OLDER ADULT KIDNEY DISEASE SELF-MANAGEMENT BEHAVIORS AND THEIR RELATIONSHIP TO DEPRESSION, SELF-EFFICACY, ILLNESS PERCEPTIONS, AND SOCIAL SUPPORT

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ABSTRACT

TIFFANY RENÉE WASHINGTON: Older adult kidney disease self-management behaviors and their relationship to depression, self-efficacy, illness perceptions, and social support (Under the direction of Sheryl Zimmerman)

One-half of older adults live with two or more chronic conditions and this number will increase over the next two decades. Among the conditions affecting older adults is chronic kidney disease, characterized by a gradual decline in kidney functioning. It is estimated that 26 million people live with chronic kidney disease, many of whom are unaware that they have the condition. This dissertation focuses on end-stage renal disease (ESRD), the irreversible stage of chronic kidney disease in which life-sustaining renal replacement therapy is required. Older adults living with ESRD experience significant physical and psychosocial life changes. Self-management can lessen the burden of ESRD, yet the self-management behaviors in this population are not well understood. To address this knowledge gap the three studies comprising this dissertation identify the self-management behaviors performed by older ESRD patients (study one); clarify potential mediators of depression, (the most prevalent mental health issue in ESRD patients) and fluid adherence, an important self-management behavior (study two); as well as the relationship of social support to self-management, and examine the psychometric properties of a social support measure (study three). A total of 107 hemodialysis patients aged 50 and older were interviewed from four North Carolina hemodialysis facilities. In study one, age was
significantly associated with self-management and older adults were engaging in more self-management behaviors than they actually reported in open-ended questioning. In study two, depression and age were significantly associated with fluid adherence, and when self-efficacy was added to the model the negative association between depression and fluid adherence was no longer significant. Finally, in study three, social support was associated with four self-management behaviors (i.e., advance directive status, cognitive symptom management, communication with physicians, and weekly exercise). Also, the Lubben Social Network Scale was found to be a reliable measure of social support. Taken together, the studies provide an understanding about the self-management of older ESRD patients and a foundation for self-management intervention research with the older ESRD population to include self-efficacy training and engagement with social networks.
I dedicate this dissertation to my beloved great-grandmother, Mable “Bones” Scarboro-Hinson (1921-2006). As the matriarch of the Hinson family, she was a venerable woman whose presence in a room demanding respect all on its own. She was a homemaker until the mid-1970s when her husband transitioned from the natural to the spiritual, and she was left to support her family by cleaning residence halls at a university. As she cleaned those rooms, I wonder if she ever imagined her great-granddaughter would obtain a Doctor of Philosophy degree that would position her to work at a university. Her indelible mark on my character gave me the fortitude to endure this temporary jaunt in life. I hope I have made you proud, Grandma Bone.
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LIST OF ABBREVIATIONS

Chronic Disease Self-Management Program (CDSMP)

Chronic Kidney Disease (CKD)

Conditions for Coverage (CfC)

End-stage renal disease (ESRD)

Geriatric Depression Scale (GDS)

Hemodialysis (HD)

Lubben Social Network Scale (LSNS)

Saint Louis University Mental Status Examination (SLUMS)
Introduction

The United States’ demographics are changing. As a result of longevity and aging Baby Boomers there will be 71 million older adults by 2030. Older adults are disproportionately affected by chronic disease and at least one-half live with two or more chronic conditions (Marengoni et al., 2011). More so, the number of older adults living with multiple chronic conditions will increase over the next two decades (Boyd & Fortin, 2010). In fact, the Centers for Disease Control and Prevention (2007) project a 25% increase in health care spending by 2030 as a result of this demographic shift and greater disease burden.

Among the chronic conditions affecting older adults is chronic kidney disease, characterized by a gradual decline in kidney functioning. It is estimated that 20 million (Centers for Disease Control and Prevention, 2012) to 26 million (National Kidney Foundation, 2013) people live with chronic kidney disease, many of whom are unaware that they have the condition. This dissertation focuses on chronic kidney disease stage five (i.e., end-stage renal disease), the irreversible stage in which a life-sustaining renal replacement therapy is required. People living with end-stage renal disease (ESRD) experience significant physical and psychosocial life changes that require the assistance of interdisciplinary health care professionals to survive, cope, and adjust. Kidneys aid in the production of red blood cells and filter toxins from the body, therefore conditions such as anemia and uremia are common in people living with ESRD. Also, ESRD causes the body’s electrolytes to become imbalanced, resulting in the need for a phosphate and potassium-
balanced diet. Changes in employment, mental health, lifestyle, and relationships are common.

Participants in the following three studies were aged 50 and older and undergoing maintenance hemodialysis (HD), one of three renal replacement therapies performed three days per week, four hours on average. ESRD is a serious public health issue with nearly 600,000 ESRD patients accounting for $33 billion of Medicare expenditures (over $87,000 per HD patient per year) (USRDS, 2012). Diabetes and hypertension are the two main causes of ESRD, accounting for 44% and 22% of new cases, respectively (USRDS, 2012). Also, race disparities persist, such that the rate of ESRD is 3.4 times higher in blacks than whites.

Sample and Generalizability

In North Carolina where these data were collected there were over 3,400 new ESRD cases in 2011; 79% were people aged 50 and older (Southeastern Kidney Council, 2012). Similarly, there were over 14,000 people living with ESRD, 77% of whom were aged 50 and older. Consistent with national figures, blacks constitute the largest percentage of new and prevalent cases (50% and 63%, respectively), compared to 47% and 34% of new and prevalent cases among whites. The majority of ESRD patients were undergoing hemodialysis (HD) (88%).

The inclusion age for the following studies was 50. The sample was primarily black (69%) and all patients were undergoing in-center HD. Therefore, the findings in the following studies are generalizable to North Carolina and neighboring southeastern states where the ESRD demographics are similar (e.g. in 2011, 74% and 78% of prevalent and
incident ESRD cases were aged 50 and older, respectively, and 70% were black in North Carolina) (Southeastern Kidney Council, 2011).

Dissertation Topic and Aims

The topic of this dissertation is self-management. Individuals undertake self-management behaviors to control the impact of chronic disease on health status (Clark et al., 1991). Historically, chronic kidney disease care occurred within a medical model in which health care professionals expected patients to adhere to treatment instructions. Costantini (2006) called for a paradigm shift in chronic kidney disease care from adherence expectations to a self-management model that incorporates patients’ values and beliefs, and encourages patients to participate in their care. To achieve this goal, nephrology professionals must promote shared decision-making and collaborative problem-solving (Lorig & Holman, 2003). In consequence, patients use knowledge about chronic kidney disease gained from interactions with health care professionals to maintain ownership of their health care (Costantini, 2006). Unfortunately, the field has been slow to respond to this paradigm shift, and better understanding of self-management is needed to lessen the burden of ESRD on patients and the health care system, and to improve relationships between patients and providers.

Fortunately ESRD health care law reflects this paradigm shift. The Medicare ESRD Conditions for Coverage were developed 30 years ago and underwent their first revision in 2008. The Conditions recognize the patient, or the patient’s designee, as a member of the interdisciplinary team (condition 494.80), and states that patients must be encouraged to be active participants in an individualized, comprehensive assessment and care plan. However, the self-management behaviors among older adults are not well-understood. Behaviors such
as cognitive symptom management (i.e., the cognitive strategies individuals employ to deal with unpleasant symptoms experienced by the disease) and communication with physicians (i.e., the amount of weekly time an individual spends communicated effectively and productively with his or her physician) have not been explored extensively in the ESRD population. Nephrology professionals cannot develop clinical interventions to encourage self-management in older ESRD patients without a better understanding of factors that are associated with self-management. The findings in these studies identify the self-management behaviors performed by older ESRD patients (study one); identify potential mediators of depression, the most prevalent mental health issue in ESRD patients, and fluid adherence, an important self-management behavior (study two); and examine the relationship of social support to self-management, and examine the psychometric properties of a social support measure (study three). In study one, age was significantly associated with self-management, and older adults were engaging in more self-management behaviors than they actually reported in the open-ended questioning. In study two, depression and age were significantly associated with fluid adherence, and when self-efficacy was added to the model the negative association between depression and fluid adherence disappeared.

Finally, in study three, social support was associated with four self-management behaviors (i.e., advance directive status, cognitive symptom management, communication with physicians, and weekly exercise time). Also, the Lubben Social Network Scale (LSNS-6) was found to be a reliable measure of social support. Taken together the studies provide a foundation for self-management intervention research with the older ESRD population to include self-efficacy training and engagement with social networks. The mandates in the updated conditions provide standards for patient assessment and care related to topics
covered in the three papers comprising this dissertation. The study’s findings provide a foundation for interdisciplinary practice related to self-management and social support in the older ESRD population.
End-Stage Renal Disease among Older Adults: Self-Management, Age, Cognition, and Self-Efficacy

Overview

End-stage renal disease (ESRD) is a serious chronic disease affecting almost 600,000 people in the United States. Older adults have the highest ESRD incident rates, and are especially burdened by depression, low health-related quality of life, and declined functional status. Older adults primarily select hemodialysis (HD) treatment which is associated with poorer blood pressure control, cardiovascular instability, and decreased independence compared to other ESRD treatment modalities. Social workers in HD settings can help patients and their families learn better self-management strategies to lessen the burden of ESRD and HD, however, little is known about the self-management behaviors of older adults undergoing HD. This mixed methods study explores the relationships between these factors and five self-management behaviors: exercise, communication with physicians, cognitive symptom management, fluid adherence, and diet adherence. A total of 107 HD patients aged 50 and older were interviewed from four North Carolina HD facilities. Overall, participants had low mean scores for exercise (2.46), communication with physicians (2.50), and cognitive symptom management (0.89) and were adherent for greater than 11 days in a two week period with fluid (11.86) and diet (11.65) regimens. There were statistically significant age group differences in the self-management behavior of fluid adherence (p < .05) and communication with physicians (approaching significance p = 0.05). There were no
statistically significant differences in self-management by cognitive status or self-efficacy. None of the respondents discussed communicating with their physicians or cognitive symptom management, yet 90% and 77% of the respondents reported engaging in these behaviors on their Communication with Physicians and Cognitive Symptom Management scales, respectively. The findings from this study support the need for interventions aimed at increasing self-management behaviors to reduce the burden of ESRD and HD in older patients. The potential to introduce a self-management intervention is promising given the amount of time ESRD patients spend in HD facilities, and the existence of interdisciplinary teams in those facilities to help patients maximize their self-management.
Introduction

End-stage renal disease (ESRD) is a serious chronic disease, affecting almost 600,000 people in the United States who require renal replacement therapy to sustain life (USRDS, 2012). People who undergo hemodialysis (HD) treatment must do so three days a week, four to five hours per day, on an ongoing basis (Schell, Germain, Finkelstein, Tulsky, & Cohen, 2010; Finkelstein, Arsenault, Taveras, Awuah, & Finkelstein, 2012). Many HD patients are burdened by depression, low health-related quality of life, and high nonadherence to diet and fluid recommendations (Kulger, Vlaminck, Haverich, & Maes, 2005; Kimmel & Peterson, 2008; Abdel-Kader, Unruh, & Weisbord, 2009; Chilcot, Wellsted, & Farrington, 2010).

Master’s-level social workers are federally mandated to assist HD patients in coping with these challenges (Browne, 2010; Federal Register, 2008). This type of federal mandate does not exist for other disease categories. Of note, social workers assist HD patients with chronic disease self-management to reduce the burden of ESRD. Self-management refers to an individual’s ability to manage the symptoms associated with a disease and perform daily tasks to control or reduce the impact of the disease (Clark et al., 1991; Browne & Merighi, 2010). Beyond diet and fluid self-management tasks, the self-management behaviors of ESRD patients on HD are not well-known.

Even less understood are the self-management behaviors of older adults on HD, the fastest growing segment of the ESRD population (USRDS, 2010). Older HD patients experience physical and psychosocial risk factors that increase their need for self-management. First, they have a low life expectancy (i.e., 3 to 5 years; Dimkovic & Oreopoulos, 2009). For example, the one-year mortality rate of ESRD patients aged 80 and older is 46% (Kurella, Covinsky, Collins, & Chertow, 2007). Additionally, older adults may
be less socially engaged than their younger counterparts, with HD often being their only “activity” outside of their home (Ifudu, Mayers, Matthew, Tan, Cambridge, & Friedman, 1994). Lack of social engagement increases their risk of mortality. They also experience accelerated declined functional status after initiation of HD which may cause them to be wheelchair bound (Ifudu, Mayers, Matthew, Tan, Cambridge, & Friedman, 1994). Finally, older patients experience a high prevalence of co-morbid conditions such as diabetes and hypertension, the two primary causes of ESRD (Bouzón, de Araoz, & Llera, 2008), which may further complicate their self-management. All of these risk factors suggest the need to better understand self-management behaviors among the growing older population of HD patients.

The potential to mitigate the burden of ESRD among older adults by increasing their self-efficacy to improve their self-management behaviors is promising. Older adults with heart disease, diabetes, and other chronic conditions who participated in the Chronic Disease Self-Management Program (CDSMP), an evidence-based, self-efficacy-building intervention, decreased their emergency department and outpatient visits, as well as their overall health distress (Lorig et al., 2001; Ritter, Lee, & Lorig, 2011). Self-efficacy is an inner belief to successfully complete a goal, and when present, relates to improved self-management. Older ESRD patients deserve these same benefits but such interventions must be informed by and tailored to their self-management behaviors. To understand these behaviors, and to inform future chronic disease self-management interventions with older ESRD patients, this paper is a mixed methods exploration of the disease self-management behaviors of older adults with ESRD. Previous research in this area has explored the self-management behaviors of ESRD patients (Curtin & Mapes, 2001; Curtin, Mapes, Schatell, &
Burrows-Hudson, 2005), but few studies have focused solely on the self-management behaviors among older adults. This study builds on existing literature by exploring the specific self-management behaviors of older adults with ESRD and examining the relationship between self-management and self-efficacy.

An exploration of the self-management behaviors of older adults with ESRD is a timely endeavor with potential significant impact on the social work profession. Nationally, clinicians and researchers are beginning to focus their attention on the aging ESRD population because the older adult population will continue to constitute the fastest growing segment of the ESRD population (USRDS, 2010; USRDS, 2012). The prevalence of ESRD patients aged 65 years and older has nearly doubled over the past two decades (Anderson et al., 2009). Further, among the renal replacement therapies available older adults overwhelmingly select HD treatment (Dimkovic & Oreopoulos, 2009). This selection is a cause for concern because other treatments, such as peritoneal dialysis (PD), a home treatment that involves fluid exchange using the peritoneal cavity, offers better blood pressure control, cardiovascular stability, and greater independence (Dimkovic & Oreopoulos, 2009). In comparison, successful HD treatments require a healthy vascular access to perform dialysis; unfortunately, conditions such as heart failure and the higher risk of infection is a barrier to healthy vascular access among older adults (Dimkovic & Oreopoulos, 2009). Also, people with ESRD already experience social and health-related burdens (Kimmel & Patel, 2006; Christensen & Ehlers, 2002), and these burdens are exacerbated in the lives of older adults, suggesting that their self-management might be similarly challenged.
Finally, the Medicare Conditions for Coverage (CfC) for dialysis facilities were updated in 2008, and now reflect the importance of promoting self-management with all HD patients (Federal Register, 2008; Browne, 2012). In the CfC, HD patients are named members of the interdisciplinary treatment team. This recognition is a significant step because federal regulations now recognize that patients are to be active participants in their own care (Alt & Schatell, 2009). It is also recognition of the benefits of successful self-management such as good quality of life, longer life expectancy, decreased morbidity, less health care utilization and related costs, and overall improved health among older adults (Ackermann, Cheadle, Sandhu, Madsen, Wagner, & LoGerfo, 2003; Bryant, Alpeter, & Whitelaw, 2006; Krien, Heisler, Piette, Butchart, & Kerr, 2007; Meng, Wamsley, Liebel, Dixon, Eggert, & Van Nostrand, 2009). It also aligns with the growing emphasis on patient-centered care in nephrology. In this approach, health care providers focus on patients’ individual needs and preferences, and self-management is emphasized as central to outcomes (Weisberg, 2011).

This study focuses on the five self-management behaviors of exercise, communication with physicians, cognitive symptom management, fluid adherence, and diet adherence, all of which are important for successful self-management among ESRD patients (Curtin, Mapes, Schatell, & Burrows-Hudson, 2005). Exercise is an important self-management behavior because it reduces the impact of co-morbid conditions such as hypertension and diabetes, the two main causes of ESRD, by improving overall physical functioning (Johansen, 2007). Physician-patient communication is another important self-management behavior among dialysis patients (Loghman-Adham, 2003), as it promotes adherence to treatment recommendations and active engagement in care. Third, ESRD
patients experience heavy symptom burden (Abdel-Kader, Unruh, & Weisbord, 2009; Claxton, Blackhall, Steven, Weisbord, & Holley, 2010). Cognitive symptom management is an effective strategy to reduce the symptom burden commonly experienced by older ESRD patients including pain, fatigue, and depressed mood, and these symptoms are exacerbated among older patients who are already experiencing physiological changes due to aging. Symptom burden is negatively associated with poor quality of life among ESRD patients (Weisbord et al, 2010). Adherence is an especially important self-management behavior, considering that ESRD patients are restricted in the amount of fluid they can consume between HD treatments because their kidneys no longer produce urine. Fluid adherence is difficult for many ESRD patients. As many as 60% of HD patients experience adherence difficulties with fluid intake which places them at an increased risk for mortality and cardiovascular disease (Denhaerynck, Manhaeve, Dobbels, Garzoni, Nolte, & DeGeest, 2007; Kalantar-Zadeh et al., 2009). In addition, ESRD patients are required to adhere to strict diets consisting of low potassium, low phosphorus, and low sodium. Up to 50% of HD patients are nonadherent with diet recommendations (Kutner, Zhang, McClellan, & Cole, 2002), which is associated with increased morbidity, mortality, poor quality of life, and decreased physical functioning (Allen et al., 2002).

