What is the lived experience of the client with end stage renal disease on hemodialysis?

Diane Scaife

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FINAL APPROVAL OF THESIS
Master of Science in Nursing

What is the Lived Experience of the Client with End Stage Renal Disease on Hemodialysis

Submitted by:
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In partial fulfillment of the requirements for the degree of Master of Science in Nursing

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Date of Defense:
December 5, 2006
What is the Lived Experience of the Client with End Stage Renal Disease on Hemodialysis

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2006
Acknowledgements

I would like to acknowledge my major advisor and committee chairperson, Dr. Jane Evans. Although Dr. Evans retired from actively teaching, she graciously continued to support and guide the completion of this thesis. Thank you also to Dr. Connie Roth-Sautter, a committee member who provided useful and scholarly revisions in the field of qualitative research analysis. A special thank you to Dr. Jane Ransom for her guidance and positive and upbeat mannerisms throughout this 2 year endeavor.

A loving thank you to my husband, Doug, and daughter, Pamela, for all the concern, support and backrubs throughout this strenuous time in my life. All is much appreciated.
# Table of Contents

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Acknowledgements</strong></td>
<td>ii</td>
</tr>
<tr>
<td><strong>Table of Contents</strong></td>
<td>iii</td>
</tr>
<tr>
<td><strong>Chapter I  Introduction</strong></td>
<td>1</td>
</tr>
<tr>
<td>Statement of the Problem</td>
<td>1</td>
</tr>
<tr>
<td>Statement of the Purpose</td>
<td>2</td>
</tr>
<tr>
<td>Research Question</td>
<td>3</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>3</td>
</tr>
<tr>
<td>Significance to Nursing</td>
<td>4</td>
</tr>
<tr>
<td>Assumptions</td>
<td>4</td>
</tr>
<tr>
<td>Limitations</td>
<td>4</td>
</tr>
<tr>
<td>Summary</td>
<td>5</td>
</tr>
<tr>
<td><strong>Chapter II  Literature</strong></td>
<td>6</td>
</tr>
<tr>
<td>Nursing Conceptual Framework</td>
<td>6</td>
</tr>
<tr>
<td>Regulator Processes</td>
<td>8</td>
</tr>
<tr>
<td>Cognator Processes</td>
<td>8</td>
</tr>
<tr>
<td>Phenomenology</td>
<td>10</td>
</tr>
<tr>
<td>Review of Research</td>
<td>12</td>
</tr>
<tr>
<td>Summary</td>
<td>19</td>
</tr>
<tr>
<td><strong>Chapter III  Method</strong></td>
<td>21</td>
</tr>
<tr>
<td>Design</td>
<td>21</td>
</tr>
<tr>
<td>Participants</td>
<td>21</td>
</tr>
<tr>
<td>Setting</td>
<td>22</td>
</tr>
</tbody>
</table>
A. Demographic Data 44
B. Examples of Open Ended Questions and Probes 45
C. University of Toledo IRB Approval 46
D. Davita Dialysis IRB Approval 48
E. Informed Consent 49
CHAPTER I

Introduction

Chronic kidney disease (CKD) is a growing health problem. In 1999, more than 340,000 individuals were receiving renal replacement therapy in the United States (US) (Brown et al., 2003). Frequently the disease is asymptomatic and, therefore, difficult to diagnose and treat in the early stages. Many with risk factors are unaware that they have CKD until severe emergent symptoms appear. Immediate hemodialysis then is initiated before the patient is adequately prepared for this change in lifestyle.

The transition to a life with routine hemodialysis treatments includes numerous stressors, both physiological and psychosocial (Klang, Bjorvell, & Clyne, 1999). Lack of understanding and knowledge can be major factors contributing to poor judgment and anxiety.

This chapter includes a discussion of lifestyle changes and adjustments associated with CKD and the progression to chronic hemodialysis treatments, the statement of the research problem, the identification of the nursing conceptual framework, the research question, the statement of the purpose, and the significance to nursing with assumptions and limitations. A concise summary of the contents concludes this chapter.

Statement of the Problem

Adult clients with End Stage Renal Disease (ESRD), a condition of the kidneys associated with the progression of CKD, face many demands and changes in their lives with the initiation of routine hemodialysis treatments. Attendance at designated hemodialysis centers with scheduled treatments is required to sustain life. Dietary
restrictions with fluid limitations are necessary to prevent cardiovascular complications. Medications may be necessary to prevent calcium and bone loss.

The limitations imposed can create conflict and stress in the life of the client with ESRD. Health maintenance with the stipulations of mandatory hemodialysis treatments and dietary restrictions can be overwhelming; reactions can vary from total acceptance to denial and rejection of the changes required for optimal health and well-being. Clients shorten or skip treatments, and ignore fluid and dietary restrictions with potential complications (Gordon, Leon, & Sehgal, 2003). Documentation in dialysis centers including weight changes, skipped or shortened treatments, electrolyte levels and blood pressure readings reflect clients’ knowledge of and adherence to the rules of surviving ESRD. What may not be documented is the reason for acceptance or rejection of these rules. To identify the underlying reasons may provide nursing staff at the dialysis centers more understanding and more effective teaching opportunities for those who have difficulties dealing with ESRD and its restrictions.

Statement of the Purpose

The purpose of this qualitative study is to identify the lived experience of the client with ESRD on routine hemodialysis treatments. Using a phenomenological method, the data collected will be examined for specific themes and meanings.

Identification of Nursing Conceptual Framework

The nursing conceptual framework chosen for this study was Roy’s Adaptation Model (RAM). The foundation to RAM is the "goal of enhancing life processes through adaptation" (Roy & Andrews, 1999, p. 32). Focal stimuli are stressors immediately affecting the person or group requiring an adaptive response (Leddy & Pepper, 1993).
Contextual stimuli (internal or external stimuli contributing to the behavior), and residual stimuli (other relevant and nonspecific stimuli) also contribute to the effect of the stressor to produce the interaction identified as stress. Four response modes of the person are vital to maintain adaptation: (a) physiologic-physical, (b) self-concept-group identity, (c) role function, and (d) interdependence. Roy's focus on adaptation makes this an excellent choice of nursing frameworks when studying a person's experiences on chronic hemodialysis treatments as patients face many changes and necessary adaptations to maintain optimum health.

Research Question

The research question for this study is "What is the lived experience of the client with End Stage Renal Disease on Hemodialysis?"

Definition of Terms

Lived Experience

Conceptual definition – the individual’s response to a specific situation or experience (Munhall, 2004). Roy and Andrews (1999) define it as the persons’ choice of adaptation or lack of adaptation to the various stimuli confronted by the individual.

Operational definition – the lived experience in this study is the human involvement of one with ESRD and hemodialysis treatments.

End Stage Renal Disease

Conceptual definition — slow, progressive, and irreversible loss of kidney function requiring dialysis or transplantation to sustain life.

Operational definition — documented diagnosis of ESRD in the chart.
Hemodialysis treatments

Conceptual definition — process of filtering blood through a machine to remove excess fluid and waste materials necessary for clients with failed kidneys.

Operational definition — documented records of attendance for hemodialysis treatments.

Significance to Nursing

Mortality rates among US hemodialysis patients are the highest in the industrialized world (Sehgal et al., 2002). Inadequate dialysis is associated with an increased morbidity and frequency of hospital admissions and rising health costs. Barriers to adequate treatments include catheter faults, underprescriptions, and shortened treatments. Does the staff at the hemodialysis units know what the person is experiencing because he or she is required to complete on the average 3 hour treatments 3 times a week to maintain his life? Do they realize all the adjustments and adaptations; physical, emotional and psychological that the client struggles with on a daily basis? The research will identify those adaptations and stresses from the perspectives of clients on hemodialysis. The knowledge obtained from this study may assist the nephrology and dialysis nurses to target those stresses and adaptations. Interventions then can be planned and focused to assist the client in meeting his needs for a healthy adaptation.

