of the grounded theory will be presented and include: 1) the experience of health fluctuates between periods of perceiving one has a sense of control and perceiving one has lost control over ESRD, 2) the implications of the diagnosis of ESRD in adolescence, and 3) finding a balance between being controlled by the disease and having a sense of control by not attending to the physiological needs of the disease. The chapter will conclude with a summary of the study and some final thoughts about the experience of being diagnosed as an adolescent with ESRD.

Grounded Theory: The Experience of Health as Perceived Control

In this study the experience of health in adults diagnosed with ESRD during adolescence was investigated. Five themes emerged from the data explaining how health is experienced by this group of people. These included, the diagnosis in adolescence, having a sense of control over ESRD, facilitators of having a sense of control, threats to having a sense of control, and descriptions of the concept "health". The five themes generated a grounded theory to explain the experience of adolescents diagnosed with ESRD and how this experience affected their perception of health. The theory developed from the participants' stories is depicted in figure 1. An overview of the theory is presented here.

According to the participants, when first diagnosed with ESRD, adolescents perceived themselves to have no control over the disease. Because adolescents initially experience having no or little control and resist the negative outcomes of this lack of control (e.g., being different from peers), they begin to desire having a sense of
Figure 1. The Experience of Health: Perceived Control over ESRD
control as the preferred way of living with the disease. When they experience a sense of control, they are also able to experience a sense of health. Having a sense of control over ESRD is possible when individuals are able to control the disease rather than be controlled by it, make conscious choices, demonstrate reasoned non-compliance, and think and do things differently with regard to the disease. As they live with the disease and are exposed to additional threats and facilitators of having a sense of control, one of two outcomes is possible. If sufficient facilitators of control are available to them, they are able to develop a sense of having control in the management of their disease. However, if insufficient facilitators are present and/or threats to control are experienced, adolescents continue to perceive that they have no control.

Participants believed that feeling in control is preferable to being controlled by the disease. When individuals perceive they are in control, they are able to experience health with ESRD by living and feeling "normal". This provides them with a way to live "outside of the disease". After gaining a sense of control initially, people with ESRD may encounter threats to that control; this can lead to a temporary crisis of control and a perception of losing control. They regain a sense of control by seeking or experiencing facilitators of control. The process of having a sense of control is not static, but is fluid and dynamic. The cycle of perceived control and perceived loss of control repeats over time as one proceeds through life.

Components and Relationships Inherent in the Theory

The components of and relationships between components in the grounded theory are described in the following section of this report.

Diagnosis in Adolescence

The unique challenges of being diagnosed as an adolescent with ESRD (others taking control, inability to do/achieve what one wants, loss of a normal life, and desire
to be like normal peers) result in adolescents initially perceiving that they have no control over their disease and that the disease controls their lives. At this time, they either make a decision to take control or continue to let others assume control. The diagnosis of ESRD during adolescence results in them viewing themselves as a person with ESRD. Over time, as they assume control of the disease, the disease becomes a part of who they are but not their whole identity.

When adolescents are diagnosed with ESRD, they experience others taking control, a loss of a normal life, an inability to do or achieve what they want, and ESRD becoming part of their life and identity. Adolescence is a time when individuals struggle for independence from their parents. When parents take charge of their adolescent's disease management, adolescents with ESRD perceive this as a threat to control. This may be exacerbated by health care professionals who assume that parents should take responsibility for their ill adolescent's diet, fluid intake, and treatment decision. Practitioners who maintain such assumptions often neglect the adolescent in decisions about the disease management and perpetuate the adolescent's feeling that he/she has no control. The symptoms, restrictions, and treatment regimens inherent in ESRD threaten adolescents' ability to do and achieve many things that are important to them, such as school, sports, and recreational activities with their friends and peers. In some cases, ESRD can constrain an adolescent's ability to pursue life goals. These restrictions threaten adolescents' control and foster their perception that their lives are controlled by the disease.

At a time when peer relationships and the desire to be like peers is particularly important, the diagnosis of ESRD leaves adolescents feeling the loss of a normal life. Perceived acceptance by others is threatened because adolescents believe they are different from their normal peers. Adolescents with ESRD struggle to feel normal, appear normal, and achieve acceptance from peers.
Adolescents went through a process of trying to take control of not only their disease but also of decisions that were being made by others. Over time they were able to assume varying degrees of control at different points in time. While for some participants, this involved a clear point of decision making to take control, for others it seemed like an evolving process. In the process of taking control participants made decisions about their disease management that were conscious, deliberate and at times awkward. These decisions related to what foods to eat or to more complicated decisions, such as what careers to pursue. Decision making that took into account the ESRD soon became "second nature" as they accepted that ESRD was part of their lives.

**Having a Sense of Control Over ESRD: The Preferred Way of Being**

According to the participants, after the initial shock of the diagnosis, having a sense of control over the disease is the preferred way of being for adolescents with ESRD and for adults diagnosed with ESRD during adolescence. Having a sense of control over the disease, rather than being controlled by it, involves finding a balance between focusing too much and not enough on the disease, treatments, and disease management. Focusing too much on ESRD restricts opportunities for a life outside of the disease. One learns how to have a sense of control over time with experience and various situations that threaten control. When someone with ESRD receives a transplant before ample time has occurred for them to learn how to have a sense of control over the disease while on dialysis and then later the transplant fails, they function as novices in controlling their disease management while on dialysis. The more time spent having to undergo dialysis allows people with ESRD to find ways to achieve the balance needed to have a sense of control in living with the disease.

People with ESRD have a sense of control over the disease when they make conscious choices regarding their disease. Having a sense of control means being
involved in the decisions regarding disease management and assuming primary responsibility for their disease management. People with ESRD make conscious choices about their disease management based upon what is best suited to their lives and personal goals. The participants believed that when they are involved in such decisions and in the implementation of their care, they better understand what is going on, make better disease management decisions, and are able to influence the desired outcomes. This allows them to have a sense of control in living with ESRD.

