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IDENTIFYING PATIENT'S REASONS OR RATIONALE FOR CHOOSING TO SKIP
OR SHORTEN HEMODIALYSIS

A Thesis Submitted
In Partial Fulfillment
of the Requirements for the Degree of
Master of Science in Nursing
at Minnesota State University, Mankato

by
Linda M. Lindberg

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July 3, 2012

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ABSTRACT

Missed dialysis treatment time has potential to increase morbidity and mortality and reduce life expectancy for people with End Stage Renal Disease (ESRD) who are dependent on hemodialysis (HD) to live. The purpose of this study was to identify some of the reasons that hemodialysis patients provide when explaining their decision to skip or shorten their prescribed HD treatment time by providing ESRD patients with the opportunity to give voice to their perspectives. A secondary purpose of this project was to increase the health care provider's understanding of the HD patient's perspectives and reasons for choosing to skip or shorten their prescribed HD treatment time. A qualitative study design was utilized to provide HD recipients an opportunity to share their reasons for choosing to skip or shorten prescribed dialysis time. Nine in-center hemodialysis patients from mid Minnesota contributed their perspectives via a semi-structured interview. The dialysis patient's right to self-manage their health care and the theory of self-efficacy was used to guide this study. The most common theme identified for choosing to decrease dialysis time was discomfort or illness (66%). Other themes expressed as reasons that dialysis treatments are missed or shortened were 'events beyond my control' (55%), 'its my choice' (44%), anger and/or depression (33%), anxiety (22%), and lack of transportation (22%). Perspectives about the experience of living on dialysis were also shared. Consideration of these results may increase the health care provider's ability to offer pertinent education and support and potentially improve adherence to an adequate HD dialysis treatment prescription with the ultimate goal being to reduce morbidity and mortality for persons with ESRD.

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CHAPTER I

INTRODUCTION

End stage kidney disease (ESRD) is a complex chronic illness that greatly alters the lives of the individuals and families of those afflicted. According to the Centers for Disease Control and Prevention (CDC), kidney disease is the ninth leading cause of death in the United States (US) (CDC, 2010). The focus of health care for chronic conditions, such as kidney disease, is on “controlling progression of the condition, increasing (duration of) survival, and enhancing quality of life” (Sabate, 2001, p. 12). Adherence to treatment and management recommendations is essential for optimal health and survival of persons with ESRD (Saran et al., 2003; Wells, 2011). Over 400,000 Americans suffer from ESRD and require dialysis or kidney transplantation to live (Centers for Medicare & Medicaid Services [CMS], 2011a). The most common type of dialysis in the US is ‘in-center hemodialysis’ (ICHD) which is typically prescribed as a three times per week treatment. According to the U.S. Renal Data System (USRDS) (2011), on December 31, 2009, there were 370,274 people receiving hemodialysis (HD) in the US.

The lifestyle of persons undergoing dialysis is greatly affected by the treatment regime. Living with ESRD and the complex treatment regimen may result in daily physical symptoms and “relentless uncertainty about life” (Costantini, 2006, p. 22). To survive and remain as healthy as possible, persons with ESRD are advised to modify their diet, limit their fluid intake, take multiple medications, and endure regular dialysis treatments to remove toxins and excess fluid from their body. For someone with ESRD the dialysis treatments must continue routinely until the person receives a kidney

transplant or dies. Discontinuation of dialysis in persons with ESRD results in death in an average of 7-10.5 days (Rich, Ellershaw, & Ahmad, 2001). The duration of each ICHD treatment most commonly ranges from 3 to 5 hours. Dialysis treatment duration is prescribed by the nephrologist and is determined by several factors including the patient's body size, gender, age, race, residual renal function, comorbid conditions, type of dialysis access, blood flow rate, and dialyzer used.

Research has shown that as many as 50% of persons with ESRD treated by HD do not adhere to their recommended treatment regime (Batson & Schwartz, 1999a; Kammerer et al., 2007; Kutner, 2001). Leggat et al. (1998) used the USRDS data to establish criteria for assessing components of HD treatment nonadherence to include skipping one or more dialysis sessions a month or shortening at least one dialysis treatment a month by ≥ 10 minutes. These definitions were also followed by Saran et al. (2003) in a large, retrospective study on nonadherence in HD using the Dialysis Outcomes and Practice Patterns Study (DOPPS) data. Leggat et al. (1998) and Saran et al. (2003) found that 7.9 to 8.5% of HD patients skipped treatments and 19.6 to 20% shortened their treatments. Leggat et al. (1998) and Saran et al. (2003) concluded that the risk of death was 25 to 30% higher for patients who skipped one or more treatments per month and the relative risk of mortality was 11% to 20% higher for patients who shortened three or more dialysis treatments a month. Skipping one or more HD treatment per month increases the hospitalization and mortality risk more than other measures of nonadherence including shortening treatments, elevated phosphorus (a measure of dietary nonadherence), and excessive interdialytic fluid weight gains (Saran et al., 2003). In addition, for multiple reasons, more than 10% of HD patients do not meet the

recommended minimum goals for an adequate dialysis (Life Options, 2004). One measurement of adequate dialysis is a urea reduction ratio (URR) of at least 65% per treatment (NIDDK, 2009). Inadequate dialysis, as measured by a low URR, also increases risk for hospitalizations and death.

Increased time between treatments has been linked with increased mortality. Bleyer, Russell, and Satko (1999) analyzed 20 years of data collected by the USRDS from 1977 to 1997, and found there was a higher incidence of sudden cardiac death on Mondays and Tuesdays in HD patients, especially those with dilated cardiomyopathy, cardiac arrhythmias, coronary artery disease, or congestive heart failure. Factors thought to contribute to the higher incidence of sudden cardiac death on Mondays and Tuesdays included circulatory system volume overload and hyperkalemia after the two days over the weekend without dialysis. Skipping dialysis treatments has the potential to result in increased circulatory system overload or hyperkalemia even greater than occurs on the weekend due to the increased length of time between treatments. The increased morbidity and mortality risk may be secondary to increased cardiac burden from volume overload, retention of fluid, and the buildup of potassium and metabolic waste, but choosing to skip dialysis time may be just one reflection of a pattern of decreased health maintenance behaviors or a lifestyle that increases risk of life-threatening events. It is important for dialysis patients to be aware of these kinds of risks because understanding the reasoning behind recommendations increases probability for adherence (Batson & Schwartz, 1999a).

“Poor adherence attenuates optimum clinical benefits and therefore reduces the overall effectiveness of health systems” by decreasing the effectiveness of treatments,

thereby increasing morbidity and costs (Sabate, 2003, n.p.). The World Health Organization (WHO) report titled “Adherence to Long-Term Therapies” advised looking beyond blaming individuals or health-care providers (HCPs) for a lack of adherence and instead consider “systematically tackling the many barriers patients and their families encounter as they strive daily to maintain optimal health” (Sabate, 2003, n.p.).

Successful management and survival with chronic disease requires that the afflicted person “take responsibility for many aspects of their own treatment on a regular and long-term basis” (Kammerer et al., 2007, p. 480). One of the strategies recommended by the WHO to improve adherence to long term therapies of chronic disease management is “providing care that is respectful of patient preferences, and ensuring that patient values guide all treatment decision-making” (Sabate, 2001, p. 12).

Understanding the perspectives of the dialysis patients is imperative for HCPs to be able to partner with these patients in ways that promote optimal self-management and to develop effective interventions that encourage adherence to the recommended treatments and health management strategies. Improved understanding is required before interventions are implemented to increase acceptance of “presumably beneficial therapeutic regimens” (Kutner, 2001, p. 326). “Effective treatment relationships are characterized by an atmosphere in which alternative therapeutic means are discussed, the regimen negotiated, adherence discussed, and follow-up planned” (Sabate, 2001, p. 7). HCPs and the treatment environment need to “be positive and inspire hope and trust” (Batson & Schwartz, 1999b, p. 58). “The (HCP) may be an expert in diagnosing an illness . . . but the patients are experts on their own issues and the activities of daily

living, including factors that enable them to carry out a treatment plan and barriers that may interfere with it” (Berger, Krueger, & Felkey, 2003, p. 50).

Adherence to recommended treatments, medication regimens, and other health care interventions and recommendations has long been of great concern to HCPs. Most HCPs strive to promote the patient’s and family’s self-efficacy and responsible personal management of their health needs. It is discouraging and frustrating when patients seem to purposefully choose to disregard recommended health care advice. Enhanced understanding of the patient’s rationale and perspective may improve the HCPs’ ability to create strategies that improve a patient’s ability to adhere to health care recommendations.

Problem Statement

Skipped or shortened HD treatments decrease adequacy of HD and have potential to increase morbidity and mortality of persons with ESRD. This problem impacts individuals, families, caregivers, community, and systems in far-reaching ways including increased financial burdens to the individual and society and potential negative effect on physical, psychological, and social well-being of dialysis patients and their family members.

Beginning January 1, 2012 the Centers for Medicare Services (CMS) payment to dialysis facilities for ICHD treatments provided to Medicare beneficiaries will be reduced if quality indicators (including a measure of the adequacy of a dialysis treatment: $URR \geq 65\%$) are not met by at least 96% of that dialysis facility’s patients (Centers for Medicare & Medicaid Services, 2011b). A reduction of reimbursement has the potential to decrease the viability of a dialysis unit and to reduce the resources available to the

dialysis HCP, potentially lowering the quality of care provided. Skipped or shortened HD treatments have the potential to reduce the adequacy of HD as measured by the URR and increase morbidity and mortality for persons with ESRD.