Assumptions

1. Clients are honest in sharing their responses, and
2. Clients desire treatments to maintain health.

Limitations
1. The sample will be a purposive sample,

2. The validity of the clients’ responses may have been influenced by desires to share only positive thoughts to demonstrate compliance to their treatments, and

3. The small sample size and interview times assess one specific area and one point of the life time.

Summary

This chapter provided a discussion of the problem of missed and skipped hemodialysis treatments of the patient with ESRD. The purpose of this study is to listen to the clients’ lived experiences about being on hemodialysis and the stresses and adaptations they struggle with to maintain their health as a patient with ESRD. Based on the findings of this study, nephrology and dialysis nurses will better understand what it means to be on hemodialysis and plan interventions specifically to these struggles. The chapter also identifies the nursing conceptual framework and research methodology, terms and the significance to nursing. Assumptions and limitations conclude the chapter.
CHAPTER II

Literature

This chapter begins with a discussion of the nursing conceptual framework used in this study. The research method of phenomenology is explored through the concepts of Husserl (Munhall 1994) and Van Manen (1990). A review of literature is included in this chapter that explores various qualitative research studies using interview data and qualitative methodology.

Nursing Conceptual Framework

This study will use Roy's Adaptation Model (RAM) as a guide to examine the implications of this study. Sister Callista Roy, the creator of this model, began her work in the 1960’s and first published in 1970 (Roy & Andrews, 1999). Her prime focus was adaptation. Persons are viewed as adaptive systems that interact with the environment and grow and develop (p. 19).

The concept of adaptation originated from scientific assumptions of the general systems theory and philosophical assumptions identified as humanism and veritivity. Humanism is defined as the broad movement in philosophy and psychology that recognizes the person and subjective dimensions of human experiences as central to knowing and valuing. Humans share in creative power to behave purposefully and strive to maintain integrity and realize the need for relationships. Veritivity is identified as the principle of human nature that affirms a common purposefulness of human existence.

Swimme and Berry (1992) added the concept of creation spirituality (Roy & Andrews, 1999) to refine philosophical assumptions of the RAM. Characteristics include a
focus on awareness, enlightenment to reach self-control balance, quietude, and reclamation of earthly creation as the core of faith.

Roy describes a human as an adaptive system who acts in unity for a purpose with interdependent parts. The human adaptive system is in constant interaction with his environment both physical and social. The environment influences the system, and the system influences the environment. Stimuli are identified as that which provoke responses. Environmental stimuli are external and internal stimuli originate within the human system. A human's behavior or outcome is the result of input stimuli and the adaptation level of the individual. The behavior may be adaptive or ineffective. The responses then act as a feedback or more input allowing the system to decide whether to increase or decrease efforts to cope with the stimuli (Roy & Andrews 1999).

The categories of stimuli are focal, contextual and residual. Focal stimuli are those internal and external stimuli most immediately confronting the human system. Contextual stimuli are other stimuli present which can contribute to the effect of the focal stimuli. Residual stimuli may be environmental factors that are present but whose effects are unclear (Roy & Andrews, 1999). The focal stimulus in this study is the need to be on hemodialysis. The contextual stimuli include factors that affect reactions to being on hemodialysis including anxiety, discomfort, fears of complications, and interference with life tasks. Residual stimuli include life experiences, values and attitudes.

The adaptation level is subdivided into three possible conditions of the life processes of the human adaptive system; (a) integrated, (b) compensatory, and (c) compromised. Integrated adaptation levels include structures and functions that work to meet human needs. Compensatory adaptation levels occur when regulator and cognator
processes are activated by a challenge to the integrated processes. Compromised adaptation levels occur when both integrated and compensatory processes are inadequate.

*Regulator Processes*

Regulator processes are identified by Roy and Andrews (1999) as those coping channels that respond automatically to internal and external stimuli. These are the endocrine, neural and chemical channels. In this study, regulator processes would include physiological and psychological reactions that the person experiences when making decisions about hemodialysis treatments. Examples would include an increase in heart rate, tension, and excitement.

*Cognator Processes*

Cognator processes respond through four cognitive-emotive channels: (a) perceptive and information processing, (b) learning, (c) judgment, and (d) emotion (Roy & Andrews, 1999). Examples of behavioral responses resulting from these processes include selective attention, memory, developing insight, problem solving and decision making. In this study, cognator coping processes are related to the learning and information processing of the client with ESRD, decision making with hemodialysis treatment times, and the expressed emotions associated with these processes.

The responses or behaviors of the adaptive system, or person, to the environment are observed through four adaptive modes identified by Roy and Andrews (1999). The four adaptive modes are (a) the physiological-physical mode, (b) role function mode, (c) self concept-group-identity mode and (d) the interdependence mode. The physiological-physical mode includes behaviors of the body and has nine components: five basic needs (oxygenation, nutrition, elimination, activity, and rest) and four complex processes, which
are the (a) senses, (b) fluid and electrolyte, and acid-base balances, (c) neurological function and (d) endocrine function. The self concept-group identity mode pertains to spiritual integrity, body image, self ideal and the personal self. The role function mode pertains to expectations one places on oneself in society and expectations one has for others with different roles. The interdependence mode focuses on relationships and the need for relational integrity. Roy's model of adaptation identifies two sub areas of self concept: the physical self and the personal self. Body sensation and body image comprise the physical self and include physical attributes, functioning, health state, sexuality, and appearance. Personal self include personal thoughts and ideas of oneself, and beliefs and values one has in relation to the universe.

The diagnosis of ESRD and subsequent life style changes necessary for life affects all four modes of adaptation. Physiological changes compromise the physiological mode of adaptation by affecting the electrolyte, fluid, and acid balance. Common physical symptoms with advancing renal disease include swelling of the lower extremities, fatigue, decreased urinary output and nausea. Alterations of daily life when placed on hemodialysis affect the role function mode and interdependence mode of adaptation. Jobs may be lost, finances change dramatically, and routine exercise is part of the past. Emotional reactions result in mood changes. Roy and Andrews (1999) note that grieving is one of the compensatory processes for the self concept mode. There are many losses experienced by the client with ESRD on hemodialysis. The client has loss of renal function. He or she may experience loss of self, loss of relationships, and loss of interpersonal relationships. If the client on hemodialysis cannot adapt to these incoming stimuli, energies will be directed at compromised processes such as low
Client with renal disease

morale and depression.

Nurses in contact with clients with ESRD need to have knowledge of these losses and changes experienced by this group. Interventions can be planned during the initial hemodialysis treatments or prior to the first treatment, if possible, to promote successful behavioral responses of the client as he adjusts to the demands of hemodialysis. Modifications can be made as behavior of the client changes to promote successful adaptation.

Phenomenology

Phenomenology is the study of one's world as experienced from the first person's viewpoint (Munhall, 1994). Phenomenology studies the meaning things have in the experience including events, the significance of objects, time management and how they are experienced in the person's world. The goal of phenomenological research is to understand the experience and thus understand what it means to be human.

Edmund Husserl (1859-1938) is known as the "father" of phenomenology. He identifies the word intentionality as a major factor of phenomenology. Intentionality is defined as a relationship between the external world and mental phenomena or psychological acts. That act is directed at an object; the "intentional object." The property of having an intentional object, of being intentional distinguishes mental phenomena from physical phenomena (objects), as physical phenomena lack intentionality.

Husserl opposes any reduction of logic to mere psychology. According to Husserl, phenomenology studies consciousness without reducing the objective meanings that contribute to experience to subjective meanings. Husserl also proposes
practicing phenomenology by "bracketing" the question of the existence of the natural world around us. Bracketing, putting aside one's own thoughts and beliefs, then will assist us to focus on the structure of experience.

Max Van Manen (1990), a phenomenologist that offers similar observations in research, guides the data analysis in this study. Van Manen (1990) (pp. 17-18) defines phenomenological research as:

1. ... "the study of the individual's life world, as experienced rather than as conceptualized, categorized, or theorized." The goal of phenomenology is to identify and understand the meaning of everyday experiences.

2. ... "the study of essences of experience." It is the study of being which exists in situations that are called entities. These situations also are referred to as lived experiences.