Un fortunately, declined cognition is a barrier to successful self-management (Sinclair, Girling, & Bayer, 2000). Cognitive impairment is prevalent among ESRD patients (Sehgal, Grey, DeOreo, & Whitehouse, 1997), and is highest in patients aged 55 and older (Anderson et al., 2009). The potential influence of cognitive status in ESRD self-management cannot be ignored; therefore, this study will also examine the relationship between cognitive status and self-management.
This study draws upon the core theoretical concept guiding the CDSMP: enhanced self-efficacy can improve self-management behaviors. According to self-efficacy theory, behavior is influenced by an individual’s belief in his or her capacity to successfully conduct self-management tasks (Bandura, 1986; Serlachius & Sutton, 2009). Among dialysis patients, increased self-efficacy is associated with improved self-care and fluid adherence (Tsay, 2003; Tsay & Hung, 2004). The relationship of self-efficacy to other self-management behaviors, such as exercise, cognitive symptom management, and communication with physicians, has not been extensively explored with HD patients, and less so with older HD patients. In light of this, and in recognition of the need to distinguish age group differences within aging HD patients in research studies (Passadakis, 2010), the aims of this study are: 1) to explore the self-management behaviors of older adults undergoing HD; 2) to examine the relationship of self-efficacy to self-management behaviors; and 3) to examine the relationship of cognitive status to self-management behaviors.

**Methods**

A total of 107 patients from four nonprofit dialysis facilities in North Carolina were interviewed to learn about their self-management behaviors. Data for these analyses were derived from cross sectional, in-person interviews conducted during each participant’s HD treatment. The interviews lasted approximately 40 minutes in duration. The interviews were conducted at four HD facilities during each participant’s treatment by a master’s level social worker or a registered nurse. Subjects received a $10 store gift card for participating in the study, regardless of whether or not they completed the interview. This study was approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.
Subjects. A list of patient names meeting eligibility criteria was obtained from a staff member in each facility. To be eligible patients had to be aged 50 or older, have a diagnosis of ESRD, undergoing in-center HD, an HD vintage (i.e., months on dialysis) of at least thirty days, cognitively and physically able to complete an interview, English-speaking, and community dwelling (i.e., persons residing in nursing homes or assisted living communities were excluded from the study).

Quantitative Measures

To obtain a bio-psychosocial profile of the participants descriptive information was obtained from each participant (i.e., age, race, years with ESRD, years undergoing HD, education, marital status, living situation, advance directive status, and health status).

Cognitive Status. A modified version of the Saint Louis University Mental Status Examination (SLUMS) was used to assess cognitive status (Banks & Morely, 2003). The SLUMS screens for dementia based on DSM-IV criteria (Tariq et al., 2006). Cronbach’s alpha scores for people with and without high school education ranged from 0.92 to 0.98 (Tariq et al., 2006). Due to dexterity limitations of dialysis patients during dialysis (i.e., being connected to the machine) and in consultation with the developers of the SLUMS (Nina Tumosa, personal communication, July 13, 2012) two items were removed from the 11-item questionnaire that would require use of a writing utensil. Thus, cognitive status was determined based on percentage of overall scores corresponding with percentages of the original version. That is, scores of the modified version ranged from 1 – 26 (1 – 30 in the original version); 1 - 16 is potentially indicative of dementia (1 -15 if less than a high school education), 17-20 indicates mild cognitive impairment (16 - 18 if less than a high school education), 21-26 indicates normal cognition (19 -23 if less than a high school education).
**Health status.** Health status was measured using the Self-Rated Health 5-item questionnaire (α = 0.92), a subscale of the Short Form-36 (Ware & Sherbourne, 1992). Respondents were asked to rate their health as excellent, very good, good, fair, or poor (note: due to distributions in the data, this variable was dichotomized as excellent, very good, and good = 1; fair and poor = 0).

**Self-efficacy.** The CDSMP’s Diabetes Self-Efficacy Scale (α = 0.85) was modified for use with HD patients (Lorig, Ritter, Villa, & Piette, 2001). In order to be more specific to their self-management tasks the modified version (α = 0.53) contains eight items related to ESRD self-management tasks including diet, medication use, treatment adherence, fluid intake, exercise, and vascular access care. Participants rated their level of confidence to perform ESRD-related tasks ranging from 0 (not at all confident) to 10 (totally confident). An example item is: How confident do you feel that you can prepare kidney friendly meals?

**Disease Self-management.** Participants reported self-management behaviors using three measures from the CDSMP. A modified version of the Exercise Behaviors Scale was used to assess weekly exercise activities. The original version (α = 0.76) contains six items and instructs respondents to rate on a 5-point Likert scale the total time in a typical week they do stretching or strengthening exercises, walk, swim, or other aerobic activities. The instrument was reduced to four items in this study to combine “bicycling”, “other aerobic exercise equipment”, and “other aerobic exercise” because based on a systematic review of exercise interventions with ESRD patients, they are most likely to perform aerobic activities that fall into one of these four categories (Heiwe & Jacobson, 2011). The Communication with Physicians Scale is a 3-item measure that assesses how often patients prepare for their doctor’s visits by doing certain things (reliability 0.89) (Lorig et al., 1996). Questions
include how frequently they prepare a list of questions for their doctor, ask questions about the things they want to know about and do not understand about their treatment, and discuss any personal problems that may be related to their illness. The **Cognitive Symptom Management** is a 6-item measure that assesses patient management of symptom burden related to the management of pain and other unpleasant symptoms (reliability 0.83) (Lorig et al., 1996). Using the prompt, “when you are feeling down in the dumps, feeling pain or having other unpleasant symptoms”, an example item is: “how often do you talk to yourself in positive ways?” The response scale for the latter two measures ranges from 0 (never) to 5 (always).

In addition to the measures used in the CDSMP, the frequency subscale of the **Dialysis Diet and Fluid Adherence Questionnaire** was used to evaluate adherent behavior of HD patients (α = .81) (Vlaminck, Maes, Jacobs, Reytjens, & Evers; 2001; Kara, Caglar, & Kilic, 2007). The four-item, self-report measure assesses the frequency and severity of patient deviation from diet and fluid guidelines. The frequency subscale asks, “How many days during the past 14 days did you not follow your diet [fluid] guidelines?” The severity subscale asks, “To what degree did you stray from your diet [fluid] guidelines?” Responses range from 0 (did not stray) to 4 (very severely strayed).

**Qualitative Measures**

To determine the extent to which the quantitative measures addressed self-management behaviors considered important to patients, the interview began with four opened-ended questions related to their kidney disease self-management behaviors: “To you, what is involved in kidney disease self-management?”; “In a typical week, what are things you do to manage living with kidney disease?”; “What helps you manage well?”, and “What
gets in the way of your ability to manage well?” These questions were introduced with a primer, “Self-management means the daily activities and behaviors you perform to live with kidney disease.”

**Analyses**

All quantitative analyses were performed using Stata 12.0 (StataCorp, 2012). Descriptive statistics including means, standard deviations, and percentages were obtained to describe the sample. To explore the self-management behaviors of the participants (aim 1), the sample was divided into three groups by age (i.e., aged 50-59, aged 60-69, aged 70 and older; Passadakis et al [2010] noted differences in age groups within aging HD patients and the importance of age group specification in research studies). Mean scores and standard deviations for the five self-management behaviors (exercise, communication with physicians, cognitive symptom management, fluid adherence, diet adherence) were obtained for each age group. The Kruskal-Wallis test was used to compare the mean score across each age group because the data were not normally distributed (alpha level set at 0.05; two-tailed) and post-hoc comparisons were conducted using the Bonferroni correction.

To examine the relationship of self-efficacy to self-management behaviors (aim 2), self-efficacy scores were categorized into three groups, each containing approximately one-third of the sample based on the distribution of the scores (Yoo, Kim, Jang, & You, 2011): low (mean score of ≤7.9), moderate (mean score 8 - 8.9), and high (mean score ≥9). The Kruskal-Wallis test was used to compare the mean score across each self-efficacy group (i.e., low, moderate, high) because the data were not normally distributed (alpha level set at 0.05; two-tailed).
To examine the relationship of cognitive status to self-management behaviors (aim 3), cognitive status was categorized as potential dementia, mild cognitive impairment, or normal cognition based on the SLUMS scoring criteria. The Kruskal-Wallis test was used to compare the mean score by cognitive status because the data were not normally distributed (alpha level set at 0.05; two-tailed).

The qualitative data were analyzed using the triangulation method. Methodological triangulation combines qualitative and quantitative data in a single study to gain a comprehensive understanding of a phenomenon (Padgett, 1998). The five self-management behaviors (i.e., exercise, communication with physicians, cognitive symptom management, fluid adherence, and diet adherence) were used as codes, and open-ended responses received a code that corresponded to the behavior’s operational definition. The codes of each behavior were then counted. A response received a code of “exercise” if it described walking or other aerobic activities or strengthening for exercise, for example. “Communication with physicians” was assigned to a response if it described behaviors performed during doctor’s visits, such as discussing personal problems or preparing a list of questions. If a response described a cognitive method to deal with unpleasant symptoms such as feeling distant or practicing visualization, it received a code of “cognitive symptom management”. Any responses related to fluid management (e.g., staying within fluid intake between treatments) or diet management (e.g., avoiding foods high in phosphorus or potassium) received a code of “fluid adherence” or “diet adherence”, respectively. The codes were counted and compared to the percentage of respondents who reported each behavior in the quantitative responses. The data had other codes in two categories: aspects of self-management (e.g.,
medication management, religion/spirituality, access care) and barriers to self-management (e.g., transportation, physical impairment, caregiving).

**Results**

**Quantitative**

In total, 123 patients were approached for interviews. Among them, four were excluded due to their inability to complete the interview (e.g., they appeared disoriented) and twelve refused to participate, resulting in an 87% participation rate. The mean age was 63 (SD=8.6) and the average dialysis vintage was 86 months (SD=90). The sample was divided nearly evenly between males (51%) and females (49%). Twenty nine percent completed high school and 44% had at least some college. The majority of participants were black (65%), reported fair or poor health status (54%), had potential dementia (52%), lived with others in a private residence (64%), and did not possess an advance directive (70%).

Participant characteristics are reported in Table 1.

Participants spent greater than one hour exercising in the past week and “sometimes” communicated with their physicians, on average. Also, participants almost never used cognitive symptom management skills (0.89; range 0 – 30). Last, participants adhered to their fluid and diet regimen for more than 11 days during the past two weeks (11.86 and 11.65, respectively).

**Self-management behaviors by age group.** The mean scores of self-management behaviors by age group are shown in Table 2. There were statistically significant age group differences in the self-management behavior of fluid adherence (p = 0.04). Compared to other age groups, the 60 to 69 age group spent more time communicating with their physicians (Mean ± SD, 2.74 ± 1.56), and the 70 and older age group spent the least (Mean ±
Similarly, the 50 to 59 age group spent fewer days in a two week period adhering to their fluid restrictions (Mean ± SD, 12.08 ± 4.03). The 70 and older age group managed their fluid intake better than any other age group as evidenced by their mean scores (13.15, higher scores indicate more days in a two week period adherent).

There were no statistically significant differences in exercise behaviors, cognitive symptom management, and diet adherence by age group, although exercise behaviors decreased as age increased (e.g., Mean ± SD, 2.82 ± 2.11 in the 50-59 age group, 1.72 ± 1.90 in 70 and older age group). The 60 to 69 age group spent more time engaging in cognitive symptom management (Mean ± SD, 0.98 ± 0.95), and less time adhering to their diet (Mean ± SD, 11.13 ± 3.91) than other age groups.

Self-management behaviors by level of self-efficacy. Group differences in self-management behaviors by level of self-efficacy are shown in Table 3. Overall, the participants had high self-efficacy for managing ESRD (Mean ± SD, 8.49 ± 1.11). The proportions of participants in the low self-efficacy group, moderate self-efficacy group, and high self-efficacy group were 30%, 34%, and 36%, respectively (these cut points were selecting to derive approximately equal groups). The low self-efficacy group spent more days over a two week period not adhering to their diet restrictions (11.19; possible range 0 to 14; higher number indicates more days adherent), but used more cognitive symptom management skills (approaching significance at p = 0.06) than the moderate and high self-efficacy groups. While not significantly different, the high self-efficacy group spent more time exercising per week, communicated better with physicians, and spent more days over a two week period adhering to their fluid restrictions.
**Self-management behaviors by cognitive status.** Group differences in self-management behaviors by cognitive status are shown in Table 4. As indicated using the SLUMS, the majority of the participants had potential dementia (52%). The proportions of participants with mild cognitive impairment and normal cognition were 37% and 11%, respectively. There were no statistically significant differences in self-management behaviors by cognitive status. Compared to other cognitive levels, participants with potential dementia had the lowest mean self-management scores in exercise behaviors \((M = 2.20)\), communication with physicians \((M = 2.39)\), and cognitive symptom management \((M = 0.92)\), but had the highest mean scores in fluid adherence \((M = 12.51)\) and diet adherence \((M = 12.27)\). Participants with normal cognition had the highest mean scores in exercise behaviors \((M = 3.27)\), communication with physicians \((M = 3.21)\), and cognitive symptom management \((M = 1.23)\), but had the lowest mean scores in fluid adherence \((M = 9.00)\) and diet adherence \((M = 10.00)\).

**Qualitative**

When describing their self-management behaviors, no respondents discussed communicating with their physicians; however, 90% of respondents reported on the Communication with Physicians scale that they do communicate with their physicians to some extent (i.e., scored 1 or more on the Likert scale ranging from never to always). Cognitive symptom management also received zero codes, but 77% of the respondents reported engaging in cognition symptom management on the Cognitive Symptom Management Scale to some extent. Exercise received 28 codes, and 73% of respondents reporting engaging in weekly exercise (i.e., walking, stretching, strengthening, swimming, or other cardio exercise). Fluid adherence received 73 codes (47% reporting being completely
adherent in a two week period), and diet adherence received 138 codes (with 57% reporting being completely adherent in a two week period (see Table 5).

**Discussion**

In the coming decades, health care social workers will encounter more older adults (Berkman, Gardner, Zodikoff, & Harootyan, 2005), and nephrology social workers are no exception. The disproportionate increase in ESRD prevalence among older adults is a public health concern and a major issue for health social work. Older ESRD patients face challenging problems such as frequent hospitalizations and a growing need for rehabilitation services (Williams, Sandeep, & Catic 2012). Therefore, a better understanding of their self-management behaviors is warranted. To the author’s knowledge, this is the first mixed methods study of the self-management behaviors of older ESRD patients (with and without potential dementia) using the theoretical assumptions guiding the CDSMP.

The first aim of this study was to explore self-management behaviors. Participants were exercising for greater than 60 minutes per week, on average. According to the Centers for Disease Control and Prevention, older adults should exercise at least two and a half hours each week to maintain good health (Centers for Disease Control and Prevention, 2011), and according to the National Kidney Foundation, dialysis patients should exercise for 30 to 45 minutes most days of the week to maximize its benefits (National Kidney Foundation, 2010). Based on these exercise recommendations, participants were exercising slightly less than is required for health benefits. Also, participants are communicating with their physicians “sometimes” to “fairly often”, on average. This finding informs the frequency of communication, but there are insufficient data to inform the quality of the communication. Quality patient-provider communication is essential for improved patient outcomes (Green,
Rothman, & Cavanaugh, 2012). Moreover, participants almost never used cognitive symptom management skills such as practicing visualization or guided imagery. Finally, in a two week period, participants spent an average of 11 days adhering to their diet and fluid.

Although participants aged 60 to 69 had the highest mean scores for communication with physicians (i.e., their mean scores were higher than the overall mean and compared to other groups), the mean score for all participants was relatively low considering the range of possible scores (i.e., 0-15, mean score = 2.50). This is concerning, because patient-provider communication is significantly associated with disease self-management, improved health outcomes, and adherence to treatment plans (Heisler, Chernett, Harris, Palmer, Hopkins, & Dennis, 2002). HD patients have frequent contact with their physicians who see their patients on a regular basis in HD facilities. This finding may imply the need to empower HD patients to make their physician encounters more productive by doing things like preparing a list of questions relating to their illness or treatment.

By parsing out the behaviors’ mean scores by age group, statistically significant age-related trends in fluid adherence became evident. With the exception of the oldest age group, there was an increase in fluid adherence with each increase in age group. This corresponds with findings from other studies showing lower adherence rates among younger HD patients (Kutner, Zhang, McClellan, & Cole, 2002; Cummings et al., 1982; Kimmel, 2000). The youngest age group adhered less than the oldest age group in a two week period (i.e., 11.14 days and 12.86 days, respectively). The total sample was adherent for 11.86 days. That translates to 2.14 days of excessive fluid consumption. It is difficult to conclude whether or not being nonadherent with fluid guidelines for, on average, 2.14 of 14 days is high enough to have serious consequences because the field lacks a threshold of adherence to prevent
complications (Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009). Still, given the complications associated with fluid nonadherence (e.g., pulmonary edema, congestive heart failure, hypertension, and mortality) (Schneider, Friend, Whitaker, & Wadhwa, 1991; Christensen, Benotsch, & Smith, 1997; Welch, 2001; Sarkar, Kotanko, & Levin, 2006; Lai et al., 2012), HD patients could benefit from comprehensive self-management interventions that target long-term fluid adherence.

The author used self-efficacy as a guiding theoretical concept for this study because self-efficacy relates to self-management behaviors in many chronic conditions, including ESRD. Despite the overall low mean scores in exercise (i.e., 2.46), communication with physicians (i.e., 2.50), and cognitive symptom management (i.e., 0.89), participants reported high self-efficacy over their self-management tasks collectively (scores range from 0 to 10; mean score = 8.49. There were differences between self-efficacy groups in cognitive symptom management (approaching statistical significance at p = 0.06), demonstrating that participation in cognitive symptom management was associated with self-efficacy. Although the causal nature and direction of the relationship cannot be determined, it may suggest that being self-efficacious over other self-management behaviors requires less use of cognitive symptom management skills. Also, higher self-efficacy scores corresponded with better self-management in the areas of exercise, communication with physicians, and fluid adherence, although the associations were not statistically significant. It could be that this study was not sufficiently powered to detect these differences, and suggests avenues for further study. Still, the findings from this study support the use of interventions with self-efficacy as a guiding construct by affirming the association between self-efficacy and self-management among older ESRD patients.
Interestingly, no one described communication with physicians or cognitive symptom management as a component of self-management, despite the fact that 90% and 77%, respectively, reported engaging in those behaviors. Fluid and diet adherence, on the other hand, were commonly considered to be self-management behaviors (receiving 73 and 138 codes, respectively). Taken together, these findings suggest that compared to other self-management behaviors, diet and fluid management are perceived as the most important. Managing aspects of the HD diet (e.g., avoiding foods high in phosphorus or potassium) and limiting fluid intake are important, because fluid nonadherence is associated with dizziness, hypertension, shortness of breath, cramping, and mortality (Schneider, Friend, Whitaker, & Wadhwa, 1991; Christensen, Benotsch, & Smith, 1997), and diet nonadherence can lead to cardiac arrest (Wright, 1981). It is not surprising that participants recognize the management of diet and fluid as important; however, this does not explain why 81% of patients continue to be nonadherent with their diet regimen and 75% with their fluid regimen (Kuglar, Vlaminck, Haverich, & Maes, 2005).