Purpose

The purpose of this qualitative study was to identify some of reasons and perspectives related to HD patients' choosing to skip or shorten their prescribed HD treatment time by providing ESRD patients with the opportunity to give voice to their perspectives. A secondary purpose of this project was to increase the HCP's understanding of the HD patient's perspectives and reasons for choosing to skip or shorten their prescribed HD treatment time. This information may provide opportunity to design interventions that promote treatment adherence and/or provide health care providers with greater understanding of, and respect for, decisions to skip or shorten treatments. "Preliminary research on self-management suggests that when practitioners include the patients' beliefs, values, and concerns into the recommended treatment regimen, CKD (chronic kidney disease) client outcomes are improved" (Costantini, 2006, p. 22).

Assumptions

The following assumptions were made prior to the implementation of this study:

1. Participants recognize the importance of following the recommended dialysis treatment regimen. Participants who choose to shorten or skip their dialysis treatments realize that HCPs believe these actions can increase the dialysis patient's potential for illness or death.
2. The participants want to continue living and to be as healthy as possible.

3. The participants will provide honest responses to researcher's questions.

Research Question

What reasons do hemodialysis patients describe in explaining their rationale for choosing to skip or shorten in-center hemodialysis treatments?

Relevance

Missed dialysis treatment time increases morbidity and mortality and reduces life expectancy for dialysis patients (Leggat et al., 1998; Saran et al., 2003). Increased morbidity can decrease quality of life and raise health care costs due to increased hospitalizations and health complications. The CMS Quality Incentive Program (QIP) has implemented a change in the way dialysis services are reimbursed by CMS from a 'composite rate plus separately billable items' to a 'bundled prospective payment system' (PPS) (Centers for Medicare & Medicaid Services, 2011a). This ESRD QIP adjustment in dialysis reimbursement (a maximum 2% penalty if the facility fails to meet or exceed a total performance score for certain measures) applies to services provided on or after January 1, 2012 and links CMS payment for dialysis services to the quality of care provided by each facility as measured by how well a dialysis facility meets or exceeds certain performance standards.

“For those facilities that fail to meet or exceed the established performance standards, payment reductions will apply to all outpatient dialysis services and items furnished to Medicare beneficiaries by that facility including dialysis treatment, prescription drugs, and clinical laboratory tests and will remain in effect for the duration of payment year 2012” (Centers for Medicare & Medicaid Services, 2011b, n.p.).

This total performance score is reduced if at least 96% of the program's Medicare patients receiving ICHD treatments do not achieve the industry determined URR best practice goal of $\geq 65\%$ (Centers for Medicare & Medicaid Services, 2011b). This payment system has the potential to greatly impact the financial reimbursement for HD services to dialysis facilities as Medicare is a primary payer for the majority of dialysis treatments. According to the 2009 data, "Medicare was the primary payer for 83% of hemodialysis patients" (USRDS, 2011, p. 184).

In addition, the nationally recognized National Kidney Foundation's 2006 kidney disease outcomes quality initiative (NKF KDOQI) guidelines recommend that dialysis units monitor and minimize the occurrence of skipped or shortened dialysis treatments. "Measurement of fractional urea removal during a single dialysis treatment obviously is not a monthly average of dialysis adequacy and has validity only if dialysis treatments are delivered reliably 3 times per week on a regular basis" (National Kidney Foundation, 2006, Guideline 4). This important document notes that "a number of studies suggested that poor compliance in HD, especially in terms of number of missed treatments, is an important predictor of mortality and hospitalizations" (National Kidney Foundation, 2006, Guideline 4.3). Increased awareness and understanding of patient's reasons for choosing to skip or shorten dialysis treatments will increase the HCP's ability to offer pertinent education and support and potentially improve adherence to the recommended ICHD adequate dialysis treatment prescription with the ultimate goal being to reduce morbidity and mortality for persons with ESRD.

Definition of Terms

Hemodialysis or HD: A treatment which removes metabolic waste and excess fluid from the blood via a dialyzer and dialysis machine. HD is a life preserving treatment for persons who have ESRD.

Hemodialysis patients: Persons with end-stage-renal disease who undergo routine hemodialysis to survive.

ICHD: In-center HD: HD that is provided in a facility (not at home).

Limitations

ESRD is a unique chronic illness requiring intense treatment and lifestyle modifications. In addition to the characteristics of the ESRD illness, each patient is unique. Findings may not be transferable to other dialysis patients or persons with other chronic illnesses.

A small number of patients were studied and all of these patients received their HD treatments in units from one Central Minnesota provider in mostly rural settings. Findings from this study may not be comparable to other individuals, populations, or locations.

The information was gathered during an isolated one time interview. Longitudinal data gathered at different months would provide more data relevant to other seasons and variables.

Theoretical Framework

The theory of self-efficacy served as the conceptual framework for this project. Self-efficacy theory involves self-management and is based on Bandura's Social Cognitive Theory (published in 1977) which "delineates the patient's confidence in their

ability to participate in behaviors related to goals” (Costantini, 2006, p. 23). This theory is founded on the belief that “what people think, believe, and feel will affect their actions and ultimately how they behave” and freedom to choose is fundamental to the theory (Peterson & Bredow, 2009, p. 118). The self-efficacy concept defines self-management as “the patients’ positive efforts to oversee and participate in their health care in order to optimize health, prevent complications, control symptoms, marshal medical resources, and minimize the intrusion of the disease into their preferred lifestyles” (Costantini, 2006, p. 23). People’s perceptions of their ability to perform certain actions provides the basis for their personal motivation, well-being, and sense of accomplishment and is most effectively influenced by the individual’s interpretation of previous actions and accomplishments but self-efficacy can also be developed by “social persuasions,” or support by others (Peterson & Bredow, 2009, p. 117). Thus, the theory of self-efficacy suggests that most human behavior is determined by both intrinsic and extrinsic factors (Peterson & Bredow, 2009).

Costantini (2006, p. 23) recommended that practitioners “facilitate (the HD patient’s) self-management strategies by asking individuals with kidney disease to describe what they believe needs to be addressed to successfully manage their illness” to promote a shared understanding between patient and HCPs. This concept empowers patients by allowing them to express their perspective and beliefs. Support of self-efficacy offers patients greater dignity and control over their renal failure regimen “and allows individuals to actively utilize their chronic illness expertise” (Costantini, 2006, p. 23).

Summary

ESRD is a challenging chronic illness with demanding management and treatment strategies. This chapter contained an introduction to kidney failure, HD, and the importance of adhering to treatment recommendations. In addition, the statement of the problem of skipped dialysis treatment time, research question, relevance of skipped dialysis treatments, and definition of terms relevant to the research issue were discussed. The theory of self-efficacy was briefly introduced as the framework for this study.

CHAPTER II

REVIEW OF THE LITERATURE

The purpose of this study was to identify some of reasons and perspectives HD patients' use to explain their decision to skip or shorten their prescribed HD treatment time. A secondary purpose of this project was to increase the HCP's understanding of the HD patient's perspectives and reasons for choosing to skip or shorten their prescribed HD treatment time. The CINAHL plus, Cochrane plus, and Medline databases were employed to find previous literature using the search words: hemodialysis, end stage renal disease, adherence, compliance, adequacy, missed dialysis treatments, and skipped dialysis treatments. Further articles of interest were located using the reference list of the initial articles. This review of literature is organized into six sections: adherence and ESRD, the experience of CKD, characteristics of nonadherence to HD, impact of nonadherence to HD, measuring nonadherence in HD patients, and interventions to improve adherence.

Adherence and ESRD

Multiple authors cited the difference between compliance and adherence as compliance being an 'obedience based approach' and adherence being more of a 'therapeutic alliance' between the patient and the HCP (Batson & Schwartz, 1999a; Kammerer et al., 2007; Sabate, 2003) in which the goals of therapy are negotiated (Berger, Krueger, & Felkey, 2003). Adherence is critical to the efficacy of medical recommendations and treatments (Kammerer et al., 2007). Most authors agree with the idea of advocating the concept of 'adherence' versus 'compliance' and that HCPs need to encourage a partnership between the patient and the HCP to facilitate obtaining optimal

treatment and health (Kammerer et al., 2007). Still, it is not uncommon to see the term ‘compliance’ used interchangeably with the term ‘adherence,’ especially in older literature.

Leggat et al. (1998) conducted a large retrospective study using USRDS data which included information on 6,251 HD patients. Results included that 8.5% of patients skipped HD and 20% shortened HD treatments (Leggat et al., 1998). These results contrast to 10% occurrence of skipped treatments and 5.4% occurrence of shortened time in the 168 HD patients studied by Gordon, Leon, and Sehgal (2003). A large cross-sectional study in Belgium and Germany measured nonadherence in 916 HD patients by surveying diet and fluid nonadherence with a self-report instrument, the Dialysis Diet and Fluid Non Adherence Questionnaire (DDFQ), and also complementary use of laboratory results and interdialytic weight gain (Kugler, Vlaminck, Haverich, & Maes, 2005). The results indicated that as many as 81.4% of HD patients have difficulty following the challenging HD dietary restrictions and 74.6% of the participating patients struggled with HD fluid restrictions.