People with ESRD have a sense of control over the disease when they are able to make decisions to not follow the advice of health care professionals based on reasons they believe to be valid. This is termed reasoned non-compliance. People with ESRD often have life and personal goals other than the resolution of negative physiological indicators that conflict with the prescribed regimen. On certain occasions, they weigh the consequences of not following the advice with the possibility of forfeiting personal goals and decide to ignore or refine the prescribed regimen. Reasoned noncompliance, for the most part, is not particularly dangerous because people with ESRD know the consequences of their behaviour and how to mediate these. For example, they may choose to eat Chinese food on the day in which they will be dialyzed because they know that the electrolytes in the food will be filtered by the dialysate. Although they are well aware of the reason for regimens or restrictions, on certain occasions, they choose not to comply because they believe their goals are more important and their reasons for not complying are more pressing. They are able to have a sense of control because they are able to make decisions about when and if they adhere to aspects of the prescribed regimen.

When people with ESRD view the disease as part of their lives, living with a regimen of disease management does not seem to be as overwhelming or inconvenient as when they viewed it as controlling their lives and impinging on their
desire to live as they wished. People with ESRD have a sense of control when they do not have to constantly think about the disease management and are able to incorporate the disease management into their daily lives.

**Health within ESRD**

Control and health are dependent on one another and reinforce one another; when individuals experience a sense of health, their perception of having a sense of control is enhanced and vice versa. When people with ESRD have a sense of control, they experience health. A sense of control enables them to do things that they want to do, to feel and act normal within the limits of the disease, and to live a life that is not entirely focused on the disease. Individuals experience a various degree of perceived control and, therefore, experience a various degree of perceived health. When people with ESRD have minimal perceived control, they perceive a minimal level of personal health; whereas those who perceive they have a lot of control over the disease perceive a greater level of personal health. Control has physical, social, and mental outcomes; therefore, individuals who have a sense of control experience physical, social, and mental aspects of health.

**Moving from Perceived Loss of Control to Perceived Control**

There are a number of facilitators of having a sense of control in living with ESRD. These facilitators include accepting, normalizing, reframing, following advice that works, being perceived positively by others, time, and appropriate resources such as, a positive attitude, positive social support, and positive health care provider relationships. When people with ESRD accept that they have kidney disease and that they can live positively with the disease, control over the disease is facilitated. Accepting the disease allows individuals to take responsibility for the disease and the effects of the disease on their lives. By taking responsibility for taking medication, dialyzing on schedule, and following the restrictions, individuals can have some
control over the impact of the disease on their lives. Furthermore, individuals are able to focus on living as they would like to live, not the disease per se, although they have the disease. Normalcy promotes a perception of control because the individuals feel normal, appear normal, and are treated the same as people that do not have kidney disease. For adolescents, normalcy is achieved when parents, teachers, and friends/peers in their lives have similar expectations of them as they would have for any other person their age. For adults, normalcy means that friends, family, employers, and other people in their lives treat them and have similar expectations as they would a person without kidney disease. When individuals do not feel remarkably different from other people, they are able to experience some control over the impact of the disease on their lives.

Control over the disease is also facilitated when individuals reframe their experiences with kidney disease into something positive and find meaning in having the disease. This helps people with ESRD to feel that their experiences with kidney disease have some positive outcomes or influences, including being opportunities for personal growth. This in turn energizes them to take control because taking control is equated with assuring positive outcomes.

Over time with kidney disease, people with ESRD learn about the disease and its management from others and from personal experience with the disease. Learning what works and what does not work helps individuals to find ways to have a sense of control over the disease. When individuals gain experience, they are able to make informed decisions regarding the advice they have received from others, choosing at times to ignore the advice. Furthermore, finding things that have worked in the past and utilizing those strategies in the future facilitates control over the disease.

Perceptions of others are influential in how people with ESRD view themselves and their ability to have control. When people with ESRD are perceived favorably by
others, such as competent and knowledgeable about the disease, control of the disease is enhanced. Conversely, when they are perceived negatively by others, such as incapable or dependent, the person's control is threatened.

Time provides people with ESRD opportunity to accept, learn about, experience, deal with losses and restrictions, and find ways to cope with the disease. Over time, having a sense of control becomes easier as they gain experience in living with the disease, learn to identify and access appropriate facilitators, and find ways to thwart the threats to control. There are other potential resources available in the lives of people who have kidney disease that when present facilitate their control, such as a positive attitude, positive social support, and positive health care provider relationships. When these resources are not available individuals' control is threatened. Other people with ESRD may be a source of positive social support. They can help each other to find ways to cope with the disease and its management and have a sense of control. However, when other people with ESRD are focused on kidney disease and the negative aspects of the disease or its management, they may perpetuate a view that control is impossible or unhealthy.

Health care professionals have the ability to facilitate or threaten a person's ability to have a sense of control over the disease. When health care professionals include people with ESRD in decisions regarding their disease management and encourage them to take responsibility for their care, control is enhanced. Health care professionals can also facilitate control by answering their questions and by treating them as people who happen to have ESRD, not ESRD patients. Furthermore, due to the chronicity and duration of ESRD, it is important that people with ESRD have consistency in health care relationships. A positive health care provider-patient relationship facilitates control because people with ESRD's opinions of and experiences with the disease are respected, validated, and considered when planning
Moving from Perceived Control to Perceived Loss of Control

Throughout the course of their lives, people with ESRD encounter a number of situations that threaten their ability to control events and experiences. When these threats occur and insufficient facilitators are present, the individual perceives a loss of control. Threats that may be encountered include others continuing or starting to take control, treatment that interferes with living as one wishes, exacerbation of the disease, and developmental changes. Parents generally take control of their adolescent's disease management because the status quo has been for parents to make important decisions for their children. Health care professionals often exert control over the disease because they believe that they have knowledge that adolescents and their families do not have regarding the disease and effective treatments. As adolescents mature they gain independence and experience in making their own decisions. However, there are times when other people attempt to maintain control, exert control, and/or try to take control away from people with ESRD. When this happens, people with ESRD feel that others do not understand how they live with the disease, do not acknowledge their expertise, and are trying to take the control away from them. Their control is threatened.