3. ... "the attentive practice of thoughtfulness-a minding, heeding, a caring attunement, a wondering about the project of living." The study of the lived experience is the study of being. The wondering and attentiveness attitude utilized in phenomenological research guides the researcher in the search for the meaning of being.

4. ..."a quest for what it means to be human." As lived experiences of other human beings are studied, the researcher may come to understand what it means to be human. It is possible the consciousness will expand, and the possibility that one can become more fully human. The ultimate goal of phenomenology is the fulfillment of our human nature: to become more fully who we are.
5. ...."has been called the science of examples." Phenomenological studies often include examples that allow readers "to see" the deeper significance of the lived experience being described.

Phenomenological research asks the question, "What is being?" Exploring the collected data, the lived experiences of hemodialysis patients will assist the researcher to understand the "being" of the hemodialysis patient.

Review of Research

This review of literature includes an extensive review of qualitative research findings relevant to this study. The skipping and shortening of hemodialysis treatments is a concern of nurses because of documented increases in mortality and morbidity. Often, adults with CKD are unaware of the progression of the disease until life threatening symptoms appear, including: difficulties breathing, excessive weight gain, and changes in elimination, and immediate hemodialysis is the only option for the relief of these symptoms and prevention of fatal events. The client faces many challenges associated with ESRD: the demands of life-sustaining treatment regime, dependency upon an external apparatus for life support, the need for life support, the need to adapt to a chronic illness, dependency upon healthcare professionals for life long support, and the development of individual coping mechanisms to deal with this disease (Pinkney, 1986). Behavioral changes and reactions to these challenges by the client is the focus of the review.

Reactions of the Client with CKD/ESRD

Nurses need to understand the experiences of living with chronic renal failure from the patient's perspective in order to effectively assist patients to live with this chronic
illness (Rittman, Northsea, Hausauer, Green, & Swanson, 1993). Rittman et al (1993) utilized the hermeneutic method in their qualitative study examining the lived experiences of patients with chronic renal failure. The Heidegger phenomenology provided the philosophical framework for their study to assist in understanding the meanings embedded in the lived experiences. The sample population consisted of 6 dialysis patients; one female, five males. Five were white, one was black. Three themes were discovered from the information collected in the interview. The theme, "taking on a new understanding of being," occurred as the patient saw the changes experienced as normal and added them to their background meaning. "maintaining hope" was a theme associated with coping. Patients talked of future transplants or returning to jobs as focuses of hope. Suffering from pain and the disability of renal failure were attenuated by hope and sustained these individuals in daily living. The theme "dwelling in dialysis" included feelings of "being home" in the dialysis unit. The chair and machine were parts of their space. The territory created was embedded with significant meanings reflecting their beings-in-the-world. It was a new place for self understandings. Topics such as compliance and technology were only briefly mentioned; the emphasis of the study was concerned with the personhood and the participant’s lived experiences. Limitations to the study included the lack of cultural/ethnic variability of the sample, which was primarily Caucasian, and varying years of hemodialysis treatments.

Similarly, Polaschek (2003a) interviewed six Caucasian men on home hemodialysis seeking to identify their concerns. Three semi-structured interviews were conducted and collected on tapes and notes made from observations during the interviews. A specific synthesis of the hermeneutic and critical social science traditions
was used as a methodology. This approach emphasizes that a contextualization of the individual interpretations of experiences will be more fully understood. Employing concepts from the philosopher, Foucault, the dominant renal discourse was viewed as a medical discourse of the body expressed in diagnoses and procedures that identified the roles of both the health professional and the patient in the renal setting. Various other discourses or responses to the dominant discourse were explored and identified in this study. The discourses, or themes, identified were: (1) suffering from the ESRD symptoms and dialysis, (2) limitations resulting from negotiating dialysis into their lifestyle, (3) ongoingness and uncertainty of life on dialysis, and (4) altered interrelationships between autonomy and dependence.

Using Foucauldian views, dominant discourse relates that dialysis is an efficacious therapy and generally removes symptoms of ESRD. In this study, however, symptoms of insomnia, hypotension, tiredness, and malaise following treatments were considered significant issues in their lives, though other literature disagreed (Polaschek, 2003b). Dominant discourse relates that dialysis can be fit into a person's usual pattern of activities and allow a reasonable normal lifestyle. The men in this study, however, revealed a need for negotiation in their daily schedule, and limitations had to be accepted. Ongoingness referred to continuation of life despite the addition of hemodialysis in their routine. Participants talked of the abnormality in their lives created by the treatment regime, thus expressing a realization over time of the ongoingness of life on dialysis for them.

The dominant discourse relates that dialysis becomes a normal part of life as patients become habituated to it over time. This study, however, suggested that the renal
clients gradually came to realize the ongoingness of life and dialysis and inherent uncertainty. Dominant discourse relates that dialysis enables a nearly normal life and enhances autonomy of the client. Participants in this study, however, noted a lack of long term relationships or changes in current relationships and a dependency on the dialysis machine.

Limitations included the use of only one type of hemodialysis and the lack of gender and ethnic variation. Although the limitations simplify the description of key results, the results cannot be generalized to the population with ESRD on any hemodialysis.

A qualitative study by Lindqvist, Carlsson, and Sjoden (2000) used an exploratory descriptive design to identify perceived consequences of people living on various modes of renal replacement therapy. A group of 86 people from three area hospitals were interviewed and relevant statements were classified into categories. Validity was supported by the high level of agreement among the researchers. An overall theme of "wish for independence and normalcy" was identified in this study. Four themes with eleven subcategories were explored: (1) the wish for normality: live as usual, keep up appearances, and social comparison; (2) wish to manage one's own life: hope/fulfilled dreams, freedom/lack of freedom, and control/lack of control; (3) deprivation of one's "normal life": losses and dependence on others; and (4) concerns: physical problems, disgusted with oneself, and broodings.

Participants revealed a desire to live as they did prior to treatments (Lindqvist, Carlsson, and Sjoden, 2000). Real feelings were hidden; participants were concerned about playing the role of the "ideal patient," showing a cheerful face to the world. To
keep this cheerful outlook, individuals made comparisons with those who had a worse outcome (things could have been worse) or those who had a better outcome (to increase hope).

Statements of hope with the possibility of a renal transplant were expressed by the patients on hemodialysis. Participants talked of fulfilled dreams and a sense of freedom after a successful transplant. Participants on hemodialysis, however, talked of a lack of freedom because of their scheduled treatments. Hemodialysis patients experienced a lack of control of their lives, but looked forward to a time when they would experience freedom again.

Participants talked about losses due to hemodialysis: physical (lack of muscle strength), psychological (lack of decision making), and social (time limitations to meet friends). Patients on hemodialysis expressed feelings of dependency because of a lack in knowledge or physical strength. This lack of physical strength or fatigue also was found under the category of "concerns." Participants talked of difficulties with extreme tiredness after hemodialysis treatments and dry skin. Other participants expressed concerns about the sites of their graft/fistula and needling problems that gave the appearance of physical abuse.

The identification of these themes provided information for further research and serves as a resource for the nurse to direct the focus of nursing assessments on these resources as well as their problems and needs.

Hagren, Pettersen, Severinsson, Lutzen, and Clyne (2005) examined the experiences of patients on hemodialysis in their qualitative study. Using content analysis, common themes were identified from data collected through interviewing 41
patients between the ages of 29 and 86 years. The three main themes identified were: (a) not finding space for living, (b) feelings evoked in the care situation, and (c) attempting to manage restricted life.

The theme "not finding space for living" referred to the demands on time and physical stability that are made by CKD and hemodialysis. Participants expressed how dialysis treatments imposed several restrictions, including sexual, marital, psychosocial, financial and work.

The theme "feelings evoked in the care situation" refers to the participants’ feelings and interactions with caregivers in the dialysis setting. Patients identified unfulfilled need for more distinct contact with the physician and a lack of compassion exhibited by the staff. Dependency on the staff was equated with feelings of vulnerability.

The theme "attempting to manage restricted life" identified various ways patients coped with managing their lives while on routine hemodialysis treatments. Denial of the seriousness of the illness was explored by 1 participant. Another actively participated in the insertion of the needles to cope with the feelings of vulnerability.