The Experience of CKD

A qualitative study by Molzahn, Bruce, and Sheilds (2008) described the experience of liminality associated with CKD and its treatment. Liminality is the concept of uncertainty and transition and is presumed to be present when a life threatening illness, such as CKD, occurs. Stories of people with kidney failure (that had been originally gathered into a book compiled by the Dialysis and Transplant Units of the Royal Victoria Hospital) were analyzed and several liminal spaces including descriptions of “living/not living, independence/dependence, restrictions/freedom, normal/not normal, worse

off/better off, and alone/connected” were identified (Molzahn et al., 2008, p. 16). These authors noted that “liminal spaces invite complexity” (p. 18) to a treatment experience that is “simultaneously (ab)normal and (in)dependent.” (p. 18). For example, those persons who felt supported by family and HCPs commented that they felt less alone although some patients described feeling alone even “within their circle of support” (Molzahn et al., 2008, p. 18). Awareness of the experiences of liminality provides insight to the perceptions of the dialysis patient and offers HCPs an opportunity to become sensitive of the multiplicity of the experience for each patient. Molzahn et al. (2008) recommended that “nurses recognize the uniqueness of each person and the possible range of experiences with CKD, rather than assuming that everyone follows a specific pattern or trajectory” (p. 19).

Characteristics of Nonadherence to HD

Similarities have been found in the characteristics of patients who skip or shorten hemodialysis treatments. In a retrospective study by Leggat et al. (1998) USRDS data on 6,251 HD patients was analyzed. African Americans, persons aged 20-39, and smokers were “significantly more likely to skip HD than whites, persons aged 40-59, and non-smokers” (Leggat et al., 1998, p. 139). Being young and male was found to be predictive of nonadherence by Kugler et al. (2005). Being young, African American, or male were predictive of increased occurrence of skipping or shortening treatments according to Gordon et al. (2003). Similar characteristics were identified in a large retrospective study of nonadherence in HD using the DOPPS data of 14,930 patients in the United States, Europe, and Japan. Conclusions included that living in the U.S.A., young age, African American ethnicity, smoking, and time on dialysis were associated with an increased

incidence of skipping or shortening dialysis (Saran et al., 2003). Skipping or shortening HD treatments was found to be much more common in the US than in Europe or Japan (Saran et al., 2003). Depression and time with ESRD in years were also found to be predictors of skipping or shortening HD treatments.

Kim and Evangelista (2010) studied the relationship between illness perceptions and treatment adherence on 151 HD patients for a 1 month period of time. Study results showed that 20.5% of the participants described difficulty remaining for their entire dialysis time. The attendance rate for the month of evaluation was 90.7% and 15.9% of the prescribed HD treatments were shortened by patient choice. Older age was associated with a higher adherence to treatment and negative perceptions of illness had a negative correlation to adherence to diet but did not predict potential to skip or shorten treatments in this study.

By analyzing results from interviews with HD patients who had a history of skipping or shortening treatments (N=168), Gordon et al. (2003) concluded that patients cite reasons for shortening or skipping HD treatment from five main categories: medical problems, technical problems, life tasks, transportation, and patient decision. The most common reasons reported for shortening treatments were medical problems (38%) and life tasks (24%). The most common reasons for skipping treatments were life tasks (33%) and transportation (22%). Technical problems were more common among women; life tasks were more common among men, younger patients, and those with hypertension; transportation problems were more common among African Americans (Gordon et al., 2003). Other patient-related factors for nonadherence included resources, knowledge and beliefs about the illness, motivation to manage the illness, confidence

about their ability to engage in illness management behaviors (self-efficacy), attitudes, perceptions and expectations of the patient regarding the outcome of the treatment and the consequences of nonadherence (Kammerer et al., 2007).

Managing the variety of complex health issues caused by ESRD places many complicated and unavoidable demands on the patient's daily life (Saran et al., 2003). Higgins (2006) cited the following barriers to adherence for persons on HD: perceptions of chronic illness, depression, health beliefs and locus of control, and situational factors. Higgins asserted that people with ESRD struggle with their loss of a 'normal life' and that their "perception of their situation will determine whether they will adhere to medical regimens" (p. 28).

Impact of Nonadherence to Hemodialysis

A large retrospective study utilizing USRDS data from 12/31/1990 to 12/31/1993 by Leggat et al. (1998) established criteria for assessing components of HD treatment adherence to include skipping one or more dialysis sessions a month or shortening at least one dialysis treatment a month by ≥ 10 minutes. Results by Leggat et al. (1998) showed that HD patients who skipped one or more HD session in a month had a 25% higher risk of death than other groups of HD patients. Those who shortened three or more treatments in a one-month time period had a 20% higher risk of death (Leggat et al., 1998). Saran et al. (2003) had similar conclusions reporting that the risk of death was 30% higher for patients who skipped one or more treatments per month and the relative risk of mortality was 11% higher for patients who shortened three or more dialysis treatments a month. Increased time between dialysis, such as occurs on weekends or when HD treatments are skipped, results in higher fluid weight gains and metabolic imbalances that have potential

to be especially detrimental to persons with cardiac arrhythmias, congestive heart failure, or coronary artery disease (Bleyer et al., 1999). Poor adherence, particularly by persons with CKD, has significant “medical, social, and economic consequences” (Kammerer et al., 2007, p. 479). “Nonadherence leads to individual suffering for patients and their families and an economic expense for society” (Higgins, 2006, p. 28).

Measuring Nonadherence in Hemodialysis Patients

Common criteria used to measure adherence to ESRD medical recommendations include skipping one or more dialysis treatments per month, shortening one or more dialysis treatments a month by 10 or more minutes, serum potassium level ≥ 6.0 mEq/L, a serum phosphate level > 7.5 mg/dL, or high interdialytic fluid weight gains measured as gaining $> 5.7\%$ of body weight between dialysis treatments (Leggat et al., 1998; Saran et al., 2003). “How well patients on dialysis are managing their care can be assessed using many parameters . . . (including) regular attendance at hemodialysis sessions” (Kammerer et al., 2007, p. 480).

Interventions to Improve Adherence

Adherence interventions used by the nursing profession are divided into three main categories by Breiterman White (2004): (a) removal of barriers, (b) educational efforts, and (c) targeted attention. Identification of barriers can occur by interviewing the patient including assessment of social, physical, treatment, and other barriers to adherence. Targeting these barriers and providing education is important as “education alone provides short-lived benefit” (Breiterman White, 2004, p. 434). Encouragement, respect for the patient’s opinion, and assisting patients in recognizing how nonadherence personally affects them will support behavior change, but it is important to realize that

“80% of people who attempt behavioral change will fail the first time” requiring ongoing persistence and encouragement to try again (Breiterman White, 2004, p. 435).

Factors that enhance adherence include: family support, knowledge of the benefits of following recommendations, education, and professional support (Higgins, 2006).

“Patients without family support have a three times greater mortality risk than those with support” (Higgins, 2006, p. 29). Findings by Saran et al. (2003) included that an increase in highly trained staff (trained nurses) lowered the odds of patients skipping treatments and larger facilities (> 75 patients) had an increased likelihood for patients skipping treatments. HD patient support and education, from nurses and other HCPs, related to tangible health benefits can result in improved adherence, but it is vital that HCPs seek to understand the difficulties and feasibility of adherence to treatment for each patient (Higgins, 2006).

A psychology-related approach to encouraging treatment adherence is offered by Batson and Schwartz (1999b) and includes strategies to increase adherence such as making the experience and setting more pleasant and improving communication between the HCP and the patient. Batson and Schwartz (1999b) advise a personal and public relations campaign in which the patients are made to feel welcome and respected by friendly supportive staff and in which HCPs develop a strong visible community presence. This approach aims to improve the public’s understanding of renal disease, thereby enhancing public support, and also provides the patient with increased support at the dialysis center. They also recommend the use of patient satisfaction surveys to gain further information and insight from the patients. Positive HCPs and positive culture of

the treatment center “inspires hope and trust” (Batson & Schwartz, 1999b, p. 58) which can encourage adherence.

The multiple difficult regimens recommended for successful management of ESRD and adherence to treatment recommendations involves much self-discipline by the patient and the ability to redesign their life to accept their “new way of being in the world” (Higgins, 2006, p. 28). Assessment of barriers to adherence requires non-judgmentally asking patients about nonadherence. This approach offers patients an opportunity to discuss their reasons for nonadherent behavior and improves potential for HCPs to partner with patients to help them set and achieve goals (Kammerer et al., 2007). These authors advise encouraging patients to be involved in their own care by avoiding blame and offering support. In addition, increased awareness of predictors of non-adherence, such as younger age or smoking, may help HCPs identify individuals who might benefit from specific interventions to encourage adherence (Kutner, 2001).

A randomized controlled study of self-efficacy training for persons with ESRD was conducted with 62 dialysis patients in Taiwan (Tsay, 2003). Half of the patients (n=31) participated in an intervention of 12 self-efficacy training sessions based on Bandura’s self-efficacy theory while the other patients (n=31) served as the control group and received routine care. Interdialytic fluid weight gain was the only measurement. The intervention group was found to have a statistically significant reduction in fluid weight gain over a 6-month period. This study supported the use of self-efficacy training for promotion of confidence in the ability to achieve positive adherence behaviors in HD patients (Tsay, 2003).

Motivational interviewing (MI) has become a popular strategy for encouraging patients to change potentially harmful behaviors (McCarley, 2009). This technique promotes respect for the patient's ability to determine their own health care. McCarley (2009) endorsed the use of MI to empower and engage dialysis patients to create a partnership with the HCP in ways that can help the patients achieve their personal goals. Russell et al. (2011) performed a pilot study incorporating MI interventions over a 3-month period to 29 participants. The results of their study indicated that MI appeared to have a positive influence on improving dialysis attendance and reducing frequency of shortening treatments.