Control is also threatened when dialysis or other treatments interfere with an individual's ability to do things that are important. Inconvenient and time consuming dialysis treatments, effects of dialysis, side effects of medications, and medical appointments often prevent or interrupt a person from being able to take part in desired activities or experiences. The disease, the treatment or the effects of the treatment may become so overwhelming that people with ESRD begin to feel that the disease is controlling them and consequently they perceive a loss of control.

Living with kidney disease involves much uncertainty and concern about the
future. Individuals on dialysis worry about symptoms, infections, complications of the dialysis procedure, changes in treatment, future transplants, and the long-term impact of kidney failure and dialysis. Individuals with renal transplants worry about possible rejection or loss of a transplanted kidney and side effects and complications associated with the immunosuppressive drugs. There are any number of additional potential exacerbations and complications of the disease that may arise of which the individual has no previous knowledge. When exacerbations of the disease arise, people with ESRD experience a threat to control because they can no longer predict how the disease can be managed so as to permit them to live as they wish. The exacerbation brings new experiences and learning and, for a time, threatens their control.

As adolescents mature and develop as adults, they encounter a number of developmental tasks that may threaten their ability to have a sense of control in living with the disease, including attaining financial and personal independence, starting careers, finding life partners, and starting families. When the kidney disease threatens or prevents individuals from achieving these developmental tasks, they may perceive that the disease is inhibiting their natural developmental trajectory. The desire and struggle to meet these developmental tasks leaves people with ESRD perceiving a loss of control over the disease because the disease is controlling important aspects of their lives.

**Cyclical Nature of the Theory**

The experience of health in adults diagnosed with ESRD during adolescence is an ongoing process that repeats over time. Perceived control and perceived loss of control occur in a cyclical pattern. Throughout the course of their lives, people with ESRD are continuously, and often simultaneously, exposed to facilitators and threats to control. As threats are experienced, they struggle to maintain or regain a sense of
control by drawing on the facilitators present in their lives. The process of taking control is repeated over and over throughout the course of their lives with ESRD.

Discussion of Significant Issues and Relation to Current Literature

A number of issues arise from the grounded theory that both supports and expand current understanding of this phenomenon in the literature. The theory raises issues regarding the fluctuating nature of the experience of health, the implications of the diagnosis of a chronic illness in adolescence, and the concept of having a sense of control as a balance between being controlled by the disease and controlling the disease.

Fluctuations in Perceived Control

The theory suggests that the people with ESRD experience health as a fluctuating entity with periods of perceived control and periods of perceived loss of control. This is congruent with the Shifting Perspectives Model of Chronic Illness (Paterson, in press). In the Shifting Perspectives Model, living with a chronic illness is viewed as an ongoing and continually shifting process in which individuals with chronic illness shift between periods of perceiving wellness in the foreground and illness in the foreground. When individuals live in the wellness in the foreground perspective, they learn to put aspects related to the illness in the background. They are not focused on the illness, rather they are focused on health, living, and satisfaction in their lives. When individuals live with illness in the foreground, the illness becomes the focus of attention along with discomforting symptoms, losses, and negative changes. At that time, the individual perceives the disease as controlling his or her life.

The grounded theory developed in the current study supports the Shifting Perspectives Model of Chronic Illness. The findings of the research study indicate that when people with ESRD perceive they have a sense of control (i.e., they put the illness
in the background), they are able to focus on life outside of the disease. At these times they perceive themselves as healthy (i.e., they put wellness in the foreground) because illness is not the focus of their attention. Those who perceive a loss of control, view themselves as controlled by the illness. They become focused on the illness (i.e., illness in the foreground) and are unable to experience a sense of health (i.e., wellness remains in the background). According to the Shifting Perspectives Model (Paterson, in press), the experience of health in chronic illness shifts over the course of one's life. In keeping with the model, the results of this study point to a number of facilitators and threats to control that result in shifts of perspectives associated with living with the disease.

The theory developed in the current study extends the Shifting Perspectives Model (Paterson, in press) in some ways. Many of the threats and facilitators identified in the current study are congruent with the threats and influences identified in the Shifting Perspectives Model. In both the Shifting Perspectives Model and the theory developed in the current study, there are a number of influences that result in the individual perceiving health or illness. The Shifting Perspectives Model identifies a number of situations that result in a shift of perspective from wellness in the foreground to illness in the foreground. The major situation involves the perception of a threat to control in living with the illness. Paterson indicates that there is a threshold of what one can bear before a perceived shift to the illness in the foreground occurs. "Any threat to control that arises from situations/incidence which the individual perceives to be stressful and exceeds the individual's threshold of tolerance will cause a change in perspective" (Paterson, in press). According to Paterson, threats to control may be related to the disease progression, life crises and situations, developmental changes, and messages from others. However, in the current study, a lack of facilitators of control and treatments interfering with living as one wished were also identified as
threats to control.

The Shifting Perspectives Model identifies a number of situations that result in a shift of perspective from illness in the foreground to wellness in the foreground. Paterson (in press) suggests that the situations that precipitate the shift to wellness in the foreground are not as well understood as the situations that cause a shift in the opposite direction. She suggests that the shift to a wellness perspective is influenced by learning about and managing threats to wellness, social support, and discomfort with the illness in the foreground perspective. To make this shift, the individual must learn to reframe the experience so that it seems less threatening, locate appropriate resources to deal with the threat, and/or make the conscious effort not to focus on the threat and its implications (Paterson). Furthermore, she suggests that having the disease over a long period of time facilitates the acceptance of the illness and the shift in one's perspective to wellness in the foreground. The grounded theory developed in this study supports these influences. However, the current study also underscored the contribution of a positive attitude and being perceived positively by others in this regard.