Hagren et al. noted that the study did not have family or social focus, but did give new insights into how patients on hemodialysis experience the restrictions of time and space for living.

Cohen (1995) examined the experience of living on hemodialysis through data collected from extensive interviews from 5 participants and their families over a period of 20 years. Three distinct phases were identified: (a) the initial or crisis phase of up to 1 year, (b) the chronic living phase up to year 15, and (c) the terminal phase when health
deteriorated. The validity of this study was confirmed by the coherence of the research conclusions. The study demonstrated the ongoing psychological impact on the patient and his family. As the health of the patient on hemodialysis deteriorated and his dependence on his family increased, feelings of resentment manifested in the relationship. Participants on hemodialysis developed new supportive relationships with the staff in the dialysis units, but the families did not share in these relationships. Cohen's study indicates that the impact of ESRD and dialysis on the family of the patient needs to be recognized as part of their experiences of living on dialysis.

Faber (2000) conducted a study using a multiple case design within a sociocultural approach. Interviews were conducted with each participant, the immediate support person, and a related health professional. Taped self reports and data collected from observations of the participants and clinical record reviews were included in the study. The data were coded and used to create a description of the world view of all the participants in the study. The credibility of the study was established by the triangulation of these various sources of information.

Faber identified issues that patients on dialysis experienced frequently including dealing with restricted fluid intake and curtailing normal activities because of scheduled treatment times. Psychosocial losses including a sense of dependence on the treatment, and the participants’ various interactions with the staff also are described in this study. Faber noted an inequality of power between the health professionals and the participants which lead to the views of the participants on hemodialysis being "subtly repressed" (p. 25).

In contrast to studying themes of patients adjusting to hemodialysis, Gordon,
Leon, and Seghal (2003) identified several reasons participants offered when skipping or shortening hemodialysis treatments. Gordon et al. (2003) used both qualitative and quantitative approaches to identify the participants’ views and to determine if there was a relationship between demographics and the emergent themes. One hundred and sixty-eight (168) participants undergoing routine hemodialysis treatments were selected from 29 facilities in northeast Ohio. Appropriate tests for reliability and statistical analysis were completed. Chart abstractions determined the number of comorbid conditions present or absent including ischemic heart disease, solid tumor, dementia, asthma, chronic obstructive lung disease, or diabetes mellitus. A semi structured questionnaire was used to interview patients about reasons for skipping or shortening treatments. Global themes were identified. The most frequent themes identified for shortening treatments included medical problems such as: cramping, illness, and low blood pressure. The most frequent themes identified for skipping treatments included life tasks and transportation. Identified limitations of the study included possible bias because questions were asked about the previous 3 month period of dialysis treatments. In addition, the noncompliance episodes might have been sporadic and thus the responses of the subject might not be accurate.

**Summary**

The qualitative research studies reviewed identified several challenges and adjustments facing the ESRD patient on routine hemodialysis treatments. Losses, both physical and psychological; limitations; and feelings of dependency were the dominant themes found in the reviewed literature. Feelings of hope mentioned in two of the
studies were overshadowed by the tremendous amounts of negative uncertainties and adjustments facing the patient on hemodialysis. The research reviewed did not, however, provide sufficient information about how people live with the diagnosis of ESRD and the need of scheduled hemodialysis treatments. The purpose of this study is to identify and augment what is known about living with ESRD. The knowledge gained from this study may assist healthcare workers to identify compensatory or compromised levels of adaptation, and promote integrated levels of adaptation, thereby enhancing the quality of life for people with ESRD.
CHAPTER III

Methods

The purpose of this study was to identify the experiences of the adult with ESRD on routine hemodialysis. The data obtained may provide reasons for accepting or rejecting the limitations and various restrictions associated with ESRD and hemodialysis. This chapter includes: (a) a description of the design of this study, (b) the selection of the participants with inclusion and exclusion criteria, and (c) the appropriate forms for protection of human rights. Material used to examine the research question and the methods of data collection and data analysis also are discussed in this chapter.

Design

A phenomenological design was used in this qualitative study. Phenomenology is the study of lived experiences in an attempt to fully understand what it means to be human. The phenomenon in this study was the lived experiences of patients on routine hemodialysis treatments. The data collected were analyzed for themes related to the research question.

Participants

A purposive sample of 5 participants was recruited from a nonprobability convenience sample of hemodialysis clients. This method of sampling, i.e., selecting participants with knowledge of the phenomenon, is used to provide information directly related to the central issues of the phenomenon. Participation was voluntary. The criteria for inclusion were (a) adult clients on regular hemodialysis treatments – regular identified as three treatments a week lasting 3-4 hours each treatment, and (b) able to understand and speak English. Exclusion criteria included: (a) clients who had two or more
interruptions of their regular dialysis schedule because of illness, access malfunction, or vacation; and (b) clients with documented diagnoses of Alzheimer or similar memory losses. The exclusion criteria were necessary to obtain participants who understood the details of the study and could give informed consent. The focus of the study was the experiences of the participant on routine hemodialysis. A sample of 4 (80%) males and 2 (20%) females completing hemodialysis treatments at a free standing hemodialysis center in a Midwestern urban setting was utilized to provide substantial information related to the phenomenon of living with ESRD and hemodialysis treatments. Four (80%) were married and living with their spouse. One was single and living with a relative.

**Setting**

The participants completed their hemodialysis treatments at a free standing hemodialysis center in a Midwestern urban setting. Interviews were conducted in the participant's home or a place of the participant's choice.

**Material**

A brief questionnaire was read to each participant to collect demographic material. Items gathered included race, age, gender, and marital status (Appendix A). One interview was conducted, lasting 20 to 30 minutes and was audio taped and transcribed. The initial question asked was "What is your experience being on hemodialysis?" Further questions were open ended to gather more information from participants to encourage the sharing of stories or further experiences of being on hemodialysis. Examples of open ended questions are found in Appendix B.
Data Collection

Protection of Human Rights

Approval for this study was obtained from the Institutional Review Boards of the Medical University of Ohio (Appendix C) and the outpatient hemodialysis center (Appendix D). Informed consents (Appendix E) were obtained prior to the interviews. A notification of the study with an information letter was distributed to hemodialysis clients in the hemodialysis center. Clients who expressed an interest were contacted and all questions answered prior to arranging the interviews. No identifying data were used in the report of the study, including names, or social security numbers. Participants were reminded that they could stop the interview at any time without danger of repercussions. They could withdraw from the study at any time, and names would be kept confidential. Participants were given a number code (1, 2, 3, etc.) which appears on the transcripts and file notes. All tapes were destroyed after transcripts were completed and edited. Transcripts and file notes will be saved in locked files at Medical University of Ohio for 7 years and then be destroyed by shredding.

Data Analysis

Data analysis was guided by Van Manen's (1990) phenomenological research methods. The following four steps were utilized throughout the analysis period:

1. Turning to the lived experience. The researcher familiarized herself with the phenomenon of the ESRD client needing routine hemodialysis and questioning the essence of the experience. This researcher was familiar with ESRD clients through her experience in a nephrology office and visiting area hemodialysis centers. The phenomenological question was "What is the lived experience of the
client with ESRD on routine hemodialysis?” Assumptions and speculations were suspended or bracketed. The researcher did this by mentally identifying and exploring personal thoughts and perceptions related to hemodialysis, and placing them aside during the process of data collection and analysis. By completing this process of bracketing, this researcher is more open to the participants’ views during the actual data collection and analysis.

2. Investigating experience as we live it. Data collection started using personal experience as a starting point. This researcher was familiar with ESRD clients and reflected on past interactions prior to the data collection. This step encourages the researcher to avoid adding personal biases into the interviews. Interviews were conducted using open ended probes and unstructured questions. Observing the client during the conversations and reviewing field notes and summaries offered further insight on the meaning of the phenomenon.