A significant statement by Gordon et al. (2003) was that "although health care professionals tend to place health as a primary value in life, it is important to recognize that other values can take precedence in patients' lives, including the family, identity, occupation, and religion" (p. 216). Determining patients' reasons for skipping or shortening treatments and developing interventions that target those reasons is advised. Gordon et al. asserted that increased understanding and "communication about patients' and HCPs' treatment goals can facilitate the development of a treatment plan that accommodates medical and patient values" (p. 216). Gordon et al. (2003) recommended that consideration be given to the reasons that patients choose to go against health care advice instead of assuming that all skipped treatment time represents nonadherence .

Summary

This chapter contained a review of the literature related to HD patients' adherence to treatment recommendations, especially as related to skipping or shortening dialysis treatment time. There are many articles related to adherence to the challenging regimens

recommended to minimize morbidity and mortality in this complex chronic illness.

HCPs should seek to understand the patient's perspective and goals and to partner with them to address this concern.

CHAPTER III

RESEARCH METHODOLOGY

The purpose of this study was to identify some of the reasons that HD patients use to explain their decision to skip or shorten their prescribed HD treatment time by providing ESRD patients with the opportunity to give voice to their perspectives. A secondary purpose of this project was to increase the HCP's understanding of the HD patient's perspectives and reasons for choosing to skip or shorten their prescribed HD treatment time. All participants were HD patients at one of the CentraCare outpatient HD units. This chapter includes a description the study design, sample, protection of human subjects, measurements, data collection procedure, and data analysis. The process for analysis of the data will also be discussed.

Design

A qualitative research design was used to gather information from participants about their reasons for skipping or shortening dialysis treatments. The student researcher met with consenting hemodialysis patients to conduct a semi-structured interview in an attempt to gain their perspectives and rationales related to skipping prescribed HD treatment time. Qualitative research designs have been described as useful approaches to gather this type of personal data with the goal of increasing understanding human experiences (Polit & Beck, 2004).

Sample

A convenience sample of nine patients with ESRD who receive their HD treatments in any CentraCare outpatient ICHD unit and who have chosen to shorten or skip dialysis treatments during the months of January 2012, February 2012, or March

2012, or not achieved HD clearance goals (as defined by URR) at least once in those three months due to personal choice to dialyze at a duration less than medically advised to meet treatment adequacy goals participated in the study. The student researcher asked dialysis Charge Nurses and Social Workers to identify patients who meet study criteria: HD patients who have...

- (a) skipped one or more dialysis sessions in the 12 week study period,
- (b) shortened a dialysis session by ≥ 10 minutes in the 12 week study period, or
- (c) who consistently dialyze less than the recommended dialysis frequency or duration due to personal choice to have a shorter dialysis duration every treatment.

Additionally, participants needed to speak and communicate in English as inability to communicate in English would have prohibited the researcher from interviewing the patient (use of interpreter services were avoided due to cost). Patients with cognitive disabilities were excluded from the study. The participant's provided written consent to take part in study prior to the student researcher receiving notice of their willingness to be interviewed.

Protection of Human Subjects

The student researcher received approval from the Minnesota State University, Mankato, Institutional Review Board (IRB) and the St. Cloud Hospital IRB. Following IRB approval (see appendix A), the student researcher sent an e-mail (appendix B) to the Charge Nurses and Social Workers from the nine CentraCare outpatient HD units to explain the project and enlist their assistance with approaching patients who meet the sample criteria and were potential study participants (as explained in the sample section of this thesis on page 22). This process was done to protect the confidentiality of the

potential participants as the student researcher did not have information about the patients until the signed consent form was obtained by either the dialysis unit Charge Nurse or Social Worker. The Charge Nurses and Social Workers were given an algorithm (appendix D) outlining the criteria for potential participants and a packet of forms to give to each participant which included two copies of the consent form (which contained an explanation of the study) and an envelope addressed to the student researcher . The Charge Nurses and Social Workers were asked to approach potential participants, provide an overview of the project, and invite them to participate (see proposed script in appendix B).

If the patient was interested, the Charge Nurse or Social Worker gave the potential participant the packet of forms. The participant was asked to return one consent form to the dialysis Charge Nurse or Social Worker (the other consent form was to be kept by the participant). The Charge Nurse or Social Worker advised the student researcher by e-mail or phone when a patient had signed consent to participate and it was determined if the consent would be sent to the student researcher by interdepartmental mail or if the student researcher would pick up the consent form. Once the consent had been signed by a participant the student researcher called the participant (using the phone number provided on the consent form) to arrange an interview with the participant for collection of qualitative data.

During the recruitment process the potential participants were informed on the written consent of the intent of the study, potential risks to them, and their rights regarding participation (see consent in appendix C). No names were used in the data. All participants were only identified by a subject number in the thesis data. Any personal

information that was obtained in connection with this study remained confidential and will be available only to the student researcher and the advising faculty members. No individual data will be identifiable in any report or publication. Participants were informed that they may withdraw from the study at any time and discontinue participation without penalty. Participants were also advised that they were not waiving any legal claims or rights because of their participation in the study. In addition, this information was included on the consent form.

Participants were informed of potential risks which included anxiety about being included in the study, and fatigue or added stress related to completing the consent form or talking with student researcher. Risks were minimized by having participants complete the consent form and interview at a time and place that was convenient for them. This was accomplished by including a section on the consent form for the participant to write a phone number that the student researcher could use to contact the participant to discuss participant preference for the interview location (at the dialysis unit or on the phone) and to make arrangements for the interview.

Potential benefits to the participant of the study included personal satisfaction of the participant by knowing that the information they provided may help themselves and other HD patients through improved understanding by the HD HCP of the concerns and priorities of persons undergoing HD. There was no monetary reward for participation. Also, there was no direct negative effect to potential participants if they chose not to participate. Their dialysis services at CentraCare were not interrupted in any way.

The signed consent forms were kept in a locked drawer in the student researcher's CentraCare office until the completion of the thesis. Then the consent forms will be kept

in a secure area at MSU- Mankato for the required three year time period and then the consent forms will be destroyed.

Measurement

A semi-structured investigator-developed interview was used to collect data for this project. Confidentiality was maintained by having the signed consent form returned to the dialysis Charge Nurse or Social Worker in a sealed envelope. The Charge Nurse or Social Worker notified the student researcher as described in the ‘Protection of Human Subjects’ section of this paper (page 23) so arrangements could be made for student researcher to pick up the documents. The interviews were arranged as described in the ‘Protection of Human Subjects’ section of this paper (page 23), and occurred while the patient was receiving dialysis or on the telephone, per patient preference. The format of the semi-structured interview is described in appendix E of this paper. Privacy was maintained in the dialysis unit by using the barrier devices available in the unit (example: curtains, headphones on surrounding patients). The interviews were audio recorded for later transcription. The audio recordings were transcribed verbatim by the student researcher. The audiotapes and transcriptions were kept in a locked drawer in the office of the student researcher until after completion of the project. Then the documents and tapes were transported by the student researcher to the primary investigator, Dr Marcia Stevens. The documents and tapes will be kept in the office of Dr. Marcia Stevens, at Minnesota State University, Mankato, Wissink Hall, Room #360, for 3 years. After 3 years the transcription documents will be shredded and the audiotapes will be destroyed in a recycle location. Any personal information that was obtained in connection with this study will remain confidential and will be available only to the student researcher and the

advising faculty members. Confidentiality was maintained by using a number assigned to each subject. No names were used except on the consent form. No individual data will be identifiable in any report or publication.

Data Collection Procedure

Charge Nurses and Social Workers in CentraCare ICHD units were asked to identify potential study participants (patients who had skipped or shortened their HD treatment time during the months of January, February, or March 2012) and approach these patients to invite them to participate in the study. If the patient was interested, the Charge Nurse or Social Worker gave them the consent forms. The potential participant was asked to review the consent form. If they agreed to participate in the study, they were asked to return a signed consent form in a sealed envelope to the dialysis Charge Nurse or Social Worker who notified the student researcher. Arrangements were made for the student researcher to pick up the consent or receive it through CentraCare interdepartmental mail. The Charge Nurse or Social Worker was asked to disclose the number of potential participants who were approached but who declined participation so the student researcher could include this information in the research data.

Consenting participants were asked to choose if they preferred that the student researcher meet with them at the HD unit or call them on the telephone to talk about their perspective and past reasons for skipping or shortening their dialysis treatments. The participants were given an opportunity to choose which method of talking with the student was preferable to them when the student researcher called them to arrange the interview using the phone number provided by the participant on the consent form. During the arranged interview, the student researcher asked patients in a nonjudgmental

way what motivates their behavior (Kammerer et al., 2007) and allowed patient to share their rationale and reasons for skipping or shortening dialysis. Please see the appendix E for the interview format that the student researcher used to gather qualitative data when interviewing consenting participants. The semi-structured interviews were audio recorded for transcription. After data gathering, the participants were encouraged to have further discussions with their dialysis team about anything that might be affecting their ability to obtain adequate dialysis and to not hesitate to ask their HCPs for further education on any topic of concern to the participant.

Data Analysis

The qualitative data collected during the interview was transcribed verbatim by the student researcher and then coded and categorized into themes using content analysis procedures (Polit & Beck, 2004).

Summary

This chapter provided an explanation of the study design, sample, setting, and ethical considerations. The instruments were introduced including the consent form and the semi-structured interview format. Details of the data collection procedure and analysis were discussed.