**Developmental Timing of the Diagnosis**

The grounded theory that resulted from the research indicates that adolescents diagnosed with ESRD initially perceive themselves to have no control over the disease. This perception results from others taking control over the disease, the loss of a "normal" life, being different from peers, and the inability to do or achieve what they want. Current research involving adolescents with diabetes supports the perception that adolescents initially feel controlled by the disease and by other people (Kyngas & Barlow, 1995; Weekes, 1995; Woodgate, 1998). Independence, the desire to be like peers, and to be accepted by peer groups is of particular importance to adolescents (Edelman & Mandle, 1990). The current study suggests that the
diagnosis of ESRD during adolescence results in feelings of a loss of control over one's life which leads to the desire to take control. It illuminates the influence that family and health care professionals can have in the way an adolescent with ESRD can view his or her disease. Their responses can be helpful when they allow and encourage adolescent individuals to take control.

The effects of the diagnosis in adolescence on the experience of health extends and raises some questions regarding the chronic illness model developed by Paterson (in press). The current study extends the Shifting Perspectives Model by providing insight into how a diagnosis in adolescence affects the individual's preferred way of living with a chronic illness. In the Shifting Perspectives Model, wellness in the foreground and illness in the foreground both have implications and purposes for the individual. Paterson suggests that there are times in individuals' lives when they purposely adopt either perspective. This differs from the current study that revealed that individuals diagnosed during adolescence prefer to have a sense of control in living with ESRD. This may be an outcome of the selection procedures for the study. It may be that people who prefer a more passive stance in disease management would not be attracted to a research study such as this because they might devalue their contribution to such a study. As well, participants' accounts were retrospective and they may have viewed their adolescence in more categorical and extreme terms than if this research was conducted prospectively.

According to the participants, the diagnosis of ESRD in adolescence is associated with a desire to take control over the disease and an experience of health because individuals have more time to learn what control over the disease means to them and how to attain it before adult life behaviours are developed. The diagnosis of ESRD becomes incorporated into the lives and self-concept of individuals as they pass through adolescence. As they mature into adulthood, the disease is not viewed
as a threat but is embraced as part of their identity. One of the participants in a study of adolescents' perspectives of chronic illness referred to her arthritis as a "friend" (Woodgate, 1998, p.218). Viewing her chronic illness this way helped her to deal with her illness. Participants in the current study viewed their ESRD as an integral part of their lives and who they were which helped them to have a sense of control over it. Participants believed that the diagnosis of a chronic illness in adulthood would be more difficult because the disease would not become a part of who they were. There is limited evidence to support the idea that the disease may not become a part of the adult's self-concept. Adult participants in a study of living with diabetes as a transformational experience viewed themselves as separate from the illness (Paterson & Sloan, 1994). However, not incorporating the disease into their self-concept did not prevent them from having control. Rather the investigators found that when participants in their study viewed the illness as separate, it helped them to focus on goals despite the limitations of the illness.

This raises the issue of how the timing of the diagnosis affects the development of self-concept and perceived control. Perhaps when people with ESRD are diagnosed prior to the formation of their self concept, the illness is incorporated into the self-concept. Living with the disease and making decisions regarding their lives are therefore based on who they are; i.e., an individual who lives with ESRD. Because it is part of their self-concept, they make decisions about their life and the disease management by taking into account that the disease is part of them; the disease itself is not viewed as a threat to their lives because it is part of their lives. Adults diagnosed with a chronic illness, however, have already largely developed their self-concepts by the time of diagnosis. Some adults view the disease as a separate entity that can be controlled (Paterson & Sloan, 1994). Just as the participants in the current study, they are able to live and focus on goals in spite of having the disease but the reasons for
doing so are different. Those diagnosed as adolescents do so because the disease is so well-integrated in their life that they are not intimidated by the disease and its effects. Those diagnosed as adults make a conscious choice to compartmentalize the disease so they can focus on living life as they wish to live it.

The timing of the diagnosis on the perceived control over the disease raises questions for further investigation. How does being diagnosed as an adult or as an adolescent affect one's perceived control over the disease? The findings of the current study and previous research suggest that both adolescents and adults are actively involved in taking control of the disease. However, it is unclear how the development of self-concept and other developmental and situational factors (e.g., involvement of parents) influences their ability to take control.

A final issue to discuss regarding the timing of the diagnosis pertains to the speed at which one takes control. Taking control in ESRD early in the course of individuals' lives can have positive and negative outcomes. The participants in the current study who took control early, maintained an overall positive attitude towards life with ESRD. One of the participants was not able to take control until she had lived with ESRD for several years. Her early experiences with ESRD were not positive and she could not envision a purposeful and satisfactory life with the disease for a long time. This negatively impacted her life choices. She did not pursue advanced education, could not plan for her future, and had no focus in her life. Once she took control of her disease, she regretted earlier choices and believed those choices were the result of not having a sense of control over the disease.

There are negative aspects associated with taking control of ESRD early in the course of the disease. Taking control early in the trajectory of the illness can lead to individuals taking control over the disease when they are not ready; i.e., they do not have the skills, resources or experience to do so effectively. Giving adolescents
control over the disease before they have had time to learn and understand the need for physiological control can result in actions that threaten their long-term health. Unsafe behaviours learned in adolescence to take control may persist into adulthood. Long-term control measures that do not attend to the physiological needs of the disease can have very serious implications for physical health. One of the participants in the current study was allowed to take control over his life and his disease early in the course of his life with ESRD. He took control over the disease by not following prescribed restrictions and treatment. He continued to take control of his disease by unsafe practices into his adult years and these behaviours negatively affected his physiological status. Consequently, he did not complete his education and experienced life-threatening consequences. Fortunately, a transplant became available and his rejection of prescribed pre-transplant regimens was no longer an issue. Unfortunately not all individuals with ESRD are able to experience a successful transplant. Although the decision about adhering to the advice of health care practitioners is an individual one and one that is ultimately made by the person with ESRD, it is evident in the case of this participant that the perception of control can be misguided if it results in a threat to well-being or to life. Further research is needed about the influence of the speed at which one takes control on the individual's disease management practices.