3. Phenomenological reflection. In this step thematic analysis was performed to seek the meaning of the phenomenon. The theme or themes were identified through selective reading of the transcripts from the interviews and reviewing the audiotapes several times. Recurrent and similar phrases identified and recorded from the collected data determined the themes pertinent to the phenomenon. These themes then were incorporated into the text describing the structure of the lived experience of the hemodialysis patient.

4. Phenomenological writing. This final step was the composition of the phenomenological text including the discovered themes associated with the lived experiences of the hemodialysis patient. It was essential that the textual
expression accurately communicated the essence and structure of being on routine hemodialysis treatments.

Credibility and confirmability are recommended to support the scientific rigor of qualitative studies (Lincoln & Guba, 1985). Credibility, i.e., asking two randomly selected participants of the study to verify the findings of the study as true to their life experiences, and confirmability, i.e., asking colleagues to audit the transcribed taped interviews, replicate the codes found on the file notes and transcriptions, and agree the findings are based on the collected data and not on researcher bias, were not completed and pose limitations to this study.

Summary

This chapter described the design of the study, the setting and selection of the participants, protection of human rights, the materials used, the method of data collection and data analysis. Data analysis used Van Manen's phenomenology theory which focused on the identification of a core variable or variables.
CHAPTER IV

Results

This chapter contains the demographic data of the sample and the descriptive statistics obtained as a result of the study. The findings for the research question also are included with a description of the data. A concise summary concludes the chapter.

Sample

Data for the study were collected from interviews; four conducted within the free-standing hemodialysis center where the individuals received their treatments, and one in a private home. All were located in a midwestern industrial city. The target population was all people in this city with ESRD on routine hemodialysis treatments. Five clients of the selected dialysis center who met the inclusion criteria were approached and all agreed to participate in the study. All signed informed consents prior to participating in this study. Information about the participants and characteristics of the sample are found in Table 1. Four of the participants (80%) were male. Three were Black and two were Caucasian with ages ranging from 41 to 72 years. Four (80%) indicated they were married and living with their spouse. One (20%) was single, and living with a relative.
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Findings

The research question for this study was: “What is the lived experience of the client with ESRD on hemodialysis?“ A single theme with several categories emerged after selective reviews of the transcriptions and audiotapes obtained from the individual interviews. The findings provided insight into how the participants in this study defined their experiences living with ESRD and the need for routine hemodialysis treatments. The three subthemes were (a) positive outlook, (b) family life, and (c) involvement in care (Figure 1).

Positive Outlook

The first subtheme “positive outlook,” emerged from several positive statements made from participants in the taped interviews. One middle-aged gentleman said “…glad this is here...” Another smiled as he commented, “I like coming to treatments and leaving here feeling better than I did before… Dialysis is definitely a good thing for me.” One female participant shared thoughts of needing time to adjust to the mental demands of hemodialysis and has a unique outlook… “About a year or so after (being on hemodialysis)... I found out I was still me... I am living... I am just getting my kidney cleaned... I don’t look as it being sick… It is a mind thing.”

A young gentleman looked forward to Mondays. “...Sunday I slow down and later I am slowing down and tiredness is starting to build back up... I look forward to Monday morning coming in...” Another gentleman looked forward to getting away when he feels he is stronger, “I got some traveling to do with my cousin.”
Figure 1
Summary of results with 1 Main Theme and 3 Sub themes

Family Life

The second subtheme “family life,” emerged from expressions of support offered from family members. Continued family responsibilities were described as reasons to continue and even accept routine hemodialysis treatments. Four of the participants lived with spouses, one lived with a brother. One gentleman and his wife were raising their two teenagers. He proudly shared, “We have dedicated most of our lives to making sure that they have done well in their life… both of them are on a roll, and very musically inclined… they are very good kids…they are very helpful...” The older female participant shared concerns about her elderly husband. “I did not want my husband to worry about anything if something happened to me,” explaining why she made funeral and burial arrangements when she first learned of her need for hemodialysis. “I am here to take care of him... I wasn’t ready to go... he has always taken care of me when he worked, and I am taking care of him now.” One participant lived with his brother, “I am taking care of him but he does not know it... he drives me crazy... he keeps me going.”
Involvement in care

The third subtheme “involvement in care,” described how participants coped with and accepted hemodialysis by learning about ESRD and the option of kidney transplantation. Participants shared thoughts of learning about ESRD and hemodialysis. One gentleman related, “You increase your knowledge of longevity...” Another participant with a diagnosis of polycystic kidney disease which can lead to eventual ESRD and hemodialysis recalled, “I just started learning as much as I could about things... visited a couple of centers before...”

A female participant shared how she fit hemodialysis treatments into her travels… “I was able to do that (miss a treatment) because I learned how to take care of myself…I learned not to drink a lot of salty stuff, and I could miss 1 day… When I went down there (traveled to Atlanta), I left on a Friday, and I did not come back until Tuesday, and I didn’t have to get dialysis (on Monday), and nothing bothered me...because if you learn how to drink, learn how to not do the fluids, and not eat a lot of stuff that you are not supposed to, you can go a little while and it won’t kill you…” She also listed her dietary restrictions yet admitted to consuming small amounts of these foods… “I found there were certain things that were against us, since we don’t have any kidneys to clean it out, I had to cool it. I can’t eat macaroni and cheese… I shouldn’t eat sweet potatoes and all…I eat fried chicken but I don’t eat chicken like I used to... I may have some now and then… we used to have fried chicken every Sunday…I have been eating potato chips, I know I can only eat a few, but otherwise, I am fine.”

A middle aged man who has had all of his teeth extracted in preparation for a transplant related, “I was worried about a kidney, but now I think I would like to have
Client with renal disease

one...I have been going to get the workup here...it’s working pretty good for the people who have them.” Another gentleman in the study focused on the positive aspects of transplants...“It’s not that I’m not scared of going through the transplant...I am aware of the complications and stuff like that, and know what can go wrong, but I try to focus more on what can go right...and it makes me feel a lot better about things...I am ready for it.” He shared feelings of hope...“with studying things and preparing yourself for it, it is a lot less anxiety for me than before...talking with people that have gone through and stuff like that, has been a good help, too.” This same gentleman related his knowledge about the benefits of kidney transplants...“My dad...was much better after his transplant...an increase in energy to get out and do things...Before he had his transplant, he just sat around the house most of the time, and now he is out and going for a walk...he rides his motorcycle a lot more after the transplant...”

An overall theme of “acceptance” emerged after further reviews of the transcribed tapes and notes. The participants expressed positive attitudes in many of the interviews. Participants shared knowledge of their time and dietary restrictions, and how they have incorporated these changes into their daily lives. One participant shared her travel issues. She accepted the need to increase her restrictions on fluid consumption to avoid complications associated with ESRD during her extended stay out of town. The findings are summarized with a statement from one of the participants, “I am fine.”

Summary

This chapter described the demographic data of the sample used in this research. Three subthemes were identified after selectively reviewing the transcriptions and audiotapes obtained from the completed interviews. The first subtheme “positive
outlook,” included descriptions of how participants psychologically and emotionally changed, and adapted to the routine hemodialysis treatments. Participants shared thoughts of feeling better after hemodialysis treatments and expressed gratitude for the availability of the treatments. The second subtheme “family life,” focused on expressions of support from family members. Participants expressed concerns and a need to support their family; raising children with a spouse. Other participants shared the desire to take care of a spouse or sibling. The third subtheme “involvement of care,” included participants expressed knowledge of hemodialysis, fluid and dietary restrictions, and the possibility of kidney transplantation. Two participants spoke positively of acquiring kidney transplants in the future. One participant expressed doubts initially but now, after talking to other recipients, was looking forward to one. Another had completed the requirements needed to be placed on the list, and related feelings of hope as he waits for word of a possible transplant.

Although there were hints of fear and anxiety (“it’s not that I’m not scared …”), the overwhelming emotions were of acceptance and adaptation.
CHAPTER V
Discussion

The final chapter discusses the findings of this study in relation to the literature reviewed and theoretical framework. Conclusions, limitations, and recommendations for further research are explained and a brief summary completes this chapter.