CHAPTER IV

ANALYSIS OF DATA

The purpose of this study was to identify some of the reasons that HD patients provide when explaining their decision to skip or shorten their prescribed HD treatment time by providing ESRD patients with the opportunity to give voice to their perspectives. A secondary purpose of this project is to increase the HCP's understanding of the HD patient's perspectives and reasons for choosing to skip or shorten their prescribed HD treatment time. A secondary purpose of this project was to increase the HCP's understanding of the HD patient's perspectives and reasons for choosing to skip or shorten their prescribed HD treatment time. This chapter contains an overview of the data analysis. A description of the sample and the findings are presented. The findings are summarized and the chapter concludes with a discussion of the findings.

Description of Sample

A convenience sample of eleven patients with ESRD who received their HD treatments in one of the central Minnesota CentraCare outpatient ICHD units and who met the criteria were invited to participate in the study using the recruitment procedures identified in Chapter III of this paper. The criteria included having chosen to shorten or skip dialysis treatments during the months of January 2012, February 2012, or March 2012, or not achieved HD clearance goals (as defined by URR) at least once in those three months due to personal choice to dialyze at a duration less than medically advised to meet treatment adequacy goals. Ten of those potential participants agreed to be interviewed although one potential participant was hospitalized during interview process so was not available for interview. The student researcher offered nine participants a

choice to complete the interview through a direct meeting with the student researcher while the participant was receiving dialysis or on the telephone, per participant preference. Five (55%) of the participants were interviewed by telephone, and four (44%) were interviewed in person while they were receiving their HD treatments. These interviews occurred in three of the CentraCare ICHD units. Demographic data of the participants is described on Table 1.

Table 1. Demographic data of study participants

N=9 participants	Years on dialysis			Age in years			Gender		Race			
Interviewed at the dialysis unit=4	2	< 2 years	0	40-49	1	Female	4	Caucasian				
	2	2-5 years	4	50-59	3	Male	0	African American				
	0	>5 years										
Interviewed via telephone=5	1	< 2 years	1	20-29	3	Female	3	Caucasian				
	2	2-5 years	0	30-39	2	Male	2	African American				
	2	>5 years	3	40-49								
			1	50-59								
Total=9	3	33%	< 2 years	1	11%	20-29	4	44%	Female	7	77%	Caucasian
	4	44%	2-5 years	3	33%	40-49	5	55%	Male	2	22%	African American
	2	22%	>5 years	5	55%	50-59						American

Data Analysis

Audio recorded responses to the interview questions (see appendix E for interview questions) were transcribed verbatim by the student researcher. Content analysis involved reviewing the transcriptions multiple times in an effort to identify patterns and to categorize the data into conceptual themes that facilitated the illumination of the research question: *What reasons do hemodialysis patients describe in explaining their rationale for choosing to skip or shorten in-center hemodialysis treatments.* The themes identified through scrutiny of participants' words and phrases guided the analysis of the responses mentioned most frequently by the participants. Themes related to the

experience of living with hemodialysis were also identified. Content analysis continued until no new themes emerged.

Identified themes are presented in Table 2 (*The experience of living on dialysis*) and Table 3 (*Rationales described by participants for choosing to skip or shorten dialysis*) below.

Table 2: The experience of living on dialysis

Themes related to the experience of dialysis	Examples of participants' words used to describe the conceptual theme	Number of participants who described this theme
Life changing	<p>"It interferes with my life"</p> <p>"I just don't like having to get up and go someplace to do my dialysis"</p> <p>"I was hoping to be playing around and having some fun now, that's why I worked so hard when I was young"</p> <p>"I already have so many scars...all over my arms and my chest...for ports...and trying to find veins..."</p> <p>"I've had... just a lot of complications, you know...and I'm mentally...I'm depressed"</p> <p>"You can't really do a whole lot because, you know, it takes a lot of your time"</p> <p>"Everyone is so much older than me. Its boring... sometimes the time goes so slow."</p> <p>"There are other things I would like to do like to be hanging out with my friends. There are things I can't do with them like swimming because of the dialysis access..."</p>	7 (77%)
Dialysis is restricting	<p>"Three days a week you are tied to that machine"</p> <p>"On dialysis you gotta live a very regimental life"</p> <p>"It feels like hell. It feels like I'm chained ...to a chair..."</p> <p>"Watching my fluids, and watching what I eat..."</p> <p>"You don't have, really, choices on dialysis because you're sick"</p> <p>"You can't get up and move around..."</p> <p>"You can't work too much, and ah, you can't vacation too far, you can't do stuff like, hunting, where you stay away for like, 2 or 3 days, you know?"</p> <p>"You live life on a leash"</p> <p>"Its frustrating. It controls you. You have to be there all the time and its depressing."</p>	6 (66%)

Continued on next page

Themes	Examples	Number of Participants
	<p>“Your ambition level is down so much”</p> <p>“After dialysis you feel terrible”</p> <p>“At the end of the run my mind is numb!”</p> <p>“I get sick and dizzy”</p> <p>“I suffer from migraines...especially on dialysis”</p> <p>“I get ill when I have dialysis..after I leave here, I, ...feel like my blood pressure drops...and I’m really tired”</p> <p>“I feel real lightheaded and dizzy”</p> <p>“My stomach bothers me after I’m on there for a while, I may have to go to the bathroom”</p> <p>“Its uncomfortable”</p>	5 (55%)
Depression	<p>“It just messes with my head...a lot! So I think that’s a lot of my depression, you know...I’ve had depression before this, but I think it adds to it”</p> <p>“You just don’t have nothing that you can really do to get...you know I tried to get motivated”</p>	4 (44%)
Hope for a different treatment modality	<p>“We went through every thing to get the transplant done”</p> <p>“We’re going to get that (home dialysis training) done, now”</p> <p>“I’m basically waiting for a dead donor”</p>	4 (44%)
Loss of dreams	<p>“I always told my wife that we were going to go on trips, you know, go places”</p> <p>“ I...loved riding horses, I have a horse...you know, and that I miss.”</p> <p>“I still have some usefulness, you know, left inside me.”</p>	3 (33%)
Loss of productivity	<p>“I’ve felt like (since) I’ve been in there they treat me like I’m a 70 year old”</p> <p>“You just simply can’t do the things, you know, that you used to do”</p> <p>“I just couldn’t do it anymore, you know...so....<u>that</u> (work) I miss.”</p>	3 (33%)
Vulnerability	<p>“I always feel vulnerable because...I can’t get up...to go to the bathroom...”</p> <p>“I do have to use the bedpan here...”</p>	3 (33%)
Anger	<p>“I get anxiety...I get angry...”</p> <p>“I can’t get up...if somebody pisses me off, I can’t get up and walk out...”</p> <p>“...very frustrated with the system...”</p>	2 (22%)

Table 3: Rationales described by participants for choosing to skip or shorten dialysis

Theme related to skipping or reducing dialysis time	Participants' words used to describe theme	Number of participants who described this theme
Feeling ill or having pain/discomfort	<p>“Usually when I get the headache its the first part of dialysis”</p> <p>“I was just feeling too tough sitting on the machine that long”</p> <p>“There are days when.... it.... hurts so much that I can't come in, 'cause I know that its just not going to work”</p> <p>“I need to come off because I gotta go to the bathroom”</p> <p>“I'm having problems with my stomach before I come, I just won't come”</p>	6 (66%)
Events beyond control/Life gets in the way of getting to dialysis	<p>“We had decided that were weren't going to go (on a weekend trip), but then we went, and then” (didn't make it back in time)</p> <p>“I don't try to miss...its just circumstances beyond my control”</p> <p>“...because of school and other things”</p>	5 (55%)
Its my choice	<p>“If I'm going to do it, I'm going to do it”</p> <p>“I do what I want”</p> <p>“I didn't want to wake up, and go sit in that freakin' chair for...you know... 3 hours!”</p> <p>“Usually its because I just don't feel like it”</p>	4 (44%)
Anger and depression	<p>“I can't...sit in that freaking chair. It makes me depressed... OK..It makes me want to scream. It makes me want to throw things at people...it makes me feel like, you know, I'm tied to a chair!”</p> <p>“It seems like your ambition level is down so much, you know, you watch more TV than you do anything else”</p>	3 (33%)
Anxiety	<p>“If there was something more to relax me and let me sleep a little bit, that would help”</p> <p>“I'm not a science project! And that's how I feel when I'm sitting there”</p> <p>“My mind races and races and races”</p>	2 (22%)
Lack of transportation	<p>“There is no way I can get here (if my friend can't bring me)... 'cause I don't drive”</p> <p>“My car needed repair”</p>	2 (22%)

Summary of Findings

There were many insightful thoughts shared by the participants related to the experience of undergoing chronic in-center hemodialysis (ICHD) treatments. The most

common theme (shared by seventy seven percent [77%]) related to the experience of ICHD was that ‘it changes your life.’ Sixty six percent (66%) discussed the restrictions on life imposed by ESRD and dialysis. Illness caused by dialysis (55%), loss of autonomy and control (44%), depression (44%), hope for a different treatment modality (transplant or change in type of dialysis) (44%), loss of dreams and productivity (33%), feelings of being vulnerable (33%), and anger at the situation (22%) were the key themes related to the experience of living with dialysis that were identified by the participants during the interviews.