**Having a Sense of Control as a Balance**

Having a sense of control over ESRD involves finding a balance between being controlled by the disease by focusing on the disease, its restrictions, and treatments and having a sense of control over the disease by not attending to the physiological needs of the disease. Having a sense of control over ESRD is key to experiencing health; however, how control is perceived by individuals with ESRD raises some questions as to appropriate control. Reasoned non-compliance has been identified in
the current study as one way that individuals have a sense of control over the disease. However, there is a fine line between feeling controlled by the strict treatment regimen and having a sense of control over the disease by not adhering to needed treatment. Having a sense of control over the disease resides between the concepts of being controlled by the disease and controlling it by not attending to the physiological needs of the disease.

Common themes among people with chronic illness is the perception that their lives are controlled by the disease and the desire to assume control in living with the disease (Kyngas & Barlow, 1995; Paterson, Thorne, Crawford, & Tarko, 1999; Paterson, Thorne, & Dewis, 1998; Paterson & Thorne, in press; Weekes, 1995; Woodgate, 1998). Much of this research has been conducted in the field of diabetes. Diabetes and ESRD have a number of commonalities. In both cases, there is no present cure, they entail a specific treatment schedule, and they share restrictions with regard to diet. There are some notable differences, however, that must be considered. The treatment for diabetes involves daily injections of insulin and can be carried out at home. For individuals with ESRD, treatment can be carried out at home, but in many cases treatment is at hospitals. Furthermore, the individual on dialysis spends a considerable amount of time undergoing treatment but the person with diabetes may spend only a few minutes on medication administration daily.

In the current study, participants felt at times that their disease was controlling their lives. They felt controlled by the disease when they were unable to take part in important activities or lead a normal life, when they experienced overwhelming symptoms, or others took control over their lives by imposing restrictions on them. In the study by Kyngas and Barlow (1995), adolescents described their diabetes as a "hell," "prison," and a "never ending nightmare" (p. 943). The researchers' findings suggest that some adolescents with a chronic illness feel controlled by their illness.
because they feel trapped by the imposed limitations of the disease, are constantly worried about the future, and feel they could not live a meaningful life with the disease. One could argue that this negative reaction may be due to the developmental stage of the individual at the time of diagnosis. However, Paterson and Thorne (in press) describe times in adults' lives with diabetes where they experience passive compliance in which they strictly adhere to health care professionals' and families' instructions regarding management of the disease. Furthermore, in the current study, the participants spoke of times in both their adolescent and adult years where they felt the disease was controlling their lives. Therefore, it appears that both adolescents and adults may experience times when they feel their lives are controlled by the disease.

The other end of the spectrum involves having a sense of control by not attending to the demands of the disease. Having a sense of control for some individuals meant that they lived as if they did not have the disease and did not regard the advice given by health care professionals. To these individuals living life by not following the treatment and restrictions was necessary to live a meaningful and satisfactory life. Their actions and behaviours appeared to ignore the physiological needs of the disease. Living a life without restrictions was more important than the implications and consequences of not attending to the needs of the disease to have physiologic control over the symptoms and complications of the disease.

This apparent disregard for needed treatment and restrictions has been labelled non-compliance (Kyngas & Hentinen, 1995; O'Brien, 1990) or nonadherence (Seley, 1993). In the current study, one of the participants took control by disregarding the health care professionals' "rules" and doing whatever he wanted to do. While he did still undergo dialysis treatments, he did at times skip treatments and disregarded the advice of health care professionals. This was the only way he felt he could have a sense of control over the restrictions of the disease on his life and to live a meaningful
and satisfactory life. To him it was important to eat, drink, and do the same things as those who he perceived to be normal; that is, to behave as those without ESRD. He did in fact suffer from a number of consequences and risked serious complications because of his behaviour.

Kyngas and Hentinen (1995) discuss non-compliance with regard to their study of the meaning attached to compliance in young diabetics. The researchers found that some adolescents with diabetes did not take care of themselves according to their prescribed treatment regimens and were indifferent and passive to their self-care. They ate what they wanted, when they wanted, did not consistently administer their insulin, or test their blood or urine glucose. Kyngas and Hentinen provide some possible meanings for non-compliant behaviours. They propose that non-compliance may be necessary to experience a sense of freedom from the disease and to live like normal people. Kyngas and Hentinen stated that for the adolescents in their study, it was important to be like their friends and that their friends determined how they would live with the disease in the sense that they wanted to live like their friends.

Perhaps having a chronic illness during adolescence sets these individuals apart from their friends at a time when being like peers and accepted by peers is a strong driving force and non-compliance with authority is often admired. However, non-compliant behaviours are not only evident in adolescents. Paterson and Thorne (in press) discuss a rebellion phase in the developmental evolution of expertise in the diabetes management of adults who had long-standing diabetes. Some of the participants in their study had experienced a stage of rebellion over the course of their lives with diabetes. There were times when they denied their diabetes to themselves and others, ignored diet and alcohol restrictions, hid the need for insulin, did not take their insulin, and falsified their glucose levels. This behaviour was motivated by the desire to take control, to be like their normal peers, not to be restricted by the treatment
regimen, feelings of immortality, and anger that having the disease interfered with other life priorities (Paterson & Thorne). This rebellion was experienced by participants in adolescence and adulthood; therefore, non-compliant behaviour was not relegated to adolescence. Furthermore, in the current study, one participant demonstrated noncompliant behaviour in both his adolescent and adult years. During both developmental stages he felt that to have a sense of control over ESRD meant he had to disregard the advice of his health care professionals choosing to eat and drink what he wanted, when he wanted, and to live like people who did not have ESRD. Perhaps for some individuals, having a sense of control by not attending to the needs of the disease and suffering the consequences is more important and necessary to live a meaningful and satisfactory life than is adherence to the advice of professionals.