Cognitive impairment is a common problem in the ESRD population (Tamura & Yaffe, 2011), and associations between cognitive impairment and self-management behaviors among participants in this study are worth discussing. Although not statistically significant, there were noteworthy differences in the degree of performance across all self-management behaviors by cognitive status. Of note, participants with potential dementia spent less time exercising, communicating with physicians, and engaging in cognitive symptom management, but spent more days adhering to fluid and diet recommendations than participants with mild or normal cognitive status. In comparison, participants with normal cognition exercised, communicated with physicians, and engaged in cognitive symptom
management more frequently, but were more nonadherent to diet and fluid recommendations than other groups (e.g., participants with normal cognitive statuses were nonadherent with fluid guidelines for an average of five days compared to people with potential dementia who were nonadherent for an average of less than three days).

Although facility staff were asked to exclude names of patients who were cognitively unable to complete an interview, over half the sample fell into the “potential dementia” range. As indicated previously, cognitive status was measured using the SLUMS and was modified by removing two items reducing the range of scores from 1-30 to 1-26. Participants with mild cognitive impairment could have been under counted in the process because the two items that were removed related to performance of motor skills (i.e., apraxia; placement of hour markers on a clock and placing an “X” in a triangle). Apraxia commonly occurs in early onset dementia (Koedam et al., 2010). Another explanation for the prevalence of potential dementia in this sample is that HD causes cognitive decline due to microbubbles that travel in the blood lines (Forsberg, Jonsson, Stegmayr, & Stegmayr, 2010). These cases were not excluded from analyses because understanding their self-management is important, especially in light of the high prevalence of cognitive impairment among HD patients.

**Implications for Social Work Practice**

Nephrology social workers possess skills to address psychosocial barriers to optimal ESRD outcomes (Browne, 2012). The low mean scores of self-management behaviors in this study suggest the need for continued social work intervention to improve ESRD self-management. Unfortunately, a comprehensive disease self-management program has yet to be designed and tested for the ESRD population (Curtain, Mapes, Schatell, & Burrows-Hudson, 2005). If a program did exist then social workers would have a tool to improve
these and other important ESRD self-management behaviors with their patients. Browne and Merighi (2010) proposed that more behavioral interventions are needed to promote adherence.

One strategy social workers might utilize to improve self-management is through awareness-raising. The findings in this study reveal that HD patients are participating in self-management in the areas of communication with physicians and cognitive symptom management to a great degree (i.e., 90% and 77% of participants, respectively), but are unaware of them as an aspect of ESRD self-management (as evidenced by the lack of codes in the qualitative findings). Also, social workers may consider communication with physicians, cognitive symptom management, and fluid adherence (i.e., self-management behaviors showing a statistically significant relationship, or approaching significance, by age group and self-efficacy) as integral to social work intervention. Specifically, social workers can educate patients about how to effectively communicate with their physicians and other health care providers, and teach patients effective cognitive strategies to respond to unpleasant symptoms such as visualization.

Given the amount of time ESRD patients already spend in an HD clinic (i.e., HD is performed thrice weekly ranging from four to five hours each treatment) (Barnett, Yoong, Pinikahana, & Si-Yen, 2007) is it reasonable to assume a disease self-management intervention can be successfully implemented in a dialysis facility? The majority of participants in this study expressed interest in a self-management intervention despite their rigorous schedule. When asked, “If there were a kidney disease self-management program offered at this facility, would you participate?” 78% of the participants responded, “yes.” Participants noted a variety of times they would participate; including their “off days”, before
treatment, or immediately after. Five participants indicated they would participate during their dialysis treatment. The logistics of implementing a chronic disease self-management program are intriguing to consider, because dialysis patients have consistent contact with their nephrology health care team which creates an opportunity to engage patients in disease self-management education (Washington, Hilliard, & McGill, in press).

**Limitations**

Several limitations of this study are worth noting. First, participants were recruited from a convenience sample and pre-identified by dialysis facility staff. Also, the sample size is too small for more advanced statistical analyses which might examine the relationship of facility and staff characteristics (e.g., facility affiliation or turnover) to self-management which themselves may account for some variation in self-management behaviors. Therefore, inferences to the larger ESRD population are cautioned. Second, the qualitative data have not been coded by a second rater, a gold standard method of qualitative analysis to improve validity. Also, these data are cross-sectional; predictors of self-management behaviors cannot be examined. Finally, this study relies on patient self-report and the data were not corroborated by the patient medical record. However, despite these limitations, this is the first study to report the self-management behaviors of older ESRD patients and utilize qualitative methods to substantiate quantitative findings related to the self-management behaviors of ESRD patients. This is important, because future research can build on these findings to inform the development of self-management interventions with older adults, the fastest growing segment of the ESRD population.
Conclusion

In conclusion, the findings from this study support the use of interventions with self-efficacy as a guiding construct, such as the CDSMP, by affirming the association between self-efficacy and self-management among older ESRD patients. Given the recent changes to the Conditions for Coverage for End-Stage Renal Disease facilities, in which the Centers for Medicare and Medicaid Services (CMS) places great emphasis on increased patient participation in their health care (i.e., self-management) (Federal Register, 2008 [§ 494.80]), and the pending growth of the aging populations, a comprehensive chronic disease self-management intervention is a timely and important venture.
References


StataCorp. (2012). Stata Statistical Software: Release 12. College Station, TX: StataCorp LP


Tumosa, N. Personal communication. July 13, 2012


### Table 1

**Descriptive Statistics**

<table>
<thead>
<tr>
<th>Participant characteristics (N = 107)</th>
<th>Mean (SD) or N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>63 (8)</td>
</tr>
<tr>
<td>Months on hemodialysis</td>
<td>86 (90)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>55 (51)</td>
</tr>
<tr>
<td>Female</td>
<td>52 (49)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>35 (33)</td>
</tr>
<tr>
<td>Black</td>
<td>69 (65)</td>
</tr>
<tr>
<td>Other(^a)</td>
<td>3 (2)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Did not graduate high school</td>
<td>28 (26)</td>
</tr>
<tr>
<td>High school diploma or GED</td>
<td>32 (30)</td>
</tr>
<tr>
<td>Some college</td>
<td>26 (24)</td>
</tr>
<tr>
<td>College graduate or higher(^b)</td>
<td>21 (20)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>43 (40)</td>
</tr>
<tr>
<td>Single</td>
<td>20 (19)</td>
</tr>
<tr>
<td>Divorced</td>
<td>20 (19)</td>
</tr>
<tr>
<td>Widowed</td>
<td>17 (16)</td>
</tr>
<tr>
<td>Other(^c)</td>
<td>7 (6)</td>
</tr>
<tr>
<td>Health Status(^d)</td>
<td></td>
</tr>
<tr>
<td>Good or better</td>
<td>49 (46)</td>
</tr>
<tr>
<td>Fair or poor</td>
<td>58 (54)</td>
</tr>
<tr>
<td>Cognition(^e)</td>
<td></td>
</tr>
<tr>
<td>Normal</td>
<td>11 (11)</td>
</tr>
<tr>
<td>Mild cognitive impairment</td>
<td>40 (37)</td>
</tr>
<tr>
<td>Potential dementia</td>
<td>56 (52)</td>
</tr>
<tr>
<td>Living Situation</td>
<td></td>
</tr>
<tr>
<td>Lives with others in a private residence</td>
<td>68 (64)</td>
</tr>
<tr>
<td>Lives alone</td>
<td>39 (36)</td>
</tr>
<tr>
<td>Advance Directive</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>75 (70)</td>
</tr>
<tr>
<td>Health care power of attorney and living will</td>
<td>18 (17)</td>
</tr>
<tr>
<td>Health care power of attorney only</td>
<td>10 (9)</td>
</tr>
<tr>
<td>Living will only</td>
<td>4 (4)</td>
</tr>
</tbody>
</table>

\(^a\)Other races are American Indian, Asian
\(^b\)Includes Bachelor’s degree, Associates degree, or graduate degree
\(^c\)Other marital statuses are not married but partnered, or separated
\(^d\)Health status dichotomized as excellent, very good, good vs. fair and poor
\(^e\)Based on the SLUMS, scores range from 1 to 26; 1 to 16 indicates potential dementia (1 to 15 if less than high school education), 17-20 indicates mild cognitive impairment (16-18 if less than high school education), 21-26 indicates normal cognition (19-23 if less than high school education).
Table 2

*Self-management Behaviors by Age Group*

<table>
<thead>
<tr>
<th></th>
<th>Total (N = 107)</th>
<th>50-59 (n = 45)</th>
<th>60-69 (n = 40)</th>
<th>70+ (n = 22)</th>
<th>p(^a)</th>
<th>Post-hoc comparison(^b)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise (range 0-20)(^c)</td>
<td>2.46 (2.10)</td>
<td>2.82 (2.11)</td>
<td>2.45 (2.12)</td>
<td>1.72 (1.90)</td>
<td>0.18</td>
<td>n/a</td>
</tr>
<tr>
<td>Communication With Physicians (range 0-15)(^d)</td>
<td>2.50 (1.47)</td>
<td>2.48 (1.49)</td>
<td>2.74 (1.56)</td>
<td>2.10 (1.22)</td>
<td>0.05</td>
<td>n/a</td>
</tr>
<tr>
<td>Cognitive Symptom Management (range 0-30)(^e)</td>
<td>0.89 (0.89)</td>
<td>0.81 (0.80)</td>
<td>0.98 (0.95)</td>
<td>0.87 (0.96)</td>
<td>0.51</td>
<td>n/a</td>
</tr>
<tr>
<td>Fluid Adherence (range 0-14)(^f)</td>
<td>11.86 (3.56)</td>
<td>11.14 (4.03)(^g)</td>
<td>12.08 (3.34)(^h)</td>
<td>12.86 (2.70)</td>
<td>0.04</td>
<td>50-59 &lt; 70+, p = 0.0001; 60-69 &lt; 70+, p = 0.0001</td>
</tr>
<tr>
<td>Diet Adherence (range 0-14)(^i)</td>
<td>11.65 (3.40)</td>
<td>11.45 (3.33)(^h)</td>
<td>11.13 (3.91)</td>
<td>13.15 (1.79)(^h)</td>
<td>0.15</td>
<td>n/a</td>
</tr>
</tbody>
</table>

\(^a\) The Kruskal-Wallis test was used to compare the mean score across age groups. Items in bold are statistically significant at < 0.05.

\(^b\) Comparisons significant at 0.05 level with Bonferroni correction. Only comparisons < 0.05 are shown.

\(^c\) Higher score more time spent exercising

\(^d\) Higher score more communication

\(^e\) Higher score more use of cognitive symptom management skills

\(^f\) Higher score more days adherent

\(^g\) 2 missing cases deleted from analyses

\(^h\) 1 missing case deleted from analyses
<table>
<thead>
<tr>
<th></th>
<th>Self-efficacy&lt;sup&gt;a&lt;/sup&gt;</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (n=107)</td>
<td>Low (n = 32)</td>
<td>Moderate (n = 36)</td>
<td>High (n = 39)</td>
<td>p&lt;sup&gt;b&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean(SD)</td>
<td>Mean(SD)</td>
<td>Mean(SD)</td>
<td>Mean(SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exercise (range 0-20)&lt;sup&gt;c&lt;/sup&gt;</td>
<td>2.46 (2.10)</td>
<td>2.03 (3.61)</td>
<td>2.11 (1.83)</td>
<td>3.13 (2.13)</td>
<td>0.24</td>
<td></td>
</tr>
<tr>
<td>Communication With Physicians (range 0-15)&lt;sup&gt;d&lt;/sup&gt;</td>
<td>2.50 (1.47)</td>
<td>2.39 (1.33)</td>
<td>2.51 (1.55)</td>
<td>2.58 (1.55)</td>
<td>0.51</td>
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<tr>
<td>Cognitive Symptom Management (range 0-30)&lt;sup&gt;e&lt;/sup&gt;</td>
<td>0.89 (0.89)</td>
<td>1.01 (0.89)</td>
<td>0.99 (0.94)</td>
<td>0.70 (0.82)</td>
<td>0.06</td>
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<tr>
<td>Fluid Adherence (range 0-14)&lt;sup&gt;f&lt;/sup&gt;</td>
<td>11.86 (3.56)</td>
<td>11.19 (3.61)</td>
<td>12.06 (3.45)&lt;sup&gt;g&lt;/sup&gt;</td>
<td>12.24 (3.64)&lt;sup&gt;h&lt;/sup&gt;</td>
<td>0.35</td>
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<tr>
<td>Diet Adherence (range 0-14)&lt;sup&gt;i&lt;/sup&gt;</td>
<td>11.65 (3.40)</td>
<td>10.29 (4.44)&lt;sup&gt;g&lt;/sup&gt;</td>
<td>12.43 (1.61)&lt;sup&gt;g&lt;/sup&gt;</td>
<td>12.05 (3.39)&lt;sup&gt;g&lt;/sup&gt;</td>
<td>0.10</td>
<td></td>
</tr>
</tbody>
</table>

<sup>a</sup>Self-efficacy scores range from 0-10. Self-efficacy mean score of total sample = 8.49, SD = 1.11.

Self-efficacy scores were categorized into low (mean score of 7.875 or less), moderate (mean score of 8 to 8.875), and high (mean score of 9 or higher)

<sup>b</sup>The Kruskal-Wallis test was used to compare the mean score across levels of self-efficacy

<sup>c</sup>Higher score more time spent exercising

<sup>d</sup>Higher score more communication

<sup>e</sup>Higher score more use of cognitive symptom management skills

<sup>f</sup>Higher score more days adherent

<sup>g</sup>1 missing case deleted from analyses

<sup>h</sup>2 missing cases deleted from analyses
Table 4

*Self-management Behaviors by Cognition*<sup>a</sup>

<table>
<thead>
<tr>
<th></th>
<th>Total (n=107) Mean(SD)</th>
<th>Potential Dementia (n = 56) Mean(SD)</th>
<th>Mild Cognitive Disorder (n = 40) Mean(SD)</th>
<th>Normal Cognition (n = 11) Mean(SD)</th>
<th>P&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise (range 0-20)&lt;sup&gt;c&lt;/sup&gt;</td>
<td>2.46 (2.10)</td>
<td>2.20 (1.77)</td>
<td>2.60 (2.46)</td>
<td>3.27 (2.15)</td>
<td>0.43</td>
</tr>
<tr>
<td>Communication with Physicians (range 0-15)&lt;sup&gt;d&lt;/sup&gt;</td>
<td>2.50 (1.47)</td>
<td>2.39 (1.50)</td>
<td>2.45 (1.50)</td>
<td>3.21 (1.10)</td>
<td>0.11</td>
</tr>
<tr>
<td>Cognitive Symptom Management (range 0-30)&lt;sup&gt;e&lt;/sup&gt;</td>
<td>0.89 (0.89)</td>
<td>0.92 (0.95)</td>
<td>0.75 (0.76)</td>
<td>1.23 (0.94)</td>
<td>0.56</td>
</tr>
<tr>
<td>Fluid Adherence (range 0-14)&lt;sup&gt;f&lt;/sup&gt;</td>
<td>11.86 (3.56)</td>
<td>12.51 (3.00)&lt;sup&gt;g&lt;/sup&gt;</td>
<td>11.74 (3.10)&lt;sup&gt;h&lt;/sup&gt;</td>
<td>9.00 (5.94)</td>
<td>0.24</td>
</tr>
<tr>
<td>Diet Adherence (range 0-14)&lt;sup&gt;i&lt;/sup&gt;</td>
<td>11.65 (3.40)</td>
<td>12.27 (2.56)&lt;sup&gt;g&lt;/sup&gt;</td>
<td>11.24 (3.70)&lt;sup&gt;h&lt;/sup&gt;</td>
<td>10.00 (5.22)</td>
<td>0.26</td>
</tr>
</tbody>
</table>

<sup>a</sup> Based on the SLUMS, scores range from 1 to 26; 1 to 16 indicates dementia (1 to 15 if less than high school education), 17-20 indicates mild cognitive impairment (16-18 if less than high school education), 21-26 indicates normal cognition (19-23 if less than high school education); 52% of patients had dementia, 37% had mild cognitive disorder, 11% had normal cognition.

<sup>b</sup> The Kruskal-Wallis test was used to compare the mean score across levels of self-efficacy.

<sup>c</sup> Higher score more time spent exercising

<sup>d</sup> Higher score more communication

<sup>e</sup> Higher score more use of cognitive symptom management skills

<sup>f</sup> Higher score more days adherent

<sup>g</sup> 1 missing cases deleted from analyses

<sup>h</sup> 2 missing cases deleted from analyses
Table 5  
*Self-management Behaviors: Mixed Methods Results*

<table>
<thead>
<tr>
<th>Self-management behaviors</th>
<th>Number of codes</th>
<th>Percentage of respondents engaged in self-management behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise</td>
<td>28</td>
<td>73%</td>
</tr>
<tr>
<td>Communication with physicians</td>
<td>0</td>
<td>90%</td>
</tr>
<tr>
<td>Cognitive symptom management</td>
<td>0</td>
<td>77%</td>
</tr>
<tr>
<td>Fluid adherence over two weeks</td>
<td>73</td>
<td>47%</td>
</tr>
<tr>
<td>Diet adherence over two weeks</td>
<td>138</td>
<td>57%</td>
</tr>
</tbody>
</table>

Percentage of respondents reporting each behavior on quantitative analysis
Depression, Social Support, Self-Efficacy, Demographics, and Fluid Adherence in Older Adults on Hemodialysis

Overview

Controlled fluid intake is an important aspect of kidney disease self-management, yet depression, the most common psychiatric issue affecting older end-stage renal disease (ESRD) patients, negatively impacts fluid adherence. Factors that mitigate depression’s deleterious effects are underexplored, and if identified, can inform the design and development of psychosocial interventions to reduce its negative impact and improve fluid adherence with older ESRD patients. This paper examines social support, self-efficacy, demographic characteristics, and health status as potential mediators between depression and fluid adherence among 107 ESRD patients aged 50 and older. Using logistic regression, age was associated with an increase in fluid adherence (adjusted odds ratio {AOR} = 1.08, 95% confidence interval {CI} = 1.02-1.14), whereas depression was associated with a decrease in fluid adherence (AOR = 0.82, 95% CI = 0.67-0.99), but when self-efficacy was entered into the model, the association between depression and fluid adherence weakened. Among black participants, depression was negatively associated with fluid adherence (r = -0.26, p < .05), and self-efficacy and age were positively associated with adherence (r = 0.24, p < 0.05 and r = 0.32, p < 0.01, respectively). Taken together, the findings from this study suggest that self-efficacy and age are important factors in fluid adherence, and self-efficacy can potentially mediate the negative effects of depression in older ESRD patients. Future interventions must
consider cultural uniqueness of ESRD subgroups, and theoretical models, such as self-efficacy theory, should guide the development of fluid adherence interventions. Advanced statistical methods (e.g., structural equation modeling) and longitudinal studies are required to determine the effects of depression on fluid adherence and the extent to which it is mediated by self-efficacy.
**Introduction**

End-stage renal disease (ESRD) is an advanced stage of chronic kidney disease requiring renal replacement therapy to sustain life. ESRD affects over 570,000 people in the United States, and is expected to grow to nearly 800,000 people by 2020 (USRDS, 2007). Older adults are driving the growth of the ESRD population (USRDS, 2011). Thirty-seven percent of people living with ESRD are aged 65 and older (USRDS, 2009), and compared to other age groups, older adults have the highest adjusted incident rate of ESRD (USRDS, 2011).