Six conceptual themes were identified by the participants as reasons they choose to skip or shorten hemodialysis. The most common theme identified by participants as reasons they decrease their dialysis time was discomfort or illness (sixty six percent [66%]). Fifty five percent (55%) of the participants discussed events ‘beyond their control’. The theme ‘Its my choice’ refers to freedom to choose and sometimes just not feeling like going (to dialysis). This theme was described by forty four percent (44%) of the participants in this study. Thirty three percent (33%) discussed anger and/or depression related to their illness and the confinements of dialysis treatments as reasons they reduce their dialysis time. Anxiety was described by two of the participants (twenty two percent [22%]) as being the reason they shortened or skipped their treatments. Two participants (twenty two percent [22%]) described transportation as the main reason they miss dialysis sessions. These themes will be further explored in the following chapter.

This chapter contained an overview of the data analysis. A description of the sample and the findings was presented. The findings were summarized and the chapter concluded with a discussion of the findings

CHAPTER V

DISCUSSION AND CONCLUSIONS

Introduction

The purpose of this study is to identify some of the reasons that HD patients provide when explaining their decision to skip or shorten their prescribed HD treatment time by providing ESRD patients with the opportunity to give voice to their perspectives. A secondary purpose of this project is to increase the HCP's understanding of the HD patient's perspectives and reasons for choosing to skip or shorten their prescribed HD treatment time. The research question that guided this study was: *What reasons do hemodialysis patients describe in explaining their rationale for choosing to skip or shorten in-center hemodialysis treatments?* Review of literature accomplished prior to conducting this study explored adherence and ESRD, the experience of CKD, characteristics of nonadherence to HD, impact of nonadherence to HD, measuring nonadherence in HD patients, and interventions to improve adherence. It was recognized that there are many articles related to adherence to the challenging health care regimens required to manage complex chronic illness. Many authors recommend that HCPs should seek to understand the patient's perspective and goals, and partner with them to manage health needs. This chapter includes a summary of the study, discussion of findings and conclusions, scope and limitations, implications for practice, and implications for research followed by a summary.

Summary of Study Design

A qualitative study design was utilized for this research project with a goal encouraging ICHD patients to verbalize their perspectives and rationales related to why

they shorten their dialysis time. A secondary goal was to explore the lived-experience and social reality of living on dialysis to enhance the understanding of nephrology nurses and other healthcare team members related to the perspectives of some dialysis recipients and, thereby increasing understanding of why dialysis patients may skip or shorten their dialysis time despite the potential health risks and the recommendations of health care providers. The dialysis patient's right to self-manage their health care and the theory of self-efficacy was used to guide this study. This theory is founded on the belief that "what people think, believe, and feel will affect their actions and ultimately how they behave" and freedom to choose is fundamental to the theory (Peterson & Bredow, 2009, p. 118). Nine ICHD recipients who met the criteria (described in Chapter III) were interviewed.

Discussion of Findings Related to The Experience of Living with Dialysis

The most common theme related to the experience of living with dialysis (identified by seventy seven percent [77%] of participants) was that 'it (dialysis) changes your life.' Participants discussed some of the physical and emotional impositions that resulted from the dialysis treatments and dialysis access. Some of the participants also discussed the change in life plans and other burdens related to ESRD and its treatment. Another common theme cited pertained to restrictions on life imposed by ESRD and dialysis. This theme was discussed by sixty six percent (66%) of the participants. Restrictions included dietary and fluid limitations and also the confinement of the dialysis treatment. Participants also discussed the inability to participate in 'normal' activities due to the need to be at dialysis three times a week and also because of the restrictions imposed by ESRD. Illness caused by dialysis (55%), loss of autonomy and control

(44%), depression (44%), hope for a different treatment modality (transplant or change in type of dialysis) (44%) were also expressed.

Review of literature performed prior to conducting this research project had identified findings related to increased potential for nonadherence in certain populations such as younger patients, African Americans, smokers, etc. (Kutner, 2001). It was notable that the age of all the participants in this study was between 26 and 59 years old. These are ages in which a person is typically independent, working, and industrious. These persons have experienced a loss or change of identity from a working (productive) person to a 'patient' who is dependent on a treatment and others for so many things including transportation, dialysis, and financial support. Loss of productivity and dreams was identified as significant to the experience of living on dialysis by thirty three percent of the participants (33%).

The humility of not being able to get up to take care of simple human needs, such as using the bathroom, was discussed by a few participants as adding to the feelings of confinement and vulnerability. One of the participants in the current study praised the nursing staff but voiced mistrust of the medical staff and voiced the opinion that the physician had manipulated (the patient's) treatment possibilities to retain financial reimbursement.

Discussion of Findings Related to Skipping or Shortening

Prescribed HD Treatment Time

Six conceptual themes were identified by the participants as reasons they choose to skip or shorten hemodialysis. The most common theme that resulted in these participants decreasing their dialysis time, identified by sixty six percent (66%) of the

participants, was discomfort or illness either prior to coming to dialysis or perceived as caused by the dialysis treatment. Fifty five percent (55%) of the participants discussed events 'beyond their control' that suggested life 'getting in the way' of getting to dialysis. Freedom to choose and sometimes 'just (not) feeling like going' (to dialysis) was described by forty four percent (44%). Thirty three percent (33%) passionately discussed anger and/or depression related to their illness and the confinements of dialysis treatments. Anxiety was described by two of the participants (twenty two percent [22%]). These individuals were deeply distressed by the extent of the angst they experience on many of their dialysis treatments finding it extremely difficult for them to control their distress with distractions. Two other participants (twenty two percent [22%]) described transportation as the main reason they miss dialysis sessions.

These findings compare to a larger study (one hundred sixty eight [168] hemodialysis recipients) which assessed reasons for shortening or skipping HD (Gordon et al., 2003). That study concluded that patients classified reasons for shortening or skipping HD treatment into five main categories: medical problems, technical problems, life tasks, transportation, and patient decision. Gordon et al. (2003) reported that the most common reasons identified for shortening treatments were medical problems (38%) and life tasks (24%). The most common reasons for skipping treatments were life tasks (33%) and transportation (22%) (Gordon et al., 2003).

Other observations noted by the student researcher while conducting the interviews for the current study was that four of the nine participants (44%) expressed gratitude toward the nursing staff but one of these same participants also expressed distrust and bitterness toward medical staff. The participant who expressed the most

anger at her situation discussed apprehension, and refusal to allow new staff to provide her care. It was unclear if this was related to mistrust, feelings of vulnerability, or fear of incompetence.

It is interesting to note that infection control guidelines recently changed to extend the requirement from personal protective equipment (PPE) for staff to now include that any visitors (including family) to the hemodialysis unit also wear an approved splatter proof coat (as a barrier to potential blood exposure). This new safety practice increases the view of a hemodialysis unit being a more technological, less relaxing, and less comfortable medical procedure area. The student researcher wondered if this new practice possibly increases the perception by hemodialysis recipients that they are 'different', less than normal, and exiled from other people.

None of the participants admitted to immediate perceived ill effects of missing or shortening HD treatments. Participants' perceptions that there are no immediate obvious health/illness consequences related to missing HD treatment time encourages actions that offer short term gratification with decreased concern long term effects of actions. It is easier to decrease treatment time when there are no perceived immediate ramifications. In fact, it was expressed by a couple of the participants that they feel more ill immediately during or after a HD treatment (than if they skipped). This parallels asymptomatic chronic illnesses (such as hypertension, early cardiac disease, or pre-diabetes) in which afflicted persons may reject following treatment recommendations despite the long term repercussions that can occur without management of the illness in its asymptomatic phase. Some participants talked about residual renal function which likely enables them to miss dialysis treatment time with less immediate side effects. The

equation for adequacy of hemodialysis (URR) does not factor in residual renal function (RRF) so these individuals with RRF actually are getting some clearance of metabolic waste and fluids from their RRF so their true URR (dialysis plus RRF) may be higher than is that provided by dialysis alone.

Two of the participants discussed that they mistrust the medical staff while the same participants were very complementary toward the nursing staff. Is it an issue of perception of authority or do the nurses versus providers interact differently with the patient resulting in different perceptions of support (as opposed to perceived control) by some patients? One HCP (nursing) providing care, the other HCP (the medical provider) encouraging compliance/adherence? This question is beyond the scope of this paper but raises an interesting consideration.

Scope and Limitations

A small number of patients (nine) participated and all of these patients received their HD treatments in units from one Central Minnesota provider in mostly rural settings. As noted earlier, ESRD is a distinctive chronic illness requiring intense treatment and lifestyle modifications. In addition to the characteristics of the ESRD illness, each patient is unique. Findings may not be transferable to other dialysis patients or persons with other chronic illnesses. Also, the data was gathered during an isolated one time interview. Longitudinal data gathered at different months would provide more data relevant to other seasons and variables.

Implications for Practice

The findings of this study endeavor to increase understanding of the lived experience of chronic hemodialysis and the reasons that ICHD recipients might choose to

shorten or skip their HD treatments. Awareness of findings related to increased potential for nonadherence in certain populations such as younger patients, African Americans, smokers, etc. (Kutner, 2001) can help nurses identify individuals who might benefit from persistent intervention efforts to promote treatment compliance. The current study supports recommendations by Costantini (2006, p. 23) that practitioners “facilitate (the HD patient’s) self-management strategies by asking individuals with kidney disease to describe what they believe needs to be addressed to successfully manage their illness” to promote a shared understanding between patient and HCPs. Support of self-efficacy offers patients greater dignity and control over their renal failure treatment regimen “and allows individuals to actively utilize their chronic illness expertise” (Costantini, 2006, p. 23). It is recommended that “nurses recognize the uniqueness of each person and the possible range of experiences with CKD, rather than assuming that everyone follows a specific pattern or trajectory” (Molzahn et al., 2008, p. 19).