Findings

The purpose of this study was to describe the lived experiences of adult patients in relation to ESRD and chronic hemodialysis treatments. The knowledge obtained may assist health care workers to identify compensatory or compromised levels of adaptation, promote integrated levels of adaptation thereby enhancing the quality of life of these patients. The research question was “What is the lived experience of the client with ESRD on hemodialysis?”

Positive reflections related to the need of scheduled hemodialysis treatments for the control of symptoms associated with ESRD are embedded in the current study and support similar themes in the literature review. One of several themes discovered by Rittman, Northsea, Hausauer, Green, and Swanson (1993) was “maintaining hope.” Those participants talked about the possibility of obtaining a renal transplant as a positive way of coping with ESRD and actually eliminating the need of hemodialysis treatments. Similarly, 2 participants in the current study are actively pursuing transplants. One gentleman is currently on a transplant list and the other is completing the necessary preliminary requirements prior to being accepted on a transplant list.

Participants in Rittman, Northsea, Hausauer, Green, and Swanson’s (1993) study became attached to their space; wanting to sit in the same chair with the same dialysis
unit each visit. Similarly two participants in the current study insisted on completing the interviews while on dialysis. The dialysis unit, the staff, and the technology created a new culture for belonging and being (Rittman et al.).

Lindqvist, Carlsson, and Sjoden (2000) found an overall theme of “wish for independence and normalcy.” Four subthemes were identified including the “wish to manage one’s own life” with subcategories of hope, freedom/lack of freedom, and control/lack of control. Participants talked of hope associated with a possible transplant, and seeing oneself as healthy with a successful transplant. In the present study, a male participant looks at the positive aspects of a possible transplant, “I am aware of the complications and stuff like that, and know what can go wrong, but I try to focus on what can go right…and it makes me feel a lot better about things. I am ready for it.” Another theme in Lindqvist et al.’s study was “wish for normality” with subcategories of live as usual, keep up appearances, and social comparison. Statements from participants in that study revealed a struggle to live life as before the start of hemodialysis treatments. In contrast, the female participant in the current study boasted of her lifestyle after the start of hemodialysis treatments 3 years ago; “When I get off dialysis, I go home, I do laundry, I cook, I do everything… I don’t have to go home and lie down… I go to Atlanta and to Florida…so I get my dialysis there…I do everything they tell me to and I am fine.” She compared her life with others in the unit, “I can tell the ones who are really trying just to live on, instead of just going there for treatment and going home and staying sick.”

The differences in attitudes found in the above studies can be related to one or more the following; (1) participants in Lindqvist et al.’s study were interviewed in one of two ways; the majority were interviewed in their homes, but a few (6 of the 86) were
Interviewed by phone. The collected data were not separated as to the type of interview, therefore the data collected and analyzed from phone interviews may differ dramatically from home interviews. The difference in responses also may be related to the time being on a treatment for ESRD. Criteria for inclusion in Lindqvist et al.’s study included a minimum of 3 months experience of the treatment in question for ESRD. Feelings of struggling may be related to an inadequate amount of time needed to adjust to the lifestyle changes associated with ESRD and its various treatments.

Hagren (2005) identified three main themes in his qualitative study including “attempting to manage restricted life.” A participant in his study actively assisted with the insertion of his needles to cope with his lifestyle changes. A participant in this current study attempted to explain the benefits of dialysis and his coping mechanisms with an acquaintance who made a decision to end his dialysis treatments… “He made that decision, and then later on he told me, ‘This is not for me’… I tried to explain dialysis and he said… ‘I am coming off it.’… I could not convince him… I was really let down when he passed.”

Cohen (1995) included interviews from subjects and family members over a 20 year period. Over time as subjects’ health deteriorated, more supportive relationships developed between the staff in the hemodialysis units and the patients. In the current study, the interviews were completed at one sitting. Four of the 5 participants in the current study spoke positively of their family members. The female participant in this study expressed her strong feelings, “I am here to take care of him (husband)... he has always taken care of me, when he was working, now I am taking care of him.” Another participant in this study reflected on his relationships… “They (hemodialysis staff) have
been very generous…any questions I have ever had they have been more than willing to answer, and inform me what is going on and it’s a different environment to have to live in.” He spoke highly of his family… “I am not working…fortunately my wife has a good paying job, and that is where our insurance comes from… (he continued on to talk of his two children)…they are very good kids…very helpful… it is a big part of our lives and we are quite proud of them.”

Implications and Relationship to Conceptual Framework

The findings of this study were examined in relation to Roy’s (Roy & Andrews, 1999) model of adaptation. Roy’s theory describes humans as adaptive systems in constant interaction with their environments. Adaptation is defined as “the process and outcome whereby thinking and feeling persons…use conscious awareness and choice to create human and environmental integration” (Roy & Andrews, 1999, p. 30). Humans display adaptive (or ineffective) behaviors in four modes: (a) physiological-physical, (b) self-concept /group –identity, (c) role function, and (d) interdependence. The physiological-physical mode includes physical and chemical behaviors of the body. The self concept-group identity mode refers to spiritual integrity, self ideal and body image. The role function mode pertains to self expectations in relation to society and expectations of others with different roles. The interdependence mode focuses on relationships and the need for relationship integrity.

Collectively, the three subthemes and overall theme found in this study reflect Roy’s (Roy and Andrews, 1999) definition of adaptation as the process and outcome whereby thinking and feeling persons, as individuals or in groups, use conscious awareness and choice to create human and environmental integration (p. 32-33). The
subthemes “positive outlook” and “involvement in care,” reflect the self-concept mode from Roy’s adaptation model. All the participants expressed acceptance, even gratitude, to have scheduled hemodialysis treatments in their lives. One participant shared thoughts of needing time to adjust… “But I found out I was still me.” All the participants actively learned about ESRD including diet and fluid restrictions, and two pursued the possibility of kidney transplantation. They chose to learn and incorporated the necessary restrictions associated with ESRD. Several participants shared thoughts of pursuing activities outside of their time on hemodialysis. One of the participants was able to manage her treatment schedule and restrictions around her travels.

The subtheme, “family life,” reflected the interdependence mode from Roy’s model of adaptation. Several participants shared positive feelings toward their family members. One shared how his two teens have been more helpful at home. Another completed her own funeral and burial arrangements in preparation for the future to assist her husband… “I did not want him to worry.”

Acceptance of ESRD, including the need of routine hemodialysis treatments, and the various restrictions associated with this chronic disease was found throughout the analysis of the collected data. The participants shared positive feelings and emotions and effective coping strategies indicating a positive adaptation to this chronic disease.

Conclusions

1. All participants shared overwhelmingly positive thoughts and feelings related to adjusting to ESRD including the lifestyle changes and scheduled hemodialysis treatments.
2. The participants interviewed are displaying adaptive behaviors to cope with this chronic disease.

Limitations

Several factors may have affected the findings in the current study. First, the sample size was small. The researcher needed to collect the necessary data in 8 weeks. Initial responses to the information letter describing the study were slow; a second distribution of the letter yielded an adequate amount of qualified participants. Because of limited time, this was a convenience sampling and also may have affected the results of the study. The participants in this study completed their hemodialysis treatments in the same free standing hemodialysis center; the sample may have been a more accurate representation of the target population if more interviews were included from other hemodialysis centers in this Midwestern city. The demographic data used in this study were limited. It is not known how long the participants have been receiving routine hemodialysis treatments. Transportation, financial status, and other health conditions were not mentioned in the demographic form. Including these issues may provide more extensive and diverse data in the interviews.

Data for this study was collected in one interview per participant. Because it was a single interview, the participant may have wanted to display a positive attitude, hence a positive interview. The interview times were prearranged, also, allowing the participant to prepare his thoughts and concerns. A longitudinal design would be more effective to understand how people cope with chronic illnesses such as ESRD and subsequent lifestyle changes as environmental stimuli, including changes in health, new experiences and feelings would be included in the study.
Implications for Practice

All of the participants expressed acceptance of needing routine hemodialysis treatments. All learned to cope with this chronic disease and the restrictions. The treatments were incorporated into their lives, the dietary and fluid limitations were added, but not thought of as restrictions. The participants realized that ESRD and hemodialysis are manageable.