Hemodialysis (HD) is the primary treatment for ESRD in the United States, used to treat over 380,000 patients (USRDS, 2012). Older adults represent the highest proportion of patients on HD (67%) (USRDS, 2009), and primarily select this as their renal replacement therapy of choice (Dimkovic & Oreopoulos, 2009). HD removes toxins and excess fluid from the body and is typically performed in an outpatient clinic three times per week, for an average of four hours per treatment (Chilcot, Wellsted, & Farrington, 2010). Self-management of HD is complex. Patients undergoing HD treatment must manage dietary restrictions (e.g., avoid potassium and phosphorus-rich foods) and are often managing multiple daily medications for blood pressure control, anemia, and other physical problems commonly associated with ESRD. Compared to peritoneal dialysis, a renal replacement therapy option using the abdominal lining to filter blood, self-management of ESRD is more complex for HD patients because HD severely restricts fluid intake. These patients’ fluid intake between treatments should not exceed 500 mL to 1.5 liters (Nanovic, 2005; Ash et al., 2006).
Unfortunately, fluid management is difficult for an estimated 50% to 70% of HD patients (Bame, Petersen, & Wray, 1993; Christenen & Moran, 1998; Kulger, Vlaminck, Haverich, & Maes, 2005) largely due to thirst and increased sodium intake (Sarkar, Kotanko, & Levin, 2006; Lai et al., 2012). When HD patients consume more than the recommended fluid intake between treatments, they can experience symptoms of fluid overload including cramping, shortness of breath, and dizziness. Deviation from recommended fluid prescriptions can result in negative health outcomes including pulmonary edema, congestive heart failure, hypertension, and mortality (Schneider, Friend, Whitaker, & Wadhwa, 1991; Christensen, Benotsch, & Smith, 1997; Welch, 2001; Sarkar, Kotanko, & Levin, 2006; Lai et al., 2012). Interventions to reduce fluid intake have shown some success, such as using visual aids to educate patients about typical fluid volume (Pace, 2007), chewing gum and providing saliva substitutes to alleviate thirst (Bots et al., 2004), self-efficacy training (Tsay, 2003), and cognitive behavioral techniques such as positive reinforcement (Sagawa et al., 2001). Still, the issue of maintaining adequate fluid levels between treatments continues to be a struggle for HD patients.

Depression is a barrier to fluid adherence. Depression severely impacts health outcomes (Egede & Ellis, 2007) and is the most common psychiatric issue affecting an estimated 20% to 30% of patients on HD (Kimmel, 2000; Kimmel, 2001; Cohen, Norris, Acquaviva, Peterson, & Kimmel, 2007; Chilcot, Wellsted, & Farrington, 2009; Feroze et al., 2012). Higher depression scores in HD patients is negatively associated with patient nutritional status and poor health outcomes (Kimmel & Peterson, 2006; Finkelstein, Wuerth, Troidle, & Finkelstein, 2008), frequent hospitalizations, and mortality (Katon & Ciehanowski, 2002; Kalendar, Ozdemir, Koroglu, 2005). Also, depression is the most
common mental health condition experienced by older adults, often goes undetected, and is exacerbated when combined with a physical illness (Lebowitz, Pearson, & Schneider, 1997), yet factors that mediate the negative effects of depression in the ESRD population are underidentified (Kimmel, 2002).

Despite the fact that depression is highly prevalent among black HD patients (Cukor et al., 2007), 37% of HD patients are black, and blacks comprise the highest prevalent rates of ESRD (USRDS, 2012), there is mixed evidence to draw conclusions about the relationship of race to fluid adherence. One study found black patients to be 1.4 times more likely to comply with fluid intake recommendations compared to whites (Bray, Peterson, & Wray, 1993); however, another study found black patients are more likely to experience fluid overload (Arneson et al., 2010). Also, review of behavioral interventions to improve fluid adherence found only one study reporting treatment effects by race (Welch, Thomas-Hawkins, 2005), but the effects were not statistically significant. An examination of race differences is important, because blacks develop ESRD at earlier ages and have a higher risk of mortality than whites (National Kidney Foundation, 2009). According to the USRDS (2012), blacks have an ESRD incident rate of 3.8 times higher than whites, especially for blacks aged 60 and older.

Few studies have examined the relationship of depression and other potentially modifiable factors to fluid adherence solely among older adults on HD, the fastest growing segment of the ESRD population, and examined differences by race. In recognition of the need to identify these factors in light of depression, this papers aims to 1) examine associations of fluid adherence and age group; 2) identify factors that can potentially mitigate the deleterious effects of depression on fluid adherence by comparing four logistic regression
models containing factors previously identified as having direct associations with fluid adherence (i.e., self-efficacy, social support, sex, age, education, and dialysis vintage; and 3) compare differences in fluid adherence by race.

An examination of potential mediators between depression and fluid adherence is an important endeavor because ESRD is a significant public health concern in the United States. Treatment of complications related to nonadherence is costly. More than seven percent of the entire Medicare budget ($29 billion) is spent on ESRD services alone, which translates to $87,000 per person on HD per year (USRDS, 2012). Fluid nonadherence relates to increased costs primarily due to frequent hospitalizations. In an emergency situation, such as when a patient experiences shortness of breath due to fluid overload, additional treatment usually occurs in a hospital setting at a cost of $6,372 per additional treatment (Arneson et al., 2010). In fact, one study found the annual costs associated with fluid overload to be as high as $266 million (Arneson et al., 2010). Thus, it is no surprise that reducing costs and improving ESRD outcomes is a Healthy People 2020 goal (U.S. DHHS, 2013). By identifying potential mediating factors associated with fluid adherence this study can inform the development and implementation of interdisciplinary interventions to improve fluid adherence and reduce associated health-care costs. Also, there is some evidence that self-efficacy, social support, and demographic factors are associated with fluid adherence. Consequently, these factors could potentially mediate depression and fluid adherence. Their mediation potential will be examined in this study.

**Self-efficacy.** In the context of this study, self-efficacy is a belief in one’s ability to successfully manage HD-related tasks, and has been shown to improve fluid adherence (Tsay, 2003; Wells & Anderson, 2011). Self-efficacy refers to a person’s beliefs about his or
her ability to carry out a behavior in various situations (Serlachius & Sutton, 2009). Self-efficacy influences health behaviors through the process of goal setting, such that individuals with high self-efficacy set goals to perform a health-related behavior to achieve a desirable health outcome (Cox, 2006; Grembowski et al., 1993). High self-efficacy is associated with improved health outcomes among chronically-ill adults (Lorig et al., 2001; Steed, Lankester, & Barnard, 2005), including decreased hospitalizations and improved quality of life among HD patients (McMurray, Johnson, Davis, & McDougall, 2002).

**Social Support.** Social supports, such as family and friends, help HD patients adhere to fluid restrictions (Smith et al., 2010; Patel, Peterson, & Kimmel, 2005; Cohen, Sharma, Acquaviva, Peterson, Patel, & Kimmel, 2007). HD patients also view their medical providers as sources of social support (Browne, 2011). In older adults with chronic disease, social support is particularly important because it is associated with better coping skills, decreased stress, and less functional decline (Hyduk, 1996; Bierman & Statland, 2010).

**Demographic Characteristics.** Sex (Everett, Brantely, Sletten, & Jones, 1995), education (Cummings, Becker, Kirsch, & Levin, 1982), age, and months undergoing hemodialysis (i.e., dialysis vintage; Kuglar, Vlaminck, Haverich, & Maes, 2005) are important demographic factors associated with fluid adherence. Women adhere better than men, and education, older age, and fewer months on dialysis are positively associated with adherence (Kutner, Zhang, McClellan, & Cole, 2002; Cummings, Becker, Kirsch, & Levin, 1982; Kimmel, 2000).
Methods

Subjects and Recruitment.

Participants were recruited from four hemodialysis facilities in North Carolina. Facility social workers distributed recruitment flyers to patients meeting eligibility criteria (i.e., aged 50 and older, undergoing in-center hemodialysis for at least 30 days, community-dwelling, and English-speaking). Patients who were cognitively or physically unable to complete an interview based on staff assessment were excluded from recruitment. The facility staff provided names and treatment schedules of eligible patients. Eligible patients were approached during their HD treatment, provided a description of the purpose of the study, and invited to participate. Informed consent was obtained prior to the interview. Patients received a $10 store gift card for participating in the study, regardless of whether or not they completed the interview. The interviews were conducted at four HD facilities during each participant’s treatment by a master’s level social worker or a registered nurse. The study was approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

Data Collection

Participants were interviewed in-person during their HD treatment between June and August of 2012. Most participants agreed to be interviewed immediately upon learning about the study and providing consent; others requested the interviewer to return during their next treatment. In the event a participant could not complete the interview during his or her treatment, the remainder of the interview was conducted during a future treatment. Response cards were provided for each set of Likert-scale questions, and participants selected their responses accordingly.
Measures

Basic demographic information, including age, race, dialysis vintage, education, marital status, and living situation (i.e., alone, with others, or in a group setting) was obtained to establish a demographic profile of the participants.

In order to adjust for other important covariates, information was obtained regarding health, disability, and cognition. Health status was obtained using the Self-Rated Health 5-item questionnaire, a subscale of the Short Form-36 (α = 0.92) (Ware & Sherbourne, 1992). Respondents were asked to rate their health as excellent, very good, good, fair, or poor (dichotomized good or better vs. fair or poor in analyses). Disability status was measured using the 8-item Stanford Health Assessment Questionnaire (HAQ; α = 0.85; Lorig Sobel, Ritter, Laurent, & Hobbs, 2001). Responses range from “0 = without any difficulty” to “3 = unable to do” related to getting out of bed and getting in and out of a car, for example.

Cognitive status was obtained using a modified version of the Saint Louis University Mental Status Examination (SLUMS) was used to assess cognitive status (Banks & Morely, 2003). Due to dexterity limitations of dialysis patients during dialysis (i.e., being connected to the machine) and in consultation with the developers of the SLUMS (Nina Tumosa, personal communication, July 13, 2012) two items were removed from the 11-item questionnaire that would require use of a writing utensil. Thus, cognitive status was determined based on percentage of overall scores corresponding with percentages of the original version. That is, scores of the modified version ranged from 1 – 26 (1 – 30 in the original version); 1 - 16 indicates potential dementia (1 -15 if less than a high school education), 17-20 indicates mild cognitive impairment (16 - 18 if less than a high school education), 21-26 indicates normal cognition (19 -23 if less than a high school education).
**Depression.** The Geriatric Depression Scale (GDS) 15-item short form ($\alpha = 0.86$) (Sheikh & Yesavage, 1986) was used as an indicator of potential depression. The GDS effectively detects depressive symptoms in older adults (Friedman, Heisel, and Delavan, 2005) and ESRD patients (Balogun, Turgut, Balogun, Holroyd, & Abdel-Rahman, 2011). Its extensive use with older adults is well-documented in the literature and is effective in the presence of cognitive deficits (Kurlowicz, 2000) and chronic illness (Greenberg, 2007). The GDS is sensitive to the detection of depression 92% of the time and has an 89% specificity when evaluated against clinical criteria for depression (Kurlowicz, 2002). An example item is: “Are you basically satisfied with life (yes or no)?” A score of five or higher suggests depression.

**Social Support.** Social support was measured using the 18-item Lubben Social Network Scale (LSNS-18). The original LSNS was adapted from the Berkman-Syme Social Network Index (Lubben, 1988). The LSNS-18 captures three sources of social support of older adults (i.e., family, friends, and neighbors) related to emotional supports, perceived tangible supports, and network size ($\alpha = 0.82$) (Lubben & Gironda, 2003). Example items are: “How many of your relatives do you see or hear from at least once a month?” and “How many friends do you feel at ease with that you can talk about private matters?”

**Self-efficacy.** The Diabetes Self-Efficacy Scale (Lorig, Ritter, Villa, & Piette, 2001) was modified for use with HD patients ($\alpha = 0.85$). The scale was originally designed in Spanish and used in a study with 20 participants; the English version is now being used in the Stanford English Diabetes Self-Management study. The scale measures the diet, exercise, symptom management, and controllability domains of self-efficacy. To modify the scale, the domains of the diabetes scale (i.e., meals/nutrition, exercise, communication with physicians,
symptom management, and medication management) were used to construct 10 items for the self-efficacy scale that relate to daily kidney disease self-management tasks. Then, an expert panel of three social workers, three dietitians, and a physician with at least two years work experience in HD settings were recruited to discuss the proposed items and make recommendations for revising the items accordingly (DeVellis, 2003). The number of items were reduced to eight as a result of the expert panel feedback. Also, four cognitive interviews were conducted with HD patients to ensure that the new questions were written from the respondent’s perspective to improve construct validity (Beatty & Willis, 2007). Analysis of the resulting scale found that Cronbach’s alpha was lower than desired ($\alpha = 0.53$). Recognizing that the scale’s performance may be affected by individual-level characteristics (most notably dementia and depression), additional analyses revealed that the scale performs slightly better in the sample excluding participants with potential dementia ($n = 51; \alpha = 0.64$), potential depression ($n = 86, \alpha = 0.59$), either potential dementia or potential depression ($n = 42, \alpha = 0.69$), and both ($n = 95, \alpha = 0.59$). The final scale resulted in eight questions, and participants rated their level of confidence about performing ESRD-related tasks from 0 (not at all confident) to 10 (totally confident). An example item is: How confident do you feel that you can prepare kidney friendly meals?

**Fluid Adherence.** Fluid adherence was measured using the fluid frequency subscale of the Dialysis Diet and Fluid Adherence Questionnaire (DDFQ). The DDFQ was designed to evaluate adherent behavior of hemodialysis patients ($\alpha = .81$; Vlaminck, Maes, Jacobs, Reytjens, & Evers; 2001; Kara, Caglar, & Kilic, 2007). The frequency subscale is a single item, self-report measure that was found to correspond with high actual interdialytic weight gains (i.e., the amount of fluid gain between treatments). The frequency of fluid
nonadherence was obtained by asking participants: “How many days during the past 14 days didn’t you follow your fluid guidelines?” To compare HD patients who were completely adherent to HD patients who were not, and to establish a binary outcome variable required for logistic regression, fluid adherence was dichotomized using a score of 0 (1 or more days nonadherent) and 1 (completely adherent; no days nonadherent).

**Statistical Analysis**

**Descriptive Statistics**

All data were checked for missing values and outliers. Descriptive statistics by the level of depression, including means, standard deviations, and percentages, were calculated to describe the sample. Depression was dichotomized using ≥5 as the cutoff score (i.e., per the scoring criteria for the GDS, with scores ≥5 indicating depressed; Friedman, Heisel, & Delavan, 2005). Chi-square and two-tailed t test were used to compare the means between groups.

**Correlations**

The association of fluid adherence and age group was analyzed using the Kruskall-Wallis test. Pairwise correlations by race were performed between fluid adherence, depression, self-efficacy, social support, cognition and demographic variables of age, education, and months on HD. The correlation coefficients were obtained and interpreted using a significance level of p < .05 and p < .01.

**Logistic Regression Models**

Multivariate logistic regression was employed to examine the relationship between depression and fluid adherence to yield adjusted odds ratios (AORs) and associated 95% confidence intervals (CIs). Four models were analyzed: 1) the primary independent variable
(depression); 2) the primary independent variable (depression) with a secondary independent variable (social support); 3) the primary independent variable (depression) with a secondary independent variable (self-efficacy); and 4) the primary independent variable (depression) with both secondary independent variables (self-efficacy and social support). Goodness-of-fit was assessed using the Hosmer-Lemeshow goodness-of-fit test, with p values > .05 indicating good fit. Each model’s pseudo r-square was calculated to determine the percentage of variance explained by the independent variables. A likelihood ratio test was performed to test the joint significance of the independent variables in the models. Health status, disability status, and demographic variables of age, months on hemodialysis, sex, race, marital status, education, and living situation were controlled in each model.

The Breusch-Pagan test was used to detect heteroskedasticity in which p > .05 indicates heteroskedasticity. The degree of multicollinearity was checked using the mean variance inflation factor (VIF) for all independent variables, with VIF values > 10 indicating multicollinearity (UCLA Statistical Consulting Group).

Descriptive analyses, correlation analyses, logistic regression, and regression diagnostics were performed using Stata 12.0 (StataCorp, 2012). Missing data were treated using casewise deletion. Less than 5% of observations with missing values were excluded from the analysis (n=5).

**Results**

Participant characteristics are presented in Table 6. In total, 123 patients were approached for interviews. Among them, four terminated due to cognitive or physical difficulties (i.e., a participant was feeling unwell), and twelve refused to participate, resulting in an 87% participate rate (n = 107).
Subject’s mean age was 63 (SD=8.6) and the average dialysis vintage was 86 (SD=90). The sample was divided nearly evenly between males (51%) and females (49%). Thirty percent graduated high school or obtained a GED and forty percent were married (40%). The majority of participants were black (65%), reported a poor or fair health status (54%), and lived with others in a private residence (64%).