Having a sense of control, while at the same time attending to the needs of the disease to have physiologic control, involves finding a balance between being controlled by the treatment and restrictions associated with the disease and controlling the disease by following prescribed treatment regimens. Reasoned non-compliance is one way that individuals had a sense of control over the disease by modifying or tailoring their treatment regimen to meet other needs in their lives (O'Brien, 1990). Taking a "time out" from treatment regimens and restrictions help individuals to take and maintain a sense of having control over their illness (Paterson & Sloan, 1994). In the current study, reasoned non-compliance involved finding that balance between being controlled by the treatment regimen and having control by disregarding the treatment regimen and placing themselves at risks for complications. The participants found they could have a sense of control by not strictly adhering to the treatment and restrictions by consuming small amounts of forbidden foods between dialysis treatments, or planning the consumption of restricted foods just prior to or during a dialysis treatment.
Similar findings were found in a study by O'Brien (1990) who investigated the long-term compliance behaviour and maintenance dialysis in adults with ESRD. O'Brien discusses how dialysis patients learn to manipulate their diet and fluid restrictions to suit individuals' lives. Some individuals learn they are able to ingest a small amount of restricted foods or fluids without jeopardizing their fluid or electrolyte balance. Reasons for individuals on dialysis not strictly adhering to treatment regimens at all times included nutritional, normalcy, and social reasons (O'Brien). The strict renal diet can leave an individual on dialysis feeling that their nutritional needs are not being met. They are often left feeling tired, hungry, and unwell which prevents them from doing things that they desire. Therefore, they modify their diets so that they have enough energy and well-being to survive and carry out their daily activities (O'Brien). Individuals on dialysis may also feel there is stigma attached to being on dialysis and a feeling of not being normal like other people (O'Brien). Therefore, they do not always follow the treatment and restrictions so that they can do what other people do and have some sense of normalcy in their lives. Furthermore, individuals on dialysis find the treatment regimen impacts on their social interactions. They feel that their renal diet causes concern of others to provide foods at meals and social gatherings that comply with the renal diet (O'Brien). Individuals with ESRD in O'Brien's study found that if they limited the amount of forbidden foods and fluids they could partake in social activities and not cause concern to others to provide appropriate foods. O'Brien found that participants in her study admitted to not strictly following the treatment and restrictions associated with being on dialysis because "they had learned their own limits and would not endanger their lives" (1990, p. 212).

Reasoned non-compliance is a common approach used by individuals to take control in chronic illness (Kyngas & Hentinen, 1995; Paterson & Thorne, in press; O'Brien, 1990; Thorne, 1990; Thorne, Nyhlin, Paterson, 2000). Decisions to modify or
tailor treatment regimens are made by weighing the consequences and benefits of not adhering to the prescribed regimen (O'Brien, 1990; Thorne, 1990). When individuals with ESRD decide that the benefits, such as taking part in an important social activity and feeling a sense of normalcy outweighs the potential consequences, such as a higher fluid gain or uncomforting symptoms associated with high phosphorous, the individual may decide not to adhere to the prescribed treatment and restrictions on certain occasions.

**Implications for Health Care Practice, Education, and Research**

The study findings presented in this thesis describe the experience of health in adults diagnosed with ESRD during adolescence. The theory developed from these findings hold implications for health care practice, education, and research.

**Health Care Practice**

The grounded theory developed from the findings of this study can be used in health care practice to provide appropriate and specialized care to individuals diagnosed with ESRD in their adolescent years. The study has a number of implications for health care professionals regarding their assessment, planning, education, and support of adolescents and adults diagnosed with ESRD during adolescence.

The study identified adolescents as individuals who initially feel they have no control over their ESRD, in part due to others taking control over their health care. Control can be facilitated by health care professionals' planning interventions and guiding parents, teachers, and others who come into contact with the chronically ill adolescent to facilitate the adolescent's active involvement in their health care. Significant others in the adolescent's life should be encouraged and taught how to support adolescents as they learn to take control.

Health care professionals should assist adolescents with ESRD to understand
what it means to them to have a sense of control over ESRD, what it means to be healthy, and to help them to have a sense of control in a way that does not ultimately result in serious physiological consequences. They should understand and acknowledge that some people with ESRD take control over their disease by not adhering to prescribed treatments at specific times and that their reasons for doing so are often based on goals and priorities that supersede following a prescribed regimen. Health care professionals should avoid labelling such behaviour as non-compliant. To do so may prevent the individual from being honest about the struggles, failures, and barriers he or she encounters in living with ESRD. Adopting a non-judgmental approach to caring for these clients will foster an open and comfortable environment for clients to share their experiences.

Health care professionals are encouraged to help people with ESRD to find ways to do and achieve what is important to them by providing them with realistic and safe ways to make self-management decisions. For example, an individual with ESRD who wants to go out for beer and pizza with his baseball team might be encouraged to consume very little fluid and sodium and potassium containing foods prior to the activity. By limiting other sources of fluid, sodium, and potassium, the individual may be able to take part in activities without causing the dangerous accumulation of fluid and electrolytes. Flexibility in dialysis schedules and clinic appointments can allow individuals to take part in activities that would otherwise conflict with scheduled treatment and appointments. Health care professionals should not assume that the individual who does not comply with treatment does not care about their disease or its implications. Further education about the disease may not be the answer; rather education should be focused on helping clients understand their personal needs and ways to achieve control over the disease using creative and personally relevant ways. Furthermore, health care professionals can assist adolescents and adults with ESRD
to identify potential facilitators of control and to encourage them to draw on these facilitators particularly at times when control over their disease is threatened.

Health care professionals would be wise to draw on the experiences of their clients to educate and support each other. Peer support should be encouraged as it can provide an opportunity for clients to exchange information and meet similar others from their peer group. Peer support programs should be tailored to individuals' needs. A thorough needs assessment may identify that some people with ESRD wish to take part in a support group, whereas others may not wish to focus on the disease in a large group and may find a mentoring program more helpful. Furthermore, the needs assessment may indicate that some individuals would benefit from having support of individuals with similar experiences as them, whereas others would benefit from the support of someone who has considerable more experience and time with the disease. Health care professionals can provide their clients with ESRD with information about successful control measures used by other clients. By giving clients various options, they may be able to find some strategies that work for their personal needs.

**Health Care Education**

The theory that has arisen in this study can be used to educate health care professionals caring for adolescents and adults diagnosed with ESRD during adolescence about the process through which these individuals experience health. Health care education curriculum pertaining to renal disease should be aimed at teaching health care professionals about issues faced by adolescents and adults diagnosed with ESRD during adolescence. Education about chronic illness and ESRD should include developmental aspects and challenges faced by adolescents and the implications of developmental transitions in living with a chronic illness.