Education is necessary for the client with ESRD and the need of hemodialysis because of the many physiological and psychological challenges associated with the disease. The participants in this study learned to cope with the assistance of staff members of the dialysis center. One of the participants knew her dietary restrictions because of booklets provided by the staff. She also learned to manage her health without the need of a treatment when visiting relatives out of state. Other participants started the process of meeting the requirements of kidney transplantation.

It is imperative that throughout the duration of their lives, clients on routine hemodialysis treatments are taught that ESRD is manageable. Early identification of individual needs and effective coping skills and strategies should be included in the care plan of all hemodialysis patients on a regular schedule. The learned skills will then assist the client to maintain his health and high levels of quality in his life despite living with this chronic illness.

Implications for Nursing Administration

Directors and managers of outpatient hemodialysis centers can facilitate education and promotion of effective coping skills of hemodialysis patients. Orientation classes for newly hired employees needs to include a review of the physical and psychological
Client with renal disease

stresses that patients with ESRD experience and coping mechanisms identified in current research. Continuing education classes need to be offered regularly; topics should include communication skills, client involvement, and medical/pharmaceutical updates related to ESRD and hemodialysis patients. Registered nurses should be strongly encouraged to join and participate in the American Nephrology Nurses Association (ANNA); attend continuing education programs, and keep abreast of ongoing changes associated with ESRD. The knowledge obtained from the staff then can be channeled to the clients on hemodialysis to assist them in adapting to this illness.

Recommendations for Further Research

To understand how patients cope with the ever changing demands of a chronic illness, a longitudinal designed study in several chronic illness populations would provide a larger amount of data with more precise results. A larger sample size within one outpatient dialysis center consisting of several interviews or studying a comparison of adaptation strategies from patients in several dialysis centers also should be considered.

Summary

Positive reflections related to ESRD and subsequent need of scheduled hemodialysis treatments are embedded in the current study and support similar themes in the reviewed literature. Participants talked of pursuing kidney transplants, taking care of their family members, or allowing family members to assist in daily activities as means of adapting to this chronic illness. The three subthemes, “positive outlook,” “family life” and “involvement in care” and the overall theme of “acceptance” support Roy’s Adaptation Model (1999), the conceptual framework used in this study. The subthemes “positive outlook,” and “involvement in care” reflect the self-concept role from Roy’s
model of adaptation. All the participants expressed gratitude for having hemodialysis treatments to maintain their lives, and all incorporated the necessary fluid and dietary restrictions. The subtheme “family life,” reflected the interdependence role from Roy’s adaptation model. Participants demonstrated actions of adaptive interdependence; acceptance of a spouse as family income and insurance provider, and anticipating and planning funeral services for self to avoid spousal stress. Acceptance was found to be the overall theme in this study. All had learned to cope and incorporate strategies and skills to control the complications associated with ESRD, and also to manage a productive lifestyle.
REFERENCES


Appendix A

Demographic Data

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Appendix B

Examples of Open ended questions

What is your experience being on hemodialysis?

How do you feel when you are hemodialysis?

Why do you come to hemodialysis?

Why do you feel ____________?

Examples of other probes

Can you tell me more about that?

When you say ........ what do you mean?
Client with renal disease

Medical University of Ohio at Toledo
INSTITUTIONAL REVIEW BOARD
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Phone: 419-383-6786 Fax: 419-383-3248
(http://www.muohio.edu/ohiu/hrp)

TO: Jane Evans, Ph.D., R.N.,
MUOT College of Nursing

FROM: Roland Shiel, M.D., Chair
Gregory Shiel, R.Ph., J.D., Chair Designee
MUOT Institutional Review Board

DATE: June 28, 2006

SUBJECT: IRB # 103198 – What is the Lived Experience of the Client with End Stage Renal Disease on Hemodialysis

The above project was reviewed and approved by the Chair of the Medical University of Ohio at Toledo Institutional Review Board as an expedited review (category #6 and #7) – Signed and Dated Consent and Authorization for Use and Disclosure of Protected Health Information is required from each participant prior to that individual taking part in this research. The full board will be notified of this action at its meeting on 07/20/2006.

Items Reviewed:
- IRB Application Requesting Initial Expedited Review of Research
- Protocol (assigned version date 06/28/2006)
- Consent/Authorization Form (version date 06/28/2006)
- Data Collection Tool (assigned version date 06/28/2006)
- Permission Letter from Performance Site – Davita Toledo Dialysis (letter date 02/22/2006)


It is the Principal Investigator's (P.I.’s) responsibility to:
1. Abide by all federal, state, and local laws and regulations; the MUOT federal assurance and institutional policies for human subject research and protection of individually identifiable health information including those related to record keeping and be sure that all members of your research team have completed the required education in these areas.
2. Ensure that all subjects, or their legally authorized representatives, date the Consent Form and Authorization for Use and Disclosure of Protected Health Information Forms at the time they sign these forms to give consent to participate in the study and authorize use and disclosure of their protected health information. Each participant must be given a signed copy of each of these documents. For study subjects that are registered at the Medical University of Ohio at Toledo (MUOT) a copy of the signed and dated Consent Form and Authorization for Use and Disclosure of Protected Health Information forms must be placed in each individual's MUOT medical record as well. If consent or authorization is revoked by a subject, it is the responsibility of the P.I. to obtain the required signed document(s) and submit these to MUOT's Health Information Management Department as required by institutional policy in compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule Privacy Rule (45 CFR 164).
3. Comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and institutional policy regarding the accounting and tracking of uses and disclosures of protected health information and security of protected health information.
4. Promptly notify the MUOT IRB at (419) 383-6786 of any untoward incidents or unanticipated adverse reactions that develop in the course of your research on human subjects. Please complete and submit RGA Form 317 for ALL SUCH REPORTS for this protocol. The Principal Investigator is also responsible for submitting to the MUOT IRB reports of adverse events that occur at other sites conducting this study and for maintaining an up-to-date cumulative table of adverse events (RGA Form 316) and submitting it to the MUOT IRB for each research project. The Principal Investigator is responsible for reporting adverse events to the appropriate federal agencies and the sponsor (when one exists).
5. Report promptly to the MUOT IRB any deviations, violations or participant non-compliance from the MUOT IRB approved protocol in accordance with the procedures outlined in RGA Form 309. In your report include the protocol number and title, the subject's initials and study ID number, date of the event, a brief description of the occurrence and a description of any corrective actions taken. The Principal Investigator is responsible for reporting deviations, violations
and participant non-compliance to the appropriate federal agencies and the sponsor (when one exists) in accordance with federal regulations, institutional policy and any other legal agreements with these organizations.

6. Obtain prior MUOT IRB review and approval for changes in procedures, inclusion/exclusion criteria, study personnel, source of participants, new or additional advertising materials, modifications to subject payments, and for any and all changes to the informed consent/assent/authorization for use and disclosure of protected health information documents.

7. Report promptly to the MUOT IRB, sponsor and all other required federal and state agencies all new information affecting the risk/benefit ratio and obtain prior MUOT IRB approval for any changes in the study documents that may be required by the new information.

8. Obtain prior MUOT IRB review and approval for all modified and/or added incentives going to the P.I., study coordinator, other study personnel, and the institution. These incentives may be in the form of money or other items of value, including, but not limited to, equipment, such as computers, and intangibles, such as frequent flyer miles.

9. Promptly notify the MUOT IRB; other required MUOT committees, departments or individuals; the sponsor (if this research is sponsored), and all other required federal and state agencies of all potential conflicts of interest before beginning this research and, during the course of this research report to those committees, departments, and agencies any changes that may affect conflict of interest for any of the study personnel. Prior MUOT IRB approval must be obtained for any changes in the study documents that may be required by information related to conflict of interest or any changes in this information during the course of the research.