The majority of the sample was not depressed (i.e., GDS ≥5, n = 86, 80%). Statistically significant group differences were found in marital status (p = 0.004), health status (p = 0.002), disability status (p = 0.0035), and self-efficacy (p = 0.006). Whereas all single participants were not depressed and 17% of married participants were depressed, 17-57% of married, divorced, widowed, or other status participants were depressed. Proportionately more people in poor or fair health were depressed (33%) compared to those in better health (9%). There were higher mean scores of disability in the depressed group than the not depressed group (0.36 and 0.16, respectively). Also, there were higher self-efficacy mean scores in the not depressed group (69) than the depressed group (61).

Fluid adherence by age group is shown in Table 7, demonstrating a statistically significant relationship between age group and fluid adherence [$\chi^2 (2) = 11.65, p < .05$]. The rate of adherence increased with age. Overall, the sample had slightly more adherent participants than nonadherent (53% compared to 47%). The 50-59 age group had the highest rate of nonadherence.

Table 8 presents the AORs and CIs related to fluid adherence associated with depression (the primary independent variable), social support and self-efficacy (the secondary independent variables), and the demographic variables. In model one, being depressed was associated with an 18% decrease in the odds of fluid adherence (AOR = 0.82,
95% CI = 0.67, 0.99). Also, for every year increase in age, the odds of fluid adherence increased by 8% (AOR = 1.08, 95% CI = 1.02, 1.14). No other demographic or health-related variables were associated with fluid adherence. The pseudo r-square of this model was 0.15 (i.e., 15% of the variance in fluid adherence was explained by the independent variables). Model two, which added social support, showed exactly the same results, (i.e., being depressed is associated with an 18% decrease in the odds of fluid adherence; for every year increase in age, the odds of fluid adherence increases by 8%; pseudo r-squared = 0.15).

In model three, the addition of self-efficacy (but not social support) eliminated the association of depression with fluid adherence, and itself related to more adherence. For every one point increase in self-efficacy (scores ranged from 39 to 80; M = 67.5, SD = 8.96), the odds of fluid adherence increased by 9% (pseudo r-square 0.21). In model four, all combined independent variables similarly explained 21% of the variance in self-management, with results virtually identical to model three.

Hosmer-Lemeshow goodness-of-fit test indicated good fit in all models (p = 0.19 - 0.27). The likelihood ratio test was statistically significant [χ² (2) = 9.01, p < .05] indicating the variables jointly contribute to fluid adherence (note: models one, two, and three are nested in model four). Heteroskedasticity was not detected in the models using the Breusch-Pagan test (p = 0.90 - 0.99). Also, the VIF test did not indicate the existence of multicollinearity (mean VIF = 1.44 - 1.46).

In the race group comparison, statistically significant correlation coefficients between depression, self-efficacy, age, and fluid adherence ranged between -0.26 and 0.32 (see Table 9). Among black participants, depression was negatively correlated with fluid adherence (p < 0.05). As depressive symptoms decreased, fluid adherence increased. Self-efficacy and
age were positively correlated with fluid adherence ($p < 0.05$ and $p < 0.01$, respectively).

There were no statistically significant correlations between depression, social support, self-efficacy, age, and fluid adherence among white participants.

**Discussion**

If nephrology professionals hope to improve fluid adherence among older HD patients, further investigation of factors that can potentially mediate the negative effects of depression on adherence is warranted. In this study, 20% of the sample was depressed. This is consistent with previous studies that report 20% to 30% of prevalent ESRD patients experience depression (Feroze et al., 2012). This is comparable to the rate of depression among older adults in the general population which is slightly lower (i.e., 18%; Centers for Disease Control and Prevention, 2010).

Depending upon how it is measured (i.e., self-report, interdialytic weight gain), 30%-70% of patients are nonadherent with fluid intake recommendations (Molaison & Yadrick, 2003; Kulger, Vlaminck, Haverich, & Maes, 2005), largely due to psychosocial barriers such as depression (Hailey & Moss, 2000). In comparison, this study had fewer patients reporting nonadherence (47%). While increased age is associated with poor adherence in other disease states (Ascione, 1994), this study found increased age was associated with better fluid adherence. This discovery is consistent with previous studies demonstrating that younger patients adhere less well to fluid management than older patients (Cummings et al., 1982; Chilcot, Wellsted, & Farrington, 2009). One hypothesis why older adults experience less difficulty with fluid adherence is related to dialysis vintage. Older adults who have spent more years on HD have had more time to develop adherent behaviors. A second hypothesis is related to how adherence is measured. In a review of 596 studies spanning 50 years of
research on patient adherence to medical treatment, DiMatteo (2004) found that when collected by clinical measures, adherence was negatively associated with age, but when measured by self-report, adherence was positively associated with age. Third, it is possible that the older age group consumed less fluid because thirst sensation diminishes with age (Stachenfeld, DiPietro, Nadel, & Mack, 1997) These hypotheses are worth exploring further in this population.

Other demographic and health factors (i.e., months on dialysis, sex, race, marital status, health status, disability status, education, and living situation) were not found to have a statistically significant relationship with fluid adherence in this study. It is possible that characteristics not accounted for in the logistic regression models, such as cognition, are important, because cognition is associated with adherence in ESRD patients (Tamura & Yaffe, 2011), and can affect adherence among older adults (Brown, 2007). Cognition was not included in this study because the distributions were too small to examine a relationship (i.e., the small number of cases caused inflated standard errors and confidence intervals making the results uninterpretable). However, a pairwise correlation between cognition and fluid adherence not presented in this paper revealed cognition to be statistically correlated with fluid adherence (r = 0.27, p < 0.001), such that as cognitive status scores increased (i.e., higher scores indicate more severe cognitive deficits) fluid adherence increased.

Previous studies have demonstrated the association between self-efficacy and fluid adherence, but few studies have examined the mediation potential of self-efficacy. The main objective of this study was to identify individual-level factors that possibly mitigate the negative effects of depression to fluid adherence in order to inform future intervention research. The findings suggest the potential of self-efficacy to mitigate negative effects of
depression. Depression was negatively associated with fluid adherence, but after adding self-efficacy to the model, the negative relationship between depression and fluid adherence disappeared and the pseudo r-square increased, suggesting self-efficacy mediates depression and fluid adherence. Even in the presence of social support (which theoretically is an important predictor of fluid adherence), self-efficacy continued to weaken the association between depression and fluid adherence. Consequently, psychosocial interventions to reduce the high prevalence of depression in older ESRD adults that are designed to increase self-efficacy may show promise. For example, although the sample size was small (n = 25 intervention group and n = 25 control group), Tsay and Hung (2004) found an empowerment program to increase self-efficacy and reduce depression in HD patients experiencing fluid adherence difficulties. Future studies should examine self-efficacy as a mediator between depression and fluid adherence.

The pairwise correlations by race revealed similar trends. The rate of depression was similar for blacks and whites, however, among black participants, depression was negatively correlated with fluid adherence (r = -0.26, p < 0.05). The association of depression in blacks compared to whites is an interesting finding and is possibly related to the added experience of discrimination among blacks which causes depression to have a greater association on health outcomes. For instance, a study examining the associations between depression and chronic disease in blacks revealed that those who reported high depression and low physical functioning perceived they were treated worse by others at work and had worse healthcare experiences than those of other races (Larson, Belue, Schlundt, & McClellan, 2006). Also, self-efficacy and age were positively associated with fluid adherence for blacks (r = 0.24, p < 0.05 and r = 0.32, p < 0.01, respectively) and whites (r = 0.24 and r = 0.21, respectively; not
significant likely due to a small sample). Investigation of factors associated with fluid adherence in blacks warrant further investigation, because in a recent study black patients were more likely to experience fluid overload and receive additional treatments to remove excess fluid in comparison to white HD patients (Arneson et al., 2010). This disparity is concerning particularly in light of high costs associated with additional treatments.

To determine the exact mediation potential of self-efficacy, advanced statistical modeling and longitudinal studies are needed. To date, studies examining the relationship between adherence and depression in HD patients have been correlational (Cukor, Rosenthal, Jindal, Brown, & Kimmel, 2009). Unfortunately, this study was not powered to test mediation using structural equation modeling. Structural equation modeling can specify the causal direction implied by this study’s findings (i.e., a direct path from depression to fluid adherence, and an indirect path mediated by self-efficacy). Given the sample size and the cross-sectional nature of these data, this study appropriately employed logistic regression, a useful analysis when examining the relationship between two or more independent variables to a dichotomous dependent variable (Klenbaum & Klein, 2010).

Three strengths of this study are worth noting. First, this is the first study to focus solely on the relationship between depression and adherence in older HD patients. Given the high rates of depression in older HD patients and the growing prevalence of older adults on HD, this study fills an important knowledge gap. Second, this study used the GDS to measure depression. This is novel, because in a recent systematic review of studies examining the association of depression to psychosocial factors, only one of 57 studies used the GDS with HD participants despite the mean age of the studies was 53 (SD = 5.6; Chan et al., 2011). As previously indicated, the GDS effectively captures depression in older adults.
experiencing cognitive deficits (which is common in the ESRD population) and chronic disease. Third, the development of an ESRD self-efficacy scale is promising. To date, none have been developed and tested to measure self-efficacy about ESRD-related tasks. Further revision and testing of the scale is forthcoming.

The measurement of fluid adherence used in this study is a limitation given its self-reported nature. Ideally, self-reported measures should be combined with clinical measures (Curtin, Svarstad, & Keller, 1999) to increase reliability and validity. A more accurate measure of fluid intake is interdialytic weight gain (i.e., weight gained due to fluid intake between treatments) or dry weight (i.e., target or ideal weight) (Chilcot, Wellsted, & Karrington, 2010) - although even these clinical measures are problematic because a threshold of adherence to prevent complications has yet to be established (Cukor et al., 2009). Self-report and the lack of clinical thresholds may result in overreporting; for example, 50% of patients in one recent study self-reported nonadherence to fluid restrictions, but only 9% were actually nonadherent using interdialytic weight gain (Khalil, Frazier, Lennie, & Sawaya, 2011). For these reasons, fluid adherence was treated as completely adherent (no days nonadherent) vs. nonadherent to any extent (1 or more days). Treating the variable as dichotomous divided the sample nearly even (55 vs. 49, respectively). However, to be certain the findings were not a result of treating the variable as dichotomous, a linear regression containing all variables in model four was performed with fluid adherence as a continuous dependent variable, and provided similar results (e.g., self-efficacy and age were associated with fluid adherence at p = 0.047 and p = 0.034, respectively).

Furthermore, fluid adherence is only one management aspect of kidney disease. Other aspects such as diet and medication adherence (Browne & Merighi, 2010), are equally
important. The relationship of these additional management behaviors to depression, self-efficacy, and social support are worth exploring. Also, it is important to note that these data were collected during the summer months in the southeast region of the country. If thirst is a primary barrier to fluid adherence, it is reasonable to assume that patients had more difficulty staying within their recommended intake given the likelihood of increased thirst in summer months. No studies have reported adherence rates in summer compared to other seasons, making it difficult to draw conclusions about the level of adherence to expect throughout the year. Finally, because these data are cross-sectional, predictors of fluid adherence cannot be examined.

**Implications for Intervention Research**

As indicated previously, the main purpose of this paper was to inform future intervention research with older HD patients by identifying mediating factors associated with fluid adherence. In this study, nearly half of the participants were nonadherent, and depression was found to be associated with adherence. Unfortunately, very few interventions to improve fluid adherence exists (Welch, Thomas-Hawkins, 2005; Hailey & Moss, 2000). Based on the findings in this study, future interventions must incorporate elements that address the barrier of depression. Also, theoretical models, such as self-efficacy theory, should guide the development of interventions (Welch, Thomas-Hawkins, 2005). Finally, interventions must consider cultural uniqueness of HD subgroups when designing and implementing psychosocial interventions to improve adherence given the associations found among black participants, and the striking race disparities in ESRD in the U.S., particularly among aging cohorts (e.g., black patients have an incident rate of 1,440 per million of the
population in older patients compared to 134 per million of the population in patients aged 30 to 39 or 37 per million of the population in patients aged 20-29; USRDS, 2012).
References


Bame S.I., Peterson N. & Wray N.P. (1993). Variation in hemodialysis patient compliance according to demographic characteristics. Social Science and Medicine, 37, 1035–1043. doi:10.1016/0277-9536(93)90438-A


Kurlowicz, L. (2000). The geriatric depression scale. *Home Care Provider.* 5, 76-77. doi.org/10.1016/S1084-628X(00)90061-3


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### Table 6
Subject Characteristics, by Depression (N = 107)

<table>
<thead>
<tr>
<th></th>
<th>All participants</th>
<th>Depressed (n=21) (GDS Score ≥ 5)</th>
<th>Not Depressed (n=86) (GDS Score &lt; 5)</th>
<th>p^g</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>63 (8.6)</td>
<td>62 (8.4)</td>
<td>64 (9.6)</td>
<td>0.44</td>
</tr>
<tr>
<td>Months on hemodialysis</td>
<td>86 (90)</td>
<td>62 (65.5)</td>
<td>68 (56.9)</td>
<td>0.85</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td>0.70</td>
</tr>
<tr>
<td>Male</td>
<td>55 (51%)</td>
<td>10 (48%)</td>
<td>45 (52%)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>52 (49%)</td>
<td>11 (52%)</td>
<td>41 (48%)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td>0.94</td>
</tr>
<tr>
<td>White</td>
<td>35 (33%)</td>
<td>7 (20%)</td>
<td>28 (80%)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>69 (65%)</td>
<td>14 (20%)</td>
<td>55 (80%)</td>
<td></td>
</tr>
<tr>
<td>Other^a</td>
<td>3 (2%)</td>
<td>0 (0%)</td>
<td>3 (100%)</td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td>0.004</td>
</tr>
<tr>
<td>Married</td>
<td>43 (40%)</td>
<td>9 (17%)</td>
<td>34 (83%)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>20 (19%)</td>
<td>0 (0%)</td>
<td>20 (100%)</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>20 (19%)</td>
<td>4 (20%)</td>
<td>16 (80%)</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>17 (16%)</td>
<td>4 (24%)</td>
<td>13 (76%)</td>
<td></td>
</tr>
<tr>
<td>Other^b</td>
<td>7 (6%)</td>
<td>4 (57%)</td>
<td>3 (43%)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td>0.86</td>
</tr>
<tr>
<td>Did not graduate</td>
<td>28 (26%)</td>
<td>4 (14%)</td>
<td>24 (86%)</td>
<td></td>
</tr>
<tr>
<td>High school diploma or GED</td>
<td>32 (30%)</td>
<td>6 (19%)</td>
<td>26 (81%)</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>26 (24%)</td>
<td>7 (27%)</td>
<td>19 (73%)</td>
<td></td>
</tr>
<tr>
<td>College graduate or higher</td>
<td>21 (20%)</td>
<td>4 (19%)</td>
<td>17 (81%)</td>
<td></td>
</tr>
<tr>
<td>Cognition^c</td>
<td></td>
<td></td>
<td></td>
<td>0.64</td>
</tr>
<tr>
<td>Normal</td>
<td>12 (11%)</td>
<td>1 (9%)</td>
<td>10 (91%)</td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>39 (37%)</td>
<td>8 (20%)</td>
<td>32 (80%)</td>
<td></td>
</tr>
<tr>
<td>Potential dementia</td>
<td>56 (52%)</td>
<td>12 (21%)</td>
<td>44 (79%)</td>
<td></td>
</tr>
<tr>
<td>Health Status^d</td>
<td></td>
<td></td>
<td></td>
<td>0.002</td>
</tr>
<tr>
<td>Poor or fair</td>
<td>49 (46%)</td>
<td>16 (33%)</td>
<td>33 (67%)</td>
<td></td>
</tr>
<tr>
<td>Good, very good, or excellent</td>
<td>58 (54%)</td>
<td>5 (9%)</td>
<td>53 (91%)</td>
<td></td>
</tr>
<tr>
<td>Subject Characteristics, by Depression (N = 107)</td>
<td>All participants M (SD) or N (%)</td>
<td>Depressed (n=21) GDS Score ≥ 5</td>
<td>Not Depressed (n=86) GDS Score &lt; 5</td>
<td>p^h</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Disability Status^e</td>
<td>0.20 (.30)</td>
<td>0.36 (0.43)</td>
<td>0.16 (0.25)</td>
<td>0.003</td>
</tr>
<tr>
<td>Living Situation</td>
<td></td>
<td></td>
<td></td>
<td>0.70</td>
</tr>
<tr>
<td>Lives with others in a private residence</td>
<td>68 (64%)</td>
<td>15 (22%)</td>
<td>53 (78%)</td>
<td></td>
</tr>
<tr>
<td>Lives alone</td>
<td>39 (36%)</td>
<td>6 (15%)</td>
<td>33 (85%)</td>
<td></td>
</tr>
<tr>
<td>Social Support^f</td>
<td>14 (5.6)</td>
<td>12 (6.1)</td>
<td>14 (5.4)</td>
<td>0.14</td>
</tr>
<tr>
<td>Self-efficacy^g</td>
<td>67 (9.0)</td>
<td>61 (8.1)</td>
<td>69 (8.6)</td>
<td>0.0006</td>
</tr>
</tbody>
</table>

^a Other races are American Indian and Asian

^b Other marital statuses are not married but partnered, or separated

^c Based on the SLUMS, scores range from 1 to 26; 1 to 16 indicates potential dementia (1 to 15 if less than high school education), 17-20 indicates mild cognitive impairment (16-18 if less than high school education), 21-26 indicates normal cognition (19-23 if less than high school education).

^d Health status dichotomized as poor (i.e., poor, fair) and good (i.e., good, very good, excellent)

^e Disability status measured using HAQ scale (range 0 - 1.875). Higher scores indicates more difficulty with daily activities

^f Social Support possible range of scores 0 - 30. Higher scores indicate more social support.

^g Self-efficacy possible range of scores 0 - 80. Higher scores indicate more self-efficacy.

^h Comparison of depressed and not depressed participants. Significance test using chi-square or two tailed t test. Items in bold indicate p values < 0.05.