A few of the study participants indicated that interventions are needed for relieving anxiety and boredom while undergoing ICHD. Possible approaches to address this concern might be the availability of relaxation strategies in the dialysis unit such as earphones with music, books on tape, family or trained volunteer visitors to reminisce with patients and offer them distraction, massage (possibly volunteer students from a school of massage to do hand or foot massages for patients), tutors, guided imagery, other distraction or relaxation techniques, or coaching of simple exercise during the first part of the treatment (such as the use of the chair exercise bike or leg lifts). Another suggestion would be to have a volunteer to help patients write their stories as a way to enhance self

esteem and facilitate perception of dialysis time as a productive time, if this is something they desire.

Currently dialysis providers are being persuaded, via CMS Quality Incentive Program (QIP), to meet certain criteria for interventions provided as a way of demonstrating provision of quality health care. With the current criteria for reimbursement through the CMS QIP the provider's reimbursement (for all of the treatments provided by at that dialysis unit) may be decreased if a few patients choose not to meet the criteria for adequate dialysis. Should there be an 'exception' such as the ability to exclude nonadherent dialysis patients (those who are making a conscious choice to receive less than adequate treatments) from the statistical criteria that determines reimbursement to a dialysis unit so that dialysis program is not penalized by decreased reimbursement for the entire population of the dialysis unit?

Concerning autonomy and health care choice...is it reasonable to choose less than adequate treatment or partial treatment? Consider the impact on society when Medicare is the primary payer for dialysis. If dialysis recipients choose less than adequate dialysis they have an increased potential for complications and hospitalizations which can further increase financial burden (to society) of ESRD care. Is this acceptable to society? This question could be applied to other illnesses or life choices. For example, should people who continue to use tobacco, drink excessive alcohol, or who are obese have the same health care treatment choices as those who do not use tobacco, drink excessive alcohol, or become obese? These are ethical subjects that are well beyond the scope of this paper but they raise interesting questions for healthcare providers.

Some participants offered comments about the medical provider's visits at the dialysis unit: one participant did not want doctor to come at the end of treatment because he does not usually feel well at the end of dialysis. Another participant wanted to see the doctor in a private setting before dialysis. From a provider's standpoint it has been thought that the hemodialysis patient's would not want to come early to see the doctor because they (patients) are already in the dialysis unit so much already. Maybe each patient should be given an opportunity to choose? This would be one aspect of their dialysis they can have some control over.

Dialysis HCPs are encouraged to continue to promote a nonjudgmental culture which promotes knowledge and patient responsibility and partnership with the health care team to meet mutually determined goals. Strategies which encourage dialysis HCPs to develop and promote the dialysis patients' personal control, self efficacy, and self-management, with a goal of empowering and supporting patients to gain control of their illness and health management, should be incorporated into the training of those who provide care to persons with ESRD.

Implications for Research

The topic of adherence to dialysis recommendations is an important one for promotion of health with this unique population and the subject offers many prospective research opportunities including:

- a. Research gathering information on patient's attitudes toward ICHD and comparing those who comply with their treatment time prescription (recommended treatment frequency and duration) to those who choose to skip or shorten treatments to provide greater insight into the phenomenon. Do the persons who comply with the treatment

regimen have similar perceptions of feeling ill or uncomfortable after dialysis? What are their thoughts and rationales about showing up for treatment? What drives them to go through the tedious and challenging treatments as recommended? What are their perspectives, insights, experiences about staff, providers, treatment? What are the contrasts between these people and the ones who resist following treatment recommendations? Is it inborn personality traits, a different life view, an attitude, more gratitude, or more resilience? Do they find more satisfaction in life outside dialysis or do they just come, grudgingly, because they feel they have no other choice?

b. Another potential research study could measure the effect of reinforcement of specific patient education by dialysis staff over time using defined strategies would aid in determining which interventions are effective.

c. Further potential research to assess how life stage and other factors (such as age, social support and social commitments i.e. occupation, children, spouse. . . , transportation reliability and or cost . . .) effect adherence to frequency and length of ICHD treatments would increase the HCPs ability to tailor the interventions to specific populations.

d. It would be also interesting to gather data from dialysis staff on their perceived reasons that patients skip treatments to compare outcomes and viewpoints of the HCP and the dialysis patients.

e. To further assess patient perceptions that patients have related to health care providers it would be interesting to do a study on patient perceptions on health care personnel: for example, the perceptions that patients have about physicians vs. nurses vs. patient care technicians vs. dietitians vs. social workers. There may be a component of personality variances but also the subjects, presentation, and types of health care issues brought

forward by each discipline may determine the interpersonal relationship and perceptions that develop between different types of health care providers and patients.

Summary

The purpose of this qualitative study was to identify some of reasons and perspectives related to HD patients' choosing to skip or shorten their prescribed HD treatment time by providing ESRD patients with the opportunity to give voice to their perspectives. A secondary purpose of this project was to increase the HCP's understanding of the HD patient's perspectives and reasons for choosing to skip or shorten their prescribed HD treatment time. A person with End Stage Renal Disease undergoing routine hemodialysis treatments can live many years due to this life saving technology but the experience is accompanied by many personal losses which may include a loss of work, diminished dreams, restricted leisure activities, lack of energy, restrictions and loss of control, future uncertainty, and ebbing feeling of well being, just to name just a few. Their choices related to treatments and many normal life activities are limited and the treatment of ESRD presents many financial and personal burdens on the dialysis recipient and their families. The reasons that ICHD recipients choose to skip or shorten their recommended dialysis treatment time are diverse but the findings of this study may provide opportunity to design interventions that promote treatment adherence and/or provide health care providers with greater understanding of, and respect for, decisions to skip or shorten treatments.

Listening to these participants tell their stories and talk about their struggles was enlightening and humbling. The uniqueness of each person and their perspectives and reactions to the circumstances, burdens, and obstacles they encounter makes every human

life journey an unparalleled, individual, and unique experience. Individual human perceptions are also unique but we rely on each other for support despite difficulties trusting at first. Health is so easy to take for granted. For dialysis patients it is a daily struggle that cannot be ignored. Constantini suggested “that when practitioners include the patients' beliefs, values, and concerns into the recommended treatment regimen, CKD (chronic kidney disease) client outcomes are improved” (2006, p. 22). Enhanced understanding of the patient’s rationale and perspective may improve the HPCs’ ability to create strategies that improve a patient’s ability to adhere to health care recommendations. Increased awareness and understanding of patient’s reasons for choosing to skip or shorten dialysis treatments will increase the HCP’s ability to offer pertinent education and support and potentially improve adherence to the recommended ICHD adequate dialysis treatment prescription with the ultimate goal being to reduce morbidity and mortality for persons with ESRD.

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APPENDICES

APPENDIX A
IRB APPROVALS AND MEDICAL DIRECTOR LETTER OF SUPPORT

MSU-Mankato IRB APPROVAL

Please note that Minnesota State University has taken the following action on IRBNet:

Project Title: [329997-2] IDENTIFYING PATIENT'S REASONS OR RATIONALE FOR CHOOSING TO SKIP OR SHORTEN HEMODIALYSIS

Principal Investigator: Marcia Stevens, PhD

Submission Type: Revision

Date Submitted: April 22, 2012

Action: APPROVED

Effective Date: April 26, 2012

Review Type: Administrative Review

Should you have any questions you may contact Patricia Hargrove at patricia.hargrove@mnsu.edu.

Thank you,
The IRBNet Support Team

www.irbnet.org

CENTRACARE Clinic

1200 Sixth Avenue North | St. Cloud, MN 56303
(320) 252-5131 phone
www.centracare.com

April 2, 2012

RE: Linda Lindberg

To Whom It May Concern:

As part of her study in her nurse practitioner program, Linda Lindberg is requesting to visit with dialysis patients in the CentraCare Kidney Program regarding their reasons or rationale for skipping or shortening their dialysis treatments. We feel that this is a worthy project that has a potential to add insight into why patients opt for suboptimal care. We support Linda's work and look forward to the results of her study.

Sincerely,



Thomas Leither, MD
Medical Director, CentraCare Kidney Program

St. Cloud Hospital
CENTRACARE Health System

1406 Sixth Avenue North | St. Cloud, MN 56303-1901
(320) 251-2700 phone | (320) 255-5711 fax
www.centracare.com



May 9, 2012

Linda Lindberg, RN
Linda.lindberg@mnsu.edu
lmteapot@aol.com

RE: Identifying Patient's Reasons or Rationale for Choosing to Skip or Shorten Hemodialysis

Dear Ms. Lindberg:

On behalf of the St. Cloud Hospital IRB committee I have reviewed and approve the recommendation from the Nursing Research Review Board to approve the research proposal: Identifying Patient's Reasons or Rationale for Choosing to Skip or Shorten Hemodialysis.

Thank you for your cooperation in keeping the IRB up-to-date on activities related to this study.

Sincerely,

A handwritten signature in cursive script, appearing to read 'Linda Chmielewski'.