10. Promptly notify the MUOT IRB of any changes in contracts, budgets, grants or other agreements with sponsors, agencies or individuals regarding the conduct of this research before initiating these changes. The IRB reserves the right to review these study related documents and changes to them to verify accuracy and consistency with regard to the research protocol in order to protect the rights and welfare of the study subjects. Changes in these documents that have the potential to affect the rights, welfare or willingness of the study subjects to participate in or continue to participate in this research and changes in subject documents (such as informed consent, assent or authorization for use and disclosure of protected health information forms, etc.) that are a result of these changes must be reviewed and approved by the MUOT IRB prior to being instituted.

Additional Information:

Other Required Review(s) or Approval(s)

Review or approval by the MUOT Institutional Review Board does not take the place of any other review or approval required by the Medical University of Ohio at Toledo, non-MUOT performance sites, the government and/or the study sponsor.

Required Procedures to Request Review and Approval for Changes/Updates to MUOT IRB Approved Research:

Please complete and submit the Request for Amendment/Changes/Users (RGA Form 314) found at <http://www.meduniversity.edu/research/rga_forms/rga314.doc> with a copy of all materials relevant to the requested change (including consent/assent/authorization for use and disclosure of protected health information forms if applicable) with the changes underlined. If you are requesting review and approval of consent/assent/authorization for use and disclosure of protected health information forms, please attach a clean copy of the revised forms to the MUOT IRB to stamp. Please remember that all changes and correspondence submitted to the MUOT IRB (regardless if they are generated by a sponsor, the P.I. or requested by the MUOT IRB) must be in writing, signed and dated by the Principal Investigator.

Federal Mandated Continuing Review:

MUOT IRB protocols must be reviewed and reapproved not less than once per year. The Institutional Review Board will try to remind you when reapproval is due. However, it is the responsibility of the Principal Investigator to have his/her own reminder system in place to initiate the reapproval process at least one month prior to the expiration date shown above. Please note that Federal Regulations prohibit the extension of the expiration date. Please see the Application for Continuing Review (RGA Form 319) found at <http://www.meduniversity.edu/research/rga_forms/rga319.doc> for items required for continuing review.

Required Final Report Upon Termination of Research:

When you decide to stop this research, you are responsible for completing and submitting a Final Report (RGA Form 320) found at <http://www.meduniversity.edu/research/rga_forms/rga320.doc> to the MUOT IRB for review.

Please contact the IRB at (419) 383-6706 if you have any questions or need assistance.
Chairman, Institutional Review Board  
Medical University of Ohio  
3120 Glendale Avenue  
Toledo, Ohio 43614  

Dear Dr. Skees,

We have reviewed the research proposal by Diane Scalea, BSN, RN entitled  
"What is the Lived Experience of the Client with End Stage Renal Disease on  
Hemodialysis". This research has relevance to the nursing care of clients on  
hemodialysis. The study design is well conceived and falls within the priorities  
for care in our facility. Only 5-9 of our clients would be interviewed. No physical  
care is involved.

The study asks for no confidential health information and thus poses no risks to  
our clients. We have ample subjects to support the research and look forward to  
working with Mrs. Scalea on her research.

Sincerely,

David A. Spears  
Regional Operations Director  
DaVita Toledo Division

Ben C. Huddleston  
Group General Counsel  
DVA Healthcare Retail Care, Inc.

Dr. Jon A. Milkstrand, Dean  
College of Nursing  
Medical University of Ohio
Appendix E

Informed Consent

RESEARCH CONSENT FORM FOR ADULT SUBJECT INFORMED CONSENT

WHAT IS THE LIVED EXPERIENCE OF THE CLIENT WITH END STAGE RENAL DISEASE ON HEMODIALYSIS

Principal Investigator – Jane C. Evans, Ph.D. (419 383-5842)

Co investigator – Diane Scaife (419 865-6997)

What you should know about this research study:

The consent form explains the purpose, risks, and benefits of the study. The researcher will also explain this form to you verbally. Routine clinical care is the best known treatment with the mail goal of helping the individual patient. The main goal of research is to gain information that may help future patients. We cannot promise that this research will help you. There is a possibility of side effects – can be serious or minor. You have the right to refuse to take part in this research at any time. Your decisions will not affect your routine care. Please review this form carefully. Ask questions at anytime. Your participation in this study is voluntary

PURPOSE

You are being asked to take part in a research study about the concerns of the client with kidney disease that are on regular hemodialysis treatments. Present research confirms that skipped or shortened hemodialysis treatments can lead to severe illnesses and death, and various reasons for skipped or shortened treatments are
mentioned. Current research does not identify the concerns of the client on hemodialysis. The purpose of this research is to discover these concerns.

PROCEDURES AND DURATION

If you decide to take part in this study, you will be asked to participate in one private audio taped interview lasting 30-45 minutes with the investigator. During the interview, you will be offered the opportunity to describe your thoughts about being diagnosed with kidney disease and the need for hemodialysis treatments.

RISKS AND DISCOMFORTS

There are no known risks to you for participating in this study. If you feel a need to talk more after this study, the social worker at your local clinic can assist you to find a specialist.

BENEFITS AND/OR COMPENSATION

We cannot and do not guarantee or promise that you will receive any benefits from this study. However, results from this study may help nurses help others in the future. CONFIDENTIALITY

By agreeing to take part in this research, you give to the Medical University of Ohio, the Principal Investigator, and everyone associated with this research study your permission to use or disclose health information that can be identified with you that we obtain or this study. We will use this information to identify common themes associated with clients with kidney disease.
IN THE EVENT OF A RESEARCH – RELATED INJURY

In the event of injury, such as stressful feelings, from taking part in this study, you can seek treatment at a health care facility of your choice. You should understand that the costs of such treatment will be your responsibility. Financial compensation is not available through Medical University of Ohio. By signing this form you are not giving up any of your legal rights as a research subject.

In the event of any injury, contact Jane Evans (419) 383-5842.

VOLUNTARY PARTICIPATION

Taking part in this study is voluntary. If you decide not to take part in this study, the decision will not affect your future relations with the Medical University of Ohio, its personnel, or any hemodialysis clinics including Gambro Health Center. You are also free to discontinue your participation in this research at any time.

OFFER TO ANSWER QUESTIONS

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. Please take as much time as necessary to think this over.

AUTHORIZATION

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN THE RESEARCH STUDY. YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTOOD THE INFORMATION PROVIDED ABOVE, HAVE HAD ALL YOUR QUESTIONS ANSWERED, AND HAVE DECIDED TO PARTICIPATE.
BY SIGNING THIS DOCUMENT YOU AUTHORIZE US TO USE OR DISCLOSE YOUR PERSONAL HEALTH INFORMATION AS DESCRIBED IN THIS FORM.

The date you sign this document to enroll in this study, that is, today's date, MUST fall between the dates indicated on the approval stamp affixed to the bottom of each page. These dates indicate that this form is valid when you enroll in the study but do not reflect how long you may participate in the study. Each page of the Informed Consent Form is stamped to indicate the form's validity as approved by the MUO Institutional Review Board (IRB).

Name of subject (please print) Signature of subject Date Time am/pm

Name of person obtaining informed consent Signature of person obtaining consent (as required by ICH Guidelines)

Signature of witness to consent process (when required by ICH guidelines)

YOU WILL BE GIVEN A SIGNED COPY OF THIS FORM TO KEEP.

If you have any questions concerning this study or consent form — please feel free to contact the Chairperson of the Institutional Review Board of the Medical University of Ohio at (419) 383 - 6796.
ABSTRACT

This study describes the lived experiences of patients with end stage renal disease (ESRD) on hemodialysis treatments. A qualitative, phenomenological design was used. Data collection was performed using unstructured interviews in the dialysis center or in patient’s homes. Single interviews with 5 patients receiving hemodialysis treatments in a free standing dialysis center were tape recorded with permission from the informants, transcribed verbatim, and analyzed with the assistance of Van Manen’s phenomenological methods. The overall theme of “acceptance” and three subthemes “positive outlook,” “family life,” and “involvement in care.” found this study support Roy’s Adaptation Model. All participants had learned to cope, and incorporate strategies to control complications associated with ESRD and manage productive lives. Early identification of the individual needs and effective coping skills and strategies should be included in the care plan of all hemodialysis patients on a regular schedule.