Column percentages presented in table.
### Table 7

**Fluid Adherence and Nonadherence by Age Group (N=104)**

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Total in Age Group</th>
<th>Adherent N (%)</th>
<th>Nonadherent N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>50-59</td>
<td>43</td>
<td>16 (37%)</td>
<td>27 (63%)</td>
</tr>
<tr>
<td>60-69</td>
<td>39</td>
<td>21 (54%)</td>
<td>18 (46%)</td>
</tr>
<tr>
<td>70+</td>
<td>22</td>
<td>18 (82%)</td>
<td>4 (18%)</td>
</tr>
<tr>
<td><strong>All Ages</strong></td>
<td><strong>104</strong></td>
<td><strong>55 (53%)</strong></td>
<td><strong>49 (47%)</strong></td>
</tr>
</tbody>
</table>

*aChi square (2) = 11.65, p = 0.03; association analyzed using the Kruskall-Wallis test*
<table>
<thead>
<tr>
<th>Variable</th>
<th>Model 1</th>
<th>Model 2</th>
<th>Model 3</th>
<th>Model 4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adjusted Odds Ratio</td>
<td>Adjusted Odds Ratio</td>
<td>Adjusted Odds Ratio</td>
<td>Adjusted Odds Ratio</td>
</tr>
<tr>
<td></td>
<td>(95% Confidence Interval)</td>
<td>(95% Confidence Interval)</td>
<td>(95% Confidence Interval)</td>
<td>(95% Confidence Interval)</td>
</tr>
<tr>
<td>Depression, Demographics, Health Status</td>
<td>Depression, Social Support, Demographics, Health Status</td>
<td>Depression, Social Support, Demographics, Health Status</td>
<td>Depression, Self-Efficacy, Demographics, Health Status</td>
<td>Depression, Social Support, Self-Efficacy, Demographics, Health Status</td>
</tr>
<tr>
<td>Depression (Not depressed)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depressed</td>
<td>0.82 (0.67, 0.99)</td>
<td>0.82 (0.68, 0.99)</td>
<td>0.89 (0.72, 1.09)</td>
<td>0.89 (0.72, 1.10)</td>
</tr>
<tr>
<td>Social support</td>
<td>1.10 (0.93, 1.10)</td>
<td>1.00 (0.92, 1.09)</td>
<td>1.09 (1.03, 1.16)</td>
<td>1.09 (1.03, 1.16)</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>1.08 (1.02, 1.14)</td>
<td>1.08 (1.07, 1.14)</td>
<td>1.09 (1.02, 1.16)</td>
<td>1.09 (1.02, 1.16)</td>
</tr>
<tr>
<td>Months on hemodialysis</td>
<td>0.99 (0.99, 1.00)</td>
<td>0.99 (0.99, 1.00)</td>
<td>0.99 (0.99, 1.00)</td>
<td>0.99 (0.99, 1.00)</td>
</tr>
<tr>
<td>Sex (Female)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0.42 (0.17, 1.07)</td>
<td>0.42 (0.17, 1.07)</td>
<td>0.47 (0.18, 1.24)</td>
<td>0.48 (0.18, 1.25)</td>
</tr>
<tr>
<td>Race (White)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>1.15 (0.70, 1.90)</td>
<td>1.15 (0.70, 1.90)</td>
<td>1.15 (0.67, 1.96)</td>
<td>1.15 (0.67, 1.96)</td>
</tr>
<tr>
<td>Marital status (Married)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>0.50 (0.12, 2.06)</td>
<td>0.51 (0.12, 2.08)</td>
<td>0.41 (0.10, 1.65)</td>
<td>0.41 (0.10, 1.65)</td>
</tr>
<tr>
<td>Divorced</td>
<td>0.94 (0.21, 4.23)</td>
<td>0.96 (0.20, 2.83)</td>
<td>1.08 (0.22, 5.40)</td>
<td>1.08 (0.21, 5.44)</td>
</tr>
<tr>
<td>Other</td>
<td>0.74 (0.21, 2.79)</td>
<td>0.76 (0.20, 2.83)</td>
<td>0.96 (0.23, 3.98)</td>
<td>0.96 (0.23, 3.98)</td>
</tr>
<tr>
<td>Health status (Good)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>1.88 (0.71, 4.99)</td>
<td>1.87 (0.70, 4.96)</td>
<td>1.42 (0.50, 4.00)</td>
<td>0.41 (0.50, 4.01)</td>
</tr>
<tr>
<td>Disability status (Not Disabled)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disabled</td>
<td>1.70 (0.62, 4.67)</td>
<td>1.69 (0.61, 4.66)</td>
<td>1.87 (0.63, 5.50)</td>
<td>1.87 (0.63, 5.50)</td>
</tr>
<tr>
<td>Education (Less than high school)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma or GED</td>
<td>1.22 (0.40, 4.17)</td>
<td>1.21 (0.36, 4.08)</td>
<td>1.37 (0.38, 4.89)</td>
<td>1.37 (0.38, 4.92)</td>
</tr>
<tr>
<td>Some college or higher</td>
<td>1.23 (0.40, 3.82)</td>
<td>1.21 (0.39, 3.79)</td>
<td>1.39 (0.43, 4.54)</td>
<td>1.39 (0.42, 4.60)</td>
</tr>
</tbody>
</table>
Table 8 (con’t)

*Logistic Regression Models of Fluid Adherence (N=104)*

<table>
<thead>
<tr>
<th>Living situation (Lives alone)</th>
<th>Lives with others in private residence</th>
<th>Psuedo R-square</th>
<th>Goodness-of-fit&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>0.76 (0.25, 2.31)</td>
<td>p = 0.21</td>
</tr>
<tr>
<td></td>
<td></td>
<td>0.75 (0.25, 2.29)</td>
<td>p = 0.19</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1.08 (0.33, 3.55)</td>
<td>p = 0.29</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1.08 (0.33, 3.60)</td>
<td>p = 0.27</td>
</tr>
</tbody>
</table>

<sup>a</sup>Adjusted odds ratio and corresponding confidence intervals in bold indicate significance at the .05 level.

<sup>b</sup>Goodness-of-fit assessed using the Hosmer-Lemeshow Test. P values > .05 indicates good fit.
Table 9
Pairwise Correlations with Fluid Adherence by Race (N=104)\(^a\)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Black Participants(^b)</th>
<th>White Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=69</td>
<td>n=35</td>
</tr>
<tr>
<td>Depression</td>
<td>-0.26*</td>
<td>0.16</td>
</tr>
<tr>
<td>Social Support</td>
<td>0.07</td>
<td>-0.20</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>0.24*</td>
<td>0.24</td>
</tr>
<tr>
<td>Age</td>
<td>0.32**</td>
<td>0.21</td>
</tr>
</tbody>
</table>

\(^a\) Fluid adherence treated as a binary variable (0 = nonadherent, 1 = adherent).
\(^b\) "Other" race dropped from these analyses (n=3).

* \( p < 0.05 \)
** \( p < 0.01 \)
Social Support in Older Hemodialysis Patients: Associations with Self-Management and A Confirmatory Factor Analysis of the Six Item Lubben Social Network Scale

Overview

Limited social support is associated with poor health outcomes in hemodialysis (HD) patients. Older adults are at risk for social isolation because the size of social networks decreases with age, yet factors associated with social support are understudied in the older end-stage renal disease (ESRD) population. Also, clinicians in HD facilities are required to choose standardized assessment tools to evaluate the psychosocial status of ESRD patients, yet measures of social support have yet to be validated with this population. Given the growing population of older adults on HD, there is a need to identify factors associated with social support and to validate measures of social support to guide practice and future research in this area. The purpose of the current study was to 1) examine the relationship of social support to self-management behaviors; and 2) examine the factor structure of the Lubben Social Network Scale - 6 (LSNS - 6) using data provided by 107 community-dwelling hemodialysis patients aged 50 and older. Advance directive status (p = 0.01), cognitive symptom management (p = 0.02), communication with physicians (p = 0.03), and weekly exercise time (p = 0.02) were associated with social support. Two measurement models were examined to test the factor structure of the LSNS - 6. The first model was based on the factor structure determined by an EFA of the LSNS - 6 previously reported in the literature. The second, alternative model was specified based on examination of the modification indices and previous theory and research. Model two demonstrated better fit as reflected in the CFI
(0.977) and TLI (0.941) scores. The Cronbach alpha was 0.81. Based on this study’s findings, patients reporting low social support practice fewer self-management behaviors. Also, the LSNS – 6 is valid for use of rapid assessment of social support in older hemodialysis patients. Nephrology professionals may consider using the LSNS-6 to assess social support, and self-management interventions in HD patients who report low social support.
Introduction

The United States population is aging. In 1900, older adults represented only 4% of the population, which grew to 13% two years ago (Administration on Aging, 2012). By 2030, older adults will represent 33% of the population. As the population ages, the burden of chronic disease increases. One disease, chronic kidney disease (CKD) affects 26 million people (National Kidney Foundation, 2013). People aged 50 and older are driving the rise in CKD prevalence (O'Riordan, 2005). Similarly, among people with end-stage renal disease (ESRD), the most severe stage of CKD, older adults are burdened with the highest incident rates (USRDS, 2010).

To sustain life for those living with ESRD renal replacement therapy is required. Older ESRD patients primarily choose hemodialysis (HD) as their choice of renal replacement therapy (USRDS, 2012). In HD, an artificial kidney (known as a dialyzer) filters the blood, a function that failed kidneys can no longer perform. Long-term dependence on this artificial method of life-sustaining treatment can cause severe psychological distress such as depression, anxiety, and low quality of life (Christensen & Ehlers, 2002; Tezel, Karabulutlu, & Sahin, 2011). In older ESRD patients, psychological distress is often caused by vascular access complications, frailty, poor mobility, cognitive impairment, multiple comorbidities (Passadakis, Thodis, & Oreopoulos, 2010).

The Impact of Limited Social Support

Limited social support is associated with psychological distress in dialysis patients (Kimmel, 2001), carrying a high risk of mortality (Christensen, Wiebe, Smith, & Turner, 1994; Thong, Kaptein, Krediet, Boeschoten, & Dekker, 2007; Untas et al., 2011), but the extent to which older ESRD patients experience social isolation is understudied. The adverse
effects on well-being and health of social isolation (i.e., having limited social ties and social networks) in older people with other chronic conditions is well-documented, shown to cause a greater risk of disability and depression (Lubben & Gironda, 2003; Lubben & Gironda, 2004; Nicholson, 2012) poor health-related quality of life (Tell et al., 1995) and mortality (Cacioppo, Hawkley, Normal, & Berntson, 2011; Holt-Lunstad, Smith, & Layton, 2010). Compared to others, older adults experience social isolation because they are more likely to have smaller social networks (McPherson, Smith-Loving, & Brashears, 2006) and experience loneliness (Dykstra, van Tilburg, & de Jong Gierveld, 2005) and depression (Cahoon, 2012). Also, older adults are more likely to experience bereavement and health-related complications, which increase their need for social support (Cornwell & Waite, 2009). This and other reasons warrant further investigation into factors associated with social support in older people on HD, especially because older patients who chose alternative treatment modalities (such as peritoneal dialysis and transplantation) have higher levels of social support than those on HD, primarily because other home-based modalities often require the assistance of a supportive friend or family member (Li & Chow, 2009; Plantinga et al., 2010).

The adverse effects of social isolation on health outcomes is concerning, and makes self-management, one’s active participation in his or her health and health care, increasingly important. Self-management is associated with improved health behaviors, improved health status, and decreased health care utilization (Ritter, Lee, & Lorig, 2011). There is growing attention to the topic of self-management in ESRD in part because the recently revised Medicare Conditions for Coverage require nephrology professionals to encourage patients to participate in their care planning (Federal Register, 2008). Also, due to the growing
prevalence of ESRD patients in the U.S., contributing to $29 billion of the entire Medicare budget (USRDS, 2012), self-management is increasingly important as is associated with decreased health care costs (Ritter, Lee, & Lorig, 2011). No studies have examined the relationship of social support to self-management behaviors, yet an examination is an important endeavor given the benefits of self-management.

Fortunately, there is evidence from numerous studies that social support can lessen the impact of living on HD. Data suggest that social support is associated with patient satisfaction, increased health-related quality of life (HRQOL), and reduced hospital visits in ESRD patients (Plantinga et al., 2010). Also, social support is associated with improved HD survival (Thong et al., 2007), and perceived social support decreases depression in ESRD patients (Tezel, Karabulutlu, & Sahin, 2011). In order to maximize these and other benefits of social support with this population, nephrology professionals must have access to valid and reliable instruments to identify social support, and assess the level and nature of social support.

Measurement of Social Support

In recognition of the need to offer nephrology clinicians measures to rapidly assess psychosocial needs of ESRD patients, and provide nephrology researchers with validated measures for use in studies, the psychometric properties of multiple instruments have been evaluated for use with this population related to these and other outcomes: depression (Beck Depression Inventory; Chilcot et al., 2011), quality of life (Quality of Well-Being Scale, Short-Form-6D, and the Kidney Disease Quality of Life Instrument; Saban et al., 2008), and illness perceptions (Illness Perceptions Questionnaire – Revised; Chilcot, Norton, Wellsted, & Farrington, 2012). However, to date, no studies have examined the psychometric
properties of existing social support measures with ESRD patients. Also, some studies use single-item measures of social support that fail to capture the complex nature of social networks (Holt-Lunstad, Smith, & Layton, 2010). These methodological shortcomings are concerning given the importance of social support and the growing number of older adults receiving HD. The availability of a valid and reliable measure of social support would be helpful to assess need, guide practice, and inform research.

One potential such tool is the Lubben Social Network Scale – 6 (LSNS-6), a short version of the Lubben Social Network Scale (LSNS), developed and used for rapid assessment of social networks in older adults (Lubben & Girona, 2003). Other versions of the LSNS exist (i.e., the original 18-item version and the revised 12-item version), with the LSNS-6 being developed to provide clinicians with a brief assessment tool for use in practice settings. The factor structure of this tool has been assessed with European older adults ((Lubben et al., 2006), and has been adapted for various uses and populations (Hong, Casado, & Harrington, 2011; Nahm, Resnick, & Gaines, 2004; Thanakwang & Soonthorndhada, 2011), and in all cases, the LSNS-6 upholds a consistent factor structure.

In studies with ESRD patients social support has been operationalized using the Social Provisions Scale (Hoth, Christensen, Ehlers, Raichle, & Lawton, 2007), the social network questions from the National Health and Social Life Survey (Browne, 2011), the Multidimensional Scale of Perceived Social Support (Kimmel et al., 1998), and the Medical Outcomes Study (MOS) Social Support Survey (Plantinga et al., 2010). Unfortunately, the psychometric properties of these scales are rarely reported, making it difficult to justify their use with ESRD patients in future research. To the author’s knowledge, no studies with ESRD patients used the LSNS. Use of the LSNS – 6 shows promise because its criterion
validity has been demonstrated in a variety of studies about older adults with chronic conditions including cancer (Novotny et al., 2010) and HIV (Emlet, 2006). Furthermore, there is a need for a brief social support assessment that nephrology professionals can use in health care settings.

The psychometric properties of the LSNS-6 have yet to be assessed with HD patients, and it is not clear that this scale is optimal for this population for various reasons. First, older HD patients experience a high prevalence of cognitive deficits (Tamura & Yaffe, 2011), which can impede accurate assessment of social support. Also, the older ESRD population is increasingly diverse. To date, the LSNS has only been evaluated with Chinese (Chi & Chou, 2001) and European older adults (Lubben et al., 2006). This is an important consideration, because the nature of social support and social networks of ethnic groups may differ. For example, black older adults frequently access informal social networks through churches and community gathering places (Carlton-Laney, 2006).

**Study Aims**

The present study has two aims: 1) to examine the associations between social support and self-management behaviors in older ESRD patients; and 2) to evaluate the performance of the LSNS-6 using confirmatory factor analysis (CFA) in a cohort of 107 older, community-dwelling HD patients, many of whom are black (65%). The objective of aim one is to inform intervention development and clinical practice with older ESRD patients. The objective of aim two is to inform future ESRD-related research using the LSNS-6. Model specification will draw upon previously reported results of an exploratory factor analysis (EFA) of the LSNS-6 with community-dwelling European elders (Lubben et al., 2006) and elderly women (Crooks, Lubben, Petitti, Little, & Chiu, 2008). In both studies,
the factors structures were similar: one family factor and one friend factor ($\alpha = 0.83$, $\alpha = 0.84$, respectively).

Methods

Sample and Data

Data for these analyses are drawn from a study that examined self-management behaviors of HD patients aged 50 years and older, English-speaking, and community dwelling. Cross sectional, in-person interviews were conducted during each participant’s HD treatment by a master’s-level social worker or a registered nurse. The interviews lasted approximately 40 minutes in duration and were conducted by the author. Participants received a $10 store gift card. Table 1 provides an overview of sample characteristics. This study was approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

Instrumentation

Lubben Social Network Scale – 6. As tested in other populations, the LSNS-6 is a two-subscale measurement of social support (i.e., a friend subscale and a family subscale containing three items each). The specific questions relate to emotional support, perceived tangible support, and network size, all identified as important factors associated with social networks (Heitzmann, 1988). The items on the friend subscale are: “How many of your friends do you see or hear from at least once a month?”; “How many friends do you feel at ease with that you can talk about private matters?”; and “How many friends do you feel close to that you can call on them for help?” The items on the family subscale are: “How many of your relatives do you see or hear from at least once a month?”; “How many relatives do you feel at ease with that you can talk about private matters?” and “How many relatives do you
feel close to that you can call on them for help?" The 5-point Likert scale measures the number of people associated with each answer (i.e., 0 = none, 1 = 1 person, 2 = 2 person, 3 = 3 or 4 persons, 4 = 5 to 8 persons, and 5 = 9 or more persons).

**Advance Directive.** To assess advance directive status, participants were asked: “Do you have a living will?”, “Do you have a health care power of attorney?”; “Do you have both?” Participants were instructed to respond yes or no.