Linda Chmielewski, MS, RN, NEA, BC
Vice President, Hospital Operations/CNO

cc: Roberta Basol, Chair NRRB

APPENDIX B

**COMMUNICATION TO DIALYSIS CHARGE NURSES AND SOCIAL
WORKERS AND RECOMMENDED SCRIPT**

Hello Dear Charge Nurses and Social Workers,

I am finally ready to proceed with my thesis project: *“Identifying patient’s reasons or rationale for choosing to skip or shorten hemodialysis.”* I would be very grateful for your help recruiting patients. Because of confidentiality I cannot approach patients until signed consent to participate is obtained. Potential participants include any in-center hemodialysis patients in the CentraCare kidney program who have chosen to:

- (a) skip one or more dialysis sessions in January 2012, February 2012, or March 2012;
- (b) shortened a dialysis session by ≥ 10 minutes in January 2012, February 2012, or March 2012; or
- (c) not achieved hemodialysis clearance goals (URR $\geq 65\%$) at least once in those 3 months due to personal choice to dialyze at a duration less than medically advised to meet treatment adequacy goals.

Additionally, potential participants must speak and communicate in English as inability to communicate in English will prohibit the researcher from interviewing the patient (use of interpreter services are avoided due to cost). Patients with cognitive disabilities will be excluded from the study.

If you have any potential participants in your dialysis units that meet the criteria and are able to help me recruit participants please let me know how many packets of information and consent forms I can send to you. Please do not hesitate to let me know if you have any questions or concerns about this project. I really appreciate your help with recruiting participants into my research project.

Sincerely, Linda Lindberg, RN

Practice Nurse at CentraCare Department of Nephrology

Recommended Script for Charge Nurses and Social Workers to Use To Invite

Potential Participants:

- 1. Dr. Anjum's nurse, Linda, is almost finished with graduate school and for her thesis she is researching the reasons that people might skip or shorten dialysis hemodialysis treatments.*
- 2. You are invited to participate in this research which would involve reviewing, signing, and returning a consent form and then meeting with Linda to discuss missing dialysis time. This meeting can happen while you are at dialysis or over the phone, if you prefer, and will most likely take less than 30 minutes. Participation is completely voluntary. There will be no negative effects if you decide you do not want to participate.*
- 3. If you are interested in participating I will give you the consent form to review. If you have any questions you can call the student researcher, Linda, on the number provided on the consent. If you decide to participate please sign the consent and return it to a Charge Nurse or Social Worker in the envelope provided. Thank-you very much for thinking about sharing your viewpoint with Linda for her research project.*

APPENDIX C
PARTICIPANT CONSENT FORM

CONSENT FORM-Skipped or shortened hemodialysis treatment study

Hello. You are invited to participate in a research study being conducted by a graduate nursing student at Minnesota State University, Mankato. Participation in this study is completely voluntary. You are a potential participant if you receive hemodialysis at any one of the out-patient hemodialysis units of CentraCare Health system and have skipped or shortened one or more of your prescribed hemodialysis sessions sometime between January 2012 and March 2012. You are also a potential participant if you choose to have your hemodialysis treatment duration be less than the duration that your Nephrologist recommends as the treatment time that would provide 'adequate dialysis' for you.

Purpose of the study:

The purpose of the study is to identify some of reasons and points of view related to hemodialysis patients' choosing to skip or shorten their prescribed hemodialysis treatment time. A secondary purpose is to improve understanding by the health care team of the hemodialysis patient's viewpoint and reasons that they choose to skip or shorten their prescribed hemodialysis treatment time.

Procedures:

If you agree to participate in this research study you will return the signed consent form to the Charge Nurse or Social worker in the sealed envelope provided, and they will forward it to the student researcher. Please keep the other copy of the consent form for yourself. Please complete and return the consent form as soon as you can, preferably within 2 days of receiving it.

With your consent the student researcher will call you to arrange to meet with you while you are receiving your hemodialysis or talk with you on the phone your viewpoint and past reasons for skipping or shortening your dialysis treatments. You will be able to decide which method of talking with the student researcher is preferable to you. This conversation will be audio taped for the purposes of gathering accurate and complete information for the study. The one-time interview will take less than 30 minutes.

Risks:

Minimal potential risks include anxiety about being interviewed, fatigue or added stress related to completing the consent and talking with student researcher.

Benefits:

Potential benefits of participating in the study include personal satisfaction knowing that the information you provide may help yourself and other hemodialysis patients through improved understanding by the hemodialysis health care providers of the concerns and priorities of persons undergoing hemodialysis. There is no monetary reward for participation.

Confidentiality:

No names will be used in the thesis data collection or analysis or in any publication of the

research. All participants will only be identified by a subject number in the thesis data. No individual data will be identifiable in any report or publication. No names will be used in the transcription of the audio taped conversation.

Participation or withdrawal:

Participation in this study is completely voluntary. You may withdraw from the study at any time without negative consequences. Your decision whether or not to participate will not affect your future relations with the CentraCare Kidney Program in any way. If you decide to participate, you are free to discontinue participation at any time.

Identification of Investigators:

If you have any questions or concerns about the research study, please feel free to contact Linda Lindberg, Graduate Nursing Student, (320) 250-9370 or Dr. Marcia Stevens, 507-389-6811 at the School of Nursing at Minnesota State University, Mankato, 360 Wissink Hall, Mankato, MN, 56001.

Rights of Research Subjects:

You may withdraw your consent at any time and discontinue your participation without penalty. You are not waiving any legal claims, rights, or remedies because of your participation in this research study. If you have any questions as a research subject or in the event of a research-related question, please contact Dr. Barry Ries, Investigational Review Board administrator at the Minnesota State University-Mankato, 507-389-1242.

Consent:

You are making a decision whether or not to participate in the above described research. Your signature below indicates that you have read the information provided above and have decided to participate. You may withdraw your consent at any time without penalty after signing this form should you choose to discontinue participation in this study. Your decision to not participate will not affect your future relations with the CentraCare Kidney Program in any way.

By signing and returning this consent form I agree to participate in this research study. I am agreeing to talk with the student researcher and to allow the interview to be audio taped.

The student researcher may call me at this telephone number _____ - _____ - _____ to discuss my preference for the interview location (at the dialysis unit or on the phone) and to make arrangements for the interview.

I agree to the audio taping of the session.

I have received a copy of this consent

Signature:

Date:

Thank-you for taking the time to consider being a part of this research project. If you have any questions about this study please feel free to call Linda Lindberg 320-250-9370.

APPENDIX D
ALGORITHM FOR FINDING PARTICIPANTS

Algorithm for Finding Participants

1. Centracare Hemodialysis Unit Charge Nurses and Social Workers were given the following criteria to identify potential participants and a packet of forms to give to potential participants. This packet included two copies of the consent form and a return envelope. Potential participants included any ICHD patients who have chosen to shorten or skip dialysis treatments during the months of January 2012, February 2012, or March 2012, or not achieved HD clearance goals (as defined by $URR \geq 65\%$) at least once in those 3 months due to personal choice to dialyze at a duration less than medically advised to meet treatment adequacy goals
2. The Charge Nurses and Social Workers were asked to approach potential participants, provide an overview of the project, and invite them to participate (Script in Appendix B).
3. If the patient was interested in participating, the Charge Nurse or Social Worker gave the participant the packet which included two consent forms and an envelope.
4. The participant was asked to return one consent form, sealed in the provided envelope, to the dialysis Charge Nurse or Social Worker. The other consent form was to be kept by the participant.
5. The Dialysis Charge Nurse or Social Worker called or emailed the student researcher (lindbergl@centracare.com) with notification of having a signed consent form. It was discussed if the student researcher would pick up the form or if the document would be forwarded to the student researcher via interdepartmental mail (to Nephrology Clinic, CentraCare, River Campus).

6. The student researcher reviewed the consent form and contacted the participant at the telephone number provided by the participant to arrange the interview with the participant for qualitative data collection.

APPENDIX E
SEMI STRUCTURED INTERVIEW FORMAT

Semi Structured Interview Format:

The student researcher used the following introduction and interview format to talk with patients:

Hi, my name is Linda. I am a graduate nursing student who has worked with people who have kidney failure for 24 years. I am currently completing my graduate nursing degree and as part of my college requirements I am writing a thesis on the reasons that people skip or shorten dialysis treatments. To learn about this, I am talking with dialysis patients to increase the understanding of reasons that people might skip or shorten their dialysis treatments. I know that the dialysis Charge Nurse or Social Worker has already talked with you about my project as you have signed a consent form and agreed to talk to me. Thank you for that. Would it be OK if I talked with you for a bit now? Do you have any questions before we start?

How long have you been on dialysis?

What has the experience been like for you?

I know that at times getting to, or staying at, dialysis is a struggle and sometimes people miss or want to shorten their treatments. Do you remember the last time you skipped or shortened a dialysis treatment and what the reason was that time?

Can you help me to understand your thoughts and other reasons that have caused you to skip hemodialysis or shorten your dialysis time?

Do you have an idea how many treatments you have skipped or shortened in the past month? How about the past 3 months?

Do you have any problems with feeling ill or having side effects of skipping treatments?

What things would improve your ability to come to all your dialysis treatments or not ask to shorten your treatments?

Are there things that you or the dialysis staff or your family, etc. can be doing to help you get all of your full dialysis treatments?

Are there other things that you think are important for dialysis staff to understand related to skipping dialysis time?

Would you mind telling me your age?

Your dialysis team wants you to be an active participant in your health management so it is important that you let us know what is on your mind and what problems might be keeping you from following your recommended treatment actions such as taking medications, coming for your full dialysis treatments, limiting your fluid intake, or dietary restrictions. Please make sure and talk to us about any concerns you may have. I really appreciate you letting me talk with you. Thank you so much for sharing your ideas, I am very grateful for your willingness to participate in this research project. Your thoughts and comments are very much appreciated.