Basic and continuing professional health education programs should not just be
focused on the physiological implications of ESRD but should include education about the process by which individuals take control of their disease. Students in health care professions should be encouraged to be open to learning from their clients with ESRD.

**Health Care Research**

Future research endeavours should be aimed at increasing the understanding of the experience of health in chronic illness. It is evident from this qualitative study that qualitative methods are useful and appropriate at discovering the personal experiences one has with a chronic illness such as ESRD. Researchers should continue to use qualitative methods and include prospective and longitudinal methods in the examination of individuals' experiences with chronic illness.

This study has identified a number of components and issues regarding the experience of health in ESRD. The issues and components of this theory need further exploration. Research should be aimed at examining the individualization of the chronic illness experience and how health is perceived and experienced by various individuals. Researchers must examine the nuances and changes in behaviours between individuals to gain a better understanding of the unique and shared experiences.

Research needs to be done to further examine how the duration on dialysis and the timing of a transplant influences one's experience of health and perception of control over ESRD. The current study investigated the experience of health in Caucasian Canadian adults aged 20 to 35 diagnosed with ESRD during adolescence between the ages of 12 and 16. Research needs to be conducted exploring the experience of health in individuals in young, middle, and late adulthood, diagnosed at different times throughout their childhood and adolescence. Studies need to be conducted that include individuals from various socioeconomic and cultural backgrounds. Furthermore, studies should be conducted that examine the experience
of health in a prospective manner as adolescents live with a new diagnosis of ESRD. Clearly there is much research to be conducted in this area.

**Study Summary**

The purpose of this research study was to explore the experience of health in chronic illness from the perspectives of young adults diagnosed with ESRD during adolescence and to gain some understanding of how these experiences develop or change over time. The reasons for conducting this study were largely based on the investigator's personal experiences with ESRD. Prior to the 1970's, there were neither reliable methods of dialysis nor hope for a successful transplant for adolescents with ESRD. Because of medical, technological, and pharmacological advances in renal replacement therapy over the past two decades, adolescents diagnosed with ESRD are surviving and growing up to become adults. Until recently, there were relatively few adolescents with ESRD that survived to adulthood. For these reasons, the exploration of this topic is timely as the experience of health in adults diagnosed with ESRD is relatively unexplored.

Literature pertaining to this research topic is sparse. Therefore, literature pertaining to the experience of chronic illness in general was examined. This literature revealed a number of physical, psychosocial, and functional challenges faced by adolescents diagnosed with chronic illness. The limited reviewed literature regarding long-term implications of ESRD revealed some evidence that adolescents who have a successful transplant have fewer physical, psychosocial, and/or functional problems than those who have not had a successful transplant. Literature pertaining to the personal meaning of health and illness in adolescents with a chronic illness indicates that adolescents are able to experience a sense of health when they are able to live a normal life and are able to see positive aspects of having a chronic illness. The preponderance of the knowledge gained from this review was based on
quantitative studies that reveal little regarding the personal experiences of the individual with a chronic illness.

The qualitative method of grounded theory was used to explore the experience of health in eight young adults diagnosed with ESRD during adolescence. Two interviews were conducted with each participant to identify, categorize, modify, and refine themes regarding their experiences of health. Five themes evolved and included; the diagnosis in adolescence, having a sense of control over ESRD, facilitators of having a sense of control, threats to having a sense of control, and descriptions of the concept "health". The findings were developed into a substantive grounded theory explaining the experience of health in this group of people.

The experience of health involves the fluctuating state of perceived control over the disease and a perceived loss of control over the disease as one is faced with both facilitators and threats to control. When individuals are diagnosed with ESRD during adolescence, they initially perceive having no control over the disease because others take control, they are unable to do things that are important, and they feel the disease sets them apart from their peers. This lack of control and their desire for independence and to be like their normal peers, results in the adolescent with ESRD attempting to take control. Over time adolescents incorporate ESRD into their developing self-concepts. Having the disease and the associated treatment that was once overwhelming and restrictive become second nature as ESRD is incorporated into their lives and how they come to define themselves. Having a sense of control over ESRD becomes the adolescent's preferred way of being throughout adolescence and into adulthood. When individuals are able to have a sense of control over the disease they are able to experience health. Having a sense of control over the disease allows one to do what one wants, to have the abilities of a normal person within the limitations of the disease, and to not focus on the disease.
The findings of the study raise a number of issues that were discussed in relation to the current literature. These issues included: 1) the experience of health fluctuates between periods of perceived control and perceived loss of control, 2) the implications of the diagnosis of ESRD in adolescence, and 3) having a sense of control involves finding a balance between being controlled by the disease and not attending to the physiological needs of the disease. These issues were discussed in relation to current literature regarding the diagnosis of chronic illness in adolescence, issues of compliance, and models of chronic illness.

The study revealed a number of implications for health care practice, education, and research. Health care professionals are encouraged to assess their clients' on an ongoing basis for their understanding of the disease, experiences of health, and what it means to have a sense of control over the disease. Interventions, education, and support should be tailored to each individual's needs. Furthermore, health care professionals need to acknowledge their client's expertise in managing their disease and provide an open, understanding, and comfortable forum for them to share their successes, failures, challenges, and strategies to take control over their disease and experience health. Health care education ought to focus on sensitizing health care professionals to some of the challenges faced by individuals with a chronic illness as they pass through adolescence and adulthood. Education programs ought to guide practitioners to assess their clients' individual needs and plan interventions that are best suited to their unique and changing needs. Further research should entail qualitative prospective and longitudinal studies to explore the developmental and historical experiences with health of individuals with ESRD. Research should be aimed at describing the experience of health in individuals at various developmental stages, undergoing different forms of treatment for their ESRD, and from various socioeconomic and cultural backgrounds. The grounded theory developed
contributes to the knowledge base regarding the diagnosis of a chronic illness in adolescence, the experience of health in adults diagnosed with a chronic illness and ESRD during adolescence, and the issue of control in chronic illness.