**Disease Self-management.** A modified version of the Exercise Behaviors Scale was used to assess weekly exercise activities. The original version (α = 0.76) contains six items (reduced to 4 in this study to combine aerobic activities other than walking and swimming) and instructs respondents to rate on a 5-point Likert scale the total time in a typical week they do stretching or strengthening exercises, walk, swim, or other aerobic activities. The Communication with Physicians Scale is a 3-item measure that assesses how often patients prepare for their doctor’s visits by doing certain things (α = 0.89) (Lorig et al., 1996). Questions include how frequently they prepare a list of questions for their doctor, ask questions about the things they want to know about and don't understand about your treatment, and discuss any personal problems that may be related to their illness? The Cognitive Symptom Management measure assesses patient management of symptom burden related to the management of pain and other unpleasant symptoms (α = 0.83) (Lorig et al., 1996). Using the prompt, “when you are feeling down in the dumps, feeling pain or having other unpleasant symptoms”, an example item is: “how often do you talk to yourself in positive ways?” The response scale for the latter two measures ranges from 0 (never) to 5 (always). The Dialysis Diet and Fluid Adherence Questionnaire was used to evaluate adherent behavior of HD patients (α = 0.81) (Vlaminck, Maes, Jacobs, Reytjens, & Evers;
The four-item, self-report measure assesses the frequency and severity of patient deviation from diet and fluid guidelines. The frequency subscale asks “How many days during the past 14 days did you not follow your diet [fluid] guidelines?” The severity subscale asks “To what degree did you stray from your diet [fluid] guidelines?” Responses range from 0 (did not stray) to 4 (very severely strayed).

**Analyses**

All analyses including sample characteristics were derived using STATA version 12 (StataCorp, 2011). To examine the relationship of social support to self-management behaviors (aim 1), social support scores were categorized into three groups, each containing approximately one-third of the sample based on the distribution of the scores: low (mean score of ≤12), moderate (mean score 13-18), and high (mean score ≥19). The Kruskal-Wallis test was used to compare the mean score across each social support group (i.e., low, moderate, high) because the data were not normally distributed (alpha level set at 0.05; two-tailed). Aim 2 employed confirmatory factor analysis (CFA) to obtain the psychometric properties of the LSNS-6. The scale’s Cronbach’s Alpha score was obtained and evaluated (a range of α = 0.70 – 0.90 is acceptable; DeVellis, 2003) and means and standard deviations of each LSNS item were obtained.

**Model specification.** Two factor analysis models were obtained and compared. The first model is the proposed theoretical model based on an EFA of the LSNS-6 previously reported in the literature (Lubben, 2006). Use of previously published EFA results is an acceptable method to inform a CFA (Adams, Matto, & Sanders, 2004). The alternative model, model two, which is nested in model one, was specified using two methods: 1) examination of modification indices (MIs; values produced in structural equation modeling
software that reflect improved fit if error terms are correlated); and 2) theory and previous research findings. A specific threshold value for selecting MIs does not exist; however, higher values indicate potential correlations (Shumacker & Lomax, 2010; Thompson, 2004). Error terms should be correlated only in instances where the researcher can provide a rationale based on theory and previous research (Thompson, 2004). Thus, the error terms were correlated only when a theoretical rationale could be provided based on findings from previous studies. The models were graphically depicted using conventional shapes to draw a path diagram (i.e., boxes for observed variables, circles for latent variables, and ellipses for error terms; Shumacker & Lomax, 2010). Factors (latent variables) are represented by circles and their indicators are represented by squares.

**Model fit.** The model fit indices selected in this study are $\chi^2$ statistic (nonsignificant $\chi^2$ indicates good fit), the root-mean-square error of approximation (RMSEA; values between .05 and .08 are acceptable), the comparative fit index (CFI; a value greater than .90 indicates good fit and 1.0 indicates perfect fit), and the Tucker Lewis Index (TLI; a value greater than .90 indicates good fit and 1.0 indicates perfect fit) (Shumacker and Lomax; 2010; Byrne, 2001). A chi-square difference test was performed to determine the better fitting model (determined by $p < 0.05$ which indicates the nested model is better fit). The CFA regression coefficients were assessed using a threshold of greater than 0.40 as acceptable (Webber, 2012).

**Power analysis.** The current study uses information from 107 subjects to validate a 6-item scale (i.e., 18 subjects per item) indicating that it was adequately powered based on Tinsley and Tinsley’s recommendation of at least 5 to 10 subjects per item (Tinsley & Tinsley, 1987). Although this study does not employ EFA, the Kaiser-Meyer-Olkin measure
of sampling adequacy was employed as a preliminary step resulting in a score of 0.712, which falls into an acceptable “middling” range per the measure’s categories (Kaiser, 1974).

Results

Descriptive statistics are presented in Table 10. The participants received treatment at one of four HD facilities in North Carolina. Subject’s mean age was 63 (SD=8.6) and the average number of months on dialysis was 86 (SD=90). The majority of participants were black (65%), had dementia (52%), reported a poor health status (54%), and lived with others in a private residence (64%). The sample was divided nearly evenly between males (51%) and females (49%). Thirty six percent attended college, and 54% were single, widowed, or divorced (54%).

Aim 1. Group differences in self-management related to advance directive status, cognitive symptom management, communication with physicians, weekly exercise time, fluid adherence, and diet adherence by level of social support are shown in Table 11. The proportions of participants in the low social support group, moderate social support group, and high social support group were 37%, 31%, and 36%, respectively (these cut points were selected to derive approximately equal groups). Participants in the low social support group had fewer advance directives than the low and high social support groups (p = 0.01). The post-hoc comparison indicated the moderate social support group had less advanced directives than the high social support group (p = 0.001). Time spent practicing cognitive symptom management techniques increased as social support increased (p = 0.02), and the high social support group practiced cognitive symptom management more frequently than the moderate social support group (p = 0.001). The high social support group had the highest communication with physicians mean scores (p = 0.03), and the moderate social support
group communicated with their physicians more frequently than the high social support group (p = 0.001). The moderate and high social support groups spent more time engaged in weekly exercise than the low group (mean scores of 2.91 and 2.71 compared to 1.70, respectively; p = 0.02). The post-hoc comparison indicated the high social support group spent more time exercising than the moderate social support group (p = 0.001). There were no statistically significant differences in fluid, and diet adherence by social support group.

**Aim 2.** The LSNS-6 mean social support score was 16.51 (standard deviation 6.89; scores ranged 3 – 30). The range of mean scores on the family factor was 2.62 to 3.62, and the range of mean scores on the friend factor was 1.81 to 3.07 (see Table 12).

The full two-factor measurement model for the LSNS-6 was based on the previously reported EFA. Table 13 shows these factors, their respective items, and the standardized coefficients for the items. The CFA resulted in standardized coefficients greater than the specified 0.40 cutoff (ranging from 0.60 to 0.92). In the first factor, family, the coefficients were 0.77 (family network size), 0.90 (family call for help), and 0.61 (family discuss private matters). The r-squared values were 0.59, 0.81, and 0.37, respectively. The second factor, friend, had coefficients of 0.77 (friend network size), 0.92 (friend call for help), and 0.78 (friend discuss private matters). The corresponding r-squared values were 0.60, 0.85, and 0.61, respectively.

The modification indices indicated that family network size covaried with friend network size, thus, their error terms were correlated (and the error terms between family discuss private matters and friend discuss private matters were also correlated) resulting in model two. The coefficients in the family factor were 0.77 (friend size), 0.91 (friend call for help), and 0.58 (friend discuss private matters). The r-squared values were 0.58, 0.82, and
0.33, respectively. The friend factor had coefficients of 0.80 (friend size), 0.89 (friend call for help), and 0.78 (friend discuss private matters). The corresponding r-squared values were 0.63, 0.80, and 0.61, respectively. The initial and alternative (nested) measurement models are depicted in Figure 1.

Model fit indices are reported in Table 14, revealing that two of four indices demonstrate good fit. Acceptable fit in model one and two were reflected in CFI (0.94 and 0.97, respectively) and TLI (0.90 and 0.94, respectively). The χ² statistic was 23.409 (8), p = 0.003 in model one and 12.837 (6), p = 0.046 in model two. The RMSEA scores were 0.13 in model one and 0.10 in model two. The chi-square difference test was 10.572 (2), p = 0.005.

The Cronbach alpha score was 0.81 for the overall scale. The range of scores by item was 0.78 (family call for help) to 0.81 (family discuss private matters). When obtained by factor, the scores were 0.78 (family) and 0.86 (friend). The reliability scores are reported in Table 15.

**Discussion**

In the coming decades, health care professionals will encounter more older adults. Thus, an understanding of psychosocial factors influencing their health and health care needs, such as social support, is increasingly important. Additionally, valid and reliable measures of social networks are needed to assess patient need and guide patient-centered practice. This paper describes self-management behaviors associated with social support and presents a validation of a widely used scale in research and practice, the LSNS-6. By identifying these factors and reporting the psychometric properties of the scale when used with HD patients
aged 50 and older, health care professionals may consider using the LSNS-6 for rapid assessment of social support, and intervene as needed.

**Clinical Practice Application**

In this study, the author identified significant associations between social support and four of six self-management behaviors. Of note, participants with high social support had more advanced directives, practiced more cognitive symptom management techniques, and communicated with their physician more frequently, and exercised more. Although the causal direction cannot be determined in this cross-sectional study, it is plausible that social support promotes self-management because social networks provide individuals with a sense of belonging and intimacy that can increase self-efficacy (Berkman, 1995). Further research is needed to determine if social support is a pathway to increasing self-management behaviors.

End-of-life care planning is a process that occurs largely between the patient, the patient’s providers, and the patient’s support system that typically results in a written directive (Teno, Nelson, Lynn, 1994; Emanuel, 2008), thus, it is no surprise that patients who reported low and moderate social support had fewer advanced directives. Nephrology professionals are required to assess the advance directive status of patients annually, and may consider assessing social support status in patients who report low social support. Also, HD patients experience a heavy symptom burden (Abdel-Kader, Unruh, & Weisbord, 2009; Claxton, Blackhall, Steven, Weisbord, & Holley, 2010), and it is concerning that participants with lower social support engage less in cognitive symptom management. Similarly, because exercise reduces the impact of co-morbid conditions experienced by ESRD patients by improving overall physical functioning (Johansen, 2007), it is a cause for concern that
participants who reported the lowest social support exercised less frequently than others. Future clinical interventions to promote cognitive symptom management and exercise in the ESRD population can utilize members of patients’ social networks to encourage the behaviors. Also, communication with physicians promotes treatment adherence in HD patients (Loghman-Adham, 2003), thus, promoting communication between patients and their providers is encouraged. Finally, the relationship of communication with physicians to advanced directive status is worth exploring. For example, patient-provider communication likely promotes the development of an advance directive, because physicians are often involved in such discussions.

This study also found that participants identified more people in their social networks than they actually called on for help or to discuss private matters. However, the author cannot draw conclusions about whether or not patients felt their current level of engagement with people in their social network is sufficient. Further research is needed to determine the question of sufficiency, and if substantiated (i.e., if there is a need to engage more people), nephrology professionals may assist patients with engaging the people in their social networks by teaching effective communication skills or promoting peer support within the HD facility. The management of ESRD is complex and requires the assistant of many helpers, especially for those who choose HD for treatment. Also, there are many reasons why HD patients may need people to call on for help, including transportation to and from treatment and other medical appointments, and for assistance with daily activities.

As indicated previously, older adults primarily choose HD to home dialysis. However, there is research to support that home dialysis has advantages such as better control of hypertension, fewer hospital visits, and decreased experiences with vascular access.
complications (Dimkovic & Oreopoulos, 2008). In older adults, home dialysis can be successfully performed when social support is provided by the health care team. Thus, by increasing social support from providers, the percentage of older adults who choose home dialysis may increase.

**Research Application**

This study’s findings provide a foundation for model specification in future research. Model one was specified based on the a priori theoretical model of the LSNS (Lubben, 2006; Lubben, 1988). After correlating the error terms based on examination of modification indices, further specification of model two was justified based on recent findings related to social support and health-related quality of life (HRQOL) in a sample of 949 hemodialysis patients (Plantinga et al., 2010). Those findings showed that HRQOL was strongly associated with mortality, stress, and depression in ESRD patients (Chan et al., 2011; Untas et al., 2011). Also, the findings showed a statistically significant relationship between tangible social support (operationalized using Medical Outcomes Study Social Support Survey; Ware, 1993) and the physical component summary and mental component summary of the SF-36. There were no other aspects of social support (i.e., emotional/informational, affectionate, positive social interaction) found to be significantly associated with HRQOL. Tangible social support in the Medical Outcomes Study (MOS) relates to “helping” with a person’s health-related needs (e.g., examples items include “Someone to help you if you were confined to a bed” and “someone to help with daily chores if you were sick”). Theoretically, these items correspond with the two “help” items on the LSNS-6: “How many relatives do you feel close to such that you could call on them for help?” and “How many friends do you feel close to such that you could call on them for help?” Tangible support is
an important component of social networks (Heitzmann, 1988; Lubben & Gironda, 2003). Also, the MIs suggested that the error terms between “family discuss private matters” and “friend discuss private matters” be added. The error terms were correlated because based on previous research, while the actual size of networks decrease with age, emotionally meaningful relationships increase (Lang & Carstnsen, 1994). This is consistent with other research that found emotional support to be an important component of the social networks of older adults (Heitzmann, 1988; Lubben and Gironda, 2003), and having greater emotional support is associated with improved functional status in older adults with chronic conditions (Seeman & Chen, 2002). Using theory and previous research as opposed to relying solely on the MIs to suggest additional parameters is consistent with reasonable steps for model respecification (Thompson, 2004). The idea that help with doing things is perceived as a type of tangible, instrumental support is documented elsewhere (Gottleib, 2010). Correlating the error terms of these items improved the model fit.

CFA best practices require researchers to test reasonable rival models based on the theoretical assumptions of an instrument (DeVellis, 2012; Thompson, 2004). As demonstrated in this study, model two was the better fitting model. Two conclusions are drawn from this finding. First, it establishes a model for structural equation modeling in future research using the LSNS. Structural equation modeling is a likely next step to determine if the negative effects of limited social support are mediated by other factors, or if social support can mediate the negative effects of depression, for example, on health outcomes in this population. In both models, only two of four fit criteria were met (CFI and TLI); however, all fit indices improved in the second model, indicating that the rationale to correlate the errors terms (which added two parameters) was sound. The CFI and TLI
improved (0.947 to 0.977 and 0.901 to 0.941, respectively). Although RMSEA did not meet the pre-established criteria, it improved from 0.130 to 0.103 (approaching an acceptable value between 0.05 and 0.08). The $\chi^2$ test did not indicate good fit in model two, however, it does approach good fit (i.e., $p = 0.003$ in model one and $p = 0.046$ in model two, $\chi^2 > 0.05$ indicates good fit). Second, the findings provide preliminary justification for using the LSNS-6 with older HD patients to assess social support. With a larger sample size, it is possible that all model fit indices would have improved. Still, these results are promising and provide initial support for adding this instrument to other standardized psychosocial assessment measures used with this population.

With the exception of the “family discuss private matters” item, the r-squared values ranged from 0.59 to 0.85 in model one, and 0.58 to 0.82 in model two, indicating that a moderate percentage of the variance in each observed variable was explained by the models. The r-square decreased after correlating the error terms between “family discuss private matter” and “friend discuss private matters” in model two (as depicted in Figure 1). This is not necessarily an indication of a poor-fitting item; the low r-square could indicate that further model re-specification is needed, especially because RMSEA only slightly improved between the models. While the reliability scores were acceptable because they fell within an acceptable range (i.e., between 0.70-0.90; DeVellis, 2003), it is possible that other modeling techniques, such as the jigsaw piecewise method (Bollen, 2000), could achieve a better model.

The results of the CFA provide justification the use of the LSNS-6 with diverse HD patients. The diversity of the sample, specifically relating to race, age, and cognitive status is a strength of this study because many instruments are used but not validated with diverse
populations. Blacks have a 3.7 greater risk of ESRD than whites (USRDS, 2010), and the majority of the sample was black (65%). The social networks of black older adults differ from whites. As indicated earlier, for example, black older adults utilize informal networks extensively (Carlton-Laney, 2006). Further, older adults have higher incident rates of ESRD compared to younger cohorts. The sample’s mean age was 63. Older adults tend to have smaller social networks than younger people, but rely on their social networks for health and well-being (Cornwell & Waite, 2009). Also, the majority of this sample had dementia (52%). Social networks of people living with dementia, particularly families, are heavily engaged in their health care decisions and management of finances (Port et al., 2005). Taken together, the potential use of this scale with diverse HD patients is promising. Group comparisons are the next step in validating this scale for HD subgroups.

Limitations and Conclusion

Related to the clinical application, the first limitation of this study is the partial information about the type of support provided to ESRD patients that can be captured using the LSNS-6. While the LSNS-6 is a reliable measure of social support, it does not allow clinicians to assess other conceptual dimension of support (i.e., the depth and closeness of the network and the types of daily interactions). ESRD is a complex disease to manage, and an understanding of the closeness of the network and the types of daily interactions can help clinicians plan effective interventions and identify members of the network who may be included in intervention work.

Related to the psychometrics, the second limitation of this is the use of STATA software to conduct CFA. Unfortunately, there are limited fit statistic options available in STATA. Software solely dedicated to structural equation modeling (and thus, capable of
performing CFA) such as AMOS offer additional fit statistics (e.g., goodness-of-fit index, incremental fit index, and normed fit index) (Byrne, 2010) and are recommended in future research. Third, this study presents a first-order CFA of the LSNS-6. A second-order CFA modeling the two factors as indicators of latent variable “Social Support” is now needed. In a second-order model, the two factors are correlated which can broaden generalizability implications (Thompson, 2004).

There is a critical need for well-developed, evidence-based interventions to ameliorate the negative effects of social isolation in older adults (Dickens, Richards, Greaves, & Campbell, 2011). The LSNS-6 is a brief, reliable measure of social support; thus, administering this measure with the growing population of older adults in HD facilities to identify their psychosocial needs related to social support is possible. Identification of social support can lead to effective clinical interventions in HD settings, which is needed because improving social support in ESRD patients can reduce depression and enhance HRQOL (Cohen et al., 2007). For example, social workers in HD facilities are tasked with assisting patients and their families adjust to and cope with ESRD (Browne, 2012). To date, there no measure of social support has been validated for use with ESRD patients, which can make it difficult for social workers to fully assess the extent improved social support is needed among their patient population. Validating the use of the LSNS-6 for a diverse sample provides social workers with a needed assessment option that is brief and reliable. Social workers may consider using the LSNS-6 during their initial psychosocial assessment, and again annually. This can easily be achieved using the LSNS-6, and can give social workers a way to track changes in social networks as it is known that the size grows smaller as people age.
References


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Table 10

*Descriptive Statistics*

<table>
<thead>
<tr>
<th>Participant characteristics (N = 107)</th>
<th>Mean (SD) or N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>63 (8)</td>
</tr>
<tr>
<td>Months on hemodialysis</td>
<td>86 (90)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>55 (51)</td>
</tr>
<tr>
<td>Female</td>
<td>52 (49)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>35 (33)</td>
</tr>
<tr>
<td>Black</td>
<td>69 (65)</td>
</tr>
<tr>
<td>Othera</td>
<td>3 (2)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Did not graduate high school</td>
<td>28 (26)</td>
</tr>
<tr>
<td>High school diploma or GED</td>
<td>32 (30)</td>
</tr>
<tr>
<td>Some college</td>
<td>26 (23)</td>
</tr>
<tr>
<td>College graduate or higherb</td>
<td>21 (20)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>43 (40)</td>
</tr>
<tr>
<td>Single</td>
<td>20 (19)</td>
</tr>
<tr>
<td>Divorced</td>
<td>20 (19)</td>
</tr>
<tr>
<td>Widowed</td>
<td>17 (16)</td>
</tr>
<tr>
<td>Otherc</td>
<td>7 (6)</td>
</tr>
<tr>
<td>Health Statusd</td>
<td></td>
</tr>
<tr>
<td>Good or better</td>
<td>49 (46)</td>
</tr>
<tr>
<td>Poor or poor</td>
<td>58 (54)</td>
</tr>
<tr>
<td>Cognition^e</td>
<td></td>
</tr>
<tr>
<td>Normal</td>
<td>11 (11)</td>
</tr>
<tr>
<td>Mild cognitive impairment</td>
<td>40 (37)</td>
</tr>
<tr>
<td>Dementia</td>
<td>56 (52)</td>
</tr>
<tr>
<td>Living Situation</td>
<td></td>
</tr>
<tr>
<td>Lives with others in a private residence</td>
<td>68 (64)</td>
</tr>
<tr>
<td>Lives alone</td>
<td>39 (36)</td>
</tr>
<tr>
<td>Advance Directive</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>75 (70)</td>
</tr>
<tr>
<td>Health care power of attorney and living will</td>
<td>18 (17)</td>
</tr>
<tr>
<td>Health care power of attorney only</td>
<td>10 (9)</td>
</tr>
<tr>
<td>Living will only</td>
<td>4 (4)</td>
</tr>
</tbody>
</table>

^aOther races are American Indian, Asian
^bIncludes Bachelor's degree, Associates degree, or graduate degree
^cOther marital statuses are not married but partnered, or separated
^dHealth status dichotomized as excellent, very good, good vs. fair and poor
^eBased on the SLUMS, scores range from 1 to 26: 1 to 16 indicates dementia (1 to 15 if less than high school education), 17-20 indicates mild cognitive impairment (16-18 if less than high school education), 21-26 indicates normal cognition (19-23 if less than high school education).
<table>
<thead>
<tr>
<th>Table 11</th>
<th>Self-management by Social Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Supporta</td>
<td>Social Supportb</td>
</tr>
<tr>
<td>Low (n = 36)</td>
<td>Moderate (n = 33)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Advance Directive&lt;sup&gt;d&lt;/sup&gt;</td>
<td>0.22 (0.42)</td>
</tr>
<tr>
<td>Cognitive Symptom Management&lt;sup&gt;e&lt;/sup&gt;</td>
<td>0.64 (0.85)</td>
</tr>
<tr>
<td>Communication With Physicians&lt;sup&gt;f&lt;/sup&gt;</td>
<td>2.32 (1.53)</td>
</tr>
<tr>
<td>Weekly Exercise Time&lt;sup&gt;g&lt;/sup&gt;</td>
<td>1.70 (1.77)</td>
</tr>
<tr>
<td>Fluid Adherence&lt;sup&gt;h&lt;/sup&gt;</td>
<td>11.83 (3.70)</td>
</tr>
<tr>
<td>Diet Adherence&lt;sup&gt;h&lt;/sup&gt;</td>
<td>11.24 (3.71)&lt;sup&gt;j&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>a</sup>Social Support scores range from 0-30. Social support mean score of total sample = 16.51, SD = 6.89. Social support scores were categorized into low (mean score of 12 or less), moderate (mean score of 13 to 18), and high (mean score of 19 or higher).

<sup>b</sup>The Kruskal-Wallis test was used to compare mean scores across levels of social support. P-values in bold are significant at < 0.05.

<sup>c</sup>Comparisons significant at 0.05 level with Bonferroni correction. Only comparison < 0.05 are shown.

<sup>d</sup>Advance directive dichotomized as no advanced directive (0) vs. a living will, health care power of attorney, or both (1).

<sup>e</sup>Higher score more use of cognitive symptom management skills.

<sup>f</sup>Higher score more communication.

<sup>g</sup>Higher score more time spent exercising.

<sup>h</sup>Higher score more days adherent.

<sup>i</sup>1 case missing from analyses.

<sup>j</sup>2+B42 cases missing from analyses.
Table 12
*LSNS-6 Mean (SD) and Range (N = 107)*

<table>
<thead>
<tr>
<th>Item</th>
<th>Mean (SD)</th>
<th>Min - Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family network size</td>
<td>3.62 (1.27)</td>
<td>0 - 5</td>
</tr>
<tr>
<td>Family call for help</td>
<td>3.02 (1.54)</td>
<td>0 - 5</td>
</tr>
<tr>
<td>Family discuss private matters</td>
<td>2.62 (1.69)</td>
<td>0 - 5</td>
</tr>
<tr>
<td>Friend network size</td>
<td>3.07 (1.62)</td>
<td>0 - 5</td>
</tr>
<tr>
<td>Friend call for help</td>
<td>2.37 (1.81)</td>
<td>0 - 5</td>
</tr>
<tr>
<td>Friend discuss private matters</td>
<td>1.81 (2.37)</td>
<td>0 - 5</td>
</tr>
<tr>
<td>LSNS-6</td>
<td>16.51 (6.89)</td>
<td>0 - 30</td>
</tr>
</tbody>
</table>

Note: The LSNS is a 5-point Likert scale (i.e., 0 = none, 1 = 1 person, 2 = 2 person, 3 = 3 or 4 persons, 4 = 5 to 8 persons, and 5 = 9 or more persons).
Table 13
*CFA Full and Alternative Models for the LSNS-6*

<table>
<thead>
<tr>
<th>Factor (Subscale Name)</th>
<th>Model 1</th>
<th></th>
<th>Model 2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Coefficient</td>
<td>R-square</td>
<td>Coefficient</td>
<td>R-square</td>
</tr>
<tr>
<td><strong>Family Factor</strong></td>
<td></td>
<td></td>
<td></td>
<td>0.77</td>
</tr>
<tr>
<td>Family network size</td>
<td>0.77</td>
<td>0.59</td>
<td>0.77</td>
<td>0.58</td>
</tr>
<tr>
<td>Family call for help</td>
<td>0.90</td>
<td>0.81</td>
<td>0.91</td>
<td>0.82</td>
</tr>
<tr>
<td>Family discuss private matters</td>
<td>0.61</td>
<td>0.37</td>
<td>0.58</td>
<td>0.33</td>
</tr>
<tr>
<td><strong>Friend Factor</strong></td>
<td></td>
<td></td>
<td></td>
<td>0.77</td>
</tr>
<tr>
<td>Friend network size</td>
<td>0.77</td>
<td>0.60</td>
<td>0.80</td>
<td>0.63</td>
</tr>
<tr>
<td>Friend call for help</td>
<td>0.92</td>
<td>0.85</td>
<td>0.89</td>
<td>0.80</td>
</tr>
<tr>
<td>Friend discuss private matters</td>
<td>0.78</td>
<td>0.61</td>
<td>0.78</td>
<td>0.61</td>
</tr>
</tbody>
</table>

Note: Analyses performed in Stata version 12. Model 1 is full model with no correlated error terms. Model 2 is alternative model with correlated error terms.
Figure 1. The two factor structure of the Lubben Social Network Scale – 6. Comparison of model one and model two.

Model One
Circles represent error terms

Model Two
Circles represent error terms
Table 14

*Model Fit Indices of the Initial and Alternative Models*

<table>
<thead>
<tr>
<th>Fit Indexes</th>
<th>Model 1</th>
<th>Model 2</th>
<th>Chi-square Difference Testa</th>
</tr>
</thead>
<tbody>
<tr>
<td>(\chi^2) (df)a</td>
<td>23.409 (8), (p = 0.003)</td>
<td>12.837 (6), (p = 0.046)</td>
<td>10.572 (2), (p = 0.005)</td>
</tr>
<tr>
<td>RMSEAb</td>
<td>0.13</td>
<td>0.10</td>
<td></td>
</tr>
<tr>
<td>CFIc</td>
<td>0.94</td>
<td>0.97</td>
<td></td>
</tr>
<tr>
<td>TLI(d)</td>
<td>0.90</td>
<td>0.94</td>
<td></td>
</tr>
</tbody>
</table>

\(a\) Nonsignificant \(\chi^2\) indicates good fit

\(b\) RMSEA values between .05 and .08 are acceptable

\(c\) CFI values greater than .90 indicates good fit and 1.0 indicates perfect fit

\(d\) TLI values greater than .90 indicates good fit and 1.0 indicates perfect fit
<table>
<thead>
<tr>
<th>Item</th>
<th>LSNS-6&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Family Factor&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Friend Factor&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family network size</td>
<td>0.80</td>
<td>0.70</td>
<td>N/A</td>
</tr>
<tr>
<td>Family call for help</td>
<td>0.78</td>
<td>0.61</td>
<td>N/A</td>
</tr>
<tr>
<td>Family discuss private matters</td>
<td>0.81</td>
<td>0.81</td>
<td>N/A</td>
</tr>
<tr>
<td>Friend network size</td>
<td>0.79</td>
<td>N/A</td>
<td>0.84</td>
</tr>
<tr>
<td>Friend call for help</td>
<td>0.76</td>
<td>N/A</td>
<td>0.83</td>
</tr>
<tr>
<td>Friend discuss private matters</td>
<td>0.76</td>
<td>N/A</td>
<td>0.75</td>
</tr>
<tr>
<td>LSNS-6&lt;sup&gt;c&lt;/sup&gt;</td>
<td>0.81</td>
<td>0.86</td>
<td>0.78</td>
</tr>
</tbody>
</table>

<sup>a</sup> Item reliability scores for full 6-item instrument  
<sup>b</sup> Item reliability scores by factor  
<sup>c</sup> Reliability scores for full instrument
Conclusion

Policy Implications

The Medicare Conditions for Coverage were published in 1976 and revised in 2008 (Browne, 2010; Federal Register, 2008). The findings of this dissertation are timely because the updated Conditions require state surveyor’s to review facility records and reports, patient medical records, and interview patients and staff related to the following:

§ 494.80 Condition: Patient assessment. Patients’ comprehensive assessments must include an evaluation of their current health status to include their ability to follow treatment prescriptions; mental health needs; support systems, and; advance directive status. Based on study one’s findings, a patient’s self-management abilities are associated with their self-efficacy. Also, based on study two’s findings, if a patient is experiencing depression, the health care team may consider assessing its effects on fluid adherence. If patients are experiencing adherence difficulties, an intervention guided by self-efficacy maybe appropriate. Finally, based on study three’s findings, social support is associated with self-management, although the causal direction cannot be inferred. Also, limited social support is associated with not having an advanced directive. Thus, the health care team may assess a patient’s social support when providing self-management education or end-of-life counseling.

§ 494.90 Condition: Patient plan of care. A psychosocial plan of care must include individualized interventions to address health outcomes and patient’s goals. This mandate
requires social workers to choose standardized assessment tools. Based on study three’s findings, the LSNS-6 is a promising option for assessing social support. Also, the plan of care must include regular evaluation of a patient’s interest in home dialysis. Lack of social support can severely impede a patient’s ability to successful perform dialysis at home.

This regulation also requires the plan of care to include education and training in aspects of dialysis management and self-care. Based on study one’s findings, patients are performing self-management behaviors (as evidenced by the quantitative findings), but do not recognize them as self-management behaviors (as evidenced by the qualitative findings). Education and training in the areas the cognitive symptom management (i.e., cognitive strategies individuals employ to deal with unpleasant symptoms experienced by the disease) and communication with physicians (i.e., the amount of weekly time an individual spends communicated effectively and productively with his or her physician) are needed, in particular.

**Practice Implications**

Results of this dissertation also have implications for nephrology social work intervention and practice in hemodialysis (HD) settings. Social workers are federally mandated to assess psychosocial needs of their patient population and treat accordingly. No other public policies that oversee a disease category mandate the inclusion of master’s-level social workers on health care teams (Browne, 2010). Nephrology social workers intervene in several ways including engaging patients in psychosocial assessments to identify individual and family strengths and needs; providing counseling to deal with social, emotional, and end-of-life concerns; educating patients about the disease process and available treatment options; and providing end-of-life counseling and case management (Browne, 2010). Unfortunately,
there are few evidence-based psychosocial interventions available for nephrology social workers to use with HD patients to improve self-management behaviors, decrease depression, and improve social networks. The previous studies focused in these three areas. Study one was a mixed methods descriptive study to examine the self-management behaviors of older HD patients and identify correlates of self-management. Study two identified potential mediators of depression to fluid adherence, an important ESRD self-management behavior. Finally, study three presented a confirmatory factor analysis of the Lubben Social Network Scale, and examined factors associated with social support among older ESRD patients. Taken together, the three studies clarified the self-management behaviors of older ESRD patients, provide preliminary evidence for a modifiable mediators of depression (i.e., self-efficacy), and support the use of a brief assessment of social isolation. These findings contribute to the ESRD literature because the self-management behaviors of older ESRD patients were not well understood, factors that mitigate depression’s deleterious effects were under-identified, and assessments of social support had not been validated for use with this population.

**Illness Perceptions**

When these studies were initially conceived, illness perceptions, the representation a person makes about his or her illness, were to be examined. Illness perceptions are a construct of Leventhal’s common sense model (CSM), which suggests that individuals regulate their illness by acting as common sense scientists and active problem solvers in order to make sense of their illness and develop coping strategies to deal with their illness (Leventhal, Leventhal, & Cameron, 2001; Serlachius & Sutton, 2009). There are three phases of the CSM: representation, coping, and appraisal. In response to a stimuli (the
illness), and individual develops a representation of the illness, develops strategies for coping, then appraises the coping behavior.

The studies were to draw from the representation phase of the CSM. The two types of illness representations (emotional and cognitive) are influenced by social factors such as previous interactions with medical providers, experience with family members or friends with the same illness, or the media’s depiction of illness (Fowler & Bass, 2006). Emotional illness representations are emotional responses to the illness, including anxiety, fear, or anger (Serlachius & Sutton, 2009). These can be influenced by previous experiences with illness or developed as an initial response to illness. Cognitive illness representations include identity (the assignment of symptom labels), causal attributes (a belief about the origin of the illness), timeline (the duration of the illness), symptom management (illness controllability), and consequences (judgments about perceived consequences).

In study one, differences in self-management behaviors by illness perceptions were to be examined. The hypothesis was that negative illness perceptions would be associated with a decrease in self-management behaviors. In study two, illness perceptions were to be included as a secondary variable in the logistic regression models (with social support and self-efficacy). The hypothesis was positive illness perceptions would be associated with an increase in fluid adherence.

There is evidence justifying the examination of illness perceptions in studies relating to self-management behaviors in the ESRD population. Illness perceptions are a predictor of quality of life (Fowler & Bass, 2006), well-being (Timmers et al, 2008), coping (Chilcot, Wellsted, & Farrington, 2010), and mortality (van Dijk et al., 2009) among older HD patients. However, no studies have examined the relationship of illness perceptions to self-
management, or modeled illness perceptions as mediator between depression and fluid adherence, as originally proposed in study one and two, respectively.

Chilcot (2012) recently summarized twelve studies examining illness perceptions in relation to ESRD health outcomes, and in each study, the Revised Illness Perceptions Questionnaire was used (Moss-Morris et al., 2002). For this dissertation, the Brief Illness Perceptions Questionnaire was used. It is shorter than the original Illness Perception Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006), and offers rapid assessment of illness perceptions with vulnerable populations such as older adults. An example item is: “How long do you think your illness will continue?” which measures the patient’s perception of his or her ideas about the duration of the illness (i.e., the timeline).

Initial analyses in this dissertation assessed psychometric properties of the Brief Illness Perceptions Questionnaire, because it has not been evaluated for use with ESRD patients. Unfortunately, the reliability score in this sample was extremely low (α = 0.36). The majority of studies using the Revised Illness Perceptions Questionnaire found statistically significant associations to this item. Still, the controllability subscale yielded a disturbingly low reliability score as a single-item measure (α = 0.36), therefore, a decision was made not to use the scale nor any of its items in the final analyses. It is the author’s recommendation that future studies utilize the Revised Illness Perceptions Questionnaire with this population, which is consistent with previous studies. It is unclear why the measure performed poorly in this dissertation, because in its initial evaluation, 132 participants in the 663 sample had renal disease (Broadbent, Petrie, Main, & Weinman, 2006). The mean age of renal patients was 58 and 70% of them were female, however, no other demographic or health status information was provided. Information such as race, depression, and cognitive
status would have aided in the decision about the scale’s potential use with renal patients. Although, test-retest reliability was performed on the renal patients, yielding scores between 0.42 – 0.75 (with the lowest scores on the controllability subscale).

**Conclusion**

A comprehensive self-management intervention has yet to be designed and tested with this population. The three studies of this dissertation provide the foundation for future intervention design and implementation. As the HD population ages, and race disparities persist, it is important to test intervention efficacy and effectiveness with the ESRD population. The findings will inform the development of a self-management intervention for this population. The Chronic Disease Self-Management Program (CDSMP), developed at Stanford University, informed the studies, and will continue to inform the development and testing of interventions the author will undertake with HD patients. The CDSMP was designed to promote successful self-management behaviors by empowering participants to take an active role in their health and health care, and is based on the assumptions that people with different chronic conditions will have similar self-management tasks, and will experience improved health by learning these tasks (Lorig et al, 1999; Lorig et al, 2001; Stanford Patient Education Center, 2012). A pilot test of the CDSMP in dialysis facilities is a novel idea given that ESRD patients would be more likely to participate in such a program if it were brought to the facilities in which they spend so much time (an average of 12 to 15 hours per week). Introducing a self-management intervention to the ESRD population is timely and important, and may lead to long-term benefits for patients (e.g., improved health outcomes, decreased health care utilization), their families (e.g., decreased caregiver burden), and society (e.g., decreased health care costs).
References


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