Study Conclusions

The following conclusions are derived from the study findings. It is important to recognize that these conclusions are based on the participants' stories regarding their experiences with health and, therefore, can not be generalized beyond the study sample.

¥ The experience of health for participants in this study is reflected both in perceiving control over their disease and perceiving a loss of control over their disease.

¥ The diagnosis of ESRD in adolescence results in the initial perception of being controlled by the disease as others take control of the disease and with the inability to be like their normal peers and to do/achieve what they want.

¥ When adolescents do not perceive themselves to have control in living with ESRD, taking control becomes desirable. During adolescence, independence, social relationships, and the desire to be like peers is of paramount importance.

¥ When faced with a chronic illness such a ESRD, adolescents strive to take control to assert their independence, and to manage the disease in a way that is least disruptive to their emerging independence, their social lives, and their desire to be like peers.

¥ Having a sense of control in living with ESRD was the preferred way of living with the disease for the study participants in both adolescence and adulthood.

¥ Through their experiences with ESRD, participants experienced times when they perceived having a sense of control and other times when they perceived a loss of control due to facilitators and threats present in their lives.
The experience of health involves a fluctuation between perceived having control and a perceived loss of control depending on the situations/events/people encountered.

Over the course of their lives with ESRD, participants experienced a number of influences that either threatened or facilitated their ability to have a sense of control.

Having a sense of control involved finding a balance between being controlled by the disease and attending to the physiological management of the disease.

When study participants perceived having a sense of control in living with ESRD, they were able to experience a sense of health that allowed them to do what they want, have the abilities of a normal person within the limits of the disease, and not to be focused on the disease.

For some, having a sense of control involved not following treatment and consequently suffering the consequences.

Final Thoughts

In this study, the experience of health in adults diagnosed with ESRD during adolescence was investigated. Participants indicated that the experience of health involved a fluctuation between perceived control and perceived loss of control over ESRD. Feeling healthy necessitated having a sense of control. Although a number of issues regarding individuals' perceived control over their ESRD should be further examined, this research identified issues concerning how health is experienced in adults diagnosed with ESRD during adolescence. The findings contributed to the development of a grounded theory describing the experience of health in a group of individuals with chronic illness. The theory developed supports, enhances, and extends previous research done on the experience of chronic illness from the perspectives of individuals with the disease.
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APPENDICES
My name is Lisa Venables and I am a Registered Nurse and a student in the Master of Science in Nursing Program at the University of British Columbia. You are being invited to participate in my master's study “Experiencing Health in Chronic Illness: The Perspectives of Adults Diagnosed with End-Stage Renal Disease During Adolescence”. The purpose of this study is to increase the understanding of how living with a chronic illness for several years affects how a person experiences health, so that health care professionals may be better prepared to care for adolescents and adults with kidney disease.

I am asking people who were diagnosed with kidney failure as an adolescent to participate in this study. I will be seeking adults who are currently on dialysis, have a transplant that is failing, have returned to dialysis after the failure of a transplant, or currently have a functioning transplant. I have asked your doctor/nurse to give this letter to people who may fit this description.

You are being approached to see if you would like to take part in this study. Participation would involve two one-hour interviews at a convenient time and place and every effort will be made to make the process as convenient as possible. In the first interview, lasting up to one hour, I will ask you questions about how being diagnosed with kidney failure as an adolescent has affected your life and what it means to you to feel healthy. To allow me to remember the interview, I will tape record the interview. At a second interview I will speak with you about my understanding of what you told me, and ask you some more questions about your experiences having kidney failure. This second meeting will take approximately one hour and will also be tape recorded.
Study: 

Experiencing Health in Chronic Illness: The Perspectives of Adults Diagnosed with End-Stage Renal Disease During Adolescence

Name: ___________________________ Gender: male female

Date of birth: _______ Present age: _______ Age at diagnosis: _______

Diagnosis: ________________________

Current renal replacement status: peritoneal dialysis
hemodialysis
other, specify

functioning transplant
failing transplant

Previous renal replacement therapies: peritoneal dialysis
hemodialysis
other, specify

renal transplant

Other chronic illnesses: ______________________

Birth country: ____________ If not Canada, years in Canada: ______

How would you describe your ethnicity/cultural background: ______________________

Level of education: ______________________

Current employment status: >35 hrs/wk disability
< 35 hrs/wk unemployed
volunteer retired
student other, specify
homemaker

Page 1 of 2
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<th>single</th>
<th>live-in partner</th>
<th>separated/divorced</th>
<th>widow/widower</th>
<th>other, specify _____________</th>
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<td>age</td>
<td>gender</td>
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<tr>
<td>Residential location:</td>
<td>at time of diagnosis</td>
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<td>presently</td>
<td>rural</td>
<td>urban</td>
<td></td>
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</tbody>
</table>

Other notable demographic information: __________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
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APPENDIX E

INTERVIEW GUIDE

Study: Experiencing Health in Chronic Illness: The Perspectives of Adults Diagnosed with End-Stage Renal Disease During Adolescence

Questions:

1) Can you tell me about what your health like before you found out you had kidney failure?

2) How did having kidney failure as an adolescent affect you at that time?

3) Can you tell me about how your health has been since you found out you had kidney failure?
   (Probe for times of overall feeling of wellbeing and times when participant did not feel well to help map the trajectory of ups, downs, and plateaus over the course of chronic illness)

4) What does it mean to you to feel healthy/well/good today?

5) Describe to me a time that you felt you were healthy/well/good?

6) Can you tell me about a time when you felt your best?

7) What helps you to feel healthy/well/good?

8) Can you tell me about a time when you found it was a struggle to feel well? What helped to make you feel better?

9) How would you describe your health compared with your friends who do not have kidney disease?

10) Can you tell me about how you think others perceive your level of health?
   (Probe for perceptions of HCP, family, and friends)

11) How does your experience compare with other people you know who have had kidney failure? (Probe for similarities and differences)

12) How do you think your experience with health has changed over the years?

13) We've covered a lot of issues today, is there anything that we haven't talked about that you think is important?